A critical comparison of the similarities and differences in the conceptualisation of disability between Indigenous people in Australia and New South Wales disability service agencies

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**Declaration Statement**

I, SUBAHARI RAVINDRAN, certify that this submission is my original work and contains no material previously published or written by another person except where acknowledged in the text. This submission does not contain any material, which has been accepted for the award of another degree.

Name: SUBAHARI RAVINDRAN  
Date: 14/12/2015
Thesis Abstract

This thesis critically compares the conceptualisation of disability in the public discourse between Indigenous people and New South Wales (NSW) government and non-government disability service agencies. This study explores intersections of the conceptualisations of disability at the Cultural Interface using the Occupational Justice Framework (Gilroy, 2009; Durocher, Gibson and Rappolt, 2014). This thesis consists of two sections.

Section 1: Literature Review

Section 2: Journal manuscript

The first section of this thesis is the literature review. The literature review examines the low participation rate of Indigenous people in disability services and the need for culturally appropriate disability services for Indigenous people. In order to ensure culturally appropriate services are provided for Indigenous people, the Western and Indigenous perspectives of disability need to be understood and each are discussed in turn in the literature review. The review initially discusses the Western conceptualisation of disability, followed by the Indigenous conceptualisation of disability. The review also explores how both Indigenous and Western perspectives on disability influence each other. The developments in disability conceptualisation throughout history are also discussed, followed by the current literature that led to the development of this study.

The second section of this thesis is a journal manuscript. The journal manuscript explores the intersections and tensions between Indigenous people and NSW government and non-government disability service agencies regarding the conceptualisation of disability. The journal manuscript also examines the outcomes and implications of the findings. The journal manuscript will be submitted to the Australian Journal of Social Issues (Appendix A).
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1. Introduction

It is tradition in many Indigenous communities to introduce oneself before commencing a discussion. I am writing as a Sri Lankan woman who has spoken and interacted with Indigenous Australian people during my research journey as a Masters of Occupational Therapy student. I had always held an interest for learning about culture and traditions. During my first year of occupational therapy I came to learn about worldviews and the impact of culture on occupational therapy practice. I learned that within Indigenous culture there is a special reverence to elders in the community. I drew parallels to my own culture where elders are respected and taken care of. Thus, when provided with the opportunity to carry out research, I gravitated towards learning about Indigenous culture and traditions and was interested in learning about the current concerns faced by Indigenous people in Australia.

My background in occupational therapy has shaped my view of Indigenous people’s experiences in the disability sector. Occupational therapy at an individual level focuses on enabling people to participate in activities that are meaningful to them. The meaning associated with the activity is shaped by the individual’s personal, cultural, historical and social context (Townsend & Wilcock, 2004). Within occupational therapy, body functions and structures and environmental factors support participation in activities that are meaningful to the individual, which ultimately promote wellbeing. On the other hand, limitations in body functions and structures and/or environmental factors restrict participation in meaningful activities and negatively impact wellbeing (Townsend & Wilcock, 2004).

A community is a group of people bound together based on their mutual interests, ideologies and characteristics. Occupational therapy at a community level focuses on the community having the opportunity to participate in meaningful activities. The right for communities to have opportunities to take on and participate in tasks, roles and activities that are meaningful to them is known as occupational justice. In contrast, occupational injustice occurs when the opportunities for participation in meaningful activities are restricted (Durocher, Gibson and Rappolt, 2014).

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1 The term Indigenous people is used to include both Aboriginal and/or Torres Strait Islanders people in Australia. An Indigenous person is a person, who is of Indigenous heritage, identifies as an Indigenous person and is accepted as an Indigenous person in their community (Australian Bureau of Statistics [ABS], 2014)
My Occupational therapy background provided me with the skills to understand the policies and procedures set by the government and non-government disability service providers. Disability service providers provide services and supports for people with disabilities, their families and carers to empower people with disabilities to live the life that they desire. Benefits of accessing disability services include the independence to participate in meaningful activities support in performing functional tasks, social inclusion and community access (Townsend & Wilcock, 2004).

My personal and professional interest led to the development of my research project that critically compares the conceptualisation of disability between Indigenous people in Australia and NSW government and non-government disability service agencies. In order to do so, I used the Occupational Justice Framework as the theoretical framework to guide my research. This is because the Occupational Justice Framework ensures the examination of occupational justice and injustice (Durocher et al., 2014).

This literature review aims to explore the Western and Indigenous conceptualisations of disability and the outcomes of the Western and Indigenous perspectives on policy and disability service provision. The literature review will initially explore the theoretical framework used to guide the study, followed by the background to the topic and the search strategy. Next, the Western attitudes to disability, how it has shaped society followed by Indigenous experience of disability will be discussed. This will be followed by reasons contributing to why Indigenous people experience high rates of disability yet have low participation rates in disability services. Finally, disability in policies and legislation and current developments in disability conceptualisation leading to the need for this study will be discussed.

2. Theoretical Framework

The theoretical framework used to guide this study is the Occupational Justice Framework. This framework illustrates the underlying belief that individuals are occupational beings (Durocher et al., 2014). Individuals have needs and wants that are essential to be met, in order to flourish. For people to have their needs met, they must be provided with the appropriate social, cultural and political contexts and opportunities that enable autonomous participation in meaningful activities. This participation in meaningful occupation promotes health and wellbeing (Durocher et al. 2014).
The Occupational Justice Framework demonstrates how the combination of ‘structural factors’ and ‘contextual factors’, contribute to the socially and historically constructed environmental context, that could result in the experience of occupational justice or injustice (Durocher et al. 2014). ‘Structural factors’ include occupational determinants such as the values underlying policies in an international and national context that drive occupational programs (e.g. income support, health and community support). ‘Contextual factors’ include personal, historical and spatial contexts, such as ethnicity, ability/disability, health status, location, age and gender. The structural and contextual factors can impact whether occupational justice or injustice occurs. The occupational justice or injustice achieved then leads to occupational outcomes. Occupational outcomes that could result from occupational injustices include occupational imbalance, marginalisation, deprivation or alienation. These occupational injustices cause communities to be excluded from meaningful occupations that they would like to perform or force communities to undertake unfavourable activities that are not meaningful to them. On the other hand, occupational rights that promote community participation in meaningful occupations, balance and choice for communities could occur as a result of occupational justice being achieved (Durocher et al. 2014).

3. Background to topic

Indigenous people in Australia experience high rates of disability, but have a low uptake of disability services (O’Neill, Kirove & Thomson, 2004; National Disability Services, 2010; NSW Ombudsman, 2010; Gilroy, 2012). The prevalence of disability in the Indigenous population in Australia is 2.4 times higher than that in the non-Indigenous population (Australian Institute for Health and Welfare [AIHW], 2011). However, when investigating the participation rate of Indigenous people in disability services, the AIHW (2011) reported that Indigenous people were severely under-represented.

The low participation rate of Indigenous people in disability services has been attributed to social, historical and cultural factors. The Indigenous people's context incorporates their social, historical and cultural factors that influence how disability is conceptualised (O’Neill, Kirove & Thomson, 2004; Gilroy, 2012). On the other hand, the Western context is shaped by international policies and events such as the Disability Rights Movement and the International Year of Persons with Disabilities and national legislation requirements such as the Commonwealth Disability Services Act 1986 (DSA). The Western context influences how disability is conceptualised by disability service agencies that provide services for people with
disabilities. The Western context also ensures that all Australians with disabilities have the opportunity to participate in disability services that cater to their needs. The social, historical and cultural contexts of both the Indigenous people and the disability services contribute to occupational outcomes that affect the participation of Indigenous people in disability services (Durocher et al. 2014).

Gilroy, Donelly, Colmar and Parmenter (2013) suggest that there are underlying tensions between disability service agencies and Indigenous communities that affect the extent of Indigenous people’s disability service participation. These tensions can be explored at the Cultural Interface, a metaphysical domain in which two different cultures and histories intersect and influence Indigenous participation in society (Gilroy, 2009). The Cultural Interface acknowledges Indigenous people’s culture and traditions and Indigenous history including colonisation and colonial policies. The influence of the Western context and knowledge on the lives of Indigenous people are also acknowledged. Moreton-Robinson (2004) argues that the Western context is influenced by the underlying concept of Whiteness, where Indigenous people are viewed as the ‘known’ as opposed to the ‘knowers’ and owners of their knowledge. Furthermore, Whiteness operates within the Western sciences, reinforcing the colonial powers and superiority over Indigenous people as normative (Moreton-Robinson, 2004; Gilroy et al., 2013).

Nakata (2007) indicates that the Cultural Interface is a space where Indigenous people and non-indigenous people constantly interact. These interactions lead to the understandings and debates about the knowledge of Indigenous people and how Indigenous people’s lives have been impacted. The interlacing of the Indigenous and non-Indigenous perspectives during interactions contributes to one’s outlook of the world, consequently influencing politics, economics and social practices. Understanding the interactions between Indigenous people and the Western ideologies held by the disability service sectors also influence disability service provision (Gilroy, 2009).

4. Search Strategy

To compose this literature review, a comprehensive, exhaustive search of academic databases, including Medline, PubMed, CINAHL, APAIS-ATSIS, AIATSIS, AGIS-ATSIS, Indigenous Collection, Indigenous Australia and Web of Science was carried out. Search terms include Australia, history, Aboriginal and Torres Strait Islander peoples, Indigenous people, First
Peoples, disability, service provision, policy, service delivery, impairment, definition, meaning and concept. A Google Scholar search with the same search terms was also performed. The literature search was limited to the English language. The results from the literature search produced a broad range of research regarding the Indigenous and Western conceptualisation of disability. However, most studies were irrelevant as they addressed specific health conditions and the development of treatment for health conditions that impact Indigenous people. To identify relevant national and international policies and legislation that shaped the conceptualisation of disability, a Google search of Australian government, NSW government websites and general websites was carried out.

5. Western Attitudes to Disability

Disability has been conceptualised from multiple perspectives for many decades. The concept of disability is shaped by cultural and political values in a national and international context (Shakespeare, 2006). Within the Western culture, there are three prominent approaches to disability that shape the way disability services are provided for people with disabilities (Dempsey & Nankervis, 2006). The three prominent approaches to disability are the individual approach, the social approach and the holistic approach (Dempsey & Nankervis, 2006).

a. Individual Approach

The individual approach to disability locates disability as a personal issue existing within the person, resulting in the person needing to adapt to society (Dempsey & Nankervis, 2006). There are two models within the individual approach. Firstly, the medical model views disability as a result of impairments those are to be ‘fixed’ by visiting a medical professional (Dempsey & Nankervis, 2006). This model is considered to be disempowering, as people with disabilities are perceived to be different from the normal, able-bodied people, due to their impairments (Marks, 1997). Humpage (2007) indicated that the medical model plays a significant role in the structure of disability service provision. The focus on perceived impairments results in the disability service providers taking a biomedical approach to disability service provision. Therefore, medical professionals hold the power and authority to carry out assessments that determine whether people with disabilities can access and receive disability support (Humpage, 2007).

Secondly, the philanthropic model portrays disability as a personal issue, positioning people
with disabilities as vulnerable. In effect, people with disabilities are treated as requiring institutional and personal care and protection. The philanthropic model gives rise to charities that also view people with disabilities as requiring protection, thus reinforcing these stereotypes (Rogowski, 2013). The philanthropic model also places the power and authority in the hands of medical professionals who determine access into disability services through standardised assessments (Gilroy et al., 2013).

**b. Social Approach**
Contrary to the medical approach, the social approach indicates that social and environmental factors contribute to the experience of disability (Dempsey & Nankervis, 2006). The social approach highlights that disability is a social construct, focusing on the societal and environmental barriers to social inclusion (Gilroy, 2012). The social model indicates that whilst individuals may have impairments, disability occurs when the environment and society fail to accommodate for the individual’s access and participation in everyday life (Marks, 1997).

**c. Holistic Approach**
The holistic approach gives rise to the biopsychosocial model, which recognises that both impairments and social constructs contribute to the experience of disability. An example of the holistic approach to disability is the International Classification of Functioning, Disability and Health (ICF) Model. The World Health Organisation (WHO) published the ICF in 2001 after several revisions and extensive research. The ICF is also referred to as the taxonomy of functioning and disability, recognising that the experience of disability is multifactorial.

As shown in Figure 1, the ICF consists of *body functions and structures* that include the specific parts of the body and its functions; *activities* an individual carries out and *participation* in activities of daily living, all which interact with *contextual factors*. *Contextual factors* are comprised of the individual’s *environmental factors* including physical and social structures that influence an individual’s functioning and *personal factors* such as the age and sex of the individual (AIHW, 2003).
The ICF places *body functions and structures, activities, participation* and *contextual factors* in relation to an individual’s *health conditions*. According to the ICF, functioning is referred to as interactions between impairments in body functions and structures, activity limitations and restrictions in participation in activities of daily living (AIHW, 2003). Consequently the individual’s disability is interpreted as the interaction between the biological condition, environmental factors and personal factors that impact body functions and structures, activities and participation (AIHW, 2003). The ICF is used to guide the implementation of government disability legislation, policies and for data collection to measure the rates of disability within populations (Madden, Choi & Sykes, 2003).

6. Indigenous Attitudes to Disability

A contributing factor for the low disability service participation rate of Indigenous people is the diversity in the conceptualisation of disability. Ariotti’s (1999) study with the *Anangu* revealed that the concept of disability, as understood in the English language was not translatable in the *Anangu* communities. Gilroy (2010) also supported that there was diversity within each Indigenous community in the traditional words or phrases that described the specific impairments.

Many Indigenous people with disabilities are also well accepted as active members within their communities and families. The acceptance is based on the local cultural protocols that
invoke family obligations to share the role of supporting people with disabilities within communities and extended family networks (Maher, 1999; Kendall & Marshall, 2004). In effect many Indigenous people with disabilities may rely on these family support networks and only consider accessing services when the family support networks are insufficient or inadequate (Kendall & Marshall, 2004).

Some Indigenous people may not identify as having a disability due to social and economic disadvantages. Indigenous people may place social and economic disadvantages such as poor education, unemployment and overcrowding and poor living conditions as the main priority. Hence, as the social and economic disadvantages become main priority in Indigenous communities, the disability may sometimes also be considered as a part of life and part of the Indigenous identity (Gething, 1994).

King, Brough and Knox (2014) indicated that Indigenous people perceive colonisation to be disabling. King et al. (2014) stated that colonial policies contributed to the discrimination of Indigenous people due to their race and culture, which was seen as a disabling factor that prevented their participation in society. Hollinsworth (2013) also reinforced that colonisation and discrimination prevented Indigenous people from readily taking on the title and identity of disability, as it was seen as a Western concept that was perceived to further disadvantage Indigenous people.

7. Distrust of disability services

Due to the history of colonial, racialised policies since Australian colonisation, Indigenous communities have developed distrust of disability services. Eurocentric, colonial policies, such as the protection through segregation policy, assimilation policy and the White Australia Policy categorised Indigenous people based on their stereotypical psychological features, physical characteristics and cultural values (McCorquodale, 1997; Kendall & Marshall, 2004; Moreton-Robinson, 2004; Elston & Smith, 2007; Gilroy 2009). These historical policies excluded Indigenous people from society and continue to influence and shape the lives of Indigenous people today.

The segregation policy and the assimilation policy signified that Indigenous people were to be excluded and separated from society. The segregation policy resulted in Indigenous children being excluded from schools, forcibly removed from their families and placed into missions.
with poor living conditions (Hollinsworth, 2013). The power to control Indigenous people’s speech and life was given to the government, resulting in social exclusion of Indigenous people (Elston & Smith, 2007). The assimilation policy focused on forcing Indigenous people to follow the same lifestyle and traditions as non-Indigenous people. The assimilation policy became dominant in trying to force Indigenous people to change their traditions and way of life to suit the Western lifestyle (Elston & Smith, 2007).

Furthermore, the White Australia Policy influenced the structure and characteristics of the Australian government in the past and present. The White Australia Policy was created to enforce the notion that true Australians were white, thus disregarding people from other cultures and groups and restricting their participation in society (Elston & Smith, 2007). The White Australia Policy also contributed to reinforcing the underlying concept of Whiteness, where the white way of thinking and white cultural values and beliefs, were the criteria for citizenship (Moreton-Robinson, 2004; Gilroy et al., 2013). The White Australia Policy gave rise to Whiteness being perceived as the norm, consequently leading to those who did not fit the norm, such as Indigenous people, facing social exclusion (Sanderson, 2004; Meekosha, 2011; Hollinsworth, 2013).

The Eurocentric, colonial policies collectively contributed to the culture of distrust that Indigenous people held for the disability service sector (Gilroy, 2009). The government policies led to the separation of Indigenous children from their communities and family (Elston & Smith, 2007). These policies contributed to Indigenous people fearing that if the disability service sector became aware of the Indigenous person with a disability, they may be segregated from their families (Gilroy, 2009).

8. Disability in Policy and Legislation

National and international policies and legislation created over time influenced how people with disabilities and Indigenous people with disabilities were treated in society. The national and international policies and legislation will be discussed in chronological order of their inception, beginning with the Disability Rights Movement and the International Year of Persons with Disabilities. The discussion of these two International movements will be followed by the Commonwealth Disability Services Act 1986 (DSA), the New South Wales Disability Services Act 1993 (NSWDSA), the United Nations Convention of the Rights of People with Disabilities (CRPD), the Declaration of the Rights of Indigenous People (DRIP)

The Disability Rights Movement gained momentum in United States of America (USA) and in the United Kingdom (UK). In the 1970s, the social approach to disability was favourable, where the focus of the disability experience was dependent on only environment factors. Advocates also began to speak up for their rights to ensure that they could engage and participate in society by sharing their experiences (Hurst, 2003).

The International Year of People with Disabilities (IYPD) in 1981 was considered to be one of the biggest achievements of the Disability Rights Movement. The IYPD brought to public spotlight the oppression people with disabilities experienced. In response to the IYPD, the Australian Government reviewed disability services and supports (Hurst, 2003). The review led to the development of the DSA (1986). The DSA (1986) was created to ensure that services met the rights of people with disabilities. The DSA (1986) was also responsible for setting out guidelines and principles that government and non-government organisations must follow in the expenditure of government funding. The DSA (1986) described a person with disability as the following:

(a) attributable to an intellectual, psychiatric, sensory or physical impairment or a combination of such impairments;

(b) permanent or likely to be permanent; and

(c) resulting in:

(i) a substantially reduced capacity of the person for communication, learning or mobility; and

(ii) the need for ongoing support services

Gilroy et al. (2013) indicated that the DSA (1986) aimed to ensure that the rights of people with disabilities were being met. The DSA (1986) focused on impairments, the consequences of the impairment on functioning and the need for adequate services and support for people with disability. Gilroy (2010) indicated that whilst the DSA (1986) focused upon ensuring adequate service provision and eligibility into services for supporting people with disabilities, enabling independence for people with disabilities was overlooked.

Indigenous people were grouped with Culturally and Linguistically Diverse people,
positioning Indigenous people as the Cultural Other within the DSA (1986). The concept of the Cultural Other is seen as an underlying, subliminal ideology that classifies a normal person to be non-Indigenous and ‘white’ skinned. Thus this ideology categorises those who do not fulfill the classification of being non-Indigenous and ‘white’ skinned as the Cultural Other (Gilroy, 2012). The approach of grouping Indigenous people with Culturally and Linguistically Diverse people, reinforcing the concept of the Cultural Other also highlighted the notion that the Indigenous histories and culture were inferior in comparison to European, Western cultures that were considered superior (Gilroy, 2012). The DSA (1986) positioned Indigenous people’s experiences of disability and disability services as connected to their Indigeneity and cultural context. Therefore Indigenous communities were considered to be responsible for their own experience of disability and disadvantages as opposed to the underlying colonial ideologies that govern the disability service sector. The consequences of Indigenous people being positioned to be blamed for their experience of disability and the underlying colonial factors that the disability service system placed upon Indigenous people also contribute to the low participation of Indigenous people in disability service agencies (Gilroy, 2010).

As each Australian state and territory was responsible for having its own legislation and guidelines to ensure funding for disability services, the NSWDSA (1993) was developed to fund arrangements in NSW. Gilroy (2010) indicated that Indigenous communities were involved and consulted for the formation of the NSWDSA (1993). Indigenous people were also mentioned in the NSWDSA (1993) and referred to as experiencing additional disadvantages due to their Indigeneity (Gilroy, 2010). Consequently, the DSA (1986) and the NSWDSA (1993) reinforced the need for enabling equitable access to services for Indigenous people (Gilroy, 2010).

To ensure participation and inclusion of people with disabilities, Australia ratified the United Nations Convention on the Rights of Persons with Disability (CRPD) in 2008 (United Nations [UN], 2006). The ratification of the CRPD promoted the right for self-determination and autonomy for people with disabilities. By ratifying the CRPD, Australia also agreed to the inclusion of all people with disabilities when developing and implementing policies for disability services provision (UN, 2006). The UN made the decision not to include a specific definition of disability. The decision was attributed to the notion that a specific definition would consequently result in the exclusion of some people and communities in society.
In 2011, Australia revoked its decision to vote against the Declaration of Rights of Indigenous People (DRIP). This decision reflected that Australia would consider the rights of Indigenous people when forming legislation and policies and providing services (United Nations [UN], 2008; Gilroy, 2012). The DRIP also ensured that Indigenous people have the right to self-determination where Indigenous people can exercise their right to autonomy and self-governance to manage their cultural traditions and also participate in society (Wehmeyer, 2005).

Resulting from systemic advocacy during the Disability Rights Movement, the Productivity Commission (2011) carried out a national inquiry to provide recommendations for the creation of a sustainable disability system that empowers people with disabilities to live the life of their choice. The report led to the development of the National Disability Strategy (NDS) 2010-2020, which was created in order to support and improve the lives of people with disabilities nationally (Productivity Commission, 2011). The NDS endorsed the creation of an inclusive society that ensures that all people with disabilities have the opportunities to participate in society as citizens (Productivity Commission, 2011).

The Australian Government introduced the National Disability Insurance Scheme Act 2013 (NDIS) to provide individualised support for people with disabilities. This individualised model informed by a person-centered approach indicated that the person with the disability has the choice to decide appropriate services for themselves. The person-centered approach gives rise to self-determination as the individual has the opportunity to self-direct their funding, choose their own disability service providers and make their own decisions on their preferred services (Kirkman, 2010).

The NDIS is regarded to have a huge potential to improving disability service provision for Indigenous people with disabilities. Indigenous advocacy organisations and spokespeople (Kendall & Marshall, 2004; Emerson et al., 2011; Aboriginal Disability Network, 2012; First Peoples Disability Network Australia, 2013) indicate that there are multiple access and equity barriers that need to be overcome to ensure that Indigenous people participate in the NDIS (Kendall & Marshall, 2004; Productivity Commission, 2011; First Peoples Disability Network Australia, 2013).
9. Conceptualising disability and culturally appropriate services

Ariotti (1999) conducted an ethnographical study that examined the conceptualisation of disability among the *Anangu* people in Western Australia, South Australia and Northern Territory tri-state region. Ariotti’s (1999) study found that there were three phases in which disability was perceived among the *Anangu*: the impairment phase, the oppression phase and the empowerment phase. The author suggested that there is a need for culturally appropriate service provision for Indigenous people. Ariotti (1999) concluded that in order to provide culturally appropriate services, the diversity between Indigenous communities and individuals regarding the conceptualisation of disability must be acknowledged.

Building upon Ariotti’s (1999) study, Kendall and Marshall (2004) examined the barriers Indigenous people faced when accessing disability services, from the perspectives of both Indigenous people and non-Indigenous service providers. Kendall and Marshall’s (2004) qualitative study explored the impact of Indigenous culture and disability in influencing how both Indigenous people and non-indigenous service providers perceived disability. A case study of an Indigenous woman with a disability was used as a frame of reference. Interviews with Indigenous and non-indigenous service providers involved in the Indigenous woman’s life were carried out. The study found that the culture played an important role in service provision for Indigenous people. Indigenous cultural factors such as family hierarchy influenced how the Indigenous woman accessed services. Furthermore, service provision for the Indigenous woman was also impacted by the stereotypes held by non-indigenous service providers. Kendall and Marshall (2004) concluded that there are multiple barriers to disability service provision for Indigenous people and that there is a need for culturally appropriate service provision. Kendall and Marshall’s (2004) study also noted that current service provision for Indigenous people is often governed by non-indigenous stereotypes and ideologies, thus identifying the mismatch between non-indigenous service providers and Indigenous people.

Gilroy (2009) adopted and modified Nakata’s (2007) theory of the Cultural Interface to explore how Indigenous people with disabilities were represented in NSW. Gilroy (2009) prioritised two main issues between Indigenous people and non-Indigenous disability services providers. The first issue was the impact of culture and the focus on cultural differences in understanding disability, which consequently prevent disability service provision for Indigenous people. The second issue that arose at the Cultural Interface was the lack of trust.
that Indigenous people had for disability services run by non-indigenous people. This lack of trust was due to the historical policies, which influenced how Indigenous people were represented within these policies. Furthermore, Gilroy’s (2010) study also explored how Indigenous people with disabilities were represented in government documents, published from 1985 to 2010. Gilroy (2010) concluded that Indigenous people with disability were also represented as a Cultural Other and compartmentalised as different, over time.

10. Conclusion

Many studies and government reports indicate that there is a need for the provision of culturally appropriate disability services for Indigenous people. Studies and government reports also indicate that the needs of Indigenous people are currently not being met. Thus in order to provide culturally appropriate disability services and meet the needs of Indigenous people, it is essential to identify how the disability service sector and Indigenous people perceive disability. A few studies have explored the intersections between Indigenous people and the disability service sector in NSW regarding appropriate service provision. Gilroy (2010) adopted the Cultural Interface theory from Nakata (2007) and identified that there are several interactions and tensions between Indigenous people and the disability service sector. In response to Gilroy’s concerns (2009; 2010) about how disability is conceptualised in the public discourse, this study will explore the similarities and differences between how Indigenous spokespeople and the government and non-government disability service agencies conceptualise disability at the Cultural Interface. The Occupational Justice Framework will also be used to guide critical data analysis and interpret the findings. This study seeks to make a unique contribution by exploring the tensions between Indigenous people and the government and non-government disability sectors in regards to disability at the Cultural Interface.

It is essential to understand these tensions during the development and implementation of the NDIS because the findings from the study will contribute to influencing the provision of culturally appropriate disability services for Indigenous people with disabilities (National Disability Services, 2010). This research could also ensure that Indigenous people’s voices are heard regarding their perspectives on disability, which is essential during the current development and implementation of the NDIS. This research will also provide recommendations addressing how the NSW disability service sector could address the low uptake of disability services by Indigenous people.

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To achieve these ends, this study aims to critically compare the conceptualisation of disability in the public discourse between Australian Indigenous people and NSW government and non-government disability service agencies. The following research questions will be addressed.

1. How do Australian Indigenous people conceptualise disability in the public discourse?

2. How do NSW government and non-government disability service agencies conceptualise disability in policies?

3. What are the similarities and differences between how disability is conceptualised by Indigenous people and NSW government and non-government disability agency policies?
11. References


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ABSTRACT

Background: The low participation rate of Indigenous people in disability services are attributed to the lack of culturally appropriate services. For culturally appropriate disability services provision, understanding how Indigenous people and the disability services sector conceptualise disability is essential. This study aimed to critically compare the conceptualisation of disability between Indigenous people and New South Wales government and non-government disability service agencies.

Methods: Purposive and snowball sampling was performed to obtain Indigenous and Policy sources. The Indigenous conceptualisation of disability by Indigenous spokespeople in journal, magazine and newspaper articles, books, speeches and audiovisual materials were included. New South Wales government disability service agency: Ageing, Disability and Home Care and seven non-government disability agencies conceptualising disability in annual reports, plans and program guidelines were included. The Occupational Justice Framework guided critical analysis of Indigenous and policy materials at the Cultural Interface.

Results: Four themes: Power and self-determination, Eligibility, Otherness and Identity and labels were identified. Disability agencies promote self-determination for Indigenous people. Agencies conceptualise disability as impairments affecting functioning, when assessing eligibility for service access. Most Indigenous people do not self-identify as disabled and are categorised as culturally different in policies. Thus Indigenous people experience marginalisation due to their cultural identity.

Conclusion: Indigenous people are required to conform to the Western conceptualisations of disability. Agencies must collaborate with Indigenous communities to address the individual community needs by recognising the diverse Indigenous conceptualisations of disability.
INTRODUCTION

Indigenous people in Australia experience high rates of disability, however have low participation rates in disability service agencies (O’Neill, Kirove and Thomson 2004: 6; Gilroy 2012: 2). In this study, the term Indigenous people includes Aboriginal and/or Torres Strait Islander people in Australia (Australian Bureau of Statistics 2014). The prevalence of disability in the Indigenous population is 2.4 times higher than in the non-indigenous population (Australian Institute for Health and Welfare [AIHW] 2011:2). The low participation rate of Indigenous people in disability services is attributed to several factors such as limited physical and geographical access, limited transportation to services and the lack of culturally appropriate services (O’Neill et al. 2004:7; Gilroy 2012:13).

An understanding of the conceptualisations of disability held by Indigenous people and disability service agencies are essential for culturally appropriate disability service provision for Indigenous people. Indigenous people’s conceptualisation of disability is shaped by their cultural and historical context (Gilroy 2012:49). The Western conceptualisation of disability is shaped by national and international policies, which in turn influence government and non-government disability services and programs. Gilroy et al. (2013:45) indicated the need for further exploration of the conflicting conceptualisations of disability between the disability services agencies and Indigenous communities.

There are evident tensions between the disability service agencies and Indigenous people affecting the extent of participation of Indigenous people in disability services (Gilroy 2009:58). This paper explores these tensions at the Cultural Interface. The Cultural Interface is a metaphysical space where Indigenous and Western cultures and histories intertwine, consequently influencing the lives of Indigenous people and their participation in society (Gilroy 2009:45-46). At the Cultural Interface, Indigenous people’s social, historical and cultural contexts and the Western context and knowledge are acknowledged.

**Conceptualising disability**

Dempsey and Nankervis (2006:5-10) state that there are three dominant approaches that have shaped disability and disability service provision: the individual approach, the social approach, and the holistic approach. The individual approach consists of the medical model and the philanthropic model, both of which view disability as a consequence of individual impairments (Dempsey and Nankervis 2006:5). The medical model conceptualises disability
as impairments that requiring fixing by health professionals (Dempsey and Nankervis 2006:5; Humpage 2007:216). The philanthropic model views people with disability as helpless and requiring protection from organisations (Gilroy 2012:111). The social approach considers societal and environmental barriers to social inclusion as disabling (Dempsey and Nankervis 2006:7). The holistic approach indicates that both impairments and environmental factors contribute to the disability experience (Dempsey and Nankervis 2006:10).

Indigenous people’s approach to disability is shaped by social, cultural and historical contexts. Ariotti’s (1999) study indicated that in several Indigenous languages spoken by the Anangu people in Western Australia, South Australia and Northern Territory, the concept of disability was not recognised or translatable. Gilroy (2010) also concluded that the concept of disability was diverse in Indigenous communities and that some Indigenous communities describe impairments using specific phrases.

In many Indigenous communities it is the family’s obligation to take on the role of supporting people with disability. There are strong family supports in Indigenous communities that ensure that the needs of people with disabilities are met. Hence, some Indigenous families only access disability services when family support is insufficient (Kendall and Marshall 2004:9).

The concept of disability has been imposed on Indigenous people by non-indigenous people (Kendall and Marshall 2004). Consequently, Indigenous people may fear that identifying as having a disability might separate them from the community and families (Gething 1994:29). This fear is due to Indigenous people experiencing discrimination due to their Indigeneity and race as a result of colonial policies such as the segregation policy, assimilation policy and the White Australia policy. These policies categorised and labeled Indigenous people by their physical appearance and race (Elston and Smith 2007:18-47). Thus Indigenous people are reluctant to identify as having a disability in fear of further disadvantages that restrict their participation in society (Elston and Smith 2007: 18-47).

Indigenous people consider the practice of categorising people by physiological features and abilities as culturally disrespectful (Moreton-Robinson 2004:76). Gilroy (2012:53) indicated that imposing non-Indigenous ideologies that categorise Indigenous people reiterate the impression that a normal person with a disability must be non-Indigenous and ‘white’ skinned. Thus those who do not fulfill this impression are considered different or the Cultural
Other (Gilroy 2012:123). The concept of the Cultural Other or ‘Otherness’ is considered to be a subliminal notion evident in government policies (Moreton-Robinson 2004:75; Hollinsworth 2013). In disability policies and legislation, Indigenous people were Culturally Othered and considered to be experiencing disadvantage due to their Indigeneity (Gilroy 2010). Gilroy (2012) concluded that due to the Cultural Othering of Indigenous people in service policies and procedures, Indigenous people were reluctant to access services.

**Disability Policy Reforms**

One of the recent developments in the Disability Rights Movement is Australia’s ratification of the United Nations Convention on the Rights of Persons with Disability (CRPD) (United Nations [UN] 2006). The ratification of the CRPD led to people with disabilities being recognised as having the right to self-determination and autonomy. Advocacy during the Disability Rights Movement led to the Productivity Commission (2011) conducting an inquiry into a ‘National Disability Care and Support’ model to ensure social inclusion of people with disabilities (Gilroy 2012:5). Following the inquiry, the Australian government released the National Disability Strategy 2010-2020. Consequently, a new funding model known as the National Disability Insurance Scheme (NDIS) was introduced (Productivity Commission 2011:10). The NDIS aims to revolutionise the provision of individualised funding and support for people with disability. This individualised funding promotes the person-centered approach and self-determination, where individuals can access disability services and supports of their choice (Lord and Hutchinson 2003:71-74; Kirkman 2010:28).

The development and implementation of the NDIS is anticipated to positively impact service provision for Indigenous people with disabilities. Whilst there is a need for culturally appropriate disability services, Indigenous advocacy organisations indicate that an individualised funding model ensures self-determination where Indigenous people’s family, culture, traditions, strengths and aspirations are acknowledged (Emerson et al. 2011; First Peoples Disability Network Australia 2013). Furthermore, Indigenous people could also be empowered to make their own decisions and choices to determine services appropriate for their needs (Productivity Commission 2011:10; Aboriginal Disability Network 2012:3).

The Occupational Justice Framework was used to frame the exploration of tensions at the Cultural Interface regarding the Western and Indigenous conceptualisations of disability (Durocher, Gibson and Rappolt 2014). The Occupational Justice Framework indicates how
structural factors and contextual factors, lead to occupational outcomes through the experience of occupational justice or occupational injustice. Structural factors include cultural values and the type of economy that inform international and national policies and programs such as employment, health, universal design and accessibility and community support. Contextual factors include personal and historical characteristics such as age, location, ability/disability and ethnicity. Occupational justice is achieved when communities are provided with appropriate environments that yield opportunities for autonomous participation in meaningful activities. Occupational injustice occurs when the environment restricts participation in meaningful activities resulting in marginalisation of communities, who are excluded from society and/or are forced to participate in activities they do not find meaningful (Durocher et al. 2014:424-426).

This study responds to Gilroy’s (2009; 2010) studies that explored the tensions at the Cultural Interface between Indigenous people with disabilities in New South Wales (NSW) and disability service provision. Gilroy (2009) concluded that cultural differences in conceptualising disability impact disability service provision for Indigenous people. Gilroy’s (2010) findings suggested that Indigenous people with disability were represented as a Cultural Other and compartmentalised as culturally different through time. Furthermore, Gilroy (2012) examined the perspectives of Indigenous and non-Indigenous disability service workers working in NSW Government funded disability services (NSW government and non-government agencies) regarding the low participation rate of Indigenous people in disability services. Gilroy’s (2012) findings concluded that NSW government and non-government disability service providers and Indigenous communities have difficulty establishing a definition of disability that is culturally inclusive. This study aimed to critically compare the conceptualisation of disability in the public discourse between Australian Indigenous people and NSW government and non-government disability service agencies. The findings from the study will inform the development and implementation of the NDIS to ensure culturally appropriate disability services for Indigenous people with disabilities.

To achieve this aim, the following research questions were addressed.

1. How do Australian Indigenous people conceptualise disability in the public discourse?

2. How do NSW government and non-government disability service agencies conceptualise disability in policies?
3. What are the similarities and differences between how disability is conceptualised by Indigenous people and NSW government and non-government disability agency policies?

**STUDY DESIGN**

This qualitative study explored the tensions between Indigenous people and NSW government and non-government disability agency policies regarding the conceptualisation of disability at the Cultural Interface. Gilroy (2009) described the Cultural Interface as the metaphysical space in which tensions of Indigenous ways of knowing, being and doing intersect with non-indigenous ways of knowing, being and doing. These intersections influence the lives of Indigenous people living in Australia.

To obtain Indigenous and policy sources, data sampling and collection occurred in two sets, Set 1: Indigenous Sources and Set 2: Policy Sources. Indigenous and policy sources produced in the English language and published between 1st January 2006 and 31st July 2015 were included in the study. The timeframe began at 2006 due to the CRPD (UN 2006), which marked a shift in global attitudes about people with disabilities. The timeframe ended on the 31st of July 2015 to ensure that the study was completed in October.

This study had an Indigenous governance committee that consisted of Indigenous and non-Indigenous people. To ensure that the research activities followed traditional Indigenous protocols and to prevent researcher bias, the Indigenous governance committee endorsed each step of the research process (Nelson 2007:239). The first author carried out data sampling, collection, and analysis. Data sampling, collection and analysis are discussed below.

*Set 1: Indigenous sources: Data sampling and collection.*

Indigenous sources included materials containing Indigenous spokespersons who addressed the Indigenous conceptualisation of disability in the public discourse. The Indigenous sources were examined for authenticity by checking if the spokesperson was an Indigenous Australian. The Indigenous sources were included if the spokesperson’s Indigeneity was explicitly stated within the source or in other sources (Newell and Burnard 2011:22).

The Indigenous sources collected included journal articles, magazine and newspaper articles, books and speeches. Due to the low rates of literacy in the Indigenous populations,
audiovisual materials such as videos (online, television and DVD), radio interviews and media transcripts of video and radio interviews were included (Australian Bureau of Statistics 2002). The Indigenous sources were included if at least one spokesperson was an Australian Indigenous person.

Purposive sampling followed snowball sampling until data saturation was reached. Purposive sampling was carried out to locate relevant Indigenous sources. Online databases; APAIS-ATSIS, AGIS-ATSIS, Medline, HealthinfoNet Indigenous, CINAHL, Indigenous Collection, Web of Science, PubMed and Google, ABC, SBS Australia, Lateline and YouTube were used to locate sources. Snowball sampling followed purposive sampling, where relevant additional Indigenous sources and Indigenous spokespeople mentioned in the initially collected sources were collected (Newell and Burnard 2011:22).

**Set 2: Policy sources: Data sampling and collection.**

Policy Sources included policy materials from both NSW government and non-government disability service agencies. This was because the NSW Government funds government and non-government disability service agencies to deliver services for people with disabilities according to s.8.1 of the *Disability Inclusion Act 2014*. In this study the NSW Government disability service agency included was the Department of Family and Community Services (FaCS) - Ageing, Disability and Home Care (ADHC). Relevant policy materials from ADHC and seven NSW non-government disability service agencies were obtained. In order for the study to be completed in October, seven NSW non-government disability service agencies were chosen. The seven non-government disability service agencies were selected as they were all established more than ten years ago and have diverse service types. These were:

1. Lifestyle Solutions (LS)
2. Ability Options (AO)
3. Northcott
4. Spinal Cord Injuries Australia (SCIA)
5. Disability Services Australia
Annual reports, strategic and reconciliation action plans and program guidelines that included the conceptualisation of disability were collected. The official websites, libraries and databases of ADHC and the non-government disability service agencies were purposively sampled. Snowball sampling was then used to identify other relevant policy documents mentioned in the included policy material (Newell and Burnard 2011:22). The authenticity of the policy materials was assessed by noting if the policy documents were endorsed as policies by the disability service agencies (Mogalakwe 2009).

**Data Analysis**

The Indigenous and policy sources were read and filtered to identify the sources that contained descriptions of, or defined disability (Fereday and Muir-Cochrane 2006). Each relevant Indigenous or policy source was then individually critically analysed, guided by the Occupational Justice Framework. For each policy source, the critical analysis occurred through the identification of structural factors that contributed to the policy. Potential occupational outcomes of the policy for Indigenous people and disability service agencies were also identified using the framework. For each Indigenous source, the critical analysis occurred through the identification of contextual factors that contributed to the production of the source, the author’s role, target audience and content regarding disability. The similarities and differences in conceptualisation of disability by the Indigenous and policy sources were then analysed at the Cultural Interface to identify inherent tensions between Indigenous and policy sources. The tensions and debate between the Indigenous and policy sources regarding the conceptualisation of disability were examined to identify common themes that described the debate. The potential occupational outcomes and implications of the tensions were identified with guidance from the Occupational Justice Framework (Gilroy 2009; Durocher et al. 2014:424-426).

**RESULTS**

Forty-five relevant Indigenous sources were identified: 20 articles (magazine or newspaper), 11 videos, 9 radio interviews, 2 journal articles, 2 speeches and 1 book. 34 ADHC documents were identified: 3 annual reports, 14 policy statements, 6 program guidelines and 11
information resources. A total of 50 sources from the seven non-government disability service agencies including annual reports, strategic plans, reconciliation action plans (RAP) and policy statements were identified (Figure 1). Three out of seven non-government disability service agencies had RAPs.

‘Insert Figure 1: Type and number of sources collected’

The 45 Indigenous sources yielded 55 Indigenous spokespeople with 25 males and 30 females. Out of the 55 Indigenous spokespeople, 23 spokespeople identified that they had a disability and 32 spokespeople did not identify as having a disability, but stated that they were advocates, carers, friends or family of Indigenous people with disabilities (Table 1).

‘Insert Table 1: Demographics of Indigenous spokespeople, the number and types of sources identified.’

The analysis of the Indigenous and policy sources revealed several similarities and differences in conceptualising disability that led to the identification of tensions between Indigenous spokespeople and ADHC and non-government disability service agencies. Four themes were developed: Eligibility, Identity and labels, Otherness and Power and self-determination. The four themes are examined below.

**Eligibility**

Eligibility is a predominant theme evident in ADHC and non-government sources. ADHC and non-government sources conceptualise disability when setting out the eligibility criteria for accessing services and programs.

There is variation in how non-government disability service agencies and ADHC conceptualise disability. Non-government disability service agencies: SCIA, VA and CPA cater to specific disabilities and refer to the specific diagnoses in annual reports (VA 2014; SCIA 2013; CPA 2012). Non-government disability service agencies: Disability Services Australia, Northcott and AO conceptualise disability broadly as physical and intellectual disabilities and long-term health conditions (Northcott 2013; AO 2014; Disability Services Australia 2014). All non-government disability service agencies also consider environmental barriers as disabling. Similarly the National Disability Strategy NSW Implementation Plan (ADHC 2012b) states that the environmental barriers in society that prevent wellbeing are also seen as disabling. Many ADHC program guidelines and information resources also refer Subahari Ravindran 311205925

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to people with disabilities as people born with impairments or acquiring impairments such as cognitive impairments, physical and sensory disabilities that affect their functioning capacity (ADHC 2012b: 51).

ADHC has set guidelines that govern the delivery of funded services. The Stronger Together: A New Direction for Disability Services stated that a clear eligibility criteria is required in order for people with disabilities to access services (ADHC 2006). One must meet the eligibility criteria for a standardised assessment to be conducted (ADHC 2006).

The 6 ADHC program guidelines require an individual to be assessed by ADHC and to fulfill the eligibility criteria to access the program (ADHC 2010d; ADHC 2011b; ADHC 2012a; ADHC 2012c; ADHC 2013b; ADHC 2013c). For example, the Transition to work program guidelines states that one must have

‘moderate to high support needs; have an intellectual, psychiatric, physical or sensory disability, must be eligible for a service under the NSW Disability Services Act 1993 and must be assessed as eligible by ADHC...’ (ADHC 2013b: 13).

ADHC program guidelines targeted at Indigenous people have similar eligibility criteria. For example the Services Our Way: Delivering to Aboriginal people with a disability indicates that for Indigenous people eligible to receive services, one must be

‘Aboriginal and have a diagnosed intellectual or physical disability including Acquired Brain Injury and late onset neurological conditions such as Multiple Sclerosis.’ (ADHC 2012c: 2)

ADHC’s Access and Equity Plan (ADHC 2009) aimed to increase participation of Indigenous people with disability, their families and carers by creating a culturally appropriate service system. The Plan states that Indigenous people face barriers to participation in services, due to their lack of awareness to their eligibility of services (ADHC 2009).

ADHC and non-government disability service agencies conceptualise disability in broad terms. Disability is not only conceptualised to be impairment focused but ADHC and non-government agencies also consider environmental barriers as disabling. However, in order to access services, one must be eligible. Program guidelines setting out eligibility criteria specifically refer to disability with an impairment focus. This is evident in all ADHC
programs.

**Identity and labels**

The theme Identity and labels addressed the Indigenous conceptualisation of disability. A few Indigenous spokespeople who appeared in a large number of relevant sources, thus dominant in the data, reported that many Indigenous people do not like to self-identify as having a disability. Rankine (Morton 2014; Unfinished Business Project 2014) indicated that Indigenous people fear institutionalisation and removal from their communities, hence do not identify as having a disability and consequently do not access services. Rankine (Morton 2014) indicates that the fear is also associated with the actions of the government during colonisation and the Stolen Generation.

Indigenous spokespeople also stated that many Indigenous people do not identify as having a disability. Many Indigenous spokespeople indicated that this was because the language and labels that ADHC and non-government disability services used to describe disability was not how many Indigenous people spoke about and described disability in their communities (Griffs 2012; Griffis 2013a; Briggs 2014). For example, in a radio interview, Griffis stated that labels such as Cerebral palsy and Autism were not how disability was spoken about in most Indigenous communities (Dowling and Kit 2015).

Many Indigenous spokespeople also stated that in some Indigenous communities there is no traditional word equivalent to the English word for disability. Griffis (2013b) indicated that disability is addressed as impairments, but in an empowering way that describes the Indigenous people’s contribution to their communities. Rankine, in a video, also reaffirmed that because there was no traditional word for disability some Indigenous people do not access or are unaware of services (Unfinished Business Project 2014).

Several Indigenous spokespeople in the public discourse identified that they or someone in their family had a disability. These spokespeople identified disability from an impairment perspective and described their disability experience.

‘You can’t say that the incident has not brought on any form of disability. He’s got a psychological and a mental disability and a physical one’ (Bellotti 2014:56).

Many Indigenous spokespeople, when addressing Indigenous people with disabilities,
indicated that disability or impairment is accepted as being part of the individual. These spokespeople suggested that there is an acceptance of Indigenous people for their strengths and abilities in communities. A few Indigenous spokespeople also indicated that the acceptance of Indigenous people in their communities, contributes to why Indigenous people do not access services. Rankine in a radio interview stated

‘Our brain injuries are not recognised as a disability. It has never in our communities. We’ve always been able to look after our people. We say he’s got a sore leg or he can’t hear properly (but) there was never a label attached to describe these disabilities’ (Cowie, 2013).

Indigenous spokespeople dominant in the data suggest that Indigenous people do not self-identify as having a disability. Some Indigenous spokespeople in the data identify as having a disability and address disability in terms of impairments and diagnosis. Many Indigenous spokespeople reiterated that Indigenous people are accepted for their strengths and contribution to the community. A few Indigenous spokespeople indicated that Indigenous people might not seek disability services due to fear of institutionalisation and separation from communities.

*Otherness*

A few ADHC sources discussed the Indigenous conceptualisation of disability (ADHC 2009; ADHC 2012c). The documents acknowledged the diversity in disability conceptualisation in Indigenous communities. The documents also indicated that Indigenous people did not like taking on the label of disability and that family support is an expected responsibility. There is an underlying notion of Otherness that is present in the ADHC and non-government policy documents where Indigenous people were categorised as the Cultural Other.

ADHC and non-government disability services policy documents provided recommendations for support to Indigenous people, but also categorised Indigenous people with people from culturally and linguistically diverse backgrounds (ADHC 2010b). For example, in the Respite program guidelines (ADHC 2011b) Indigenous people were categorised with people from culturally and linguistically diverse backgrounds, whilst holistic and culturally appropriate services were promised. In the Stronger Together: A New Direction for Disability Services (ADHC 2006), Indigenous people were referred together with Culturally and Linguistically Diverse people and described to be experiencing barriers in accessing services. ADHC (2006)
promised to improve service access for Indigenous people and people from culturally and linguistically diverse communities by ensuring that everyone has equitable access to services, based on functional need, despite their background.

ADHC and non-government disability service agencies categorise Indigenous people with Culturally and Linguistically Diverse people. Whilst Indigenous people’s culture and conceptualisation of disability is acknowledged, Indigenous people are Culturally Othered within the documents.

**Power and self-determination**

Both Indigenous spokespeople and policies refer to self-determination when describing disability. Indigenous sources focus on recognising inherent capabilities within people with disabilities. Policies refer to self-determination and giving power to Indigenous people with disabilities. There are also underlying imbalances in power between ADHC, non-government and Indigenous sources.

Most Indigenous spokespeople who identified as having a disability or had family members, who had a disability, stated that having a disability did not prevent or interfere with their aspirations, goals and their community contributions. They also stated that they would rather be recognised for their strengths and abilities. In a radio interview, Pedersen stated:

> ‘He’s [my brother is] a lot more open-minded, he’s got an open heart, he shares a lot more. That for me, there’s no disability in that. There’s a great ability in being human and that’s one thing that’s always resonated with me with my brother is that he makes people happy.’ (Ramsey 2012a)

Multiple ADHC documents and non-government disability service agencies reflect the principle of self-determination and giving power to people with disabilities to make decisions for themselves (ADHC 2010c; ADHC 2011c; ADHC 2013b). ADHC sources also indicate that Indigenous people have the choice to participate in society and experience wellbeing (ADHC 2011a; ADHC 2010a). However when providing information resources targeted at Indigenous people there is a mismatch between the language used and the intentions of the disability service agency. For example the Shoulder-to-Shoulder document indicated

> ‘There are several organisations that can help with your child’s health and therapy and they can also help you understand what is best for your child.’(ADHC 2012d:8).
This statement indicated the intention to enable Indigenous people with disabilities to be provided with the choice to make their own decisions in their lives. But the document stated that the service providers knew what is best for the Indigenous people. The Shoulder-to-Shoulder document demonstrates that whilst the intention was ensuring self-determination, the language used conveys that ADHC has power over the choices provided for Indigenous people (ADHC 2012d).

Indigenous people also reiterated the mismatch in language used by disability service agencies and Indigenous people. Rankine stated that the way that Indigenous people convey information maybe different to the disability service sector, resulting in misunderstandings (Disability Media Australia 2012). An example was when an Indigenous woman in LS RAP (2012) stated that she was only able to help her children once she converted what the service providers were saying about her child’s disability into the Indigenous way. Few Indigenous spokespeople in the data indicated that most Indigenous families have greater priorities and learning the language of the disability services sector was considered a burden. An Indigenous elder in the LS RAP (2012) indicated that they would like to work together with LS for appropriate service delivery, but if the agencies approach Indigenous people with the mentality that agencies are the experts, the agencies will be wasting their time. Rankine in a video stated

‘I mean it’s getting better, there’s been a lot of work happening, but there’s still a long way to go as far as getting it. At least try and get it right, so people can function. Some of these services are act as if they are doing you a favour, when they are supposed to be for the people’ (Disability Media Australia 2012)

Most Indigenous people and ADHC and non-government disability service agencies indicate the need for culturally appropriate services for Indigenous people with disabilities. Several Indigenous spokespeople state that advocating to bridge the gap between Indigenous people’s needs and the disability service sector is essential. Table 1 illustrates that 12 out of 55 Indigenous spokespeople were representatives from Australian Disability advocacy agencies. The advocacy agencies were located on the People with Disability Australia online directory (People with Disability Australia 2015). Board and staff members mentioned in the advocacy agency websites were filtered against the 55 Indigenous spokespeople. Griffis and Rankine (Table 1) from the same advocacy agency appear more frequently in Indigenous sources regarding disability in the public discourse. These spokespeople spoke about their personal
experiences with disability when targeting Indigenous people and also spoke about the need for culturally appropriate services and the diverse Indigenous conceptualisations of disability when addressing mainstream audiences.

Indigenous, ADHC and non-government disability service agency sources focus on self-determination when describing disability. Indigenous spokespeople, ADHC and non-government disability service agencies focus on strengths and abilities and ensuring that Indigenous people are provided with the choice to make their own decisions regarding service provision. However, whilst the agencies intend for self-determination, findings suggest that the language used in the documents are currently not culturally appropriate for Indigenous people.

**DISCUSSION**

There are several similarities and differences in how disability is conceptualised by Indigenous people, ADHC and non-government disability service agencies. Findings indicate that ADHC and non-government disability service agencies adopt the holistic approach to conceptualising disability, including both impairment and social and environmental factors (Dempsey and Nankervis 2006:5-10). The impairment factor is adopted when the diagnosis and assessments are carried out to ensure access and eligibility into services. The social and environmental factors are addressed during service delivery. ADHC and non-government disability service agencies also focus on self-determination where people with disabilities are in charge of their own service planning (Lord and Hutchinson, 2003:71-74).

Findings show that Indigenous communities value cultural protocols such as acceptance and celebrating the strengths of Indigenous people with disabilities. Findings also suggest that Indigenous spokespeople did not self-identify as having a disability, due to fear that they would be removed from their communities and institutionalised. Our findings reinforced Gilroy’s (2009; 2010) claims that reported that Indigenous people fear and distrust disability services due to the historical policies representing Indigenous people as the Cultural Other and as passive recipients of services.

The categorisation of Indigenous people based on their race, cultural values and beliefs contributes to the concept of the Cultural Other (Gilroy, 2012:123). It is evident that categorising Indigenous people as the Cultural Other is a cultural value that has an influence on ADHC and non-government disability service agency policies and programs (Durocher et al. 2012:123).
Gilroy (2010) studied Indigenous people’s representation in government documents from 1985 to 2010 and concluded that Indigenous people were represented as the Cultural Other over this time period. Our findings also show that relevant ADHC and non-government disability policies from 2006 to 2015 also Culturally Othered Indigenous people. These findings imply that due to the consistent Cultural Othering of Indigenous people in policies, Indigenous people continue to be marginalised from disability service access, as their culture and values are categorised as different in policies (Durocher et al. 2014).

ADHC (2006) states that equitable access based on functional need are to be provided for Indigenous people, despite their background. To attain equitable access based on functional need, one must be eligible as determined by a standardised assessment (ADHC 2006). Findings show that eligibility criteria into programs were predominantly impairment focused, where one must have a disability, such as an intellectual or physical disability. Indigenous spokespeople who dominate the sources state that there were no translatable words describing disability in Indigenous communities, consistent with previous research (Ariotti 1999). Moreton-Robinson (2004:76) indicates that Indigenous people view labeling and categorising Indigenous people based on their perceived abilities as culturally disrespectful, due to previous colonial policies categorising Indigenous people based on their features. Our findings also highlight this view as Indigenous spokespeople state that many Indigenous people do not self-identify as disabled. Findings also highlight that some Indigenous spokespeople could not relate to the language and labels used by disability service agencies to describe disability. Policy documents such as ADHC’s Access and Equity Plan (ADHC 2009) acknowledge cultural factors such as Indigenous people not wanting to identify with the perceived negative label of disability. However by stating that access to services is based on functional need, Indigenous people’s background and Indigenous people’s cultural values are overlooked. Hence findings suggest that Indigenous people are required to conform to the medical diagnosis and give up their cultural identity to take on the label of disabled, in order to access services.

ADHC and all seven non-government disability service agencies promote self-determination. Agencies indicate that cultural values are considered when catering to the needs of the Indigenous communities (ADHC 2009). However, when addressing Indigenous people with disabilities, the services take the individual approach that is medical model and philanthropic model focused (Dempsey & Nankervis, 2006:5-10; ADHC 2012d). Agency policies address
Indigenous people as needing help from agencies, as demonstrated by the language used in the documents (ADHC 2012d). This in turn demonstrates that the agencies display power over and undermine the capabilities of Indigenous communities, by taking on the individual approach. Furthermore, Indigenous people are required to identify with the label of disabled to become eligible to access services, which is medical model focused. Thus the concept of self-determination is contradicted, as assessing eligibility is seen to be necessary for Indigenous service provision by ADHC and non-government disability service agencies. As a consequence, Indigenous people and communities are limited in opportunities for autonomy and experience marginalisation (Durocher et al. 2014),

Results show that 12 of the 55 Indigenous spokespeople in the data were part of Australian disability advocacy agencies. The two Indigenous spokespeople who appear most frequently in the public discourse, Griffis and Rankine, were representatives of the same advocacy agency (First Peoples Disability Network Australia 2015). As these two Indigenous spokespeople are most common in the public discourse, other spokespeople’s voices and conceptualisation of disability is under-represented and less common in our data. Indigenous spokespeople from advocacy agencies have the power to influence the public discourse (Durocher et al. 2014:425). The two spokespeople dominant in the data, target policy makers and disability service providers when indicating that Indigenous people do not identify with the label of disability. When these dominant spokespeople target Indigenous people in communities, they share their experiences of disability and identify with the label of disability. Most other Indigenous spokespeople who were not part of advocacy agencies and were less frequent in the data, identify with the label of disability and conceptualise disability from an impairment perspective. These less dominant spokespeople mainly targeted Indigenous communities and the mainstream audience. Thus the spokespeople’s perception of disability varied according to their position of power in the public domain and target audience.

**LIMITATIONS**

There were a few limitations in this study. One limitation in this study was the access to documents. The data collection and sampling was limited by the number of annual reports and documents displayed on the websites of the disability service agencies. Some Indigenous sources, such as videos, were only available online for a limited period of time before the expiration date, hence some relevant sources may have been missed. Therefore implications
and recommendations made in this study were based upon the data gathered during the set time period. This study also identified that there is diversity in the perspectives and number of Indigenous voices in the Australian public forum regarding the conceptualisation of disability. However, the Indigenous voices and their perspectives identified in this study are not representative of the perspectives of all Indigenous people and Indigenous communities in Australia. Nevertheless, future research could investigate upon a broader representation of Indigenous voices in the public forum regarding disability. This could ensure that the voices of Indigenous people in Australia and their concerns regarding disability, within communities are heard in order for successful disability service provision.

CONCLUSION

ADHC and non-government disability services predominantly adopt an individual approach to disability, where access to services is based on eligibility. Findings suggest that Indigenous people are required to conform to the Western conceptualisation of disability to access services that promise self-determination. With the development of the NDIS, Indigenous people have the opportunity to access services of their choice. NSW disability service agencies could ensure that they work with Indigenous spokespeople to develop RAPs to ensure culturally appropriate services. Indigenous spokespeople could be provided with opportunities to speak about their experiences and conceptualisation of disability to their own communities and disability service agencies, thus enabling disability service agencies to recognise that Indigenous people are experts of own their culture, values and beliefs. Agencies could also seek advice from Indigenous spokespeople and Indigenous elders within communities about their needs and cultural protocols to ensure a shift from the individual approach to disability towards ensuring choice and self-determination for Indigenous people, regarding service provision.

ACKNOWLEDGEMENTS

This research project is an unfunded project carried out at the University of Sydney. There are no conflicts of interest to declare.
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doi:10.1353/eas.0.0006.


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### Table

**Table 1:** Demographics of Indigenous spokespeople, the number and types of sources identified.
Table 1: Demographics of Indigenous spokespeople, the number and types of sources identified.

<table>
<thead>
<tr>
<th>Spokesperson (n=55)</th>
<th>Advocacy agency</th>
<th>Number of Sources</th>
<th>Sex</th>
<th>Identifies disability</th>
<th>Types of sources</th>
</tr>
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<tbody>
<tr>
<td>2. *Rankine, G (First Peoples Disability Network Australia 2015)</td>
<td>First Peoples Disability Network Australia (2015)</td>
<td>6</td>
<td>F</td>
<td>✓</td>
<td>Videos, radio interviews, Articles (magazine and newspaper) &amp; speeches</td>
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<td>3. Gilroy, J (Gilroy 2012:8)</td>
<td>N/A</td>
<td>3</td>
<td>M</td>
<td>✓</td>
<td>Articles (magazine and newspaper)</td>
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<td>4. Kennedy, G (Sobott 2015)</td>
<td>N/A</td>
<td>3</td>
<td>F</td>
<td>✓</td>
<td>Videos, radio interviews, Articles (magazine and newspaper) &amp; Book</td>
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<td>5. Widders, S (Widders 2014)</td>
<td>N/A</td>
<td>3</td>
<td>M</td>
<td>✓</td>
<td>Radio interviews, Articles (magazine and newspaper)&amp; Book</td>
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<tr>
<td>7. Oscar, J (The George Institute for Global health Australia 2014)</td>
<td>N/A</td>
<td>2</td>
<td>F</td>
<td></td>
<td>Radio interviews &amp; Book</td>
</tr>
<tr>
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<td>11. *Bostock, L (Bostock 2014)</td>
<td>Aboriginal Disability Network NSW (2015)</td>
<td>2</td>
<td>M</td>
<td>✓</td>
<td>Articles (magazine and newspaper) &amp; Videos</td>
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<td>First Peoples Disability Network Australia (2015)</td>
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<td>13. Flanders, L (Flanders 2014)</td>
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<td>F</td>
<td>✗</td>
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<td>*Clarke, L (Ramsey 2012b)</td>
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<td>Miller, L (Outback Academy, n.d.).</td>
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<td>RGM Artists 2012</td>
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<td>Disability Advocacy Service Inc. n.d.</td>
<td>(Disability Advocacy Service Inc. n.d.)</td>
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<td>Collins 2014</td>
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<td>45.</td>
<td>Wilson, S (Aboriginal Drug and Alcohol Council SA Inc. n.d.)</td>
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<td>Radio interview</td>
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<td>46.</td>
<td>Hodges, B (Carers Australia Incorporated 2014)</td>
<td>N/A 1 M ✗</td>
<td>Radio interview</td>
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<td>47.</td>
<td>Barba, B (Barba 2014)</td>
<td>N/A 1 F ✗</td>
<td>Book</td>
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<tr>
<td>48.</td>
<td>Blair, W (Blair 2014)</td>
<td>N/A 1 M ✗</td>
<td>Book</td>
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<td>49.</td>
<td>Mundine, P (Mundine 2014)</td>
<td>N/A 1 F ✓</td>
<td>Book</td>
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<td>50.</td>
<td>Grant, K (Grant 2014)</td>
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<td>Book</td>
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<td>51.</td>
<td>Campbell, H (Campbell 2014)</td>
<td>N/A 1 F ✓</td>
<td>Book</td>
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<td>Rotumah, T (Chesterton 2008)</td>
<td>N/A 1 F ✓</td>
<td>Articles (magazine and newspaper)</td>
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<td>53.</td>
<td>Avery, S (Avery 2014)</td>
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<td>54.</td>
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<td>N/A 1 F ✗</td>
<td>Journal Article</td>
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</table>

*Note. The spokespeople with asterisks beside their names are the Indigenous spokespeople who are representatives of Australian Disability advocacy agencies (People with Disability Australia 2015).*
FIGURE

Figure 1: Type and number of sources collected
Figure 1: The types of Indigenous sources, ADHC sources and all seven of the non-government disability service agencies: Ability Options (AO), Northcott, Spinal Cord Injuries Australia (SCIA), Vision Australia (VA), Cerebral Palsy Alliance (CPA), Lifestyle Solutions (LS) and Disability Services Australia are graphed against the number of each of the sources collected.
Section 3: Appendix

Appendix A: Journal Manuscript Guidelines
APPENDIX A : JOURNAL MANUSCRIPT GUIDELINES

Notes for contributors

The Australian Journal of Social Issues is a quarterly publication that welcomes submissions examining issues of social justice and social policy that are of relevance to Australia.


Types of Submissions

The AJSI accepts research article submissions up to 8,000 words, including abstract, tables, notes and references. The journal also invites shorter submissions up to 5,000 words that review and analyse current policy debates, theory and practice. These will appear in a Forum section. The editors will consider proposals for thematic issues on significant current issues and debates. All submissions are peer-reviewed.

Manuscripts can be submitted electronically at http://mc.manuscriptcentral.com/ajsi

Preparing your Documents for Submission

Title page document – a separate document containing the manuscript title, author names, the corresponding author, author affiliations, a note on each author up to 80 words in length, 5 keywords and an abstract of up to 200 words.

Main document – Remove all obvious author identifying information including self-citations and acknowledgements. Arrange your document in the following order: main text, Acknowledgements, References, Endnotes.

Text – 12 point Times New Roman font, 1.2 or 1.5 line spacing.

Quotations – indent quotations of more than 40 words. For shorter quotations, include them in the paragraph and use single quotation marks.

Interview quotations – should be indented, even where shorter than 40 words, and followed by italicized identifying information in brackets, for example: (Suzanne, daughter, regional area).

Headings – first word capitalized, 12 point casing, aligned with left margin, no numbering.

Table and figures – include on separate sheets following the list of references or in separate files. Number tables and figures separately and numerically, include a short descriptive title, and insert any notes and legend below. Indicate placement in the text, for example: ‘Insert Table 1 here’.

Acknowledgements – to ensure anonymity, remove acknowledgments from the submission; these can be inserted before the list of references once the article is accepted for publication. Declare your research funding sources here.

Endnotes – use sparingly, in text explanations are preferred. Place endnotes after the list of references.
References in the text – Harvard author-date style. Organise cited references in ascending date order. Use ‘a’, ‘b’, to distinguish between works published in the same year by a single author. Examples:- The major improvement was in the quality of the poisons used (Banks & Braes 1997a:122).

Later studies (for example, Heathwood et al. 1995; Banks & Braes 1997b, 2010; Enquist 2010; Viorella 2010) reinforced the case for insurance law reform. Roy (1997a:408) argues that ...

Referencing examples

At the end of the manuscript, include a list of all references cited in the text, arranged alphabetically by author, chronological year of publication and presented under the heading ‘References’. Do not use ‘et al.’ or ampersands (‘&’) here. Examples to follow include:

Official publications


Books


Book chapters


Journal articles


Newspaper articles


Media releases


Reports

Working/discussion papers


Theses


Conference papers


In-text Hyperlinks

Hyperlinks are an increasingly important component of documenting the sources used and enhancing the readers’ experience of journal articles; however writing out the full details of the link can reduce the readability of the publication. When inserting hyperlinks in the references follow the above examples. For in-text hyperlinks provide short description rather than the full link to ensure that any unnecessarily long links are hidden and the text reads well. Never use a URL as a hyperlink within a sentence: Instead of ‘full details are available at: ‘http://www.comlaw.gov.au/Details/C2013A00020’ use ‘full details are available in the National Disability Insurance Scheme Act 2013’. We recommend that authors cut and paste their hyperlinks into the ‘Edit Hyperlink’ dialog box in Word and then give it a shortened name. This way the electronic version of the journal can display an active link to the source document without excessively compromising the readability of the text.

Presenting Research Methodologies and Ethics

The Australian Journal of Social Issues has a broad readership. To ensure the readability of the journal to its diverse and multi-disciplinary audience, authors should ensure their submission can be read across disciplinary boundaries and include, where relevant, the following items in their manuscript:

■ Incorporate a dedicated discussion of the methodology, outlining the approach taken, its relevance to the research issues at hand and any innovations involved;

■ Provide details of any formal ethical approval, recruitment strategy, the process used for obtaining informed consent and any ethical concerns that arose during the research;

■ Explain the research setting and include the sample size and/or key characteristics of participants where relevant;

■ Describe the process of analysis for desktop reviews, e.g. coding strategies, including computer coding, and when part of a research team, the role of each person in the analysis, consideration of any bias and strategies for ensuring consistency between researchers;

■ Outline any limitations of the research including that relating to the data and methodology;
Limit the use of jargon but where used place it in single quotation marks and explain its meaning in the text;

Declare any funding arrangements and the role of the funding body in the research.

Submission

Submit your manuscript electronically at http://mc.manuscriptcentral.com/ajsi When submitting your manuscript through the online submission system, ScholarOne, you will be asked to identify your funding sources, declare any conflicts of interest, affirm that the manuscript is being submitted to the AJSI only and that it has not been submitted, in press or published elsewhere.

The Review Process

The AJSI employs a double-blind peer review process where the identities of authors and referees are concealed from each other. The expert assessments of two referees are sought and a third may be consulted from time to time. Most papers require some revision. Once a paper is accepted, the editors will correspond with you to ensure that your article fully complies with the AJSI style in the final proofs. To facilitate the publication process, please ensure your manuscript is correctly laid out.

Journal Copies

All authors receive a hard copy of the issue in which their article appears and a PDF proof copy.

Revised November 2014