National Disability Insurance Scheme (NDIS) and intersectional challenges for Australia's Aboriginal people's

Introduction

The National Disability Insurance Scheme (NDIS) finished its trial period in July 2016 and has commenced rolling out across Australia (https://www.ndis.gov.au/about-us/our-sites). Some described it as "… the most significant policy reform for people with a disability since the Disability Services Act 1986 (DSA)" (https://nacchocommunique.com/2017/03/22/naccho-aboriginal-health-disability-and-ndis-your-top-10-questions-answered-about-the-national-disability-insurance-scheme/), others since the introduction of Medicare (2017, MO pers comm., 2 August). The purpose of this research paper is to investigate the intersectional issues between being Aboriginal and the person with a disability. The difficulties faced by having both these identities intersect when engaging with the new and rhetorically described 'revolutionary health and social inclusion' policy known as the NDIS. The reason this research is important is to learn and best understand the intersectional issues faced by Aboriginal people who will soon be required to use the NDIS. This research should be used to ensure best practice when interacting with individuals and their families to achieve the most appropriate outcomes in regards to culturally appropriate and effective service delivery. The correct implementation of the NDIS for Aboriginal Australia will ensure maximum usage of the NDIS by Aboriginal people to maximise both community participation and their life journey. In addition, this research reduces the knowledge gaps that relate to Aboriginal people with a disability accessing service provisions.

Literature review

The arena of public policy regarding the delivery of services to Aboriginal people with disabilities is deeply under researched (Hollinsworth, 2013, p. 601; King, Brough & Knox, 2014, p. 738-9, 48; Angell, Muhunthan, Irving, Eades, Jan, 2014, p. 1). And, as a consequence, little is known of the intersectional issues which occur between Aboriginal people and disability public policy implementation. In additional, this lack of research

has contributed to an inadequate level of knowledge regarding the most effective way to implement public policy within this area (p. 1).

The United Nations has several different interpretations of 'disability', some of these include the loss of ability or something able to be done before, for example writing, or riding a horse (Booth, 1981, p. 1). The difference is, as felt by the disabled person as to what they could do, or what they can now do (p. 1). It is important to recognise the term 'disability' is a non-Aboriginal concept (King, Brough & Knox, 2014, p. 743; Biddle, Al-Yaman,Gourley, Gray, Bray, Brady, Pham, Williams & Montaigne, 2012, p. 13; Massey et al., 2013 cited in Stephens, Cullen, Massey and Bohanna, 2014, p. 262). Many Aboriginal people with a disability do not self identity (http://www.carersaustralia.com.au/storage/ATSI%20Forum%20Report%20Final.pdf) and there is no equivalent word for disability in Aboriginal discourse (http://www.carersaustralia.com.au/storage/ATSI%20Forum%20Report%20Final.pdf. The Aboriginal community interpret 'disability' through the lens of community participation, such as cultural activities like fishing or camping (Hollinsworth, 2013, p. 610; King, Brough & Knox, 2014, p. 746,748;). "Aboriginal people living with disability experience their disability very much within the context of their Indigenous identity" (p. 748). For example, an Aboriginal man is responsible for caring for Country, family and lore regardless of having a perceived mainstream interpretation of 'disability'. Mokak (1997, p. 15) identified that Aboriginal culture does not perceive having been born with or having a 'disability' as being sick. The tendency of Aboriginal people not identifying as disabled contributes to the under reporting of disability in Aboriginal communities (Aboriginal Disability Network New South Wales, 2007, p. 10).

Statistics reflect a large number of chronically disabled Aboriginal people within Australia (Booth, 1981, p. 5). The rate of disability within the Aboriginal community is more than double that of the non-Aboriginal community (Briddle et al., 2012, p. ix). Half of all Aboriginal people above the age of 15 have a disability, and more than one third of the population above the age of 65 (Biddle et al., 2012 cited in Stephens et al. 2014, p

Comment [B2]: Definition & identity

Comment [B3]: Statistics

261). The National Disability Insurance Agency states appropriately five percent of NDIS participants are Indigenous (https://nacchocommunique.com/2017/03/22/naccho-aboriginal-health-disability-and-ndis-your-top-10-questions-answered-about-the-national-disability-insurance-scheme/). The 2006 Australian census found 36% of Aboriginal people with a disability live in major cities, 46% in regional areas and 18% in remote locations (ABS 2006 cited in Briddle et al., 2012, p. 38). More than half of the Aboriginal community with a disability live away from major capital cities where the majority of support services exist. This creates additional challenges for service provision engagement.

The general disadvantaged experienced by Aboriginal people due to colonisation (e.g. loss of culture, dispossession of Country, stolen children, poverty, in adequate services to name are few) is further magnified by the disadvantages associated with having a disability (Mokak, 1997, p. 14). This is referred to as double disadvantage or dual disability (p. 14).

Comment [B4]: Dual Disadvantage

The idealistic policy objective of the NDIS is all Australians, regardless of disability will receive some form of support to maximise their involvement in the community and on their individual life journey. In theory, all Australians with a disability will be provided with the funds to choose, according to their needs, services they need for their support and community engagement (https://www.ndis.gov.au/about-us/what-ndis). In the past, often what has prevented consideration of intersectional issues in relation to Aboriginal public policy implementation is inherit, and sometimes insidious racism.

Comment [B5]: NDIS expectations

The European invasion of the land mass known as Australia from 1788 resulted in the murderous dispossession of Aboriginal lands (King, Brough & Knox, 2014, p. 740). This time also brought the ravages of diseases to which Aboriginal people had no immunity protection (p. 740) bringing about further physical and cultural death. Government 'protectors' oversaw all aspects of Aboriginal people's lives from freedom of movement; forbidding the use of traditional languages and undertaking of traditional customs; employment including access to wages (or non-access in many cases); removal of

Comment [B6]: Racism

children and marriage (Lake & Reynolds, 2008). All these historical experiences have shaped the way in which Aboriginal Australia interprets governments and public policy. Understandably, there is a deep mistrust. Historically governments have inflicted mainstream public policy on Aboriginal people and their communities. This has resulted in policy failure due to a lack of consideration given to historical influences and the cultural differences between Aboriginal Australians and their communities with mainstream Australia.

Health benefits have predominantly been measured using Westernised health constructions, which are very different from the health construct in Aboriginal culture (Angell et al., 2014, p. 10). "Culture and identity are central to Aboriginal perceptions of health or ill health" (Biddle et al., 2012; Massey et al., 2013 cited in Stephens et al., 2014, p. 262). Drew, Adams and Walker 2010 (cited in Stephens et al., 2014, p 262) found "Aboriginal people often view health in a broad sense that includes consideration of the physical, cultural and spiritual components of wellbeing". In addition, the Aboriginal community places great emphasis on good relationships.

> *"Aboriginal people, and most notably include respect and reciprocity as basic values for good relationships – in life and in health care settings. These are the themes that Aboriginal people identified as being important to them and their families, and while all are cultural issues, they can be categorized as being about sociality, cultural and structural concerns" (*McBain-Rigg & Veitch, 2011, p. 71).

This understanding of the importance of relationships within Aboriginal culture is required to effectively communicate with Aboriginal people and communities. To effectively deal with the intersectional issue of differing culture values between Aboriginal and mainstream Australia, it is important to understand the requirement of, and fundamental role of Aboriginal health workers.

Comment [B7]: Cultural differences

There is an abundance literature which recognises the importance of using Aboriginal health workers to ensure effective communication (Angell et al., 2014, p. 11; Mokak, 1997, p 15; McBain & Veitch, 2011, p. 70). Aboriginal people know the most appropriate ways to engage with their own people through the use of language and recognition of cultural practices and value systems (p. 70; Angell et al., 2014, p. 11; Mokak, 1997, p 15). Research has showed Aboriginal and non-Indigenous mainstream Australian interpret cultural barriers differently (McBain & Veitch, 2011,p. 70). Aboriginal people place a heavy emphasis on social relationships, respect and trust while health practitioners have less of a focus on interpersonal relationships (p. 70). The use of Aboriginal health workers reduces these intersectional barriers and the inevitable misunderstandings that result (Mokak, 1997, p 15). There is a fundamental need for Aboriginal health workers to collaborate and assist in the implementation of the NDIS. Culturally inappropriate communication may have the impact of Aboriginal Australians who want to engage with the NDIS not receiving appropriately supported services because they are left unaware of their rights and entitlement for support (Productivity Commission 2011 cited in Stephens et al., 2014, p. 264). This has historically been the case for Aboriginal people under previous support structures (Griffs, 2010, p. 7), including financial management.

> **Comment [B8]:** Role of Aboriginal Health workers

Due to self-directed/managed funding being a new component brought in as part of the NDIS, there is little literature that has considered the topics and its possible impacts. First People's Disability Network (2013a cited in Stephens et al., 2014, p. 267) acknowledge the difficulty Aboriginal people will have due to little of no experience in self-managing disability funding. These responsibilities will include quarterly reporting to relevant funding bodies for example. All people regardless of race who qualify for NDIS funding need to be aware of their rights and responsibility so they can best plan their support needs and control their own destiny (http://www.carersaustralia.com.au/storage/ATSI%20Forum%20Report%20Final.pdf). Again, this reiterates the importance of using Aboriginal health workers to ensure the conveying of information in a culturally appropriate and effective manner.

> **Comment [B9]:** Self-directed funding

Methodology

This research considers how the NDIS can navigate and deal with the intersectional issues currently faced by Aboriginal people who have a disability. The data for this research project was obtained using qualitative one-on-one interviews as a way to obtain knowledge around the NDIS and possible intersectional issues. Conducting research using in-depth qualitative interviews provide a mechanism to investigate the social world including culture, society and behaviour via analysis of people's words (Hogan, Dolan & Donnelly, 2013, p. 9). The qualitative research process provides an "in-depth understanding" of the social phenomenon being explored through the standpoint of the subject's point of view (p. 10).

The participants were sourced primarily because of their knowledge and understanding of living with a disability, and working and advocating within the disability sector. One participant has a number of roles including a disability advocate and parent of a 27-year-old woman with down syndrome. Another is an Indigenous man "pushing towards the better side of thirty" (2017, ES pers. Comm., 2 August) is an University academic who has Post Traumatic Stress Disorder (PTSD). The third interviewee, 37, is the wife (a beautiful woman) of the researcher who has a disability herself. Each interview ranged in duration from 15 to 25 minutes. Each of the three interviews were held at a different venue to suit the participant and promote comfortability to foster the sharing of their stories and experience (Hogan, Dolan & Donnelly, 2013, p. 9). The first interview was conducted at the office of Queensland Advocacy Incorporated (QAI). The second, in the academic's office. The third was conducted at the home of the participant.

An in-depth interview model was utilised including the use of open-ended questions to elicit as much information from the interviewee as possible (p. 93). The interview was then transcribed and coded using a thematic coding system to identify key themes. Data analysis was conducted using a thematic approach because the research was

primarily concerned with the content of the researcher-interviewee interaction, not the finer details of speech delivery (p. 187).

It is worth noting the interviewer himself has a disability and identifies as Aboriginal. It is important to note the researcher made a conscious decision to conduct the research using the framework of reflectivity. The reflexive approach used Alvesson and Skoldberg's process of using a high level of self-consciousness in regards to the researchers own position as an interpreter and author throughout the research and writing process (den Outer, Handley & Price, 2013, p. 1504). Including the process of interpretation, the political component of the research (p 1504) and self-identification as an Aboriginal person with a disability. The researcher has conducted the research in a reflexive manner all be it "with the recognition objective reality can never be fully captured" (Hogan, Dolan & Donnelly, 2013, p. 10).

Findings

Perhaps reflecting the lack of research, both in academia and the public policy sphere regarding Aboriginal disability and corresponding public policy intersectional challenges, only six of the eleven issues/themes raised by the interviewee have been considered in previous research.   These included NDIS expectations (https://www.ndis.gov.au/about-us/what-ndis).   The different culture and value system of Aboriginal communities and main-stream Australia, in particular, the Aboriginal communities high regard for the significance of relationships (Biddle et al., 2012; Massey et al., 2013 cited in Stephens et al., 2014, p. 252; Drew, Adams & Walker 2010 cited in Stephens et al., 2014, p. 262; McBain-Rigg & Veitch, 2011, p. 71). The importance of culturally appropriate communication to maximise the opportunity for effective communication (p 71; Mokak, 1997, p. 15; Productivity Commission 2011cited in Stephens et al., 2014, p 264). The importance of using Aboriginal health workers as communicators (p 264; McBain-Rigg & Veitch, 2011, p. 71; Mokak, 1997, p. 15). The historical impact of colonisation (King, Brough & Knox 2014, p. 740) and concerns regarding self-directed funding (FPDN 2013a and NDCA cited in Stephens et al., 2014, p. 267).

Notably six, more than half, of the eleven issues/themes identified in the interview process were raised by all three participants. Including concerns the NDIS expectations would not be met. That Aboriginal people will not be informed about the NDIS, let alone understand an incredible complex public policy process (including self-management of funding). The need for understanding the cultural differences between Aboriginal communities and mainstream Australia. The importance of using cultural effective communication methods and the need for Aboriginal family members to receive information.

All three participants were worried NDIS outcomes would not reach policy expectations. "Promises that no one will be any worse off I'm not so sure that's the true" (2017, MO pers comm., 2 August). Interviewee MB (2017, pers comm., 19 August) acknowledged the importance for both the requirement of the NDIS to be properly resources and funded to ensure Aboriginal people have access to the services mainstream Australia. In addition expressed concerns Aboriginal people would not hear about the NDIS, let alone understand the requirements of a complex public policy (19 August).

Interviewee ES (2017, pers comm., 2 August) identified a lack of consultation between government and Aboriginal people with disabilities and their families. He cites this lack of consultation as one of the contributing factors that have contributed to "[NDIS] has not been developed in a way that is fully cognisant of the intersectional issues of Indigenous disability". He also stresses the importance of continuous consultation because the NDIS would not be a panacea for "fixing" disability within the Aboriginal community, that the public policy issue would always be in existence and hence the requirement for continued discourse (2 August). Whilst he acknowledged some consultation had occurred, he was anxious about the communication not fostering a strong narrative about Aboriginal people with a disability.

"Even though when they have had targeted Indigenous awareness programs as part of NDIS they very much appealing to what I believe is a stigmatised and a stereotypical understanding idea of disability in a sense that isn't building progressively toward a different narrative conversation about disability" (2 August).

These intersectional concerns about a lack of understanding the needs of Aboriginal people with disabilities, consultation and marginalised discourse was reiterated in the interviewees concerns regarding the historical occurrence of Aboriginal people being blamed for policy failure. "Aboriginal people themselves end up becoming blamed for failures of program implementations … continue to be categorised the architects of their own failure" (2 August).

Conclusion

This research project has identified numerous intersectional issues regarding implementing the NDIS to better the lives of Aboriginal people. Clearly more concise and constructive research needs to be conducted to maximise the opportunity of policy success. There are five foremost findings of this research project. They include concerns the NDIS will not achieve its policy goal for Aboriginal communities. Aboriginal people not receiving information about the NDIS, let alone understand the requirements of a complex public policy (particularly in relation to self-directed funding). A lack of appropriate consultation; and concern Aboriginal people will again be blamed for policy failure when in reality intersectional issues had not been properly addressed. The NDIS is a historical opportunity for correctly implementing a health and social inclusion policy to reach its rhetorical goals of creating more opportunity and social inclusion, and ultimately a better life for Aboriginal people with a disability.

Reference list

Angell, Blake, Muhunthan, Janani, Irving, Michelle, Eades, Sandra, & Stephen, Jan 2014, 'Global Systematic Review of the Cost-Effectiveness of Indigenous Health Interventions', PLOS ONE, vol. 9, no. 11, pp 1-10. Retrieved 10 September 2017, from ProQuest.

Aboriginal Disability Network New South Wales (ADN) 2007, Telling It Like it Is, *Standing Committee Investigating Overcoming Aboriginal Disadvantage* prepared by the Aboriginal Disability Network New South Wales

Biddle, Nicholas, Al-Yaman, Fadwa, Grouley, Michelle, Gray, Matthew, Bray, J. Rob, Brady, Brendan, Pham, Le Anh, Williams, Emma & Montaigne, Maxine 2012, 'Indigenous Australians and the National Disability Insurance Scheme: The extent and nature of disability, measurement issues and service delivery models', *Australian National University, Australian Institute of Health and Welfare*, Canberra.

Booth, C 1981, *The Disabled Person*. United Nations International Year of the Disabled Persons.

Carers Australia 2013, National Disability Carers Alliance 2013, 'Implementing the NDIS in Aboriginal and Torres Strait Islander Communities: Key Points from Roundtable. Canberra, viewed 6 September, http://www.carersaustralia.com.au/storage/ATSI%20Forum%20Report%20Final.pdf

den Outer, Birgit, Handley, Karen & Price Margaret 2013, 'Situational analysis and mapping for use in education research: a reflexive methodology', *Studies in Higher Education*, vol. 38, no. 10, p 1504-1521. Retrieved 4 September 2017, from Web of Science.

Griffs, Damian 2010**, '**First Submission to the Productivity Commission Inquiry in to Disability Care and Support', *First Peoples Disability Network*, Sydney

Hogan, John, Dolan, Paddy & Donnelly, Paul (ed.) 2009, 'Approaches to Qualitative Research Theory & its Practical Application: A Guide for Dissertation Students, Oak Tress Press, Ireland. Retrieved 6 September 2017, from ProQuest Ebooks.

Hollinsworth, David 2013, 'Decolonizing Indigenous disability in Australia', *Disability & Society*, vol. 28, no. 5, pp 601-615. Retrieved 16 August 2017, from Taylor & Francis Online.

King, J.A, Brough, M & Knox, M 2014, 'Negotiating disability and colonisation: the lived experience of Indigenous Australians with a disability', *Disability & Society*, vol. 29, no. 5, pp 738-750. Retrieved 16 August 2017, from Taylor & Francis Online.

Lake, Marilyn and Reynolds, Henry 2008, *'Drawing the global colour line: white men's countries and the question of racial equality'* Melbourne University Publishing, Melbourne, Australia

McBain-Rigg, Kristin and Veitch, Craig 2011 *'Cultural barriers to health care for Aboriginal and Torres Strait Islanders in Mount Isa'*, Australian Journal of Rural Health, vol 19, pp 70-74. Retrieved 1 September 2017, from Wiley-Blackwell Full Collection.

Mokak, R 1997, 'Aboriginal People and Disability: What are.the Issues and Where Do We Go From Here?', *Aboriginal and Islander Health Worker Journal*, vol. 21, no. 5, pp 14-15.

National Disability Insurance Scheme n.d. About Us, Australian Government, Canberra, viewed 6 September, https://www.ndis.gov.au/about-us/our-sites.

National Disability Insurance Scheme n.d. About Us, Australian Government, Canberra, viewed 6 September, https://www.ndis.gov.au/about-us/what-ndis.

NACCHO Aboriginal Health News Alert n.d. National Aboriginal Community Controlled Health Organisation, Canberra, viewed 6 September, https://nacchocommunique.com/2017/03/22/naccho-aboriginal-health-disability-and-ndis-your-top-10-questions-answered-about-the-national-disability-insurance-scheme/

Stephens, Anne, Cullen, Jennifer, Massey, Libby & Bohanna, India 2014, 'Will the National Disability Insurance Scheme Improve the Lives of those Most in Need? Effective Service Delivery for People with Acquired Brain Injury and other Disabilities in Remote Aboriginal and Torres Strait Islander Communities', *Australian Journal of Public Administration*, vol. 73, no. 2, pp 260–270. Retrieved 16 August 2017, from Wiley-Blackwell Full Collection.