

Inclusion of marginalised Aboriginal and Torres Strait Islander Peoples with neurocognitive disability in the National Disability Insurance Scheme (NDIS)

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Given the ambiguity surrounding the extent and experience of neurocognitive disability (NCD) among marginalised Aboriginal and/or Torres Strait Islander peoples in Australia, evidence regarding the level and nature of NCD is crucial to ensure equitable access and inclusion into the National Disability Insurance Scheme (NDIS). This paper reports the results of the implementation of The Guddi Protocol (a culturally informed and appropriate screening protocol for Aboriginal and/or Torres Strait Islander peoples) at two locations in Queensland. Results indicated high levels of NCD, and additional qualitative data revealed a number of factors associated with the complex disablement of study participants, namely: i) intergenerational trauma; ii) a social context of disadvantage, marginalisation and exclusion; and iii) the non-identification of disability. The results are linked to implications for NDIS inclusion for this population, and recommendations are made. Unless the extent and nature of complex disability and the issues surrounding culturally safe policy, and service design and engagement are addressed with and by Aboriginal and Torres Strait Islander peoples, including those who experience complex disablement, marginalised people will continue to be effectively excluded from the NDIS.

Keywords: Indigenous health; Disability; Neurocognitive disability; Health policy

Introduction

Since colonisation, and within an ongoing social context of oppression, dispossession, and exclusion, the strength and resilience of the First Peoples¹ of Australia has frequently been evidenced (Dudgeon et al., 2014). In the case of people with a disability, many Aboriginal and Torres Strait Islander people are adept at self-advocacy and navigating complex disability and health systems. However, for others, particularly those marginalised due to homelessness or rural and remote living, and/or those who have a neurocognitive disability (NCD), the

outlook can be bleak. Marginalised Indigenous people with a NCD are some of the most vulnerable people in Australian society (Stephens et al., 2014). It is imperative that human service reforms such as Australia's National Disability Insurance Scheme (NDIS) be informed of the level and nature of NCD amongst marginalised Aboriginal and Torres Strait Islander people, in order to be responsive to the needs of this population.

Indigenous disability in Australia

Social and health inequities between Indigenous and non-Indigenous Australians are well documented. Lower life expectancy and higher rates of poverty, mental and chronic illness, disability, and homelessness are reported for Indigenous Australians (ABS, 2016; Beer et al., 2012; Dodson, 2010; Gracey and King, 2009). The overall rate of disability amongst Indigenous Australians is at least twice that of non-Indigenous Australians, including a high proportion for younger age groups (Biddle et al., 2012; SCRGSP, 2011). High levels of disability occur in Aboriginal and Torres Strait Islander communities for a range of complex reasons including poverty, poor health care, poor nutrition, exposure to violence and substance abuse. Moreover, factors such as rural and remote living, culturally inappropriate services, and socioeconomic disadvantage are barriers to Aboriginal and Torres Strait Islander people in accessing disability planning and support services (Productivity Commission, 2011). Given the high incidence of disability amongst Aboriginal and Torres Strait Islander peoples, the NDIS has particular relevance for this group. Despite these relatively high rates of disability in Indigenous Australian populations, a dearth of research has been noted and current figures are thought to be underestimates (Beer et al., 2012; Biddle et al., 2012).

Internationally, countries such as New Zealand, Canada, and the United States report similar disparities and over-representation of Indigenous people in disability populations (FNIGC, 2012; NCD, 2003; Wiley, 2009). New Zealand and Canada have a strong history of implementing effective reform strategies to address these disparities. New Zealand introduced the New Zealand disability strategy (Ministry of Health New Zealand, 2001), which aimed to establish a fully inclusive society where people with disabilities could integrate into community life on their own terms (Wiley, 2009). Canada has shown a similar commitment to its First Nations' people with disabilities, through the inclusion of First Nations people into the participation, planning and delivery of its healthcare services since the introduction of the 1979 Indian Health Policy (Health Canada, 1979). An outcome of both New Zealand and Canada's effective approach to disability reform has been the emergence of Indigenous health providers who contribute a broad range of valuable community-based, culturally appropriate primary healthcare services (Boulton et al. 2004; Lavoie et al. 2012), and increased community engagement and workforce developments (Wiley, 2009).

Neurocognitive disability

Neurocognitive disability (NCD) is a complex condition relating to multiple disabilities arising from any damage to the brain caused by traumatic or non-traumatic force impacting on cognitive, physical, emotional and/or behavioural functioning (Hoppestad, 2006; MacDonald, 2016). NCD can result from a variety of mechanisms including, but not limited to brain injury, dementia, alcohol or drug use, infections, and Foetal Alcohol Spectrum Disorder (FASD). It is postulated that the prevalence of FASD is increasing in Indigenous communities (Townsend et al., 2015). A longitudinal study of cognitive impairment and dementia in Aboriginal Australians, found dementia incidence for this population to be among the highest in the world, and is associated with head injury and age (LoGiudice et al., 2016). Indigenous NCD typically has an early onset, with many Indigenous children falling behind even on very early childhood development outcomes (Australian Government, 2013). Although these studies offer initial insights into Indigenous NCD and its impact, the nature of NCD among Australia's First Peoples remains poorly understood. Prevalence has not been accurately established but is thought to be high (Cairney et al., 2007; Henderson, 2010; Li et al., 2014).

NCD can involve a broad range of consequences including physical, cognitive, emotional, psychological, behavioural, and social impacts. Symptoms commonly include: impaired executive function and judgement; difficulty with memory, concentration, decision-making and problem-solving; and changes to personality and behaviour including anger outbursts (Thompson, 2009). Moreover, NCD is associated with further marginalisation such as homelessness, mental illness, and experiences with the criminal justice system (Burra et al., 2009; Spence et al., 2004). Indeed, it is estimated that 40% of people with NCD have been found to have mental health and other health conditions (AIHW, 2011; Hibbard et al., 2000, 1998). Over-representation in the criminal justice system and the homeless compounds, disadvantages and complicates service provision (Townsend et al., 2015). Given the ambiguity surrounding the extent and experience of NCD among Aboriginal and Torres Strait Islander peoples, cumulative evidence regarding the nature of NCD among Indigenous Australians, is needed. This will enable evidence-based policy and service development that addresses the expected level of need for the NDIS, and to ensure people are NDIS ready.

Disability policy in Australia

Disability policy development in Australia was limited throughout the first part of the 20th Century. In 1970, the Henderson poverty enquiry found disability to be the greatest single cause of poverty in Australia (Henderson, 1975; Henderson et al., 1970). This resulted in an increased debate about the most appropriate method of approaching this problem. However, a national approach to disability policy was not seen until 2008, when the Australian Labor Government announced the decision to commence the development of a National Disability

Strategy to reform the disability services sector (FaHCSIA, 2008). The Strategy, which was launched in 2011, committed Australia for the first time in its history to a national approach to supporting people with disability to maximise their potential and participate as equal citizens in Australian society (COAG, 2011). The Strategy, included the implementation of the NDIS. The NDIS is a significant disability reform that promises eligible Australians with disabilities (referred to by the Scheme as ‘participants’) access to reasonable and necessary funded support; and certainty, choice and control over how supports are delivered (NDIS Act, 2013). It is purportedly a life-long approach to supporting people with permanent impairment arising from intellectual, cognitive, neurological, sensory or physical health conditions. Inclusion in the Scheme will require people with disabilities to demonstrate permanent and significantly reduced functioning to meet access requirements. The NDIS will fund ‘reasonable and necessary’ supports aimed at assisting participants to reach their goals, objectives and aspirations, and enable people to participate socially and economically.

The criteria of reasonable and necessary will be determined by NDIS staff according to operational guidelines. Importantly, philosophical emphasis is placed on the centrality of the individual who has a disability. Registered participants will exercise choice and control in relation to service types, and which service providers are engaged. Depending on the nature of the person’s disability, intermediaries may be relied on to assemble the best package on behalf of participants (NDIA, 2016a). The NDIS represents significant changes in how Australia addresses the needs of people with a disability, with shifts from a state-based to a federally managed system, and from block-funded supports to individualised funding initiatives (Wiesel and Habibis, 2015). Given that the NDIS is outcomes focused, the governing body in charge of overseeing the implementation of the Scheme (i.e. the National Disability Insurance Agency; NDIA) will measure the impact of the Scheme on the lives of people with disabilities (NDIA, 2015).

The NDIS and Indigenous Australians with disabilities

In 2011, the Productivity Commission identified that Indigenous Australians may not have equal access to services (Productivity Commission, 2011). Consequently, the NDIA has identified the need to ensure that Indigenous Australians with disabilities benefit fully from the NDIS (NDIA, 2015). Efforts have been made to improve NDIS inclusion for marginalised groups, including Indigenous Australians, through Participant Readiness activities that have been funded by the Department of Social Services and/or State Governments. However, Indigenous Australians with disabilities have remained consistently under-represented in the NDIS trial sites (NDIA, 2016b, 2017a), and calls have been made for urgent action regarding this disparity (AbSec, 2017). Aboriginal and Torres Strait Islander trial sites have found a lack of cultural knowledge to be the most significant barrier to engaging the Aboriginal and Torres Strait Islander community. Six years after the Productivity Commission Report identified concerns that Indigenous Australians may not have equal access to NDIS services,

the NDIA released its Aboriginal and Torres Strait Islander Engagement Strategy (NDIA, 2017b). This Strategy aims ‘to develop a collaborative planning and working model to inform practice which can meet the needs of Aboriginal and Torres Strait Islander peoples with disability, their families, carers and communities’ (NDIA, 2017b:5). The Strategy acknowledges the need to improve the evidence base for Aboriginal and Torres Strait Islander peoples with disability.

The current study

Since 2015, the authors have worked towards developing methods to determine the extent and nature of NCD amongst Aboriginal and Torres Strait Islander people, to facilitate equitable access to the NDIS. Working with Traditional Owners, Elders, and other respected community members, an interview protocol titled ‘The Guddi’ was developed. The Guddi Protocol consists of items relating to demographic information, thinking skills (e.g. orientation; naming; verbal comprehension; verbal fluency; thinking; recall; executive function), depression, psychosis, post-traumatic stress disorder and levels of function over important life domains. The Guddi Protocol includes several validated scales including the KICA-Cog (a screen for cognitive impairment, particularly dementia) and KICA-Dep (a screen for depression) components of the Kimberly Indigenous Cognitive Assessment (see LoGiudice et al., 2006; Smith et al., 2009), as well as the 36-item World Health Organisation Disability Assessment Schedule (WHODAS) 2.0. The Guddi Protocol therefore reflects a quantitative measure of NCD that is administered using culturally safe and appropriate conversational methods. All results generated from The Guddi Protocol are initially interpreted by the lead psychiatrist on the team, and clinical consensus made regarding presence of NCD. The items comprising the protocol were reviewed by Traditional Owners, Elders and other respected Aboriginal and Torres Strait Islander peoples to ensure the questions and language used were culturally responsive. This paper reports on the findings of the implementation of The Guddi Protocol at two locations in Queensland (Study 1 and Study 2). In both locations, partner services reported suspected high rates of NCD in their service-users, a lack of capacity to assess NCD, and a dearth of culturally appropriate assessment tools. Services raised concerns that people with complex NCD would be unable to access or participate in the NDIS.

Method

A key aspect of The Guddi is that it should be used by Aboriginal and Torres Strait Islander peoples and services in ways they consider most appropriate to their people and community. As a result, the approach to employing The Guddi Protocol can vary, reflecting the heterogeneous nature of people and services. For this study, The Guddi Protocol was

implemented at two distinct locations in Far North Queensland (Study 1) and North Queensland (Study 2), and was informed by a 'Proper Way' process. Proper Way is a colloquial term that broadly refers to the carrying out of any business according to the wishes, values, and customs of Aboriginal and Torres Strait Islander communities (Somerville et al., 2017). From the outset, this research methodology was predicated on research principles which prioritised Indigenous world views, and adhered to the Australian Institute of Aboriginal and Torres Strait Islander Studies Ethical Guidelines (AIATSIS, 2012). The overarching research design was co-developed with an Indigenous Elder and Cultural Advisers who highlighted the importance of employing culturally safe, qualitative research methodologies throughout the project. Consequently, yarning² underpinned the delivery of The Guddi at both sites. Consistent with Proper Way protocols, this research was conducted with the blessing of Traditional Owners and Elders at both sites. The Traditional Owners, Elders, and a Cultural Adviser provided guidance to the research team throughout the project to ensure the materials, data collection, and data analysis processes were culturally safe and appropriate.

Participants

Although the authors acknowledge the distinct cultural differences within and between Aboriginal and Torres Strait Islander clans and communities, given the small number of Torres Strait Islander participants, a decision was made to respectfully combine data for the purpose of reporting the cumulative sample and research findings. Study 1 comprised 44 Aboriginal and Torres Strait Islander peoples ($n=27$ male) between the ages of 20 and 69 years ($m=41.24$ years; $SD=12.48$ years) who were accessing a crisis accommodation service (Night Shelter) at the time of the study (September-November 2015). Participants in Study 2 included 32 Aboriginal and Torres Strait Islander peoples ($n=10$ male) aged between 18 and 76 years ($m=49.75$ years; $SD=14.37$ years) who voluntarily took part in an Indigenous health service conducted in February 2017. Altogether, 76 Indigenous peoples ($n=37$ male) between the ages of 18 and 76 years ($m=45.19$ years; $SD=13.96$ years) participated in this research. The recruitment and data collection methods employed in Study 1 and Study 2 are described in detail below. As will be shown, The Guddi Protocol was administered at both sites, with in-depth yarning about participants' life experiences occurring in Study 1 only, in line with the wishes of the local community.

Study 1 procedure

In Study 1, the research team partnered with a crisis accommodation service (Night Shelter) in Far North Queensland. Following ethical approval from the Far North Queensland Human Research Ethics Committee (protocol HREC/14/QCH/122-941), a process of embedding was undertaken. An Indigenous Cultural Advisor was embedded in the service for 10 weeks prior

to data collection to allow Shelter clients to engage with the research. The advice of Elders and community leaders (particularly those residing at the Shelter) was sought during this time to ensure participant recruitment was respectful, and promoted participant engagement. Following the embedding process and subsequent face-to-face recruitment procedures, the Chief Investigator or another clinically trained researcher and the Cultural Guide administered The Guddi Protocol with those who had consented to participate in the research. All participants were informed they could opt out at any time without impacting their relationship with the Shelter, and that their anonymity would be safeguarded in any project reports. Participants with an acute health condition were offered treatment by the medical specialists within the project team and/or the Shelter medical staff.

To ensure that the nature and extent of people's experience of NCD was understood, participants in Study 1 were also provided an opportunity to yarn about their life experiences in more detail. A semi-structured, culturally appropriate yarning schedule, developed over a number of discussions with a much-respected Elder, constituted the framework for this activity. Individual yarning sessions with consenting individuals were conducted by two researchers (principal investigator and the cultural adviser) in places nominated by the participant (e.g. in the carpark; garden; staff lunch room). Both interviewers were aware of cultural issues such as men and women's business, and were prepared to cease the yarning session and/or seek clarification from the participant as to whether they wished to continue. The duration of yarning sessions was primarily determined by participants and averaged approximately 45 minutes. The majority of participants provided permission to audio-record the conversation. Data were manually recorded using field notes for the five participants who withheld consent to audio-record. To conclude the data collection phase, the audio-taped yarning sessions were transcribed verbatim and de-identified.

Study 2 procedure

In Study 2, the research team were approached to partner with an Aboriginal and Torres Strait Islander health service provider in North Queensland, to undertake a 'Health Week.' Existing clients of the service, their families and other community members were invited to participate in a health screen using The Guddi Protocol. The validated measures that comprised The Guddi Protocol in Study 1 were also used in Study 2, however some KICA-Cog questions were omitted for brevity, due to time constraints at Study 2. Following the administration of The Guddi Protocol and review of results by the Chief Investigator, participants were assisted to complete an NDIS Access Request Form to be forwarded to the NDIA for assessment of their eligibility where appropriate.

Data collection with those who consented to participate was primarily undertaken at the service centre. However, where people requested an alternate site, such as their home or town camp, this was undertaken. As with Study 1, Indigenous people advised on all processes and

procedures, and approved all materials and research team members prior to data collection. The service played an active part in all aspects of the recruitment and assessment; assisting participants, collecting data, and ensuring any follow-up requirements were addressed. All participants were informed they could opt out of the health screen at any time without this impacting on their relationship with the service, and that their anonymity would be safeguarded in any project reports.

Data analysis

Quantitative data analysis: Quantitative data was collected at both sites (Study 1 and Study 2) using The Guddi Protocol. Level of NCD was assessed across a number of cognitive domains including orientation, naming, verbal comprehension, verbal fluency, abstraction, recall, and executive function. Domains were selected on the basis of those most commonly used in general clinical assessments for NCD, in addition to the modification of existing culturally sensitive Indigenous cognitive assessment tools (Kipps and Hodges, 2005; LoGiudice et al., 2006). The results from these assessments were used in conjunction with professional clinical judgement to formulate a NCD diagnosis. All descriptive statistics (e.g. number and percentage of participants with NCD) were conducted using IBM SPSS software (Version 22.0).

Qualitative data analysis: Consistent with the wishes of the local community, qualitative data was also collected in Study 1 using in-depth yarning research methods to understand participants' life experiences. The qualitative data was thematically analysed using an approach delineated by Braun and Clarke (2006). To safeguard objectivity, each transcript was analysed by one researcher (CT) with a second analysis provided by an additional researcher (the transcripts were divided between MM, CW, and AL). All four researchers conducted manual line-by-line (open) coding to systematically identify raw data that could be meaningfully analysed. Initial codes were subsequently generated and raw data relevant to each code were collated. All initial codes were confirmed and defined through group discussion. Following confirmation of the initial codes, all four researchers individually collated the codes into themes which were again confirmed through group discussion. A final review of the three finalised themes was conducted by another author (JC; an Aboriginal woman) to ensure accurate interpretation of the data from a cultural perspective. The inclusion of qualitative data complemented the quantitative data collected by contextualising the evidence-base of NCD among Australia's First peoples.

Results

The results of the neurocognitive component of The Guddi Protocol found extremely high levels of NCD among participants. As shown in Table 1, 32 (72.7%) of the 44 participants

from Study 1, and 20 (62.5%) of the 32 participants from Study 2 received a formal NCD diagnosis. When figures from both studies were combined, 52 (68.4%) of 76 participants received a clinical diagnosis of NCD.

Table 1: Neurocognitive disability (NCD) diagnosis

<i>Study 1 (n=44)</i>			
	Male	Female	Total (%)
Diagnosed with a NCD	22	10	32 (72.7)
No diagnosis	5	7	12 (27.3)
Total	27	17	44 (100)

<i>Study 2 (n=32)</i>			
	Male	Female	Total (%)
Diagnosed with a NCD	7	13	20 (62.5)
No diagnosis	3	9	12 (37.5)
Total	10	22	32 (100)

<i>Combine results: Cumulative sample (n=76)</i>			
	Male	Female	Total (%)
Combined cohorts			
Diagnosed with a NCD	29	23	52 (68.4)
No diagnosis	8	16	24 (31.6)
Grand Total	37	39	76 (100)

To triangulate the professional diagnoses of NCD, participants were asked if they had ever been hit on the head and knocked out (i.e. loss of consciousness or blacked out). Table 2 shows the total number of self-reported head-injuries in Study 1 and Study 2 according to gender. Roughly half the cohort for both studies reported head injuries resulting in loss of consciousness, with 24 (54.55%) of the 44 participants in Study 1 and 15 (46.88%) of the 32 participants in Study 2 stating they had been knocked unconscious. In both studies, the majority of self-reported head injuries were sustained by males.

Table 2: Self-reported head injuries
Self-reported head injuries for Study 1 (n=44)

	Male	Female	Total (%)
<i>Study 1</i>			
Self-reported head injury	17	7	24 (54.55)
No head injury	6	5	11 (25)
Missing	4	5	9 (20.45)
Total	27	17	44 (100)

Self-reported head injuries for Study 2 (n=32)

	Male	Female	Total (%)
<i>Study 2</i>			
Self-reported head injury	10	5	15 (46.88)
No head injury	9	5	14 (43.75)
Unsure	1	0	1 (3.12)
Missing	2	0	2 (6.25)
Total	22	10	32 (100)

Combined results

Self-reported head injuries for Study 1 and Study 2 (n=76)

	Male	Female	Total (%)
<i>Cumulative Sample</i>			
Self-reported head injury	27	12	39 (51.32)
No head injury	15	10	25 (32.89)
Unsure	1	0	1 (1.32)
Missing	6	5	11 (14.47)
Total	49	27	76 (100)

Thematic analysis from the in-depth yarning undertaken in Study 1 revealed a number of factors relevant to NDIS inclusion, with evidence of complex disablement. Factors which

contributed to this disablement were identified, and have particular relevance to the delivery of the NDIS to Aboriginal and Torres Strait Islander peoples, namely:

- i) Intergenerational trauma;
- ii) Social context of disadvantage, marginalisation and exclusion; and
- iii) The non-identification of disability.

Intergenerational trauma

A high level of intergenerational physical and psychological trauma was evident, and traumatic experiences were frequently reported by participants in their past and current lives. Traumatic childhood experiences were common, with many participants reporting physical abuse and neglect, and/or witnessing violence and domestic violence. Although not every participant reported abuse, family instability and/or family loss was reported by many participants, and was typically distressing for participants to share. Most participants reported the death of significant others during childhood, often from their immediate family. Either as a direct result of deaths in the family, or for other reasons, many participants were raised by extended family, frequently moving to live with different family members as circumstances changed. Family instability was not described by all participants as traumatic. However, for many it appeared to involve considerable upheaval, dislocation, and distress. For some, the loss of a loved one, or relocation into a different household was seen as the beginning of a negative trajectory in their lives. Crucially, experiences of trauma were reported intergenerationally, and childhood experiences of parental abuse and neglect were seen to be repeated in participants' adult lives.

Another important theme relating to loss involved the loss of land and culture. Many participants highlighted the importance of their connection to land, and to cultural and spiritual traditions, which could be a source of comfort and strength. However, many reported a sense of loss in relation to these factors in a number of ways. For example, childhood relocation from remote to urban areas meant some participants lost their connection to traditional family lands and lifestyle. Other participants noted a loss of culture generationally; expressing distress that younger generations did not understand nor respect traditional beliefs and practices. This created a crisis of cultural identity for two male participants in particular, where their expectations of respect as Elders were not matched by the attitudes of the younger community members.

Social context of disadvantage, marginalisation and exclusion

Beyond these experiences of trauma and loss, participants were seen to be further disadvantaged in multiple ways. The results of The Guddi Protocol evidenced the complex disablement experienced by participants. The additional yarning component in Study 1

revealed participant experiences of and responses to disability, and the ways this interacted with other factors such as chronic illness, mental illness, homelessness and engagement with the criminal justice system. These multiple forms of disadvantage interacted in complex ways which appeared to perpetuate disadvantage. Cycles of poverty, violence and addiction were seen intergenerationally. This was particularly evident in terms of alcohol and/or drug problems which were often seen in participants' past and present experiences.

Reflective of The Guddi Protocol results, impaired cognitive function, poor concentration, poor planning and problem solving were seen in many participants. These cognitive issues significantly diminished individuals' ability to understand their conditions, and also inhibited capacity to self-advocate and make decisions and choices about their health or future plans. A lack of agency in relation to self-care and help-seeking was evident for many participants.

Disadvantage was also seen more broadly in relation to experiences of marginalisation and social exclusion. Participants repeatedly spoke about a clash of cultures between '*white man's world*' and their own, and described feeling separate or excluded from mainstream culture. Systems such as Centrelink or health services were described as alienating and bewildering. Some participants expressed frustration at difficult processes which meant they were unable to obtain formal identification, which created more barriers to gaining employment and accommodation. From early educational experiences to adult encounters with health and social services, participants related experiences of not understanding these systems and of not being understood.

Non-identification of disability

Compounding participant exclusion from mainstream disability services was the non-identification of disability, despite many being current clients of community housing and health services. Participants for whom NCD was evident typically did not identify as having NCD. For example, although some participants related experiences of prolonged unconsciousness, they had not considered possible long-term health implications, nor made any connection between those incidences and subsequent difficulties. The daily challenges of finding a bed for the night, money for medication and food, and surviving the vicissitudes of homelessness overshadowed their disability. Disability was simply seen as part of their general disadvantage and assistance was not sought. Crucially, participants with NCD in Study 1 declined referral to existing or future services, including the NDIS. During the administration of The Guddi Protocol in Study 2, the clinical team noted participants' reports of stigma when trying to access mainstream services and their subsequent mistrust of these services. Frustration was expressed at services which were seen as unhelpful and/or unwelcoming.

Discussion

Based on the extant literature and the evidence reported in this paper, we argue that strategies to increase the inclusion of marginalised Aboriginal and Torres Strait Islander people with NCD in the NDIS must be over-arched by a framework that privileges Aboriginal and Torres Strait Islander peoples' customs and culture, and positions the expertise and knowledge of Aboriginal and Torres Strait Islander people at the forefront of all strategies. The results reported in this paper underscore the high level and complex nature of NCD amongst marginalised Aboriginal and Torres Strait Islander people. They also provide evidence, long stated by many Indigenous groups and scholars, that there are a range of inter-connected and multi-causal issues which will negatively impact on the inclusion of Indigenous people with a disability in the NDIS (FPDN, 2013; Gilroy et al., 2016; Townsend et al., 2017). It has been reported that current surveys relating to Indigenous disability likely underestimate actual prevalence rates and that these rates are expected to increase substantially over time, which has relevance for NDIS inclusion (Biddle et al., 2012; Productivity Commission, 2011). To ensure inclusion of marginalised Aboriginal and Torres Strait Islander people in the NDIS, greater understanding of the level and nature of NCD for this population is needed. This involves better understandings of:

- Culturally safe and appropriate assessment processes;
- Recognition of the impact of the past on Aboriginal and Torres Strait Islander peoples' access and engagement with disability services;
- An acknowledgement of Indigenous concepts of disability; and
- Greater understanding of the impact of trauma.

Culturally safe and appropriate assessment processes

The difficulties associated with understanding NCD and determining prevalence amongst Aboriginal and Torres Strait Islander populations has been noted (Biddle et al., 2012; Productivity Commission, 2011). Historically, research about Indigenous populations is typically carried out through a lens of 'Western' knowledge and ways of knowing (Smith, 1999) which has caused distress and harm to Indigenous people (Biddle, 2012). Indeed, the manner in which knowledge is acquired 'may be as critical for eliminating health disparities as the actual knowledge that is gained' (Cochran et al., 2008: 22). In addressing this imbalance, research methods must be used which are reflective of participant perspectives, and allow for the data to 'emerge in a culturally appropriate manner' (Barnett and Kendall, 2011:28). Therefore, determining the extent of NCD will require increased culturally safe and appropriate assessment tools, as determined by Indigenous peoples. Importantly, assessment tools must be developed and applied by Aboriginal and Torres Strait Islander people with experience and skills in the area of NCD, and others whom they trust and respect. In order to

understand the nature of need for this population, it will be necessary for the NDIA to engage with and recognise these results and their implications for all aspects of the Scheme. Our findings in relation to Indigenous disadvantage, concepts of disability, and the experiences of trauma all have relevance for NDIS inclusion.

Recognition of the impact of the past on NDIS inclusion

The processes through which Australian Indigenous peoples have been socially and economically disadvantaged and alienated from the dominant culture, and dispossessed of their own lands are well documented (Dodson, 2010; Hunter, 2007, 2009). Similarly, the ongoing denigration of Indigenous culture, and a social context of racism and discrimination have had a significant impact on the health and wellbeing of Indigenous Australians (Biddle, 2012). The results of this study speak to this intergenerational disadvantage and the concomitant impacts on individual self-determination and agency. In the main, participants in this study showed low health literacy and a reduced capacity to self-advocate and seek help. These factors can be attributed to NCD, but must also be understood within a broader social context of racism, poverty, and marginalisation. In this context, NCD may be experienced, not so much as a disability, but rather ‘as an aspect of more general challenges and disadvantage’ (Hollinsworth, 2013:601). Equitable service provision requires an awareness of the ways historical disadvantage has ‘disabled’ Aboriginal and Torres Strait Islander people intergenerationally, and incorporate this into practice (Hollinsworth, 2013).

Another factor long seen to be a significant barrier to help-seeking by Aboriginal and Torres Strait Islander peoples involves a mistrust of government services (Biddle, 2012; Gething, 1994; Gilroy et al., 2016), and this was strongly evidenced in our results. Collectively, Aboriginal and Torres Strait Islander peoples have been impacted by a history of negative experiences with government operated services which have caused broad disadvantage, higher rates of child removal, and policies which created the Stolen Generation. These past negative experiences have generated a culture of mistrust and a reluctance to seek help from government organised services. Many communities still fear family members with disabilities will be removed, which inhibits engagement with mainstream services (Sotiri and Simpson, 2006). Moreover, individuals requiring limited assistance may also feel reluctance or shame to be reliant on non-Indigenous services and carers (Ariotti, 1999; Ypinazar et al., 2007).

Compounding negative experiences and disengagement from services is a lack of culturally appropriate and culturally informed services for Aboriginal and Torres Strait Islander people (Kendall and Barnett, 2015). This lack of appropriate health service provision has been described as a human rights issue and linked to the over-representation of Indigenous Australians in the criminal justice system (Baldry et al., 2012). The services associated with this study reported a lack of culturally appropriate services and service systems able to respond to the needs of marginalised Aboriginal and Torres Strait Islander people who have a NCD. This can be attributed in part to a lack of evidence and understandings about culturally

appropriate supports to guide service provision. Perceptions of cultural barriers to health service access have been found to be different between Indigenous consumers and health practitioners, with consumers emphasising social relationships, respect and trust, and practitioners more focussed on environments and systems (McBain-Rigg and Veitch, 2011). Greater understanding of individual experiences and perceptions of Indigenous families and communities about appropriate service responses for addressing complex disability are needed. Gilroy and colleagues (2016) reviewed peer-reviewed and gray literature relating to workforce capacity enhancement strategies in the context of NDIS delivery to Indigenous people with a disability in rural and remote areas of Australia. The results emphasised the need for culturally sensitive and informed services. The application of community-centred approaches, cultural training for all workers, and the development of an Indigenous disability workforce were seen as important for ensuring that services were culturally safe and appropriate to the needs of consumers. To ensure inclusion of Aboriginal and Torres Strait Islander people with complex disability in the NDIS, there must be a high level of understanding of the impact of historical and contemporary marginalisation on the ways people perceive services and systems, and their agency to engage with services. Failure to acknowledge and respond to these factors will mean services will continue to be a poor cultural fit.

Indigenous concepts of disability

Another significant barrier to NDIS inclusion for this group, relates to different conceptions of disability. Our results indicated a high level of non-identification of NCD, and participants displayed a lack of understanding about NCD and the ways it was impacting on their lives. Participants appeared unaware of their right to services which may have been beneficial for their social and emotional wellbeing. This can be attributed in part to the impaired awareness typical of NCD, which is not specific to Aboriginal and Torres Strait Islander peoples. However, it has been noted that Indigenous concepts of disability greatly contribute to the non-identification of disability for this group, and these broader factors relating to Indigenous concepts of disability must be acknowledged and understood. For example, there is no word for disability in traditional languages (FPDN, 2013), and diversity across Indigenous groups mean that there is no singular Indigenous conceptualisation of disability (Sotiri and Simpson, 2006). It has been suggested that in order to engage with mainstream disability services, Indigenous Australians have needed to compromise their own cultural understandings and accept service provider conceptualisations and practices in relation to disability (Ariotti, 1999; Gilroy et al., 2016). Therefore, in all aspects of strategic inclusion, community-specific cultural ways of knowing must inform how people with complex disability are engaged around these issues. Crucially, workforce training which recognises the specialised needs of Aboriginal and Torres Strait Islander peoples with NCD is needed to overcome these barriers to inclusion.

Impact of trauma

The impacts of collective trauma, grief and loss on the health and social and emotional wellbeing of Indigenous Australians is well documented (AIHW, 2011; Krieg, 2009; O'Donoghue, 1993). The current results revealed the significant trauma associated with intergenerational violence, loss, and separation from land, culture and community. Memmott and Chambers (2010) have described the separation from traditional land and community and family networks as 'spiritual homelessness,' and call for holistic, empowering approaches of support services. Disability services based on medical models of healthcare are not responsive to the needs of this population. It is imperative that a 'trauma lens' be applied both in the crafting and implementation of policy in order to develop new practices which 'rather than reinforcing old familiar patterns of control over others in health care, build on connection and relationship and our collective humanity' (Kreig, 2009:S32). This will include recognition of the significance of intergenerational violence and trauma exposure, altered staff perspectives on symptoms and behaviours, routine culturally safe screening for trauma, introduction of approaches that avoid re-traumatisation, building a sense of control and empowerment, and respecting cultural difference and diversity. Models of care based on social and emotional wellbeing frameworks are desirable, but more research is needed to better understand trauma-informed practices for this population (Atkinson, 2013).

Conclusion: implications for NDIS inclusion

The NDIS is a significant disability reform which promises eligible Australians with disabilities arising from intellectual, cognitive, neurological, sensory or physical health conditions access to reasonable and necessary care, as well as certainty, choice and control over how services and funded supports are delivered. There have been long standing concerns that Aboriginal and Torres Strait Islander peoples will face greater barriers to accessing funded supports within the NDIS than non-Indigenous Australians (Productivity Commission, 2011; Russell, 2013). This is of particular concern for people who are marginalised. These concerns have been borne out in the NDIS trial sites and the results presented in this paper.

Work still needs to be done to ensure that Aboriginal and Torres Strait Islander peoples are not excluded from disability services to which they are rightfully entitled. Inclusion strategies by the NDIA for marginalised Aboriginal and Torres Strait peoples with NCD require recognition and understanding of the effects of a composite interplay of long-term trauma and marginalisation, and evidence-based models of engagement and service provision which address these complexities in culturally safe and informed ways.

It is also imperative that data such as has been established in the current study be incorporated into NDIS operational plans. Coordinated responses from multiple service

sectors are also required to ensure sustained inclusion in the NDIS by Aboriginal and Torres Strait Islander peoples with complex disability. This will require expert analysis by the NDIA and a range of human services as to how NDIS inclusion can best be sustained within a complex array of needs and service systems and within a framework that has the respect and blessing of Indigenous Elders, alongside understanding the nuances of culture and custom. Critically, in order that the NDIA's (2017b:4) stated commitment to 'walk with Aboriginal and Torres Strait Islander communities in delivering the NDIS across Australia' is realised, Aboriginal and Torres Strait Islander peoples must determine how disability policy is designed and implemented for marginalised people with NCD and other complex disabilities. Unless the extent and nature of NCD and the issues surrounding culturally safe policy, service design and engagement are addressed with and by Aboriginal and Torres Strait Islander peoples (including those who experience complex disablement), marginalised Indigenous people will continue to be effectively excluded from the NDIS.

Notes

¹ The authors acknowledge the distinct history and culture of Aboriginal and/or Torres Strait Islander peoples. The terms First Peoples, Indigenous, and Aboriginal and Torres Strait Islander peoples are respectfully used in this article to collectively refer to peoples who are descendants of the original inhabitants of Australia, while recognising the heterogeneous nature of Aboriginal and/or Torres Strait Islander clans and communities.

² Yarning is 'an Indigenous cultural form of conversation' (Bessarab and Ng'andu, 2010:37) and represents a culturally safe method of engagement both in terms of building initial relationships with participants and collecting information.

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The white man system is something...but we don't know...we don't know it really proper.
(Homeless Indigenous participant, Far North Queensland)

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