

PROFESSIONAL PERSPECTIVE

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

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The aims of National Disability Insurance Scheme (NDIS) are to provide long-term, person-centred care and support to all Australians with a significant and ongoing disability, including individuals with an acquired brain injury (ABI). The scheme has significant potential to provide equitable opportunity of access to health and disability services. Historically, however, service provision in remote and outer regional areas of Australia lags behind more densely populated centres. Aboriginal and Torres Strait Islanders living with disability are already significantly marginalised. Further to this, people with an ABI are very often misunderstood and overlooked by disability services, health professionals and governments, and frequently fall victim to the criminal justice system. This paper provides an overview of the state of ABI disability for Aboriginal and Torres Strait Islanders in remote and outer regional settings, and the present sets of barriers they face to obtaining quality care and effective interventions. A significant opportunity has emerged with the advent of the NDIS but equitable benefit can only be achieved if additional and specialised measures are devised and implemented to appropriately screen for, and assess, incidence of ABI; disability services are appropriately resourced to overcome the pre-existing disadvantage, and education, training and recruitment of Aboriginal and Torres Strait Islanders with the NDIS is undertaken to lead attitudinal changes in community to disability and health services. This paper concludes with recommendations for the NDIS to meet its laudable objectives.

Key words: *Aboriginal and Torres Strait Islander, acquired brain injury, disability, DisabilityCare Australia, health service provision*

The National Disability Insurance Scheme (NDIS) is changing the funding and provision of disability services in Australia. Predicated

on a needs-based allocation of resources, eligible participants of NDIS funds will be able to choose according to their Support Plans how

to spend allocated funding with the services they want for their necessary supports (NDIS 2013). But will the new market-based model be a good fit for Aboriginal and Torres Strait Islander people living with disability residing in Australia's outer regional and very remote communities? The Productivity Commission has stated that

In remote communities, disability support services are practically non-existent (beyond basic HACC and limited mobile respite and allied health programs). Remoteness, poor infrastructure, lack of housing, and in some cases security issues will present a long term challenge for [the NDIS] — and improvement in service capability will depend in large part on broader government initiatives in this area. (Productivity Commission 2011: 531)

There is a strong likelihood that significant numbers of Aboriginal and Torres Strait Islander people living with a disability are both under-represented and not receiving services (FPDN 2013b; Productivity Commission 2011). Indigenous people experience a profound or severe core activity limitation, or disability, at more than double the rate of non-Indigenous Australians (AIHW 2009; Biddle, Al-Yaman, Gourley et al. 2012), most of whom live in regional or remote/very remote areas. 2006 Census data counted the number of people living with a disability at 9,000 (46%) people in regional areas, and 3,500 (18%) people in remote/very remote areas (Biddle et al. 2012). People in regional, remote and very remote areas are up to 2.5 times more likely, than non-Indigenous Australians, to need assistance (Biddle et al. 2012). Physical disability is the most common type of disability group among Indigenous Australians followed by sight, hearing and speech-related limitations. 30% experience intellectual or psychological-related disability (AIHW 2009). Half of all Indigenous Australians aged 15 years and over had some type of disability or long-term health condition, and, disability rates increase with age with one third of Indigenous people over 65 have a core activity need for assistance (Biddle et al. 2012).

ABI is commonly referred to as the 'invisible' disability (Synapse 2013) and these figures

are likely to underestimate the problem. This paper will focus on ABI to illustrate the complexity and potential pitfalls of the NDIS. ABI refers to any damage to the brain that occurs after birth (AIHW 2006) with the exception of Foetal Alcohol Spectrum Disorder (FASD) (BIA 2012) and is a leading cause of disability affecting approximately 1 in 45 Australians (Fortune and Wen 1999). The prevalence of ABI is notably higher in Aboriginal and/or Torres Strait Islander communities compared to the general Australian population (8–23% of Indigenous people affected compared to 2.2%) (AIHW 2007). People who experience the effects of an ABI require diverse rehabilitation and care and support needs to treat multifarious and complex co-morbidities for the rest of their lives (QBISM 2013).

ABI can be caused by a head injury from an external force (traumatic) or from chronic disease and progressive injury such as stroke, alcohol or drug misuse, tumours, haemorrhages, poisoning, infections, and restricted oxygen supply to the brain (AIHW 2006). Risk factors for brain injury and chronic disease co-exist in regional, remote and very remote communities. They include high body mass, physical inactivity, poor nutrition, that lead to chronic diseases, stroke and heart attack are known to occur at high rates in these communities (Department of Prime Minister and Cabinet 2008) with hospital admissions for stroke approximately 1.5 times greater than for the general population (Thrift and Hayman 2007). Substance use (smoking, alcohol, inhalant and illicit drugs) are high (AIHW 2011; Jayawant, Rawlinson, Gibbon et al. 1998; Productivity Commission 2011) and Indigenous Australians are more likely to suffer a head injury due to assault than their mainstream counterparts (Jamieson, Harrison and Berry 2008). It is reasonable to assume that there are likely to be high numbers of people with ABI who will be eligible for NDIS support than presently estimated, and there is no evidence that this need is decreasing (Biddle, Yap and Gray 2013).

The consequences of ABI are complex and individualised according to the extent and location of damage (Fortune and Wen 1999). A mild injury can result in a severe cognitive,

physical and psychosocial disability (BIA 2012) affecting thinking and planning, daily routines functioning, walking, conversation, interpersonal relationships, memory and attention etc. (Jamieson et al. 2008). People living with a disability, generally, are said to be more likely to experience stressful life events (Biddle et al. 2012). Divorce, domestic violence, job loss, and overcrowded housing, compound the cost and impact of ABI on the individual affected, and their carer's, families and even whole communities. There are ongoing costs of ABI disability that are born by the injured person, immediate family and community as services and resources are absorbed to cope with their daily function limits. Services are needed for life with members of families and communities shouldering the burden of care in a frequently ad hoc and unplanned manner (Jamieson et al. 2008; Bohanna, Stephens, Wargent et al. 2013).

People living with ABI constitute a highly marginalised and under-serviced group within the Australian health and disability sector. For this reason, our discussion focusses on a range of challenges that face the NDIS that apply to both people living with disability generally as well as with an ABI, drawing upon data specific to ABI wherever possible. We contend that ABI needs to be afforded a high level of attention, as despite its high, known prevalence, it is widely under-assessed, misunderstood by communities, and under-serviced by the disability and health systems. The NDIS includes the potential to offer flexible assessment and training to this group who have evident ongoing support needs as a result of their ABI. The NDIS might be flexible enough to consider the following key aspects for service delivery in remote and very remote communities. Many of these aspects are relevant to all disability types, but are considered here through the lens of those coping with the effects of ABI.

Being 'Remote'

In 2006, 26% of Aboriginal and Torres Strait Islander Australians lived in remote or very remote areas, compared to around one per cent

of non-Indigenous Australians (ABS 2006). Remoteness is a significant barrier for service access for Indigenous Australians with an ABI, as there are often no or very limited disability support services and workers in remote communities (FPDN 2013b). Realistically, the majority of service provision in very remote communities is firmly centred on low level attendant care (Massey, Jane, Lindop et al. 2013). Missing or limited services for people with ABI and disabilities generally in the remote communities of the Northern Territory and Far North Queensland include limited access to primary care, community based overnight (24/7) or extended care, respite and permanent care options with low and high care capacity, therapy and rehabilitation services, clinical therapeutic interventions such as physiotherapy, speech therapy, and specialist services for sensory impairments, life-skills programs, particularly for young people and in home support. Infrastructure currently used is commonly aged care funded (FPDN 2013b; Massey et al. 2013).

The Indigenous Concept of Health and Disability

A person's views of health can impact on the quality of care they receive, as well as their views of the health care providers and staff (AHMAC 2004). Aboriginal and Torres Strait Islander people often view health in a broad sense that includes consideration of the physical, cultural and spiritual components of wellbeing (Drew, Adams and Walker 2010). Culture and identity are central to Aboriginal perceptions of health or ill health. In many cultural linguistic groups, there may not be a word that translates directly into English that means 'disabled' or that describes a particular type of disability (Biddle et al. 2012; Massey et al. 2013). Being labelled with an English speaking word or term is often undesirable and can have stigmatising effects (ADN 2007; FPDN 2013b). This then leads to an unwillingness to self-identify and contributes to the under-reporting of disability in Aboriginal communities (ADN 2007). Our Australian health system has a focus on acute care and marginalises the

treatment and support for people and families caring for those with a disability and may fail to consider the broader impact of a person's condition and quality of life (ADN 2007; Drew et al. 2010). Services that are able to address a combination of issues for example cognitive impairment, mental illness *and* drug and alcohol misuse, are incredibly uncommon (FPDN 2013b).

Aboriginal and Torres Strait Islander people are unlikely to engage with non-Indigenous services if they experience or perceive that the service lacks cultural competence (Drew et al. 2010). Cost barriers, favourable treatment given to some family members over others, overt racism and stereotyping and “structural racism”, where lack of cultural knowledge and sensitivity result in processes that are incompatible with the local Aboriginal or Torres Strait Islander cultural approaches and values (FPDN 2013b), are all known reasons for Indigenous people to turn away from a health service (ADN 2007). There is a paramount need for all services and service providers to take in a culturally sensitive and secure approach.

Support and services for people with intellectual disabilities including mental health, drug and alcohol therapy (Gray and Wilkes 2010) and social and emotional well-being programs, are urgently required. Poor public infrastructure makes excursions from homes extremely difficult for many, particular those requiring assistive aids, to circulate and live amongst their communities. Daily activities such as banking, shopping, attending ceremony, church or other cultural and sporting events are not possible without significant reliance on family carers and friends. Lack of an accessible vehicle also limits attendance at day centres (Massey et al. 2013). The persistent concerns of over-crowded and inadequate housing are compounded for those Aboriginal and Torres Strait Islander people living with a disability. Modifications to homes and the provision of public infrastructure is known to be very slow in many places, sometimes in excess of 12 months from submission of paperwork to completion of works (Massey et al. 2013). Another under-considered factor affecting the way people live is extreme weather conditions which are typi-

cal for communities in hot, dry or hot and wet communities. Heat, humidity or flood rains coupled with poor infrastructure cut-off whole communities and make it impossible to access homes. There are often significant barriers to accessibility for people living with a disability, which includes access to move around in their physical environment, transportation, information and communications due to a lack of accessibility in their communities (Mines and Mines 2011). One wonders how the NDIS system of choice will fare any better without concerted parallel efforts to bridge the gaps in health service provision, housing, infrastructure and public health education?

Staffing

Remote services often rely on the ‘fly in/fly out’ ‘outsider’ service delivery model where the development of trust and engagement is an ongoing challenge (ACI 2011; FPDN 2013b). There are limited allied health services available to people with an ABI in remote communities, but also a lack of adequate transport and support for people to travel out of their community to visit health professionals reinforces barriers. Rehabilitation within remote or regional hospitals is restricted due to limited numbers of allied health staff and rehabilitation physicians, in addition to a lack of expertise in working with people with ABI. Indigenous people with disability have a higher rate of case complexity compared to non-Indigenous Australians and higher rates of a second or third disability and comorbidity, as a result of chronic disease. Off-site case management, where the coordinator is not readily available, is an additional barrier to responsive and appropriate care and few disability-specific charitable organisations (e.g. CP Australia, Royal Society for the Blind, Lung Foundation Australia) are present in the very remote communities (Massey et al. 2013). Biddle et al. (2012) report that the average hours of respite assistance provided to Indigenous users was 6.7 hours per week in remote/very remote areas. What's more, individuals with a brain injury and their families are often not informed about the

limited availability of services provided by remote hospitals prior to discharge from a metropolitan centre (ACI 2011). Poor information exchange and communication/cooperation between service providers leads to an inability to provide optimal care (Massey et al. 2013) and additional costs (QBISM 2013).

Off-Community Care

Similar to carers in the broader Australian community, carers of people with a disability in Aboriginal and Torres Strait Islander communities care deeply for the wellbeing of their own. Kinship systems, cultural connectedness to land and sea, language and tradition are values all community members are entitled to share. Therefore, the care for people with disability is often shouldered by many members of communities. But when care needs escalate beyond the capacity of the community and its services, people with disabilities are effectively removed. Supported accommodation facilities, aged care facilities or hospitals in urban centres were 'home' to 19% of Aboriginal and/or Torres Strait Islander people requiring assistance, in 2006 (Biddle et al. 2012). The distress this causes is difficult to articulate but often contains a very real fear of death in a place far from their own country. Refusal to relocate is common, placing a disproportionate burden of care on family carers and community services (Massey et al. 2013). For people with ABI, if their behaviours breach the communities' care threshold because of anti-social or threatening behaviours, it is the criminal justice system that often provides accommodation and care. While it is well known that Aboriginal and Torres Strait Islander Australians are over represented in jails across Australia, what is less known is a large number of prisoners with an Indigenous heritage have a cognitive impairment (Sotiri, McGee and Baldry 2012). The 2010 National Prisoner Health census found that 41 per cent of female and 38 per cent of male prison entrants reported having sustained at least one head injury that led to loss of consciousness and Aboriginal and Torres Strait Islander people with a cognitive impairment (compared to

the non-disabled population) are more likely to come to the attention of police, are more likely to be charged, and are more likely to be imprisoned (Sotiri et al. 2012).

Carers Support

Carer support is essential to any system that hopes to offer support and promises relief to those who manage heavy workloads. Carers are also in need of training and capacity building opportunities to develop their skills to provide in-home care. Currently carers most often only receive low-level support and basic services such as occasional meal provision and occasional laundry assistance (Massey et al. 2013).

Information

In addition, Indigenous Australians who want to engage with the disability system may be unaware of their rights or entitlements to receive supports (Productivity Commission 2011). Historically, a major barrier for many Aboriginal and Torres Strait Islander people with a disability is access to information (FPDN 2010). The relative isolation of the communities means that people with a disability are exposed to their own situation only and are not able to compare their experiences with the experiences available to others. In the NDIS system and its reliance on market choice and access to information, prospective participants and their families are at risk of not advocating their needs effectively because they have a limited understanding of their options and opportunities that maybe available more broadly, which may be appropriate to their needs (Massey et al. 2013). The role that the NDIS takes as an information broker, and the training provided to its staff to do this effectively will also be a measure of its success.

Assessment and Eligibility for Support

The existing disability support systems in Australia have been described as a 'market failure' by the First Peoples Disability

Network. Wide-ranging systematic failures pose a constant set of barriers to adequate support and the poor levels of access and responsiveness of the support systems result in severe personal and systemic disempowerment (FPDN 2013b). ABI carries additional burdens starting with poor training in detection and widespread lack of awareness means that symptoms are being misinterpreted or obscured by competing co-morbidities (ACI 2011; Crosson et al. 1989; Farmer and Johnson-Gerard 1997; Gauld, Smith and Kendall 2011; Linden, Braiden and Miller 2013; Springer, Farmer and Bouman 1997).

The paucity of assessment instruments available for assessing psychosocial and cognitive functioning in Aboriginal and Torres Strait Islander Australians represents a challenge to undertaking evidence-based assessment (Dingwall and Cairney 2009; Dingwall, Pinkerton and Lindeman 2013; Sheldon 2010). Assessment instruments are developed to assess, through a series of questions or tasks, human behaviours, needs, thinking processes, emotions and personality characteristics (Groth-Marnat 2009). The assessment process is in itself an opportunity for individuals to articulate their care and support needs, identify issues that need to be addressed in any personal plan, and can be used to collect data (Productivity Commission 2011). Before any instrument is used effectively, however, the assessor must understand the theoretical basis of the instrument, examine its practical utility, determine the appropriateness of the normative sample on which the test was validated, and be satisfied with its reliability and validity (Groth-Marnat 2009). Most assessments are designed for use with Western, English-speaking populations. If tasks are used with cultural groups for which they are not designed they may yield inaccurate results, which can lead to discrimination and misdiagnosis (Dingwall and Cairney 2009). There is a concern that the assessment, management and outcomes of brain injury in Aboriginal and Torres Strait Islander communities and individuals will continue to be inadequate (BIA 2012). This shortcoming might be addressed by the development of culturally appropriate and valid ways to assess

Aboriginal and Torres Strait Islander people with ABI.

Eligibility for the NDIS scheme is also complicated by the age distribution of Aboriginal and Torres Strait Islander populations. The Productivity Commissions recommended that a younger age threshold apply based on lower life expectancy. A lower threshold may create an equity issue if higher levels of support flow to people in the NDIS scheme than the aged care sector. 31% of the Indigenous disability population needing assistance were aged 45–64 years, and 20% were aged 65 years and over in the 2006 Census (Biddle et al. 2012). Similarly, lower levels of funding were recommended to children under 15 years of age based on the assumption that families provide most care to children, but this fails to account for special needs school resourcing in regional, remote and very remote communities, or, that children may be cared for by non-immediate family members, communities of extended family according to local custom (Biddle et al. 2012; Bohanna et al. 2013). Identifying a sole, parental carer, can be problematic and has the potential to effect over a third of the population of Aboriginal and Torres Strait Islander Australians (Biddle et al. 2012).

Improving Service Delivery

Why are service providers so reticent to provide services in remote and outer regional Australia? There are significant issues to be tackled before a full 'suite' of community support services are available to disabled people. These include inadequate funding, staffing recruitment and retention, inadequate buildings and facilities and case management from a distance, inefficient communication of information, complex and lengthy referral and assessment processes (Massey et al. 2013).

Remoteness both reduces the scope of services and drives up cost. Levels of current funding available to service providers is 'demonstrably' inadequate (Massey et al. 2013). Service providers presently report that they are unable to meet the needs of disabled people in Aboriginal and Torres Strait remote communities

(ACI 2011). The very real costs are not adequately factored in to current funding allocations (e.g. freight and transport imposts). This leaves people reliant upon the aged care sector resources (FPDN 2013b; Massey et al. 2013). Where people do receive in-home care and support, the state of housing exacerbates the stressors of people with cognitive and functioning disabilities. Overcrowding, a lack of hot water, refrigeration and laundry facilities, are regular features of daily life (Massey et al. 2013).

It is widely assumed that the opening market for the provision of disability services will result in new market opportunities for rural and remote communities. But without provisions to assist start-up agencies, how will this be achieved? The NDIS needs to give consideration to providing one-off start-up funding to meet the Registered Service Provider requirements.

Existing Policy Settings

For real improvement, it is necessary to draw attention to these issues at the highest level and to develop strategic responses. We recommend that the NDIS urgently consider initiatives to support improvement to disability access across regional, remote and very remote Australia to bring it closer to those standards expected in the broader Australian community.

Remote Indigenous communities and communities in remote areas with significant populations are entitled to standards of services and infrastructure broadly comparable with that in non-Indigenous communities of similar size, location and need elsewhere in Australia. (COAG 2012)

Policy frameworks recognise that Aboriginal and Torres Strait Islander People have unique needs. These include the National Disability Strategy (COAG 2011), the Carer Recognition Act 2010 (Carer Recognition Act 2010) and anti-discrimination legislation to address Equal Employment (Equal employment opportunity (Commonwealth Authorities) Act 1987). Australia is a signatory of The United Nations Convention on the Rights of Persons with Disabilities (United Nations 2006) and United Na-

tions Declaration on the Rights of the Indigenous Peoples (United Nations 2008). The *Close the Gap: National Indigenous Reform Agreement* (COAG 2012) sets out key principles for programs and service delivery that state clearly that Indigenous engagement in health care reform should be central, programs and services should be directed and resourced over an adequate period of time, and programs and services should be physically and culturally accessible. Access to quality, effective health services by strengthening the service infrastructure, has been seen as essential to improving access by Aboriginal and Torres Strait Islander peoples to health services. The NDIS must overcome the significant issue of government service mistrust (Biddle et al. 2012). Adopting appropriate cultural practices is the first step to overcoming these major barriers. This might include delivery of culturally competent services, developing appropriate models of service delivery and provide leadership for a community-wide shift in attitudes to disabilities. As the First Peoples Disability Network Australia states:

For positive change to happen in the lives of Aboriginal and Torres Strait Islander people with disabilities the change must be driven by community itself. It cannot be imposed, implied, intervened or developed with well-meaning intention from an external service system that the vast majority of Aboriginal and Torres Strait Islander people with disabilities have little or no experience of in the first place. (FPDN 2013a)

Community-Based Models of Care

Community-based rehabilitation (CBR) and care models have the potential to bring about stronger living standards and quality of life. The goal of early intervention and rehabilitation is to bring about the highest possible level of recovery following a loss of function. Adoption of CBR may be useful in addressing discrepancies between service provision and true partnership where partnership is seen as a desirable way of engaging with individuals, their families, carers and communities, in everyday practice, to substitute for in-patient, in-hospital care and delay people being moved out of their homes and into residential care. According to

the Western Australia Advocacy agency for mental health carers, *Arafmi*:

The NDIS needs to look at these potential arrangements both during the roll-out of the scheme, but perhaps more importantly ensuring the scheme's sustainability issues over extended period of time. The most important outcomes from CBR are partnerships and inclusion. (Arafmi 2013: 18)

Investing in CBR holds multiple possibilities. Models of care as advocated by *Arafmi*, based on true partnerships, can help bridge the information divide. Noted above, and of particular concern to ABI advocates is the widespread expedient use of prisons and mental health facilities for the management of unconvicted Aboriginal persons with cognitive impairments (NDCA 2013). Community-based interventions with a focus on treatment and support coupled with culturally appropriate assessment measures can divert people from prison. The National Disability and Carers Alliance call for a shared response between the disability sector and criminal justice to support CBR responses (NDCA 2013). Initial services in this area might be most effective taking a case-management generalist approach rather than attempts to duplicate multi-speciality structures currently in use in metropolitan rehabilitation services.

What the NDIS Might do Well

Appropriate levels of resourcing are likely to be contested, but the forthcoming Barkly Region trial in the Northern Territory will have an opportunity to address these issues. Advocacy and resource allocation might most appropriately be decided when accurate epidemiological data is collected and updated, especially as there is a gap in appreciation of the incidence and prevalence of ABI in regional, remote and very remote communities. The Australian government spends 30% more per capita on Indigenous Australians with disabilities than non-Indigenous Australians (Biddle et al. 2012) but this funding is not enriching the lives of service target populations in regional, remote and very remote communities. Despite this invest-

ment, chronic disparities among service provision and ongoing underreporting of disability, particularly ABI, are persistent (Biddle et al. 2012). The NDIS itself might take some basic steps towards bridging the gaps between service provision, community infrastructure and support funding provided by the NDIS for eligible participants. Building the capacity of Registered Service Providers and advocates, and negotiating flexible care packages to support families as well as individuals, that may deviate from the mainstream model, as required. Aboriginal and Torres Strait Islander people commonly have had little or no experience in self-managing disability funding packages and this challenge must be well understood and recognised by the NDIS (FPDN 2013a). Individual support packages must take into consideration the true cost of accessing services as well as acknowledging the barriers to meaningful information regarding the support available or the nature of the disability or health condition they may have. It will be beholden upon the NDIS system to engage with Aboriginal and Torres Strait people to provide "Foundational stories . . . going through step-by-step, in language, what a particular disability is. People need to be informed of their rights [capacity and potential] so that they can be empowered to make decisions about their own lives." (NDCA 2013: n.p.)

In certain circumstances it may be prudent to pay family members to provide care (Productivity Commission 2011) and given the questionable feasibility of the self-directed funding model in regional, remote and very remote communities, alternative funding approaches such as block funding of services may be appropriate. As stated by a participant at a recent Roundtable discussion:

We need to keep block advocacy funding. Unless we walk hand in hand with Aboriginal people and lead them through that front door, we will have a system that goes for 25 – 30 years and our people will be behind that door. (NDCA 2013: n.p.)

As mentioned above, start-up funding, for new or existing organisations, or funding of larger organisations to provide management expertise, mentoring and capacity building over

the long-term (Biddle et al. 2012; Productivity Commission 2011). Similarly, there must be maintained a strong role of government to regulate and monitor the providers to protect vulnerable people from rogue operators “who have not acquired sufficient experience in social care, or who potentially pose a threat to the user” (Biddle et al. 2012: 28).

The NDIS should employ or contract Aboriginal and Torres Strait Islander Australian people for work undertaken with Aboriginal and Torres Strait Islander people and that this be seen as an important employment opportunity in some communities (FPDN 2013a). Assessment of Aboriginal and Torres Strait Islander clients with ABI should preferably be conducted with Indigenous men and women who represent a variety of age groups, languages and cultures (Bohanna et al. 2013). The NDIS needs to remain committed to the use of valid assessment instruments. Only validated and culturally acceptable instruments provide an accurate assessment of Aboriginal and Torres Strait Islander Australians with ABI (Bohanna et al. 2013).

All staff, regardless of ethnic background, need to be provided training and accredited professional development in the area of cultural competence and awareness (Bohanna et al. 2013; Massey et al. 2013) and promote training and community awareness of disability. The difficulties associated with staff recruitment and retention, sourcing expertise from within communities, and reservations individuals might have in accepting assessment support from outsiders when necessary, can be ameliorated with culturally appropriate engagement practice (Bohanna et al. 2013), training, and flexible working conditions in order to attract Indigenous employees (Biddle et al. 2012).

Trial and proposed NDIS assessors, Local Area Coordinators and support service providers, need to receive the appropriate levels of education and training in ABI. It is important to understand how the whole service system impacts on an individual who presents with dual diagnosis. Treatment for mental health illness and disorders differ to cognitive impairment therapies. ABI is often treated from a disability perspective, while mental illness is treated

within the health context. This can lead to individuals being shifted between services without an integrated approach to care. Coordinated approaches to care are likely to be more effective (NDCA 2013).

Training will assist in preparing service providers to deliver culturally competent assistance to Aboriginal and Torres Strait Islander Australians and complement community-driven awareness about the NDIS, ABI and disabilities generally. It was Nelson Mandela who stated that a nation should not be judged by how it treats its highest citizens, but its lowest ones. And so too the NDIS will be judged by how its reforms benefit regional, rural and remote Aboriginal and Torres Strait Islander people living with the effects of a disability – arguably among Australia’s most in need.

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References

- ABS. 2006. *4713.0 – Population Characteristics, Aboriginal and Torres Strait Islander Australians*. Canberra: Australian Bureau of Statistics (ABS).
- ACI. 2011. *Acquired Brain Injury Rehabilitation Service Delivery Project Developing a Model of Care for Rural and Remote NSW*. Sydney: Agency for Clinical Innovation (ACI): Brain Injury Rehabilitation Directorate.
- ADN. 2007. *Telling it Like it Is. A Report on Community Consultations with Aboriginal People with Disability and their Associates Throughout NSW, 2004 – 2005*. Strawberry Hills: Aboriginal Disability Network of New South Wales Inc. (ADN).
- AHMAC. 2004. *Cultural Respect Framework for Aboriginal and Torres Strait Islander health 2004*

- 2009. Adelaide: Australian Health Ministers' Advisory Council (AHMAC).
- AIHW. 2006. 'National community services data dictionary', *Information Series* (Vol. Version 4, pp. 444). Canberra: Australian Institute of Health and Welfare (AIHW).
- AIHW. 2007. *Disability in Australia: Acquired brain Injury* (Vol. 55). Canberra: Australian Institute of Health and Welfare (AIHW).
- AIHW. 2009. *Australia's Welfare 2009, Australia's Welfare Series No. 9. Cat. No. AUS 117*. Canberra: Australian Institute of Health and Welfare (AIHW).
- AIHW. 2011. '2010 National Drug Strategy Household Survey report', *Drug Statistics Series No. 25 (Vol.25)*. Canberra: Australian Institute of Health and Welfare (AIHW).
- Arafmi. 2013. *Community Consultations and Development of Best Practice Guidelines for funded Service Organisations and Indigenous Families and Carers of People with tier 3 Psychiatric Disability in Remote West Australian Indigenous Communities: A Practical Design Fund Project*. Perth: Mental Health Carers Arafmi WA Inc.
- BIA. 2012. *National NDIS Consultation Report, June – September 2012*. Sydney: Brain Injury Australia (BIA).
- Biddle, N., F. Al-Yaman, M. Gourley, M. Gray, J. R. Bray, B. Brady, L. A. Pham, W. Emma and M. Montaigne, M. 2012. Indigenous Australians and the National Disability Insurance Scheme: The extent and nature of disability, measurement issues and service delivery models. Retrieved November 1, 2013, from <http://caep.anu.edu.au/sites/default/files/Seminars/presentations/Indigenous%20Australians%20and%20the%20National%20Disability%20Insurance%20Scheme%20-%20Online%20version%20-%20June%2011%202013.pdf>
- Biddle, N., Yap, M. and Gray, M. 2013. *CAEPR Indigenous Population Project: 2011 Census Papers, Disability*. Paper 6. Canberra: The Australian National University.
- Bohanna, I., Stephens, A., Wargent, R., Catherall, J., Timms, C., Graham, D. and Clough, A. R. 2013. *Assessment of Acquired Brain Injury in Aboriginal and Torres Strait Islander Australians: Guidance for Disability Care Australia*. Cairns: The Cairns Institute, James Cook University.
- COAG. 2011. *National Disability Strategy 2010 – 2020 Australian Disability Enterprise*. Canberra: Council of Australian Governments (COAG).
- COAG. 2012. *National Indigenous Reform Agreement (closing the gap)*. Canberra: Council of Australian Governments.
- Crosson, B., Barco, P. P., Velozo, C. A., Bolesta, M. M., Cooper, P. V., Werts, D. and Brobeck, T. C. 1989. 'Awareness and compensation in post-acute head injury rehabilitation', *Journal of Head Trauma Rehabilitation* 4(3): 46–54.
- Department of Prime Minister and Cabinet. 2008. *The Health of the Adult begins in the Womb: Prime Minister's Science, Engineering and Innovation Council Working Group on Working Group on Aboriginal and Torres Strait Islander Health focusing on Maternal, Foetal and Post-natal Health*. Canberra: Department of Prime Minister and Cabinet.
- Dingwall, K. and Cairney, S. 2009. 'The importance and challenges of assessing cognition in Indigenous Australians', *Australasian Psychiatry* 17(1): doi: 10.1080/10398560902948670
- Dingwall, K., Pinkerton, J. and Lindeman, M. A. 2013. "'People like numbers": a descriptive study of cognitive assessment methods in clinical practice for Aboriginal Australians in the Northern Territory', *BioMed Central Psychiatry* 13(42): doi: 10.1186/1471-244X-13-42
- Drew, N., Adams, Y. and Walker, R. 2010. 'Issues in mental health assessment with Indigenous Australians', in N. Purdie, P. Dudgeon and R. Walker (eds.), *Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice* (191–209). Canberra: Australian Government Department of Health and Ageing.
- Farmer, J. E. and Johnson-Gerard, M. 1997. 'Misconceptions about traumatic brain injury among educators and rehabilitation staff: A comparative study', *Rehabilitation Psychology* 42(4): 273–285.
- Fortune, N. and Wen, X. 1999. *The Definition, Incidence and Prevalence Of Acquired Brain Injury in Australia*. Canberra: Australian Institute of Health and Welfare, Australian Government.
- FPDN. 2010. *First Submission to the Productivity Commission Inquiry Into Disability Care and Support*. Sydney: First Peoples Disability Network (FPDN) Australia.
- FPDN. 2013a. *FPDN 10 Point Plan for the Implementation for the NDIS in Aboriginal Communities*. Retrieved from <http://fpdn.org.au/latest-news/2-fpdn-10-point-plan-for-the-implementation-for-the-ndis-in-aboriginal-communities>

- FPDN. 2013b. *Making the National Disability Insurance Scheme accessible and Responsive to Aboriginal and Torres Strait Islanders: Strategic issues*. Sydney: First Peoples Disability Network (FPDN) Australia.
- Gauld, S., Smith, S. and Kendall, M. B. 2011. 'Using participatory action research in community-based rehabilitation for people with acquired brain injury: from service provision to partnership with Aboriginal communities', *Disability and Rehabilitation* 33(19 – 20): 1901–1911. doi: 10.3109/09638288.2010.550382
- Gray, D. and Wilkes, E. 2010. *Reducing Alcohol and other Drug Related Harm: Resource sheet no. 3. Cat. no. IHW 35*. Canberra: The Closing the Gap Clearinghouse.
- Groth-Marnat, G. 2009. *Handbook of Psychological Assessment* (5th ed.). Hoboken: John Wiley and Sons, Inc.
- Jamieson, L. M., Harrison, J. E. and Berry, J. G. 2008. 'Hospitalisation for head injury due to assault among Indigenous and non-Indigenous Australians, July 1999 – June 2005', *The Medical Journal of Australia* 188(10): 576–579.
- Jayawant, S., Rawlinson, A., Gibbon, F., Price, J., Schulte, J., Sharples, P., Sibert, R. J. and Kemp, A. M. 1998. 'Subdural haemorrhages in infants: Population based study', *British Medical Journal* 317: 1558–1561.
- Linden, M. A., Braiden, H. J. and Miller, S. 2013. 'Educational professionals' understanding of childhood traumatic brain injury', *Brain Injury* 27(1): 92–102.
- NDCA. 2013. Implementing the NDIS in Aboriginal and Torres Strait Islander Communities: Key Points from Roundtable. Retrieved November 15, 2013, from <http://www.carersaustralia.com.au/storage/ATSI%20Forum%20Report%20Final.pdf>
- Massey, L., Jane, A., Lindop, N. and Christian, E. 2013. *Disability Audit – NE Arnhem Land/NT Gulf – A Snapshot of Indigenous Australian Disability in the Very Remote Communities of the Groote Eylandt Archipelago (Angurugu, Umbakumba, Milyakburra), Elcho Island (Galwin'ku), and Ngukurr (including Urapunga)*. Alyangula: MJD Foundation Limited.
- Mines, R. and Mines, K. 2011. *Meeting the Needs of Aboriginal and Torres Strait Islander people with disabilities. Inclusive Community Development; Community Based Rehabilitation and its potential application in Aboriginal and Torres Strait Islander communities. Submission to FaHCSIA*. NSW: First Peoples Disability Network Australia (FPDNA).
- NDIS. 2013 National Disability Support Scheme. Canberra. National Disability Insurance Scheme (NDIS): Department of Families, Housing, Community Services and Indigenous Affairs. Available from <http://www.ndis.gov.au/>
- Productivity Commission. 2011. *Disability Care and Support*. Report No. 54. Canberra: Australian Government Productivity Commission.
- QBISM. 2013. *A Comprehensive Service System for Queenslanders with Brain Injury: Positioning paper*. Brisbane: Quarterly Brain Injury Services Meeting (QBISM) Group.
- Sheldon, M. 2010. 'Reviewing Psychiatric Assessment in Remote Aboriginal Communities', in N. Purdie, P. Dudgeon, and R. Walker (eds.), *Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles And Practice*. Canberra: Australian Government Department of Health and Ageing.
- Sotiri, M., McGee, P. and Baldry, E. 2012. *No end in Sight. The Imprisonment, and Indefinite Detention of Indigenous Australians with a Cognitive Impairment*. Sydney: Aboriginal Disability Justice Campaign.
- Springer, J. A., Farmer, J. E. and Bouman, D. E., 1997. 'Common misconceptions about traumatic brain injury among family members of rehabilitation patients', *Journal of Head Trauma Rehabilitation* 12(3): 41–50.
- Synapse. 2013. Lack of Brain Injury Awareness in Schools – Fact Sheet. Retrieved 1 December, 2013, from <http://synapse.org.au/get-the-facts/lack-of-brain-injury-awareness-in-schools-fact-sheet.aspx>
- Thrift, A. G. and Hayman, N. 2007. 'Aboriginal and Torres Strait Islander peoples and the burden of stroke', *International Journal of Stroke* 2(1): 57–59. doi: 10.1111/j.1747-4949.2007.00090.x
- United Nations. 2006. *Convention on the Rights of Persons with Disabilities*. Geneva: United Nations.
- United Nations. 2008. *United Nations Declaration on the Rights of Indigenous Peoples*. Geneva: United Nations.