

## **Implementing the NDIS in Aboriginal and Torres Strait Islander Communities**

### **Key Points from Roundtable**

*The following report is a summary of the views expressed by participants at the NDIS Roundtable held at Parliament House on 6 June 2013. The content does not represent the views of the Alliance and its member organisations.*

#### **The Context: Disability in Indigenous Communities**

The prevalence of disability in Indigenous communities is approximately twice that of the rest of the Australian population. Factors which contribute to such high rates of disability include lack of access to adequate health prevention programs (particularly maternal health), lack of quality or adequate housing, lack of sanitation, exposure to violence, and alcohol and substance abuse.

Indigenous communities are not homogenous; the needs of people with disability in the Torres Strait will be very different to those of people with disability in other Aboriginal communities.

Through engagement and research projects, many Indigenous people with disability have identified their aspiration to continue the culturally significant roles they had before acquiring a disability. The ability to gain access to respite facilities which are in the community and close to family has also been highlighted, as well as having the option to pass away on country, not far away.

#### **Accessing NDIS Supports**

**Self-identification:** Many Indigenous people with disability don't self-identify as having a disability. There is often no comparable word for disability in Aboriginal languages.

**Recommendation:** A concerted outreach approach will be essential to ensuring indigenous people with disability have access to the NDIS. Organisations need to be resourced to begin what will often be a new conversation in Indigenous communities around disability. Accessing the NDIS may require some people to take on a new identity of 'disability'.

**Information:** A lack of access to meaningful information is a common barrier for Indigenous communities. Many Indigenous people with disability and their families are unaware of what disability supports are available. Many people don't understand the disability or health condition they have. *"No one knows about the new system, no one knows about the NDIS. Many people haven't engaged with the first system, or it didn't engage with them."*

**Recommendation:** *"Foundational stories are essential, going through step-by-step, in language, what a particular disability is. People need to be informed of their rights so that they can be empowered to make decisions about their own lives."*

**Advocacy:** Very few Indigenous people with disability have access to advocacy and very few know their rights and are able to express their rights. Families of people with disability are often concerned about coming forward to access services for fear of their children being taken away.

**Recommendation:** *“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.”*

**Assessment tools:** A generic assessment tool which is used for all Australians won't work. *“The NDIS must look at cultural wellbeing. How is our relationship with land and culture going to be integrated?”*

**Recommendation:** There must be different assessment tools for Aboriginal people and for Torres Strait Islander people.

### **Considerations for Support Packages**

**Transport:** Some Indigenous communities are extremely remote. There is often a lack of understanding around the cost involved in delivering services in remote Australia. In many communities there is no public transport and people are forced to use private taxis which can be prohibitively expensive. As a result, many Indigenous people with disability, their families and carers are completely socially isolated. Being alienated from cultural activities is identified as a significant issue, particularly the inability to go to funerals.

**Recommendation:** Individual support packages must take into consideration the true cost of accessing services.

**Aids and Equipment:** Most assistive technology is not suited to the environment in which Indigenous communities live. Equipment often has extremely low durability and is difficult to repair locally. Very few homes are accessible for people with disability which leaves them completely dependent upon family members. Very few buildings in Indigenous communities are accessible.

**Recommendation:** Assistive technology must be adapted to ensure its appropriateness in different contexts; this requires time and investment of resources. When allocating aids and equipment, the suitability of the community environment must also be considered.

**Individualised funding:** The focus of the NDIS on the individual may not be compatible with the Indigenous emphasis on the community. In areas with high rates of poverty, an Indigenous person on a Disability Support Pension may be the wealthiest person in their community, and they may face a cultural obligation to share their resources. *“The NDIS is based on contemporary understandings of productivity and work. How will activities such as painting and carving fit into this notion?”*

**Recommendation:** Acknowledgement that *“We don't live in our communities as individuals, we live as a community. The individual, person-centred approach isn't how we live. The NDIS has to be flexible otherwise it won't work.”* There need to be opportunities for people to create cooperatives, to pool their money to access services and develop solutions together. There needs to be a focus on building the community capacity to support people.

**Dual diagnosis:** Particular concerns for those with an Acquired Brain Injury (ABI) and a mental illness. 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.

**Recommendation:** It is important to understand how the whole service system impacts on an individual who presents with dual diagnosis. Coordinated approaches to care are essential.

### **Other Concerns**

**Incarceration of Aboriginal people with cognitive impairment:** There is widespread use of prisons for the management of unconvicted Aboriginal persons with cognitive impairments (such as intellectual disability, Acquired Brain Injury, Foetal Alcohol Disorder and mental illness). There are higher rates of Aboriginal persons with cognitive impairments in Australian prisons than non-Aboriginal persons. The majority of Indigenous people who come through the legal justice system are never detected as having a disability.

*“There are many people coming through the court system with Acquired Brain Injury, but there is a reluctance to spend money on the assessment process to target therapies or services towards their needs”.*

**Recommendation:** A shared response between the disability sector and criminal justice is needed with community-based responses which focus on treatment of significant benefit. Awareness raising and resourcing for young people with cognitive impairments is important to divert them from prison. Programs and pathways are also needed for people with cognitive impairments who are in the criminal justice system to get out.

**Importance of a workforce strategy:** Participants expressed concerns about the availability of a workforce which is appropriately trained to understand, interpret and respond to cultural differences. The impact of culture on behaviour was highlighted, particularly for those with psychiatric conditions, and how this may impact on interpretations of psychosis and the need for confinement and restraint of individuals.

**Recommendation:** *“Cultural competency is different to cultural awareness. It’s about understanding that behaviour also operates within cultural constructs”.* Cultural awareness training isn’t enough. There is a need for a culturally *competent* disability workforce.

**Research:** There is a need for greater research into the prevalence and impact of disability in Indigenous communities. However, *“Research has become a dirty word among many Indigenous communities”*

**Recommendation:** There is a need for inclusive, ethical research which is undertaken by and for Aboriginal and Torres Strait Islander people. This research needs to be driven by the needs of Indigenous communities, by their advocacy.

**Successful Program example:** Suncare Community Services, Queensland

The focus is on the entire family, not just the person with a disability or carer. The organisation tries to find ways to maintain the family structure, by talking with the whole family and looking at what everyone's needs are. Their community-based programs provide an opportunity for people to celebrate being indigenous. The Aboriginal Art Group provides an opportunity for people with disability to tell stories, create art and demonstrate to the community that Aboriginal and Torres Strait Islander people with disability can make a contribution to their communities. Participants of the art group have had a reduction in accessing psychiatric services.

## **Roundtable Presentations**

**Damian Griffis**, Executive Officer, First Peoples Disability Network

**Gayle Rankine**, Chairperson, First Peoples Disability Network

**Ray Mines**, Motivation Australia

**Libby Massey**, Machado Joseph Disease Foundation

**Patrick McGee**, Aboriginal Disability Justice Campaign

**Jennifer Cullen**, CEO, Synapse

**John Gilroy**, University of Sydney

**Phillip French**, Australian Disability Law Centre

**Michelle Bates**, Lifestyle Solutions

**Mathew Bowden**, CEO, People with Disability Australia