



NACCHO

National Aboriginal Community
Controlled Health Organisation
Aboriginal health in Aboriginal hands

www.naccho.org.au

Consultation Paper: Supporting you to make your own decisions

NDIA

September 2021

About NACCHO

NACCHO is the national peak body representing 143 Aboriginal Community Controlled Health Organisations (ACCHOs) Australia wide on Aboriginal and Torres Strait Islander health and wellbeing issues. NACCHO's work is focused on liaising with governments, its membership, and other organisations on health and wellbeing policy and planning issues and advocacy relating to health service delivery, health information, research, public health, health financing and health programs. Our members provide about three million episodes of care per year for about 350,000 people across Australia, including about one million episodes of care in very remote regions.

Sector Support Organisations, also known as affiliates, are State based and represent ACCHOs offering a wide range of support services and Aboriginal and Torres Strait Islander health programs to their members including advocacy, governance and the delivery of state, territory and national primary health care policies.

ACCHOs range from large multi-functional services employing several medical practitioners and providing a wide range of services, to small services which rely on Aboriginal Health Workers/Practitioners and/or nurses to provide the bulk of primary health care services, often with a preventive, health education focus. Our 143 ACCHOs operate approximately 700 facilities, including about 450 clinics. ACCHOs and their facilities and clinics contribute to improving Aboriginal and Torres Strait Islander health and wellbeing through the provision of comprehensive holistic primary health care, and by integrating and coordinating care and services. Many provide home and site visits; medical, public health and health promotion services; allied health; nursing services; assistance with making appointments and transport; help accessing childcare or dealing with the justice system; drug and alcohol services; and help with income support.

Collectively, we employ about 6,000 staff, 56 per cent of whom are Indigenous, making us the second largest employer of Aboriginal and Torres Strait Islander people in the country.

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Key Recommendations:

To support Aboriginal and Torres Strait Islander participants, their communities, families, and carers to make decisions for themselves, NACCHO recommends:

1. The Australian Government provides additional communications funding to NACCHO to continue and expand its NDIS communications work for Aboriginal and Torres Strait Islander participants, their communities, families and carers.
2. The NDIA and the NDIS Commission develop more culturally appropriate communications and information for Aboriginal and Torres Strait Islander participants.
3. The NDIA engage Aboriginal and Torres Strait Islander communities and organisations in the ongoing design and implementation of the NDIS, including planning processes. This should be done in true partnership as outlined in the National Agreement on Closing the Gap.
4. To ensure the cultural safety of all Aboriginal and Torres Strait Islander NDIS participants, mandatory cultural safety training for all NDIA staff, contractors and NDIS planners must be enforced by the NDIA.
5. Ongoing funding of Community Connector positions, or similar roles in urban, regional and remote locations.
6. Funding and administration of the Remote Community Connectors Program should be shifted to NACCHO to ensure it is Aboriginal and Torres Strait Islander led.
7. Funding be directed to NACCHO to develop and implement flexible care workforce models to trial across urban, regional, and remote Aboriginal Community Controlled Health Organisations (ACCHOs) to address market challenges for Aboriginal and Torres Strait Islander peoples NDIS service provision.
8. The development of strategies and funding models to attract, develop and retain Aboriginal and Torres Strait Islander workers for a sustainable integrated health and care workforce.

Introduction

NACCHO welcomes the National Disability Insurance Agency's (NDIA) consultation on their *supporting you to make your own decisions* consultation paper. NACCHO will respond to the following questions outlined in the consultation paper:

- How can we help people with disability to make decisions for themselves?
- Are there different things to consider for people with different disabilities or cultural backgrounds?
- What is the best way to support people with disability to make decisions about their NDIS plan? This includes decisions about using or changing their plan

All these questions will be answered in one consolidated response as they are all interrelated to the access, delivery and utilisation of the NDIS for Aboriginal and Torres Strait Islander people.

Aboriginal and Torres Strait Islander people are twice as likely to experience a disability than other Australians (9% have a severe or profound disability compared to 4% for non-Indigenous people¹). This is compounded with higher rates of chronic illness² in Aboriginal and Torres Strait Islander people compared to other Australians, higher rates of poverty³, numerous barriers to accessing services⁴ and racism from different sources⁵. Aboriginal and Torres Strait Islander people also have many other compounding factors such as remote locations, English as a second/third language, and specific cultural elements and traditions that can often be overlooked and can affect the experience of disability.

The National Agreement on Closing the Gap (the National Agreement) demonstrates the commitment from all levels of Government on making a change in ways policies and programs affecting Aboriginal and Torres Strait Islander people are developed⁶. Shared decision making between Aboriginal and Torres Strait Islander people and government, strengthening the community-controlled sector, improving mainstream institutions, and improving collection and access to Aboriginal and Torres Strait Islander data are the priority reforms that underpin the agreement. Disability is a key focus of the National Agreement, including the call for partnership actions to strengthen the community-controlled sector in providing disability programs, services, and policy. This is an opportunity for Government to work together in genuine partnership with Aboriginal and Torres Strait Islander organisations, communities and

¹ Aboriginal and Torres Strait Islander Health Performance Framework 2020 report, section 1.14 Disability.

² AIHW. (2016) Australian Burden of Disease Study: impact and causes of illness and death in Aboriginal and Torres Strait Islander people 2011.

³ ACOSS and UNSW (2018). Poverty in Australia 2018

⁴ Disabled People's Organisations Australia (2019). CRPD Shadow Report consultation survey results

⁵ Marwick et al. (2019). Experiences of racism among Aboriginal and Torres Strait Islander adults living in the Australian state of Victoria: a cross-sectional population-based study.

⁶ Coalition of Peaks (2020). National Agreement on Closing the Gap.

people to ensure the needs and rights of Aboriginal Torres Strait Islander people with a disability are recognized and the provision of culturally safe services.

How can we help Aboriginal and Torres Strait Islanders make decisions for themselves, including about their NDIS plan?

Aboriginal and Torres Strait Islander people were not considered in the design of the NDIS, nor was the community-controlled sector consulted during the design phase. A one size fits all assumption was made which has resulted in significant barriers for Aboriginal and Torres Strait Islander people to access the NDIS and utilise culturally safe services. To ensure true choice and control for Aboriginal and Torres Strait Islander participants, it is critical that NDIS processes and pathways recognise:

- Aboriginal and Torres Strait Islander understanding of health and wellbeing encompasses a holistic view of physical, cultural, and spiritual components of health and wellbeing. This is critical in the context of the NDIS as plans need to take into consideration meeting the cultural needs of Aboriginal and Torres Strait Islander participants.
- That any Aboriginal and Torres Strait Islander person with disability has the same rights to access care and other services and should not be denied care based on stereotypes, assessments on quality of life, or judgments about their relative worth based on the presence or absence of disabilities⁷.
- Aboriginal and Torres Strait Islander peoples often require more support than other Australians to gain access to, and participate in, services such as the NDIS. This support must be specialised. Therefore in 'healthy' markets there will also be sub-sets of thin market cohorts where operational costs are prohibitive to suppliers due to the wrap-around support required to operate in a holistic model of care.

One of the current key issues NACCHO hears from its Affiliates and members is the lack of culturally appropriate NDIS information and communications for Aboriginal and Torres Strait Islander people. A lack of culturally appropriate information leads to a lack of meaningful understanding of the NDIS by Aboriginal and Torres Strait Islander people with disability, their carers, and their families. This means they are not appropriately empowered to make decisions about their disability, NDIS plans, goals, or services.

Aboriginal and Torres Strait Islander peoples living in urban centres are more likely to have access to mainstream services and information, whereas those living in regional or remote locations may have varying levels of access to targeted services, programs and dedicated government staff to deliver information to the community. Often these services are infrequent, not coordinated, or even absent particularly in very remote areas. Those living in remote

⁷ Australian Human Rights Commission (2020). Guidelines on the rights of people with disability in health and disability care during COVID-19

communities may also have lower English proficiency with English being the second, third or fourth language spoken within the community. There is inconsistent access to culturally appropriate information on the NDIS for Aboriginal and Torres Strait Islander peoples.

NACCHO welcomes the Department of Social Services' preliminary commitment through the Aboriginal Torres Strait Islander Market Capability Project (NDIS Ready), which, as one of its outcomes, looks to improve community understanding of the NDIS. This outcome will predominantly be achieved through a broad Communications Initiative. NACCHO is working with key stakeholders, and its Affiliates and members to codesign and develop solutions at a national, jurisdictional and local level to support the ACCHOs and community in understanding entitlements under the NDIS. This will ensure that all communications materials developed and disseminated are useful and applicable across communities and recognises the cultural nuances and place based needs of different communities.

The communication materials of the NDIS Ready Communications Initiative include easily understandable and accessible information and advice on engaging with the NDIS, such as what a plan is, stepping Aboriginal and Torres Strait Islander participants through the planning process, the roles and responsibilities of various Government agencies and actors in the NDIS (such as the difference between the NDIS Commission and the NDIA).

It must be recognised the work of the NDIS Ready Communications Initiative should be considered the beginning of the communications work that needs to be done across Australia to support Aboriginal and Torres Strait Islander communities' access to, and understanding of, the NDIS.

NACCHO recommends the Australian Government provide ongoing and sustainable communications funding. This funding can be used to continue and expand NACCHO's work with our Affiliates and member services to further develop culturally appropriate communications materials for Aboriginal and Torres Strait Islander participants, their communities, families and carers. This is a critical first step in empowering Aboriginal and Torres Strait Islander participants self determination in their decision making.

Further, NACCHO recommends that the NDIA and the NDIS Commission ensure all communications and information resources are culturally appropriate. This needs to be done in close consultation with Aboriginal Community Controlled Organisations, including NACHO, its Affiliates and member services to ensure the development of culturally appropriate materials.

Aboriginal and Torres Strait Islander people continue to experience a combination of racism and ableism by mainstream providers especially if they have very little training or knowledge of the ways that disability intersects with different cultural experiences. Often service provision forms have a 'tick box' for Aboriginal and Torres Strait Islander people **or** disability, not both⁸. This can lead to Aboriginal and Torres Strait Islander people missing out on culture because of

⁸ Disabled People's Organisations Australia. Ibid.

their disability and is an example of institutional racism. This has been further reinforced by research indicating that few service providers understand the complexity of issues confronting Aboriginal and Torres Strait Islander people. As a result, services and programs are rarely culturally safe or appropriate and mainstream services targeting Aboriginal and Torres Strait Islander people do not always understand the issues facing individuals with disabilities and their families⁹.

The notion of disability is a western term and can be undesirable or stigmatizing to the person and the community. This can lead to an unwillingness to identify when help is needed and reach out to engage with services. Associations with terminologies like 'disability' and 'disabled' within Aboriginal and Torres Strait Islander communities have led to racist connotations that Aboriginality is the 'cause' of some disabilities (especially cognitive disability). This can further limit access to services; specifically, those mainstream services that are not culturally competent¹⁰.

There is a clear preference for Aboriginal and Torres Strait Islander peoples to access community-controlled services for disability, aged-care, health or otherwise and will bypass mainstream services to access one where they are confident their cultural safety is guaranteed. More concerning is that Aboriginal and Torres Strait Islander peoples will not access a service (or at least defer accessing) if they perceive that, or have an experience, where their cultural safety is compromised. For this reason, ACCOs, including ACCHOs, are critical to the successful uptake and delivery of NDIS services to Aboriginal and Torres Strait Islander peoples. To ensure the successful uptake and utilisation of NDIS disability, a multidisciplinary and culturally competent workforce is needed to support and provide services to Aboriginal and Torres Strait Islander peoples.

NACCHO recommends the Australian Government adopts a whole of Government integrated funding model to support the development of an Aboriginal and Torres Strait Islander care workforce. It is only with an appropriate culturally safe care workforce that Aboriginal and Torres Strait Islander participants will be properly empowered to make decisions about their disability, including having genuine choice and control over the disability services they access.

NACCHO recommends funding directed to NACCHO to develop flexible care workforce models to trial across urban, regional, and remote Aboriginal Community Controlled Health Organisations (ACCHOs) to address market challenges for Aboriginal and Torres Strait Islander peoples NDIS service provision.

⁹ National People with Disabilities and Carer Council. (2009). SHUT OUT: The experience of people with disabilities and their families in Australia.

¹⁰ Avery, Scott, (2020). Statement of Dr Scott Avery to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with a Disability.

Further, NACCHO recommends the development of strategies and funding models to attract, develop and retain Aboriginal and Torres Strait Islander workers for an integrated health and care workforce.

NACCHO has heard, anecdotally but repeatedly from our Affiliates and members that NDIS access and planning processes are not culturally safe, not appropriately taking into account the needs of Aboriginal and Torres Strait Islander participants, their families and carers. This includes a lack of culturally safe Local Area Coordinators and other Partners in the Community.

NACCHO invites the NDIA to engage Aboriginal and Torres Strait Islander communities and organisations to change the current NDIS design to ensure it is more appropriate for, and can better meet the needs of, Aboriginal and Torres Strait Islander communities. Culturally appropriate NDIS processes and procedures will empower Aboriginal and Torres Strait Islander participants, their families and carers to make decisions about their plans and disability services.

Despite being preferable, it will not always be feasible to embed the provision of NDIS information, planning and Local Area Coordination (LAC) within an Aboriginal Community Controlled Organisation (ACCO). Accordingly, these services need to be provided by culturally competent and well-trained staff and organisations. To ensure the cultural safety of all Aboriginal and Torres Strait Islander NDIS participants, all NDIA staff, contractors and NDIS planners must be required to have completed cultural awareness training. This is consistent with Priority Reform Three of the National Agreement.

Further, under Priority Reform Two of the National Agreement, there needs to be an ongoing commitment from governments to provide ongoing funding and support to strengthen the ACCHO sector to deliver disability/NDIS services to their communities. This includes ACCHOs' work supporting their community to better understand the NDIS and support participants through NDIS access and planning processes.

In recognition of the need to better support Aboriginal and Torres Strait Islander people, NDIA have funded NACCHO to coordinate the Aboriginal Disability Support Liaison Officers (ADLO) for urban and regional areas.

While the ADLO goes some way to helping Aboriginal and Torres Strait Islander people access and use NDIS services in a culturally safe way, it is time limited 12-month funding, with no option of further funding. These roles, or similar roles, must be permanently funded to support Aboriginal and Torres Strait Islander people to access and utilise NDIS services, including the appointment of culturally appropriate LAC providers (or allowing ACCHOs and/or Affiliates to undertake this role). Long-term funding post June 2021 for the extension of culturally appropriate links to the NDIS for Aboriginal and Torres Strait Islander people is essential, and one way to improve equitable access to services.

The Remote Community Connector Program (RCCP) has ongoing funding but is not led by the Community Controlled sector. Funding and administration of the RCCP should be shifted to NACCHO to ensure it is Aboriginal and Torres Strait Islander led.