National Disability Strategy

Submission

December 2020

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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Introduction

This submission to the Department of Social Services will look at six questions from *National Disability Strategy – Position Paper*.

- Do you have any comments on the vision and outcome areas being proposed for the new Strategy?
- What do you think about the guiding principles proposed here?
- What is your view on the proposal for the new Strategy to have a stronger emphasis on improving community attitudes across all outcome areas?
- How do you think that clearly outlining what each government is responsible for could make it easier for people with disability to access the supports and services they need?
- What do you think of the proposal to have Targeted Action Plans that focus on making improvements in specific areas within a defined period of time?
- How could the proposed Engagement Plan ensure people with disability, and the disability community, are involved in the delivery and monitoring of the next Strategy?

This submission has been prepared by NACCHO with valued input from the Aboriginal Health Council of Western Australia (AHCWA), the Aboriginal Medical Services Alliance of the Northern Territory (AMSANT) and the Victorian Aboriginal Community Controlled Health Organisation (VACCHO).

Aboriginal and Torres Strait Islander people are twice as likely to experience a disability than other Australians (9% have a severe condition compared to 4% for non-Indigenous people[1]). This is compounded with higher rates of chronic illness[2] in Aboriginal and Torres Strait Islander people compared to other Australians, higher rates of poverty[3], numerous barriers to accessing services[4] and racism from different sources[5]. Aboriginal and Torres Strait Islander people also have many other factors such as remote locations, English as a second/third language, and specific cultural elements and traditions that can often be overlooked - all of which can affect the experience of disability.

The National Disability Strategy (the Strategy) needs to take into consideration the specific needs of Aboriginal and Torres Strait Islander people. The New Zealand Disability Strategy 2016-2026 recognises the importance of cultural identity for people who are Maori who have a disability[6] and this should be reflected in the Australian National Disability Strategy for Aboriginal and Torres Strait Islander people. This should include the principles of partnership with Aboriginal and Torres Strait Islander people, full participation in all elements of society with opportunities for self-determination and self-management and protection of the culture and identity of all Aboriginal and Torres Strait Islander people[7].

The Australian National Agreement on Closing the Gap (the National Agreement) demonstrates a commitment from all levels of governments to changing the way policies and programs affecting

[1] Aboriginal and Torres Strait Islander Health Performance Framework 2017 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] Ministry of Social Development. (2016). New Zealand Disability Strategy 2016–2026.
[7] Ministry of Social Development. (2016) ibid.

Aboriginal and Torres Strait Islander people[8] are developed and delivered. 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 and policy. This provides an opportunity to work together to recognise the needs and rights of Aboriginal Torres Strait Islander people with a disability and make structure changes. Stronger evidence is required on the prevalence of disability and the impact of disability on Aboriginal and Torres Strait Islander people and communities. Given this is currently a notable gap, this is where the Strategy can have the biggest impact.

(Q1) Do you have any comments on the vision and outcome areas being proposed for the new Strategy?

NACCHO and the Affiliates broadly endorse the six outcome areas for the new Strategy with two additional suggestions.

First, the *Health and Wellbeing* outcome should have a broader focus to encompass social and emotional wellbeing (SEWB) as well as mental health. Aboriginal and Torres Strait Islander people with psychosocial disability constitute a significant proportion of First Nations people with disability[9]. Twenty-five percent of Aboriginal and Torres Strait Islander people who access disability support services have a primary diagnosis of a psychosocial disability[10]. Psychosocial disabilities differ from other forms of disability in significant ways, and so require targeted support and dedicated activities to ensure inclusion of these people. Aboriginal and Torres Strait Islander people also experience disproportionate challenges associated with their SEWB more generally. Around one third of Aboriginal and Torres Strait Islander people experience high or very high levels of psychological distress, with the overall suicide rate for Aboriginal and Torres Strait Islander people almost double the rate for other Australians[11]. As such, it is also especially important to recognise and address the SEWB needs of Aboriginal and Torres Strait Islander people with non-psychosocial forms of disability. The Strategy needs to specifically outline measures and activities to ensure the SEWB of people with a disability is upheld.

Second, the double discrimination that impacts Aboriginal and Torres Strait Islander people with a disability needs to be addressed within each outcome area. The Strategy needs to be inclusive in its vision and outcomes to all with a disability. Double discrimination occurs when people are discriminated due to dual aspects of their identity (e.g., discrimination experienced as an Aboriginal person and as a person with disability). An Aboriginal and Torres Strait Islander person with a disability is a member of two (or more) communities: one representing their Aboriginality and the other their disability. For these peoples, addressing their disability without acknowledging their

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[8] Coalition of Peaks (2020). National Agreement on Closing the Gap.
[9] Australian Institute of Health and Welfare (2019). Disability support for Indigenous Australians <http://www.aihw.gov.au/reports/australias-welfare/disability-support-for-indigenous-australians>
[10] AIHW (2019). Ibid.
[11] Australian Institute of Health and Welfare (2015). The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples <hthttps://www.aihw.gov.au/reports/indigenous-health-welfare/indigenous-health-welfare-2015/contents/table-of-contents>

Aboriginality (or other identities including LGBTQIA+ etc.) can make them feel secluded from one of their representative communities[12].

(Q2) What do you think about the guiding principles proposed?

The *Involve and Engage* principle could be made stronger to *control and lead*. In the same way that Aboriginal and Torres Strait Islander people are best placed to lead the delivery of services for their people, people with a disability are best placed to lead the development of policy, programs, and services for themselves based on their own lived experience. If the principle is retained as *Involve and engage* there needs to be more emphasis on partnerships. Implementation of the Strategy must be developed in partnership with organisations such as ACCHOs that are instrumental in providing services to Aboriginal and Torres Strait Islander people with disability. This is reinforced by the National Agreement priority reform of formal partnership and shared decision-making[13]. This commits government to building and strengthening structures that empower Aboriginal and Torres Strait Islander people for shared decision making to accelerate policy and programs and ensuring Aboriginal and Torres Strait Islander people with a disability have a voice.

To ensure the *Engage the Broader Community* principle is fully addressed, it is crucial to have culturally appropriate materials and education to engage the community. It is also necessary to educate mainstream services to provide culturally appropriate services, information, and support for Aboriginal and Torres Strait Islander people when using their services. This is further reinforced by the first priority under the National Agreement; formal partnerships and shared decision-making. This commits government to building and strengthening structures to empower Aboriginal and Torres Strait Islander people and share decision-making for policy and initiatives that impact them[14].

The *Address Barriers faced by Priority Populations* principle could be made stronger to *Embed an Intersectional Approach*. This reflects a more strength-based discourse, and a shift in language to be more positive, particularly in relation to the word barriers, which has negative connotations. Shifting to a positive discourse would consider the experience of people with disabilities and provide opportunities to improve outcomes. An intersectional approach acknowledges and addresses the multiple dimensions to a person's identity that frame the layers in which social inequity can accumulate including, as outlined above, multiple identities of an Aboriginal and Torres Strait Islander person with a disability[15]. This also highlights the need to develop an equitable, needs-based approach to funding for the implementation of activities under the Strategy.

An additional principle around cultural safety should be included. There are limited services that address disability in a culturally appropriate way, and this should be addressed across all domains for all Aboriginal and Torres Strait Islander people with a disability including justice, education, employment, and health. More input into the recognition of the individuality of Aboriginal and Torres Strait Islander people with disability and the increased employment of Aboriginal staff in these ACCHOs to advocate for culturally appropriate services is needed.

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[12] FPDN. (2016). Intersectional dimensions on the right to health for Indigenous peoples – A disability perspective.
[13] Coalition of Peaks. (2020). Ibid.
[14] Coalition of Peaks. (2020). Ibid.
[15] FPDN. (2016). Ibid.

(Q3) What is your view on the proposal for the new Strategy to have a stronger emphasis on improving community attitudes across all outcome areas?

To date, there has been a lack of promotion of the social model of disability and has continually lacked infrastructure to fully enable people with disability to live life to the fullest. This is further compounded for Aboriginal and Torres Strait Islander people with a disability. Keeping with the goals of the NDIS for people with disability to 'live an ordinary life', an ordinary life for Aboriginal and Torres Strait Islander people includes culture, community, family, holistic wellbeing, and culturally safe services. In a 2019 study conducted by the Disabled People's Organisations Australia, 76.5% of respondents experienced discrimination on the basis of their disability and, of the 3% of those surveyed who identified as Aboriginal and Torres Strait Islander people, 60% were discriminated against on the basis of their race[16].

Social and cultural norms or expectations of behaviour shape how people behave. These social norms can often be unspoken and set the social standards of appropriate or inappropriate behaviours[17]. People learn about the rights of people with a disability in many ways over the course of their lives, including how to engage with and treat people with a disability. Although often it is not until someone has a personal connection with a person with a disability that the rights of people with a disability are really considered and respected. Education about disability should start at a young age, and more information should be provided in general to key stakeholders, community groups and organisations about how to support people with a disability as a colleague, client, or community member.

Attitudes towards people with a disability can be improved by increasing awareness and promotion of ability and inclusivity and the positive contributions that people with disability can make to their community. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) outlines the principles for all signatories *to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity[18].* Australia is a signatory to the CRPD and is committed to promote the full realisations of people with a disability and ensure that human rights are upheld without discrimination based on disability[19].

Consultation with Aboriginal and Torres Strait Islander people with disabilities and their community-controlled organisations to develop awareness campaigns that are respectful and communicated through different types of media channels is essential[20]. This will encourage inclusion of Aboriginal and Torres Strait Islander people with disabilities in society and help to address miscommunication and intersectoral discrimination when accessing healthcare and other essential services. This will go some way to help inclusivity of Aboriginal and Torres Strait Islander people with a disability and impact on wider attitudes and behaviours towards them.

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[16] Disabled People's Organisations Australia (2019). CRPD Shadow Report consultation survey results
[17] World Health Organization. (2009). Changing cultural and social norms that support violence.
[18] United Nations (2006). Convention on the Rights of Persons with Disabilities. Pp 4.
[19] United Nations (2006). Ibid.
[20] Ben Gauntlett. (2019). The critical task of changing community attitudes towards disability. https://humanrights.gov.au/about/news/speeches/critical-task-changing-community-attitudes-towards-disability.

(Q4) How do you think that clearly outlining what each government is responsible for could make it easier for people with disability to access the supports and services they need?

While accountability of government is important for people with disability and service providers, there is an ongoing pressing need for simple, clear information to enable informed choice of disability services. Aboriginal and Torres Strait Islander people continue to feel misunderstood by mainstream providers especially if they have very little training or knowledge of the ways that disability intersects with different cultural experiences. This is further reinforced by research indicating that few service providers seem to grasp the complexity of the issues confronting Aboriginal and Torres Strait Islander people[21]. For example, often service provision forms have a 'tick box' for Aboriginal and Torres Strait Islander people **or** disability, not both[22]. The impact of this can lead to Aboriginal and Torres Strait Islander people missing out on culture because of their disability.

A way to address these barriers is Government partnering with Affiliates and ACCHOs to develop clear information on process to ensure there are culturally appropriate pathways for Aboriginal and Torres Strait Islander people with disabilities. As such, the Strategy mentions on page eight that it will "outline the important role of the non-government sector in improving outcomes for people with disability". However, the Strategy should also emphasise the importance of community-controlled organisations in improving outcomes for Aboriginal and Torres Strait Islander people with disabilities. Building the community-controlled sector is priority two under the National Agreement. Disability is identified as one of the first sectors to develop and strengthen[23] and this provides an opportunity to link the work currently underway by NGOs and government into the Strategy.

The Strategy also needs to provide clarity on who is responsible for filling gaps in access to disability services. There are a number of Aboriginal and Torres Strait Islander people who are not eligible for the NDIS so the Strategy needs to provide a framework on where these people can access the help and support needed for their disabilities.

Finally, the strategy should explicitly outline who is responsible as a provider of last resort in thin market areas[24]. To date there seems to be no cohesive plan for how this is managed or who should take on this role. There is considerable underspend for Aboriginal and Torres Strait Islander participants on active plans as there are limited choices for NDIS supports in areas of thin markets.

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[21] Disabled People's Organisations Australia (2019). ibid
[22] Disabled People's Organisations Australia (2019). ibid
[23] Coalition of Peaks. (2020). Ibid.

[24]Thin Market definition: In the context of the NDIS, thin markets exist where there is a gap between the needs of participants and the services available in the market. This can occur in a particular location (where the services are needed), and/or for a particular service, and/or for certain cohorts of participants; and is driven by difficulties in serving a client's need or their location, such as high cost.

Case Study

The Northern Territory has a significant underspend of approximately of 33% of NDIS plan budgets in 2018-19, resulting in over $1 million of underutilised funds. This is money that should be spent of disability support services and capacity building for NDIS participants. A considerable issue with the utilising of NDIS funds is the ability to coordinate all necessary supports, particularly in areas of thin markets. Coordination of services (by an ACCHO) is required to ensure the best use of providers time (especially for FIFO providers) and access for all Aboriginal and Torres Strait Islander people who need it.

There is a clear preference for Aboriginal and Torres Strait Islander people to access community-controlled services including disability and health, and many individuals will bypass mainstream services to access one where they are confident their cultural safety is guaranteed. For this reason, ACCHOs are critical for the successful uptake and delivery of the NDIS to Aboriginal and Torres Strait Islander people to ensure the cultural and systemic barriers outlined previously are addressed.

There also needs to be consideration for how to manage perceived conflicts of interest, as this is a common issue raised when discussing disability within in the ACCHO sector. Currently providers cannot be the assessor, coordinator, and provider. Again, this does not recognise the realities of remote service provision and thin markets where there are limited providers. NACCHO acknowledges recommendation 16b of the Tune review that the NDIS rules are amended to outline circumstances in which it is not appropriate for the providers of support coordination to be the provider of any other funded supports in a participant's plan, to protect participants from provider's conflicts of interest[25]. However, NACCHO also notes that Tune clarifies this position by stating that it is not appropriate in all cases, such as circumstances **'where there is only one provider in a community, or where the participant has specific cultural safety needs'**[26] (emphasis added). It is appropriate for Aboriginal and Torres Strait Islander NDIS participants to receive multiple supports from a single provider if that provider is culturally safe.

(Q7) What do you think of the proposal to have Targeted Action Plans that focus on making improvements in specific areas within a defined period of time?

The inclusion of targeted Action Plans will provide an important way to measure progress against the Strategy and implementation of the underpinning activities. The Action Plans must be clear and transparent with information provided in the Strategy as to how the priority areas for targeted action plans will be decided. The Action Plans need to be developed in partnership with stakeholders including ACCHOs and other Aboriginal and Torres Strait Islander organisations.

The Action Plans need to include:

- *Activities around sustainable workforce in the disability sector*. The Strategy needs to align with the numerous workforce plans that are in development including the National

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[25] Tune, D. (2019) Review of the National Disability Insurance Scheme Act 2013, Removing red tape and implementing the NDIS participant service guarantee. Recommendation 16b.

[26] Tune, D. (2019) Review of the National Disability Insurance Scheme Act 2013, Removing red tape and implementing the NDIS participant service guarantee. 7.40 p 120.

Aboriginal and Torres Strait Islander Health Workforce Plan 2021-2031 and the National NDIS Workforce Plan.

- *Measurement of outcomes and impacts of the strategy.* The Action Plans need to have clear measurement of outcomes to ensure there is sustainable change to enable Aboriginal and Torres Strait Islander people with a disability to lead full lives with dignity and free from discrimination.
- *Reporting*. To ensure that outcomes are in line with the Strategy vision and outcomes. This should include ongoing consultations with relevant stakeholders, reporting on outcomes from government and non-government services and available publicly.

(Q8) How could the proposed Engagement Plan ensure people with disability, and the disability community, are involved in the delivery and monitoring of the next Strategy?

In order to ensure people with disability are involved in delivery and monitoring of the new Strategy, there must be collaboration, effective engagement and partnerships with the relevant stakeholders including ACCHOs and peak bodies. This includes the active involvement of Aboriginal and Torres Strait Islander service providers and subject matter experts in all stages of co-design including planning, development, brainstorming and refining, through to implementation, monitoring and evaluation. When engaging with Aboriginal and Torre Strait Islander communities on disability the triple 'I' is recommended for engagement; Introduction by a local community member, Initiate follow up contact to demonstrate commitment, and Invitation to return by the community to ensure buy-in from community[27]. Aboriginal and Torres Strait Islanders have an untapped knowledge and best-practice models that can inform policy and practice across the sector, in particular, in the area of inclusive participation in community and support systems. The communications and engagement plan needs to link the Strategy and the NDIS to ensure understanding of these two separate but linked policies.

Conclusion
Updating the Strategy provides government with an important opportunity to specifically include the rights and contributions of Aboriginal and Torres Strait Islander people with disabilities as the previous strategy did not include specific references to Aboriginal and Torres Strait Islander communities. This will allow more emphasis on building the capacity of Aboriginal and Torres Strait Islander people with a disability and enable a greater understanding by governments and the broader public of the complexities faced and experienced by Aboriginal and Torres Strait Islander people.

NACCHO and the Affiliates would like to be considered as the peak organisation for Aboriginal and Torres Strait Islander health nationally and to be engaged for implementation and review of the new Strategy.

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[27] Ferdinand, et al. (2019). Understanding disability through the lens of Aboriginal and Torres Strait Islander people – challenges and opportunities.