



NACCHO

National Aboriginal Community
Controlled Health Organisation
Aboriginal health in Aboriginal hands

www.naccho.org.au

Developing a Guide to the Guiding Principles – Australia’s Disability Strategy

**Department of Social
Services**

December 2022

ABOUT NACCHO

NACCHO is the national peak body representing 145 Aboriginal Community Controlled Health Organisations (ACCHOs). We also assist a number of other community-controlled organisations.

The first Aboriginal medical service was established at Redfern in 1971 as a response to the urgent need to provide decent, accessible health services for the largely medically uninsured Aboriginal population of Redfern. The mainstream was not working. So it was, that over fifty years ago, Aboriginal people took control and designed and delivered their own model of health care. Similar Aboriginal medical services quickly sprung up around the country. In 1974, a national representative body was formed to represent these Aboriginal medical services at the national level. This has grown into what NACCHO is today. All this predated Medibank in 1975.

NACCHO liaises with its membership, and the eight state/territory affiliates, governments, and other organisations on Aboriginal and Torres Strait Islander health and wellbeing policy and planning issues and advocacy relating to health service delivery, health information, research, public health, health financing and health programs.

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 practitioners and/or nurses to provide the bulk of primary health care services. Our 144 members provide services from about 550 clinics. Our sector provides over 3.1 million episodes of care per year for over 410,000 people across Australia, which includes about one million episodes of care in very remote regions.

ACCHOs contribute to improving Aboriginal and Torres Strait Islander health and wellbeing through the provision of comprehensive 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. Our services build ongoing relationships to give continuity of care so that chronic conditions are managed, and preventative health care is targeted. Through local engagement and a proven service delivery model, our clients 'stick'. Clearly, the cultural safety in which we provide our services is a key factor of our success.

ACCHOs are cost-effective. In 2016, a cost-benefit analysis of the services provided by Danila Dilba to Aboriginal and Torres Strait Islander people in the Greater Darwin region was undertaken by Deloitte Access Economics. The findings demonstrated that each dollar invested in the health service provides \$4.18 of benefits to society. ACCHOs are also closing the employment gap. Collectively, we employ about 7,000 staff – 54 per cent of whom are Aboriginal or Torres Strait Islanders – which makes us the third largest employer of Aboriginal or Torres Strait people in the country.

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Recommendations:

- The guide needs to be able to consider the historical ways Aboriginal and Torres Strait Islander people have faced systemic barriers and inflexibility in ways to include them in the decision-making process. Allowing for the development of programs to be created in community for community will ensure cultural safety is central and allow for informed choice and control.
- Institutional racism needs to be identified and eliminated through systems level change. The Guide needs to reflect this and prioritise Aboriginal and Torres Strait Islander people with disabilities to co-design programs.
- The guide needs to consider the needs of Aboriginal and Torres Strait Islander people with disability and the intersectionality with other communities.
- The wording of the guide should reflect a more updated view of disability in-line with this WHO model, within the context of a social model of disability rather than the medical diagnosis people have.
- The guide needs to include UNDRIP principles for Aboriginal and Torres Strait Islander people's rights.
- The guide needs to consider principles of cultural safety and accessibility for Aboriginal and Torres Strait Islander people with disabilities.
- The Guide needs to align with the National Agreement, particularly the four priority reforms that underpin the agreement.
- The guide should reflect the need to support early access to services for young Aboriginal and Torres Strait Islander people with a disability.

Introduction

NACCHO welcomes the opportunity to provide a submission to “*Developing a Guide to the Guiding principles – Australia’s Disability Strategy*”.

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 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.

National Agreement on Closing the Gap

In July 2020 the Australian Government, all state and territory governments, and the Coalition of Peaks signed the *National Agreement on Closing the Gap* (National Agreement). The reforms and targets outlined in the National Agreement seek to overcome the inequality experienced by Aboriginal and Torres Strait Islander people, and achieve life outcomes equal to all Australians. All governments have committed to the implementation of the National Agreement’s four Priority Reform Areas, which seek to bring about structural change to affect ways in which governments work with Aboriginal and Torres Strait Islander organisations, communities and individuals. The four Priority Reforms are:

Priority Reform Area 1 – Formal partnerships and shared decision-making

This Priority Reform commits to building and strengthening structures that empower Aboriginal and Torres Strait Islander people to share decision-making authority with governments to accelerate policy and place-based progress against Closing the Gap.

Priority Reform Area 2 – Building the community-controlled sector

This Priority Reform commits to building Aboriginal and Torres Strait Islander community-controlled sectors to deliver services to support Closing the Gap. In recognition that Aboriginal and Torres Strait Islander community-controlled services are better for Aboriginal and Torres Strait Islander people, achieve better results, employ more Aboriginal and Torres Strait Islander people and are often preferred over mainstream services.

Priority Reform Area 3 – Transformation of mainstream institutions

This Priority Reform commits to systemic and structural transformation of mainstream government organisations to improve to identify and eliminate racism, embed and practice cultural safety, deliver services in partnership with Aboriginal and Torres Strait Islander people, support truth telling about agencies’ history with Aboriginal and Torres Strait Islander people, and engage fully and transparently with Aboriginal and Torres Strait Islander people when programs are being changed.

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.

Priority Reform 4 – Sharing data and information to support decision making

This Priority Reform commits to shared access to location-specific data and information (data sovereignty) to inform local-decision making and support Aboriginal and Torres Strait Islander communities and organisations to support the achievement of the first three Priority Reforms.

Principle 1: Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons

With the introduction of choice and control through selecting the supports via individualised planning, the NDIS has allowed more choice and control for a person with a disability. However, as the scheme is still relatively new, the ability for choice and control is seriously impacted by thin markets. The competitive market model of the NDIS envisages providers competing for participants' service needs. This model rewards those providers who can operate efficiently and are able to operate profitably and sustainably. However, this competitive market model will understandably fail in 'thin markets' where the participant numbers are very small, and no efficiency gain can be realised. Thin markets exist particularly, but not exclusively, in remote and very remote locations, where a number of our ACCHOs work. Thin markets also exist in urban locations as Aboriginal and Torres Strait Islander people often require more support than other Australians to gain access to, and participate in, the NDIS. Thin market challenges can lead to participants being forced to take the first available service rather than having the ability to choose the most appropriate for them.

Aboriginal and Torres Strait Islander people also have many other compounding factors including, English as a second/third language, and specific cultural elements and traditions that can often be overlooked and can affect the experience of disability. Prior to colonisation, there was no word for 'disability' in traditional Indigenous languages, rather disability was understood as part of the human experience with evidence suggesting that Aboriginal and Torres Strait Islander people with disability were treated the same as non-impaired people. An important part of empowering Aboriginal and Torres Strait Islander people with a disability is by offering the choice to have information conveyed in their own language. This allows the participant to fully understand the choices that they are making.

The guide needs to be able to consider the historical ways Aboriginal and Torres Strait Islander people have faced systemic barriers and inflexibility in ways to include them in the decision-making process. Allowing for the development of programs to be created in community for community will ensure cultural safety is central and allow for informed choice and control.

Principle 2 Non-discrimination

People with a disability have long faced additional discrimination compared to the wider community in Australia. 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 Aboriginality (or other identities including LGBTI+ etc.) can make them feel secluded from one of their representative communities⁶.

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

⁶ FPDN. (2016). Intersectional dimensions on the right to health for Indigenous peoples – A disability perspective.

identified as Aboriginal and Torres Strait Islander people, 60% were discriminated against on the basis of their race⁷.

This is a clear demonstration that Australia is not inclusive for Aboriginal and Torres Strait Islander people with a disability. Aboriginal and Torres Strait Islander concepts and perspectives of disability must be integrated into all disability policies and programs if they are to be inclusive and effective for Aboriginal and Torres Strait Islander people. Institutional and individual racism are the most significant barriers to inclusion for Aboriginal and Torres Strait Islander people with a disability. There is significant evidence that the discrimination faced by Aboriginal and Torres Strait Islander people with disability is not only greater than their non-disabled peers but also has a greater impact on their engagement with services and society^{8 9}.

Institutional and individual racism are the most significant barriers to inclusion for Aboriginal and Torres Strait Islander people with a disability. Consistent with the National Agreement and the new National Aboriginal and Torres Strait Islander Health Plan 2021-2031 (the Health Plan), this institutional racism needs to be identified and eliminated through systems level change. The Guide needs to reflect this and prioritise Aboriginal and Torres Strait Islander people with disabilities to co-design programs.

Principle 3 Full and effective participation and inclusion in society

People with a disability have been shown to face significant barriers to employment, social inclusion and education. In 2011 Australia was ranked 21st out of 29 OECD countries¹⁰ for employment participation rates for people with a disability. In the same report, Australia was ranked 27th out of 27 countries for risk of living below the poverty line. This is magnified in Aboriginal and Torres Strait Islander communities.

There is no single Aboriginal and/or Torres Strait Islander identity, which means there will be no single meaning of inclusion for Aboriginal and Torres Strait Islander people. What inclusion means for Aboriginal and Torres Strait Islander people will depend on the context of an individual's circumstances in the context of their culture, backgrounds, experiences, families and communities. This meaning will be further contextualized by other intersections for an Aboriginal or Torres Strait Islander person.

Despite this, any understanding of inclusivity for Aboriginal and Torres Strait Islander people must recognise:

- The Aboriginal and Torres Strait Islander understanding of disability, health and wellbeing, which is a holistic view of physical, cultural, and spiritual components of health and wellbeing.
- 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,

⁷ Disabled People's Organisations Australia (2019). CRPD Shadow Report consultation survey results.

⁸ Temple, J., et al., (2020). Exposure to interpersonal racism and avoidance behaviours reported by Aboriginal and Torres Strait Islander people with a disability.

⁹ Trounson, J. (2020). A systematic literature review of Aboriginal and Torres Strait Islander engagement with disability services.

¹⁰ 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>.

assessments on quality of life, or judgments about their relative worth based on the presence or absence of disabilities

- Aboriginal and Torres Strait Islander peoples often require more support than other Australians to gain access to, and participate in, services they have an entitlement to access, 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.

The guide needs to consider the needs of Aboriginal and Torres Strait Islander people with disability and the intersectionality with other communities.

Principle 4 Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity

The World Health Organisation (WHO) International Classification of Functioning, Disability and Health recognises the need to consider other parts of an individual in context of their disability. It provides a framework to consider the dynamic between body, health, environment and personal factors, including culture¹¹. This focus on the social model that captures and promotes the holistic view of a person is central to Aboriginal and Torres Strait Islander culture so needs to be a key element in the guide.

The social model of disability distinguishes between impairment and disability and notes that it is not the impairment or diagnosis that disadvantages them, it is society. This is supported by the Aboriginal and Torres Strait Islander view of health as holistic encompassing, physical, cultural, and spiritual components of health and wellbeing. Aboriginal and Torres Strait Islander people focus on the strengths and differences of an individual, not on the "deficits". This can be a struggle for Aboriginal and Torres Strait Islander people who are looking for disability support as western structures and policies articulate disability as deficits and not opportunities or strengths.

The wording of the guide should reflect a more updated view of disability in-line with this WHO model, within the context of a social model of disability rather than the medical diagnosis people have.

Principle 5 Equality of opportunity

We know that Aboriginal and Torres Strait Islander people continue to experience racism across the health sector and that this impacts on health outcomes. Racial discrimination is an important social determinant of health, and accounts in large part for the disparity in health outcomes between Aboriginal and Torres Strait Islander people and other Australians. This disparity is the result of a process of systemic racism that has been experienced by Aboriginal and Torres Strait Islander people over many generations and can lead to unequal, sub-optimal or inappropriate health-service provision. Aboriginal and Torres Strait Islander people may be misdiagnosed, have symptoms dismissed or not get the culturally appropriate care they need. This can make Aboriginal and Torres Strait Islander people less likely to seek care and it can contribute to higher rates of early discharge from services.

The UNDRIP represents one of the most significant developments in advocacy for Indigenous people's rights globally. Its central concern is self-determination¹², as made clear in Article 3:

¹¹ WHO. (2001). International Classification of Functioning, Disability and Health

¹² Synot, E, (2019) The Universal Declaration of Human Rights at 70: Indigenous rights and the Uluru Statement from the Heart, Australian Journal of International Affairs 73(4) p320-5.

Indigenous peoples have the right to self-determination. By virtue of that right they freely determine their political status and freely pursue their economic, social, and cultural development.

Adopting UNDRIP standards allows states to work towards recognising Indigenous peoples' rights to self-determination, participation in decision-making, respect for and promotion of culture, and equality and non-discrimination.

The guide needs to include UNDRIP principles for Aboriginal and Torres Strait Islander people's rights.

Principle 6 Accessibility

When thinking of accessibility, most people only consider physical access to programs or buildings. However, it is important to acknowledge that accessibility is broader than this.

Cultural safety is an important consideration for accessible services, policies and programs. There is a clear preference among Aboriginal and Torres Strait Islander people to access community-controlled services. Indeed, many will bypass mainstream services to access those where they are confident their cultural safety is guaranteed. ACCHOs are highly visible in Aboriginal and Torres Strait Islander communities with research showing ACCHOs are best placed to respond to the social and cultural determinants of health. To enhance cultural safety for their clients, ACCHOs and other Aboriginal Community Controlled Organisations (ACCOs) often engage local community members as part of their workforce. This workforce includes community and family support workers who often have no formal qualification but are essential to help bridge the gap between health professionals and families. Aboriginal and Torres Strait Islander people are often unfamiliar with disability systems, including the NDIS, and eligibility requirements. They are also often reluctant to access government services due to historical and personal experiences of institutionalised racism and a lack of cultural safety. For these reasons, ACCO and ACCHO services have identified a need to expand into and/or support disability services to ensure cultural safety and appropriateness for Aboriginal and Torres Strait Islander people with a disability.

The guide needs to consider principles of cultural safety and accessibility for Aboriginal and Torres Strait Islander people with disabilities.

Principle 7 Equality of people

The National Agreement on Closing the Gap (the National Agreement) commits all levels of Government to making a change in ways policies and programs affecting Aboriginal and Torres Strait Islander people are designed 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 four 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 future policy and programs can have significant impact.

The Guide needs to align with the National Agreement, particularly the four priority reforms that underpin the agreement.

Principle 8 Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

The importance of early access to services for young children with a disability is crucial to help reduce future issues of social, emotional, and economic participation within society.

For Aboriginal and Torres Strait Islander people, health is understood as social and emotional wellbeing (SEWB), which connects the health of a person to the health of their family, kin, community, connection to Country, culture, spirituality, and ancestry. The interconnectedness between Aboriginal and Torres Strait Islander people, their kin and community plays a central role in their identity. Aboriginal and Torres Strait Islander people support each other, including those with disability.

Research has raised concerns for the limited support for Aboriginal and Torres Strait Islander families looking after children with disabilities:

"[I] see a lot of mothers particularly because they're the main caregivers in this areas with what I would call post-traumatic stress. We see that all the time."

"Yeah, it took me a long, long time to get there, it took me a long time –there were nights where I would just cry my eyes out because I had no idea what to do with him, because nobody would help."¹³

Our Aboriginal and Torres Strait Islander children require access to culturally appropriate and responsive services so they can benefit from early intervention support no matter where they live. The guide should reflect the need to support early access to services for young Aboriginal and Torres Strait Islander people with a disability.

¹³ Lilley, Sedgwick & Pellicano. (2019). We look after our own mob: Aboriginal and Torres Strait Islander Experiences of Autism. Macquarie University: Sydney.