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NACCHO National Aboriginal Community Controlled Health Organisation Aboriginal health in Aboriginal hands

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Promoting inclusion

Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of people with Disability

June 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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Introduction

NACCHO welcomes the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability's issues paper into Promoting Inclusion. NACCHO has developed this response to the issues paper with valued input from the Victorian Aboriginal Community Controlled Health Organisation. This submission will respond to the following questions outlined by the issues paper:

- What does inclusion mean for Aboriginal and Torres Strait Islander people with disability;
- Do you think Australia is an inclusive society? If not, why not? What are the barriers and challenges to inclusion for people with disability? Including for: First Nations people with disability;
- What makes an inclusive society?
 - What is the role of governments through legislation, policy making, funding and operation of public systems and services, in achieving an inclusive society?

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 are often overlooked and can negatively affect their experience of disability.

This is in addition to the array of barriers, negative attitudes, stereotypes, and misconceptions regularly faced by people with disability, which limit their social inclusion⁶. This includes discrimination in education, employment, healthcare, and other opportunities, as well as physical access to buildings, transport, and other infrastructure. These barriers and opinions can limit the social inclusion of people with a disability.

In a 2019 speech, the Disability Discrimination Commissioner Ben Gauntlett stated that current community attitudes towards people with disability are 'not good', as it is presumed that people with disability do not have a meaningful role in society⁷. This attitude is particularly pervasive for Aboriginal and Torres Strait Islander people who experience 'double discrimination' due to their identity as an Aboriginal and Torres Strait Islander person and as a person with a disability.

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 Social Policy Research Centre, Disability Studies and Research. (2011). Community attitudes to people with disability: scoping project.

⁷ Ben Gauntlett. (2019). The critical task of changing community attitudes towards disability. <u>https://humanrights.gov.au/about/news/speeches/critical-task-changing-community-attitudes-towards-disability.</u>

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 people⁸ 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 developing and delivering disability programs and policy. This is an opportunity to work together in genuine partnership to recognise the needs and rights of Aboriginal Torres Strait Islander people with a disability and to do something about it.

1. What does inclusion mean for Aboriginal and Torres Strait Islander people with disability?

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, such as disability.

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

- The Aboriginal and Torres Strait Islander understanding of 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,
 assessments on quality of life, or judgments about their relative worth based on the presence or
 absence of disabilities⁹.
- 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.

⁸ Coalition of Peaks (2020). National Agreement on Closing the Gap.

⁹ Australian Human Rights Commission. Ibid.

2. <u>Do you think Australia is an inclusive society? If not, why not? What are the barriers and challenges to inclusion for people with disability? Including for: First Nations people with disability</u>

For Aboriginal and Torres Strait Islander people, Australia is not an inclusive society. This is particularly the case when it comes to disability.

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 health services; specifically those mainstream health services that are not culturally competent¹⁰.

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 race¹¹.

Despite being almost twice as likely to experience disability compared to non-Indigenous Australians, the uptake of the National Disability Insurance Scheme (NDIS) for Aboriginal and Torres Strait Islander people is significantly lower. The design of the NDIS did not consider Aboriginal and Torres Strait Islander people, and there are significant barriers to accessing and remaining within the Scheme.

Despite the higher rates of disability (and chronic health conditions) ACCHOs generally lack the infrastructure to provide services to people with disability and lack the funding to make their clinics fully accessible. This is on top of chronic housing shortages in remote and very remote areas, which exacerbates workforce issues and further reduces their ability to deliver disability services.

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^{12,13}. For these people, addressing their disability without

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

¹¹ Disabled People's Organisations Australia (2019). CRPD Shadow Report consultation survey results.

¹² Temple, J., et al., (2020). Exposure to interpersonal racism and avoidance behaviours reported by Aboriginal and Torres Strait Islander people with a disability.

¹³ Trounson, J. (2020). A systematic literature review of Aboriginal and Torres Strait Islander engagement with disability services.

acknowledging their Aboriginality (or other identities including LGBTI+ etc.) can make them feel secluded from one of their representative communities¹⁴.

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.

This needs to involve Aboriginal and Torres Strait Islander governance, the prioritisation of the ACCHO sector in developing and delivering services to their communities, genuine partnership between governments and Aboriginal and Torres Strait Islander people to co-design programs and policies which affect them and addressing the social determinants of health and wellbeing (such as housing, education, and employment) so that people are able to access and benefit from programs.

Furthermore, in alignment with the National Agreement and the NDIS National Workforce Plan 2021-2025, ACCHOs must be the preferred providers of disability programs and services within communities. In areas where there are no ACCHOS, Aboriginal community-controlled organisations (ACCOs) should be prioritised. In instances where funding is unable to be provided to a community-controlled organisation, governments and PHNs must ensure that funded organisations are held accountable for providing culturally competent services to Aboriginal and Torres Strait Islander people. These services must prioritise shared decision-making and service delivery with Aboriginal and Torres Strait Islander organisations.

A lack of Aboriginal and Torres Strait Islander disability service providers and culturally competent services is one of the main drivers for poor access to services and poorer outcomes for Aboriginal and Torres Strait Islander people. Urgent action is required in this space.

There must be active involvement from Aboriginal and Torres Strait Islander people in every level of decision-making structures. Aboriginal and Torres Strait Islander people must be involved in co-designing, planning, and implementing disability services and programs. Covid-19 grants, bushfire recovery funding, and sexual health programs are successful examples of partnership with government that have been nationally led and co-ordinated by NACCHO and targeted to local community needs.

Building the capacity of NACCHO's jurisdictional Affiliates and its 143 members is vital to improve disability literacy, reduce the stigma around disability issues, and to improve community engagement with the National Disability Insurance Agency (NDIA). The ongoing prevalence of racism in mainstream services, coupled with culturally inappropriate and unengaging clinical messaging, act as an ongoing barrier in achieving these goals.

The ACCHO Model of Care¹⁵ recognises cultural needs (for example, the concept of taking the appropriate time to establish a trusting and respectful relationship with the whole family unit and their cultural values) and the additional needs of a population with high co-morbidities who often have poor housing, are financially poor and have limited access to transport. This Model of Care has proven to be

¹⁴ FPDN. (2016). Intersectional dimensions on the right to health for Indigenous peoples – A disability perspective. ¹⁵ Panaretto et al., 2014. Aboriginal community-controlled health services: leading the way in primary care. *The Medical Journal of Australia, 200* (11).

successful, however, there are additional costs involved with providing culturally appropriate care which further complicate this environment.

- 3. What makes an inclusive society?
 - a. <u>What is the role of governments through legislation, policy making, funding and operation of public systems and services, in achieving an inclusive society?</u>

The National Agreement represents a new approach where policy making that impacts Aboriginal and Torres Strait Islander people occurs in full and genuine partnership with Aboriginal and Torres Strait Islander people¹⁶. In looking to improve the activities of Government, including legislation, policy making, funding and operation of public systems and services, and in seeking to improve outcomes for Aboriginal and Torres Strait Islander people, it is essential that all reforms align with the National Agreement. Self-determination must be at the heart of these reforms.

This includes the ongoing implementation and design of the NDIS. The NDIS is the largest social reform since the introduction of Medicare¹⁷. However, the NDIS is not accessible to Aboriginal and Torres Strait Islander people with a disability nor for ACCHOs to become NDIS service providers. The needs, situation, and culture of Aboriginal and Torres Strait Islander people were not taken into consideration when developing the NDIS, creating a system that creates accessibility and service gaps at best and exploitation at worst for Aboriginal and Torres Strait Islander people.

NACCHO recommends that the NDIA engage Aboriginal and Torres Strait Islander communities and organisations in the ongoing design and implementation of the NDIS, including Independent Assessments. The NDIA and any other relevant government department and agencies must engage Aboriginal and Torres Strait Islander communities and organisations in partnership to co-design Independent Assessments. This includes genuine co-design of the processes and tool uses in the context of Aboriginal and Torres Strait Islander people with disability but also the rollout and communications of Independent Assessments. NACCHO is willing with the Australian Government to ensure this occurs.

Consistent with providing more equitable access to services through access to culturally safe services and Priority Reform Three 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.

NACCHO welcomes the Department of Social Services' preliminary commitment through the Aboriginal Torres Strait Islander Market Capability Project (NDIS Ready), which, through four key initiatives, looks to build the capability of ACCHOs to register and deliver services sustainably under the NDIS to their communities.

However, the NDIS Ready Project represents the implementation of just four of 23 recommendations made to government on how to improve access to the NDIS for Aboriginal and Torres Strait Islander people with disability. NACCHO recommends the government fund the full suite of 23 recommendations – to further build the capacity of ACCHOs to deliver disability services to their communities.

¹⁶ Coalition of Peaks (2020). National Agreement on Closing the Gap.

¹⁷ Productivity Commission (2017). <u>https://www.pc.gov.au/news-media/news/pc-news/pc-news-august-</u> 2017/ndis-costs - accessed 24/6/2021

Further the development of culturally safe workforce and pathways into the care workforce for Aboriginal and Torres Strait Islander people is a *critical* need that must be addressed if ACCHOs are going to have the capacity to sustainably deliver disability services.

Thin markets (where there is a gap between the needs of participants and the services available in the local market) exist for many Aboriginal and Torres Strait Islander people with disability. This is because Aboriginal and Torres Strait Islander people often require more support than other Australians to gain access to, and participate in, the NDIS. This support must be specialised and therefore in 'healthy' markets (or areas with lots of services available) there are sub-sets of thin markets. This results in a lack of appropriate services to respond to the needs of Aboriginal and Torres Strait Islander people with disability.

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 and the Health Plan.

NACCHO recommend the NDIA develop a strategy, in partnership with community, for building an ongoing workforce of Aboriginal and Torres Strait Islander planners that would culminate in a culturally appropriate workforce for Aboriginal and Torres Strait Islander peoples and communities in all regions of Australia.

In recognition of the need to overcome these barriers for Aboriginal and Torres Strait Islander people, NDIA have funded the National Community Connector Program (NCCP). NACCHO has received funding to help support Aboriginal and Torres Strait Islander communities with Community Connectors. Community Connector positions were established within ACCHOs to provide culturally appropriate advice and access to the NDIS.

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

While the NCCP goes some way to helping Aboriginal and Torres Strait Islander people access and use NDIS services, it is time limited 12-month funding, with no option of further funding. These 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.

Further, consistent with Priority Reform Three of the National Agreement, in areas where it is not practical to establish an ACCHO as the LAC and a mainstream LAC must be established; the NDIA must, at the very least, include provisions in contracts of any mainstream LAC providers Key Performance Indicators relating to Aboriginal and Torres Strait Islander people with disability. These provisions must be made transparent and be enforced by the Agency.

Ensuring more equitable access to services for Aboriginal and Torres Strait Islander people with disability is to ensure there are culturally safe service available. Aboriginal and Torres Strait Islander people have shown a strong preference to access services provided Aboriginal and Torres Strait Islander professionals, largely because they provide culturally safe services¹⁸. That is, the services provided by Aboriginal and Torres Strait Islander professionals is more responsive to the ongoing impacts of colonisation and past government policies and practices which still negatively affect Aboriginal and Torres Strait Islander people.

¹⁸ Lilley, R. (2020). Inclusion, acceptance, shame and isolation: Attitudes to autism in Aboriginal and Torres Strait Islander communities in Australia.