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National Aboriginal Community Controlled Health Organisation
Aboriginal health in Aboriginal hands
www.naccho.org.au

NACCHO Submission to the National Guideline for Supporting Learning, Participation, and Wellbeing of Autistic Children

Submission to the Autism CRC

August 2022

ABOUT NACCHO

NACCHO is the national peak body representing 144 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

NACCHO recommends the Autism CRC:

1. initiate a partnership with the Aboriginal and Torres Strait Islander community-controlled health sector.

NACCHO recommends the Guidelines:

2. promote ACCHO-based ASD support and the need to further develop ACCHO NDIS capacity and capability.
3. prioritise ACCHO NDIS support services over mainstream ones for Aboriginal and Torres Strait Islander children with autism.
4. emphasise that improved ASD outcomes for Aboriginal and Torres Strait Islander people require consideration of cultural differences in perceptions of disability and autism by Aboriginal and Torres Strait Islander people.
5. include a definition of cultural safety, and guidance on practical actions to eliminate racism.
6. specify the need for mainstream providers to deliver culturally safe services to Aboriginal and Torres Strait Islander people.
7. provide a discussion of the social determinants and cultural determinants of Aboriginal and Torres Strait Islander health, and consider how to address and promote them respectively.
8. acknowledge the underdiagnosis of ASD among Aboriginal and Torres Strait Islander children, limitations of existing data, and need for more co-designed research.

Introduction

NACCHO welcomes the opportunity to provide a submission to *National guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia* (the Guideline).

In 2018, there were over 200,000 Australians with Autistic Spectrum Disorder (ASD)[1]. The prevalence of ASD for Aboriginal and Torres Strait Islander people is largely unknown and suspected to be underdiagnosed. This may be due to barriers to accessing diagnostic services[2] or misdiagnosis.[3] It is known that Aboriginal and Torres Strait Islander people are twice as likely to experience a disability than other Australians[4], and that they are less likely to access services than other Australians. There are several reasons for this, including limited availability of culturally safe services, marginalisation and lack of trust in government[5]. The impact of disability exacerbates the divide in health and wellbeing outcomes for Aboriginal and Torres Strait Islander peoples and other Australians.[6] These disparities warrant innovation and policy reform.

The *National Agreement on Closing the Gap* (National Agreement) seeks to implement structural reform across all aspects of Aboriginal and Torres Strait Islander health and wellbeing. The *National Guideline for Supporting the Learning, Participation, and Wellbeing of Autistic Children and their Families in Australia* (Guidelines) should integrate the Priority Reforms of the National Agreement. It is worth briefly expanding on the intent and scope of the National Agreement, to clearly delineate government commitments and ongoing obligations.

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.

[1] ABS (2019). Autism in Australia from Disability, Ageing and Carers, Australia: Summary of Findings, 2018. ABS: Canberra.
[2] Bailey et al (2020) 'Indigenous Australians with Autism a scoping study' *Autism, 24*(5).
[3] Roy et al (2010) 'Missed diagnosis of autism in an Australian Indigenous psychiatric population'. *Australasian Psychiatry, 18*(6)
[4] AIHW (2017) 'The Aboriginal and Torres Strait Islander Health Performance Framework Report' AIHW: Canberra.
[5] Lilley et al (2019). We look after our own mob: Aboriginal and Torres Strait Islander Experiences of Autism. Macquarie University: Sydney.
[6] Bailey et al (2020) 'Indigenous Australians with Autism a scoping study' *Autism, 24*(5).

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.

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.

The Guidelines are to be commended for Recommendation Nine, 'Respecting Australia's First Nations Peoples', which states:

> 'supports should be culturally safe for Aboriginal and Torres Strait Islander Peoples, built on an acknowledgment of the barriers to accessing supports that they may experience, an understanding of current and historical truths and their enduring impact; and respect for deep connection to Country, language, customs, and traditions'.

However, while it is appreciated that the Guidelines have been developed to contain 'sufficient flexibility to apply to all children', one size does not, and cannot, fit all. Recommendation Nine, or a series of complementary guidelines specific to Aboriginal and Torres Strait Islander children and carers, need to be more detailed, elaborating on and unpacking these concepts and providing further points of guidance relating to them.

Recommendation Nine sits within the section 'Guiding Principles'. Recommendations relating specifically to Aboriginal and Torres Strait Islander children and carers should also occur under the subsequent four sections (Goal Setting; Selecting and Planning Supports; Delivering Supports; and Outcomes, Quality and Safeguarding).

Shared decision-making authority

It is regrettable that the Guideline Development Group (GDG) did not include an Aboriginal and Torres Strait Islander person or representative from an Aboriginal and Torres Strait Islander organisation. While NACCHO has been included on the Reference Group, our advocacy around the National Agreement has not manifested in the Guidelines to the degree required to ensure effective learning, participation, and wellbeing of Aboriginal children with autism and their families.

NACCHO acknowledges the statement that the GDG 'seeks to enter into a long-term partnership with the Aboriginal and Torres Strait Islander community, that will grow over time and support proper way collaboration and consultation' and encourages the Autism CRC to take concrete steps to establishing such a partnership.

NACCHO recommends the Autism CRC act on the recommendation of the GDG and take concrete steps to initiate a partnership with the Aboriginal and Torres Strait Islander community-controlled health sector.

Building the Aboriginal and Torres Strait Islander Community-Controlled Sector

Aboriginal and Torres Strait Islander people have a clear preference for using Aboriginal and Torres Strait Islander services. Many Aboriginal and Torres Strait Islander children and carers with ASD access an Aboriginal Community Controlled Health Organisation (ACCHO) for their health needs.

ACCHOs provide a holistic, multidisciplinary model of care that encompasses primary health as well as social and emotional wellbeing and are well placed to provide services for Aboriginal and Torres Strait Islander peoples.[7]

The beneficial health outcomes for Aboriginal and Torres Strait Islander patients who are cared for by Aboriginal and Torres Strait Islander health staff are well documented and recognised in key policy documents, including the *National Aboriginal and Torres Strait Islander Health Plan*, and the *National Aboriginal and Torres Strait Islander Health Workforce Strategic Framework*. ACCHOs are the preferred model for delivery of Aboriginal and Torres Strait Islander primary care. Over 50% of Aboriginal and Torres Strait Islander people prefer to attend an ACCHO over a non-Indigenous practice and this number is growing. Many ACCHOs already provide NDIS services and support for clients with ASD.

NACCHO has been working to build the capacity and capability of our sector to delivery NDIS services to local communities, and an increasing number of ACCHOs are entering this space. Through the Aboriginal Disability Liaison Officer (ADLO) program, dedicated support is provided to Aboriginal and Torres Strait Islander people with disability in urban and rural areas to access the NDIS and use their plans. ADLOs are generally members of the communities they work in, understand the culture and often speak the local languages. The insights of ADLOs can contribute to NDIA-led co-design initiatives to improve the way NDIS works with Aboriginal and Torres Strait Islander communities.

Case Study – Queensland ACCHO report on ADLO operations

An example which stands out is a mother of three children on the Autism Spectrum referred to us from the family health and wellbeing team. Initially when the ADLOs started working with her, she was very overwhelmed and reluctant to disclose the severity of the situation at home or the impact that this was having on her wellbeing. Since working with Mum, the ADLOs have provided support to gain access to the NDIS for two of the children and are still awaiting access determination for her youngest child.

The ADLOs worked closely with Mum to provide information about the NDIS, the process of getting a plan and the types of services she was able to advocate for in the planning meeting. They also did some pre planning sessions prior to the NDIS planning meeting.

During the meeting, the ADLO was present and had been prepared to jump in and help Mum where needed. The ADLO was impressed with the way Mum conducted herself in the meeting, she asked questions, was assertive and stated explicitly the supports she required in her children's plans. This was a significant change in Mum's demeanour and attitude, where she had been timid in asking for help or reluctant to indicate that she was not coping when she first contacted the ADLO. A few months later she was able to assertively state the help that was needed to improve her family's circumstances.

[7] Bell et al (2000) 'Aboriginal community-controlled health service'. In 'General Practice in Australia' Department of Health and Aged Care: Canberra.

The Autism CRC is encouraged to leverage the growing capacity of the ACCHO sector to ensure adequate and culturally safe support for Aboriginal and Torres Strait Islander children with autism.

NACCHO recommends the Guidelines promote ACCHO-based ASD support and the need to further develop ACCHO NDIS capacity and capability in delivering services to children with autism.

NACCHO recommends the Guidelines prioritise ACCHO NDIS support services over mainstream ones for Aboriginal and Torres Strait Islander children with autism and their families.

Aboriginal and Torres Strait Islander perceptions of disability and autism

Service providers must acknowledge differences in the awareness and understanding of disability and autism in Aboriginal and Torres Strait Islander communities. According to one study:

> 'In contrast to the Western perspective which emphasises impairment and the need for remediation, some Indigenous Australians view disability as a characteristic of the individual, something to be supported by the broader community rather than ameliorated. Indeed, labelling, and categorising individuals with regard to their abilities or impairments is considered disrespectful in some Aboriginal and Torres Strait Islander communities.'

However, this does not mean that Aboriginal and Torres Strait Islander children with autism and their families do not want or require support. It does mean that an appreciation of these perceptions play an integral part in providing ADS support to Aboriginal and Torres Strait Islander people.

NACCHO recommends the Guidelines emphasise that improved ASD outcomes for Aboriginal and Torres Strait Islander people require consideration of cultural differences in perceptions of disability and autism by Aboriginal and Torres Strait Islander people.

Needs-based policy decisions regarding funding and provision of supports

Evidence-based policy decisions are fundamental in the ASD space, as they are across Aboriginal and Torres Strait Islander health to address the disparity in health outcomes. The 'Target Users' section of the Guidelines states that, Governmental bodies can use this Guideline to make evidence-based policy decisions regarding funding and provision of supports.[8] At the same time they should also be able to use this Guideline to make needs-based policy decisions regarding funding and provision of supports to a sector that suffers a disproportionally high burden of disease.

This is critical given the known paucity of data on the prevalence of autism in Aboriginal and Torres Strait Islander communities.

Cultural safety

The provision of culturally safe care to Aboriginal and Torres Strait Islander people delivers better health outcomes. Commendably, the Guidelines (i.e., Recommendation Nine) implicitly support cultural safety, however, no definition of cultural safety is provided. There are several strong definitions which might be included in the Guidelines, including that outlined in the Indigenous Health Performance Framework.[9]

NACCHO recommends the Guidelines include a definition of cultural safety, and guidance on practical actions to eliminate racism.

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[8] Autism CRC (2022) 'National guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia' p 21

[9] https://www.indigenoushpf.gov.au/

Workforce training

The Guidelines state that 'it is important that practitioners and other professionals undertake appropriate training to ensure they have the knowledge and skills to implement the Guideline within their service'. The Guidelines should make it clear that this statement applies equally to cultural safety training.

The *National Aboriginal and Torres Strait Islander Health Plan* (Plan) includes a goal to ensure, 'all health care, whether government, community or private, is free of racism'. It goes on to state:

> 'Racism is a key social determinant of health for Aboriginal and Torres Strait Islander people, and can deter people from achieving their full capabilities, by debilitating confidence and self-worth which in turn leads to poorer health outcomes. Evidence suggests that racism experienced in the delivery of health services contributes to low levels of access to health services by Aboriginal and Torres Strait Islander people. There are several pathways from racism to ill-health – experiences of discrimination, linked with poor self-assessed health status, psychological distress, depression and anxiety, and health risk behaviours such as smoking and alcohol and substance misuse. Experiences of racism are compounded by the traumatic legacy of colonisation, forced removals and other past government discriminatory policies. The consequences of these events have been profound, creating historical disadvantage that has been passed from one generation to the next.'[10]

However, while Aboriginal and Torres Strait Islander people have a clear preference for using Aboriginal and Torres Strait Islander services, the reality is that the limited availability of ACCHO services and access to specialist autism supports will mean that many will need to access a mainstream service. Mainstream workforces must therefore be sufficiently culturally competent to provide services to Aboriginal and Torres Strait Islander peoples.

NACCHO recommends the Guidelines specify the need for mainstream providers to deliver culturally safe services to Aboriginal and Torres Strait Islander people.

Barriers to accessing supports

This might include language and cultural barriers, lack of culturally appropriate services and a distrust of institutional care due to personal and historical experiences of systemic and interpersonal racism. ACCHOs are therefore well suited to provide dental services for Aboriginal and Torres Strait Islander peoples, and the focus should be on increasing their capacity and capability to do so.

However, whilst Aboriginal and Torres Strait Islander people have a clear preference for using Aboriginal and Torres Strait Islander services, the reality is that the limited availability of ACCHO dental services will mean that many will need to access a mainstream service. Mainstream workforces must therefore be sufficiently culturally competent to provide services to Aboriginal and Torres Strait Islander peoples.

The Guidelines do not sufficiently elaborate on concepts of social determinants and cultural determinants of Aboriginal and Torres Strait Islander health, or the practical implications of these within ASD service provision. Recommendation Nine of the Guidelines alludes to 'barriers to accessing supports' and to 'historical truths and their enduring impact'. There is, however, no discussion or Guideline outlining what precisely is meant by these terms and their implications. An AIHW analysis of results from the Australian Bureau of Statistics health survey data estimated that around one-third (34%) of the health gap between Indigenous and non-Indigenous Australians was due to 'social

[10] Australian Government (2013) 'National Aboriginal and Torres Strait Islander Health Plan' p14-15 https://www.health.gov.au/resources/publications/national-aboriginal-and-torres-strait-islander-health-plan-2013-2023

determinants' (employment and hours worked, highest non-school qualification, level of schooling completed, housing adequacy and household income). Around 47% of the Gap includes differences in access to health services and the impact of cultural and historical factors on health.[11] Recommendation Nine also mentions, 'respect for deep connection to Country, language, customs, and traditions', but makes no reference to 'cultural determinants of good health and wellbeing'. Including a discussion of cultural determinants of good health helps balance a deficit approach.

NACCHO recommends the Guidelines provide a discussion of the social and cultural determinants of Aboriginal and Torres Strait Islander health, and consider how to address and promote them respectively.

Poor data on ASD levels among Aboriginal and Torres Strait Islander children

In examining the prevalence of ASD in Aboriginal and Torres Strait Islander people, Leonard et al. (2011) found Indigenous mothers were significantly less likely than non-Indigenous mothers to have a child diagnosed with ASD.[12] Bent et al (2015) found Aboriginal and Torres Strait Islander people with autism may be less likely to receive a diagnosis if they are less severely affected.[13] Roy et al (2010) examined potential cases of missed ASD diagnosis in a caseload of Aboriginal and Torres Strait Islander adults previously diagnosed with schizophrenia, finding that Aboriginal and Torres Strait Islander Australians with ASD may be misdiagnosed.[14] This data is both troubling but also fragmentary and in need of a comprehensive and methodical update. Future research addressing gaps should be led by Aboriginal and Torres Strait Islander researchers and co-designed with local Aboriginal Community Controlled Organisations.

NACCHO recommends the Guidelines acknowledge the underdiagnosis of ASD among Aboriginal and Torres Strait Islander children, limitations of existing data, and need for more co-designed research.

[11] AIHW (2018) 'Determinants of health for Indigenous Australians'. https://www.aihw.gov.au/reports/australias-health/social-determinants-and-indigenous-health

[12] Leonard et al (2011) 'Autism and intellectual disability are differentially related to sociodemographic background at birth'. Plos One. https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0017875

[13] Bent et al (2015) 'Mapping the diagnosis of autism spectrum disorders in children aged under 7 years in Australia, 2010–2012'. Medical Journal of Australia, 202(6), 317–320

[14] Roy et al (2010) 'Missed diagnosis of autism in an Australian indigenous psychiatric population.' Australasian Psychiatry, 18(6), 534–537.