Central Australian
Aboriginal Congress
ABORIGINAL CORPORATION | ICN 7823

Comments on the
National Children's Mental Health and Wellbeing Strategy
18 February 2021

Executive Summary [see text for details]

A. Central Australian Aboriginal Congress (Congress) welcomes the release of the Draft *National Children's Mental Health and Wellbeing Strategy*, and endorses its positive vision for the social and emotional wellbeing of Australia's children, including Aboriginal children[1].

B. While overall the draft Strategy is very positive, there are a number of areas which could be strengthened and/or made more explicit in relation to the needs of Aboriginal children and their families.

Addressing colonisation, racism and poverty

C. Further to the general recognition contained in the text of the draft Strategy on the negative effects of racism, discrimination and poverty on child health and wellbeing, we ask that specific objectives or actions be added that:

- recognise the rights to self-determination of Aboriginal peoples as established under international agreements to which Australia is a signatory, including the *United Nations Declaration on the Rights of Indigenous Peoples*
- support the establishment of a First Nations Voice to Parliament as recommended in the *Uluru Statement from the Heart,* as the overarching framework within which the health and wellbeing of Aboriginal and Torres Strait Islander children may be addressed
- address poverty and inequality as drivers of poor Aboriginal child health wellbeing through recommending that Jobseeker and similar citizenship entitlements should be set at such as level as to enable families to properly care for their children, including an additional loading for those in remote or very remote areas to address significantly higher costs of living.

A definition of Aboriginal community control

D. We support the recommendation that child and family mental health and wellbeing services for Aboriginal and Torres Strait Islander communities should be delivered by Aboriginal Community Controlled Organisations. However, for clarity we propose including the National Aboriginal Community Controlled Health Organisation (NACCHO) definition of Aboriginal community control.

[1] Congress uses the term 'Aboriginal' as the most appropriate term in the Central Australian context to refer to Australia's First Peoples.

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Aboriginal health in Aboriginal hands.

The Congress model of integrated child and family services

E. We suggest including a summary of the Central Australian Aboriginal Congress integrated model of child and family services as a case study to illustrate the value of reorganising Australia's mental health services system towards a more integrated, multidisciplinary model.

Making the NDIS work for Aboriginal children in remote areas

F. We suggest that the Strategy be amended to:

- recognise that the NDIS does not work well to support the health and wellbeing of Aboriginal children in remote areas
- recommend the trialling, in collaboration with Aboriginal community controlled health services, of innovative solutions such as population-level funds pooling of NDIS funds at a regional level to fund early childhood development services for children aged 0 to 6 years
- recommend the resourcing of coordination, logistical support and information sharing to support integrated delivery of visiting NDIS-funded services to remote Aboriginal communities

Background

1. Central Australian Aboriginal Congress (Congress) is a large Aboriginal Community Controlled Health Service (ACCHS) based in Alice Springs. We are one of the most experienced organisations in the country in Aboriginal health, a national leader in primary health care, and a strong advocate for the health of our people. Since the 1970s, we have developed a comprehensive model of primary health care that includes:

    a. multidisciplinary clinical care;

    b. health promotion and disease prevention programs; and

    c. action on the social, cultural, economic and political determinants of health and wellbeing.

2. Congress delivers services to more than 14,000 Aboriginal people living in Alice Springs and remote communities across Central Australia including Ltyentye Apurte (Santa Teresa), Ntaria (Hermannsburg), Wallace Rockhole, Utju (Areyonga), Mutitjulu and Amoonguna.

Our overall response to the Strategy

3. We welcome the draft *National Children's Mental Health and Wellbeing Strategy* as a positive contribution to setting new directions for the mental health and wellbeing of Australia's children in general and Aboriginal and Torres Strait Islander children in particular. In particular, we support the fact that:

    a. while it is a mainstream, national Strategy it pays attention to the needs of Aboriginal and Torres Strait Islander children and their families, and to the needs of those in rural and remote areas;

    b. it proposes a reframing of the way Government thinks about mental health and wellbeing of children from an emphasis on diagnosable deficits to a continuum from 'healthy' to 'coping' to 'struggling' to 'unwell';

    c. it proposes significant and necessary reforms to Australia's mental health system including in particular

        - increasing the availability and access to both universal services and targeted support for children who are struggling or unwell, and

        - supporting and funding greater integration, including funding care-coordination for children with complex needs, trialling sites with innovative integrated service-delivery models, and enabling all members of a multidisciplinary team to make Medicare claims for case conferencing;

    d. it has a strong emphasis on using evidence-based programs and on embedding evaluation in all services;

    e. it recognises the leading role of ACCHSs in developing innovative models, and recommends that:

> *Child and family mental health and wellbeing supports for Aboriginal and Torres Strait Islander communities should be delivered by Aboriginal Community Controlled Organisations wherever possible, with activity and outcome measures to be collaboratively determined between the funder, service provider and the community to ensure they are appropriate* [page 48]

4. While overall the draft Strategy is positive, there are a number of areas which could be strengthened and/or made more explicit in relation to the needs of Aboriginal and Torres Strait Islander children and their families. Our comments fall under four areas:

   a. addressing the ongoing legacy of colonisation, racism and poverty;

   b. including an explicit definition of Aboriginal community control;

   c. highlighting the Congress model of integrated child and family services; and

   d. supporting a regional cash out of NDIS funds for children under 7 years old to address market failure in remote and remote areas.

Addressing colonisation, racism and poverty

5. In traditional times, our people's access to the land and its resources and their cultural practices ensured that children were healthy and well, cared for by networks of kin. However, the processes of colonisation – including the dispossession and impoverishment of our communities; the forcible removal of children from their families and its intergenerational effects; the suppression of culture and language; and the ongoing experience of racism and discrimination – have had profound effects on the health and wellbeing of our children, and on their families' capacity to provide care for them.

6. As a result, a high proportion of Aboriginal children have significant developmental issues. For example, the Australian Early Development Census (AEDC) results for 2015 show that by the time they start school [2]:

   a. Aboriginal children in Central Australia are six times as likely to be vulnerable on two or more of five developmental domains compared to their non-Indigenous classmates (43% of Indigenous children, 7% of non-Indigenous children); and

   b. 60% of Aboriginal children in the region are developmentally vulnerable on at least one domain (22% for non-Indigenous children).

A human rights approach

7. Given this context, any approach to improving the health and wellbeing of Aboriginal families and children must recognise the rights to self-determination of Aboriginal peoples as established under international agreements to which Australia is a signatory, including the *United Nations Declaration on the Rights of Indigenous Peoples* [3], which states:

> *Article 23: Indigenous peoples ... have the right to be actively involved in developing and determining health, housing and other economic and social*

programmes affecting them and, as far as possible, to administer such programmes through their own institutions.

8. While local action through Aboriginal community controlled organisations as recognised by the Strategy is essential, further structures are needed at a national level to give full effect to these rights. This includes the establishment of a national representative body for Australia's First Nations, a 'Voice to Parliament', plus a Makarrata Commission to supervise a process of agreement-making and truth-telling between governments and Aboriginal and Torres Strait Islander peoples, as recommended in the *Uluru Statement from the Heart* [4]. These proposals have the overwhelming support of Aboriginal people. A constitutionally enshrined Voice to Parliament would provide the overarching framework within which the health and wellbeing of Aboriginal and Torres Strait Islander children may be addressed.

9. In addition to the general recognition contained in the text of the draft Strategy on the effects of racism and discrimination on child health and wellbeing, we ask that the Strategy be amended to include specific objectives or actions:

a. recognising that any approach to improving the health and wellbeing of Aboriginal and Torres Strait Islander children must recognise the rights to self-determination of Aboriginal peoples as established under international agreements to which Australia is a signatory, including the *United Nations Declaration on the Rights of* Indigenous Peoples; and

b. supporting the establishment of a First Nations Voice to Parliament as recommended in the *Uluru Statement from the Heart* as the overarching framework within which the health and wellbeing of Aboriginal and Torres Strait Islander children may be addressed.

Addressing poverty, inequality and unemployment

10. The draft Strategy acknowledges the effects of poverty and unemployment on the health and wellbeing of children. However, this acknowledgement is not reflected the Strategy's objectives and actions. The Strategy also does not address the evidence around inequality: as well as absolute economic deprivation (poverty), relative economic deprivation (inequality) is related to higher infant and adult mortality rates, to reduced life expectancy, and to higher rates of illness [5]. In relation to these issues, we note that:

a. in remote areas across Australia both poverty and inequality are *worsening* for Aboriginal people, with Aboriginal incomes falling and the income gap to non-Indigenous people widening [6];

b. Aboriginal people are disproportionately dependent on citizenship entitlements such as the Newstart Allowance, the Parenting Payment and the Youth Allowance [7]. These are inadequate to meet the needs of families and their children, especially in remote areas where the cost of living is much higher, especially for food [8];

c. between a half- and a third- of the gap in life expectancy between Aboriginal and non-Indigenous people in the Northern Territory is due to socioeconomic disadvantage [9].

11. All these issues profoundly affect the health and wellbeing of Aboriginal children, and their families' capacity to care for them and give them the same opportunities as non-Indigenous children.

12. Actions to address poverty and inequality as drivers of poor Aboriginal child health and wellbeing should be included in the Strategy by recommending that Jobseeker and similar citizenship entitlements should be set at such as level as to enable families to properly care for their children, including an additional loading for those in remote or very remote areas to address significantly higher costs of living.

A definition of Aboriginal community control

13. We welcome and support the recommendation of the Strategy that child and family mental health and wellbeing services for Aboriginal and Torres Strait Islander communities should be delivered by Aboriginal Community Controlled Organisations wherever possible. However, we believe it is important to be clear what constitutes an 'Aboriginal community controlled organisation'.

14. Congress has noted in recent years an increasing number of organisations providing services to Aboriginal communities which brand themselves as Aboriginal organisations, but which do not have any formal governance structures by which the Aboriginal community may exercise control. Some of these organisations may do good work; some may have a degree of acceptance in the local community; some may even invite Aboriginal people to serve on their Boards. However, they are not Aboriginal community controlled, as they do not have any formal processes by which the Aboriginal community may exert that control, in particular governing Boards of Management made up of Aboriginal people locally elected by the community they serve.

15. Accordingly, we ask that the National Aboriginal Community Controlled Health Organisation (NACCHO) definition of Aboriginal community control is added [1], noting that this is (as is most appropriate for the Strategy) specifically referring to Aboriginal community controlled health services:

> ***An ACCHO is 'a primary health care service initiated and operated by the local Aboriginal community to deliver holistic, comprehensive, and culturally appropriate health care to the community which controls it, through a locally elected Board of Management.***

The Congress model of integrated child and family services

16. The Strategy recommends a reorganisation of Australia's mental health services system towards a more integrated, multidisciplinary model of care. To that end, it provides an outline of what an integrated child and family care service would look like

[box on page 36] and how it would address multiple objectives across the Strategy. We believe this is a vital reform.

17. We believe that the Congress integrated model of child and family support may be of interest here, and would be happy for it to be included as a case study of the kind of integrated model that is needed. The model has been described in the peer-reviewed literature, copies of which we provide accompanying this submission [10, 11].

18. The Congress integrated model of family and child support grew from the community-elected Congress Board's determination to improve the developmental outcomes of Aboriginal children in Central Australia, based on their belief that the best way to "close the gap" is to make sure it is not created in the first place. As a result, over a decade a more Congress has developed a range of evidenced-informed, culturally appropriate early childhood learning programs within our child and family services.

19. The Abecedarian Approach Australia (3a) is used as a strategic population health approach with specific interventions to improve the health and developmental trajectory for developmentally vulnerable children. Congress operates:

    a. two early learning centres for children from both working families and non-working families (this includes support and engagement of parents and carers to participate in the Centre); and

    b. a Preschool Readiness Program.

20. In addition, our multi-disciplinary team approach within comprehensive primary health care ensures all children have access to a range of integrated, multidisciplinary services including:

    a. routine and systematic child health checks and developmental screening through all of our clinics (using the ASQ-TRAK assessment tool) for children 0-5 years old, with support provided to parents and carers to attend appointments. This includes following up recalls when appointments are due to ensure children are able to attend;

    b. further developmental assessments for delay and disability provided through our Child and Youth Assessment Service (CYATS) of allied health professions in collaboration with Alice Springs paediatricians and community health services. This includes the capacity to diagnose Foetal Alcohol Spectrum Disorder (FASD) along with other neurodevelopmental disorders in collaboration with paediatricians from Alice Springs hospital and supported by PATCHES paediatrics and the Telethon Institute in Western Australia;

    c. close collaboration with education providers to support children to be healthy and developmentally ready for preschool and school, and to gain any additional supports needed for preschool and school; and

    d. an Intensive Family Support program to support vulnerable families to keep children safe at home and for families involved with the child protection system, in addition to providing support for parents more broadly through the Parenting Under Pressure Program.

21. We suggest that Strategy could include a summary of the Congress integrated model of child and family services as a case study to illustrate the value of reorganising Australia's mental health services system towards a more integrated, multidisciplinary model.

Making the NDIS work for Aboriginal children in remote areas

22. A fundamental tenet of the National Disability Insurance Scheme (NDIS) and similar personalisation schemes is giving people choice and control over the services they receive. This is well intended and in some contexts reasonable given the strong relationship between disempowerment and poor health and wellbeing [12, 13].

23. However, promoting personal choice in contexts where people are not able to meaningfully exercise that choice is likely to cause stress and undermine social and emotional wellbeing. In particular, personalisation schemes such as the NDIS do not work unless there are sufficient service providers to meet demand and provide choice [14]. This basic requirement is not met in many regional and remote areas where populations are dispersed and the costs of delivering services are high. Central Australia is one such area.

24. These difficulties are exacerbated by the challenges of personalised service approaches when dealing with disadvantaged populations. Populations bearing the burden of multiple, complex overlapping social and health challenges are those least able to navigate the complex bureaucracy of personalised systems such as the NDIS [14]. These differences are multiplied significantly in cross cultural situations such as apply for Aboriginal people in Central Australia where large sections of the population speak English as a second, third or fourth language and where many mainstreams services providers have little experience of delivering culturally-responsive care.

25. Taken together, this means that the NDIS does not work well to support the health and wellbeing of Aboriginal children in remote areas, and may even serve to "widen the gap" between their outcomes and those children in well-serviced mainstream and urban areas where the NDIS works more as it is intended. To address this structural issue, Congress proposes trialling a population-level approach to early childhood development based on the 'cash-out' of NDIS funds for regional and remote areas.

How a population-level pooling of NDIS funds model would work

26. Despite the high level of developmental vulnerability in the early years (see paragraph 6 above), Aboriginal children are unlikely to be diagnosed with a neurodevelopmental disorders (for example Foetal Alcohol Spectrum Disorder, or Autism Spectrum Disorder) until around aged 7 when these conditions are more apparent and easier to assess. For children aged 0 to 6, the focus should therefore be on universal access to evidence-informed early childhood programs adapted to local social and cultural contexts (Child Health and Development Centres). If these primary prevention programs have not averted a disability, once a child reached 7 years old, a definitive diagnosis is able to be made and an individual pathway and plan made as per the usual NDIS procedures (though see below for suggestions on implementation).

27. Therefore, for Aboriginal children aged 0 to 6, an estimate of the population-level of vulnerability should be used to pool NDIS funds, from what would have been individual packages, to provide sustainable, universally accessible, evidence-informed, culturally adapted, early childhood programs. This will achieve economies of scale; enhance the purchasing power of remote and rural participants; attract and sustain the necessary services; and increase the efficiency of service delivery.

28. As an example, we estimate the required funds pool for Central Australian Aboriginal children aged 0 to 6 to be conservatively $21 million per year, as follows:

	0 to 6 Population	Target population	Remote Loading	Package per child	Total funds
Alice Springs	739	318	40%	$ 23,380	$ 7,431,473
Remote areas	1235	531	50%	$ 25,050	$ 13,300,648
Central Australia	**1974**	**849**			**$ 20,732,121**

29. The assumptions behind this calculation are as follows:

    a. *0 to 6 population*: Census 2016 figures [15], correcting for the average 20% Northern Territory undercount of Aboriginal people [16];

    b. *Target population*: 43% of the total population, based on AEDC figures of proportion of Aboriginal children vulnerable on two or more of five developmental domains [2];

    c. *Remote loading*: as per NDIS increased service limits applying from 1 July 2019 [17];

    d. *Package per child*: conservatively based on the assumption of the national average NDIS package for autistic children aged under seven ($16,700 per year) [18], multiplied by the remote loading.

    e. *Total funds*: target population multiplied by the package per child.

30. Another way to estimate need could be based on the ASQ-Trak scores for children under 6 years of age. The use of this tool is in its early stages as part of routine child health checks in Central Australia but already it is clear that based on a sample of around 400 Aboriginal children in Alice Springs about 18% are below threshold and a further 21% are borderline on one or more domains. These proportions are much higher for children from remote communities. The ASQ Trak will give an earlier indication of developmental vulnerability into the future than the AEDC scores but it is fair to say that this tool is showing levels of vulnerability consistent with the AEDC scores. Whether children are below threshold or borderline, they will benefit greatly from being able to engage in a CHaDC with wrap around services as required.

31. To maintain access to additional specialist services under the NDIS to those children who are diagnosed with a specific disability while aged 0 to 6, a proportion of the total funds – rather than the whole amount – could be pooled.

Care coordination and logistics for the NDIS

32. For those children aged 7 and up on NDIS individual packages, a major challenge to effective service provision is care coordination and logistics in an environment marked by a low number of clients across a very large geographical region. In this context, 'fly-in / fly-out' services to remote communities are a necessity, but such visits need to be coordinated with local primary health care service and other providers who have the regular contact with NDIS clients.

33. This includes ensuring that PHC services and other community-based services have capacity and room to host the visit; are able to locate and support clients to attend appointments and other demands of visiting services; that that there is accommodation available to visiting providers; and that appointments do not clash with other visiting services. Accordingly, there needs to be ongoing resourcing of coordination and logistical systems to support the effective delivery of visiting NDIS-funded services to remote Aboriginal communities.

34. In addition, systems to ensure more integrated care and information sharing for Aboriginal NDIS clients is required. Central Australian Aboriginal people are highly mobile and may need to access care at different locations at different times of the year or different periods in their lives. In this situation, ensuring that all providers have access (with appropriate consent) to a client's NDIS plan is critical to ensure that their needs are known and that service providers have access to the resources to be able meet those needs. This will also ensure that services are not duplicated.

35. Accordingly, appropriate protocols for sharing NDIS plans across relevant service providers needs to be developed. This may include, for example, that NDIS participants will have their plan uploaded onto My Health Record so that providers are aware of the services they are entitled to or are receiving.

36. We suggest that the Strategy be amended to:

a. recognise that the NDIS does not work well to support the health and wellbeing of Aboriginal children in remote areas;

b. recommend the trialling, in collaboration with Aboriginal community controlled health services, of innovative solutions such as population-level funds pooling of NDIS funds at a regional level to fund early childhood development services for children aged 0 to 6 years;

c. recommend the resourcing of coordination, logistical support and information sharing to support integrated delivery of visiting NDIS-funded services to remote Aboriginal communities.

References

1. National Aboriginal Community Controlled Health Organisation (NACCHO). *Aboriginal Community Controlled Health Organisations (ACCHOs)*. Available from: https://www.naccho.org.au/acchos.
2. Australian Department of Education and Training, *Australian Early Development Census National Report 2015: A Snapshot of Early Childhood Development in Australia*. 2016, Commonwealth of Australia: Canberra.
3. United Nations. *United Nations Declaration on the Rights of Indigenous Peoples*. 2007; Available from: http://www.un.org/esa/socdev/unpfii/en/drip.html.
4. *Uluru Statement from the Heart*. Available from: https://ulurustatement.org/.
5. Baum F, *The new public health (third edition)*. 2nd ed. 2007, Oxford: Oxford Univeristy Press.
6. Markham F and Biddle N, *Income, poverty and inequality*. 2018, Centre for Aboriginal Economic Policy Research,: Canberra.
7. Australian Bureau of Statistics (ABS). *4714.0 - National Aboriginal and Torres Strait Islander Social Survey, 2014-15*. 2016 2 February 2017]; Available from: http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4714.02014-15?OpenDocument#Publications.
8. Northern Territory Council of Social Services (NTCOSS), *Cost of Living Report*. 2019, NTCOSS: Darwin.
9. Wilson, T., Y. Zhao, and J. Condon, *Limited progress in closing the mortality gap for Aboriginal and Torres Strait Islander Australians of the Northern Territory.* Australian and New Zealand Journal of Public Health, 2019. **43**(4): p. 340-345.
10. Ah Chee D, Boffa J, and Tilton E, *Towards an integrated model for child and family services in Central Australia.* Med J Aust, 2016. **205 (1)**.
11. Moss B, Harper H, and Silburn S R, *Strengthening Aboriginal child development in Central Australia through a universal preschool readiness program.* Australasian Journal of Early Childhood, 2015. **40**(4): p. 13-20.
12. Syme S, *Social determinants of health: The community as an empowered partner.* Preventing Chronic Disease: Public Health Research, Practice, and Policy, 2004. **1(1)**(1-5).
13. Tsey, K., *The control factor: a neglected social determinant of health.* Lancet, 2008. **372**(9650): p. 1629.
14. Malbon, E., G. Carey, and A. Meltzer, *Personalisation schemes in social care: are they growing social and health inequalities?* BMC Public Health, 2019. **19**(1): p. 805.
15. Australian Bureau of Statistics (ABS). *2016 Census Community Profiles*. 2016; Available from: http://quickstats.censusdata.abs.gov.au/census_services/getproduct/census/2016/communityprofile/7?opendocument.
16. Australian Bureau of Statistics (ABS). *Census of Population and Housing: Understanding the Increase in Aboriginal and Torres Strait Islander Counts, 2016* 2077.0 2018 6 November 2018; Available from: http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/2077.0Main+Features1232016?OpenDocument.
17. National Disability Insurance Scheme (NDIS). *Increased price limits for NDIS service providers including updates for Western Australia*. 2019; Available from: https://www.ndis.gov.au/news/2970-increased-price-limits-ndis-service-providers-including-updates-western-australia.
18. National Disability Insurance Scheme (NDIS). *NDIS Plans*. 2019; Available from: https://www.ndis.gov.au/news/1276-ndis-plans.