Central Australian
Aboriginal Congress
ABORIGINAL CORPORATION | ICN 7823

Submission to the Department of Social Services / National Disability Insurance Agency

National Disability Insurance Scheme Thin Markets Project

6 August 2019

Executive Summary [see text for details]

Principles for action

A. Any approach to providing care to Aboriginal people with disabilities through the NDIS 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.*

What are 'thin markets' in the Aboriginal context?

B. 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. These differences are multiplied significantly in cross cultural situations such as apply for Aboriginal people in Central Australia.

C. The availability of culturally secure, appropriate service providers is therefore another factor that needs to be taken into account in assessing the existence and extent of 'thin markets'.

D. In all cases, Aboriginal organisations – and especially Aboriginal Community Controlled Health Services – be formally recognised as the preferred providers for services under the NDIS for Aboriginal people.

Responding to thin markets in Aboriginal Central Australia

The importance of early childhood development

E. Quality early childhood development programs are a key, cost-effective intervention to support cognitive, social, communicative, physical and emotional development and prevent the onset of significant cognitive disability.

Funds-pooling for Central Australian Aboriginal children aged 0 to 6

F. For Aboriginal children aged 0 to 6, an estimate of the population-level of disability should be used to pool NDIS funds to provide sustainable,

Central Australian Aboriginal Congress Aboriginal Corporation
ABN 76 210 591 710 | ICN 7823
PO Box 1604, Alice Springs NT 0871
(08) 8951 4400 | www.caac.org.au

universally accessible, evidence-informed, culturally adapted, early childhood programs. We estimate that the funds pool for Central Australian Aboriginal children aged 0 to 6 will be conservatively $21 million per year.

G. 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.

1. Pooled funds could be combined with Early Childhood Early Intervention (ECEI) funds and existing early childhood programs in remote communities to increase the scale and extent of the access to Child Health and Development Centres.

Care coordination and logistics for the NDIS

H. Ongoing funding is required for central coordination and logistical support for the effective delivery of visiting NDIS-funded services to remote Aboriginal communities.

I. Appropriate protocols for sharing NDIS plans across all service providers should be developed and agreed to ensure that NDIS clients' needs are known; that service providers have access to the resources to be able meet those needs' and to reduce duplication.

Regional collaboration and planning

J. The establishment of a Central Australian Regional Disability Services Forum could drive collaborative, needs-based planning and system design to ensure that Central Australian residents have fair access to the NDIS.

K. Such a regional planning forum could be used as a national demonstration project, to determine whether it is a model that could have application in other regional and remote areas of Australia where thin markets are likely to significantly affect the operations of the NDIS.

Background

2. 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:

    - multidisciplinary clinical care;
    - health promotion and disease prevention programs; and
    - action on the social, cultural, economic and political determinants of health and wellbeing.

3. 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.

4. Congress welcomes the Department of Social Services (DSS) / National Disability Insurance Agency (NDIA) *National Disability Insurance Scheme Thin Markets Project*. We commend DSS and the NDIA for recognising that the NDIS faces significant challenges in areas where markets fail to provide the necessary services, particular in remote areas such as Central Australia and for Aboriginal people.

Principles for action

5. In traditional times, Aboriginal people's access to the land and its resources and their cultural practices ensured that they were healthy and that those who needed were 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 Nations.

6. As a result, today Aboriginal people in Central Australia have very high levels of disability (7% of those aged 15 or more report having a profound or severe disability). Families provide much of the care needed (19% of Aboriginal people in the region report providing unpaid care to family members) while

their capacity to do so is reduced due to poverty, isolation and lack of services [1][1].

7. Given this context, any approach to providing care to Aboriginal people with disabilities through the NDIS 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* [2], which states:

   Article 22: Particular attention shall be paid to the rights and special needs of … persons with disabilities in the implementation of this Declaration.

   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;

The role of Congress

8. Congress is a registered provider under the NDIS for some limited allied health services such as adult psychology. We are in the process of extending registration to other allied health services, and while we do provide services to NDIS-eligible clients, we are as yet unable to claim as the internal systems to ensure this is done are still being developed. Congress has been successful in obtaining a small grant under the Transitions Assistance funding scheme under the Boosting Local Care Workforce program that will assist the development of these key internal systems.

9. We have been working closely with the NDIA including commencing roles for Remote Community Connectors and Evidence, Access and Coordination of Planning (EACP). We will shortly be recruiting for a social worker to undertake the EACP activities including ensuring all potentially eligible children and adults are referred to the NDIA for assessment.

10. Also of relevance for addressing the healthy development of children, and preventing or reducing the prevalence of developmental disabilities Congress provides an evidence-based Child Health and Development Centre (CHaDC) known by its Central Arrernte name *Arrwekele akaltye-irretyeke ampere* and a preschool readiness program for Aboriginal children 0-5 years.

11. The Arrwekele akaltye-irretyeke ampere (CHaDC) is based on play based learning, conversational reading, enriched care and language priority ensuring communication in Aboriginal languages and English. It also provides a healthy

[1] Note that the figures in this paragraph are from the 2016 Census and are certainly underestimates of the scale of the problem.

meal each day. Children from disadvantaged families attend from the age of 6 months until they are eligible for preschool. They are all assessed using Child Health Checks with ASQ-Trak and they undertake more detailed assessment for neurodevelopmental disorders as required. If needed, wrap around support services such as speech pathology and paediatric occupational therapy can be provided using the centre as a base to enable effective interventions with children and education of their parents as to what is needed.

12. Congress also provides therapeutic interventions such as speech pathology and occupational therapy for individual children and young people with delay and diagnosed disability who are not in a centre based program. Additionally we provide therapeutics though at this stage have limited NDIS billing rights.

13. Given our existing work in early childhood development we are seeking to become a provider of Early Childhood Services through an NDIS partnership grant. This is also an ongoing discussion with the NDIA.

What are 'thin markets' in the Aboriginal context?

14. The fundamental tenet of the NDIS and similar personalisation schemes around people having choice and control over the services they receive, is well intended. There is a strong relationship between disempowerment and poor health and wellbeing [3, 4].

15. However, promoting personal choice for people in context where they 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 [5]. 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.

16. To these well-recognised descriptions of 'thin markets' must be added the challenges of personalised service approaches when dealing with disadvantaged populations, especially in cross-cultural situations.

17. 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 [5]. 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 language and where the historical (and sometimes contemporary) experience of mainstream services lead many Aboriginal people to be suspicious of them and to avoid engagement.

18. The availability of culturally secure, appropriate service providers is therefore another factor that needs to be taken into account in assessing the existence of thin markets, as well as the more commonly recognised factors described in this project's Discussion Paper.

19. In addressing thin markets as experienced by Aboriginal people, ACCHSs have a number of significant advantages:

    - they have been shown to be more effective in delivering outcomes than mainstream services, achieving comparable outcomes, but with a more complex caseload [6];
    - they are more effective in supporting the delivery of specialist and allied health services [7];
    - Aboriginal people show a clear preference for the use of ACCHSs, leading to greater access to care and better adherence to treatment [8, 9]. The capacity of ACCHS to deliver culturally safe care is fundamental to this preference; and
    - they are significantly more successful in training and employing local Aboriginal people including language speakers, which further supports access and engagement of vulnerable families [10].

20. In addition, and crucial in terms of promoting choice and control, ACCHSs embody an empowered model of service delivery that guarantees community input into decision-making and high levels of Aboriginal leadership across the organisation. Clients of Aboriginal community-controlled health services are able to exercise choice and control over their services through participation in membership structures and governing Boards which gives them the power to influence service delivery.

21. Accordingly, we recommend that in all cases, Aboriginal organisations – and especially ACCHSs – be formally recognised as the preferred providers for services under the NDIS for Aboriginal people.

Responding to thin markets in Aboriginal Central Australia

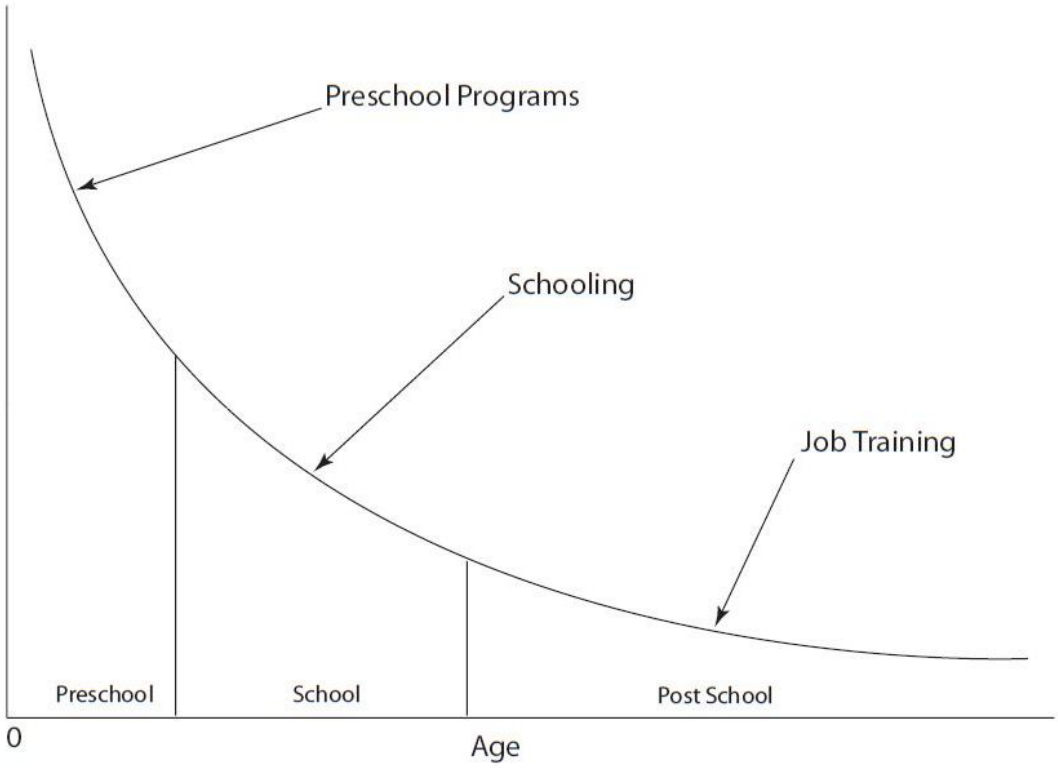
The importance of early childhood development

22. It is well established that social and environmental influences in early childhood shape health and wellbeing outcomes across the life course. Adverse childhood experiences are highly correlated to a wide range of physical health problems, as well as to increased levels of depression, suicide attempts, sexually transmitted infections, smoking, and alcoholism [1].

23. The pathways by which these early experiences create these effects are complex. However, we know that during the first few years of life interactions between genetic make-up, environment and early experience have a dramatic impact on how the brain forms. During these critical first few years, children need stimulation and positive relationships with care givers to develop neural systems crucial for adult functioning [2].

24. The key implication from this evidence is that it is too late to wait until the child is ready for school at around age five as by this point many of the developmental gateways for language acquisition, self-regulation and cognitive function have been passed, and a child's developmental trajectory already set [3]. This is not to say that nothing can be done to help developmentally challenged children during their school years and later in life, but those who begin school behind are increasingly found to remain behind without targeted, costly interventions that require increasing amounts of resources and effort (see Figure 1) and produce diminishing returns as the child gets older [4].

Figure 1: Rates of return to human capital investment for disadvantaged children [5]



25. Fortunately, quality early childhood development programs are a key, cost-effective intervention to address and offset the effects of unhealthy early childhood development. These programs are proven to support cognitive, social, communicative, physical and emotional development and thereby improve long term health, education and employment outcomes for young

children from disadvantaged families. They also have been shown to prevent the onset of significant cognitive disability [11-14].

Funds-pooling for Central Australian Aboriginal children aged 0 to 6

26. A high proportion of Central Australian Aboriginal children are known to have significant developmental issues. The Australian Early Development Census (AEDC) results for 2015 show that by the time they start school [15]:

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

27. Despite this high level of developmental vulnerability in the early years, Aboriginal children are unlikely to be diagnosed with a neurodevelopmental disorder or disability (for example Foetal Alcohol Spectrum Disorder, or Autism Spectrum Disorder) until around aged 7 when these conditions are much 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).

28. 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 is a 'market deepening' strategy that 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.

29. There are a number of different ways to estimate the required funds pool for Central Australian Aboriginal children aged 0 to 6 which we think will 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**

30. The assumptions behind this calculation are as follows:

    - *0 to 6 population*: Census 2016 figures [1], correcting for the average 20% Northern Territory undercount of Aboriginal people [16];
    - *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 [15];
    - *Remote loading*: as per NDIS increased service limits applying from 1 July 2019 [17];
    - *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.
    - *Total funds*: target population multiplied by the package per child.

31. 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.

32. 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.

33. We stress that these are estimates that would need to verified through further study. We believe that the total figure of $21 million p.a. is conservative, but could be combined with the Early Childhood Early Intervention (ECEI) funds

to increase the scale and extent of the access to Child Health and Development Centres and key wrap around services such as speech pathology and occupational therapy.

34. Note also that some remote communities already have Early Childhood Centres delivering a Northern Territory Department of Education program known as Families as First Teachers, an early learning and family support program for remote Aboriginal families aimed at improving developmental outcomes by working with families and children prior to school entry. With the additional NDIS resources implemented through a regional planning process (see below) these centres could be greatly enhanced and enable many more children to access key services on many more days per week. They would also become the locus for the additional allied health services that many children need.

35. This will require early childhood educators to be recruited to live in the larger remote communities in Central Australia such as Ntaria, Ltyentye Apurte, Mutitjulu, Yuendumu, Utopia and others. These staff will need housing and this will need to be funded through the very large NDIS underspend. There will also need to be housing for overnight accommodation from visiting staff such as speech pathologists and paediatric occupational therapists.

Care coordination and logistics for the NDIS

36. For those children aged 7 and up and adults 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.

37. 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.

38. Accordingly, there needs to be ongoing resourcing of coordination and logistical to support the effective delivery of visiting NDIS-funded services to remote Aboriginal communities.

39. 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.

40. 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.

Regional collaboration and planning

41. The provision of disability services to Aboriginal people across Central Australia is complex. A service system that relies solely on the conventional structures of personalised care, founded on a one-to-one relationship between client and service provider, is likely to disadvantage those who need support most, and result in a widening gap in access to much needed services.

42. This paper has put forward a number of suggestions for how the NDIS can be modified to better meet the needs of Aboriginal people in the region. However, these reforms are suggestions. Their implementation requires a collaborative process of system design, implementation and monitoring.

43. The Northern Territory Aboriginal Health Forum (NTAHF) provides a model for a collaborative, needs-based planning process which has been effective in driving effective system reform for primary health care in the Northern Territory.

44. A similar regional forum for Central Australia for disability services would help ensure that the disability services system for Aboriginal people and other residents of the region works on a more integrated basis and that funding is allocated in the best possible way, to where it is most needed, through services which are the most effective.

45. A Central Australian Regional Disability Services Forum would need to include DSS, the NDIA and other Australian Government agencies (e.g. the Department of Health's Indigenous Heath Division); Northern Territory Departments of Health and Education; representation from Aboriginal community-controlled services (from the Aboriginal Medical Services Alliance Northern Territory – AMSANT); representation from mainstream non-government providers (from the Northern Territory Council of Social Services – NTCOSS); and representation from private providers.

46. Key initial tasks of a Central Australian Regional Disability Services Forum might initially include:

    - ensuring that NDIS funds for Central Australia are allocated and equitably expended at a level commensurate with need across the population;

- designing a funds-pooling system from individual packages to fund early childhood development services, and collaboratively planning when, where and how to invest these resources; and
- designing and overseeing the implementation of systems for greater care coordination and information sharing for individual NDIS packages.

47. It is essential that such a regional disability services forum be resourced appropriately for it to play its role.

48. Such a regional planning forum could be used as a national demonstration project, with some evaluative components built in from the start, to determine whether it is a model that could have application in other regional and remote areas of Australia where thin markets are likely to significantly affect the operations of the NDIS.

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