Central Australian
Aboriginal Congress
ABORIGINAL CORPORATION | ICN 7823

Submission to:

Joint Standing Committee on the National Disability Insurance Scheme

Provision of services under the NDIS Early Childhood Early Intervention Approach

August 2017

1. Summary and context for this submission

Central Australian Aboriginal Congress (Congress) is the largest Aboriginal community-controlled health service (ACCHS) in the Northern Territory, providing a comprehensive, holistic and culturally-appropriate primary health care service to more than 14 000 Aboriginal people living in and nearby Alice Springs each year, as well as the remote communities of Ltyentye Apurte (Santa Teresa), Ntaria (Hermannsburg) and Wallace Rockhole, Utju (Areyonga), Mutitjulu and Amoonguna.

As an ACCHS, Congress functions within the framework of a comprehensive primary health care (CPHC) model, which aims to address health inequities and close the health gap between Aboriginal and non-Aboriginal people by providing multidisciplinary clinical care as well as addressing the broader social determinants of health.

A key role for primary health care services in supporting the healthy growth and development of Aboriginal children is in the area of early childhood, especially in the years from pre-birth to 4 years of age. These are the critical years for determining a person's whole life story including their life long health and well-being.

Congress' core services and programs therefore include an integrated and comprehensive approach to child and family support services which includes providing centre-based early childhood learning programs at two sites in Alice Springs.[1] These programs are key primary and secondary prevention strategies which are proven to support cognitive and emotional development and improve long term health and education outcomes for young children from disadvantaged families. They also have been shown to prevent the onset of significant cognitive disability compared to children from disadvantaged families who cannot access such crucial services.

The rollout of the National Disability Insurance Scheme (NDIS) and the Early Childhood Intervention (ECI) approach is a real opportunity to enhance the primary prevention of disability as well as support very early identification of disability at a population level, and reduce its impact, and cost, over a life time. The need for an ECI approach in remote Aboriginal communities is high, yet how this is approach is delivered differs vastly from metropolitan and regional areas, and mainstream service provision. This

has been shown in the Barkly Region of the Northern Territory, a demonstration site for the NDIS rollout in remote communities, where there has been very little up take of the scheme. This is because there are not sufficient providers in this remote area to provide the required services to the many Aboriginal people who are eligible for such services. There needs to be a different approach in remote areas to address these system issues including the ability to pool funding for eligible clients to service providers to ensure they can employ the required professional staff to provide the services. The individual funding model is unlikely to create an adequate market for the required professions in remote areas as it is reliant on professions moving to the newly created market. This for a person establishing a new business is risky, particularly in these remote communities where the market is not well known. The most logical first step is for the entry to be made through a centralised service provider, later on, the relevant professional may then create their own practice but this may not occur and continued, pooled individual grant funding will be required.

The following submission outlines:

- Why early childhood programs at a population level for disadvantaged children are vital to preventing intellectual and emotional disability
- How these programs can be effectively delivered to children and families in remote Aboriginal communities including:
    a) population-level centre-based early learning programs for all children from disadvantaged families for the primary prevention of disability;
    b) individual, specialised support services for children within the same program who have been identified and diagnosed early with developmental delay which will lead to permanent disability if not addressed or a specific disability.
- The criteria for accessing both the population level and individual interventions, and relevant funding mechanisms
- Why Aboriginal Community Controlled Health Services are the most appropriate partners, providers and brokers of ECI services for Aboriginal families in remote areas.

Key recommendations:

The rollout of the NDIS and ECI approach in remote Aboriginal communities should take into consideration:

1. That centre-based early childhood programs at a population level for disadvantaged children are funded through partnering organisations and are vital to prevent intellectual and emotional disability and should work in conjunction with individual NDIS-funded services for children with a diagnosed developmental delay or more specific disability.
2. That individual NDIS-funded services are embedded within centre-based early learning programs for all children from disadvantaged families so children who have been diagnosed with developmental delay not due to a reversible acute cause, and children with more specific disabilities, can be integrated with children within wider population-based services.
3. That Aboriginal Community Controlled Health Services are the most appropriate providers and brokers of ECI services for Aboriginal families in remote areas.

2. Intellectual disability and early childhood

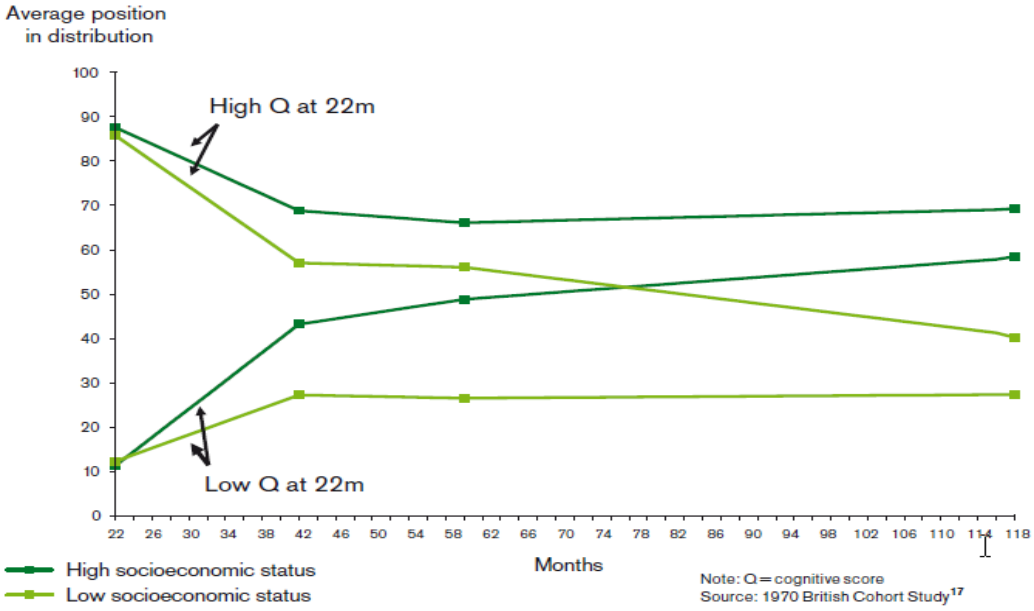
Disadvantage and brain development

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] By the age of five, 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]

Children who grow up in a disadvantaged environment do not develop the brain capacity to do well in education and, even though they attend primary school, will on average do less well and often drop out as soon as they are old enough. Traits such as impulsivity, poor concentration, lack of self-control and self- discipline are more likely. [4]

The following graph shows how much the early childhood environment impacts on brain development for children born with both high IQ and low IQ. The difference in outcomes for children from low income families is likely due to children's experiences in the first three years of life in their homes. The things that make the difference include daily one on one interactions and talking with young children, daily reading going to bed at regular times, being physically active and having a good playgroup of children of similar age.[5] Without these critical early childhood experiences of responsive care and stimulation children lose their brain capacity even to the point of having an intellectual, emotional or other disability by age 3.

Figure 6 Inequality in early cognitive development of children in the 1970 British Cohort Study, at ages 22 months to 10 years

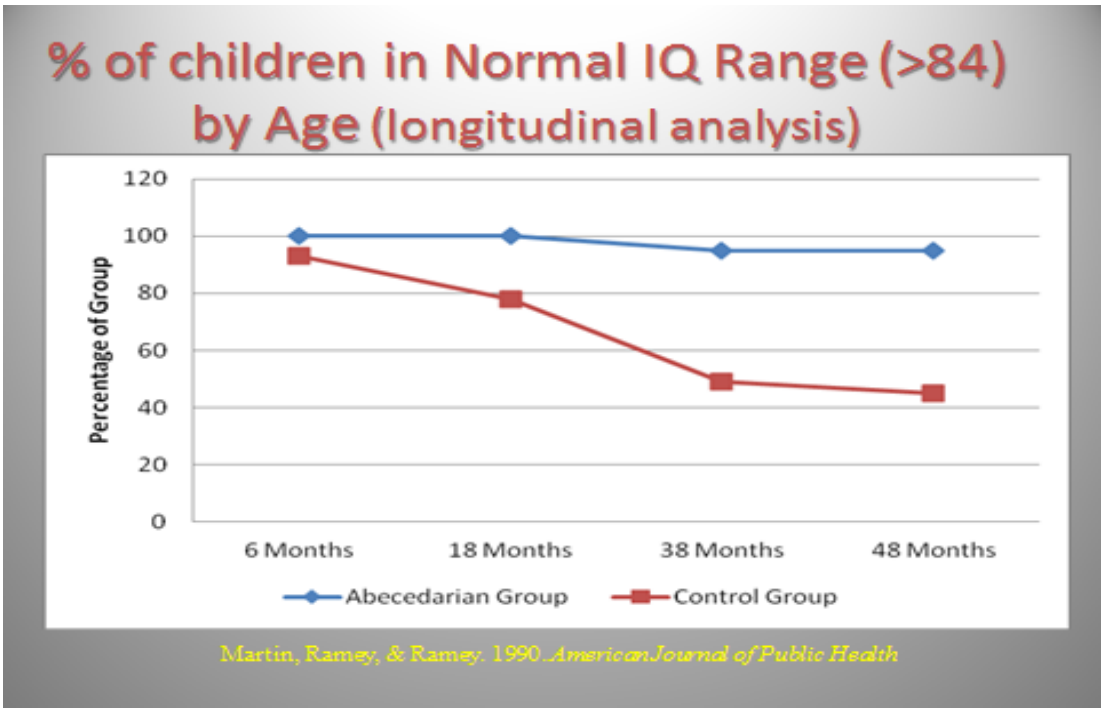


Fair Society, Healthy Life[6]

Early childhood education programs prevent intellectual disabilities in children from disadvantaged backgrounds.

There is substantial evidence to show that structured early childhood programs improve the trajectory for children from at-risk and vulnerable families by supporting cognitive and emotional development. As noted above, in the first few critical years, children need responsive care and stimulation including strong, positive relationships with primary care givers to develop neural systems crucial for adult functioning and positive mental health. For example, the Abecedarian Approach is a preventative program for children at high risk of developmental delay due to social and economic disadvantage. It has four main elements – Learning Games, Conversational Reading, Enriched Care Giving and Language Priority.

The Abecedarian intervention has been shown through randomised controlled studies to prevent intellectual disabilities in children from disadvantaged families.[7] Nearly all disadvantaged children with an IQ in the normal range who underwent the Abecedarian program maintained their IQ while more than half of the children who did not go through the program dropped their IQ below 84 by age 3 (see graph below). This is consistent with data from many other studies, showing that many children from disadvantaged backgrounds dramatically lose their brain capacity after birth as neural networks and connections are not developed at critical stages. This shows intellectual disability in children from disadvantaged families is preventable at a population level.



Longitudinal studies show that this approach has long lasting effects well into adulthood with participants doing better at school and gaining more years of education and better employment outcomes well into adulthood.[8] For example, adults who had participated in the Abecedarian program

as a child were four times more likely to have earned a university degree by the age of 30, compared with those who had not participated in the program.[9]

3. The level of need in the Central Australian Aboriginal population.

Aboriginal children in Central Australia are at higher risk of intellectual and emotional disability

Too many Aboriginal children in and around Alice Springs grow up in an environment marked by poverty, substance abuse, and lack of responsive care and stimulation, with low levels of formal education and school attendance coupled with economic marginalisation and social exclusion. This does not apply to all families – there are many who are working, and able to care for their children well. Nevertheless, the overall picture shows that[10]:

- the median individual income for Aboriginal people over the age of 15 in Alice Springs is $248 per week, one third (34%) of that for non-Aboriginal people in the town;
- 86% of Aboriginal and Torres Strait Islander adults in Alice Springs did not complete schooling to Year 12; 10% did not go to school at all;
- only 37% of the Aboriginal population of Alice Springs over the age of 15 are employed (81% for non-Aboriginal residents)
- 15% of babies born to Alice Springs Aboriginal mothers are of low birth weight, with 23% of these mothers being under the age of 20,[11] though note that on Congress' own data this has improved to 11% in 2016/17.
- Aboriginal children born to teenage mothers are more likely to have poorer educational outcomes.[12] Teenage motherhood is much more common among Aboriginal girls at 21 per cent compared with 4 per cent of all births. [13]

The implication of this level of disadvantage is reflected in the developmental outcomes and educational attainment of Aboriginal children in the Northern Territory. According to the Australian Early Development Census:

- Sixty per cent of Aboriginal children in the Alice Springs region are developmentally vulnerable on at least one measure of childhood development.
- Aboriginal children are twice as likely as non-Aboriginal children to be developmentally vulnerable in at least two measures and in Alice Springs 43% of Aboriginal children are developmentally vulnerable on two or more domains compared with 7% of non-Aboriginal children.[14]
- Additionally, school attendance rates in the Northern Territory are 14 to 30% lower for Aboriginal students.[15]

As a result, the NAPLAN scores for Territory school children are the lowest in the nation by a large margin at years three, five and seven. This is primarily the flow on effect of early childhood disadvantage

4. A tiered approach to preventing and managing intellectual disability in remote Aboriginal communities

4.1. Targeted population approach

Ideally all children would have access to evidence-based early learning programs. However, early childhood interventions are most effective when they are targeted towards younger children from disadvantaged families.[16] As noted above, Aboriginal children, particularly in remote areas, are much more likely to be developmentally vulnerable and at risk of developmental delay and intellectual disability. Hence there is a strong argument for preventive early learning programs, accessible to all Aboriginal children from vulnerable families, both in town and remote areas of Central Australia. This can be achieved through the capacity in the NDIS to fund organisations as partners for the provision of such population level services to children at risk of developing a disability.

Early childhood programs should be provided by primary health care services and integrated with other health programs.[1,17] This is because health services are a primary contact for pregnant mothers and very young children.[18] The provision of these early learning services by primary health care services also allows for: the provision of child health and development checks including language assessments and immunisations; the early identification of further needs; referrals to allied health and specialist services; as well as coordinated care and case management (see tailored interventions, below). It also enables Medicare to be used to maximise the provision of eligible services with the least cost to the NDIS.

Early childhood programs should be delivered through Aboriginal community-controlled health services, inclusive of supportive services including family/parent engagement and support, transport and the provision of nutritious food. This recognises and integrates the multiple factors needed for healthy child development (e.g. stimulation and nutrition), as well as the social determinants of health (e.g. social support for low-income families, transport).[19]

All programs must be adapted to the local context and culture. They must also be rigorously monitored and evaluated with measurable indicators and outcomes.

Criteria for entry into a targeted population early learning program.

Minimum eligibility criteria for enrolment and participation in an early learning program operated by an ACCHS should be:

- Age between 6 months to 3.5 years (after which they attend preschool through education providers).
- Aboriginal
- Non-working parents/family or total family income at less than 50% of median family income (weighted to number of other adults and dependents in the family)
- Parents' educational attainment ≤ year 11.

Additional criteria:

- High risk vulnerable families e.g. identified through other family and parenting support programs.

Funding mechanisms: Currently, very limited and non-recurrent block and grant funding from Commonwealth, State and Territory Aboriginal health budgets fund some targeted population, centre based early learning programs for non-working families. However, the NDIS should take over this role for non-working, disadvantaged families and provide for universal services and invest in systemic supports to build community and social capacity, in line with the National Disability Strategy and the existing capacity in the NDIS to fund population level services with partnering organisations for children at risk of developing a disability. Mainstream childcare centres for working families will not address this need and a new funding mechanism needs to be found and the NDIS through its partnering capacity is the answer.

As both a primary disability prevention and early identification and intervention strategy, this should become a major focus of the NDIS into the future. Although it could be seen to be a costly intervention, the economic return on these types of services is around $10 for every $1 invested over a lifetime and the OECD has advised Australia that investing in these types of Early Childhood Services is the single most important thing the nation can do to achieve economic growth and be competitive into the future.[20,21,22,23]

It needs to be seen as an investment in building the capacity of the future working population rather than allowing too many Australians to be incapacitated through preventable early childhood disadvantage, lack of educational attainment, employment and overt disability. The nation cannot afford not to take this type of approach and the NDIS provides a sustainable source of funds to address what is the most critical area in the healthy development of the population.

4.2. Early identification and tailored interventions within an early learning program

Routine child health and development assessments conducted by primary health care services and as part of centre-based early learning programs will allow for the early identification of children with developmental delays and disability. This will enable children to be enrolled in the NDIS at an individual level and eligible for the provision of early individual interventions including speech pathology, occupational therapy, specific interventions e.g. for autism, FASD etc. as well as identifying specialist educational needs through the NDIS.

Depending on complexity of support needed, these additional services should be integrated into the child's regular activities and services provided within the early learning centres funded under the partnering program. Comprehensive, specialist services integrated into a population-wide early childhood program, will give children continued stimulus through exposure to the program and related support services, and avoids discrimination and placing children within a 'deficit model.' The integration of children with a known developmental delay within wider population-based early learning centres is an important part of the proposed model.

As noted above, the provision of an early learning program by one health service provider has the benefits of streamlining referral processes as well as coordinated service delivery and case management, particularly for children and families with complex needs. Partnerships with specialist and tertiary services, i.e. pediatric services, for diagnosis and management plans are essential to this model.

Once Aboriginal children have undertaken a 715 child health check then key allied health services become Medicare eligible as well as eligible under the NDIS and this combined funding should help to ensure that the required services are available. In addition to this, children with a diagnosed disability can be eligible for a care plan which also enables additional funding of allied health care under Medicare. Neither funding source alone is sufficient to attract and retain staff to remote areas but both working in tandem will be able to ensure a sustainable funding source for these critical services.

Criteria for admission into tailored interventions:

- ASQTrak assessment to screen for developmental delay and need for further assessment
- Paediatric assessment for diagnosis of developmental delay due to a non- acute, reversible cause or a more specific disability and management plan.

Funding for tailored interventions.

Tailored interventions should come under the current NDIS funding model for individual support services. ACCHSs would participate as both as both an Early Childhood Partner for population level preventive services as well as an Early Childhood provider for more specialized, wrap around services for children with a diagnosed disability.

Recommendation 1

That centre-based early childhood programs at a population level for disadvantaged children are funded through partnering organisations and are vital to preventing intellectual and emotional disability and should work in conjunction with individual NDIS-funded services for children with a diagnosed disability.

Recommendation 2

That individual NDIS-funded services are embedded within centre-based early learning programs for all children from disadvantaged families so children who have been diagnosed with developmental delay not due to a reversible, acute cause, and children with more specific disabilities, can be integrated with children in wider population-based services.

4.3. The benefits of this model within the context of the roll out of the NDIS and ECI approach in remote Aboriginal communities.

The Commonwealth Ombudsman has recently documented some of the key barriers to accessing NDIS services and the low uptake of NDIS services by Aboriginal people in the Barkly Region of the Northern Territory.[24] These include:

- Issues around choice and control, and that the concept of active consumers of available and accessible services has not been effective in remote Aboriginal communities, and engagement with the NDIS has been at lower levels than projected.
- Language and cultural barriers. Many Aboriginal people – particularly in remote communities – still have a low level of understanding of the NDIS. Many participants simply agree with a plan or

a proposed service provider rather than experience embarrassment by asking questions or admitting they do not understand the arrangement.
- The economies of scale created by the individual fund holding model did not trigger the creation of new allied health services that were needed to ensure service provision in a remote area (therefore individuals had no access to these services).

The model above addresses many of the issues highlighted by the Ombudsman. ACCHS are well positioned to be the providers of early childhood learning programs through early childhood partnering for services at a population level as well as the provision and facilitation/brokerage of services for children with additional needs under the NDIS, as well as being advocates for parents/carers. In remote areas it is important that ACCHS are able to play both roles as they fulfill the criteria for exemption to have different organisations partnering and providing services.

Importantly, evidence shows that there is a preference by Aboriginal people to use ACCHSs where they exist.[25,26] This is because:

- ACCHSs provide culturally secure services, and attract, train and retain Aboriginal staff leading to greater cultural appropriateness of services.
- As comprehensive primary care services providers, ACCHSs are proficient at providing supportive services beyond direct health care including family and parenting support. They also have existing relationships with relevant services;
- ACCHS also involve communities in the development of services through a strong, local member base and governance structures. Community involvement, including carers, is important for the establishment of early learning programs, to create a common purpose and goals, as well as gain buy-in by the users of the service.[27]
- ACCHSs are accountable for the services they provide to both users and funders. Reports to funders are compulsory and de-identified results are publicly available.

Recommendation 3

That Aboriginal Community Controlled Health Services are the most appropriate providers and brokers of services for Aboriginal families in remote areas.

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