

Statement of Donna Ah Chee and Dr John Boffa Central Australian Aboriginal Congress Aboriginal Corporation

Name: Donna Ah Chee

Address: 14 Leichhardt Terrace, Alice Springs NT

Occupation: Chief Executive Officer

Date: 17 September 2021

1. This statement made by me accurately sets out the evidence that I am prepared to give to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. This statement is true and correct to the best of my knowledge and belief.
2. The views I express in this statement are my own based on my education, training and experience. I make this statement on behalf of Central Australian Aboriginal Congress Aboriginal Corporation (**Congress**) and I am authorised to do so as the Chief Executive Officer. Congress is an Aboriginal community-controlled primary health care service employing over 400 staff to deliver comprehensive primary health care to more than 17 000 Aboriginal people through our services in Alice Springs and six remote communities in Central Australia.
3. I am a Bundjalung woman from the far north coast of New South Wales who has lived in Alice Springs for over 30 years. I am married to a local Yankunytjatjara/Arrernte man and together we have three children.

Professional background

4. I am currently the Chief Executive Officer of Central Australian Aboriginal Congress. I have been in the role of CEO since my appointment in 2012.

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5. I have the following qualifications:
- 2015 Australian Institute of Company Directors fellowship course
 - 2000 Graduate Certificate in Management, La Trobe University
 - 1992 Associate Diploma in Business (Aboriginal Organisations), Institute for Aboriginal Development Alice Springs
 - 1989 Advanced Certificate in Management (Aboriginal Organisations), Institute for Aboriginal Development Alice Springs
6. In 2016 I won the Australian Medical Association award for excellence in health care (joint with John Boffa).
7. I have had extensive involvement in evidence-informed policy development in my longstanding leadership roles in Aboriginal organisations. I am currently the chair of the Northern Territory Tripartite Forum on Children and Families and a former chair of the Aboriginal Medical Services Alliance of the NT (AMSANT), the Aboriginal Benefit Account Advisory Committee (ABAAC) and the Literacy for Life Foundation (LFLF). I am a director on the board of the National Aboriginal Community Controlled Health Organisation (NACCHO) where I previously served as CEO, and a former board member of the Australian National Advisory Council on Alcohol and Drugs (ANACAD), the Northern Territory PHN and the Menzies School of Health Research. I am an expert member of the National Aboriginal and Torres Strait Islander Health Implementation Plan Advisory Group (IPAG), former chair and current member of the Northern Territory Aboriginal Health Forum (NTAHF) and I represent Congress on the Alice Springs Peoples' Alcohol Action Coalition (PAAC).
8. I have considerable experience in research and have been the lead investigator in some key research projects including the 'Grog Mob' program which pioneered the three streams of care model within a primary health care service.

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- 9. I have many years' experience as a CEO of major Aboriginal corporations, serving as CEO of the National Aboriginal Community Controlled Health Organisation (NACCHO) from May 2011 to May 2012, and CEO of the Institute for Aboriginal Development in Alice Springs from 1995 to 1999.
- 10. As the CEO I report directly to the Board of Directors, through the Chair.

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Name: Dr John Boffa

Address: 14 Leichhardt Terrace, Alice Springs NT

Occupation: Chief Medical Officer Public Health, Central Australian Aboriginal Congress

Date: 17 September 2021

11. This statement made by me accurately sets out the evidence that I am prepared to give to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. This statement is true and correct to the best of my knowledge and belief.
12. The views I express in this statement are my own based on my education, training and experience. I make this statement on behalf of Central Australian Aboriginal Congress (Congress) and I am authorised to do so as the Chief Medical Officer Public Health. Congress is an Aboriginal community-controlled primary health care service employing over 400 staff to deliver comprehensive primary health care to more than 17 000 Aboriginal people through our services in Alice Springs and six remote communities in Central Australia.

Professional background

13. I am currently the Chief Medical Officer Public Health of Central Australian Aboriginal Congress. I have been in the role since 2000 and prior to this I was the Senior Medical Officer at Congress from 1995.
14. My qualifications and awards are:
 - Monash University, Bachelor of Medicine, Bachelor of Surgery (Honours 1), 1985
 - RACGP Vocational Registration: QA&CE Reference number 507065
 - Accredited RACGP General Practice Training Supervisor 1992 – 2002

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- 1999 Masters of Public Health Melbourne Consortium for Public Health (Honours 1, Latrobe University)
 - 2002 RACGP General Practice Refresher Course, Melb., Jan 18-20
 - 2012 NT Australian of the Year (for alcohol and early childhood reform)
 - 2013 to current, appointed Adjunct Associate Professor with the National Drug Research Institute, Curtin University, Perth
 - 2014 Menzies Medallion (Joint award with June Oscar), Menzies School of Health Research, Darwin
 - 2016 Australian Medical Association award for excellence in health care (joint with Donna Ah Chee)
15. From 1988 I worked as the Senior Medical Officer at Anyinginyi Congress Aboriginal Corporation in Tennant Creek before moving to the Central Australian Aboriginal Congress in 1994.
16. In my various roles in Aboriginal health, I have worked with Aboriginal health leaders on significant Aboriginal health policy developments including the National Aboriginal Health Strategy Working Party Report (1989), the Royal Commission into Aboriginal Deaths in Custody (1991) and the transfer of administrative responsibility for Aboriginal health from ATSIC to the Commonwealth Department of Health (1994).
17. I have also been involved in key developments in Aboriginal community controlled primary health care including the development of the CARPA Standard Treatment Guidelines, core services and core indicators for primary health care, and addressing the broader determinants of Aboriginal health. I have worked on alcohol policy, especially alcohol supply reduction measures as well as the development of early childhood programs and services.

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18. In my current role I work closely with the CEO and have responsibility for the Public Health Division which has four sections employing about 40 staff in health policy, research, health promotion and continuous quality improvement.
19. As the Chief Medical Officer Public Health I report directly to the CEO.

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Central Australian Aboriginal Congress

21. Congress is a large Aboriginal community controlled health service (ACCHS) based in Alice Springs, Northern Territory. 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.
22. Congress delivers services to more than 15,000 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. Please note that we use the term 'Aboriginal' as the most appropriate term in the Central Australian context to refer to Australia's First Peoples. In using the term 'Aboriginal' we also extend this to include Torres Strait Islander people.
23. Over the last 20 years, the community-elected Congress Board of Directors has focused on improving the developmental outcomes of Aboriginal children. This has led to the creation of an innovative model for the delivery of child and family services, based on the belief that the best way to 'close the gap' is to make sure it is not created in the first place. Embedded in Congress' way of working is a strong focus on prevention. These services include:
- The **Child Health and Development Centre**, *Ampe Rlterrke Amangkeme* which translates to Child Strong Growing Up. The centre accepts children from disadvantaged, non-working families from the age of six months until the child enters preschool. The centre has developed a culturally adapted version of the Abecedarian approach, using evidence-based strategies for

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play-based learning and the promotion of healthy development with a strong focus on Aboriginal language and culture, along with family engagement. The effectiveness of the centre is shown in two recent, independent evaluations (currently pending publication).

- The **Congress Children and Family Intensive Support Service** (incorporating the Targeted Family Support Service [TFSS] and Intensive Family Support Service [IFSS]), which provides services that build on the strengths of families and communities to care for children within their culture while supporting families to navigate through the formal (Western) world. The service works to support families to keep children safe at home and supports families who are identified as being at risk of involvement with the child protection system. In addition, the service provides support for parents more broadly through the model of the Parenting Under Pressure (PUP) program.
- The **Child and Youth Assessment and Treatment Service (CYATS)** was established by Congress in 2018 in response to the prevalence of developmentally vulnerable Aboriginal children in the communities we serve. CYATS provides a best-practice service for the early detection and treatment of neurodevelopmental conditions such as FASD, ADHD and Autism Spectrum Disorder (ASD). CYATS provides a multidisciplinary approach to diagnostic assessment, early intervention, and support for families to access the NDIS. This service, the first of its kind in the Northern Territory, is founded on a strong partnership with Alice Springs Hospital paediatrics and other health and education agencies, and is integrated with other child, youth and parenting programs within Congress. An important part of CYATS is the level of engagement by the team with the families.

Contextual Background

24. In traditional times, Aboriginal people's access to the land and its resources ensured that they were healthy and that those who needed were cared for by networks of kin. However, the processes of colonisation including the

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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. This includes both high levels of disability and extreme rates of incarceration.

25. Given this context, any approach to addressing the needs of Aboriginal people with disabilities must recognise, in addition to the rights under the United Nations Convention on the Rights of Persons with Disabilities, the rights to self-determination of Aboriginal peoples as established under international treaties to which Australia is a signatory, as well as the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP), which Australia endorsed in 2009. Articles 22 and 23 which are particularly relevant, state that:

Particular attention should be paid to the rights and special needs of ... persons with disabilities in the implementation of this Declaration. [Article 22]

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. [Article 23]

26. Congress initiated CYATS in 2018, in response to the prevalence of developmentally vulnerable Aboriginal children in the communities we serve. The establishment of CYATS was given further impulse by the roll-out of the NDIS and the fact that there was a very low rate of diagnostic and treatment services for children with developmental delay in Central Australia. Prior to the NDIS it was arguably unethical to screen for developmental delays as there was little or no effective support for families once a diagnosis had been made. The NDIS has turned this on its head and it is now not acceptable for primary health care services to not maximise the screening of all children for developmental delay through the ASQ-Trak and refer children vulnerable on two or more domains for

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an Early Childhood Early Intervention (ECEI) plan which can provide initial treatment and a more comprehensive assessment. Typically, an ECEI plan lasts for 12 months (but, in the context of COVID, there has been flexibility for plans to last for up to 18-24 months); following this period, a review provides the opportunity to undertake a more comprehensive assessment to gain further evidence to increase supports if the child meets diagnostic requirements. Other outcomes of this review might include that the plan continues as is to further support the child's developmental outcomes, or their progress is such that they can come off their plan.

27. Congress would suggest that the lack of multidisciplinary, comprehensive assessment and diagnostic services in Alice Springs prior to establishing CYATS in 2018 would absolutely mean that there are young people and adults in our community who have been denied opportunities and the supports they deserve as a result of not having been diagnosed and appropriately treated for neurodevelopmental disability in childhood. This is shown by the enormous demand for, and not enough services to provide, comprehensive assessment and diagnostic services. Congress hopes that eventually the demands on our CYATS service will reach a plateau as we catch up on the historical backlog and can work to meet current demand. It is important to note that Congress is working with children and families who experience high levels of trauma, where parents may have limited cognitive functioning which is compounded by the intergenerational impacts of trauma.

28. It has been an ongoing struggle to get a service like CYATS funded. It is currently funded through a number of short-term grants from different funding sources including the Indigenous Health Division (core funding), Territory Families, the NT Department of Health (NT DoH), NIAA and the NDIA. The NDIA does not fund an assessment service and so it has been very difficult to secure and maintain the funding needed for CYATS. Without CYATS children would not then get on to an NDIS plan. Congress believes that the NT DoH has missed an opportunity to be able to fund the necessary assessment services within the

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larger regional ACCHS across the NT by utilising some of the funds that they previously provided into their own Disability Services. These positions have instead continued to exist and are often competing with the NDIS in the service delivery space although there has been a recent move to undertake some assessments.

29. It is of fundamental importance to locate assessment services within ACCHS and Congress argues that this is critical. Reasons for this include the relationship built on trust that ACCHSs have with the community, along with cultural responsiveness which, in such a sensitive area, is vitally important. In addition, our ability to recruit the specialist workforce is key with the NT DoH unable to recruit a neuropsychologist and this position is critical to the assessment team.
30. The main goal for the NT and all state governments should be to ensure that all children and youth have access to the appropriate assessments which can then trigger the required funds through the NDIS for service delivery when needed. It is not too late to change this and it could become the major source of funding for CYATS services in all of the regional centres of the Northern Territory.
31. A more recent opportunity to get this vital assessment service properly funded came with the NDIA tender for assessment panels. Congress was advised by Dan English, the then NT based manager for the NDIS, that we would be able to tender as part of this process for “assessment panels” which fund the work of our CYATS service. When the tender guidelines emerged, the criteria ruled out a service like Congress applying as it had to be a service over multiple LGAs and the time allowed for assessments was not possible in the context of Aboriginal children and young people as well as other barriers. We were not able to submit and were advised that if a national tender was awarded that was not able to service Central Australia the NDIA would come back to negotiate with Congress.
32. Dan English advised once the successful national tender was awarded to a Perth based HR company that they appreciated that this organisation would not be able to meet our needs and they would come to negotiate with Congress. This

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did not occur and Dan English became yet another key person in the NDIA to move on. This is the first issue addressed in our letter to Minister Reynolds of May this year (Attachment 1). Congress has received no response, despite a reminder send on 5 July 2021, which was responded to by a Ministerial office staffer, who advised that the correspondence was forwarded to the Minister's office. Despite this assurance, we still have not received a reply.

Aboriginal children with disability in out-of-home care

33. In Congress' view it is clear that there is a strong link between poverty and inequality, trauma, adverse childhood experiences and involvement with the child protection system. Congress actively advocates for governments to commit to action that will reduce poverty and inequality by addressing the social determinants of health.
34. The impact of overcrowded housing is significant for Aboriginal communities, including here in Alice Springs and Central Australia. Housing conditions are a key social determinant of child neglect.
35. Other social determinants of child neglect include: parental alcohol and other drug (AOD) use; domestic and family violence; parental mental health; family resources including parental educational attainment; and social and community networks.
36. Harmful alcohol use by parents and carers is a key risk factor for child neglect and is known to be associated with a lack of responsive care and stimulation in early childhood. Congress has been a strong advocate for decades on population-level alcohol supply reduction reforms that work to reduce preventable alcohol related harms. The Northern Territory has been implementing a range of evidence-based measures, and early indications suggest that these combined measures are beginning to show large declines in child neglect. Alcohol use in pregnancy is causally linked to FASD and the combination of prenatal alcohol exposure and lack of responsive care and

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stimulation can certainly lead to problems with neurodevelopment in young children which, left unaddressed, can result in cognitive and emotional disability.

Assessments and diagnoses of disability of First Nations children in out-of-home care

- 37. It is Congress' experience that disability is under-identified and/or under-diagnosed in Aboriginal children, including those in out-of-home care. Until Congress established the CYATS team in 2018, this type of assessment and treatment service did not exist in Alice Springs. Another key requirement is to effectively screen all children under 7 for signs of developmental delays using a validated tool known as the ASQ Trak. This is a key role for the primary health care system and is now especially important as children with evidence of developmental delays are eligible for an ECEI plan which then gives resources for treatment and a more in depth assessment to occur.
- 38. For many years now Aboriginal community controlled primary health care (PHC) services have been undertaking child health checks which is a Medicare claimable preventative health check. This health check has always included a clinical assessment of developmental delay but until the ASQ-Trak tool was developed there was not a rigorous, objective way of undertaking these assessments with a tool specifically validated for Aboriginal children.
- 39. The ASQ-Trak is now being delivered as part of the child health check by Congress and some other primary health care services. If children are below normal on two out of the five domains in this assessment, they are eligible for an ECEI plan which is very significant. However, the referral to the NDIA needs to include an assessment of the functional impairment that the child has and not only the ASQ-Trak scores. This is additional work for the PHC staff but, with templates and training, is not overly difficult to do. However, there is not the level of systematic trainings and support needed in all of this to ensure it is being well implemented across the primary health care system. Many children with developmental delay will respond well to interventions and do not have an

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underlying neurodevelopmental disorder but all need to receive a response and the NDIS can provide this if the system works well. Children also need a more in-depth assessment to find out whether they do have an underlying neurodevelopmental disorder. This type of population level screening for developmental delay is the key first step to ensuring that all children eligible for support from the NDIS are being identified.

40. This is difficult, however, to implement well in a climate where Central Australia has the greatest workforce crisis it has ever seen. Between Congress and the NT DoH remote clinic sites, primary health care services are short 37 nurses at the moment across Central Australia and the turnover is very high. In this context, it is not possible to ensure that child health checks are being performed at an acceptable level and that nurses and Aboriginal Health Practitioners in particular are sufficiently trained and supported to undertake the ASQ-Trak assessment. This is the most significant barrier to identifying children eligible for the NDIS in Central Australia.
41. When children are identified early with developmental delay and functional impairment they can access the early supports they need through the NDIS without the need for any type of specific diagnosis. With the right supports many children will improve and not go on to be diagnosed with ASD, ADHD and other neurodevelopmental conditions which means only the children who really have these underlying conditions are diagnosed and this is not usually until the children are a little older at age 7. Without this early intervention, which can be funded now through the NDIS, many more children will unfortunately reach threshold for a diagnostic label.
42. Broadly speaking, it is Congress' experience across the range of programs we deliver to children and families that most of the time, families are relieved to receive a diagnosis for their child. Families usually already know that their child is different; receiving a diagnosis can be empowering as it can provide relief along with extra resources and support. For parents and caregivers of a child

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with disability, there is often the worry of ‘what will happen to the child when I’m not here?’ With a diagnosis, there comes a formal relationship and connection to services for the child and their family that can provide a sense of relief and support for parents.

43. Prior to Congress establishing CYATS, children were sometimes being labelled with a diagnosis that was not as a result of a comprehensive assessment. Subsequently, the diagnostic label was not accompanied by recommendations for treatment and at that point, the NDIS was not yet operational. Now, with CYATS, there is a holistic approach where a diagnosis also comes with the appropriate, evidence-based supports.
44. Through its thorough assessment process, CYATS have also been able to remove (or correct) suggested diagnoses (e.g. suspected FASD) that may have been made by a clinician who did not have access to the appropriate assessment tools.

Barriers to assessment and diagnosis

45. Congress fundamentally believes that services targeted to Aboriginal children and families should be delivered by Aboriginal community-controlled organisations. Aboriginal community controlled organisations have a range of interlinked structural advantages in delivering such services and hence see improved outcomes compared to non-Indigenous services, whether government or private. The advantages of the ACCHS model include:
- **A holistic approach to service delivery**, including through addressing the social determinants of child and family wellbeing, based on a lived understanding of the Aboriginal concept of health.
 - **Culturally secure services**. Aboriginal community-controlled health organisations are able to provide their care within a culturally secure setting, based on local knowledge, an Aboriginal governance structure and workforce, and strong relationships with the communities that they serve.

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- **Better access, based on community engagement and trust:** a strong practice of community engagement founded on strong relationships with the community, in turn based on a sense of ownership and history. Aboriginal people consistently prefer to use Aboriginal organisations such as ACCHSs over mainstream services giving them a strong advantage in addressing access issues.
- **Aboriginal governance:** individuals and communities are encouraged and enabled to participate in decisions on service delivery, including through formal governing Boards.
- **An Aboriginal workforce:** community-controlled services are significantly better at attracting, training and retaining Aboriginal staff leading to greater cultural appropriateness of services as well as benefits through providing employment and capacity building in the Aboriginal community.
- **High levels of accountability.** Aboriginal community-controlled services are highly accountable to their funders through robust data collection and a reporting regime which is above the requirements of mainstream health and wellbeing services.

Lack of culturally appropriate and trauma-informed assessments

46. Congress agrees that Aboriginal people perceive disability differently to western culture and has attached the statement we have done to explain this at the request of the funding agency for Individual Capacity Building grant (Attachment 2)
47. Congress firmly believes that ACCHSs are best placed to undertake diagnostic assessments for Aboriginal children and young people. ACCHSs are trusted by the Aboriginal community and ACCHSs are (and are required to be) accountable to the communities they serve. As a service delivered by Congress, CYATS provides assessments that are culturally appropriate and trauma informed.

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48. Congress emphasises that the key to its model is the Aboriginal Family Support Worker position within the team. CYATS could not undertake this work without this role which provides critical cultural brokerage between families and clinicians.
49. Due to its placement within an ACCHS, our CYATS team are able to elicit different and more in-depth and accurate information from families than the level of information that mainstream service providers might receive from or about the same family. Often families carry a distrust of mainstream services but have a greater, more trusting relationship with an ACCHS such as Congress.
50. Congress, as an ACCHS, also has a deeper understanding of disability within the Aboriginal family and community context. In our experience, there is found to be a more tolerant approach to 'difference'; families are more accepting of making allowances and are inclusive of children. Families are good at adjusting for impairment in the Aboriginal community context and there is a 'village' approach to caring. This is consistent with the Aboriginal concept of 'health', which refers to *'not just the physical wellbeing of an individual but refers to the social, emotional and cultural wellbeing of the whole Community in which each individual is able to achieve their full potential as a human being thereby bringing about the total well-being of their Community. It is a whole of life view and includes the cyclical concept of life-death-life'*.¹

Better practice models of diagnostic assessments for First Nations children and young people

51. Congress initiated CYATS in 2018 as a best-practice, evidence based service to address the prevalence of developmentally vulnerable Aboriginal children in Alice Springs. This service is the first of its kind in the Northern Territory. It is founded on a strong partnership with Alice Springs Hospital paediatrics and other

¹ National Aboriginal Community Controlled Health Organisation, 'Aboriginal Community Controlled Health Organisations (ACCHOs)': <https://www.naccho.org.au/acchos>.

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health and education agencies, Territory Families, and is integrated with other child, youth and parenting programs within Congress.

52. The CYATS program currently has a waitlist of 120 children/young people with an estimated waiting time of 12-18 months.
53. As noted above, critical to the success of the team is the Aboriginal Family Support Worker position, which has a key role in providing cultural brokerage between families and clinicians. The Aboriginal Family Support Worker understands our families' cultural context and the pressures on and challenges faced by children and families in our community.
54. Congress has worked hard to stabilise the funding model for the CYATS program. The program was initiated through seed funding from the Commonwealth Department of Health, facilitated by the FASD National Consortium (Telethon Institute and PATCHES paediatrics). Building on the seed funding, which was able to pay part of the salary of a neuropsychologist (a key component for a FASD diagnosis), Congress successfully applied for funding from several different sources including NT Government departments and the National Disability Insurance Agency. Maintaining ongoing funding for the program was a challenge, with the program's future looking uncertain in 2019 as the Australian Government component was set to cease at the end of that year.
55. CYATS is now funded by several sources, including the Indigenous Health Division from core funding, the NT Government (Territory Families; Alcohol and Other Drugs), the NIAA, and the NDIA / NDIS, which includes both grant funding and funds derived from fee-for-service delivery. Whilst these funding agreements have different lengths/end dates, the program funding is relatively secure until at least 2023.

Impacts of lack of assessments and diagnoses

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56. Diagnosis as a result of comprehensive assessment provides children and families with access to supports which, importantly, includes access to NDIS-funded supports and services.
57. Access to timely diagnostic services is key. If families are not able to access comprehensive assessment services in a timely way before their child turns six, then it can be too late. It is accepted that there is a 24-month period between the ages of three to five years old; prior to three years old, it is generally only very extreme impairments that can be diagnosed.

Access to supports and services

Early intervention

58. 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. At birth only 25% of the brain is developed but by age four 92% is fully developed and the final maturation occurs in the late teenage years. Children need stimulation and positive relationships with caregivers to develop the neural systems that are crucial for adult functioning. 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 has already been set. This is key to Congress' concerted focus on early childhood development and early intervention.
59. In Alice Springs and Central Australia, high levels of disadvantage have a significant effect on child development and disability. Too many Aboriginal children are growing up in an environment marked by poverty, substance abuse, family violence, loss of a significant carer, lack of responsive care and stimulation, with low levels of formal education and school attendance coupled with economic marginalisation and social exclusion. Aboriginal people in Central Australia have a lower mean individual income; lower rates of school completion to year 12; low rates of employment; and a higher proportion of babies born with

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low birthweight. This is all set out in our written submission to this Royal Commission (September 2020).

60. The impact of such high levels of disadvantage can be seen in measures such as the Australian Early Development Census (AEDC) where the results for 2015 show that by the time they start school, Aboriginal children in Alice Springs are six times as likely to be vulnerable on two or more developmental domains, and 60 per cent of Aboriginal children in the region are developmentally vulnerable on at least one domain.
61. With such a clear link between high levels of disadvantage and the prevalence of developmental vulnerability, Congress continues our advocacy to all levels of government on action that addresses the social determinants of health. Access to programs and services that support development and provide enriched care for all families, and especially those families experiencing disadvantage is critical.
62. Congress undertook an independent evaluation of our Nurse Family Partnership program and this was able to demonstrate a very large impact on the prevention of child neglect and child removal compared to matched controls, especially for first time mothers (Attachment 3).
63. The harms caused by alcohol consumption must also be discussed as these harms are completely preventable. Parental alcohol dependence is a major cause of child neglect and developmental disability. Early evidence is suggesting that the NT alcohol firms have contributed to a very large reduction in substantiated child neglect in the Northern Territory.
64. Addressing the consumption of alcohol amongst all women of child-bearing age and their partners is the key primary prevention approach to reducing developmental disabilities caused by alcohol consumption.

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65. Congress' primary work with children and families aims to prevent Aboriginal children and families, including those with disability, from becoming involved in the child protection and out-of-home care system from the outset.
66. Congress believes it is critical to strengthen families. We do this by working with highly vulnerable families through well-established, evidence informed programs that focus on primary and secondary prevention. Quality childhood development programs are a key, cost-effective intervention to address and offset the effects of adverse early childhood development. Such programs are proven to support social, communicative, physical and emotional development. This flows on to improvements in long-term health, education and employment outcomes for young children from disadvantaged families.
67. Congress has developed our suite of early childhood development programs and services in a way that removes barriers – inasmuch as possible – for families to be able to access them. This includes embedding a bicultural approach across our programs and services for children and families, providing transport to increase opportunities for access, and having a flexible, family-led model of delivery. For example, our CYATS and Children and Family Intensive Support Service (CaIFS – incorporating Targeted Family Support Services [TFSS] and Intensive Family Support Service [IFSS]) are not restricted to the physical location of the service but can operate flexibly to meet families in settings where they are most at ease.
68. Within our CaIFS program, working in bicultural pairs combines the skills and knowledge of both workers to build an understanding of family functioning in both the formal world and informal world. Caseworkers bring particular skills in negotiating and understanding the formal world of the family, while Aboriginal Family Support Workers bring extensive knowledge and skills in understanding the informal world of the family and a particular understanding of the cultural context. Moreover, Aboriginal staff with language skills are integral to family engagement and success of this service, as with other Congress programs.

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69. This approach is effective in improving engagement with children and families, improving outcomes for families and contributes to a high level of worker satisfaction and increased staff retention. This is critical in the child protection context. As a testament to the success of this program, **only seven** children have been removed from their parents through a child protection intervention, out of close to 100 families that the service has provided intensive support to over the last six years.

The role of ACCHSs in primary and secondary prevention of disability and supports for children with disability

Congress' multidisciplinary approach

70. As noted throughout this statement, Congress operates a range of evidence-informed, culturally appropriate early childhood development programs that are integrated into our model of comprehensive primary health care. Congress' key early childhood and family-focused programs and services are outlined below:
- The **Australian Nurse Family Partnership Program (ANFPP)** is a sustained home visitation program that promotes healthy development in pregnancy and early childhood. The focus of the ANFPP program is on the primary carer of the child, usually the mother. The ANFPP aims to improve pregnancy outcomes, improve child health and development and improve parents' economic self-sufficiency. The mother is visited, from no later than 28 weeks' gestation until the child is two years of age, by the same Nurse Home Visitor and Aboriginal Community Worker throughout the program, in order to build and maintain strong, trusting relationships. An independent evaluation of this service at Congress from 2009 to 2015 has shown that this service has had a major impact on reducing child protection involvement and days in out-of-home care, increasing birth spacing, reducing nutritional disorders such as childhood anaemia, and reducing hospitalisations for injury. These benefits are reported in the long term studies of the nurse

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home visitation model that was developed by Professor David Olds in the USA over the last 30 years.

- A **Child Health and Development Centre**, *Arrwekele akaltye-irretyeke ampere*, referred to above.
- A 55-place **long day care centre** for children from working families which also incorporates an Abecedarian approach with the limits of its funding model.
- A **Preschool Readiness Program**, which provides targeted interventions to up to 10 children between the ages of 3.5 to five years old who have been identified as having developmental delays, or who come from families experiencing vulnerabilities or disadvantage. The program helps children and families to prepare for preschool, whilst providing intensive support across developmental domains such as fine motor development, gross motor development, speech, receptive language and expressive language. An independent evaluation found that responsive supports provided by this program was able to reduce barriers to participation for Aboriginal children.
- The **Congress Children and Family Intensive Support Service**, as noted above.
- 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. The ASQ-TRAK is a developmental screening tool for observing and monitoring the developmental progress of Aboriginal children at two, six, 12, 18, 24, 36 and 48 months of age. It is based on seven questions from the Ages and Stages Questionnaire which were adapted to be more culturally appropriate for Aboriginal children and families.

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- **CYATS**, as noted above. .

The NDIS

71. Congress would suggest that because of the lack of availability of comprehensive neurodevelopmental assessment services prior to the establishment of our CYATS program in 2018, there would still be a significant cohort of children, young people and adults who were not able to access appropriate assessment and diagnosis and would therefore be missing out on NDIS services and supports. There is certainly an unmet need for adult diagnostic services; whilst Congress does have an adult neuropsychologist (part-time) there are other components of an assessments as is illustrated by the CYATS model.
72. Through the work Congress has done in assessment and diagnosis over the last three years (and into the future), we would hope that these children and young people will be set up with the supports they need to carry them into adulthood. Added to this is our hope that through working with families across a range of domains, including assessment and diagnosis of neurodevelopmental disability for those children who need it, that involvement with child protection and out-of-home care will be prevented as much as possible. As noted above, and through independent evaluations that have been made on our Children and Family Intensive Support Service (IFSS and TFSS), our model works and should be invested in especially within Aboriginal community controlled health services.

Early Childhood Early Intervention

73. Congress has been involved in negotiations with the NDIA since 2017 to provide better access to one of the most critical services that is needed in the primary prevention of disability in children – this is our Child Health and Development Centre. Initially, we were advised that Central Australia along with Darwin would be the two NT sites for Early Childhood Early Intervention Partnership grants.

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After years of negotiation on this issue Congress was on the verge of receiving a funding grant at around \$28 000 per child for the ongoing funding of our Child Health and Development Centre in Alice Springs as well as the establishment of a new centre in Ntaria (Hermannsburg). The critical correspondence in relation to this are attachments 4, 5 and 6 (including the sub-attachments under attachment 6). This all fell through with the departure of Lizzie Gilliam and the arrival of Dan English. This was also elevated to the NT Aboriginal Health Forum to which the NDIA's Deputy CEO (Markets, Government and Engagement), Lisa Studdert, was invited. Both Lisa Studdert and Dan English attended an NTAHF meeting in early 2021, where the issue of these ECEI Partnership Grants and, more fundamentally, how to make the NDIS work better for Aboriginal children, was raised – to no avail. Following this, we were advised that there were no longer going to be any ECEI Partnership grants and we would need to get individual children individual access to ECEI plans based on assessment demonstrating developmental delay and functional impairment. It then took more than six months to work up a transparent and effective assessment and referral process for this but it has now started to work well.

74. In Congress' experience, there has been a significant improvement – starting from a very low base - by the NDIA to support children to accessing the ECEI. Congress now has 40 children aged 0-6 years on NDIS plans. We are finding that in many cases, children are now very quickly having access met (in some instances as fast as within 24 hours) however there are still significant delays in planning, where there can be delays of up to 6-8 weeks for planning meetings to commence. We understand the reasons for these delays are essentially due to not enough NDIS planners, particularly in remote regions such as Alice Springs and Central Australia. We would suggest that a way to address this issue is that NDIS could provide an interim plan for children in remote regions, which would include a baseline of funds that could be immediately available to commence treatment/therapies. The package could then be reviewed and adjusted as necessary, however critical time is not lost in the process of waiting for a formal

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planning meeting and the child is immediately funded to be able to start receiving support services.

75. Recently there has been further clarity provided around the evidence required to access NDIS, with ASQ-TRAK screening results now being accepted as evidence. This is a really positive step in the right direction. ASQ-TRAK is a tool that can be used by a range of practitioners (including doctors, nurses, child health nurses, early childhood educators, Aboriginal family support workers) and across a range of settings, making it an accessible and effective screening tool.

Post-NDIS plan support

76. Access to allied health services, in general, is poor. This is a problem not limited to children with disability in out-of-home care. Generally speaking, Australia's allied health workforce is unequally distributed and the rate of allied health professionals is the lowest in remote and very remote areas, compared with major cities. In Congress' experience, there are limited services and long wait lists. This is not a reflection on the referrer or of families' needs, there simply is not an adequate supply of allied health professionals to meet demand.
77. In Congress' experience, there may be some delays for children in out-of-home care in accessing services through Territory Families (usually related to something minor such as timeliness in getting signatures from guardians) but this is not significant.
78. Congress understands that Territory Families now has a specialist outreach disability team that consults to the Territory Families workforce across the NT. The establishment of this team, in Congress' view, has shown improvements in the previously observed lack of experience in disability within Territory Families.
79. Congress would comment that culturally appropriate care through an NDIS plan is dependent on the presence of Aboriginal community controlled organisations operating within the NDIS provider market.

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80. Through the transition of NT Government disability services that were provided through the NT Office of Disability to the NDIS, Congress has observed that there has been a reasonably flexible transitional period to ensure that children are not worse off under the NDIS.

Outcomes when children are not provided with timely and appropriate interventions

81. Congress knows that prevention is key. Over the last 20 years, the community-elected Congress Board of Directors has focused on improving the developmental outcomes of Aboriginal children. Our comprehensive range of evidence-based programs and services, delivered through a model of culturally-appropriate primary health care, aims to break the cycle of disadvantage at every stage.

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Date: _____

Witness: _____

Date: _____

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