

Statement of Amelia Paterson and Hannah Blaine, Central Australian Aboriginal Congress

Name: Amelia Paterson

Address: 21 Gap Rd, The Gap, NT 0870

Occupation: Paediatric Clinical Neuropsychologist

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. I make this statement on behalf of Central Australian Aboriginal Congress and I am authorised to do so.

Professional background

3. I am currently one of the paediatric clinical neuropsychologists at The Central Australian Aboriginal Congress (Congress). I have been in this role since September 2019. I am an endorsed clinical neuropsychologist and board approved neuropsychology supervisor. I am experienced in the assessment of neurodevelopmental disorders in Aboriginal children.
4. Prior to working at Congress I worked for NSW Health as a clinical neuropsychologist.
5. In my role as paediatric clinical neuropsychologist, I work as part of a multidisciplinary team conducting neurodevelopmental assessments for children and young people. My work tends to be with older children, up to 18 years of

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CONTINUED STATEMENT OF: Amelia Paterson & Hannah Blaine, CYATS
Team, Central Australian Aboriginal Congress Aboriginal Corporation

age. My team leader is Gayle Simpson, and our team is part of the broader,
Child Youth and Family Services division of Congress.

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Name: Hannah Blaine
Address: 21 Gap Road, The Gap NT 0870
Occupation: Paediatric Clinical Neuropsychologist
Date: 17 September 2021

6. 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.
7. I make this statement on behalf of Congress and I am authorised to do so.

Professional background

8. I am currently the Paediatric Clinical Neuropsychologist of Central Australian Aboriginal Congress. I have been in this role since November 2020. I am an experienced Clinical Neuropsychologist, with a Masters of Clinical Neuropsychology from the University of Melbourne. I have been practicing in the profession for six years, and specifically working in the area of child development since 2018.
9. Prior to working at Congress, I worked for Queensland Health in the Child Development Service, predominantly in the Fetal Alcohol Spectrum Disorder Clinic as a Senior Clinical Neuropsychologist.
10. I am currently working in the Congress Child and Youth Assessment and Treatment Service. This is a multidisciplinary team that provides neurodevelopmental assessment for children aged 0 to 18 years. My role predominantly involves diagnostic neuropsychological assessment, either in isolation or as a part of the wider team. I report to the CYATS Team Leader, Gayle Simpson.

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Central Australian Aboriginal Congress

11. Congress is an Aboriginal Community Controlled Health Service (ACCHS) which provides comprehensive health services for Aboriginal people in Central Australia. It is the largest Aboriginal community-controlled health organisation in the Northern Territory, providing a comprehensive, holistic and culturally-appropriate primary health care service to Aboriginal people living in and nearby Alice Springs.
12. Congress is 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, Congress has developed a comprehensive model of primary health care that includes:
 - a. Multidisciplinary clinical care,
 - b. Health promotion and disease prevention programs, and
 - c. Action on the social, cultural, economic and political determinants of health and wellbeing.
13. 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.

Child and Youth Assessment and Treatment Service

14. Congress' Child and Youth Assessment and Treatment Service (CYATS) is a best-practice service for the early detection of neurodevelopmental conditions such as FASD, ADHD and Autism Spectrum Disorder (ASD), and applies a multidisciplinary approach to diagnostic assessment, early intervention, and

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support for families to access the NDIS. It has been operating since its establishment in 2018, and provides neurodevelopmental assessment, diagnosis and treatment for children and young people aged 0-18 years. 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.

15. CYATS operates with a small team that currently comprises the following positions:

- Team Leader
- Neuropsychologists (x 2)
- Speech pathologists (x 2)
- Occupational therapist (x 2)
- Clinical case coordinators (x 2)
- Aboriginal family support worker (x 1)
- Paediatrician provided in partnership with Alice Springs Hospital

Aboriginal children with disability in out-of-home care

16. In Congress' experience, there is no pattern that is specifically related to neurodisability of Aboriginal children being placed into a particular out-of-home care setting. Our observation is that Aboriginal children are generally placed into foster family placements. Patterns of placement might relate more specifically to age or sibling groups; sibling groups might have a higher rate of placement into residential care but we would suggest this is more likely related to keeping siblings together, and not related to disability.

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

Identification of disability for First Nations children with disability in out-of-home care

17. It is Congress' experience that disability is under-identified and/or under-diagnosed in Aboriginal children, including those in out-of-home care. The CYATS team is still frequently seeing children in out-of-home care at age 10-14 years old, and sometimes up to 17 years old who may have never had an assessment or comprehensive assessment that would have been appropriate to their circumstances. That is, these children having been placed in out-of-home care during their childhood have already gone through many years of early development - and whilst in out-of-home care - without having been assessed.
18. CYATS data shows that the age range in which there are the highest number of diagnostic assessments are in the 10-12 year old age group.
19. Both these points illustrate the lack of diagnostic services available in Alice Springs prior to the establishment of CYATS in 2018.
20. It is important to note that there is no equivalent service for remote communities so for children who have spent their lives living out bush, or living transiently between town and bush, they are also not likely to have had the opportunity to access comprehensive assessment services.
21. In regard to labelling, academically there is a concept of Aboriginal clinicians considering that diagnostic labels are pathologising. In the experience of the CYATS team, working one-on-one with families, this is not found to be a primary concern for the families for whom we provide assessments. When the process of a multi-disciplinary assessment is undertaken through an Aboriginal community controlled health service such as Congress, we find that there is an acceptance of a diagnosis by families as it helps them to better understand their child's behaviours. Families are given choice at every stage of the assessment process

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so, generally speaking, CYATS does not see a push-back from families about the labelling of a diagnosis. From the outset, the CYATS team is transparent about the assessment process and the questions that may be asked throughout, so that at the end of this process it is not a surprise for families when it leads to a diagnostic label. Likewise, if a potential diagnosis changes throughout the assessment process, families are brought in to be included as part of these conversations. CYATS considers all aspects of a child's life throughout the assessment process, including home/family life and school. This means the process is family-led, holistic, multifaceted and grounded in context for the child and their family.

22. The CYATS team will also make a decision about whether or not an assessment (and the use of associated testing tools) is appropriate for a child given their context (e.g. language/s spoken, school attendance, time spent in an urban setting). For example, for a child who is primarily exposed to an Aboriginal language/s and lives in a remote community who may then come into town and has low attendance at school, it would likely not be appropriate to undertake an assessment. In this scenario, we would be testing what the child does not know / has not been exposed to rather than their true abilities with the tests currently available. For this reason, there is a process of in-depth thinking and formulation about whether a child should go through an assessment and highlights the importance of context. It is also important to note that resistance to assessment may be a common response by any family who is undergoing the diagnostic process with their child; this is not limited to Aboriginal families.
23. In regard to health checks for children entering out-of-home care, Congress would point out that a health check is not the appropriate mechanism to diagnose disability. Rather, health checks may provide opportunity to identify whether there is a developmental delay that requires a comprehensive assessment, and to make the appropriate referrals. Congress has a straightforward referral process from our clinics into CYATS, the Child Health and Development (CHaD) service, paediatrics and the child development team.

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Availability and accessibility of assessments

24. Congress would suggest that for Aboriginal children in out-of-home care, Territory Families are not routinely getting kids to health checks as a baseline (or routine) process. If Territory Families do get kids in for a health check, often the child is not going with someone who knows them well or who is familiar with that child's history.
25. Having said that, Congress would like to acknowledge that there have been significant improvements with Territory Families in recent years. We acknowledge that we are all working in this space for the same reason – that is, to see the best outcomes possible for the children and families in our community. Congress has built rapport and respect in order to develop a collaborative, reciprocal relationship with Territory Families. At an operational level, Congress works with Territory Families to support caseworkers and build their knowledge that Congress is a comprehensive, quality service. Wherever possible, Territory Families caseworkers are involved in the process and journey of assessment and diagnosis for children in their care. Congress has found that developing a collaborative relationship with Territory Families at a management level, whilst there is often a turnover of caseworkers, the leadership will ensure that there remains a flow of information to support these positions. It is also acknowledged by Congress that demand exceeds supply for Territory Families as well, and caseworkers are often required to take on a high workload and the statutory nature of Territory Families means it is not an option for them to implement a wait list.
26. The CYATS team has received feedback that for children and young people involved in the youth justice system, that there is variability in the way that assessments are provided when young people are transported between facilities. Congress understands that there is generally a preference for the CYATS assessment to be undertaken.

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Barriers to assessment and diagnosis

27. In terms of barriers to accessing assessments and diagnosis, Congress provides CYATS as a free service. The referral pathway is very straightforward and there is a clear understanding of the things that need to be done and the associated timeframes. For a free service such as Congress CYATS, which is for 0-18 year old children and young people there is a waitlist of 12 to 18 months. Whilst it is not ideal to have a waitlist, when compared to other much larger, single-diagnosis and age-limited services in larger regional and metropolitan centres, Congress is doing reasonably well in comparison. The CYATS team is much smaller in comparison to other services in metropolitan centres. Additionally, CYATS provides assessment for all neurodevelopmental issues as well as acquired injuries (e.g. stroke, traumatic brain injury); essentially, CYATS is a smaller service with a much broader scope than what is usually seen in other jurisdictions.
28. To provide further context, currently there is an assessment waitlist for CYATS of 120 children/young people (that equates to about 12-18 months). This includes both non-Territory Families and Territory Families children/young people. Currently, there are low numbers of Territory Families children on the CYATS waitlist (13 children in out-of-home care on waitlist) and Congress understands there are still some kids in out-of-home care (25 have been identified) who have not been referred for assessment. Congress understands that there is some data-matching work being done by Territory Families of children/young people who have been seen by CYATS and provided with a diagnosis, and those in out-of-home care who have not yet been referred for assessment. This is to address the issue of low numbers of referrals on the waitlist.
29. Since 2018, CYATS has assessed 84 children/young people in out-of-home care; some of these children/young people have received a diagnosis and others have not met criteria for diagnosis.

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30. Congress regularly fields requests to accept referrals from remote children and families living in communities where the primary health care service is not operated by Congress (that is, the clinic is operated either by the NT Government or another Aboriginal community controlled health service). Whilst CYATS does accept referrals from remote communities where Congress operates the clinic (that is, Ltyentye Apurte/Santa Teresa, Ntaria/Hermannsburg, Wallace Rockhole, Utju/Areyonga, Mutitjulu and Amoonguna), there is no scope to be able to service these children so these referrals remain on the waitlist, as families may move between bush and town and there may be scope to provide an assessment if this does occur at a later time.
31. Congress understands that the Alice Springs Hospital have made considerations for a neuropsychologist to accompany the child health specialist outreach visits to undertake child assessments, but it is understood that they have not been able to secure a service provider to undertake this work. Likewise, it is understood that school-based psychologists and allied health providers are endeavouring to provide a similar service to Congress in order to alleviate demand, with agencies actively trying to troubleshoot how best to service children and families in remote communities. Congress understands this work to be in its early stages.
32. To increase accessibility of CYATS assessments, Congress believes that our flexible approach is key to the model. The assessment process is not confined to the clinic, meaning that the CYATS team is able to be responsive to families' needs and meet families where they are at. In addition to this, CYATS does not have a 'failure to attend/discharge for service' if families do not attend appointments. This is in recognition that what is culturally appropriate for families may not necessarily be what works best for therapists – Congress has adapted our model to support and be led by families and their needs and priorities.

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Lack of culturally appropriate and trauma-informed assessments

- 33. Broadly speaking, there is often a focus on the assessment tools rather than the expertise of the clinician. Congress considers that it is much more beneficial to focus on the training, expertise and openness of the clinician, than on the 'perfect' tool. Adjusting the clinician is much more achievable, especially in fostering an openness to listening to families and community.
- 34. 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.
- 35. Key to Congress' CYATS 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.
- 36. Congress understands that the 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. Differences are likely to be seen in responses to questions on matters such as current worries and concerns, or prenatal alcohol exposure.
- 37. Congress, as an ACCHS, also has a deeper understanding of disability within the Aboriginal family and community context. In Congress' experience, there is found to be a more tolerant approach to 'difference' (for example functional impairment) in the families we work with; 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 relevant when considering kinship placements for out-of-home care rather than Aboriginal children being placed with non-Indigenous families.

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38. Trauma is always considered and always sits alongside diagnostic thinking within the CYATS assessment process. CYATS clinicians will actively seek information about a child's history and takes a lifespan approach to assessments. In Congress' experience, this level of information is not readily provided by Territory Families; the CYATS clinical case coordinator plays a key role in gathering this information prior to an assessment, to allow for any adjustments of assessments to be made accordingly.

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

39. Congress believes that CYATS delivers evidence-based best practice. The service provides clients with what they need throughout the process, and the information provided during the assessment and diagnostic process will accompany children and adolescents throughout their lives. In theory, these assessments will never need to be repeated.
40. Congress considers that covering all allied health disciplines within the assessment process is important. Isolated or piecemeal assessments leave families with missing pieces of information, whereby the child may be given a label without understanding the story. All the information related to an assessment must be integrated. For families, being able to know and understand what difficulties cause what behaviour helps to provide a comprehensive picture.
41. Congress operates CYATS in a multidisciplinary model, as recommended by the *Australian Guide to the diagnosis of FASD*¹. A child or young person receives a full assessment, supported by an Aboriginal Family Support worker, working within the context of an Aboriginal community controlled health service.
42. As noted above, the CYATS program currently has a waitlist of 120 children/young people which equates to a wait time of, on average, 12-18 months. Since becoming operational in 2018, the CYATS team are still

¹ Accessed from: <https://www.fasdhub.org.au/fasd-information/assessment-and-diagnosis/guide-to-diagnosis/>

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addressing the assessment demand that has existed for the last decade or longer; there will come a point in time where the team will be able to focus on current demand having completed the historical backlog.

Impacts of lack of assessments and diagnoses

- 43. For children in primary school, when an assessment is not provided early enough the child’s behaviour and responses to their behaviour becomes a concern for everyone involved. Too often these children are labelled as naughty, defiant and oppositional, which impacts on their mental health and their perception of themselves. This extends beyond health and education and into justice. It is critical for all who are involved in the care of a child to have an understanding of their diagnosis early on. Families are impacted when a child’s behaviour is deflected to being a family issue that a family is not taking care of their child, rather than being seen as a family that needs education and support. Congress has observed failed family reunifications because there has been a lack of understanding of a child’s needs as they have not been assessed; this is setting families up to fail if the supports are not there. Any child who is diagnosed with disability requires equitable access to the supports that they should be entitled to.
- 44. Within the youth justice system, it is Congress’ experience that it is common to see undiagnosed disability that is pathologised as ‘bad’ behaviour. This becomes a perpetuating issue when children are losing connection and access to family, culture and community that carries into adolescence; these young people, along with the challenges of undiagnosed disability, also have questions about their identity which are reflected in their behaviours.

Access to supports and services

- 45. In regard to developmental delay and cognitive disability, the CYATS team notes that it is *developmental delay* that can be diagnosed early (that is, at a young age). This does not mean that there is no disability, however the child needs to reach an age where average ability is at a stage where a disability can be

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diagnosed. For a child with developmental delay *only*, early intervention provides greater opportunity to remediate this through intervention. For delays across several areas of development, early intervention is most effective within the child's first five years.

- 46. Having said that, enriching environments more broadly are important. Access to programs and services that support development and provide enriched care is important. There are systemic challenges that families face, including housing and the resources for carers to provide an environment that supports child development; additionally, the availability of early childhood learning centres to cater for children, including those in out-of-home care is a systemic barrier. Congress has observed that access to childcare and early learning centres is particularly difficult for children who are in kinship care arrangements.
- 47. Access to appropriate prevention and early supports does reduce the risk of children being placed in out-of-home care. However families need to have a strong voice – they need to know who to ask and what to say to be supported.
- 48. Causal pathways for cognitive disability are not just dependant on early childhood experiences. However children are at higher risk of being diagnosed if they do not have enriching early experiences and early intervention.

Reasons for removals

- 49. The CYATS neuropsychologists have observed that 'neglect' is often listed by Territory Families as being a reason for child removal, however they are generally not privy to the greater detail about the neglect and what it entails.
- 50. Disability contributes to a higher level of need and a child with disability requires a higher level of supervision. If a family does not have the resources or access to supports, this may be perceived as neglect and increase the risk of removal, however generally CYATS is not seeing this as the direct cause of removal. Families face many challenges around the social determinants of health and

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Congress acknowledges that there are many organisations and agencies working to overcome these barriers.

Care criminalisation

51. For young people in detention, Congress' data suggests the vast majority (83%) would have an undiagnosed or inaccurately diagnosed neurodevelopmental disorder and often these young people have previously had involvement with Territory Families. Congress would certainly agree that there are young people being criminalised for their disability whereby they cognitively could not understand the severity and consequences of their behaviour.
52. Congress would suggest that our data mirrors the findings of the Bower² study of young people in youth detention in Western Australia, which found that almost 90 per cent of young people assessed had at least one domain of severe neurodevelopmental impairment, whilst 36 per cent received a FASD diagnosis.
53. In saying this, Congress would also note that our assessments are adjusted for cultural purposes and in consultation with families; that is, diagnoses need to fit

² Bower C, Watkins RE, Mutch RC, et al. Fetal alcohol spectrum disorder and youth justice: a prevalence study among young people sentenced to detention in Western Australia. *BMJ Open* 2018;8:e019605. doi:10.1136/bmjopen-2017-019605

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within the context for the child. If the diagnostic criteria were strictly adhered to, Congress suggests there would be an even higher rate of diagnosis.

54. CYATS has completed assessments for 23 young people in detention or under court orders.

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