

*This is an addendum to my joint statement with Dr John Boffa signed 17 September 2021. It contains the full text of a statement I wished to read out during my oral evidence to the Disability Royal Commission on 20 September 2021. This statement is made in my capacity as CEO of the Central Australian Aboriginal Congress.*

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I would like to begin by acknowledging the Central Arrernte traditional owners of the land on which we are giving evidence here today and pay my respects to their elders, past, present and emerging.

Thank you for the opportunity to make a brief opening statement in which I want to highlight 3 key areas from our statement that I think are vitally important.

The **first** and most important area is to ensure that all Aboriginal children with developmental delay under the age of 7 are detected as early as possible and then quickly get on to an Early Childhood Early Intervention Plan so they can receive the extra support they need as well as a more comprehensive assessment.

After 4 years of struggle I am pleased to say that over the past few months about 40 Aboriginal children who are Congress clients are now accessing these plans and getting the support they need to give them the best chance of returning to a pathway of healthy development.

It is the role and the responsibility of the primary health care system to make sure that all children are screening regularly at different ages using a validated tool known as the ASQ – Trak. This can be done in about 45 minutes by appropriately trained Aboriginal health workers and nurses and it is the gateway into the NDIS for children who need it. The majority of Aboriginal children in Central Australia are yet to be assessed using this tool and if they have been assessed are yet to be referred for an ECEI plan. The challenge is to put in place the systems that make sure this is being done at a population level for all Aboriginal children who present to health services regularly throughout their early years.

The **second** key issue is the need to ensure that there is the capacity to undertake comprehensive multidisciplinary assessments for children who need this based on what is now considered the best practice model developed by Congress in our Child and Youth Assessment and Treatment Service or CYATS.

Of the group of children with developmental delay some will have more serious underlying neurodevelopmental disorders and these need to be diagnosed as soon as possible as well. This is the next level of assessment for a much smaller group of children following population screening. It is often not possible to make a formal diagnosis of a disability until children get closer to the age of 7 but in the most severe cases it is possible to make a diagnosis earlier. At present there is no Commonwealth or state or territory funding agency responsible for funding these vital services.

A recent national tender process by the NDIA to fund “assessment panels” was so structurally flawed that it was never going to fund a service like CYATS. The NDIA undertook to come back and negotiate with Congress as it was accepted that the new national service cannot assess Aboriginal children in a culturally safe way but we are yet to hear back from them.

Children and young people who do get a diagnosis are then getting on to substantive NDIS plans that give them the best chance to live a normal life. Without these assessments this would not be happening and children and young people in need would not access the very scheme that is there to meet their special needs.

The **third** and final issue I want to highlight, is the key need to establish secure care rehabilitation facilities for young people with neurodevelopmental and other disabilities so we can get them out of detention centres once and for all. In the submission from the Congress neuropsychologists it is clear that most young people in detention are in this category and the NDIS needs to find a way to fund the longer term, secure, therapeutic care that these young people need based on successful models from other parts of the world such as the Diagrama model. This could be done in partnership with the NT government and would address one of the key recommendations of the Royal Commission into the Protection and Detention of Children in the Northern Territory.

You may have noticed that all of the 3 key points I have made are in relation to children and young people. Of course access for adults with disability to the NDIS is also vitally important but there is a real opportunity for the NDIS to transform the life story of many disadvantaged children if we can get the early childhood and youth services right and this is where there is the most potential for benefit that is yet to be realised.

Signed: \_\_\_\_\_

Date: 23 September 2021