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Submission to the Joint Standing Committee on the National Disability Insurance Scheme inquiry into independent assessments.

AusDoCC[1] is a national grassroots charity, founded in 2012 to support people affected by a disorder of the corpus callosum (DCC) and their families. We support people through addressing the lack of recognition, knowledge and services and the reduction of the isolation felt by people with a DCC. As a rare and 'invisible' anomaly, people with a DCC and their families often face many hurdles in accessing support and being understood. We, representatives of AusDoCC, offer this submission into the implementation and performance of the NDIS with some key recommendations.

A disorder of the corpus callosum (DCC) is a congenital neurological anomaly classified by the atypical development of the corpus callosum. Comprised of around 200 million nerve fibres that connect the left and right hemispheres of the brain, the typical corpus callosum is involved in the coordination of cognitive, sensory and motor information. For approximately 1 in 3000 people, this structure does not develop at all, or grows in an unexpected way; thicker, thinner, a different shape or with partial absence. If a person is born with a DCC, the corpus callosum will not later develop, and there is no treatment to correct the anomaly.

People with a DCC have a variety of strengths, abilities and challenges. A DCC may be a person's only or main congenital anomaly, but it can also present with other anomalies or as part of a syndrome. There are many known genetic causes for DCCs and some environmental causes, that can help explain some differences among people, but often a cause won't be found. For many people, a DCC is their primary diagnosis or condition that they have to explain and understand their disabilities, even if they are subsequently diagnosed with other health challenges or disabilities as they age.

People with a DCC who seek support under the NDIS have a permanent disability that is attributable to neurological impairment and can result in substantially reduced functional capacity, thereby meeting the NDIS access requirements.[2] The NDIS provides people with a DCC with "the reasonable and necessary supports they need to live an ordinary life".[3]

Many people within our DCC community have become distressed by the news of the coming independent assessments. We thank the committee for recommending this inquiry and the opportunity to share the concerns of our community. Some of these overlap with our prior submission made to the committee late 2020 when we initially heard of the significant and detrimental changes planned.

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[1] www.ausdocc.org.au
[2] https://www.ndis.gov.au/about-us/operational-guidelines/access-ndis-operational-guideline/access-ndis-disability-requirements
[3] https://www.ndis.gov.au/about-us/operational-guidelines/overview-ndis-operational-guideline/overview-ndis-operational-guideline-about-ndis#4.3

Our key recommendations for the committee are provided below, followed by an explanation of these key recommendations.

Key recommendations

The committee should **acknowledge**:

- The needs of people with a rare and invisible disability, such as a disorder of the corpus callosum, may be overlooked in a single cross sectional assessment with an unknown person,
- The implementation of mandatory independent assessments fails to provide choice and control for the participant – which was a hallmark strength of the NDIS,
- People with a disability deserve the right to choose who completes any assessments or write reports about them and they maintain the right to view and edit this personal documentation,
- Annual independent assessments with unknown assessors are burdensome and potentially retraumatising.

The committee should make **recommendations** to:

- Cease the roll-out of compulsory independent assessments,
- Engage participants and disability advocacy organisations to co-design a suitable way forward.

We will provide our explanation for our recommendations using the terms of reference

the development, modelling, reasons and justifications for the introduction of independent assessments into the NDIS

Within their submission to this inquiry, DSS and NDIA noted that the reforms being introduced will deliver an NDIS that empowers participants and provides choice and control along with flexibility. [4] However, the implementation of mandatory assessments with a stranger where a score dictates funding levels and the person has no ability to see, confirm or challenge the information gained, is the **absolute opposite** of what we would consider empowerment, choice and control or flexibility.

The justification of reducing the participant's burden of obtaining reports is shortsighted as the burden has been confounded with uncertainty and the anxiety that comes with needing to be heard in one single session. A gruelling three hour session with a stranger talking about all the things you can't manage without support, simply can't be considered less burdensome than asking professionals you know and trust to write a report about your current circumstances. If the roll out was to help those potential participants who do not have providers to write reports, then it is a wasteful endeavor when simply funding those individuals separately would have sufficed.

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[4] Submission 13: DSS & NDIA joint submission, Independent Assessments, March 2021

From our understanding, the real justification for independent assessment is about cost cutting – and this must be significant cost cutting considering that the implementation of comes at a significant cost. Our understanding also aligns with the NDIA strategic plan acknowledging that independent assessments is a measure to meet the goal of financial sustainability.

We draw your attention to the NDIS CEO report to the Council for Economic Development Australia:

> The NDIS was born out of the drive to "do better" almost ten years ago.
>
> Before the NDIS, funding for disability support would go to an organisation. As a person with a disability, you might not have had any choice about which organisation gave you support. You might not have had a say in who supported you and how. Support was capped, inequitable and dependent entirely on where you lived. [5]

We are disappointed that these words and this vision was temporary and the NDIS will be transformed into something with capped funding based upon your mandatory assessment undertaken with a stranger, with no choice. We return to inequitable supports when we focus solely on impairment and functioning through standardized assessments and pay no attention to the persons goals, circumstances and informal supports.

We are greatly concerned about the feedback from participants who have moved through the pilot program, in particular those who have been retraumatised through the gruelling and intrusive process. We also worry that the inadequate data that NDIA has offered to date is incomplete and biased. We are aware that some participants are being paid to enter the pilot programs, and wonder how this may be influencing their feedback. The complete lack of transparency related to the pilot program is a concern. All data and methods of collection should be made available, opposed to cherry picked statistics provided without context.

> **the independence, qualifications, training, expertise and quality assurance of assessors;**

As DCCs are rare, there is inconsistent knowledge among different service providers. Many providers have no knowledge of DCCs, and how to support a person with the anomaly, this leads to uninformed opinions. While the suggestion is that independent assessors will focus on function not diagnosis, without the underlying knowledge of the participant and the impact of their DCC, the assessor **will not** gain a complete picture of the person, their strengths and challenges. This process will then induce risk.

> **the appropriateness of independent assessments for people with particular disability types, including psychosocial disability**

The neuropsychological syndrome that is associated with disorders of the corpus callosum becomes more apparent as the demands on a person increase. This neuropsychological syndrome is characterised by "reduced interhemispheric transfer of sensory-motor information; reduced cognitive processing speed;

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[5] https://www.ndis.gov.au/news/4413-ceo-address-council-economic-development-australia#:~:text=The%20economic%20impact%20of%20the,care%20for%20have%20adequate%20support.

and deficits in complex reasoning and novel problem-solving”. [6] These features can limit a person’s understanding or their ability to respond with complete and correct information in one setting.

A person’s needs can therefore be easily overlooked in a quiet single session assessment. Long term therapeutic relationships with trusted providers allow the time and holistic approach to see the participant beyond numbers on standardised form and allows a thorough, informed view of their strengths, abilities and challenges. This information will not be ascertained through a session with an independent assessor.

The independent assessments have potential to cause harm. Many adults with a DCC have suffered from burn out. As they often have an invisible disability they are often not afforded the same accessibility considerations of people with a visible disability. Those adults with visible disabilities and DCCs can have their DCC overlooked. Parents of young children with a DCC are repetitively forced to share their information to gain the supports their child needs, whether at school, workplace accommodations, afterschool activities and beyond. People are exhausted. We thought NDIS was going to mean less paperwork, less burden, less judgement, less repetition of telling your story to strangers. But the implementation of independent assessments will bring that back to the foreground. We do acknowledge that many adults and families have significant anxiety already in relation to NDIS reviews, but at the very least they have their providers to offer support and recommendations. We do agree with making systemic improvements, but only those that are co-designed with people affected by those changes.

We believe that independent assessments, implemented in a mandatory capacity, will be detrimental for the DCC community. If this was optional, we would potentially support aspects of the implementation as we understand there are some benefits for people who don’t have long-term providers. However, people with a disability are more than a number on a standarised form. It is worrisome to see a return to the attempt to put people into standarised boxes and the changes have already triggered distress and mental health concerns among the disabled community.

The NDIS has provided such needed support to many within our community. We forward to opportunities to engage with the NDIS in relation to independent assessments. NDIS presents a major opportunity towards improving the lives of people with a disorder of the corpus callosum, and we value a genuine commitment to community engagement and co-design.

We thank you for this opportunity to feedback to the committee, and we will be available should you require further information.

With thanks,

The AusDoCC Committee and Community
AusDoCC: Australian Disorders of the Corpus Callosum

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[6] Brown, W. S., & Paul, L. K. (2019). The neuropsychological syndrome of agenesis of the corpus callosum. *Journal of the International Neuropsychological Society, 25*(3), 324-330. https://doi.org/10.1017/S135561771800111X