

Submission
No 260

**INQUIRY INTO IMPLEMENTATION OF THE NATIONAL
DISABILITY INSURANCE SCHEME AND THE PROVISION
OF DISABILITY SERVICES IN NEW SOUTH WALES**

Organisation: Royal Institute for Deaf and Blind Children

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Royal Institute for Deaf and Blind Children

Inquiry into the implementation of the National Disability Insurance Scheme and the provision of services in New South Wales

Submission to

Portfolio Committee No. 2 Health and Community Services



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Submission summary

Royal Institute for Deaf and Blind Children (RIDBC) is pleased to make this submission to the PLACEHOLDER.

In this submission, RIDBC responds to items b, c and h of the terms of reference, namely:

- b. the experience of people with complex care and support needs in developing, enacting and reviewing NDIS plans,
- c. the accessibility of early intervention supports for children; and
- h. the challenges facing disability service providers and their sustainability,

RIDBC has the capacity to provide further information on a wider range of issues and would welcome the opportunity to provide any further information that may assist the Inquiry.

In summary, RIDBC submits that the Inquiry should consider and/or make the following recommendations:

1. That the NDIA ensure that Planners have a general understanding about different types of disability and that specialist teams or expertise is utilised for types of disability that require specialist knowledge such as sensory disability.
2. That the NDIS interface with mainstream services is made clearer at an operational level and that this information is publically available.
3. That the NDIA develop and provide clearer guidelines on early intervention eligibility criteria and access for families, Providers and referral agencies.
4. In order to ensure that evidence based outcomes can be achieved, planning and associated packages for NDIS participants should be reflective of evidence based practice where it exists.
5. That the NSW Government develop an alternative funding mechanism for services previously funded for its residents through disability services that are not eligible for funding through the NDIS.

About Royal Institute for Deaf and Blind Children

Royal Institute for Deaf and Blind Children (RIDBC) is Australia's largest non-government provider of therapy, education and cochlear implant services for children and adults with vision or hearing loss, their families, and the professionals that support them.

Our Mission is to provide quality and innovative services to achieve the best outcomes for current and future generations of Australians with vision and/or hearing loss.

We pride ourselves on working in collaboration with families, children and adults to tailor services that support and fit individual needs and life goals.

Services for children, adults, families and professionals:

- Assessment and diagnostics
- Early intervention and early learning programs
- Specialist preschools, schools and school support
- Therapy and re/habilitation services
- Audiology and cochlear implant services
- Research, postgraduate and professional education.

SCIC Cochlear Implant Program, an RIDBC service, is Australia's largest and most comprehensive cochlear implant program, setting new benchmarks and delivering the highest level of care and support at every stage of the cochlear implant journey.

RIDBC Renwick Centre conducts world-leading research and provides continuing professional education and postgraduate courses in a range of fields relating to the development and education of children with hearing or vision loss.

RIDBC services are provided to over 8,000 people from eighteen permanent sites across Australia, and by working remotely in rural and regional areas.

As a charity, RIDBC relies heavily on fundraising and community support to continue to make a difference in the lives of people with vision or hearing loss.

For more information about RIDBC, visit www.ridbc.org.au.

Response to the Terms of Reference

This submission addresses 3 specific issues in response to particular terms of reference (b, c and h).

1. The experience of people with complex care and support needs in developing, enacting and reviewing NDIS plans;

Current NDIA processes are having a significantly negative impact on participants receiving timely access to plans and subsequent access to essential services, despite evidence that correlates early access to specialist services and longer term outcomes. The scope of supports provided to participants in their Plans is highly variable despite similarities in needs and the substantial evidence available regarding the inputs required to achieve speech and language goals for hearing impaired participants. Plans developed by planners with little or no experience in disability have resulted in a lack of support to participants. Planner knowledge is highly varied, as is their understanding of the interface arrangements with mainstream services, and the interpretation of reasonable and necessary supports.

Avenues for resolving disputes for both participants and providers are not clear, adequate or readily accessible. Specifically, it is difficult to contact NDIA as besides the 1800 number, there is no direct link for participants to speak to Planners, and calls to the 1800 number are generally not returned. Minimal feedback is provided to explain decisions, and if someone is not eligible or does not have something funded there are no alternatives provided. This is disadvantageous to those who may have had this support previously funded under state block funding. The cost impact of this has the potential to impact on service providers or the participant.

As a provider of assistive technology for hearing services through our cochlear implant program we have been providing upgrades for implants and other accessories to improve functional capacity for many of our clients. Our clients' experience with the process for approval of their Assistive Technology is variable with some clients having everything they request included in the Plan; and others having to provide assessments and quotes for a reasonable and necessary determination. The documentation for the recommendation of assistive technology is onerous and is resulting in delayed access for assistive technology due to the additional workload associated in providing this information to the NDIA. These reasonable and necessary decisions are inconsistent despite participants with similar hearing impairment and functional capacity. Similarly the lack of understanding by planners around the interface of the Scheme with mainstream services, such as Australian Hearing, has caused confusion with participants, who are unclear about the types of services that are provided and funded through NDIS funding.

Recommendations:

That the NDIA ensure that Planners have a general understanding about different types of disability and that specialist teams or expertise is utilised for types of disability that require specialist knowledge such as sensory disability.

That the NDIS interface with mainstream services is made clearer at an operational level and that this information is publically available.

2. Accessibility of early intervention supports for children

Up until the introduction of the NDIS, families were guided through the journey to access all the services required to realise a return on investment. Families who are in a high level of shock and grieving are now left to navigate a highly complex service environment and are unable to gather relevant information to make informed decisions that will have a lifelong impact on the development of their children. These long term impacts are across all elements of society including, but not limited to, education, health and employment.

As families await access to the NDIS and development of a Plan, early intervention providers are delivering services without receiving payment, as previous funding arrangements have been phased out. NDIA planning and funding are not responsive to the urgent need for access to specialist service providers and the critical therapy required by children recently diagnosed with hearing loss and their families.

The Early Childhood Early Intervention (ECEI) eligibility criteria for early intervention will ensure scheme entry opportunities for children currently receiving support which was previously funded through state based funding. However, it is suggested that this criteria is poorly understood by families who are now directed to ECEI partners in the first instance, as opposed to the NDIA which was the pathway established during the NDIS trial and early rollout. Previous referral pathways enabling access to mainstream services for diagnostic assessments have also been disrupted as referral agencies are now directing children to ECEI partners. As a specialist provider for children with hearing and or vision impairment RIDBC continues to provide supports to children who are yet to access NDIS funding through partners.

As children transition to the NDIS and receive funding for a lower level of support, Providers are having to fund the shortfall through charitable contributions or children are receiving less intervention. For the purposes of ensuring the ongoing viability of high quality programs, decisions regarding service provision and funding should require that funded supports are consistent with international best practice and are demonstrably able to meet the needs of children with a hearing or vision impairment. RIDBC submits that there can be no single approach to early intervention that is applied to all families under all circumstances. Significantly, on an increasing regularity for children with multiple diagnoses, there is a complete lack of understanding of the multiple interventions required and the impact of sensory deficit on the usefulness of other therapies. Effective early

intervention involves rigorous assessment of children's and families' needs and the provision of programs that seek to match those needs.

Recommendation:

That the NDIA develop and provide clearer guidelines on early intervention eligibility criteria and access for families, Providers and referral agencies.

3. Challenges facing disability service providers and their sustainability;

The Royal Institute of Deaf and Blind Children has been providing NDIS supports to clients in NSW since the NDIS trial phases in 2013 and early transition in 2015 through to full Scheme rollout in 2016 - 2017. Access to the Scheme has been delayed and we continue to support large numbers of clients who are yet to transition through the provision of quality evidence based early intervention.

Determining the funding provided through NDIS for supports is difficult as participants / families have discretion as to what they choose to disclose, with NGOs on the whole providing services to ensure children are not disadvantaged and achieve their optimal outcome. In our experience service agreements with NDIS Participants are generally in the order of 40-50% of the actual direct service delivery costs of specialist providers' evidence-based, multidisciplinary ECEI services which have a demonstrated ability to consistently produce high-level language development, communication, education and whole-of-life outcomes for children who are deaf or hard of hearing. Despite the significant evidence supporting the positive outcomes associated with comprehensive transdisciplinary early intervention programs, the current NDIS sessional reimbursement model fails to recognise the actual costs of validated and effective comprehensive transdisciplinary early intervention programs.

The low level of public resources made available to agencies providing comprehensive transdisciplinary early intervention services, results in a reliance on charitable fundraising in order to prevent passing on additional costs to families, or market failure as a result of service closures. The shift from block funding to individualised NDIS Plans has impacted on Provider cash flow.

Australia's indigenous communities are known to have amongst the world's worst ear disease particularly otitis media that results in hearing loss that impact significantly on a range of social determinants including education, employment incarceration, and mental health. RIDBC has for over a decade been funded by the NSW Government to provide a range of hearing screening initiatives to indigenous populations across NSW. This critical program managed to establish local community connections and buy in that made significant contributions to good ear health for the populations served. RIDBC has been advised that this funding will no longer be available as all NSW ADHC funding had been invested as NSW contribution to the NDIS. Obviously the NDIS is not in a position to fund

population screening for the state's most at risk populations. While this is likely an unintended consequence of the NSW Government's transition to NDIS, it is an issue that needs to be addressed and a funding mechanism for non NDIS eligible programs previously funded by ADHC needs to be developed ASAP.

Similarly, RIDBC has been funded to provide an alternate format production (AFP) service for children who are blind or have low vision. The service is world renowned and collaborates with both NSW Government programs to develop literacy resources for children across NSW to an incredibly high standard. The low volume highly resource intensive requirements of the program do not fit an NDIS funding model and in reality cut across so much more of the life journey than the disability needs of children and young people across NSW being able to access recourses that develop and maintain literacy. As with the indigenous hearing screening program, ADHC funding has been incorporated into the NSW NDIS contribution. Without a reliable source, the viability of this world renowned service is unlikely. The impact for children and young people and their families across NSW will be significant and will impact on the literacy of children who are blind or have low vision for generations to come. While the impact of this on the NSW and Australian economy can be measured and will be significant, the impact on children and their families is immeasurable, but avoidable.

Recommendation:

In order to ensure that evidence based outcomes can be achieved, planning and associated packages for NDIS participants should be reflective of evidence based practice where it exists.

That the NSW Government develop an alternative funding mechanism for services previously funded for its residents through disability services that are not eligible for funding through the NDIS.