Submission to the JSC–NDIS inquiry into hearing services under the NDIS

Cora Barclay Centre response to the latest NDIA advice re planning and funding for DHH children under the NDIS

Submitted by:

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[redacted]

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Introduction

Australia is an acknowledged world leader in the field of hearing and language development services for children who are deaf or hard of hearing (DHH).

This is due to:

(1) its ***comprehensive, national, evidence-based framework*** for the identification, referral and management of hearing loss in children;
(2) its ***70 year commitment to continuous improvement of services and outcomes*** through research, development and training (e.g., the National Acoustics Laboratory/Australian Hearing, Cochlear Ltd, the Macquarie Hearing Hub, the Hearing CRC, and the research programs of universities and First Voice centres etc; and
(3) its expert services (including Australian Hearing) and distinctive ***family-centred, multi-disciplinary early intervention model*** for developing speech and language in DHH children – developed and delivered through about 10 highly specialised providers including the 5 Australian First Voice centres, RIDBC and a number of (rapidly disappearing) smaller services.

The result of the above has been ***extraordinary children's speech, language, education, social and employment outcomes*** as demonstrated by the annually published outcomes data of 600+ children in First Voice member centre progams and recent survey results of reported outcomes for young DHH adults now aged 18-28 years.

Unfortunately, the transition of children's hearing and language services to the NDIS has caused a wide range of serious problems in relation to eligibility; scope and duration of services; referrals; and planning and funding inconsistencies and delays that are threatening children's outcomes and the financial sustainability of specialist providers.

Attempts to resolve these problems over the past 3 years have failed, causing service cuts and 'market failure' with forced mergers of both larger (Taralye, Victoria **[1 Feb 2018]** and the Cora Barclay Centre, SA **[imminent]** and smaller specialist providers. If participant funding - *that actually flows through to specialist providers* - is not increased immediately, more services will fail. NSW providers appear the most vulnerable due to the rapid roll out of Full Scheme in that State.

In the 6 months prior to Christmas 2017, positive developments on funding and referrals appeared imminent in the form of:

1. a new planning tool [HIP-Q] and increased funding levels (reference packages); and
2. new ECEI referral arrangements including the recommendation (from the JSC-NDIS and sector representatives) that Australian Hearing be engaged by the NDIA as its agent for managing referrals and planning for DHHin children.

The Cora Barclay Centre is deeply concerned by recent NDIA advice (8 February, 2018) indicating it does not intend to proceed with any of the above based on an analysis by the Scheme Actuary and (presumably) its disinclination to institute special ECEI access arrangements for a particular diagnostic group such as DHH children and their families.

This submission is provided to facilitate discussion at the coming JSC public hearing on 7 March 2018 in Sydney, and beyond.

1. RE NDIA ADVICE ON *IMPROVED PLANNING AND REVIEW PROCESSES*

The NDIA proposes to strengthen planning and referral for DHH children through a number of internal measures including: (1) increased quality assurance on plans; (2) some involvement of NDIA technical officers; (3) a heavy emphasis on increased staff training.

Cora Barclay Centre Response

Cora Barclay Centre does not believe that the proposed measures will be adequate in either the short or long-term; for the following reasons:

- NDIA reliance on generic planners and delegates in a highly specialised field that they do not understand;
- the large number and varied backgrounds of NDIA planners and ECEI agents across Australia who will need significant and ongoing training. Our crude estimate is that there will be 700 or more ECEI access planners across Australia;
- the contracting out of ECEI access planning poses problems in contract monitoring and compliance and is likely to result inconsistencies in participant funding. Staff turnover will exacerbate this issue;
- planning and funding consistency issues will be compounded by the fact that hearing loss is unique in that it is a “hidden” disability; demand is small (currently 3.5 % of 0-6 year olds), and the NDIA does not have an ‘investment-outcomes’ based model for funding early intervention but determines funding for all participants on a ‘deficit model’ based on the level of functional impairments at the time of planning.
- The NDIA ‘deficit’ funding model does not work for DHH children. ***Most babies with hearing loss have no functional impairment at the time of their first plan***; they simply have a hearing loss. However, this can quickly translate into major functional impairments and disabilities (e.g., in communication, learning, social. Emotional and mental health) if not managed in accordance with the COAG-endorsed clinical pathway and if the child does not receive timely, specialist early intervention.

Recommendation: that the NDIA engage Australian Hearing as its national agent to manage referrals, planning and advice on participant funding.

2. RE NDIA POSITION ON FUNDING FOR DHH CHILDREN

Based on a literature review, analysis of scheme data and an analysis of HIP Q data on 220 participants, the NDIA has advised its intention to abandon the HIP-Q and reference packages as the means for determining participant funding and to use the audiological information from Australian Hearing in conjunction with the generic PEDI-CAT planning tool.

The main reason given is that the HIP-Q is not sufficiently robust or consistent with the NDIS principles of reasonable and necessary support to be a reliable indicator of support needs for children with a child. This is particularly so with the proposed Key Risks to Outcomes (KRO) factors.

In terms of the quantum of funding for DHH children the Actuary’s report notes that (1) there is nothing in ‘the literature’ to indicate what may be appropriate funding levels and (2) that many plans for children with HI are not fully utilised (perhaps suggesting that even current levels of funding may be excessive).

Other points of note in the Actuary’s report are:

- **children with HI generally have a lower funding than other disability groups which “is not surprising given the very high needs of some children in the scheme (including intellectual, physical and neurological disabilities)”**)
- **parents frequently exercise choice re how plan funding is used for their HI child;**
- **the Agency does not intend to publish reference packages but will continue to update them along the way.**

Cora Barclay Centre Response

Cora Barclay Centre is deeply concerned at the NDIA's decision not to proceed with the implementation of the HIP-Q and reference packages, as expected, for the following reasons:

- this approach was expected to immediately improve funding and reduce financial pressure on specialist providers. This is urgently needed to prevent further service cuts and closures;
- instead there appears to be a risk of funding being reduced still further below service delivery costs due to participant under-utilisation of current funding;
- KROs are clearly relevant in determining funding and should be retained;
- the sector had played a significant role in the development of the HIP-Q/reference package approach and believed that it promised greater transparency and greater consistency in funding. This is clearly not the case;
- the NDIA's advice indicates that it does not yet grasp the need for an 'investment-outcomes' funding model for EI programs with reliable, proven outcomes and proven cost-benefit;
- the NDIA continues to ignore the concrete proof of Australia's extraordinary outcomes for DHH children as evidenced by 10 years of speech and language assessment from 5 of Australia's leading specialist providers (of which more below).

Recommendation: that the NDIA immediately institute short term measures to increase funding to families of DHH children and work with the sector to co-design an NDIA "investment-outcomes' funding model for early intervention programs with proven outcomes and cost-benefit.

OTHER COMMENTS

1. Re participants' under-utilization of funding

Cora Barclay Centre believes that the failure of participants to fully utilise their funding is a widespread phenomenon in the NDIS and particularly so in children's early intervention services.

We believe this is something that is not yet understood by the Agency, providers, advocates and participants and requires considerable further research and analysis before it should be allowed to influence participant funding in any way.

At the coal face, the most relevant factors in under-utilization of funding appear to be:

1) ***NDIA portal*** **problems** including:
   i. major delays in payments;
   ii. errors with large numbers of migrated (pre-portal) plans that have still to be remedied;
   iii. the highly transactional nature of the payments system including problems with matching payments with scheduled services;
   iv. provider experience that there may be particular problems with children's plans and trans-disciplinary plans;
2) ***participant inexperience in understanding and managing their funding*** including:
   i. general unfamiliarity and inexperience with the new funding/payments approach
   ii. anxiety about using their funding too quickly; and
   iii. difficulties in tracking expenses with multiple providers who may have different approaches to claiming.

2. Re the NDIA ignoring the evidence of DHH children outcomes in Australia

The NDIA continues to ignore speech and language outcomes data from First Voice (FV) member centres that have been collected routinely for each child in FV early childhood intervention programs *for over 10 years*.

These published data show that – year in and year out – over 70% of deaf and hard of hearing (DHH) children in FV member centre EI programs *routinely and predictably* achieve levels of speech and language that are comparable to those of normal hearing children of the same age.

These data derive from the same internationally-endorsed assessments used by the National Acoustics Laboratory (NAL) in its LOCHI (Longitudinal Outcomes for Children with Hearing Impairment) study. *They are not, and do purport to be, research findings*. They are clinical assessment data collected primarily for the purpose of informing each child's early intervention therapy plan by objectively assessing, monitoring and reporting their progress each year. They are also used by service providers, in consultation with each child's family, to scale down the intensity of services (and therefore costs) when it is clinically appropriate to do this, thereby ensuring that children and families are not over-serviced.

There is absolutely no reason for the NDIA to doubt the validity of these assessment data. Cora Barclay Centre would be pleased to explain the assessments and assessment protocols to the NDIA.

Other outcomes data collected and published by leading providers – e.g., that over 90% of children graduating from FV ECI programs are educated in mainstream classrooms in mainstream schools – are just as valid and easily demonstrated from client records and graduate outcomes surveys.

In regard to secondary schooling outcomes, the Cora Barclay Centre (which maintains contact with many ECI graduates through its student services program), maintains a comprehensive record (provided by families) of students' year 12 results and acceptance rates for tertiary education. These show that over 90% of DHH students supported by the Centre successfully complete year 12 with the majority progressing to tertiary education. This picture was confirmed in the results of last year's survey of graduates from FV member centre ECI programs between 1993 and 2002 (now young adults in the 18 to 28 years age group).

These and other outcomes reports have been provided on numerous occasions to the NDIA over the past four years and seem to have been entirely ignored. As has the findings of the Deloitte Access Economics Cost Benefit Analysis Study (2017) and other similar studies. This is extremely difficult to understand in a Scheme that is based on the "insurance principle" and is committed to evidence-based practices and proven client outcomes.

The importance of these outcomes reports for DHH children is that they underpin our argument that participants who chose specialist, multidisciplinary EI programs with proven outcomes and proven cost-benefit should be funded at a level sufficient to meet program costs.

3. Re the need for an 'investment-outcomes' funding model in the NDIS

NDIS funding is essentially based on assessed levels of functional impairment and disability. This approach is designed to deliver 'reasonable and necessary' funding for adults and children with permanent lifelong disabilities and personal support needs, and to give participants control over the use of those funds.

However this approach does not make sense where the evidence shows that an appropriate investment in highly effective, evidence-based early intervention will deliver life-changing outcomes on a proven, reliable and cost-beneficial basis. Funding in such cases should be on an 'investment-outcomes' basis with the allocated funding covering the (auditable and transparent) costs of the EI program.

Such is the case with children who are deaf or hard of hearing.

At the time of their first presentation to the NDIA, most children with hearing loss will have no discernible functional impairment. They will simply have a hearing loss.

If this is optimally managed, and the child receives appropriate specialist early intervention, the child will typically develop fluent communication (usually speech and language), attend mainstream schools, complete year 12 and achieve lifelong social and economic independence.

Impairment and disability will only manifest if the family and child do not follow the COAG endorsed clinical pathway and do not receive adequately resourced habilitation/early intervention services from a provider with specific expertise in speech and language communication in deaf children.

Furthermore, contrary to the standard NDIA approach, the level of funding required by a family and child to achieve the desired outcomes does not derive from the child's level of hearing loss – it is the product of multiple factors that cannot be accurately predicted at birth and are best assessed (as in all genuine evidence-based medical and educational habilitation programs) by expert members of a multidisciplinary team and not by a generic planner applying a generic planning tool supplemented with the entry audiological information.

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