



## **Submission to the Joint Standing Committee on the National Disability Insurance Scheme**

### **Inquiry into the provision of services under the NDIS Early Childhood Early Intervention Approach**

**From First Voice**

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18 August 2017

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## **ABOUT FIRST VOICE**

First Voice member centres (FV) in Australia and New Zealand provide highly specialised, evidence-based early intervention (ECEI) programs to more than 1,000 children who are deaf or hard of hearing (D/HH). This is one of the largest cohorts of children receiving ECEI services for hearing loss in the world.

FV programs are designed specifically for the development of fluent speech and language in D/HH children and are constantly reviewed and improved in the light of new research evidence and parent/family input. Children and families attending FV member centres typically achieve high-level outcomes in speech, language, education, social participation and employment.

FV accepts children with all degrees of hearing loss across all social, economic, ethnic, cultural and religious backgrounds; for example, 32% of the Cora Barclay Centre's current caseload is families from Culturally & Linguistically Diverse (CALD) backgrounds and the Centre's socio-economic profile reflects Adelaide as a whole.

FV members include some of the world's oldest and most respected organisations specialising in language development and speech for D/HH children.

- Cora Barclay Centre, SA – founded in 1946 - 71 years' experience
- Hear and Say, Qld – founded in 1992 -25 years' experience
- Taralye, Vic – founded in 1968 - 49 years' experience
- Telethon Speech & Hearing, WA – founded in 1966 - 51 years' experience
- The Shepherd Centre, NSW & ACT – founded in 1970 - 47 years' experience

FV and its member centres have enormous knowledge, experience and expertise to contribute to the design, development and implementation of NDIS policy and funding arrangements for children who are D/HH to ensure the best possible outcomes for children and their families.

## **PREVIOUS SUBMISSIONS**

The nature and practice of FV ECEI programs, their rationale, the evidence behind them, their outcomes - and the manifold issues arising from the transition of children's hearing and language services to the NDIS - are described in detail in our previous submissions to the Joint Standing Committee. Our suggested way forward is broadly outlined in the Sector Model (Attachment 2).

Prior submissions include:

1. First Voice, Submission to the Joint Standing Committee on the NDIS inquiry into the provision of hearing services in the NDIS (Jan 2017)
2. First Voice, Supplementary Submission to the JSC – NDIS inquiry into hearing services (March, 2017)
3. The Shepherd Centre, Submission to the Joint Standing Committee on the NDIS inquiry into the provision of hearing services in the NDIS (Jan 2017)
4. The Shepherd Centre, Supp. Submission to the JSC – NDIS inquiry into hearing services (march, 2017)
5. Cora Barclay Centre, Submission to the Joint Standing Committee on the NDIS inquiry into hearing services in the NDIS (16 Feb 2017)
6. Cora Barclay Centre, Supplementary Submission to the Joint Standing Committee on the NDIS inquiry into hearing services in the NDIS (March 2017)
7. The Shepherd Centre, Submission to the Joint Standing Committee on the NDIS inquiry into the provision of services under the NDIS Early Childhood Early Intervention Approach (10 Aug 2017)
8. The Shepherd Centre, Submission to the Joint Standing Committee on the NDIS inquiry into the Transitional arrangements for the NDIS (10 August 2017)

First Voice welcomes the opportunity to make this submission to the Committee on the important matter of early childhood early intervention (ECEI) arrangements under the NDIS. Our submission focuses exclusively on this topic and should be read in conjunction (for comprehensive background information and clinical detail) with the above-listed submissions.

## **SUMMARY & RECOMMENDATIONS**

1. The communication, education, social participation and life outcomes of Australian children who are deaf or hard of hearing (D/HH), whose parents want them to learn to listen, speak, are at significant risk under the NDIS.
2. *Prior to the NDIS*, D/HH children attending specialist listening and spoken language (LSL) early childhood intervention typically achieved communication, education, employment and life outcomes on par with children without hearing loss.
3. Maintaining these outcomes is important not only for D/HH children and their families but also for the long-term financial sustainability of the NDIS.
4. NDIS ECEI arrangements do not support current high-level outcomes. The NDIS needs purpose-designed ECEI policy and funding arrangements based on “investment-outcomes” principles that support and enhance children’s outcomes rather than undermining them.
5. The continuing, predictable achievement of these outcomes requires 3 things:
  - i. adherence to the national (and internationally endorsed) clinical guidelines;
  - ii. service provision at all stages by expert providers specialising in hearing, listening, speech and language development specifically for children who are D/HH;
  - iii. adequate funding from the NDIS to participants that flows through to specialist providers of LSL ECI (and ECEI) programs and services.
6. Not one of the essential requirements above is met under the current NDIS ECEI policy guidelines and funding approach.
7. The situation is now at crisis point as NDIS full scheme implementation is fast-tracked in NSW with an estimated 600 D/HH children to enter the scheme over the next six months with inadequate funding. South Australia is already in crisis due to its location in the NDIS Children’s Trial. The scheme will be progressively rolled out in other states and territories over the next two years.

## **RECOMMENDATIONS**

The problems identified and discussed in this submission would be solved by:

- (1) the appointment of Australian Hearing by the NDIA as the exclusive Early Childhood Partner for children who are D/HH, to be the expert manager of the referral process and advisor on funding levels of children who are D/HH; and
- (2) introduction of a specific-purpose “investment–outcomes” policy and funding model for ECEI as broadly outlined in the Sector Model (attachment 2), in particular:
  - Evidence-based services from accredited providers, and
  - Comprehensive package funding

## ***TERMS OF REFERENCE***

As part of the committee's inquiry into the implementation, performance and governance of the National Disability Insurance Scheme (NDIS), the committee will examine the provision of services under the NDIS Early Childhood Early Intervention (ECEI) Approach, with particular reference to:

- a. the eligibility criteria for determining access to the ECEI pathway;
- b. the service needs of NDIS participants receiving support under the ECEI pathway;
- c. the timeframe in receiving services under the ECEI pathway;
- d. the adequacy of funding for services under the ECEI pathway;
- e. the costs associated with ECEI services, including costs in relation to initial diagnosis and testing for potential ECEI participants;
- f. the evidence of the effectiveness of the ECEI Approach;
- g. the robustness of the data required to identify and deliver services to participants under the ECEI;
- h. the adequacy of information for potential ECEI participants and other stakeholders;
- i. the accessibility of the ECEI Approach, including in rural and remote areas;
- j. the principle of choice of ECEI providers;
- k. the application of current research and innovation in the identification of conditions covered by the ECEI Approach, and in the delivery of ECEI services; and
- l. any other related matters.

## 1. RE THE NDIA'S ECEI APPROACH: AN OVERALL ASSESSMENT

1. **Policy context:** The introduction of the NDIS is a major and complex national policy reform whose focus has understandably been on policies and processes to meet the needs of people with permanent disabilities and lifelong support needs who represent the vast majority of participants in the scheme.
2. **The purpose of ECEI is to start infants and young children as early as possible (and clinically appropriate) on an evidenced-based program that will minimise functional impairment and associated lifelong impacts thereby securing best possible, cost-effective outcomes for the child, family, community and national economy.**
3. **This submission** provides an assessment of current and proposed NDIA ECEI approaches as they apply to children who are deaf or hard of hearing (D/HH) whose parents choose specialist ECEI programs for their child to develop speech and language.
4. **Our assessment** is that the current NDIA ECEI approach does not work for D/HH children choosing speech and language and we welcome the NDIA's commitment to designing new arrangements in collaboration with the sector. However, for reasons outlined in this submission, we believe that currently proposed solutions to problems in referral and funding require further consideration and development to meet the needs of D HH children and their families.
5. **Key areas of immediate concern**
  - 1) referral delays
  - 2) funding delays
  - 3) chronic underfunding of participants
  - 4) administration, reporting and billing arrangements that are time-wasting, undermine children's outcomes and are detrimental to family-centred service delivery.
6. **The current situation**

Children who are D/HH are worse off under the NDIS than before and Australia's leading specialist providers of listening and spoken language ECEI are not financially sustainable.
7. **Underlying Causes**
  - 1) the NDIS's lack of an NDIS "investment-outcomes" early intervention policy and funding model for evidenced-based ECEI programs with proven outcomes and cost benefit
  - 2) the NDIS's apparent lack of understanding of children's listening and language development services and the fundamental importance of speech and language to quality of life and life outcomes

## 2. OVERVIEW: MEETING THE NEEDS OF FAMILIES WITH DEAF CHILDREN

The early stages of the journey for families of newly diagnosed D/HH children are complex and challenging. A broad understanding of their situation is important in determining the best possible ECEI approach for families with newly diagnosed children under the NDIS.

- 95% of children with hearing loss are born to hearing parents
- the vast majority of these families want their child to learn to listen and speak
- one-third of cases are diagnosed at birth, it is an unexpected event, and the shock and grief suffered by parents/families can be profound
- many families need intensive family counselling and support during the first months' post-diagnosis
- in addition, there is a plethora of information and opinion on the Internet, in publications and pamphlets, and proffered as "free advice" (often by relatively uninformed) friends, acquaintances and various service providers
- in these circumstances, parents require extensive specialised support to enable informed decision-making
- a significant complicating factor is the critical importance of timely commencement of specialist ECEI. If this is not appropriately addressed, parents may delay decisions – putting their child's outcomes at risk.

### ***The evidence-based approach***

- The evidence shows that the achievement of optimal speech and language in hearing-impaired children requires:
  - i. the earliest possible diagnosis and referral; (clinical target within **1 month**)
  - ii. earliest possible optimisation of hearing through hearing aids or implantable devices (such as cochlear implants); (clinical target **within 3 months**) and
  - iii. immediate commencement of specialist speech and language ECEI (clinical target **within 6 months**)
- the relevant clinical protocols and guidelines are well documented and endorsed; in Australia through the COAG-endorsed National Framework for Neonatal Hearing Screening; in the USA through the American Academy of Paediatrics Joint Committee on Infant Hearing (JCIH) 2013 Supplement, *Principles and Guidelines for Early Intervention After Confirmation that a Child is Deaf or Hard of Hearing*; and internationally through the Moeller Principles
- the critical factors in these documents are: (1) no delays; (2) expert, evidenced-based service provision at all stages; and (3) accountability in referral management and service provision through accreditation and routine reporting.

### ***What this means for ECEI under the NDIS***

If optimal outcomes are to be achieved the NDIS approach to ECEI for families of newly diagnosed D/HH babies and young children needs to reconcile the shock and grief of the family with the need for rapid referral to specialist speech and language services.

It is evident from the NDIS Children's Trial and elsewhere that generalist NDIA ECEI access partners and planners do not operate within a policy framework that supports timely referral to specialist providers of speech and language programs for D/HH children and are not adequately equipped to manage their referral pathway and determine their service needs and funding levels.

### 3. THE NDIS AND ECEI FOR D/HH CHILDREN 2013-2017

#### Multiple transition issues

From July 2013, significant problems have been evident in the transition of children's listening, speech and language services from the health sector to the NDIS.

Early identified issues include:

- access/eligibility;
- referral delays;
- participant and provider uncertainty on the range, level and duration of ECEI services;
- inter-jurisdictional issues concerning the interface between the disability, health and education sector;
- widely varying and inconsistent decisions on eligibility and participant funding;
- chronic underfunding of families in relation to providers' costs;
- onerous reporting and invoicing/billing issues.

Notwithstanding four years of submissions and discussions - undertaken constructively and with goodwill - and an NDIA Expert Reference Group on children's hearing services under the NDIS since 2015 – no issues have been resolved. The issue of access/eligibility is apparently resolved, given the communication from the NDIA that the CEO had authorised eligibility thresholds for children with hearing loss; however these thresholds have not been published and they are not being used by the NDIS in determining eligibility.

#### The four priority issues

- 1) access/eligibility for D/HH children – *to be confirmed*
- 2) the breakdown in the referral pathway to specialist ECEI providers
- 3) the shortfall in participant funding levels
- 4) NDIA funding and billing arrangements for evidenced-based, outcomes focused ECEI.

**1) Access/eligibility:** This issue has been announced to have been resolved. The decision that was communicated was welcomed by the sector and especially by families with children with lower levels of hearing loss. However it has not been published and as such 'eligible' children are still being refused NDIS plans.

**2) The referral pathway to specialist ECEI providers:** the current NDIA ECEI access partner approach is not suitable for the support and guidance of families with newly diagnosed D/HH children. Some of the reasons for this are set out in *The Shepherd Centre* submission to this inquiry. They include the time and complexity of the NDIS approach and the likelihood of delays in commencement of specialist early intervention for children who are D/HH. Another concern is the generalist nature of the access partner role and consequential lack of knowledge of the imperatives of listening and spoken language ECEI. This not to say that the current NDIS approach may not be appropriate for other childhood conditions.

The NDIS Children's Trial Site experience (mirrored in the population-based trials) is that the lack of an appropriate NDIS ECEI policy and funding framework, combined with generalist NDIA ECEI access partners lack of understanding of hearing loss, results in frequent delays in referral and an increasing number of children taking months or years to find a specialist evidence-based provider with proven outcomes.

These delays put children's communication and life outcomes significantly at risk.



**3) Shortfall in participant funding levels.**

**Problems with the current policy guidelines:**

- Current ECEI policy guidelines are heavily oriented to responding to the needs of children with obvious and measurable physical, intellectual, mental health, behavioural, developmental, and multiple disabilities and impairments. Sensory disabilities are less straightforward.
- The national guidelines – based on a hierarchy of severity of need through assessment of functional impairment - do not readily accommodate the requirements of D/HH children whose condition is unseen and there may be no functional impairment observable at the time of the initial plan.
- The majority of early diagnosed D/HH children do not have additional disabilities and have no functional impairment at the time they join the NDIS - they look normal, and are normal, apart from their hearing loss. The purpose of their early childhood intervention is to assist in the development of normal speech and language, through listening and hearing, thereby *preventing* the development of functional impairment and disability.
- The primary preventative nature of ECEI for D/HH children appears to be different from many other childhood disability conditions where functional impairment is quite evident at the outset and the goal of ECEI is to minimise future impairment and disability.
- NDIA ECEI access partner and planner roles are generalist roles and the needs of D/HH children may be difficult to appreciate in the context of supporting children with other disabilities.
- The experience of many families with deaf children in the NDIS is that NDIA access partners and planners have little understanding of children's hearing loss and frequently query why families are seeking NDIS funding when their child has no measurable functional impairment. **[refer Attachment 1 for a list of reported NDIA staff comments to families. The Cora Barclay Centre is considering a survey of families on their experience of the NDIS registration and planning processes to gather more reliable information on this]**
- There also appears to be a lack of understanding of the critical life impacts of D/HH children failing to develop effective communication capability.
- Another practical factor contributing to the chronic shortfall in participant funding for D/HH children is that NDIS pricing, funding and billing arrangements are unsuitable for complex, multidisciplinary early intervention programs.
- In summary, the national policy guidelines being managed by generalist access partners and planners with little or no knowledge of the impact of hearing loss on communication development in deaf children generally results in low levels of funding far below the costs of evidence-based ECEI programs.
- ***Detailed analysis of First Voice member centres' programs shows that around 30–40% of specialist multidisciplinary team members' time is spent on short, unscheduled, and often informal – but nevertheless important – information sharing, education, diagnostics, monitoring and other such-like activities and interactions that are not recognised by, or billable, under the mainstream NDIS pricing schedules.*** Yet these program delivery characteristics are typical of all such specialist, multidisciplinary programs in the health, education and community development fields.
- However the NDIA is yet to accept their reality in regard to funding and invoicing for ECEI programs for D/HH children and their families.
- Neither does the NDIA appreciate the damage that the highly transactional nature of current funding arrangements inflicts on the efficacy of ECEI programs and the relationship between families and their child's multidisciplinary team.

### Financial Impacts

- Families customarily receive NDIS funded plans that are **\$6-10K per child per year** less than the actual cost of services.
- For every **100 children** receiving specialist LSL ECEI this represents a shortfall to the provider of **\$800K a year**. Estimated annual funding shortfalls under full scheme to each of The Shepherd Centre, the Royal Institute of Deaf & Blind children (NSW & ACT), and Hear & Say (QLD), are in the order of **\$2.5-3M** a year – with losses of over \$1M a year for smaller centres around Australia.
- NDIS funding levels are rapidly undermining the financial viability of Australia's leading specialist centres who will very soon have to cut services to survive. This will put children's outcomes at risk and reduce families' choices if services fail altogether.
- Given the high-level communication, education and employment outcomes achieved by D/HH children under pre-NDIS arrangements – and their proven positive cost-benefit – this is a demonstrable failure of public policy.
- The estimated NDIS cost of **fully funding** services to 0–12-year-old D/HH children is approx. **\$23M a year**. At current NDIA expenditure levels, estimated expenditure is around **\$10M**.
- **Thus, it would cost an additional \$13M a year – in an overall budget of \$22B – for the NDIS to fund all D/HH children in the 0–12 years age group at the desired level.**

### Recent developments

- As discussed above, the major cause of funding problems for D/HH children is the national ECEI policy and funding guidelines that were introduced in August 2015.
- For the last **48 months (2 years)** NDIS funding has been a serious issue for D/HH children, their families and specialist providers. This has caused financial losses to many services but the Cora Barclay Centre in the NDIS Children's Trial Site, which now has over 200 of its 260 caseload in the NDIS, has been particularly hard hit with losses at \$40K per month resulting audited losses of around **\$1.5M** attributable to the NDIS (per the recent SA Government-commissioned audit by Grant Thornton, June 2017). Other specialist centres are now incurring similar losses, with The Shepherd Centre reporting a financial loss of over **\$900K** largely due to the NDIS.
- The NDIA's proposed solution to these problems is *reference packages* for hearing-impaired children. These were first mooted in March 2016 and are now on their third draft iteration. Nothing expected to be decided until late 2017.
- Proposed reference package arrangements for determining participant funding levels include improved pre-plan documentation of client information to assist planners with participant funding levels based on specified therapy hours for different levels of hearing loss plus loadings where relevant for *Key Risk to Outcomes* factors (KROs).
- While the latest iteration of the reference packages are likely to result in increased funding for D/HH participants, and somewhat relieve the current dire situation, sector analysis indicates there will still be a significant funding gap.
- Also, if administered by generalist NDIA planners as expected, they will not address the problem of inconsistent funding levels for D/HH children with similar needs across Australia.
- The underlying problem in the proposed new approach is that it is not based on ECEI "investment-outcomes" principles. Instead it is essentially a modification of the NDIS itemised fee-for-service, pricing and billing arrangements for people with lifelong personal support needs.
- The Sector Model (attached) proposes an alternative 'investment' approach that is as close as possible to the NDIA's current thinking and consistent with the early intervention objectives of the NDIA Act.
- This would see retrospective, pro rata billing against the annual value of the participant's plan, similar to the School Leavers Employment invoicing arrangements (SLES).

**4) Administration, reporting and billing arrangements**

- Current administration, reporting, and itemised service billing arrangements place a very heavy administrative burden NDIS participants and their chosen providers. The estimate of The Shepherd Centre is that it has incurred an incremental cost (over previous systems) of **\$700K** to date to meet NDIS administration requirements.
- The arrangements also adversely affect family-centred practice and the relationship between the clinical team and the family by their requirement for frequent discussions about money and billing.
- The Sector Model approach would alleviate these problems.

## 4. ABOUT EARLY INTERVENTION

### **PURPOSE OF EARLY INTERVENTION:**

The purpose of early intervention is to minimise impending functional loss or damage (*habilitation*) or to optimize the restoration of functional loss (*rehabilitation*). It is justified on the basis of both client/patient outcomes and economic benefit, especially where the benefit exceeds the costs of intervention.

There are many examples of highly successful and cost-effective habilitation and rehabilitation in the health services sector. Notable examples include post-traumatic cardiac, stroke, and spinal injuries rehabilitation.

### **KEY CHARACTERISTICS:**

Early intervention (in both the health and community development sectors) is typically:

- evidenced-based;
- timely;
- outcomes-focused;
- informed and/or led by experts;
- undertaken by a multi-disciplinary team;
- highly interactive between team members and the client/patient (and often their family);
- tailored to each individual while working within a proven, evidence-based regime;
- based on continuous assessment of the client/patient's progress (often on a range of different fronts and criteria:) and
- continued for as long as is necessary and prudent to achieve the optimal physical, psychological, emotional and social outcomes.

These characteristics are all deeply embedded in the early childhood intervention practices of Australia's leading specialist, multidisciplinary providers of evidence-based early intervention speech and language development services and programs for D/HH children.

Current, and proposed, NDIA ECEI access arrangements do not accommodate these requirements.

### **PRE-NDIS OUTCOMES FOR D/HH AUSTRALIAN CHILDREN:**

The result of pre-NDIS family-centred, evidence-based practice has been consistently high and predictable communication, education, social participation and employment outcomes thereby achieving the NDIS's statutory aim of 'optimising the social and economic independence of people with disabilities'. ECEI graduate outcomes for children finishing First Voice centres programs 1993-2002 include: 95% of respondents attended a mainstream school; 86% completed year 12; 82% undertook tertiary education; 62% have a tertiary level qualification; 77% have been in regular employment; and 84% have been involved in community activities or organisations. (**First Voice, Report on education, employment and social outcomes of first voice member centre graduates (18 – 28 years), Jan 2017**)

## 5. COMMENTS ON SPECIFIC TERMS OF REFERENCE

### a. the eligibility criteria for determining access to the ECEI pathway;

For the first 4 years of the NDIS eligibility was a serious issue marked by a significant number of children with unilateral hearing loss and mild bilateral hearing loss being excluded from the scheme. This included children who were already in ECEI programs as well as newly diagnosed children. NDIA decisions across Australia were highly inconsistent in relation to this matter.

First Voice has recently been advised that new NDIS eligibility/access criteria are imminent that will automatically admit to the scheme children with a hearing loss of 25 dB or more in two adjacent frequencies in either ear. This is a welcome decision and will resolve one of the several key transition issues of concern to families and expert providers.

### b. (determining) the service needs of NDIS participants receiving support under the ECEI pathway;

This has been largely addressed earlier in this submission under the heading of **Problems with the current policy guidelines** (pp 8 & 9). **The two critical matters in determining service needs for D/HH children are (1) the method used; and (2) who undertakes the assessment and advises the NDIA on participant funding.**

In summary:

- i. Service needs of babies and very young children who are D/HH cannot be reliably determined by generalist NDIA ECEI access partners) through a one-off functional assessment.
- ii. this is because most D/HH children are normal babies, apart from their hearing loss, and functional impairment has not yet occurred.
- iii. In addition, experience tells us that the early intervention needs of a particular child and family are (1) not yet knowable on an individual child basis and (2) require the expert knowledge of trained and skilled specialists for their determination both initially and on an ongoing basis throughout each plan term (generally 12 months).
- iv. In specialised, multidisciplinary ECEI, the mix and intensity of services requires joint decision-making by the family and the clinical team working closely together and informed by objective assessments of the child's progress;
- v. while improved clinical and social pre-plan information (as in the proposed new reference package approach) will improve decision-making, involvement of a participant's specialist service provider (where there is one) would make a considerable difference in getting a plan right;
- vi. the involvement of an agency such as Australian Hearing with relevant knowledge and experience would substantially resolve the situation
- vii. NDIS experience to date shows wide variations in participant funding influenced by NDIA planners' attitudes and parent advocacy skills. This would also be overcome with the active involvement of Australian Hearing as national manager of the ECEI referral pathway and the NDIA's advisor on appropriate funding levels children's/families consistent with NDIA guidelines.

### c. the timeframe in receiving services under the ECEI pathway;

The timeframe in receiving services under the ECEI pathway should be determined by the evidence relating to the importance of timeliness in commencement of ECEI. In the case of children who are D/HH, it should follow the evidence-based newborn hearing screening clinical guideline that ECEI therapy should be commenced as soon as possible after confirmation of diagnosis – and no later than six months of age.

Research shows that each month of delay increases the difficulty of achieving age-appropriate speech and language and comprehension before school commencement, thereby putting children's education and whole of life outcomes at risk. To ensure adherence to the referral pathway and associated clinical protocols which are fundamental to achieving optimal outcomes in D/HH children, it is recommended that Australia Hearing be appointed by the NDIA as the exclusive manager of referrals and funding advice.

**d. the adequacy of funding for services under the ECEI pathway;**

Please refer to term of reference b above and to page 9 & 10 of this submission.

**e. the principle of choice of ECEI providers;**

**Opening comment:** This is a complex, sensitive and nuanced issue requiring further analysis, discussion and debate within the agency and involving a wide range of stakeholders.

Participant "choice and control" is a fundamental principle of the scheme. It is a principle whose application seems fairly straightforward in regard to people with permanent lifelong personal support needs, but one whose application requires careful consideration in the in regard to the early intervention objectives of the NDIS, and the scheme's overall requirement for long-term financial sustainability through increased economic productivity,

*Choice and control in relation to people with permanent disabilities and lifelong personal support and related needs:*

Everyone understands and supports the compelling arguments for the NDIS to give primacy to the principles of choice and control for people with permanent, lifelong disabilities in relation to their personal support needs, choice of providers and lifestyle preferences. It is a fundamental matter of dignity, respect for individuals' preferences, personal fulfilment and human rights.

*Choice and control in relation to evidence-based early intervention programs with predictable, proven cost-beneficial outcomes*

The purpose of early intervention is to minimise impending functional loss or damage (habilitation) or to optimize the restoration of functional loss (rehabilitation). It is justified on the basis of both client/patient outcomes and economic benefit, especially where the benefit exceeds the costs of intervention.

In the case of children who are D/HH and their families, the basis of early intervention is simple: a known investment in an evidence-based program to achieve a predictable beneficial outcome.

The language and speech programs provided by specialist providers of listening and spoken language programs for D/HH children fully satisfy the criteria and objectives of the Act. They are evidence-based; cost-effective; and have proven whole-of-life outcomes including social participation and employment.

When all is said and done, ***the NDIS is a funding mechanism for the distribution of public funds to meet a range of legislated and practical policy goals and objectives.*** Strategic objectives include:

- choice and control for people with permanent lifelong disabilities to give them a better life and life outcomes, including increased employment where appropriate
- fair sharing of available resources, based on assessed needs and a participants' reasonable aspirations for their life
- universal access to the scheme based on explicit eligibility criteria, fairly and consistently applied across Australia
- evidence-based services



- an outcomes focus
- reduced levels of lifelong functional impairment and disability through effective, evidence-based early intervention
- increased employment for people with disabilities and associated economic productivity
- reduced costs of lifelong services and supports
- a long-term sustainable scheme (costing less than other alternatives) based squarely on insurance principles.

Any complex societal system for the provision of funding and services people for people in need requires a weighing and reconciling of “competing principles” according to varying circumstances and objectives.

First Voice has submitted to the NDIA on numerous occasions that the key choice for parents of deaf and hard of hearing children relates to their choice of communication for their deaf child – spoken language, sign language or both.

This choice having been made, a number of specialist providers of both sign and spoken language programs are available that are evidence-based and designed specifically for language development in deaf children. These providers exist to assist D/HH children to achieve the best possible communication and life outcomes.

First Voice member centres fall into this category as does RIDBC and some others. Our approach is family-centred programs through expert multi-disciplinary teams of health and education professionals working closely together and with the family and child – as in comparable specialist medical and health rehabilitation programs such as stroke, spinal injuries and cardiac rehabilitation units.

Our view is that it is consistent with the objectives of the NDIS, and the wishes of most hearing families of D/HH children, that D/HH children achieve the best possible communication, education, asocial participation and employment outcomes possible. Specialist providers with evidence-based programs deliver this in a proven predictable way to more than 70% of those who choose their programs.

We live in a democratic society. It will always be, and should be, open to families to choose any NDIS registered provider they prefer, including non-specialist ones.

However as stressed at the beginning of this submission, the child’s whole life prospects are at stake because delays in commencing specialist evidence-based speech and language programs – whatever the reason - reduce the prospects of age-appropriate speech, language and comprehension before school starts.

In an “investment-outcomes” ECI model, ***the NDIS would fund participants*** choosing specialist ECEI providers with proven outcomes at the cost of the programs, subject to provider conditions including:

- i. quality accreditation;
- ii. annual publication of children’s outcome results
- iii. financial transparency, including random audit;
- iv. scalable service arrangements (reduction in intensity and cost as progress is made) with cost savings occurring in a plan period to passed back immediately to the NDIA

## ATTACHEMENTS

### ATTACHMENT 1

#### NDIA access partner and planner comments to Cora Barclay Centre parents about their child's hearing loss

The extent of the problem of the NDIA relying on non-expert, generic ECEI Access Partners and planners is evident from the list below of the types of comments, advice and decisions made by NDIA Access Partners and planners to families of children who have chosen the Cora Barclay Centre for the development of language and speech for their hearing-impaired child:

1. "your child has cochlear implants, what else might they need?"
2. "Your child has no measurable functional impairment, come back when they do"
3. "I suggest you wait and see for 12 months how things are going, and then come back"
4. "your child doesn't need support yet"
5. "I think you should go to your local speech pathologist"
6. "I can't see the need for your child to attend the music group at the Cora Barclay Centre, why don't you try the music group at your local library"
7. "your child only has a unilateral hearing loss, they will be all right"
8. "your child only has a unilateral/mild bilateral loss, they are not eligible for the Scheme"
9. "you should see your Local Area Coordinator and access mainstream services"
10. "your child is about to start school, NDIS funding is no longer available"
11. "we don't fund Teacher of the Deaf services, your child's education is the responsibility of the school"
12. "I know people in the general community who are deaf like your child"

NDIA staff comments such as these are quite frequent. They demonstrate a significant lack of understanding of the fundamentals of language development and speech in D/HH children and the importance of developing communication in these children.



## ATTACHMENT 2



### THE SECTOR MODEL: An Evidence-Based Approach to Early Intervention for Children who are Deaf or Hard of Hearing (D/HH)

The introduction of the NDIS has changed the life journey for children who are D/HH from a safe and predictable journey of language development to one of uncertainty where outcomes will for the first time in Australia's history be worse than for previous generations. The sector has come together to provide a model that can exist within the NDIS to ensure the future of this cohort.

#### OUTLINE

1. **Screening and other health/medical services** - newborn hearing screening, diagnosis, paediatric audiology, hearing aid provision and management and provision of cochlear and other implantable hearing devices to be maintained as at present with the addition of:
  - a) \*National hearing screening program at age 4 years prior to school commencement; and
  - b) \*National guidelines for the provision of cochlear and other implantable devices to achieve national consistency and equity (to be developed collaboratively with interested parties)
2. **Eligibility** for automatic access to NDIS funding, *as per NDIA decision June 2017*
3. **Audiology & hearing aids:** *Australian Hearing* to remain the national, obligated provider of uncontestable paediatric audiology and hearing aid services for infants, children and young people to 26 years of age
4. **\*Referral management:** *Australian Hearing (AH)* to be designated and funded to undertake the role of national, obligated manager of referrals of children who are D/HH to *accredited* ECI providers. AH to adhere to COAG-endorsed universal neonatal hearing screening program clinical protocols, or equivalent (e.g. USA JCIH (2013) protocols).
5. **\*Guided Pathway** - referrals from screening, and any later diagnosis, to be through a "guided pathway" managed by *Australian Hearing* which strongly encourages families to visit, or be visited by, accredited ECI providers with specialised knowledge and skills in *language/communication development* (speech or sign) for children who are D/HH. This is to ensure that families make fully informed choices.
6. **\*Evidence-based services from accredited providers** - organisations (and group or solo practitioners with relevant skills and experience) providing evidence-based *language development* ECI (speech or sign) to be accredited for guided referral pathway purposes and, where relevant, '*comprehensive package funding*'.
7. **\*'Comprehensive package funding' for NDIS participants to cover ECI service costs from accredited providers** - *Australian Hearing* to be designated and funded to determine/advise on NDIA plan funding allocations for D/HH children in accordance with revised and boosted NDIA reference packages. NDIS participants choosing *accredited* multi-disciplinary ECI programs with proven children's outcomes to be funded on a comprehensive package basis permitting pro rata monthly invoicing. Participants choosing NDIS *non-accredited* providers to be funded on service hours. *(See NB footnote below)*
8. **\*Provider accreditation** - Criteria to be developed in consultation with relevant parties. Conditions of accreditation to include (1) relevant skills and experience for *developing language* (speech or sign) in D/HH children; (2) obligation to produce an annual outcomes report for children on service and (3) provider obligation to advise the NDIA promptly re reductions in a child's service intensity [scaling down] during an annual plan period, with savings immediately passed back to the funder (the NDIA).
9. **\*Age bracketing** - *Consideration be given* to structuring the services and funding model around 4 age groups: 0–5 yrs; 6–11 yrs; 12–18 yrs; and 19–26 yrs with the first two groups funded and managed on early intervention 'investment–outcomes' principles and with children being assessed for *functional impairments* at age 12 years with subsequent funding based primarily on assessed needs.

Items with **red asterisks** are urgent and must be enacted immediately to hold the current slide in children's outcomes. Items with **black asterisks** are important changes that should be actioned as soon as possible. Items without asterisks to be maintained unchanged.

NB: Comprehensive package funding, pro rata billing and scaling down were all permitted in the SA Children's trial up to August 2015.

## ATTACHMENT 2

### PUBLIC POLICY PRINCIPLES:

1. **Informed Participant Choice** of language (Speech and Sign)
2. **Informed Participant Choice** of *accredited*, specialist providers of evidence-based programs with proven outcomes **or** other NDIS *non-accredited* registered provider if they so choose
3. **Reasonable and necessary** 'comprehensive package' funding for families choosing *accredited* providers: 'reasonable and necessary' defined as sufficient NDIS funding to meet the direct service costs of proven programs (i.e. not calculated just on sessional inputs)
4. **Evidence-based practice** from screening to school completion, or age 26 years
5. **An Early Intervention outcomes-based focus** designed to fulfil the NDIS goal of 'optimising the social and economic independence of people with disabilities'
6. **Value for money** – i.e., maintaining a positive benefit to cost ratio of better than 2 to 1

### DEAF CHILDREN'S OUTCOMES BEFORE AND SINCE THE NDIS (refer Attachments 2 & 3)

1. Prior to the NDIS, D/HH children receiving services from Australia's 15 to 20 specialist early intervention language development providers typically achieved age-appropriate speech and language before starting school (70 – 80%); attended mainstream classes in mainstream schools (95%) with 86% completing year 12 and over 60% gaining tertiary qualifications and subsequent employment (77%).
2. All this for a better than 4:1 return on government investment and 2:1 overall return on investment.

### RE COST TO GOVERNMENT (refer Attachment 4)

The estimated cost to government (NDIS) of the <b>Sector Model</b> for children aged 0–12 years is:	<b>\$23.2M pa</b>
The estimated cost of <b>NDIA reference packages</b> (1 June 2017) is:	<b>\$10.4M pa</b>
The difference between the two different approaches is:	<b>\$12.8M pa</b>

The estimated full scheme NDIS budget is \$22B pa, an increase of \$15B pa from the combined expenditure of all Australian governments on disability services prior to the NDIS.

**Hearing/language development sector services are currently highly cost effective** (Attachment 3).

**Under the proposed Sector Model an investment of an additional \$12.8M pa will secure optimal outcomes for Australian children who are D/HH. The failure to make this investment (and to introduce a purpose-designed early intervention model for evidence-based multi-disciplinary services) will cause worse outcomes for D/HH Australian children under the NDIS than pre-NDIS. This would be a shocking outcome with many possible ramifications.**

### EXTREME URGENCY:

Due to (1) financial impacts on sector service providers (**refer Cora Barclay Centre audited losses of \$1.4-1.6M during 4 years under the NDIS making it financially unsustainable**) and (2) the imminent accelerated roll-out of the NDIS in NSW with estimated annual losses to The Shepherd Centre of \$1.9M pa and RIDBC \$2.5-3M pa.

### NEXT STEP

**NDIA to meet with sector representatives including the authors of this paper and Australian Hearing as a matter of urgency to work through both the current NDIA model and proposed Sector Model in a co-design project to agree a new set of policy and funding settings that will ensure optimal outcomes for D/HH children under the NDIS without further delay.**

### Attachments

1. Sector Model: Supporting Information
2. First Voice Graduate Outcomes Survey Report - Executive Summary, Jan 2017
3. Deloitte Access Economics, Cost Benefit Analysis – Executive Summary, Jan 2017
4. First Voice/RIDBC comparative cost model, June 2017

**Michael Forwood**  
First Voice

**Bart Cavalletto**  
RIDBC

**30 June 2017**

## ATTACHMENT 2

### ATTACHMENT 1 Sector Model: Supporting Information

#### EARLY INTERVENTION GOAL:

The **Aim of the NDIS** is to “optimise the social and economic independence of people with disabilities”.

The **purpose of this Sector Model** is to provide a model that can exist within the NDIS and will optimise the communication, education, social participation and economic outcomes for children who are D/HH.

#### RATIONALE:

Prior to the NDIS Australia enjoyed arguably the world’s best system for the identification and management of children who are D/HH and Australian children achieved extraordinary communication, education, social participation and economic outcomes (refer Attachment 2)).

Unfortunately, pre-NDIS evidence-based services arrangements for D/HH children have been effectively destroyed by the NDIS which has failed to develop policies, funding and payment mechanisms that support specialist, evidence-based, multi-disciplinary early intervention with proven outcomes for D/HH children.

Over the past four years this has been evidenced by:

1. exclusion of children requiring intervention from access to NDIS – particularly in the SA NDIS Trial Site;
2. significant delays from confirmation of diagnosis to commencement of expert ECI;
3. failure to guide families to specialist providers of evidence-based language development (speech & sign) ECI;
4. chronic underfunding of NDIS participants choosing specialist ECI providers of listening and spoken language (LSL) and sign language programs with proven, cost-beneficial programs and outcomes;
5. a pattern of significant variations in NDIS funding packages for children/families with comparable needs;
6. failure to adopt appropriate invoicing arrangements for specialised, multi-disciplinary ECI programs that are based on *EI investment principles* rather than on sessional payments/individual items of service (i.e. inputs-based funding not linked to outcomes)

***The net result of the above will, for the first time in Australia’s history, result in worse language outcomes in D/HH children than for previous generations, undermining their life outcomes and destroying the financial viability of Australia’s 15 – 20 specialist providers of ECI for children who are D/HH.***

As things stand at the end of June 2017, NDIA’s latest proposals for **referral arrangements** (managed by non-expert NDIA staff), **reference package funding levels** (which are 30-50% short of actual evidence-based service costs), and **itemised sessional invoicing** (too transactional, too administratively burdensome, too inflexible, and destructive to client relationships) fall far short of what is needed to regularly and predictably (the hallmark of an ‘investment EI model’) achieve optimal communication, education, social participation and economic outcomes for D/HH children. This is because NDIA proposals do not satisfy the basic requirements for effective evidence-based multi-disciplinary service delivery.

It is evident that the NDIA’s approach to solving these and related problems over the past 2-3 years has been ineffective and families and providers will continue to “sink” under the latest NDIA funding proposals.

**A quick, collaborative, co-design approach is needed, commencing immediately.**

#### URGENCY: FINANCIAL IMPACTS OF NDIS PARTICIPANT FUNDING ON D/HH ECI PROVIDERS

1. The Cora Barclay Centre (CBC) in SA has suffered NDIS revenue losses of \$1.4-\$1.6M over the past 4 years (**certified by SA Govt independent audit**). Restitution to date has been \$215K from the SA Government, with a further \$215K pending the audit. The Centre has an annual operating budget of \$2.8M and is currently losing \$40K per month (\$500K per year) directly attributable to NDIS under-funding. In addition, the Centre is absorbing significantly increased administration costs in supporting families with NDIS access, planning, funding, review and portal problems. Under the NDIS, most of the very substantial burden of administration is borne by service providers and families/participants, not by the NDIA. Most of this is unfunded. The latest NDIA reference package funding proposal does not solve the under-funding problem and remains 30-50% short of direct service delivery costs. **Starting in January 2018, CBC will have to implement progressive service cuts to achieve a balanced budget. These will involve: an estimated 18 ECEI**

## ATTACHMENT 2

*children (0-5 yrs) coming off service altogether; abolition of ECEI groups, family counsellor and case management; 39 children aged 6 & 7 years (Reception/Year1) no longer receiving a 1:1 service; and 69 D/HH students (currently receiving a monthly or termly service) being re-directed to group only programs – with all service reductions diminishing their outcomes.*

2. Taralye, (Vic) has already been 'forced' by the NDIS to merge with another larger and wealthier provider.
3. The NDIS accelerated full scheme roll-out in NSW is due to commence on 1 July 2017 with stated goals of 87% of children having an initial NDIS funded plan by 31 December 2017. This will impact heavily on the State's two largest expert providers, The Shepherd Centre and RIDBC, who project annual shortfalls in NDIS revenue required for break-even in service delivery costs of around \$1.9M (TSC) and \$2.5-3M (RIDBC) based on the recent (June 2017) NDIA draft National Reference Packages.
4. Queensland and WA are still some way off but in time will face similar shortfalls on average of around \$6-10K per child per year when the Scheme is rolled out.

**In summary, current NDIS planning, funding and FFS invoicing arrangements are a major threat to all of Australia's renowned specialist family-centred, multi-disciplinary LSL and Auslan ECI providers who currently achieve extraordinary life-long outcomes for D/HH children (thereby assisting them in becoming economically productive while avoiding lifelong disability services costs to government). These unintended consequences are in direct contradiction to the NDIS insurance principle and statutory and policy commitments to early intervention, evidence-based practice, a client-outcomes focus and value for money for government expenditure.**

The model we propose for urgent co-design discussions involving the NDIA, First Voice, RIDBC, the Deafness Forum of Australia, Australian Hearing and C/wealth DSS is outlined above. Its aim is to quickly put in place arrangements under the NDIS for the identification, timely referral and expert provision of evidence-based ECI for children who are D/HH thereby enabling current and future generations of children who are D/HH to achieve the same communication and life outcomes as children without hearing loss.

### COMPARISON B/W NDIA AND SECTOR PROPOSED MODELS

KEY SUCCESS FACTOR	NDIA MODEL	SECTOR MODEL	COMMENTS - PROPOSED SOLUTIONS
1. Universal access	✓	✓	Recently resolved by NDIA
2. Expert children's audiology and HA fitting	✓	✓	Currently undertaken by Australian Hearing
3. Timely referrals in accordance with clinical protocols	✗ Non-expert NDIA staff managing referrals; no details available of possible guided pathway	✓ Referrals managed by experts strictly following clinical protocols	Appoint Aust. Hearing (AH) as national referral manager. <b>SA trial shows NDIA staff not committed to 'no delays'.</b>
4. Guided referral pathway to specialist evidence-based ECI services	✗ Non-expert/generalist NDIA staff managing referrals and limited by NDIA interpretation of the participant choice principle	✓ Guided referral pathway to accredited evidence-based expert providers with proven outcomes	Appoint Aust. Hearing (AH) as national referral manager. <b>SA trial shows NDIA staff committed to participant 'choice' over evidenced-based practice.</b>
5. Ongoing accountability of referral agency/manager	✗ NDIA approach not known; unlikely to include routine KPR reporting as per medical practice	✓ routine reporting as per clinical protocols	Routine reporting by referral manager in accordance with clinical protocols is necessary to ensure compliance
6. NDIS participant funding covering specialist providers' service costs	✗ 30-50% shortfall in participant funding	✓ 3 funding levels - Intensive, Medium & Low designed for appropriate funding and clinical team flexibility	Need to increase NDIA reference package funding by 30-50%
7. M-D team retains ability to manage client services	✗ clinical decisions constrained by NDIA pre-set <u>annual</u> plan and sessional billing arrangements	✓ clinical team flexibility to get best children's outcomes	Pro rata billing required as it is not possible to determine client service mix in advance. Also, client needs change during plan period
8. Strong bond required b/w clinical team and family for ECI	✗ transactional model & individual services billing antipathetic to client-clinical team bond	✓ flexible service mix and pro rata invoicing against annual plan value	NDIA FFS model seriously undermines client/clinical team relationship
9. Services continue after ECEI as required	✓ New access criteria and NDIA draft reference packages provide for services and funding beyond age 6 years (ECEI)	✓ funding and services continue as appropriate for optimal outcomes	Recently resolved by NDIA