Response to the 2017 Price Controls Review Consultation on NDIS pricing arrangements

From First Voice

Submitted by:

Michael Forwood
Chair, First Voice
C/- Cora Barclay Centre
185 Melbourne Street
NORTH ADELAIDE SA 5006
Tel: 08 8267 9200
Email: mforwood@corabarclay.com.au

13 April 2017

Contents

1. Introduction

1.1 The focus of our response

The purpose of this submission is to advise the National Disability Insurance Agency (NDIA) of significant risks to children who are deaf and hearing impaired under the current funding arrangements of the National Disability Insurance Scheme (NDIS).

Specifically, it aims to:

1. reinforce the urgency of finding solutions to key funding issues affecting hearing-impaired children under the NDIS; and
2. propose an alternative funding model for early intervention programs, such as those provided by First Voice member centres, that routinely deliver high-level outcomes with a proven positive return on investment as per the purposes of the NDIS Act.

Please note that the issues raised within this paper are not specific to the terms of reference for the pricing review. However they are provided in response to the Agency's invitation to provide feedback on *any aspect of NDIS pricing arrangements* to help inform this and future price reviews (Price Controls Review, p2).

1.2 Background and context

First Voice and its five Australian member organisations have been engaged in lengthy discussions with the NDIA over the past two years to determine an appropriate funding and service model for children receiving early childhood intervention within the NDIS for permanent childhood hearing loss.

While the NDIS offers significant advances to people with permanent lifelong disabilities and associated permanent lifelong needs, it has proven to be a "difficult fit" in regard to childhood hearing services.

The difficulty of this "fit" appears to be based on two key issues:

1. The NDIS funds *inputs* rather than *outcomes*

While independent research from Australia and overseas demonstrates that best practice listening and spoken language early intervention delivers consistent high-level outcomes, the NDIA does not fund the necessary investment to achieve/sustain these outcomes.

2. Hearing services early intervention can only consistently deliver high-level outcomes if it adheres to a rigorous medical model of practice

Early intervention for permanent childhood hearing loss operates on an internationally-endorsed medical practice model requiring, inter alia, no delays in commencement of early intervention and service provision by expert providers. Current NDIS policies and funding arrangements are not compatible with these requirements causing deaf children to be worse off under the NDIS than previously.

Evidence from the NDIS Children's Trial in South Australia shows concerning patterns of referral delays; funding delays; referrals to providers lacking the necessary expertise to develop language in deaf children and inconsistencies in Participant funding levels.

There is widespread concern from parents, professional groups, advocacy organisations and service providers that hearing-impaired children and their families will be worse off under the NDIS than under previous arrangements. Failure to resolve these issues will create life-long disadvantage to children with hearing loss, and set Australia's highly developed hearing services sector back many years. Despite the scheme now being in a stage of full rollout, and intensive and ongoing representations to and discussions with the NDIS over the past 2 years, these funding issues remain unresolved.

2. Listening & spoken language early intervention in Australia

2.1 Listening and spoken language therapy is multi-disciplinary, evidence-based and family focused

In Australia, listening and spoken language early intervention programs are typically provided through multi-disciplinary teams comprising specialist health and educational professionals including certified auditory-verbal therapists, teachers of the deaf, speech pathologists, paediatric audiologists, psychologists, child and family counsellors, social workers, occupational therapists, specialist kindergarten professionals, and youth workers. Some programs are also provided in conjunction with cochlear implant programs, in which case the team also includes cochlear implant surgeons, paediatricians and other medical and health personnel.

These programs are evidenced-based, family-friendly and reflect early childhood early intervention best practice. First Voice member centres track and report consolidated speech and language outcomes annually.

Listening and spoken language programs have the singular purpose of assisting children with permanent hearing loss to learn to listen and speak. The approach is predominantly through parent education and training. It also assists a child in achieving cognitive development, effective spoken communication, improved social participation, optimal schooling outcomes and post-schooling educational and employment options comparable to children with typical hearing.

More than 90 per cent of infants born with deafness or permanent hearing loss are born to parents with typical hearing. More than 85 per cent of these families choose spoken language as the primary mode of communication for their children with hearing loss. These parents typically select approaches that support listening and spoken language.

2.2 Proven and published outcomes for hearing-impaired children in Australia

> Deaf children develop language & transition to mainstream schools

Children who are deaf or hearing-impaired who attend best practice listening and spoken language early intervention programs develop speech and language outcomes by age five on par with children with normal or typical hearing. Published outcome data (2015)[1] shows that listening and spoken language early intervention for childhood deafness results in **near normal speech and language skills by school commencement age**.

These data show that the vast majority (74-87%) of children with permanent hearing loss score within or above the normal range for typically-hearing children of the same age. Measures include total language, auditory comprehension, expressive communication, vocabulary and speech performance. These findings are consistent with previous outcomes data on children enrolled in listening and spoken language programs of First Voice members.

Almost all children with permanent hearing loss graduate from a best practice listening and spoken language early intervention programs at age five years and **transition into a local mainstream primary school**.

> Graduates achieve strong education and employment outcomes

First Voice recently conducted a survey of young people who graduated from one of its members' early intervention programs between 1993 and 2002 to evaluate long-term education, employment and social outcomes.

The 2017 graduate outcomes study[2] found that 95 per cent of deaf children who received speech and language early intervention attended mainstream schools, with 82 per cent being accepted into higher education and training courses after school. Sixty two per cent had completed tertiary qualifications, compared with only 43 per cent of the general population; and 77 per cent had experienced regular paid employment.

It can be expected that outcomes will have further improved over the ensuing 10 to 15

[1] Sound Outcomes: First Voice Speech and language data, 2015
[2] First Voice (2017). Report on education, employment and social outcomes of First Voice member centre graduates (18-28 years). http://www.firstvoice.org.au/wp-content/uploads/2016/09/First-Voice-Graduate-Outcomes-Report.pdf

years as a result of continuing improvements in assistive technology, early intervention therapy, and earlier identification and diagnosis since the introduction of universal newborn hearing screening in Australia between 2005 and 2007.

2.3 New Australian research demonstrates the cost benefit of early childhood intervention for hearing loss

One of the core principles of the NDIS is to invest in early intervention with the aim of reducing future disability supports and maximizing employment and economic participation. Nowhere is this more relevant than for children with hearing loss who, if diagnosed, referred and supported early with effective strategies, including amplification and education, achieve outcomes that enable them to achieve their full life potential.

A cost benefit analysis[3] conducted by Deloitte Access Economics in 2017 found that for every dollar invested in a best practice listening and spoken language early intervention for children who were deaf, there was a $2.20 return on investment. This was accounted for by increased income due to improved employment and educational attainment, improvements in well-being, and avoided school and social services costs.

These two studies come at a critical time in the design and review of NDIS pricing arrangements, as they reinforce the importance of evidenced-based early intervention therapy and the acute need for an appropriate, purpose-built early intervention outcomes-based funding model before the NDIS is rolled out to a further 3,500 hearing-impaired children across Australia.

3. The need and case for special funding provisions

3.1 Listening and spoken language early intervention operates on a proven, medical model of practice

If early childhood intervention for permanent childhood hearing loss is to remain within the NDIS, it needs special provisions related to service and funding so as not to disadvantage hearing-impaired children.

Best practice listening and spoken language programs differ in material respects from many early childhood early intervention programs that aim to mitigate children's intellectual, behavioural, mental health or physical functional losses that are already manifest or imminent from a child's condition.

With early identification and advanced hearing technology, the vast majority of deaf children - even those with the most severe or profound hearing losses - can have sufficient access to the sounds of the speech spectrum to follow an early intervention approach designed to achieve typical developmental milestones in listening, speech, language, cognition, and conversational competence in the majority of deaf children.

A key difference between listening and spoken language early intervention and early intervention programs for many other conditions and disabilities is the ability to predict high rates of successful habilitation outcomes for hearing-impaired children based on normative assessments and published data.

However, these outcomes are predicated on a medical model of service intervention, based on compliance with the clinical protocols and pathways from newborn hearing screening to commencement of family-centred, multi-disciplinary listening and spoken language early childhood intervention.

[3] Deloitte Access Economics (2017). Cost benefit analysis of First Voice's early intervention program – a sound investment. http://www.firstvoice.org.au/wp-content/uploads/2016/09/First-Voice-Deloitte-Access-Economics-Cost-Benefit-Analysis.pdf

The six critical elements of this approach are:

- **early detection (within 1 month of birth);**
- **no delay in hearing technology (as soon as practicable);**
- **no delay in early intervention therapy (within 6 months);**
- **service provision by highly skilled and experienced specialist health and education professionals; and**
- **ongoing assessments and reporting on each child's progress.**

This approach achieves life-changing outcomes with the majority of children achieving life-long social and economic independence.

It is therefore critical that there are referral arrangements within the NDIS to ensure:

1. informed choice by parents via a guided pathway to expert providers
2. streamlined, evidence-based identification, diagnosis, application of hearing devices/implants and other relevant technology (if chosen); and
3. commencement of appropriately funded early childhood intervention before 6 months if diagnosed at birth; otherwise commencement of intervention within 6 months of diagnosis.

It is vital that infants and children diagnosed with permanent hearing loss receive timely referrals and appropriate funding within the NDIS to access the services they need. There are many instances within the NDIS where this is not occurring.

Timing is critical in the management of childhood hearing loss. Failure to deliver an adequately funded and seamless process from screening to completion of early intervention puts children at risk. Research shows that any delays in diagnosis, aiding/implanting of hearing devices and commencement of early intervention therapy are detrimental to communication, brain development and life outcomes.

Australia's operating environment is the outcome of many years of evidence-based research, advocacy and public policy development (dating from the establishment of the Commonwealth Acoustic Laboratories in 1946) to develop an integrated national and state-based approach. It is critical that this operating environment is protected, maintained and built on in the years ahead.

3.2 Current NDIS funding arrangements are not appropriate for children receiving intensive, multi-disciplinary listening and spoken language early childhood intervention services

Multi-disciplinary, listening and spoken language early childhood intervention is a highly specialised, complex, inter-connected medical and education approach to developing speech and language in deaf babies and young children. The multi-disciplinary team typically includes highly qualified and internationally certified listening and spoken language specialists (LSL ©), speech pathologists, paediatric audiologists, teachers of the deaf, early childhood educators, psychologists, family counsellors, occupational therapists and other relevant consultant medical and health professionals. These work together in a highly interactive way, much of which is impossible to measure for the purposes of fee-for-service payments. It has been estimated that over 30 per cent of professional team members' time is spent in informal, often unscheduled, discussions and interactions of varying duration - from very short to very long. These interactions are inherent in this multi-disciplinary, family-centred program approach.

The dynamics of the children's speech and language programs described above are comparable in many respects to evidence-based medical and health rehabilitation programs in areas such as spinal injuries, head injuries, craniofacial surgery and rehabilitation and other such multi-disciplinary, tight-knit programs that are funded on a program basis. No one would ever consider funding such programs on an inputs/fee-for-service basis. They can only be effectively funded on a whole-of-program basis.

Another illuminating analogy might be funding for schools - which is based on periodic (termly) payments of an annual fee applicable to all students, and not on an hours-of-teaching per student basis with no payment to the school if the student doesn't turn up!

What is needed under the NDIS is an optional early intervention funding arrangement specifically for early intervention programs with objectively proven outcomes and objectively proven position return on investment.

Current NDIS fee-for-service funding and payment arrangements may be suitable for NDIS Participants with permanent disabilities needing lifelong personal services and supports, but they are totally unsuitable for multi-disciplinary listening and spoken language early childhood intervention programs for the following reasons:

1. their transactional nature undermines the relationship between the team and the family and their child, thereby impairing children's outcomes;
2. aggregate NDIS fee-for-service payments for hearing-impaired children typically result in a funding shortfall to participants and providers of over 30 percent of actual program costs representing approximately $6-8K per child per year for a child on a weekly therapy program. For a service provider with a caseload of say 250 children, this translates into an annual shortfall of around $1.75M per year;
3. they are totally inconsistent with the ongoing research and development culture of the major providers which is essential to maintaining and improving deaf children's communication, education, social and employment outcomes into the future.

Australia's leading multi-disciplinary speech and language early childhood intervention programs currently achieve the world's-best outcomes with a proven return on investment of more than $2 for $1 invested. They, and similar early intervention programs with proven, cost-beneficial outcomes, should be funded by the NDIS on an outcomes-focussed, 'investment' basis designed to maintain outcomes not on a transactional, fee-for-service inputs basis designed for people in the main scheme with life-long support needs.

An upfront investment funding model is warranted because the majority of hearing-impaired children going through expert listening and spoken language early intervention programs will require little or no lifelong support.

It is submitted that funding and pricing arrangements should be consistent with children attaining their goals in regard to communication, education and life-long economic and social independence. If appropriate funding is provided, these children can achieve language and communication outcomes at the same level as children with typical hearing. This delivers a significant and life changing outcome for children and families, and a long-term economic benefit to the individual, the community and the Australian government.

A scalable funding model is needed to accommodate children's different communication needs

The funding provided by the NDIS for a child should be sufficient to pay for the services that a child needs to achieve and maintain age-appropriate communication outcomes and social development. The cost of services varies according to the needs of the child and their families' chosen approach to developing communication, however in general:

- **Children who are pre-lingual and those with communication skills below their peers** require intensive services to enable them to develop and improve communication up to their age-appropriate level. These services typically involve integrated assessments, audiological management, therapy services, social skills intervention and family support, which costs from $18,000 to $24,000 per annum depending on the specific needs and circumstances of the child.

- **Children with risk factors that mean that they are likely to have communication skills below their peers** require intensive services to enable them to improve up to their age-appropriate level. These services involve integrated assessments, audiological management, therapy services, social skills intervention and family support which cost from $18,000 to $24,000 per annum depending on the specific needs and circumstances of the child. Known risk factors include late diagnosis, delayed commencement of early intervention, children from culturally and linguistically diverse (CALD) families and children with additional disabilities.

- **Children with communication developing along an age-appropriate trajectory but with risk factors that will put their ongoing development at risk** require ongoing therapy and supports to ensure they maintain their rate of communication development in line with their peers. These services involve integrated assessments, audiological management, therapy services, social skills intervention and family support which will cost from $12,000 to $18,000 per annum depending on the specific needs and circumstances of the child. Most children with hearing loss fit into this category.

- **Children with communication developing along an age-appropriate trajectory and without risk factors that put their ongoing development at risk** require sustaining therapy to ensure they maintain their rate of communication development in line with their peers. These services involve integrated assessments, audiological management, therapy services, social skills intervention and family support which cost from $6,000 to $12,000 per annum depending on the specific needs and circumstances of the child.

As previously stated, current NDIS planning and funding arrangements are manifestly inadequate and are resulting in a typical gap of $6K-8K per child per year between the service delivery cost of listening and spoken language early intervention programs and the level of funding provided to NDIS participants with children who are deaf or hearing-impaired.

During the three years of NDIS trials, and since, service providers have continued to provide the full level of services necessary to achieve optimal outcomes for each child. This has been possible because, with the exception of South Australia, only a small proportion of each provider's caseload has been located in one of the NDIS trial sites; however this situation is quickly changing.

Current NDIS funding arrangements cannot be allowed to continue under the full scheme. If NDIS funding to families of children who are deaf or hearing-impaired remains inadequate, early intervention services will have to be reduced and children's communication, education, social participation and whole of life outcomes will be compromised.

This would seem to be significantly at odds with NDIS principles, aims and objectives, including its underlying insurance principle and its commitments to early intervention, evidence-based practice and value for money.

3.3 There are policy and funding "disconnects" between the NDIS and expert service providers that impact on children, families and providers

The NDIS policy and funding arrangements for the full scheme have been developed primarily for people with disabilities requiring lifelong personal services and supports. These arrangements are inconsistent with basic requirements for effective multi-disciplinary listening and spoken language early intervention.

There are five main areas of "disconnect" between NDIS policy and funding arrangements and early intervention practices that are impacting on children, families and providers.

1. The main scheme principle of **participant choice and control** ***conflicts with*** the requirement for evidence-based early intervention to adhere to clinical best practice protocols to achieve optimal client outcomes.

2. The apparent intention of the NDIA to **limit Tier 3 funding** to people with significant, lifelong needs for personal care and support ***conflicts with*** the fundamental objective of early intervention to anticipate and identify health and disability needs at all levels and to prevent or reduce the need for lifelong supports to the greatest possible extent in the interests of the well-being of individuals and the national economic interest (the insurance principle). For example a small investment in early intervention for 0-5 year old children with unilateral hearing loss or mild bilateral hearing loss may result in 30 per cent or more of these children avoiding poor educational, social and life outcomes. Economics and common sense both indicate

that this investment should be made in as many children as possible with low level hearing loss. In budgetary terms it represents low cost and high return. This

3. **Planning and funding decisions** in the NDIS are made by NDIA planners (essentially an administrative function) with little or no knowledge of (1) the child and family, (2) the child's needs in relation to developing spoken communication, or (3) the requirements of the program they have chosen. NDIA planner knowledge of a participant's chosen service provider may not be important for people with lifelong personal support needs, but the situation is clearly different with early intervention. Thus current NDIA planning arrangements ***conflict with*** the fundamental need in early intervention for decisions about client service plans to be made by the clinical team in the light of all available evidence and in conjunction with the child's family.

4. **Funding allocations** in the main scheme are based on assessed functional impairments and needs and this ***conflicts with*** the fundamental early intervention requirement for (investment) funding to be sufficient to meet the cost of a participant's chosen intervention for as long as is prudent and necessary to minimise functional impairment and maximise lifelong social and economic independence.

5. **Main scheme funding and payment arrangements** are based on inputs, are transactional, administratively burdensome for families and their providers and ***undermine*** the close relationship between families and providers that is necessary in intensive, inter-connected, family-centred early intervention. Wherever possible early intervention programs should be funded on outcomes, not inputs.

4. Outcomes-based funding of early childhood hearing services within the NDIS

Outcomes-based funding arrangements are critical for multi-disciplinary early childhood hearing services as the object is to achieve, on behalf of our young clients, practical, lifelong gains.

An outcomes-based funding model should be considered within the NDIS for early childhood hearing services wherever the NDIA (as government funder) has reliable evidence of concrete, evidenced-based outcomes with a positive benefit-to-cost ratio.

In relevant and appropriate service areas, outcome-based funding:

- improves outcomes for people receiving services
- rewards providers that deliver high-quality programs with proven outcomes
- provides an incentive for service providers to objectively measure and report on client outcomes with a view to admission to an outcomes-based funding to fee-for-service payments
- ensures value for money for the funder and client.

Although the NDIA does not directly fund service providers, outcomes-based funding can be achieved under the NDIS by providing sufficient funding to NDIS participants to cover the costs of clearly defined early intervention programs provided by their chosen service provider where such programs deliver proven outcomes for an explicit and transparent cost.

In the terms of the NDIS Act and policy framework, the demonstrated cost of any such cost-effective program should be construed as the level of funding that is "reasonable and necessary" to achieve a participant's personal long-term goals.

It is essential that the NDIS has mechanisms for ensuring such programs are financially sustainable to ensure the integrity and continuance of high quality, evidence-based multi-disciplinary programs that are delivering proven outcomes.

Outcomes-based funding arrangements should apply to whatever providers' programs satisfy NDIA criteria in relation to:

1. quantitative, evidenced-based outcomes
2. demonstrated benefit-to-cost ratio and
3. transparent and auditable program costs.

In the absence of such a mechanism, it is likely that multi-disciplinary programs with proven outcomes will be inadequately funded which will ***EITHER*** (1) necessitate service reductions that compromise outcomes ***OR*** (2) render the service provider financially unsustainable.

Either of these outcomes will have a devastating effect on children with hearing loss. Children who are deaf or hearing impaired are entitled to a clear and adequately funded pathway of services under the NDIS that will secure their future.

5. Immediate and urgent issues

Address NDIS funding shortfalls and payment arrangements

Changes are urgently required to funding arrangements for multi-disciplinary, listening and spoken language early intervention services under the NDIS. While it may be possible to improve the situation by modifying existing fee-for-service arrangements, the failure of this to occur during the past four years would suggest it is difficult or impossible. The most likely difficulty would seem to be that any changes made specifically for hearing-impaired children would create precedent with flow on effects across the broader system. The alternative approach would be to introduce an optional, alternative early intervention funding mechanism – based on investment principles - specifically for programs with proven outcomes and proven cost benefit such as those provided for hearing-impaired children.

While it is for the NDIA and the Federal Government to determine how best to proceed, First Voice strongly supports an outcome based funding approach.

This approach was used in the first two years of the NDIS Children's Trial in South Australia, whereby the NDIA agreed to provide families with sufficient funding to cover the costs of their chosen early intervention communication program with the Cora Barclay Centre subject to certain conditions including transparency of costs; scaling of services in line with the child's measured progress in speech, language and social development; immediate passing back to the NDIS of savings from scaling down; annual reporting on program outcomes; and openness to audit at the discretion of the NDIA.

Unfortunately, these arrangements were abandoned in August 2015 when new early childhood intervention policy and funding arrangements were introduced nationally.

Since then expert service providers have sustained significant revenue losses that they have "carried" without refusing or reducing services to unfunded or under-funded hearing-impaired children because of their commitment to children's outcomes. Expert service providers have also been absorbing the cost of providing unfunded services to children during the period between the child's commencement of service and NDIA provision of funding to the child's family. With some providers these unfunded service costs run into hundreds of thousands of dollars.

Under the NDIS Act the NDIA is prohibited from making retrospective payments to families or providers for services delivered prior to a child receiving a funded plan. This prohibition is inappropriate where ***immediate commencement of early intervention*** is necessary for the achievement of optimal outcomes for the child – as is the case with hearing-impaired children.

The NDIS Act, rules and terms of business need to be amended to address the problem related to respective payments where immediate commencement of early intervention is necessary – in the case of hearing impaired infants and children.

6. Developing a long term, sustainable funding solution

Protracted issues and difficulties

Since the NDIS started in 2013 a range of serious policy and funding issues have emerged in relation to the transition of children's hearing services to the NDIS. These issues relate to eligibility; scope of services; duration of services; referral arrangements; inconsistencies in funded plans; unresolved interface issues with health and education and a substantial shortfall in participant funding compared with service costs.

Individually and collectively these pose a real threat to whole-of-life outcomes of future generations of deaf children in Australia. Notwithstanding concerted efforts by many people over a long period, none of these issues has been resolved. This suggests that there is a fundamental underlying incompatibility between NDIS policy and funding arrangements and requirements for successful early intervention for hearing-impaired children.

NDIS policy and funding arrangements for the full scheme have been developed primarily for people with disabilities requiring lifelong personal services and supports. These arrangements are inconsistent with basic requirements for effective multi-disciplinary listening and spoken language early intervention.

First Voice believes the root problem is that NDIS policies and funding arrangements are fundamentally at odds with what is required for evidenced-based early intervention programs to achieve and sustain high- level client outcomes.

It is therefore not surprising that these arrangements have given rise to the operating policy and funding issues that have defied resolution – despite extraordinary consultation and goodwill on both sides - over an extended period of time.

An alternative funding model for hearing impaired children

The NDIA's approach to date has been to attempt to minimise the impact of various issues by "massaging" solutions into the policy and funding settings within the main scheme. This hasn't worked. So if an "issue by issue" approach within existing NDIS policy and funding settings doesn't work, we need to look elsewhere – we suggest to alternative policy and funding arrangements.

We believe an alternative policy and funding model is needed under the NDIS designed specifically for early intervention programs meeting specified criteria on outcomes, cost-benefit, financial transparency, and accountability. This would be designed initially to meet the requirements of early intervention services for hearing-impaired children, but could also be a model for other comparable EI programs/providers.

7. Conclusion

Fundamental problems exist in relation to children's hearing services under the NDIS. These issues present real threats to deaf children's outcomes and to the goal of optimising their lifelong social and economic independence.

Current NDIA initiatives to address these issues, including reference packages and early childhood early intervention access partners, appear unlikely to provide definitive, long-term solutions. The root problem is that NDIS policy and funding settings are incompatible with basic requirements for effective early intervention and do not work with complex, expert, multi-disciplinary early intervention programs such as those provided to hearing-impaired children in Australia.

While specific solutions are needed to address some immediate and urgent issues, these will not negate the need to address the broader structural fit and alignment of early intervention for children with hearing loss within the NDIS.

The best way forward is to develop an outcomes-based funding model for hearing-impaired children designed to be applicable more widely across the early intervention sector in relation to evidence-based programs achieving real outcomes with a positive cost benefit.