

Chapter 3

Early Intervention services

Introduction

3.1 This chapter focuses on the critical and urgent need to address the issues related to access and provision of early intervention services for children who are deaf and hard of hearing.

3.2 This chapter first discusses the lack of clear guided referral pathway since the transition to the NDIS and the issues raised by participants about the delays between diagnosis and start of intervention therapies. Secondly, it explores plan development issues and shortfalls in funding provided to children with hearing loss.

3.3 Thirdly, it discusses how the introduction of baseline reference packages has potential to remediate current plan issues. It outlines the process undertaken by the NDIA to develop the reference package. It also discusses the funding level options put forward by the hearing sector for early intervention reference packages. Finally, this chapter discusses how the children, their families and carers as well as the hearing sector are directly impacted by the delayed release of the early intervention packages.

An early intervention pathway

3.4 The current system where newborn babies are assessed generally in a hospital setting, before being referred to Australian Hearing for technical intervention is described by Ms Margaret Dewberry, Adviser, Deafness Forum Australia:

At the moment, Australian Hearing generally does not do the diagnosis; that is done through hospital systems, particularly for newborns, where it is certainly done in hospital systems, and perhaps community health or something like that for older children. From there they ring Australian Hearing. It is as simple as that. You tell Australian Hearing the age of your child. If that child is under 26, they are eligible. They might ask about their residency or citizenship status because you have to be an Australian citizen or permanent resident to be eligible. That information is taken verbally, and that is the end of the story of the eligibility check.

With the NDIS there are many more steps to make sure you meet the criteria and so on. That will slow things down, and that is the concern. We want children to be diagnosed and go immediately to intervention.¹

3.5 Professor Greg Leigh, Director, Royal Institute for Deaf and Blind Children observed that this current immediate early intervention service is world class, and it is essential that the transition to the NDIS does not jeopardise early intervention outcomes:

1 Ms Margaret Dewberry, Adviser, Deafness Forum Australia, *Committee Hansard*, 24 March 2017, p. 9.

The system that we have achieved for early identification of hearing loss and effective engagement with intervention services beyond that identification is, without doubt, at the forefront of services internationally, arguably matched only by services in Denmark...We simply do not lose children in our system. As we have heard from colleagues here this morning, the absolutely critical feature of the delivery of intervention services to children who are deaf or hard of hearing is timeliness. There is no scope for the loss of a day in the progress from identification to engagement with intervention services to ensure that children develop age-appropriate language and communication abilities... Why would you want to mess with a system that is the envy of the world?.²

3.6 Currently, there is no guided referral pathway to assist parents under the NDIS, which can lead to delays that did not occur prior the introduction of the NDIS. For example, Taralye, a Victorian service provider, noted that prior to the introduction of the NDIS, no waiting period for early intervention existed in Victoria for families with children who are deaf. However, this has not been the case since the introduction of the NDIS and the 'complicated and time-consuming' approval process.³

3.7 First Voice highlighted the potential negative consequences if the early intervention system under the NDIS was to fail:

One of the core principles of the NDIS is to invest in early intervention with the aim of reducing future disability supports. 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, can indeed achieve their full life potential...we must ensure that the key principles of Australia's world leading hearing services system for early childhood hearing loss – which includes early diagnosis, timely referral and amplification, and access to adequately funded service pathways – are fully supported and fully integrated into a 'good fit' public policy operating framework within the NDIS, and not diluted or compromised in any way.

Failure to do so would create systemic and life-long disadvantage to generations of children with hearing loss and their families, and set Australia's highly developed and internationally renowned hearing services sector back many years.⁴

3.8 First Voice noted that as a consequence of there being no guided referral pathway to assist parents under the NDIS there can be delays to the start of early interventions that affects children's outcomes. To overcome this, First Voice recommended that a guided referral pathway be established:

The evidence clearly shows that optimal outcomes require urgent, informed decisions followed by immediate action. Without appropriate guidance,

2 Professor Greg Leigh, Director, Royal Institute for Deaf and Blind Children, *Committee Hansard*, 20 February 2017, pp. 4–5.

3 Taralye, *Submission 50*, p. 6.

4 First Voice, *Submission 48*, p. 22.

parents will not have the knowledge to make the informed choices that would make possible the outcomes they wish for their child. A guided referral pathway is required so that parents are provided with the information and options they need for their child to achieve the outcomes they want.⁵

3.9 First Voice noted the urgency with which the early intervention process needs to be clarified given the large number of hearing-impaired children anticipated to join the Scheme in the next two years:

As at March 2017 only 235 hearing-impaired children have joined the NDIS of whom 150 are on service with the Cora Barclay Centre in the NDIS Children's Trial Site in SA. On current estimates a further 4,000 children are due to join the scheme in the next 12 to 24 months. Urgency is needed to fix these problems or a generation of hearing-impaired children will have worse outcomes than prior to the NDIS.⁶

3.10 First Voice concluded: 'Based on service providers' knowledge and experience of the different referral arrangements across Australia, it should not be difficult to design a national guided referral pathway that is neutral, family friendly, transparent and accountable'.⁷

3.11 The Royal Institute for Deaf and Blind Children concurred with the need to establish a timely early intervention pathway for hearing services under the NDIS:

Under the NDIS there is a delay in access to the [Hearing Services Program] early intervention pathway as the family await access to the NDIS and development of a Plan prior to accessing services. There is need for a streamlined approach to ensure early access and intervention through either the Hearing Services Program or the NDIS.⁸

3.12 A number of other inquiry participants advocated for the creation of a guided early referral pathway, including Telethon Speech and Hearing (TSH), Mr Mark Wyburn, Secretary, Parents of Deaf Children, Dr Jim Hungerford, Chief Executive Officer, The Shepherd Centre, and Mr Bart Cavalletto, Director, Services, Royal Institute for Deaf and Blind Children.⁹

3.13 The Shepherd Centre argued that having an NDIS guided referral pathway would minimise the delay between the emergence of permanent hearing loss and the

5 First Voice, *Submission 48*, p. 10.

6 First Voice, *Submission 48.1*, p. 1.

7 First Voice, *Submission 48.1*, p. 2.

8 Royal Institute for Deaf and Blind Children, *Submission 37*, pp. 9–10.

9 Telethon Speech and Hearing, *Submission 46*, p. 2; Mr Mark Wyburn, Secretary, Parents of Deaf Children, *Committee Hansard*, 20 February 2017, p. 36; Dr Jim Hungerford, Chief Executive Officer, The Shepherd Centre, *Committee Hansard*, 20 February 2017, p. 7; and Mr Bart Cavalletto, Director, Services, Royal Institute for Deaf and Blind Children, *Committee Hansard*, 20 February 2017, p. 12.

provision of appropriate services. The Centre explained how the pathway would function:

A guided referral pathway (such as within the NDIS, or potentially subcontracted) which would receive all of the referrals following diagnosis of hearing loss in children. The diagnosis, along with other relevant information, would be used to screen against the eligibility criteria for NDIS support. Families of eligible children would then be supported to ensure they rapidly obtain the required services from appropriate organisations, based on parent choice. The pathway would collect the standard demographic and audiological data on the diagnosed children; along with the NDIS identifier for those children eligible for the NDIS.¹⁰

3.14 The Shepherd Centre estimated that, based on the existing models of referral services, approximately 20 staff would be required to provide a national guided referral pathway and coordination service, at an annual cost of approximately \$3 million.¹¹

3.15 The Royal Institute for Deaf and Blind Children made three recommendations to assist parents and to minimise delays in early intervention:

- the Newborn Hearing Screening Pathway be maintained;
- consideration be given to the need for extension of the Hearing Services Program to cover the provision and fitting of devices other than hearing aids for children, particularly cochlear implants; and
- referral pathways that currently exist, providing Australia with a world class coordinated and sequential hearing and early intervention program, be maintained or replicated without causing delay to service access.¹²

Critical need for a central point of contact for newly-diagnosed children

3.16 When discussing the importance of a clear early intervention pathway for newborns diagnosed with hearing loss, it was suggested that the establishment of a central point of contact for parents of newly diagnosed children would be essential.

3.17 Professor Greg Leigh, Director, Royal Institute for Deaf and Blind Children explained the current scenario whereby Australian Hearing serves as a first point of reference for parents:

We currently have a system where children coming out of newborn hearing screening are referred to infant diagnostics locally within a state, then directly to Australian Hearing, and then from Australian Hearing to early intervention providers through a range of processes that provide information to families about where their options sit. In most cases that happens within a month of identification of children through newborn hearing screening. So, without saying it has to be that system, we need to

10 The Shepherd Centre, *Submission 40*, pp. 16–17.

11 The Shepherd Centre, *Submission 40*, pp. 16–17.

12 Royal Institute for Deaf and Blind Children, *Submission 37*, p. 11.

look to something that replicates that that has, for want of a better term, be honest broker who sits there as the point of first reference for a child coming out of diagnostic audiology.¹³

3.18 Professor Leigh suggested that under the NDIS there would be a need for a similar 'honest broker' to help parents through the process:

So we really do need some system, some honest broker who is not beholden to any of the parties in this...Ideally, I would like to see that system funded and agreed by the NDIS to be the mechanism by which children with hearing loss are taken from diagnostic audiology to engage with a range of approved and duly qualified service providers who are capable of doing the things we have been talking about doing, with a minimum of loss of time.¹⁴

3.19 One parent of a child diagnosed with hearing impairment contrasted their experiences with Australian Hearing during the initial diagnosis phase for their child and subsequent interactions with the NDIS as the Scheme rolled out:

We were fortunate that the system worked well for our family – [our child] was picked up during [the] newborn screen, diagnosed at five weeks, referred to Australian Hearing at 8 weeks of age and was fitted with hearing aids while still a young baby. [Our child] has been in early intervention since [they were] 9 weeks of age. [Our child] was given the best possible chance of developing normal speech and language before we'd really even figured out what hearing loss meant for the future. We will be forever grateful for that.

When [our child] was three years old, [they were] accepted as a participant to the NDIS. Our first planning meeting was not what we expected; our planner had no knowledge of paediatric hearing loss and was unable to provide any recommendations or guidance. Luckily, we had three years' experience under our belts, so were able to advocate well for our [child].¹⁵

3.20 The parent concluded: 'I don't know what we would have done had [they] been newly-diagnosed'.¹⁶

3.21 Mr Peter Miller, Director, Deafness Forum of Australia, observed that parents of newly diagnosed children often have little experience with hearing impairment and, as such, need support to understand the options available to support their child:

From personal experience, when parents find out their child is deaf they have no idea, because 90 per cent of deaf children are born to hearing parents. Hearing parents, in the first instance, would have no experience with their deaf child or what is best for them, whether it is hearing aids,

13 Professor Greg Leigh, Director, Royal Institute for Deaf and Blind Children, *Committee Hansard*, 20 February 2017, p. 8.

14 Professor Greg Leigh, Director, Royal Institute for Deaf and Blind Children, *Committee Hansard*, 20 February 2017, p. 8.

15 Name withheld, *Submission 3*, p. 2.

16 Name withheld, *Submission 3*, p. 2.

cochlear implants or going through sign language. They do not know, so it becomes really important that the process of getting the right support is clear and understood. That has been the benefit of having Australian Hearing. Everyone knew, doctors knew, that when they diagnosed a deaf child they went straight to Australian Hearing. There was a very clear path. Choice is always good, but sometimes choice can actually make it quite difficult for parents...The solution would be perhaps to not have so much choice but to have some clear direction, some clear option for parents, because in this situation—the early intervention with children—it is parents who make that decision.¹⁷

3.22 Ms Leonie Jackson, Chief Executive Officer, The Deaf Society, identified a need for parents being empowered to make an informed choice, rather than to simply be lead down one intervention pathway:

It is critical that they [families] have a person that leads them through the process and provides the various options to them so the family can make an informed choice. That person needs to be independent of those various service providers, and they need to understand that their job is to empower the family to make that informed decision, not to spoon feed them or lead them down a particular path.¹⁸

3.23 Can:Do Group, provider of specialist services for people with hearing and vision impairments in South Australia also expressed support for a central point of contact who understands both the principals of early intervention and the impact of hearing loss on a baby and family. Can:Do argued that the role should be filled by a psychologist, social worker or someone trained in both audiology and counselling.¹⁹

Proposed effective and rapid guided referral pathway to service to be provided by Australian Hearing

3.24 In June 2017, providers of specialist intervention for children with hearing loss provided the committee with a consensus statement describing the essential components required for an effective and rapid referral pathway to service.²⁰

3.25 The requirements for an effective referral pathways are:

- It must be designed to meet the international minimal standards of one month to diagnosis, three months to hearing aid fitting and six months to funded therapy;
- It must be funded by the NDIS and provided by Australian Hearing; and

17 Mr Peter Miller, Director, Deafness Forum of Australia, *Committee Hansard*, 24 March 2017, p. 7.

18 Ms Leonie Jackson, Chief Executive Officer, The Deaf Society, *Committee Hansard*, 20 February 2017, pp. 51–52.

19 Can:Do Group, *Submission 8*, pp. 4–5.

20 Shepherd Centre, Cora Barclay Centre and The Royal Institute for Deaf and Blind Children - Essential Components of Support for Children with Hearing Loss, additional information received 16 June 2017.

- Australian Hearing must remain an independent and objective referral pathway – it must not also provide therapy services.^{21 22}

3.26 The providers of specialist intervention for children with hearing loss believe the 'referral pathway needs to be provided by people who have expert knowledge in childhood hearing loss and must be accessible across Australia'.²³ Therefore, they recommend Australian Hearing to undertake this role as 'they already receives all children after they have had their hearing loss diagnosed, so is ideally placed to provide this service if funded to do so; due to its national footprint, expertise, and independence'.²⁴

Plan development

Current Planning process

3.27 Section 31 of the NDIS Act states that the development of a plan should so far as reasonably practicable be individualised, directed by the participant and maximise participant choice and control.

3.28 Variations and inconsistencies in supports provided within individual NDIS plans were reported throughout the inquiry. These variations were attributed to two main factors: firstly, that many planners lack the expertise to determine what 'reasonable and necessary' supports are for a person who is deaf or hard of hearing and secondly, the advocacy ability of individuals (parents in the case of children) in articulating and arguing for their support needs.

Skills and expertise of NDIS planners

3.29 Many submitters²⁵ commented on the lack of expertise amongst planners about the needs of deaf and hard of hearing people. For example, Canberra Deaf Children's Association reported:

Our members report their NDIS planners typically have no experience in hearing loss and were unable to provide guidance around what services or

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- 21 Shepherd Centre, Cora Barclay Centre and The Royal Institute for Deaf and Blind Children - Essential Components of Support for Children with Hearing Loss, additional information received 16 June 2017, p. 1.
- 22 The provision of speech therapy services by Australian Hearing is a new development, see Australian Hearing, *Speech Pathology Services*, available at: https://www.hearing.com.au/wp-content/uploads/2015/06/AH1053-Speech-pathology-brochure_print.pdf (accessed on 12 September 2017).
- 23 Shepherd Centre, Cora Barclay Centre and The Royal Institute for Deaf and Blind Children - Essential Components of Support for Children with Hearing Loss, additional information received 16 June 2017, p. 1.
- 24 Shepherd Centre, Cora Barclay Centre and The Royal Institute for Deaf and Blind Children - Essential Components of Support for Children with Hearing Loss, additional information received 16 June 2017, p. 1.
- 25 See for example: Deaf Australia, *Submission 51*, p. 26; Disability Services Commissioner, *Submission 25*, p. 1; Audiology Australia, *Submission 35*, p. 10.

providers were available. In some cases the NDIS did not know and could not advise what support the child required, beyond hearing aids.²⁶

3.30 The Royal Institute for Deaf and Blind Children noted:

Currently, decisions on service types and funding levels that are available to deaf and hard of hearing people are being made by NDIA planners who in most cases have little or no knowledge of a deaf or hard of hearing person's requirements and do not typically have relevant clinical expertise with this population. This has resulted in wide levels of funding availability for children and adults with similar needs and stands to compromise the quality and adequacy of available services.²⁷

3.31 National Disability Services (NDS) was also of the view that 'better planning is needed', and that this requires the NDIA to develop hearing impairment expertise amongst the pool of planners:

While we understand the current pressure on the NDIA to accelerate the development and activation of plans, there is frustration with the quality of new plans. As many planners do not understand the different supports needed depending on the type and cause of the hearing impairment and age of the participant, plans are inconsistent and of variable quality.²⁸

Importance of advocacy

3.32 A second reason cited for variations in individual NDIS plans was the variations in advocacy skills amongst NDIS clients. It was argued that the inclusions in plans depended in some part on the ability of individual participants to articulate and advocate for their support needs. For example, Ms Jackson said:

Plans go through if a person knows the system, if they are an advocate themselves and they know what to ask for, but that does not represent everybody. In particular, when we are talking about families that have had a child recently diagnosed, they do not know what to ask for. They do not know what they need at that point in time.²⁹

3.33 Ms Ann Porter, Chief Executive Officer and Director, Aussie Deaf Kids concurred:

We do have members who have quite varied packages—children with the same sort of hearing loss getting quite different packages (...) We want every child to get the services they deserve, not just the child whose family has some of the best advocates or can read the journals. We want it to be right for everybody.³⁰

26 Canberra Deaf Children's Association, *Submission 15*, p. 3.

27 Royal Institute for Deaf and Blind Children, *Submission 37*, p. 12.

28 National Disability Services, *Submission 29*, pp. 2–3.

29 Ms Leonie Jackson, Chief Executive Officer, The Deaf Society, *Committee Hansard*, 20 February 2017, p. 50.

30 Ms Ann Porter, Chief Executive Officer and Director, Aussie Deaf Kids, *Committee Hansard*, 20 February 2017, pp. 37–38.

3.34 Ms Porter emphasised: ‘...for a family coming in—when you do not know what an audiologist does and you have no idea what early intervention even is—I do not know how those parents can navigate the system’.³¹

3.35 These sentiments were echoed by Mr Mark Wyburn, Secretary, Parents of Deaf Children, who outlined his initial experience outside of the NDIS:

If we had not been the experienced parents we were when the NDIS came along we would have had a very bad outcome. In the first 12 months of our son's diagnosis we were in a bit of a fog. I am tertiary educated, my wife is a very clever person as well and we battled to understand our direction. It was probably not until about 12 months after that that we got an idea of which path we wanted our child to take with regard to early intervention. Even though he was getting it, we did not know if it was right or wrong. He was just having it.³²

3.36 Mr Wyburn continued to explain the difficulties his family faced in advocating for appropriate supports to be included in his son's NDIS plan when his son entered the NDIS after 4.5 years of self-funded supports:

We were very skilled advocates by then and we found it incredibly confronting. We were challenged on the efficacy of the therapy that we were undertaking. Even though we had been doing it 4 1/2 years, we were questioned on whether or not that was suitable and why it was so expensive. I do not begrudge the planners that their knowledge is not broad enough to cover every disability, because that is an impossibility to be quite honest. They have not got the capacity.³³

Delays in plan development

3.37 Another concern is the delays that have crept into the system. Delays in plan development, approval and enactment can have significant consequences for the health, social and educational outcomes for children who are deaf or hard of hearing. Hearing Business Alliance encapsulated these concerns:

We are concerned about any delay for children and adults receiving services. With children, any delay could have significant impact on the child's ability to learn, impacting on the development of speech and language (...) Hearing loss that is not treated can have negative psychological, cognitive and social impact.³⁴

3.38 A mother of a five year old girl with moderate hearing loss described the impact of delays for her daughter:

31 Ms Ann Porter, Chief Executive Officer and Director, Aussie Deaf Kids, *Committee Hansard*, 20 February 2017, p. 36.

32 Mr Mark Wyburn, Secretary, Parents of Deaf Children, *Committee Hansard*, 20 February 2017, p. 36.

33 Mr Mark Wyburn, Secretary, Parents of Deaf Children, *Committee Hansard*, 20 February 2017, p. 36.

34 Hearing Business Alliance, *Submission 24*, p. 3.

Another negative experience with the NDIS has been delays. Delays in our planner responding to emails (up to three months, at one point), delays in funding becoming available and delays in plan review meetings. The thing with hearing loss is that a delay – even one of 'just a few months' can last a lifetime. There's a limited window for speech development and having to wait months for funding or action can mean your child 'misses the boat' so to speak. I challenge you to spend a week without hearing and see how far behind you fall at work. Now imagine that happening at school, and imagine the frustration of missing out while your peers and teacher move on.³⁵

3.39 The Shepherd Centre stressed the particular importance of minimising delays for babies and children diagnosed with hearing loss, saying that any delay must not be longer than six months:

...newborn hearing loss has been referred to as a neurological emergency and it can be thought of as a slow-motion stroke. If a child can't hear complex and useful sounds during their first few years of life their brain will eventually lose the ability to even process sound. Once this ability is lost it is incredibly difficult to ever recover it.

Minimising the time from onset of loss through to receiving high-quality auditory stimulation (from the combination of an appropriate hearing device and appropriate early intervention) is critical for the successful support of a child with hearing loss. This delay must be kept as short as possible and should be a maximum of 6 months.³⁶

3.40 Concerns over delays in the delivery of services were also expressed by the Deafness Foundation, Children and Young People with Disability Australia and Vicdeaf.³⁷

Shortfalls in supports and funding

3.41 Inquiry participants highlighted a number of instances where allocated funding was insufficient to meet individual care needs, thus compromising the outcomes for deaf and hard of hearing NDIS participants. Concerns were also identified around variations in the amounts of funding received for individuals with comparable care needs. As a consequence, inquiry participants such as the Deaf Society asserted that 'some participants are worse off than before they entered the Scheme because of inconsistency in assessments and allocation of funding'.³⁸

3.42 The variability in plans is jeopardising outcomes for children who receive funding that is less than reasonable or necessary for their needs. For example, The Shepherd Centre observed that:

35 Name withheld, *Submission 3*, p. 3.

36 The Shepherd Centre, *Submission 40*, pp. 8–10.

37 Deafness Foundation, *Submission 10*, p. 2; Children and Young People with Disability Australia, *Submission 30*, p. 4; and Vicdeaf, *Submission 45*, p. 2.

38 The Deaf Society, *Submission 27*, p. 4.

As a result of the lack of reference packages, children across Australia who have been transferred to the NDIS have received widely varying and normally totally inadequate funding packages...Overall the effective funding provided by the NDIS often covers less than 50% of the cost of the services these children need to achieve age-appropriate outcomes.

These problems are extremely severe and acute. If allowed to continue, they will prevent children from being able to achieve the outcomes that their families and society can currently expect.³⁹

3.43 Mrs Aleisha Davis, General Manager, Clinical Programs, The Shepherd Centre, highlighted the experience of paediatric clients in the Australian Capital Territory and New South Wales:

... what we are seeing in New South Wales is that the Early Childhood Early Intervention transition provider packages, which my colleagues have talked about this morning, do not fit for children with hearing loss. Families can see that it does not fit, which raises the anxiety for them, as well. What we are seeing is a model without the reference packages that is not fitting and is causing up to 150/200 days between when children are applying for packages and when they are getting accepted and quoted for packages, which does not fall into the timeliness factor, which is where the risk comes in.⁴⁰

3.44 Similarly, First Voice described the current planning and funding arrangements as 'manifestly inadequate' and resulting in a typical gap of \$6000 to \$8000 per child per year.⁴¹

3.45 National Disability Services also reported that concerns about the provision of hearing services for children have emerged over the past three years 'with funding often insufficient to cover the costs of the required supports'⁴²

Inconsistencies leading to plan reviews and appeals

3.46 Ms Jackson highlighted that as a result of dissatisfaction with plans that have been prepared, the Deaf Society had recently been involved in a number of appeals processes, creating stress for deaf and hard of hearing people and their families:

Over the last six months we have assisted 60 individuals who have received their plan, and all of the 60 plans have been sent back for review through the appeals process. It is quite disappointing because that is another three-month wait, an additional three months, for the appeal process for them to finally get in the end what they require. These 60 people include families of deaf children, and what we are noticing now is how time critical it is—and we have seen that today—to make sure that the right services are provided

39 The Shepherd Centre, *Submission 40*, p. 18.

40 Mrs Aleisha Davis, General Manager, Clinical Programs, The Shepherd Centre, *Committee Hansard*, 20 February 2017, p. 10.

41 First Voice, *Submission 48*, p. 13.

42 National Disability Services, *Submission 29*, p. 5.

as soon as possible to these families and make sure they have a great start in life, reducing the stress on the family and the deaf people as well.⁴³

3.47 Ms Jackson said of that 60 plans that went for review, '40 came back with an increase, not to the level that the individual was actually comfortable with, but they accepted that it was an increase nonetheless'.⁴⁴

3.48 The Canberra Deaf Children's association reported the following case:

Another of our member's (Baby O – bilateral cochlear implants) parents reported that they had to have numerous reviews of their existing plan due to complications with an inexpensive specialist piece of equipment. During one of the reviews their funding was reduced by half. When this decision was questioned by the parents they were told that because Baby O was progressing well, the level of intervention was therefore no longer required and was reduced. The reason that Baby O was doing well on his hearing and language comprehension scores was because of the early intervention he had been receiving (through his NDIS funding). The reviewer had no comprehension of the benefits the early intervention was providing and without it, the family will probably need increased funding next year. Baby O's family have still not received the piece of equipment 9 months after it was approved and have just started an internal review to try and get back to the previous year's level of funding.⁴⁵

Development of Reference packages

3.49 Many inquiry participants were of the view that much of the variations in plans could be overcome by the development of baseline reference packages to guide Scheme participants and planners in the preparation of individual plans. For instance, the Royal Institute for Deaf and Blind Children said:

The reference packages should provide an expected consistent annual funding level for participants with similar support needs and characteristics and reflect the development of the individual support plans. The reference packages should ensure that services are available from identification through screening.⁴⁶

3.50 Deaf Australia concurred with the need for baseline packages to guide plan development, stating: 'Deaf Australia proposes that reference packages must address the holistic needs of both deaf and hard of hearing constituencies, and their diverse preferences in terms of access to information and communication, including through Auslan, technologies and other supports'.⁴⁷

43 Ms Leonie Jackson, Chief Executive Officer, The Deaf Society, *Committee Hansard*, 20 February 2017, p. 48.

44 Ms Leonie Jackson, Chief Executive Officer, The Deaf Society, *Committee Hansard*, 20 February 2017, p. 51.

45 Canberra Deaf Children's Association, *Submission 15*, pp. 5–6.

46 Royal Institute for Deaf and Blind Children, *Submission 37*, pp. 17–18.

47 Deaf Australia, *Submission 51*, p. 4.

3.51 As noted in chapter one, in January 2017, the NDIA advised that it was developing reference packages to guide planners and LAC partners in building participant plans, including guidance on reasonable and necessary funded supports.⁴⁸

3.52 The NDIA outlined the purpose of reference packages:

Reference packages aim to provide an annual benchmark funding guide for the level of support for participants with similar support needs and characteristics. Informed by evidence provided by the research literature and EIHERG, NDIA staff have drafted a suite of typical support packages for children with hearing impairment relative to age and severity of impairment. This analysis will be further tested with stakeholders over the coming months.⁴⁹

3.53 The NDIA further advised the committee that in addition to the reference packages for early interventions, it would soon commence work on ‘evidence based reference packages across the lifespan’:

This will continue the methodology applied to early childhood in updating reference packages for adults. This includes development of resources and will see staff trained and competent in interpreting the needs of children and others with hearing impairment and considering their needs against the benchmark data.⁵⁰

NDIA and the development of reference packages

Consultation with stakeholders

3.54 With respect to consultation with key stakeholders in the design of NDIS hearing services, particularly in the development of reference packages, the NDIA said that it maintained ongoing dialogue with a broad range of stakeholders, including:

- Office of Hearing Services, administered by the Department of Health
- Department of Social Services
- Department of Veteran’s Affairs
- Australian Hearing
- academics
- peak bodies
- service providers.⁵¹

3.55 The NDIA advised that a number of these stakeholders are members of the NDIS Early Intervention Expert Hearing Reference Group (EIHERG) which comments on issues such as the implementation of the NDIS access criteria; potential

48 National Disability Insurance Agency, *Submission 13*, p. 3

49 National Disability Insurance Agency, *Submission 13*, p. 3.

50 National Disability Insurance Agency, *Submission 13*, pp. 3–4.

51 National Disability Insurance Agency, *Submission 13*, pp. 7–8.

for delays in referral from newborn hearing screening programs; and the clinical standards, governance, and expertise required to deliver specialist hearing services for infants and young children. The EIHERG membership includes:

- Telethon Speech and Hearing
- Hear and Say
- Office of Hearing Services
- Monash Health
- Shepherd Centre
- Taralye
- Aussie Deaf Kids
- Cora Barclay
- Royal Institute for Deaf and Blind Children
- Deafness Forum
- Speech Pathology Australia
- Australian Hearing
- Parents of Deaf Children
- The Deaf Society of NSW.⁵²

3.56 In answers to questions on notice, the NDIA explained that it has consulted with the EIHERG on six occasions through a series of face-to-face, full-day workshops with preparatory phone consultations:

EIHERG workshop outcomes have been incorporated into practical guidance for staff. The first workshop informed the development of draft access guidance for hearing impairment which ensures a consistent approach to access for children to the NDIS. The initial ‘reasonable and necessary’ framework—a qualitative description of the reasonable and necessary supports for hearing impairment—was drafted at the second workshop. This ensures consistent, evidence based approach to funding provided to children. The third workshop focused on quantifying reasonable and necessary supports for early intervention of hearing impairment, which is informing the development of benchmark packages, due for finalisation by the end of April 2017.⁵³

3.57 The NDIA undertook to continue to work with the EIHERG to ensure they have appropriate input to the typical support packages for deaf and hearing impaired people.⁵⁴

52 NDIA, *Submission 13*, pp. 7–8.

53 NDIA, answers to questions on notice, 24 March 2017, SQ17-000063, pp. 1–2.

54 NDIA, answers to questions on notice, 24 March 2017, SQ17-000063, pp. 1–2.

3.58 However, a number of inquiry participants involved with the EIHERG acknowledged the efforts of the NDIA to engage with key stakeholder groups, but questioned the impact the stakeholder feedback has had on policy development. For example, Ms Margaret Dewberry, Adviser, Deafness Forum Australia said:

There is enormous goodwill within the NDIA. We certainly feel we are listened to, but we are still not clear what is going to be the outcome.⁵⁵

3.59 The Shepherd Centre similarly observed that while the NDIS was receptive to feedback through the EIHRG and other forums, it was difficult to identify changes that have been made in response to that feedback:

The consultation processes that have occurred have been neither transparent nor accountable, despite the best efforts of the individuals involved from the NDIA. Representatives from specialist early intervention services have been well represented on the NDIA's Early Intervention (Hearing) Expert Reference Group. However the group has met infrequently and there have not been any outcomes produced.

Expert stakeholders including The Shepherd Centre have also made many representations (written, face-to-face, phone/email) to the NDIA outside of this expert reference group with no actions forthcoming.

The NDIA staff have been consistently professional and responsive. However despite ongoing dialogue there has been no change to the fundamental issues with the NDIS service and funding framework being applied to childhood hearing services.⁵⁶

3.60 Similar comments were made by Hear and Say, Taralye and First Voice.⁵⁷

Timeframe and delays

3.61 The NDIA advised it would be publically releasing the early intervention reference packages by the end of April 2017:

...at the end of April we are looking to be announcing this [reference packages]. I think we have two more sessions with the expert group—one on the telephone and one face-to-face—scheduled. It would be towards the end of that April period, as I understand the time line.⁵⁸

3.62 Mr de Natris, Expert Adviser, NDIA, concurred with this April timeframe for the release of the early intervention reference packages:

We probably are at a point where those baseline packages are all but done. It is interesting that we can all agree on the evidence, we can all agree on

55 Ms Margaret Dewberry, Adviser, Deafness Forum Australia, *Committee Hansard*, 24 March 2017, pp. 6–7.

56 The Shepherd Centre, *Submission 40*, p. 26.

57 Hear and Say, *Submission 33*, p. 7; Taralye, *Submission 50*, p. 9; and First Voice, *Submission 48*, pp. 16–17.

58 Ms Louise Glanville, Deputy Chief Executive Officer, NDIA, *Committee Hansard*, 24 March 2017, p. 16.

what should be provided; it is the intensity of what will be provided that probably differs between some of the sections. We will have that work done by the end of April and we will be implementing it to get national consistency.⁵⁹

3.63 However, at September 2017, the early intervention reference packages have still not been released. The committee understands the NDIA is undertaking further work, including actuarial modelling on this matter and that the reference packages will not be available before the end of 2017.

What should be included in reference packages

3.64 The Disability Council of NSW considered that any reference packages should take a holistic approach to the individual's experience of disability, rather than a narrow measure of clinical impairment. The Council said:

It is absolutely vital that reference packages refer to the full range of hearing services from which an individual could benefit - even if a service is not currently available in that person's locale, as some people with disability may have the capacity and desire to advocate for new services or even to move to obtain appropriate services. Further, planners and decision-makers need to fully understand the very varied needs of the different individuals they work with, and provide advice which is:

- unbiased
- evidence-based
- complete
- accessible.⁶⁰

3.65 As noted earlier in this report, Deaf Australia is of the view that the reference packages must address the holistic needs of both deaf and hard of hearing constituencies and their preferences in terms of access to information and communication.⁶¹

3.66 To address inadequacies in funding, the Shepherd Centre proposed a protocol for NDIS early intervention reference packages. The proposed protocol would define the level of service that would be funded for each child, based on diagnosis and need, along with specification of the other features that are needed. The key elements of the proposed protocol are:

- all children with all levels of permanent hearing loss be eligible for support, with scaled funding depending on need:
 - low - \$12 000 per annum
 - medium - \$16 000 per annum

59 Mr Peter de Natris, Expert Adviser, NDIA, *Committee Hansard*, 24 March 2017, p. 14.

60 Disability Council of NSW, *Submission 54*, p. 11.

61 Deaf Australia, *Submission 51*, p. 4.

- high - \$21 000 per annum;
- services eligible for funding must meet required quality standards including breadth of support program, support in addition to face-to-face hours, and compliance with minimal outcome measures; and
- funding for additional services beyond the core program is provided in addition to the standard funding, such as for any other additional disabilities.⁶²

3.67 The Shepherd Centre estimated that implementation of the proposed protocol would require a total annual funding of approximately \$47 million.⁶³

3.68 First Voice similarly recommended a scalable early childhood intervention protocol, with four levels determined on what degree of support was needed for a deaf or hard of hearing child to achieve and maintain age-appropriate communication.⁶⁴ The levels proposed by First Voice were:

- children who are pre-lingual and those with communication skills below their peers require intensive services costing from \$18 000 to \$24 000 per annum;
- children with risk factors that mean that they are likely to have communication skills below their peers require intensive services costing from \$18 000 to \$24 000 per annum;
- 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 costing from \$12 000 to \$18 000 per annum (most children with hearing loss will fit in this category); and
- children with communication developing along an age-appropriate trajectory and without risk factors that put their ongoing development at risk require sustaining therapy costing from \$6 000 to \$12 000 per annum.⁶⁵

3.69 Hear and Say, a not-for-profit organisation located in Queensland that provides hearing, speech and language support to children with hearing loss and their families, also advocated for a scalable model of funding that would provide ‘adequate funding for specialised, intensive and evidence based early intervention programs which aim to achieve and maintain age-appropriate communication for all children with hearing loss’.⁶⁶

Impact of the delay in finalising the reference packages

3.70 In August 2017, the committee sought the view of service providers on the impact of the NDIA further delaying the release of the reference packages.

62 The Shepherd Centre, *Submission 40*, p. 21.

63 The Shepherd Centre, *Submission 40*, p. 21.

64 First Voice, *Submission 48*, p. 13.

65 First Voice, *Submission 48*, pp. 12–13.

66 Hear and Say, *Submission 33*, p. 5.

3.71 Submitters reported that many children continue to receiving inadequate plans, which lead to shortfall in the funding provided for children with hearing loss. The Shepherd Centre explained that 'this shortfall is due to the NDIS not having established reference packages that appropriately fund the specialised and integrated services that children with hearing loss require to achieve age-appropriate language'.⁶⁷

3.72 As described by the Royal Institute for Deaf and Blind Children, this is resulting in 'providers having to fund the shortfall through charitable contributions or children are receiving less intervention'.⁶⁸

3.73 For example, the Cora Barclay Centre, which 'has been 100% committed to ensuring that all participants continue to have access to a full range of services with the belief that no child should be disadvantaged due to having insufficient support through the NDIS has borne the financial burden of providing full services despite receiving insufficient funding from the NDIS'.⁶⁹

3.74 Another issue is that early intervention providers cannot be paid retrospectively. Given the critical importance of starting immediately after diagnosis the delivery of early intervention services to achieve the best possible outcomes, many early intervention providers provide services without receiving payments. As CYDA explained

The early intervention service cannot provide services before an NDIS plan has been approved and expect to receive payment for the services provided. Therefore the early intervention service is left in the difficult position of having to provide services to families without receiving payment for these services or ask families to wait until their eligibility is assessed and their plans approved before they can access their preferred provider.⁷⁰

3.75 The situation is becoming financially untenable for the sector. For example, the Cora Barclay Centre in South Australia is currently incurring losses in the order of \$40 000 to \$50 000 per month in order to continue to provide adequate therapies and supports to children.⁷¹

3.76 The Shepherd Centre which services children in the ACT and NSW has suffered a financial loss of over \$900 000 in 2016 alone due to the NDIS. The Centre reports that the funding situation has not improved in 2017 and that 'overall, for the 62 plans approved so far this year for children in our early intervention program, the average cost of the service was \$16 700 and the average funding was \$10 500. The average shortfall of \$6 200 per child is the equivalent of \$2.1 million dollars a year for the 340 children who participated in our EI program in 2016'.⁷²

67 The Shepherd Centre, *Submission 40.3*, p. 1.

68 The Royal Institute for Deaf and Blind Children, *Submission 37.1*, p. 5.

69 Cora Barclay Centre, *Submission 55.2*, p. 3.

70 CYDA, *Submission 30*, p. 4.

71 Cora Barclay Centre, *Submission 55.2*, p. 3.

72 The Shepherd Centre, *Submission 40.3*, p. 3.

3.77 The Shepherd Centre stated:

This cannot continue and very soon, as charities exhaust their reserves, services must be cut. We have already seen one major charity in the sector conclude that this is not sustainable and it has decided to be absorbed into a larger charity. This reduces the choice and options available to parents, a market failure that is in direct contrast to the aim of the NDIS.⁷³

3.78 The consequences of providers having to reduce or cease effective programs will result in 'an increase in the number of children and then adults with delayed language and potentially with no functional spoken language at all'.⁷⁴

3.79 The Shepherd Centre concluded:

The future negative impacts of this will be massive, for the child; for society; and also for the NDIS (with the need to then provide life-long support due to the permanent disability that should have been avoided).⁷⁵

3.80 All submitters urged the NDIA to immediately establish and release reference packages that fund the cost of effective early intervention programs.⁷⁶

Committee view

Guided referral pathway

3.81 The committee noted with great concern that the transition to the NDIS has disrupted a world class system which had worked very well until now. Guided pathways – to ensure a family engages with a service that will meet their needs – were previously available, but have been lost with the move to the NDIS. This is resulting in delays in the start of funded therapies, which are critical to ensure children can be taught to communicate as well as any other child (with spoken or signed language) and can become active participants in the social and economic life of their community. The committee is strongly of the view that an appropriate system must be immediately implemented to support the children. The committee is disappointed that despite the NDIA being cognizant of these issues it has not been proactive in exploring options to introduce an effective guided referral pathway for the estimated 4000 children that will join the NDIS by 2019–20.

3.82 The committee understands that the referral pathways and the Hearing Services Program had worked very well. The committee agrees that a nationally accessible expert independent broker is required to advise and guide families. The committee believes Australian Hearing is best placed to take on this role because it already receives all children after they had been diagnosed. Additionally, it has a national footprint and the required expertise. The committee is of the view that

73 The Shepherd Centre, *Submission 40.3*, p. 3.

74 The Shepherd Centre, *Submission 40.3*, p. 3.

75 The Shepherd Centre, *Submission 40.3*, p. 3.

76 See: Cora Barclay Centre, *Submission 55.2*, p. 4; First Voice, *Submission 48.1*, p. 3; Taralye, *Submission 50.1*, p. 1; The Royal Institute for Deaf and Blind Children, *Submission 37.1*, p. 5 and The Shepherd Centre, *Submission 40.3*, p. 3.

Australian Hearing be formally appointed and appropriately funded to be the independent referral pathway for access to early intervention services under the Scheme.

Recommendation 4

3.83 The committee recommends Australian Hearing be formally appointed as the independent referral pathway for access to early intervention services under the NDIS and funded appropriately to take on this new role.

3.84 In terms of Australian Hearing providing therapy services such as their new speech pathology program, the committee understands the concerns of other organisations in the sector wanting to ensure that any organisation tasked with providing independent advice free from the perception of a conflict of interest. However the committee is concerned that there may be instances where Australian Hearing would be the best placed organisation to provide particular services, and would not want to formally limit the utilisation of its expertise.

Reference packages

3.85 The committee strongly supports the introduction of baseline reference packages. Inquiry participants as well as the NDIA have described at length the benefits of introducing early intervention reference packages. There is no doubt that the NDIA will eventually introduce them. The questions are when will they be released and will they be appropriate? Whilst the committee has not had the opportunity to see the draft national reference packages prepared by the NDIA, it has been advised by service providers who have seen the draft packages that they are far below the cost of providing effective services. The committee recommends the NDIA ensures the final early intervention reference package fully fund the costs of programs that have been shown to be effective. They also need to enable a holistic approach to the needs of the deaf and the hard of hearing. The committee supports the proposed scalable early childhood intervention protocol put forward by submitters. The committee also urges the NDIA to release, as a matter of urgency, the early intervention packages.

Stopping funding gaps

3.86 Prior to the introduction of the NDIS, early intervention providers were block funded and started providing early intervention services to children as soon as they came to their centres. With the transition to the NDIS and the change to a fee for service model, early intervention service providers are facing significant financial challenges because they have to bear the costs of services until the participant's plan is enacted. The NDIS does not pay for services provided before a plan is enacted. This is a cause of great concern for the committee as this is not financially sustainable for service providers. The committee heard that some of the providers of specialist early intervention services may have to stop or reduce their services if this issue is not resolved. This is putting at risk the delivery of essential and timely supports for children. Given the importance of minimising delays between diagnosis and commencement of funded early intervention services, the committee is of the view

that early intervention programs must start as soon as possible after diagnosis and must be funded by the NDIS from the start.

Recommendation 5

3.87 The committee recommends NDIA ensures that the early intervention packages take a holistic approach to the needs of participants and include:

- **scaled funding, depending on need;**
- **funding provision for additional services beyond core supports, depending on need; and**
- **retrospective payment of the costs borne by approved service providers for the provision of necessary and reasonable supports between time of diagnosis and plan enactment.**

NDIA approach and unacceptable delays

3.88 The committee acknowledges the efforts made by the NDIA to consult with key stakeholders in the design and development of reference packages. However, in light of the evidence received by the committee, the committee urges the NDIA to clearly communicate outcomes of these consultations to key stakeholders and to provide regular updates to the sector.

3.89 During the course of the inquiry, the NDIA had indicated a release date of end of April 2017 for the reference packages. At the time of finalising this interim report, the reference packages are yet to be released. This significant delay is a great source of concern for the committee and highly distressing for NDIS participants, their families and carers and the hearing sector.

Recommendation 6

3.90 The committee recommends the NDIA urgently finalise, publish and introduce the early intervention reference packages.

Next steps

3.91 The committee will review the reference packages once available, as well as assessing the efficacy of the revised eligibility criteria in its final report.

Hon Kevin Andrews MP
Chair

Senator Alex Gallacher
Deputy Chair

