



Joint Standing Committee on the National Disability Insurance Scheme

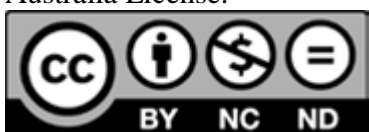
Provision of hearing services under the
National Disability Insurance Scheme

September 2017

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Executive Summary

It is anticipated that approximately 16 000 to 20 000 people with hearing impairments as their primary disability will join the NDIS by 2019-2020. This will represent a small cohort within the Scheme (less than 3% of NDIS participants). However the introduction of the NDIS has undoubtedly had a disruptive effect on what is broadly recognised as international best practice in the support provided to deaf and hearing impaired. Some extremely concerning issues have emerged and need to be resolved to ensure deaf and hard of hearing people continue to receive world class services.

An interim report

In March 2017, the committee delayed finalising its report pending release by the NDIA of (a) key operational guidelines for access criteria to the Scheme for deaf and hard of hearing people and (b) baseline reference packages to guide plan development for early intervention services. The NDIA had indicated to the committee that it would release the guidelines and packages by the end of April 2017. While the NDIA released guidelines for access criteria on 1 September 2017, the early intervention packages remain outstanding. Without definitive information about the early intervention packages, the committee cannot report and make considered recommendations. This is a cause of great concern for many families, the hearing sector and this committee.

The committee has therefore decided to release an interim report while it awaits the release of the packages. This interim report focuses on the access criteria to the Scheme and the issues pertaining to access and delivery of early intervention services.

Access criteria

Until now, there has been a lack of clear access criteria to determine eligibility to NDIS services for deaf and hard of hearing people. This has caused great uncertainty for future access to services and supports for deaf and hard of hearing people, especially for newly diagnosed infants and children. The committee is relieved that clear guidance to determine access to the Scheme has finally been articulated and publically released by the NDIA. However, the committee is frustrated it has taken so long.

Based on the evidence received to date, the recently released access criteria for early intervention requirements for deaf and hard of hearing people aged 0-25 appear to be technically consistent with the current practices of Australian Hearing, and are therefore broadly welcomed by stakeholders. In regards to the access criteria for those 26 years or older, the committee is concerned that the requirements may leave some people not eligible to the Scheme despite their need for reasonable and necessary supports.

Early intervention services

The committee is also concerned with the disruptions to early intervention services that have occurred since the introduction of the NDIS. The NDIS is failing to

streamline intervention services: from referral pathways, to access and funding of services for newly diagnosed participants.

Guided pathways to ensure families could engage as early as possible with services that meet their needs have been lost. It is a clinical fact that timely early intervention for deaf and hard of hearing children produces optimal results, yet evidence of delays to access therapies is mounting. Confusion, absence of guided advice, lack of choice and control over access to services, are regularly reported by families and carers. Inadequate and underfunded NDIS plans are commonly awarded to children, and as a result opportunities for children to be taught to communicate as well as any other child (with spoken or signed language) are being lost. The committee believes it is critical the NDIA addresses these issues as a matter of urgency. The introduction of a guided referral pathway is necessary to ensure no delay between diagnosis and commencement of therapies. Appropriately designed and funded early intervention reference packages must also be implemented.

Recommendations and next steps of the inquiry

The committee has made a number of recommendations in relation to the matters discussed in this interim report. The committee intends to release its final report once the NDIA has introduced its early intervention reference packages. In addition to discussing the appropriateness of the packages, the final report will discuss the other issues raised during the inquiry not reported in the interim report. The committee will continue to consult the hearing sector as required until the committee completes its inquiry.

Recommendations

Recommendation 1

2.57 The committee recommends the NDIA monitors eligibility rates for adults with hearing impairments to build a clearer picture of the number and needs of the people who have been found ineligible for NDIS services and reports on its finding in 12 months.

Recommendation 2

2.58 The committee recommends the NDIA reviews immediately the cases of people with hearing impairment who were previously found ineligible and tests their eligibility against the revised guidelines.

Recommendation 3

2.59 The committee recommends the Australian, state and territory governments clarify and make public how they will provide services for people who are deaf and hard of hearing who are not participants in the NDIS.

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.

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.

Recommendation 6

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

Chapter 1

Introduction

Referral of inquiry and terms of reference

1.1 The Joint Standing Committee on the National Disability Insurance Scheme (NDIS) was established on 1 September 2016. The committee is composed of five Members and five Senators.

1.2 The committee is tasked with inquiring into:

- a. the implementation, performance and governance of the NDIS
- b. the administration and expenditure of the NDIS; and
- c. such other matters in relation to the NDIS as may be referred to it by either House of the Parliament;

1.3 After 30 June each year, the committee presents an annual report to the Parliament on the activities of the committee during the year, in addition to other reports on any other matters it considers relevant.

1.4 The committee is also able to inquire into specific aspects of the Scheme. The committee agreed to undertake an inquiry into the provision of hearing services under the NDIS on 30 November 2016.

1.5 The terms of reference for the inquiry are as follows:

1. That the joint committee inquire into and report on the provision of hearing services under the National Disability Insurance Scheme (NDIS), with particular reference to:
 - (a) the eligibility criteria for determining access to, and service needs of, deaf and hearing impaired people under the NDIS;
 - (b) delays in receiving services, with particular emphasis on early intervention services;
 - (c) the adequacy of funding for hearing services under the NDIS;
 - (d) the accessibility of hearing services, including in rural and remote areas;
 - (e) the principle of choice of hearing service provider;
 - (f) the liaison with key stakeholders in the design of NDIS hearing services, particularly in the development of reference packages;
 - (g) investment in research and innovation in hearing services; and
 - (h) any other related matters.

Reporting by the committee

1.6 Initially, the committee delayed the completion of its report because it was expecting the release by the NDIA of key operational guidelines relating to a) the access criteria to the Scheme for deaf and hard of hearing people and b) to the

development of early intervention reference packages. The NDIA indicated that they would release these guidelines for by the end of April 2017.¹

1.7 On 1 September 2017, the NDIA publically released the access criteria to the NDIS. The NDIA is yet to release the early intervention reference packages.²

1.8 As a result, the committee has decided to release this interim report, which focuses on these two critical issues: the access criteria to the NDIS for deaf and hard of hearing people and early intervention services.

1.9 The committee intends to release its final report once the early intervention reference packages have become public. The final report will discuss the reference packages and will address the other terms of reference not covered by this interim report as well as additional issues raised by participants.

Structure of interim report

1.10 This interim report is comprised of three chapters, as follows:

- this chapter (chapter one) outlines the administration of the inquiry and provides an overview of hearing services and the transition to the NDIS;
- chapter two discusses the eligibility criteria and the recently released NDIA guidelines for determining access to the NDIS; and
- chapter three focuses exclusively on early interventions issues and the development of the early intervention reference packages.

Conduct of the inquiry

1.11 The committee received 55 submissions to the inquiry from individuals and organisations. These submissions are listed in Appendix 1.

1.12 The committee also conducted two public hearings on 20 February 2017 and 24 March 2017.

1.13 Transcripts from these hearings, together with submissions and answers to questions on notice are available on the committee's website.³

Acknowledgements

1.14 The committee would like to thank the individuals and organisations that made written submissions to the inquiry, as well as those who gave evidence at the two public hearings. We are grateful for their time and expertise.

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

2 NDIA, additional information received, 1 September 2017.

3 www.aph.gov.au/joint_ndis

Note on terminology and references

1.15 References to submissions in this report are to individual submissions received by the committee and published on the committee's website. References to Committee Hansard are to official transcripts.

1.16 The committee intends to use the term deaf and hard of hearing to encompass the diverse community that has some form of hearing impairment, including people who identify as deaf, hard of hearing, or deafblind.

1.17 The diversity of the deaf or hard of hearing community was best described by Ms Philippa Angley, Executive Officer to the Chief Executive Officer, National Disability Services:

NDIS participants with hearing impairment are diverse. There are those who acquire a hearing impairment as they age, which is well after they have developed language; children who are born deaf or who may become deaf as a young child; children who may receive a cochlear implant, children born to parents who decide that their child will be part of the deaf community and not receive a cochlear implant or may receive hearing aids; there are people who are born or become deafblind, and I think they are a particularly marginalised group within the disability population; there are Indigenous Australians with hearing loss; there are those living in rural and remote areas, where access to services is much more limited; and, of course, there are people from culturally diverse backgrounds.⁴

1.18 Ms Angley noted that as a consequence of this diversity, attention should be focussed on the need to design and implement an NDIS that supports all eligible people with hearing impairment and their varied needs: 'There is no single solution that will meet the needs or preferences of all'.⁵

Overview of hearing services

1.19 One in six Australians is affected by hearing loss. Prevalence rates for hearing loss are associated with increasing age, rising from less than one per cent for people aged younger than 15 years to three in every four people aged over 70 years.⁶

1.20 In Australia, between 9 and 12 children per 10 000 live births will be born with a moderate or greater hearing loss in both ears. Around another 23 children per 10 000 will acquire a hearing impairment that requires hearing aids by the age of 17 through accident, illness or other causes.⁷

4 Ms Philippa Angley, Executive Officer to the Chief Executive Officer, National Disability Services, *Committee Hansard*, 20 February 2017, p. 40.

5 Ms Philippa Angley, Executive Officer to the Chief Executive Officer, National Disability Services, *Committee Hansard*, 20 February 2017, p. 40.

6 Access Economics, *The economic impact and costs of hearing loss in Australia*, a report by Access Economics Pty Ltd, February 2006.

7 Australian Hearing, *What are the most common causes of hearing loss?*, <https://www.hearing.com.au/causes-hearing-loss-australia/> (accessed 24 August 2017).

1.21 All babies born in Australia are screened for hearing loss at birth under the Australian Government's Universal Newborn Hearing Screening program. Those who receive a 'refer' result from their screening (or are detected later) will go on to a diagnostic service and then, if a hearing loss is diagnosed, attend Australian Hearing and/or a Cochlear Implant service for further assessment and assistance.⁸

1.22 The majority of hearing services are provided by the Hearing Services Program (the Program), which provides services to a range of people with mild to profound hearing loss, including children and young adults, some Indigenous Australians and aged and disability pensioners. The Program is delivered through Australian Hearing and through other accredited private sector providers.

1.23 Therapies, including education and communications programs are mostly delivered by a range of private providers, including charitable organisations. Access and referral pathways to these services vary depending on jurisdictions.

Hearing Services Program (the Program)

1.24 The Office of Hearing Services (OHS) was established in 1997 to administer the Hearing Services Program (the Program). The Program provides access to subsidised hearing services and devices for eligible people, and supports research that assists with reducing the incidence and consequences of hearing loss in the community.⁹

1.25 The Program has two streams for the delivery of hearing services: the Voucher Scheme and the Community Service Obligations (CSO). Additionally, it supports and funds program-relevant research, including through the National Acoustic Laboratories (NAL).

1.26 Hearing services are provided under the Voucher Scheme by a national network of private hearing services and Australian Hearing.

1.27 Australian Hearing is the sole provider of hearing services for the CSO stream.¹⁰ The organisation was originally established by the Australian Government in 1947 to provide hearing services to children and veterans who suffered hearing damages during World War II. Australian Hearing is a statutory authority constituted under the *Australian Hearing Services Act 1991*, reporting to the Minister for Human Services.

The Voucher Scheme

1.28 The Voucher Scheme enables eligible clients to obtain hearing services and devices from a national network of private hearing services providers and Australian Hearing. In 2015–16, around 690 000 clients received a service under the Scheme,

8 Department of Health, *Submission 1*, p. 4.

9 Department of Health, *Submission 1*, p. 5.

10 Australian Hearing, *Submission 47*, p. 1.

with approximately 1.2 million services being delivered. The average age of eligible clients was 77, with 89 per cent of program clients aged over 65.¹¹

1.29 The Scheme gives participants access to a wide range of fully or partially subsidised hearing devices, maintenance, and ongoing support. These services are provided by approximately 300 private providers, offering services out of approximately 3700 sites, accredited with the program, including Australian Hearing.¹²

1.30 The majority of people who receive a voucher from the program are over 65 years of age and are ineligible for the NDIS. Voucher clients who are not eligible for the NDIS will continue to receive services through the Program.

Community Service Obligations (CSO)

1.31 The Community Service Obligations (CSO) provides specialist services to young Australians aged 0–26 years, including young NDIS participants, Voucher eligible adults with complex hearing needs, Indigenous groups, or participants in the Remote Jobs and Communities Program or the Community Development Employment Projects Program.¹³

1.32 In 2015–16, DHS provided \$65.3 million to Australian Hearing for CSO services.¹⁴ Australian Hearing reports that under the CSO in 2015–16:

- 29 850 children or young adults under 21 received 67 864 services;
- 3628 young adults aged between 21–26 received 7736 services;
- 23 344 adults with specialised needs received 53 771 services;
- 4300 Indigenous people received 8256 services; and
- 578 cochlear implant speech processors were funded through the speech processor upgrade program.¹⁵

1.33 Australian Hearing services include assessing hearing, fitting hearing devices and providing counselling and rehabilitative programs to enable eligible customers to manage their hearing impairment.¹⁶

1.34 Australian Hearing works closely with newborn hearing screening programs and early intervention agencies to streamline service access. Newly diagnosed children are offered an appointment within two weeks of the referral receipt.¹⁷

11 Department of Health, *Submission 1*, p. 6.

12 Department of Health, *Submission 1*, p. 5.

13 Department of Health, *Submission 1*, p. 7.

14 Department of Health, *Submission 1*, p. 7.

15 Australian Hearing, *Annual report 2015-16*, p.16, <https://www.hearing.com.au/wp-content/uploads/2016/10/Australian-Hearing-Annual-Report-2016-FINAL.pdf> (accessed 25 August 2017).

16 Australian Hearing, *Submission 47*, p. 1.

1.35 The system has been described as world class, especially in the field of early intervention services and programs for newborns and young children:

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...¹⁸

Transition of services to the NDIS

1.36 Commonwealth, state and territory programs providing services and supports to people who are deaf and hard of hearing are transitioning in full or in part to the NDIS.

1.37 There are four Commonwealth programs transitioning in full or in part to the NDIS. They are:

- Hearing Services Program (the Program) funded by the Department of Health transitioning part of its services to eligible NDIS participants. It is expected that by 2019–20, when the NDIS reaches full national roll out, a portion of program clients under 65 years of age will transition to the NDIS;¹⁹
- National Auslan Interpreter Booking and Payment Service (NABS) funded by the Department of Social Services. Funds for clients under 65 years will be transitioned to the NDIS;²⁰
- Remote Hearing and Vision Services for Children up to 18 years of age in outer and remote locations across Australia funded by the Department of Social Services. It is a small program currently providing services to fewer than 60 children²¹ via remote service delivery methods. The Royal Institute for Deaf and Blind children is the sole provider of this program. It is expected most participants will be eligible for the NDIS. The program is transitioning in full to the NDIS;²²
- Better Start for Children with Disability, which assists eligible children with developmental disabilities to access funding for early treatment, diagnostic and management services. Under the program, children under the age of six with an eligible diagnosis can access early intervention funding up to \$12 000 (a maximum of \$6 000 per financial year). There are currently more than 5900

17 Australian Hearing, *Submission 47*, p. 5.

18 Professor Greg Leigh, Director, Royal Institute for Deaf and Blind Children, *Committee Hansard*, 20 February 2017, p. 4.

19 Department of Health, *Submission 1*, p. 11.

20 Department of Social Services, *Submission 12*, p. 2.

21 Department of Social Services, *Submission 12*, p. 3.

22 Department of Social Services, *Remote Hearing and Vision Services for Children*, <https://www.dss.gov.au/disability-and-carers/programmes-services/for-people-with-disability/remote-hearing-and-vision-services-for-children> (accessed 28 August 2017).

children receiving services under the program of which more than 1500 have a primary disability of hearing impairment or deaf blindness.²³ It is expected that most children will be eligible to the NDIS. The program is transitioning in full to the NDIS.²⁴

1.38 State and territory support programs for deaf and hard of hearing people, including early intervention programs are also transitioning to the NDIS. These programs were mostly delivered by the non-government sector, which received block funding to provide a range of services.

The NDIS Transition Plan

1.39 The NDIA anticipates that approximately 16 000–20 000 participants with hearing impairment will enter the NDIS by 2019–2020.²⁵

1.40 The National Disability Insurance Agency (NDIA) advised that as of 31 March 2017 there are 1966 NDIS participants with hearing impairment. This represents approximately three per cent of current NDIS participants.²⁶

1.41 In February 2016, the Department of Health released the Hearing Services Program NDIS Transition Plan. This transition plan describes the 'activities, dependencies and timeframes', that need to take place to effectively support the transition of eligible Hearing Services' clients to the NDIS.²⁷

1.42 The transition plan identifies the key objectives and the proposed strategies to ensure a smooth transition. The plan also identifies the roles and responsibilities between Department of Health (Health), Department of Social Services (DSS) and the National Disability Insurance Agency (NDIA).

1.43 The scope of the transition plan includes identifying and implementing the activities that will enable program clients who will be eligible to move across to the NDIS to receive services. It will also identify program clients who will not be eligible to move to the NDIS and how the Program will continue to support those clients e.g. clients over 65 years of age, and clarify responsibilities of stakeholder agencies for ensuring a successful transition.

1.44 In its submission to this inquiry, the NDIA advised that it was undertaking a range of activities to ensure support under the NDIS for people with hearing

23 Department of Social Services, *Submission 12*, p. 3.

24 Department of Social Services, *Submission 12*, p. 3.

25 National Disability Insurance Agency, *Submission 13*, pp. 1–2. This figure does not include those who might have hearing impairment in addition to their primary disability (e.g. someone with intellectual disability might also have a hearing impairment).

26 NDIS, *National Public Dashboard*, 31 March 2017. <https://www.ndis.gov.au/medias/root/h81/h56/8800927318046/National-Dashboard-as-at-31-March-2017-Accessible-FINAL.pdf> (accessed 24 July 2017).

27 Department of Health, *Hearing Services Program NDIS Transition Plan*, February 2016.

impairment is appropriate, evidence based and consistent with the *National Disability Insurance Scheme Act 2013* (the NDIS Act). These activities include, but are not limited to:

- developing guidance material for use by NDIA National Access Team, planners and Local Area Coordination (LAC) partners on levels of hearing loss likely to require NDIS supports;
- developing reference packages to guide planners and LAC partners in building participant plans, including guidance on reasonable and necessary funded supports;
- supporting arrangements for transition of people from former Commonwealth Programs;
- designing referral pathways with a particular focus on early childhood/early intervention (ECEI) to ensure appropriate supports are received as early and efficiently as possible;
- working with service providers to assist their transition to the NDIS environment; and
- working with key stakeholders and deafness/hearing loss communities to build their understanding and engagement in NDIS processes.²⁸

1.45 The NDIA advised the committee it was 'developing evidence based guidelines to support consistency in decision about accessing the NDIS and reasonable and necessary supports for people with hearing impairment'.²⁹

1.46 In its submission, the NDIA also provided information about the development of the reference packages both for early interventions and for evidence based reference packages across the lifespan.³⁰

1.47 During the course of the inquiry, the NDIA advised the committee it was anticipating releasing the early intervention reference packages by the end of April 2017.³¹

28 National Disability Insurance Agency, *Submission 13*, p. 1.

29 National Disability Insurance Agency, *Submission 13*, p. 2.

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

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

Chapter 2

Eligibility criteria

Introduction

2.1 This chapter examines the eligibility criteria for determining access to, and service needs of, deaf and hard of hearing people under the National Disability Insurance Scheme (NDIS).

2.2 During the course of the inquiry, two main issues arose in relation to eligibility criteria: firstly, the lack of publicly available information on the criteria used to assess eligibility for NDIS services for deaf and hard of hearing people, and secondly, the repercussions for deaf and hard of hearing people deemed not eligible for NDIS services.

2.3 In March 2017, the NDIA indicated it was going to release guidance material for access decision making for implementing the NDIS access criteria for deaf and hard of hearing people toward the end of April 2017.¹

2.4 In August 2017, the NDIA provided to the committee the reviewed guidance for determining access to the NDIS for deaf and hard of hearing people. On 1 September 2017, the NDIA publically released the document.²

2.5 Late August 2017, the committee sought the views of the hearing services sector on the reviewed guidance and changes.

2.6 This chapter first outlines the issues raised during the inquiry in relation to eligibility criteria due to the lack of guidelines. Then, it discusses the changes to the eligibility criteria that are coming to effect now and how they are likely to alleviate the access issues faced to date by deaf and hard of hearing people.

Eligibility criteria

2.7 Sections 22 to 25 of the NDIS Act 2013 detail the criteria for access to the Scheme. To become an NDIS participant a person must:

- have a permanent impairment that significantly affects their ability to take part in everyday activities, or have a developmental delay;
- be aged less than 65 when first applying to enter the NDIS and meet additional age requirements if living in SA or TAS;
- live in Australia in an NDIS area on a specified date; and
- be an Australian citizen or hold a permanent visa or a Protected Special Category visa.

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

2 NDIA, additional information received 1 September 2017.

2.8 An impairment that varies in intensity, for example when an impairment is of a chronic episodic nature may still be permanent, and may meet the eligibility requirements for the Scheme.

2.9 In addition to these eligibility criteria there are also Early Intervention Requirements. A prospective participant will meet the early intervention requirements if they meet each of the following requirements::

- the person:
 - i. has one or more identified intellectual, cognitive, neurological, sensory or physical impairments that are, or are likely to be, permanent (section 25(1)(a)(i)); or
 - ii. has one or more identified impairments that are attributable to a psychiatric condition that are, or are likely to be, permanent (section 25(1)(a)(ii)); or
 - iii. is a child who has developmental delay (section 25(1)(a)(iii)); and
- the NDIA is satisfied that provision of early intervention supports is likely to benefit the person by reducing their future needs for disability related supports (section 25(1)(b)); and
- the NDIA is satisfied that provision of early intervention supports is likely to benefit the person by:
 - i. mitigating or alleviating the impact of the person's impairment upon their functional capacity to undertake communication, social interaction, learning, mobility, self-care or self-management (section 25(1)(c)(i)); or
 - ii. preventing the deterioration of such functional capacity (section 25(1)(c)(ii)); or
 - iii. improving such functional capacity (section 25(1)(c)(iii)); or
 - iv. strengthening the sustainability of informal supports available to the person, including through building the capacity of the person's carer (section 25(1)(c)(iv)); and
- the NDIA is satisfied that early intervention support for the person is most appropriately funded or provided through the NDIS (section 25(3)).³

2.10 Until now, the continuing lack of clear eligibility criteria for access to NDIS services for deaf and hard of hearing people was of significant concern, with inquiry

3 NDIA, *Access to the NDIS, Early Intervention requirements*, <https://www.ndis.gov.au/operational-guideline/access/early-intervention-requirements.html> (accessed 31 August 2017).

participants describing the negative impact that this uncertainty was having within the deaf and hard of hearing community.

2.11 In regard to the criteria to be used, the majority of inquiry participants argued that eligibility should be based on a holistic assessment of need rather than an arbitrary audiological measure. There was also widespread support for the eligibility criteria to capture children with unilateral as well as bilateral hearing loss.

Impact of uncertainty

2.12 The ongoing lack of publically available eligibility criteria has caused considerable consternation within the deaf and hard of hearing community. One parent of a child with a profound hearing loss in one ear and a mild-severe hearing loss in the other ear described the situation:

The uncertainty of whether [name withheld] will be eligible for NDIS is very concerning. Is she 'deaf enough' to qualify for services? I believe that any child who has a hearing loss, whether in one ear or two, who requires hearing aids or cochlear implants in order to fully access sound should be automatically eligible for NDIS.⁴

2.13 Children and Young People with Disability Australia also noted the impact of this uncertainty, stating that:

It is critical that information about eligibility for the NDIS for people who experience deafness is made available as soon as possible. The lack of information is a key concern to children, young people and families who need to make decisions around services, supports and access to devices without knowing whether they will be supported into the future through government funded programs.⁵

2.14 This uncertainty has also had consequences for businesses that provide services to the deaf and hard of hearing community. For example, the Hearing Business Alliance observed:

Our members would also like clarity from NDIA as to what criteria are proposed for determining eligibility for the provision of hearing services to clients? To date information provided to us through NDIS information meetings has been unclear, inconsistent and conflicting.⁶

2.15 Similarly, Country Hearing Care, a small family-owned private, independent practice, situated in a relatively remote rural location in northern Victoria said that the uncertainty had resulted in a feeling of financial vulnerability:

There has been a significant amount of confusion regarding the patient eligibility criteria for determining access to services. We have received conflicting information during NDIS presentations...This confusion, along with rumours and speculation about possible subsequent changes to Office

4 Name withheld, *Submission 7*, p. 1.

5 Children and Young People with Disability Australia, *Submission 30*, pp. 3–4.

6 Hearing Business Alliance, *Submission 24*, p. 2.

of Hearing Services (OHS), including the revision of OHS fees, has made us, as small business owners, feel financially vulnerable, insecure and concerned as we try to plan ahead in an uncertain business landscape.⁷

2.16 Neurosensory, a provider of comprehensive hearing and balance services indicated that due to the lack of established eligibility criteria, it is impossible for clinicians to determine who may be able to access hearing and other hearing related services.⁸

Holistic assessment of need

2.17 The majority of inquiry participants argued strongly that any eligibility criteria for deaf and hard of hearing people to access the NDIS should be based on a holistic assessment of need, rather than a simple measure of a hearing loss threshold. For example, Deafness Forum Australia articulated the case for broad-based eligibility criteria:

Eligibility for the NDIS should not be based on hearing threshold levels alone. This measure does not provide any information on the impact of the hearing loss on a person's ability to undertake activities, or participate in employment or socially. An average hearing threshold level can be misleading if viewed in isolation especially if the person has other disabilities. When a person has their hearing assessed the determination of a hearing threshold level is only one component of the assessment process. Audiological assessment includes a broad range of information gathering including, a discussion of the impact of the hearing loss on the person's functioning, a discussion of the individual's needs and goals, as well as a diagnostic hearing assessment to determine the degree and type of hearing loss.⁹

2.18 The Deafness Forum of Australia said that it supported a holistic approach to eligibility based on the WHO International Classification of Functioning, Disability and Health and that it would be concerned if eligibility was reduced to an average hearing threshold level for people with hearing loss.¹⁰

2.19 The Australian Society of Rehabilitation Counsellors (ASORC) also argued in support of a holistic assessment rather than an 'abstract measure' of clinical impairment:

ASORC is concerned that NDIS' existing assessment processes do not assess the individual's experience of overall disability but focuses on assessing disability within a compartmentalized approach, therein excluding people from the system when their whole-of- life experience of disability is

7 Country Hearing Care, *Submission 28*, p. 3.

8 Neurosensory, *Submission 32*, p. 4.

9 Deafness Forum Australia, *Submission 38*, p. 7.

10 Deafness Forum Australia, *Submission 38*, p. 7.

severe-profound in its impacts on education, employment and social inclusion.¹¹

2.20 ASORC contended that if a 'narrowly-framed approach was pursued, it would have significant economic impacts on Australia's productivity and frustrate the capacity of the NDIS to achieve the national impact it was designed to achieve'.¹²

2.21 The Independent Audiologists Australia Inc concurred with this view, stating: 'Functional ability, not a measure of impairment should determine eligibility for the NDIS'.¹³

2.22 Can:Do Group, a provider of specialist services for people with hearing and vision impairments in South Australia, supported the use of functional outcomes to determine eligibility for the NDIS, particularly for children with unilateral hearing loss:

For some clients a mild hearing loss is devastating to their lifestyle, while for others a severe hearing loss is manageable without devices...We have supported some families who have not been deemed eligible for NDIS supports due to having a unilateral loss. We have also supported three families that went through an appeal process with the NDIA which they found incredibly stressful. Two of the three of them ultimately received an NDIS package for their child with a unilateral loss. It is important to acknowledge that although this may require less intensive intervention or less funding, early intervention support and funding allocated for families to access support is important to minimise the need for further intervention and supports later on.¹⁴

Unilateral hearing loss

2.23 A second issue relating to eligibility arose as to whether or not children diagnosed with unilateral hearing loss should be eligible for assistance under the NDIS, with the majority of inquiry participants arguing strongly for the inclusion of such children in the NDIS. For example, Professor Greg Leigh, Director, Royal Institute for Deaf and Blind Children, argued that given the ability to identify children with mild and unilateral levels of hearing loss it would be 'indefensible' to deny them the support they needed to achieve development milestones:

A fundamental precept of any screening program is that you do not screen and identify something that you do not have the potential to do something about. With the advent of newborn hearing screening, for the first time we can identify children with very mild and unilateral levels of hearing loss

11 Australian Society of Rehabilitation Counsellors (ASORC), *Submission 5*, p. 4.

12 Australian Society of Rehabilitation Counsellors (ASORC), *Submission 5*, p. 4.

13 Independent Audiologists Australia Inc, *Submission 14*, p. 1. Similar arguments were made by William Demant Holding A/S and Macquarie University Speech and Hearing Clinic. See William Demant Holdings A/S, *Submission 52*, p. 5 and Macquarie University Speech and Hearing Clinic, *Submission 22*, p. 2.

14 Can:Do Group, *Submission 8*, pp. 2–3.

very early in their life span...The notion that, as a society, we do actively seek to identify those children and then do not put in place something that puts the minimum standards of support in place to ensure developmental outcomes for them is, frankly, indefensible.¹⁵

2.24 Mr Chris McCarthy, Chief Executive Officer, Hear and Say, similarly argued for the inclusion of children with unilateral hearing loss within the eligibility criteria:

For me, eligibility really does need to be around all children with hearing loss. It is very important that, for those first years, it does not matter what level of hearing loss a child has. We have gone to the effort of investing in a universal newborn-hearing screening program, and I think it would be foolish for us as a society not to actually act on the information that we are given when we have identified those children.¹⁶

2.25 Ms Margaret Dewberry, Adviser, Deafness Forum Australia, considered that 'any child who is diagnosed with a hearing loss is going to need intervention. I think it should be the default position—because it is now—that somebody with the right expertise assesses what that intervention needs to be'.¹⁷

2.26 First Voice suggested that it was critical that all children developing permanent hearing loss prior to age six be eligible for early intervention services under the NDIS.¹⁸ First Voice said that the 'scale of such supports would then be proportional to their current or expected reduction in functional capacity due to their hearing loss'.¹⁹

2.27 The Shepherd Centre expressed similar sentiments, arguing that all children developing permanent hearing loss prior to age six should be eligible for early intervention services under the NDIS, with the scale of support proportional to need.²⁰

2.28 In his appearance before the committee, Mr Michael Forwood, Chief Executive Officer, Cora Barclay Centre, and Chair, First Voice, continued to advocate for the inclusion of children with unilateral hearing loss into the NDIS, observing that relatively low-cost early intervention would have beneficial outcomes over the long term:

If the NDIS were to rule out of eligibility for funding children with unilateral hearing loss, we would be faced with taking them on service without any funding, because the families want the service and we know

15 Professor Greg Leigh, Director, Royal Institute for Deaf and Blind Children, *Committee Hansard*, 20 February 2017, p. 15.

16 Mr Chris McCarthy, Chief Executive Officer, Hear and Say, *Committee Hansard*, 20 February 2017, p. 3.

17 Ms Margaret Dewberry, Adviser, Deafness Forum Australia, *Committee Hansard*, 24 March 2017, p. 10.

18 First Voice defined permanent hearing loss prior to age six as a diagnosed permanent hearing loss of 21dB or greater, averaged over three or more frequencies, in one or both ears.

19 First Voice, *Submission 48*, p. 9.

20 The Shepherd Centre, *Submission 40*, p. 13.

there are significant improvements, so it is a significant NDIS issue... In terms of the insurance principle, this would have to be the lowest-hanging fruit for the NDIS. Thirty to 40 per cent of kids are going to perform poorly and possibly end up on disability services and pensions, and, to me, in terms of economics, an early intervention that might cost \$3,000 or \$5,000 and monitoring in case they have progressive hearing loss is a no-brainer.²¹

2.29 The Shepherd Centre also highlighted the 'false economy' of not supporting children diagnosed with unilateral hearing loss as early as possible:

However, even children born with a mild hearing loss, or a loss affecting only one ear, are at high risk of developing communication, educational and social delays once they enter school. Once these deficits are apparent the children would then be eligible under the NDIS. However, it would be a false economy to not provide expert early support to these children, only for them to fall behind and then having to subsequently receive much greater support to try and help them catch up. Unfortunately this is the current situation – some children with unilateral loss or with mild bilateral loss are being denied NDIS access, not due to their functional need but solely due to an arbitrary audiological measure.²²

2.30 The inclusion of unilateral hearing loss within the NDIS eligibility criteria was supported by a large number of inquiry participants, including Deaf Australia, Aussie Deaf Kids and Parents of Deaf Children, Telethon Speech and Hearing, Canberra Deaf Children's Association and National Disability Services.²³

Impact on people not eligible for the NDIS

2.31 Inquiry participants also identified a need to clarify the services that would remain available for people deemed ineligible for the NDIS. Carers Australia NSW and Carers Australia Victoria highlighted that between 1 July 2016 and 30 September 2016, the National Disability Insurance Agency (NDIA) received 665 requests for access to the NDIS on the basis of a hearing impairment. Of this number 72 were deemed ineligible.²⁴ The organisation continued:

Our first concern is for the ineligible applicants. No further demographic information about these individuals is available, so we cannot be sure why they were denied access. However, this shows a substantial number of people with a hearing impairment may be excluded from the individualised, self-directed support offered by the NDIS. This is particularly concerning in

21 Mr Michael Forwood, Chief Executive Officer, Cora Barclay Centre and Chair, First Voice, *Committee Hansard*, 20 February 2017, pp. 16–17.

22 The Shepherd Centre, *Submission 40*, p. 13.

23 Deaf Australia, *Submission 51*, p. 3; Aussie Deaf Kids and Parents of Deaf Children, *Submission 39*, pp. 2–3; Telethon Speech and Hearing, *Submission 46*, p. 2; Canberra Deaf Children's Association, *Submission 15*, pp. 1–2 and National Disability Services, *Submission 29*, p. 2.

24 Carers Australia NSW and Carers Australia Victoria, *Submission 21*, p. 3.

states and territories rolling their entire disability support system into the NDIS, such as NSW.²⁵

2.32 The Royal Institute for Deaf and Blind Children shared these concerns, observing that there was a 'critical need to ensure that there is no diminution of the Federal Government's commitment to the provision of free and universally available access to hearing services' following the full NDIS rollout.²⁶ The Institute said:

Any change to eligibility criteria will necessitate that the Government consider alternative arrangements for those young adults (under 26) with less complex hearing needs who are currently CSO clients eligible for services under the Hearing Services Program but who may be ineligible for services under the NDIS. This is an issue that requires Government policy consideration in light of its promise that no current recipients of Hearing Services would be worse off under the transition from the Hearing Services Program to the NDIS.²⁷

2.33 Vicdeaf expressed concerns that deaf and hard of hearing individuals from migrant backgrounds who are not eligible for the NDIS due to their residency status may go without access to any supports or services as state funded programs are transitioning to the NDIS:

Many of these migrants are presently accessing vital services through Department of Health and Human Service (DHHS) block funded programs. As this funding slowly dwindles with more rollout zones occurring within years to come, if no provisions are put in place, a disadvantaged sub-community within the Deaf and hard of hearing cohort may go without access to any supports or services.²⁸

2.34 The Royal Institute for Deaf and Blind Children expressed grave concern that 'assistance could become worse for those who do not qualify for the NDIS',²⁹ arguing that:

Hearing services and funding should not go backwards, as appears to be happening under the NDIS. Australia will lose its reputation as a world leader in hearing services and research, to the detriment of our population under the current policy settings.³⁰

NDIA reviewed guidance for eligibility criteria

2.35 The NDIA recently completed the revised guidance for determining access to the scheme and reasonable and necessary supports for hearing impairment. The NDIA

25 Carers Australia NSW and Carers Australia Victoria, Submission 21, p. 3.

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

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

28 Vicdeaf, *Submission 45*, p. 2.

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

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

updated guidance for determining access for hearing impairment, both under section 24 and section 25 of the NDIS Act 2013.

2.36 The NDIA publically released the amendments to the operational guidelines on 1 September 2017.

2.37 The amendments clarify the access criteria for early intervention as well as the requirements for eligibility for adults over 25 years of age.

Early intervention for deaf or hard of hearing people aged 0–25

2.38 The revised guidance for early intervention requirements are:

The NDIA will be satisfied that a person meets the early intervention requirements without further assessment when the person:

- is aged between birth and 25 years of age; and
- has confirmed results from a specialist audiological assessment (including electrophysiological testing when required) consistent with auditory neuropathy OR hearing loss ≥ 25 decibels in either ear at 2 or more adjacent frequencies, which is likely to be permanent or long term; and
- the hearing loss of the person necessitates the use of personal amplification.³¹

2.39 The NDIA provided the following information:

This streamlined access approach for early intervention acknowledges a rich body of evidence that recognises that early intervention support up to and including the age of 25 is critical for people with hearing impairment as the developing brain requires consistent and quality sound input and other support over that period to develop normally and ameliorate the risk of lifelong disability.

This same body of evidence suggests that brain development and language capability have been achieved by the age of 26. Therefore, adults aged 26 years and over are not immediately accepted to be likely to benefit from the same early intervention approach because there is no requirement to support the development of the auditory pathways. Adults aged 26 years and over with hearing impairment will therefore be assessed normally, on a case by case basis, having regard to the availability of all relevant evidence.³²

2.40 The effect of this change is that prospective participants who are aged 0–25 (inclusive) who meet the audiometric criteria will meet the early intervention requirements without further assessment.

31 NDIA, additional information received 1 September 2017.

32 NDIA, additional information received 1 September 2017.

2.41 Overall, experts from the hearing sector have found these access requirements appropriate.³³ First Voice and the Shepherd Centre described the requirements as 'reflecting the current practices of Australian Hearing'.³⁴

2.42 However, Aussie Deaf Kids, a not-for-profit parent organisation that aims to empower parents raising a child with hearing loss through support, information and advocacy, raised some concerns about the requirement that '*the hearing loss of the person necessitates the use of personal amplification*'.³⁵ Aussie Deaf Kids stated:

There are three points that need consideration with this statement:

- 1) This denies culturally Deaf parents the right to choose not to use personal amplification for their child. While many Deaf parents choose listening devices for their children, the child's right to the NDIS should not be premised on their use of a device.
- 2) It is essential children with absent or underdeveloped auditory nerves should receive automatic eligibility; these children do not benefit from amplification.
- 3) There is minimal empirical evidence as to the efficacy of amplification devices for babies and young children with MBHL or UHL. Parents should not feel pressured to use a device simply to access NDIS funding. These children, however, do require ongoing audiological management and access to early childhood intervention and should, therefore, be eligible to receive early childhood intervention through the NDIS, irrespective of their use of a listening device.³⁶

2.43 Additionally, Aussie Deaf Kids suggested to include the terms bilateral and unilateral in the section relating to the level of hearing loss as these terms are understood by parents and used to describe their child's hearing loss.³⁷

2.44 Whilst the hearing sector welcomes the reviewed guidelines for early intervention requirements, The Shepherd Centre stressed that 'appropriate National Reference Packages are still required to ensure that the required early intervention support is funded as required'.³⁸

Additional guidance for hearing impairments for adults over 25

2.45 The NDIA advised that it also made the following changes:

the following text will be removed from List D, Section 4:

33 See for example: The Shepherd Centre, *Submission 40.3*, p. 4; Cora Barclay Centre, *Submission 55.2*; p. 4; Royal Institute for Deaf and Blind Children, *Submission 37.1*, p. 6.

34 The Shepherd Centre, *Submission 40.3*, p. 4.

35 Aussie Deaf Kids, *Submission 39.1*, p. 3.

36 Aussie Deaf Kids, *Submission 39.1*, pp. 3-4.

37 Aussie Deaf Kids, *Submission 39.1*, p. 3.

38 The Shepherd Centre, *Submission 40.3*, p. 4.

“Deafness/hearing loss – a 45 decibels or greater hearing impairment in the better ear, based on a 4 frequency pure tone average (using 500, 1000, 2000 and 4000Hz)”

An Additional Section entitled ‘Additional guidance for hearing impairments’ has been added at 8.3.3:

“8.3.3. Additional guidance for hearing impairments

Hearing impairments may result in reduced functional capacity to undertake communication, social interaction, learning and self-management activities. Generally, the NDIA will be satisfied that hearing impairments of ≥ 65 decibels in the better ear (pure tone average of 500Hz, 1000Hz, 2000Hz and 4000Hz) result in substantially reduced functional capacity to perform one or more activities. This audiometric criterion reflects the lower limit of what is likely to constitute a substantially reduced functional capacity to undertake relevant activities.

Hearing impairments < 65 dB decibels in the better ear (pure tone average of 500Hz, 1000Hz, 2000Hz and 4000Hz) in conjunction with other permanent impairments (for example vision or cognitive impairments), or where there is evidence of significantly poorer than expected speech detection and discrimination outcomes, may also be considered to result in substantially reduced functional capacity to undertake relevant activities.”³⁹

2.46 Some submitters⁴⁰ raised concerns about the changes to the requirement of a hearing impairment of >65 decibels in the better ear, based on a 4 frequency pure tone average to access the Scheme. The Royal Institute for Deaf and Blind Children explained:

There is a significant variation with the access for adults aged 26 years and over who will only be accepted with a hearing impairment of ≥ 65 decibels in the better ear, based on a 4 frequency pure tone average. An adult with a hearing impairment of ≥ 45 decibels in the better ear will experience a reduced functional capacity to undertake relevant activities. However, to gain access to the NDIS they would need to have another permanent impairment. A hearing impairment of this level does require hearing aids in order to undertake communication, social interaction, learning and self-management activities.⁴¹

2.47 The Shepherd Centre and First Voice articulated the potential consequences of this requirement:

The effect of the eligibility threshold is that a person who is profoundly deaf in one ear (that is, cannot hear anything at all on that side) and has a hearing loss of 60dB in the other ear (often referred to as severe hearing loss) would not be automatically eligible.

39 NDIA, additional information received 1 September 2017.

40 Royal Institute for Deaf and Blind Children, *Submission 37.1*, p. 6; The Shepherd Centre, *Submission 40.3*, p. 4.; Taralye, *Submission 50.1*, p. 4.

41 Royal Institute for Deaf and Blind Children, *Submission 37.1*, p. 6

A person with this level of hearing loss is totally dependent on devices for their functional access to sound – either hearing aids or cochlear implants. If these devices are appropriately provided and fitted the person should have sufficient access to sound to be able to hold spoken conversations and to be able to participate through their hearing in society and the workforce.

However if the person does not have these devices they will probably not be able to have effective spoken conversations or be able to participate in society or the workforce through their hearing.⁴²

2.48 The Royal Institute for Deaf and Blind Children raised the issue of the potential risk for people not meeting the criterion to be unable to fund their required hearing aids:

This cohort of hearing impaired adults may not be in a position to fund their required hearing aids and are not eligible for the Australian Government Hearing Services Program. For those of working age they may be unable to find employment as they are unable to fund the hearing supports they need.⁴³

2.49 Taralye expressed 'extreme concern that the removal from the guidelines of the pure tone average range, for a moderate hearing loss to be replaced with audiometric readings consistent with a severe or worse hearing loss do not take cognisance of the impaired functional capacity of clients with unilateral, mild and moderate hearing losses in spite of this being well documented in research'.⁴⁴

2.50 The Cora Barclay Centre found 'a lack of clarity in the proposed changes to the Operational Guidelines that Section 8.3.3 pertains to adult hearing loss only'.⁴⁵

Committee view

Eligibility criteria

2.51 In light of the evidence received throughout the inquiry on the issues and lack of clarity pertaining the access requirements to the NDIS for deaf and hard of hearing people, the committee welcomes the release of the NDIA's reviewed operational guidelines to determine access to the NDIS for deaf and hard of hearing people.

2.52 The committee notes that there are early indications from the sector⁴⁶ that the recently released access criteria for deaf and hard of hearing people aged 0-25 appear to be technically consistent with the current practices of Australian Hearing, and are therefore welcomed.

42 The Shepherd Centre, *Submission 40.3*, p. 4; First Voice, *Submission 48.2*, p. 6.

43 Royal Institute for Deaf and Blind Children, *Submission 37.1*, p. 6.

44 Taralye, *Submission 50.1*, p. 4.

45 Cora Barclay Centre, *Submission 55.2*, p. 4.

46 See for example: The Shepherd Centre, *Submission 40.3*, p. 4; Cora Barclay Centre, *Submission 55.2*, p. 4; Royal Institute for Deaf and Blind Children, *Submission 37.1*, p. 6.

2.53 For the criteria of hearing impairment for those 26 years or older, the committee is concerned that the access requirement of more than 65 decibels in the better ear, based on a 4 frequency pure tone average, may leave some people with no access to supports. Ineligibility to the Scheme may negatively impact on the social and economic participation of this cohort. The committee recommends the NDIA monitors eligibility rates for adults with hearing impairments to build a clearer picture of the number and needs of the people who have been found ineligible for NDIS services and reports on its finding in 12 months.

Deaf and hard of hearing people ineligible for the NDIS

2.54 The committee is concerned about the deaf and hard of hearing people, especially children who have been denied access to the NDIS since the beginning of the Scheme rollout because of the lack of clear NDIS operational guidelines. For example, the committee heard that children were denied access to the NDIS because of unilateral hearing loss or mild hearing loss despite their high risk of developing communication, educational and social delays. The committee is concerned that some people, including children, are currently left with no access to support. To ensure consistency and equity of access to the Scheme, the committee recommends the NDIA reviews the cases of people with hearing impairment who were previously found ineligible. The committee recommends the NDIA tests their eligibility against the revised guidelines.

2.55 The committee is also concerned that with the transition of Australian, state and territory government programs to the NDIS, some people are at risk of being left with no services. Given that governments contributed to services before the NDIS, it is not clear how services will be delivered to people not eligible. This cohort may include some individuals over the age of 65 and disadvantaged groups such as migrants and refugees because of the NDIS eligibility criteria around age and residency status. The committee recommends the Australian, state and territory governments clarify and make public how they will provide services for people who are deaf and hard of hearing who are not participants in the NDIS.

NDIA capacity to address operational issues

2.56 The committee is concerned about the NDIA not addressing in a timely manner the emerging and ongoing operational issues associated with the implementation and rollout of the NDIS. Indeed, along with other examples of operational issues the committee has been made aware of through the other inquiries it has conducted, the lengthy process and series of delays that occurred between the time the NDIA started to work on the guidelines and their public release are raising doubts about the capacity of the NDIA to address its current operational issues.

Recommendation 1

2.57 The committee recommends the NDIA monitors eligibility rates for adults with hearing impairments to build a clearer picture of the number and needs of the people who have been found ineligible for NDIS services and reports on its finding in 12 months.

Recommendation 2

2.58 The committee recommends the NDIA reviews immediately the cases of people with hearing impairment who were previously found ineligible and tests their eligibility against the revised guidelines.

Recommendation 3

2.59 The committee recommends the Australian, state and territory governments clarify and make public how they will provide services for people who are deaf and hard of hearing who are not participants in the NDIS.

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

Appendix 1

Submissions, additional information, tabled documents and answers to questions on notice

Submissions

1. Commonwealth Department of Health
2. Blamey Saunders hears
3. Name Withheld
4. ACT Disability, Aged and Carer Advocacy Service Inc. (ADACAS)
5. Australian Society of Rehabilitation Counsellors Inc (ASORC)
6. Name Withheld
7. Name Withheld
8. Can:Do Group
9. Australian College of Audiology Ltd
10. Deafness Foundation
11. Name Withheld
12. Department of Social Services
13. National Disability Insurance Agency
14. Independent Audiologists Australia Inc
15. Canberra Deaf Children's Association
16. SHHH Australia Inc
17. Mr Paul Hickey
18. Able Australia
19. WA Deaf Society
20. Australian Lawyers Alliance
21. Carers NSW
22. Macquarie University
23. EARtrak
24. Hearing Business Alliance Ltd
25. Disability Services Commissioner
26. Federation of Ethnic Communities' Councils of Australia
27. The Deaf Society

28. Country Hearing Care
29. National Disability Services (NDS)
30. Children and Young People with Disability Australia
31. Services for Australian Rural and Remote Allied Health (SARRAH)
32. Neurosensory
33. Hear and Say
34. Deaf Services Queensland
35. Audiology Australia
36. Senses Australia
37. Royal Institute for Deaf and Blind Children (RIDBC)
38. Deafness Forum of Australia
39. Aussie Deaf Kids and Parents of Deaf Children
40. The Shepherd Centre for deaf children
41. Deaf Children
42. Hearing Care Industry Association (HCIA)
43. People with Disability Australia (PWDA)
44. Deafblind Australia
45. Vicdeaf
46. Telethon Speech & Hearing WA
47. Australian Hearing
48. First Voice
49. Australasian Newborn Hearing Screening Committee
50. Taralye
51. Deaf Australia
52. William Demant Holding
53. Australian Sign Language Interpreters Association Inc
54. Disability Council NSW
55. Confidential

Additional information

1. Additional information provided by Audiology Australia on 6 March 2017
2. Additional information provided by National Disability Services (NDS) on 6 March 2017 (1)
3. Additional information provided by National Disability Services (NDS) on 6 March 2017 (2)
4. Additional information provided by the Shepherd Centre, the Cora Barclay Centre and The Royal Institute for Deaf and Blind Children. Essential Components of Support for Children with Hearing Loss. Received 16 June 2017.
5. Additional information provided by the Shepherd Centre, the Cora Barday Centre and The Royal Institute for Deaf and Blind Children. NDIS Comparative Cost Modelling. Received 16 June 2017.
6. Additional information provided by Deaf Australia
7. Additional information provided by NDIA on 1 September

Answers to questions on notice

1. Answers to questions take on notice by Aussie Deaf Kids & Parents of Deaf Children at public hearing in Melbourne on 20 February 2017
2. Answers to questions take on notice by Deafness Forum of Australia at public hearing in Melbourne on 24 March 2017
3. Answers to questions take on notice by National Disability Insurance Agency at public hearing in Melbourne on 24 March 2017
4. Answers to questions take on notice by Deaf Australia at public hearing in Melbourne on 24 March 2017
5. Answers to questions take on notice by National Disability Insurance Agency at public hearing in Melbourne on 24 March 2017

Appendix 2

Public hearings

Melbourne VIC, 20 February 2017

Members in attendance: Senators Gallacher, Hume, Siewert and Mr Andrews, Ms Macklin, Mr Wallace

Witnesses

ANGLEY, Ms Philippa, Executive Officer to the Chief Executive Officer, National Disability Services

BALFOUR-OGILVY, Ms Jessica, Clinical Manager, Hear and Say

CAVALLETTO, Mr Bart, Director, Services, Royal Institute for Deaf and Blind Children

COLES, Dr Tony, Chief Executive Officer, Audiology Australia

COLLINGRIDGE, Dr Louise, Executive Officer, Independent Audiologists Australia Inc.

COLLINS, Mr Grant, Vice President, Independent Audiologists Australia Inc.

DAVIS, Mrs Aleisha, General Manager, Clinical Programs, Shepherd Centre—for deaf children

DILLON, Professor Harvey, Director, National Acoustic Laboratories

FORWOOD, Mr Michael, Chief Executive Officer, Cora Barclay Centre, and Chair, First Voice

HUNGERFORD, Dr Jim, Chief Executive Officer, Shepherd Centre—for deaf children

JACKSON, Ms Leonie, Chief Executive Officer, The Deaf Society, through interpreter

KING, Ms Alison, Principal Audiologist, Paediatric Services, Australian Hearing

LEIGH, Professor Greg, Director, Royal Institute for Deaf and Blind Children

McCARTHY, Mr Chris, Chief Executive Officer, Hear and Say

PEARCE, Ms Wendy, Head of Clinical Support, Australian Hearing

PORTER, Ms Ann, Chief Executive Officer and Director, Aussie Deaf Kids

QUINN, Ms Nina, Member, Hearing Care Industry Association

RIDGWAY, Mr Jason, President and Chair of the Board, Audiology Australia

SOUTH, Dr Sandra, Research and Policy Manager, Audiology Australia

WILSON, Mr Ashley, Chairman, Hearing Care Industry Association

WYBURN, Mr Mark, Secretary, Parents of Deaf Children

Melbourne VIC, 24 March 2017

Members in attendance:

Members in attendance: Senators Gallagher, Siewert and Mr Andrews, Ms Macklin.

Witnesses

DE NATRIS, Mr Peter, Expert Adviser, National Disability Insurance Agency

DEWBERRY, Ms Margaret, Adviser, Deafness Forum of Australia

GARRETT, Ms Trisha, Assistant Secretary, Office of Hearing Services, Department of Health

GLANVILLE, Ms Louise, Deputy Chief Executive Officer, National Disability Insurance Agency

MIERS, Mr Kyle, Chief Executive, Deaf Australia, through Mark Quinn and Mark Sandon, interpreters

MILLER, Mr Peter, Director, Deafness Forum of Australia

RUNDLE, Ms Vicki, Acting Deputy Chief Executive Officer, Markets and Supports, National Disability Insurance Agency