

Chapter 2

Final Report

Introduction

2.1 The committee has considered issues around the provision of hearing services in the NDIS for a considerable time. Initially, it was a relatively straightforward inquiry, with the focus on how a reportedly successful, low cost, and efficient program could be adapted to meet the criteria of the NDIS. However, the inquiry has exposed what the committee believes are fundamental issues within the Scheme, specifically in relation to the provision of hearing services, but that go to the very design and operation of the Scheme more generally.

2.2 For this reason, the committee is of the view that it is important to go back to the objectives and guiding principles of the Act to test the NDIA's decisions on how best to provide hearing services, particularly for children. Primarily, how participants access the Scheme and are provided with information to inform their decision making about the types of supports required, and who is best placed to provide those supports.

Principles directly relevant to the provision of hearing services

2.3 While all the Objects and Principles apply equally to all participants, Section 3(d) of the Act commits the Scheme to provide early intervention supports to participants, and Section 5(f) places the best interest of a child as paramount and commits to promoting their development:

(f) if the person with disability is a child—the best interests of the child are paramount, and full consideration should be given to the need to:

- (i) protect the child from harm; and
- (ii) promote the child's development; and
- (iii) strengthen, preserve and promote positive relationships between the child and the child's parents, family members and other people who are significant in the life of the child.¹

2.4 Section 25 of the Act (below) sets out the criteria for early intervention services to be provided through the Scheme:

(1) A person meets the early intervention requirements if:

(a) the person:

- (i) has one or more identified intellectual, cognitive, neurological, sensory or physical impairments that are, or are likely to be, permanent; or

¹ *National Disability Insurance Act 2013*, s. 4(11).

(ii) has one or more identified impairments that are attributable to a psychiatric condition and are, or are likely to be, permanent; or

(iii) is a child who has developmental delay; and

(b) the CEO is satisfied that provision of early intervention supports for the person is likely to benefit the person by reducing the person's future needs for supports in relation to disability; and

(c) the CEO is satisfied that provision of early intervention supports for the person is likely to benefit the person by:

(i) mitigating or alleviating the impact of the person's impairment upon the functional capacity of the person to undertake communication, social interaction, learning, mobility, self-care or self-management; or

(ii) preventing the deterioration of such functional capacity; or

(iii) improving such functional capacity; or

(iv) strengthening the sustainability of informal supports available to the person, including through building the capacity of the person's carer.

[...]

(3) Despite subsections (1) and (2), the person does not meet the early intervention requirements if the CEO is satisfied that early intervention support for the person is not most appropriately funded or provided through the National Disability Insurance Scheme, and is more appropriately funded or provided through other general systems of service delivery or support services offered by a person, agency or body, or through systems of service delivery or support services offered:

(a) as part of a universal service obligation; or

(b) in accordance with reasonable adjustments required under a law dealing with discrimination on the basis of disability.

2.5 The Explanatory Memorandum to the Bill explains Section 25:

This clause recognises that a person may need support to help minimise the impact of a disability from its earliest appearance, and that the provision of support may improve the person's functioning or prevent the progression of their disability over their lifetime.²

2 National Disability Insurance Bill 2013, *Revised Explanatory Memorandum*, available at: https://www.aph.gov.au/Parliamentary_Business/Bills_Legislation/Bills_Search_Results/Result?bId=r4946 (accessed 5 June 2018).

Pathway to packages

Lack of information

2.6 One of the central tenets of the NDIS is to provide participants with Choice and Control. Section 3(e) of the *National Disability Insurance Scheme Act 2013* states that one of the objects of the Act is to:

(e) enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports.

2.7 However, given that the concept of choice and control is predicated on those exercising those choices being fully cognisant of the all aspects of those choices, it seems that reliance on this concept alone may result in conflict with the best interests of the participant.

2.8 During its inquiry, the committee found that families of newly diagnosed children often have little experience with hearing loss and do not understand the support options available to them. For example, Mr Peter Miller, Director, Deafness Forum of Australia, highlighted that the vast majority of deaf children are born to hearing parents:

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, 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.³

2.9 As a result, many families of deaf and hard of hearing children are at risk of compromising their child's developmental outcomes by making uninformed decisions about the use of early intervention therapies.

2.10 One parent of a child diagnosed with hearing impairment contrasted their experiences during the initial diagnostic phase and the subsequent interactions for their child after the NDIS 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

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

provide any recommendations or guidance. Luckily, we had three years' experience under our belts, so were able to advocate well...⁴

2.11 The parent concluded: 'I don't know what we would have done had [they] been newly-diagnosed'.⁵

Guided referral pathway

2.12 To alleviate issues raised by a lack of information, submitters suggested that the guided referral pathway in place prior to the introduction of the NDIS should be retained. The committee heard that, since hearing services was encompassed by the NDIS, there have been delays between diagnosis and the start of early intervention therapies, and that some of the delays were as a consequence of there being no guided referral pathway to assist parents under the Scheme.⁶ Given the time-critical nature of intervention for children with hearing loss, ensuring the system is at least as good as the one it is replacing, is crucial.

2.13 A number of other inquiry participants advocated for a guided referral pathway to assist parents under the NDIS, including Telethon Speech and Hearing, 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 (RIDBC).⁷

2.14 Providers warned that delayed early intervention can impact a child's full development, for example, through the emergence of permanent delays. Indeed, the results of the National Acoustics Laboratories' study into Longitudinal Outcomes for Children with Hearing Impairment provides evidence for the benefits at five years of age of early hearing-aid fitting by six months or cochlear implantation by 12 months of age combined with educational intervention for language development of children in Australian children.⁸

2.15 First Voice argued that failure to integrate and streamline early intervention hearing services within the NDIS 'would create systemic and life-long disadvantage to

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

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

6 For example: The Shepherd Centre, *Submission 40*, pp. 16–17; Telethon Speech and Hearing, *Submission 46*, p. 2; First Voice, *Submission 48*, p. 22; Taralye, *Submission 50*, p. 6; 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, RIDBC, *Committee Hansard*, 20 February 2017, p. 12.

7 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, RIDBC, *Committee Hansard*, 20 February 2017, p. 12.

8 Teresa Ching et al. 'Learning from the Longitudinal Outcomes of Children with Hearing Impairment study: summary of 5-year findings and implications, *International Journal of Audiology*, October 2017.

generations of children with hearing loss and their families, and set Australia's highly developed and internationally renowned hearing services sector back many years'.⁹ It recommended that a guided pathway be established to overcome unnecessary delays and to empower parents to make informed choices:

The evidence clearly shows that optimal outcomes require urgent, informed decisions followed by immediate action. Without appropriate guidance, 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.¹⁰

2.16 In its interim report, the committee expressed its concern that the transition to the NDIS has disrupted a world class system which had worked very well. 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 ensuring that children can be taught to communicate as well as any other child (with spoken or signed language) and become active participants in the social and economic life of their communities.

2.17 The committee is still strongly of the view that an appropriate system must be immediately implemented to support children who are deaf or hard of hearing. 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.

2.18 The committee sought to address the issues by recommending that 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. It was expected that this arrangement would mitigate some of the delays and ensure that families of newly diagnosed deaf and hard of hearing children are provided with independent information and support from an Agency with appropriate expertise.

2.19 On 2 March 2018, the Australian Government responded to the committee's recommendation advising that the NDIA 'would continue to work' with Australian Hearing on its in-kind arrangements post 30 June 2019 but did not provide any further information or commitment.¹¹

2.20 At the 7 March 2018 hearing, Ms Vicki Rundle, Deputy CEO, NDIA, agreed that a solution for the in-kind Australian Hearing arrangements post June 2019 needed to be implemented and advised that the matter was under consideration:

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

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

11 *Government response to the Joint Committee on the NDIS, Interim report: Provision of hearing services under the National Disability Insurance Scheme*, March 2018, p. 3.

We've got to work through the arrangements for Australian Hearing once they're no longer an in-kind service, so there's a question mark in our minds there about what we could do to strengthen the early childhood intervention approach. We're working at the moment with the Department of Social Services on a range of in-kind matters, transitioning services from in kind into full-scheme arrangements. Only yesterday I talked to them about Australian Hearing. That is something that we will be considering very shortly because we'll need to give some lead-in time and more certainty to Australian Hearing, rather than waiting till it's too late...What we're planning to do with many in-kind services in states and territories is cash them out, because cashing them out gives participants money to spend and gives them a broader range, where at the moment they're locked into some of those in-kind services and they have reduced choice. With hearing, there's a question about whether we would do that or whether we would prefer someone like Australian Hearing. I clearly can't talk about any decision, because a decision hasn't been made, but that's the question that we need to ask ourselves.¹²

NDIA reluctance to implement change

2.21 While the NDIA agreed that the current referral and access processes could be improved, it is reluctant to 'carve out' a special pathway from the Scheme for families of deaf and hard of hearing children.

2.22 Ms Rundle argued that it is not the Agency's role to influence people in the marketplace, particularly within a Scheme that is designed to promote individual choice and control. Furthermore, that such an action could encourage other sectors to follow.¹³

2.23 However, the committee is of the view that the Scheme should be adapted to suit participants, rather than the other way round, and that the continuing pursuit of a model of 'choice and control' may be at the expense of participants' outcomes. Considering that the lack of a guided pathway has the potential to cause lifelong disadvantage to children, it would be negligent of the Agency to not provide families with a guided pathway. Introducing a guided pathway would not preclude families from choosing to divert from the pathway if they so desired, but it would ensure that, for those who desire prompt access to services, any unnecessary delays due to poor knowledge or uncertainty are mitigated.

2.24 A myriad of evidence received during the inquiry indicated that families of newly diagnosed children who are deaf and hard and hearing already face a limited choice of specialist service providers. While this is partly due to thin markets in some areas it is also due to an absence of new providers seeking to enter the marketplace.

2.25 Guided pathways are intended to help newly diagnosed families with limited knowledge about disability understand their available support options and to empower them to make informed decisions. If they represent the best possible approach for

12 Ms Vicki Rundle, Deputy CEO, NDIA, *Proof Committee Hansard*, 7 March 2018, p. 28.

13 Ms Vicki Rundle, Deputy CEO, NDIA, *Proof Committee Hansard*, 7 March 2018, pp. 3–4.

individuals to achieve outcomes under the NDIS, guided pathways should be embraced by the Agency.

2.26 In the event that a special pathway was implemented to guide families of deaf and hard of hearing children, the Agency argued that it would be required to undertake its own due diligence before it could recommend certain providers or a pathways over others:

What we found was that some children are accessing services from other providers, not just the main 10 providers, for example, for hearing around the country...I say this with the greatest of respect but I think it is not for us to accept at face value that the current service system that is there represents absolute best practice pathway for children. I am sure it possibly does. All I'm saying is that, for us to use the legislation in such a way as to dictate a pathway for people to a particular provider, we also have to undertake our own due diligence to make sure that that array of providers do represent the practice that we would aspire to in order to get the outcomes that we want for those children.¹⁴

2.27 The committee is not proposing to dictate a pathway to a particular provider. The committee wants to ensure that participants have access through an honest independent broker to the information and the resources (adequate plans) to undertake transdisciplinary therapies to achieve the best possible outcomes with a specialist provider of their choice that is operating in their area. The Agency has the resources to undertake due diligence of the 10 or so main providers.

2.28 In the committee's view the Agency's reluctance to carve a preferred pathway from the Scheme is unreasonable. Implementing a preferred pathway at this time would not preclude the NDIA from refining it in future, but the approach would at least guarantee that children with hearing loss today are given the best possible chance to attain acceptable outcomes in the interim. The committee does not want to wait until there is evidence that the new processes are delivering worse outcomes than the previous system before changes are made.

2.29 The evidence for the effectiveness of the previous model is compelling. Outcomes data published annually by First Voice member centres demonstrates that children in members' programs regularly match or surpass their peers, with over 70 per cent achieving age-appropriate results by the time they commence school. The results show that the majority develop into independent, contributing members of society, with high levels of education, social participation and full time employment.¹⁵ As highlighted by Cora Barclay Centre, the data derives from the same internationally-endorsed assessments used by the LOCHI study:

They are not, and do not purport to be, research findings. They are clinical assessment data collected primarily for the purpose of informing each child's early intervention therapy plan by objectively assessing, monitoring

14 Ms Vicki Rundle, Deputy CEO, NDIA, *Proof Committee Hansard*, 7 March 2018, p. 4.

15 First Voice, *Report on Education, Employment & Social Outcomes of First Voice Member Centre Graduates (18-28 years)*, March 2017, p. 3.

and reporting their progress each year. They are also used by service providers, in consultation with each child's family, to scale down the intensity of services (and therefore costs) when it is clinically appropriate to do this, thereby ensuring that children and families are not over-serviced.¹⁶

2.30 In the committee's view, destroying an existing process with detriment to participants in order to continue to pursue the ideal of a pure market is verging on the irresponsible.

An ECEI Partner for early intervention hearing services

2.31 The Early Childhood Early Intervention (ECEI) Partner approach aims to determine and facilitate the most appropriate support pathway for children with disability or developmental delay aged 0–6 years and their families. The approach is designed to uphold the eligibility criteria of the NDIS while helping to ensure that less severe cases are supported outside of the Scheme.

2.32 ECEI Partners assess each child and provide a recommendation to the NDIA regarding the most appropriate pathway for that child. Depending on individual circumstances, families are provided with a combination of information, emotional support, referral to mainstream services, short-term intervention, or help to access the NDIS for longer-term intensive supports as part of a funded NDIS plan.¹⁷

2.33 Australian Hearing is federally funded under the Hearing Services Program to provide hearing services around Australia. Australian Hearing's national network of hearing centres includes more than 110 permanently staffed venues, and visits more than 330 other locations in urban, rural and remote areas of Australia. It also regularly visits more than 220 Aboriginal and Torres Strait Islander communities around the country.¹⁸ Australian Hearing employs the bulk of specialist paediatric audiologists (specialist that are difficult to come by outside of the organisation).

2.34 The appointment of Australian Hearing as the NDIA's ECEI Partner for early intervention hearing services was proposed by the sector as a viable solution which could resolve many of the issues:

The system we have proposed is that the NDIA hire Australian Hearing as their Early Childhood Partner, and then Australian Hearing who have the expertise and who naturally [would see these children], then they can carry through that function and do things very, very well, but that's a change to the Agency's normal practice of one size fits all, so we're struggling with that.¹⁹

16 Cora Barclay Centre, *Submission 55.3*, pp. 4–5.

17 NDIS PITC Program Round Three, *Statement of Requirements* October 2017, p. 7.

18 Australian Hearing, *About Australian Hearing*, <https://www.hearing.com.au/About-us/Our-services-to-you> (accessed 21 May 2018).

19 Dr Jim Hungerford, CEO, The Shepherd Centre, *ACT Legislative Assembly—Inquiry into the implementation of the NDIS in the ACT*, 11 May 2018.

2.35 The committee agrees with the sector that appointing Australian Hearing as the ECEI Partner for early intervention hearing services would likely resolve many of the issues around inadequate information, planning expertise, and mitigate delays to services. In the proposed model, Australian Hearing would act as a 'one stop shop' for information and referrals, including coordinating services in and outside the NDIS (as per the Act).

Recommendation 1

2.36 The committee recommends that the NDIA contract Australian Hearing as the national ECEI Partner for early intervention hearing services for families of deaf and hard of hearing children.

Transdisciplinary packages

Coordinated multidisciplinary approach required

2.37 During the inquiry, specialist providers pointed out that early intervention hearing services are not amenable to being funded on a transactional basis because the nature of the work requires a coordinated multidisciplinary approach to ensure that the children achieve age-appropriate milestones.²⁰ Mr Forwood compared the arrangement to that of a rehabilitation program:

You don't take a person in a stroke unit, try to forecast in the year ahead how many units of particular kinds of services they will need—how many will be individual therapy, how many will be in group sessions et cetera—cost it out, say it comes to \$130 000, give them the money and then say: 'Go and spend it wherever you like. You can get an orthopod from over here, you can get a neurosurgeon from here, you can see a neuropathologist here, you can get your own physiotherapist. All of the money is spent in the program, because it is a program...'²¹

2.38 Mr Forwood argued that the nature of the work requires a team to assess, monitor, and work with the family and individual to achieve the best possible outcomes:

The family and the child are at the centre of everything we do. There is a multidisciplinary team with many different disciplines, and the leaders of those teams are extraordinarily highly skilled and trained people, who have a minimum of a master's degree in audiology, speech pathology or deaf education...They specialise just in teaching deaf children how to communicate and how to learn to listen, to speak and how to teach the

20 For example: Mr Michael Forwood, Director, First Voice, and CEO, Cora Barclay Centre, *Proof Committee Hansard*, 7 March 2018, pp. 13–14; Dr Jim Hungerford, *Proof Committee Hansard*, 7 March 2018, p. 21.

21 Mr Michael Forwood, Director, First Voice, and CEO, Cora Barclay Centre, *Proof Committee Hansard*, 7 March 2018, pp. 13–14.

parents. That is a model that does not work on an individual, transactional, 'so many sessions at a time per annum' model.²²

2.39 Mr Cavalletto argued the current situation between early intervention hearing services and the NDIS was akin to forcing a square peg into a round hole:

As Jim and Greg have said, we do have a world-class system, and it really appears that we are trying to break something to make it fit into an NDIS system that is not delivering on what the sector has been delivering for 70 years. It would be a really sad legacy for the NDIA if they broke hearing services and the language outcomes and the communication outcomes for children that have been achieved over 70 years. That's where it looks like we're heading. Decisions are being made unilaterally, not in consultation with the sector.²³

2.40 Dr Hungerford argued that allowing specialist service providers to submit transdisciplinary quotes for participants' packages would help to integrate early intervention hearing services into the Scheme:

I believe that [the NDIA] was set up with mechanisms in place to achieve what we want, which was the transdisciplinary package based on a quote. That has been part of the system since inception and was used very successfully initially, but the agency is moving away from that because it wants to move to a transactional basis so it can count number of sessions, to multiply out to a dollar value. We used—and I believe also in South Australia there was good use of—the quote system for a transdisciplinary package. We implemented it in Canberra. The agency accepted it very well. They saw the evidence of the efficacy of the program. Based on that, they then accepted the quotes we put in, and everything ran very well. However, as alluded to by Michael, because they want everybody to operate on the same basis, they have withdrawn the ability to maintain that.²⁴

2.41 At the public hearing, the NDIA acknowledged there is currently a gap in the information it provides to families about early intervention therapies:

...there is probably a gap in the way that we provide information to parents—to the consumer, if you like—about what constitutes the sorts of interventions you'd expect to see and how they could choose to purchase those in a way that gets that sort of multidisciplinary approach.²⁵

NDIA response

2.42 In response to the sector's suggestions, Mr Peter De Natris, Strategic Adviser, NDIA, explained that transdisciplinary package quotes had been withdrawn because they had become a means for the Scheme to deliver beyond 'reasonable and necessary'

22 Mr Michael Forwood, Director, First Voice, and CEO, Cora Barclay Centre, *Proof Committee Hansard*, 7 March 2018, pp. 13–14.

23 Mr Bart Cavalletto, Director, Services, RIDBC, *Proof Committee Hansard*, 7 March 2018, pp. 12 and 22.

24 Dr Jim Hungerford, *Proof Committee Hansard*, 7 March 2018, p. 21.

25 Ms Vicki Rundle, Deputy CEO, NDIA, *Proof Committee Hansard*, 7 March 2018, p. 29.

supports and into the responsibilities of other service systems such as early childhood education or health:

In relation to your question around the transdisciplinary quotes that were originally in the trial, the transdisciplinary approach is a term used to say that there are multidisciplinary needs for a child around their delay or the functional impact of their diagnosed disability. It assumes that you are using a highly collaborative key worker model, with a key person leading that model, and that different systems are working in collaboration around the child. We put that into the NDIS because it was a term used in best practice in early childhood intervention. However, we found that it became a vehicle for the scheme to creep into delivering outside what 'reasonable and necessary' was. In other words, it started to pay for things that were generally probably the role of early childhood education or health.²⁶

2.43 However, under the Act, the NDIA has a responsibility to ensure that participants' supports from other service systems are coordinated with those of the NDIS. Section 4 of the NDIS Act stipulates that people with disability should be supported to receive supports outside of the NDIS:

(14) People with disability should be supported to receive supports outside the National Disability Insurance Scheme, and be assisted to coordinate these supports with the supports provided under the National Disability Insurance Scheme.²⁷

2.44 The committee draws the Agency's attention to Jordan's Principle. It was introduced by Canada as a means to prevent First Nations children being denied essential services or experiencing delays in receiving them.²⁸ It was named in memory of Jordan River Anderson, a young boy from Norway House Cree Nation, who spent more than two years unnecessarily in hospital while Canada and Manitoba argued over payment for his at-home care. After waiting more than two years for both governments to resolve their dispute (over payment for services that would have allowed him to experience life outside of a hospital setting), Jordan died at five years of age.²⁹

2.45 In 2007, the Canadian Parliament unanimously supported a motion in support of Jordan's Principle stating that, 'in the opinion of the House, the government should immediately adopt a child-first principle, based on Jordan's Principle, to resolve jurisdictional disputes involving the care of First Nations children'.³⁰ Under Jordan's

26 Mr Peter De Natris, Strategic Adviser, NDIA, *Proof Committee Hansard*, 7 March 2018, p. 30.

27 *National Disability Insurance Act 2013*, s. 4(14).

28 Canadian Government, *Jordan's Principle*, <https://www.canada.ca/en/indigenous-services-canada/services/jordans-principle.html> (accessed 15 May 2018).

29 Vandna Sinha and Sam Wong, 'Ensuring First Nations Children's Access to Equitable Services through Jordan's Principle: The Time to Act is Now', *Paediatrics & Child Health*, vol. 20, no. 2, 2015, pp. 62–64.

30 Cindy Blackstock, 'Jordan's Principle: Canada's broken promise to First Nations children?' *Paediatrics & Child Health*, vol. 17, no. 7, 2012, pp. 368–370.

Principle, where a jurisdictional dispute arises between two parties over payment for services for a First Nations child, the party of first contact must pay for the services without delay or disruption. The paying party can then refer the matter to jurisdictional dispute mechanisms after the service or support has been provided.³¹

Committee view

2.46 The committee is troubled by evidence that the NDIA has phased out its acceptance of transdisciplinary package quotes from specialist providers. The committee acknowledges the Agency's concerns regarding overlap with other service systems but it is of the view that the NDIA should investigate ways in which overlap could be overcome rather than eliminating use of an effective mechanism altogether.

2.47 The committee is not convinced that the current NDIA approach to packages of supports and access to services for children who are deaf and hard of hearing is employing a child-first principle. Evidence indicates that the NDIA is failing to put these children first by ignoring feedback from expert specialists about the level of investment required to achieve the best possible outcomes and the process in which interventions should be delivered.

2.48 The committee agrees with Dr Hungerford that the NDIA is condemning these children to lifelong disadvantage by not providing them with adequate levels of investment through integrated transdisciplinary packages during their critical early childhood years. A coordinated multidisciplinary approach has been established as best practice in the delivery of early childhood intervention, therefore, the NDIA should be doing all it can to ensure that these children receive transdisciplinary packages funded at the appropriate level.

2.49 The committee agrees with the sector that transdisciplinary package quotes should be reintroduced. The mechanism ensures that children with hearing loss are being given the best possible opportunity to achieve their full potential.

2.50 In practice, the committee's proposed model will see families of newly diagnosed children referred to Australian Hearing for assessment. Australian Hearing will determine whether the individual is eligible for supports under the NDIS or is best referred to mainstream services. Depending on individual circumstances, families will be provided with a combination of information, emotional support, referral to services, or help to access the NDIS for longer-term supports as part of a funded NDIS plan.

Recommendation 2

2.51 The committee recommends that the NDIA reintroduce transdisciplinary packages quotes from specialist service providers for children who are deaf and hard of hearing and require access to early intervention services.

2.52 The committee also wants to see a far broader whole-of-government approach to the provision of hearing services. If the sticking point that is preventing the transdisciplinary approach is that the NDIA is picking up the cost of health or

31 Cindy Blackstock, 'Jordan's Principle: Editorial Update', *Paediatrics & Child Health*, vol. 13, no. 7, 2008, pp. 589–590.

education professionals, then a mechanism should be put in place where costs are shared, and reimbursed through budget transfers, or direct invoicing.

Recommendation 3

2.53 The committee recommends that the Australian Government put in place an arrangement similar to 'Jordan's Principle' in Canada to ensure that a child- first approach is taken in the delivery of services for children with hearing loss.

Quantum of funding

Shortfalls in funding

2.54 The committee is troubled by evidence that NDIS packages for deaf and hard of hearing children who require access to early intervention services are being funded at below the market cost of providing services.

2.55 During the inquiry, the committee received a plethora of feedback from specialist service providers about shortfalls in funding between the costs of providing early intervention hearing services and the funding provided in plans.³²

2.56 Mr Bart Cavalletto, Director, Services, RIDBC, explained that the hearing element alone of intervention programs cost an average of between \$15 000 to \$16 000 to deliver:

...if Jim's assertion is correct—and I'm sure it is—we've then got service providers with access to packages of \$9,000 where families are choosing to split that across providers. But it actually costs on average \$15,000 to \$16,000 for the hearing element of that program alone. So an average package of \$15,000 to \$16,000 is being funded for us as providers at probably closer to \$5,000 to \$6,000.³³

2.57 Dr Hungerford advised the ACT Legislative Assembly that the cost of The Shepherd Centre's early intervention program per child per year is approximately \$18 000.³⁴

2.58 Early childhood early intervention hearing programs run for a small number of years and use specialist multidisciplinary teams to achieve spoken language outcomes. The investment enables many of these children to attend school with minimal support, graduate and enter tertiary study at the same rate as any other child, and go on to achieve employment. As noted by Dr Hungerford, the actual payback, to

32 For example: Mr Bart Cavalletto, Director, Services, RIDBC, *Proof Committee Hansard*, 7 March 2018, p. 12; Mr Michael Forwood, Director, First Voice, and CEO, Cora Barclay Centre, *Proof Committee Hansard*, 7 March 2018, p. 20; Dr Jim Hungerford, CEO, The Shepherd Centre, *Proof Committee Hansard*, 7 March 2018, p. 24.

33 Mr Bart Cavalletto, Director, Services, RIDBC, *Proof Committee Hansard*, 7 March 2018, pp. 25–26.

34 Dr Jim Hungerford, CEO, The Shepherd Centre, *ACT Legislative Assembly—Inquiry into the implementation of the NDIS in the ACT*, 11 May 2018.

the family, to the individual, to society, and to the government on their investment is considerable:

Children who complete our early intervention program—ready to move onto school—typically graduate from the program with the same quality of spoken language as any other child. So for many of them, if you met them, if they had long hair and you couldn't see their devices, you wouldn't realise that they were deaf.³⁵

2.59 The sector provided evidence that the average NDIS package for children whose primary diagnosis is hearing loss is around \$13 000, but from within this, even less is allocated specifically for early intervention hearing programs:

...from that \$13,000 only a proportion is allocated towards services either towards speech and language or towards Auslan, so the actual amount of money that is then put towards that area is much lower, and then the amount of money that's actually dedicated to an individual provider is lower again. So I think the typical provider income is much closer to around the \$8,000 or \$9,000 mark.³⁶

2.60 According to the NDIA, the average package for participants with hearing impairment in the Scheme at the end of December 2017 was \$15 000.³⁷ However, it is unclear whether this figure represents people with multiple disabilities who also have a hearing loss or those with a primary diagnosis of hearing loss. Either way, NDIS packages for deaf and hard of hearing children who require access to early intervention services are being funded at below market cost, given the early intervention hearing programs alone cost between \$15 000 and \$18 000 to deliver.³⁸

2.61 As a result of shortfalls in funding, specialist service providers are bearing significant financial costs in order to continue provision of services to families.³⁹ According to Mr Cavalletto, several providers are fundraising at least 50 per cent of their funding so as to continue to provide these vital programs:

Earlier, there was a comment around the fact that the system is doing well and is being supported. I would suggest to you that the reason for that is that providers are using donated funds and are fundraising really hard to fill the gap that is in the system. I would suggest to you that most of us here at

35 Dr Jim Hungerford, CEO, The Shepherd Centre, *ACT Legislative Assembly—Inquiry into the implementation of the NDIS in the ACT*, 11 May 2018.

36 Dr Jim Hungerford, CEO, The Shepherd Centre, *Proof Committee Hansard*, 7 March 2018, p. 24.

37 Ms Vicki Rundle, Deputy CEO, NDIA, *Proof Committee Hansard*, 7 March 2018, p. 2.

38 Dr Jim Hungerford, CEO, The Shepherd Centre, *ACT Legislative Assembly—Inquiry into the implementation of the NDIS in the ACT*, 11 May 2018; Mr Bart Cavalletto, Director, Services, RIDBC, *Proof Committee Hansard*, 7 March 2018, pp. 25–26.

39 For example: Mr Bart Cavalletto, Director, Services, RIDBC, *Proof Committee Hansard*, 7 March 2018, p. 12; Mr Michael Forwood, Director, First Voice, and CEO, Cora Barclay Centre, *Proof Committee Hansard*, 7 March 2018, p. 20; Dr Jim Hungerford, CEO, The Shepherd Centre, *Proof Committee Hansard*, 7 March 2018, p. 24.

the table would be looking at, at least, 50 per cent of our funding coming from fundraising, and that is not a sustainable way forward for a program that benefits society in Australia.⁴⁰

Focus on early investment

2.62 The sector raised concerns that without appropriate investment into multidisciplinary early intervention packages, deaf and hard of hearing children are at risk of permanent language and communications difficulties that will have lifelong impacts. For these children, a larger amount of funding is required upfront in order to prevent permanent disability and lifelong disadvantage.

2.63 The current approach to determine level of funding is based on permanent lifelong support needs rather than on early investment to maximise outcomes. The sector is of the view that a greater emphasis on early investment is required:

What we are saying is that there are two parts to the NDIS. There are the permanent lifelong support needs, and they have designed a system that works for that, but the NDIS needs to have an investment-outcomes early-intervention alternative policy and funding mechanism which is designed for situations such as ours and for children who are deaf or hearing impaired, where you make an investment in an evidence based program to get a proven outcome.⁴¹

2.64 The committee agrees that the focus of the NDIA should be on early intervention. The current approach appears to contradict one of the key objectives of the Scheme: to provide reasonable and necessary early intervention supports for participants to support their independence and social and economic participation.

2.65 The Act stipulates that the provision of supports, including early intervention supports, is intended to:

- (a) support people with disability to pursue their goals and maximise their independence; and
- (b) support people with disability to live independently and to be included in the community as fully participating citizens; and
- (c) develop and support the capacity of people with disability to undertake activities that enable them to participate in the community and in employment.⁴²

2.66 The NDIA should be creating packages based on the level of investment required. While planners should have some regard for consistency between truly identical cases, the Scheme is designed to be individually focused; therefore, packages

40 Mr Bart Cavalletto, Director, Services, RIDBC, *Proof Committee Hansard*, 7 March 2018, p. 12.

41 Mr Michael Forwood, Director, First Voice, and CEO, Cora Barclay Centre, *Proof Committee Hansard*, 7 March 2018, p. 14.

42 *National Disability Insurance Act 2013*, s. 4.

of supports should be created regardless of the supports provided to other participants as long as they are outcomes focused.

Lack of evidence between funding levels and outcomes achieved

2.67 In 2017, the NDIA undertook a suite of work to better understand the recommended quantum of support required for children with hearing loss. This included an analysis of data collected through a pilot of the Hearing Impairment Planning Questionnaire (HIP-Q).⁴³

2.68 The HIP-Q was developed in the first half of 2017 with a view to providing guidance to planners in their assessment of children with hearing loss and the resulting application of funded supports. Following the NDIA's analysis of the tool's reliability and validity, the Agency concluded that the HIP-Q was not sufficiently robust to be a reliable indicator of the support needs of children with hearing impairment. It also found the tool was inconsistent with the Scheme's principles of reasonable and necessary support.⁴⁴

2.69 The Agency advised the committee that plans for children with hearing loss would instead be developed using part A of the HIP-Q (the diagnosed level of hearing impairment), along with the PEDI-CAT and guided planning questionnaire, and that these tools would be accompanied by planning guidance and training.⁴⁵

2.70 The NDIA also conducted a literature review and an analysis of service providers' data, but argued that 'nowhere in the evidence and all the literature that we looked at could anybody give us, with any certainty, what level of funded supports should be given to get a particular outcome or a particular set of outcomes'.⁴⁶

2.71 Ironically, the NDIA's concern about a lack of evidence between funding levels and outcomes achieved in the previous model has resulted in it implementing its current approach despite a lack of evidence between funding levels and outcomes achieved. The design of the Scheme and its market-based approach to early intervention has neither been trialled nor evaluated robustly. It is peculiar that the NDIA would favour an untested approach over an existing system that has delivered demonstrable language and communication outcomes over a considerable number of years.

Inappropriate assessment tool

2.72 During its 2017 inquiry into the NDIS ECEI Partner approach, the committee heard that the NDIA is using the Paediatric Evaluation of Disability Inventory-computer Adaptive Test (PEDI-CAT) assessment tool to determine the severity of functional impact in children with disability, the results of which are then used to inform decisions about required levels of funding.

43 Ms Vicki Rundle, Deputy CEO, NDIA, correspondence received 21 December 2017.

44 NDIA, additional information received 21 December 2017.

45 Ms Vicki Rundle, Deputy CEO, NDIA, correspondence received 21 December 2017.

46 Ms Vicki Rundle, Deputy CEO, NDIA, *Proof Committee Hansard*, 7 March 2018, p. 31.

2.73 Use of the tool in the NDIS planning process was heavily criticised for its limitations, including that:

- the results are often not a true indication of the child's functional capacity or needs;
- the tool was developed primarily to assess children with cerebral palsy and is focused on physical impairment needs;
- there is a risk of misinterpretation of results;
- there are differing levels of experience by operating personnel; and
- the tool uses a potentially unreliable algorithm to provide an overall score which it was never intended for.⁴⁷

2.74 In relation to children with hearing loss, the committee heard that the PEDICAT is particularly unsuitable. As deaf children do not exhibit the 'classic' signs of disability, the PEDI-CAT often results in a mild score and, subsequently, inadequate levels of funding in their NDIS packages.⁴⁸

2.75 Dr Hungerford explained that the PEDI-CAT tool is based on the observation of already present deficits, so for a baby with hearing loss, there is nothing to observe or measure:

The PEDI-CAT for paediatric hearing loss is totally unsuitable because it is based on the observation of already present deficits. For a baby with hearing loss, there is nothing that you can observe in that instance. We're required in New South Wales to use PEDI-CAT on all of the children we're supporting, and with every single child the PEDI-CAT rating is well below their actual needs rating...⁴⁹

Inappropriate outcomes framework

2.76 The NDIA's outcomes framework was criticised for being ill-equipped to determine whether deaf and hard of hearing children are achieving age-appropriate milestones.⁵⁰

2.77 The Shepherd Centre argued that the information currently being collected by the Agency is insufficient to capture the complexity of language development during

47 Joint Committee on the NDIS, *Provision of services under the NDIS ECEI Approach*, December 2017, pp. 23–25.

48 Dr Jim Hungerford, Chief Executive Officer, The Shepherd Centre, *Proof Committee Hansard*, 27 September 2017, p. 12; and Dr Jim Hungerford, CEO, The Shepherd Centre, *ACT Legislative Assembly—Inquiry into the implementation of the NDIS in the ACT*, 11 May 2018.

49 Dr Jim Hungerford, Chief Executive Officer, The Shepherd Centre, *Proof Committee Hansard*, 27 September 2017, p. 12.

50 For example: Dr Jim Hungerford, *Proof Committee Hansard*, 7 March 2018, p. 11; Professor Greg Leigh, Director, Renwick Centre, RIDBC, *Proof Committee Hansard*, 7 March 2018, p. 12; Mr Michael Forwood, Director, First Voice, and CEO, Cora Barclay Centre, *Proof Committee Hansard*, 7 March 2018, p. 13.

the first years of life, and that for babies and young children who do not yet have language, the framework is particularly inadequate.⁵¹

2.78 Dr Hungerford explained:

The agency is using a lot of measures, which are assessing the impact in life domains; however, they are not assessing the impact on language for the children, whether it's signed or spoken language. Language is a lagging result from therapy. Clearly, whether or not a child has good language on school entry is observable at that time, but you can't predict that from whether or not the child is able to feed itself when it's two or whether it's able to roll over et cetera when it's 18 months of age. The information that the agency is currently collecting does not establish whether or not the children were achieving the outcomes that children with hearing loss should be able to.⁵²

2.79 Professor Greg Leigh, Director, Renwick Centre, RIDBC, expressed concern at the Agency's casual approach to monitoring and evaluation:

I note that the NDIA's evidence on this is that the outcomes of the current changes that have been and are about to be put in place are going to be tested in the longer term. I note, for the record, that it has taken 70 years for us to get what we're currently describing as a system and pathway to the state of operation that currently exists today. That's 70 years of tweaking and development that has been evidence based and has relied on inputs from significantly different parts of the sector that functions extraordinarily well as an operating whole. It's almost inconceivable to me that we would make such wholesale changes to the way we're doing this, measure it at some point down the track and then, hopefully, retrieve the system that we currently have in place, if that evidence suggests that we haven't been successful in doing that.⁵³

2.80 Mr Forwood raised similar concerns:

Are we going to wait for 18 years while this generation go from nought to the completion of year 12—we have some statistics to show that they are not concluding year 12, as they once would have—or are we going to go back and be sensible, look at what we had in place and work out some way of accommodating that within the NDIA?⁵⁴

51 The Shepherd Centre, *Submission 40.5*, p. 2.

52 Dr Jim Hungerford, *Proof Committee Hansard*, 7 March 2018, p. 11.

53 Professor Greg Leigh, Director, Renwick Centre, RIDBC, *Proof Committee Hansard*, 7 March 2018, p. 12.

54 Mr Michael Forwood, Director, First Voice, and CEO, Cora Barclay Centre, *Proof Committee Hansard*, 7 March 2018, p. 13.

Distribution of funding in plans

2.81 The NDIA acknowledged that its distribution of funding to deaf and hard of hearing children has frequently not been appropriate for the severity of hearing loss.⁵⁵

2.82 At the March 2018 hearing, Ms Rundle, Deputy CEO, NDIA, conceded that some planners' decisions had resulted in inappropriate plans for deaf and hard of hearing children:

...when we looked at the plans, we found that the distribution across the plans wasn't as we would have expected to have seen, which led us to the conclusion that we had planners making decisions that weren't consistent and that the right distribution wasn't there...You would expect some children who have severe hearing loss to have a particular set of needs, and it's likely that the cost of the supports would be higher than for someone else who has a mild or moderate hearing loss. What we found is that the distribution across the plans didn't reflect that last year.⁵⁶

2.83 The NDIA argued that it is working to improve distribution in funding by refreshing guidance for planners and introducing specialist advice teams.⁵⁷ However, it noted that it would not be feasible to set up specialists in every region due to the small size of the hearing cohort:

For hearing, if you think about the overall number of people coming into the scheme and anticipated to come in with hearing impairment, we'll need to think about the most effective way—and also the most efficient way, in terms of use of government resources—as we set up specialist advice for hearing. It may not be represented in every single region, but a planner in a region would have ready access to that specialist knowledge pretty much straight away, if they needed it.⁵⁸

Committee view

2.84 The committee agrees with the NDIA that families of deaf and hard of hearing children require greater guidance around early intervention hearing services and that this guidance should be delivered by specialists in a cost effective way. Contracting Australian Hearing as the national ECEI Partner for early intervention hearing services would resolve inadequate levels of funding, and ensure consistency and equity in the Scheme.

2.85 In the proposed model, Australian Hearing would be responsible for developing packages for children who require access to early intervention hearing services under the NDIS. These packages would then be approved by the NDIA through a fast-tracked early intervention channel. Families would be guaranteed development of plans by specialists who are experts in their field. The arrangement

55 Ms Sarah Johnson, Scheme Actuary, NDIA, and Vicki Rundle, Deputy CEO, NDIA, *Proof Committee Hansard*, 7 March 2018, p. 5.

56 Ms Vicki Rundle, Deputy CEO, NDIA, *Proof Committee Hansard*, 7 March 2018, pp. 31–32.

57 Ms Vicki Rundle, Deputy CEO, NDIA, *Proof Committee Hansard*, 7 March 2018, pp. 1 and 9.

58 Ms Vicki Rundle, Deputy CEO, NDIA, *Proof Committee Hansard*, 7 March 2018, p. 9.

would also mitigate unnecessary delays between diagnosis and service provision by guiding families to a 'one stop shop' who can provide information, referrals, and service coordination.

Hon Kevin Andrews MP
Chair

Senator Alex Gallacher
Deputy Chair