



The Shepherd Centre

Giving deaf children a voice



Sydney · Macquarie · Liverpool · Wollongong · Canberra · Online & Telepractice

Website: www.shepherdcentre.org.au

ABN: 61 000 699 927

Submission to the Productivity Commission study into the costs of the NDIS

Dr Jim Hungerford, CEO

Phone: 02 9370 4400

March 2017

Contents

About The Shepherd Centre – for deaf children	3
Executive summary.....	4
Context.....	5
The profound impact of early childhood hearing loss	5
Critical aspects of support for children with hearing loss.....	6
Responses to the study	7
Appendices.....	18
Appendix 1: The profound impact of early childhood hearing loss.....	19
Speech and Language.....	19
Literacy	19
Socioeconomic Issues.....	20
Effects of unilateral or mild hearing loss.....	20
References.....	21
Appendix 2: Critical aspects of support for children with hearing loss.....	23
Outstanding outcomes are possible	24
Appendix 3: Proposed protocol for NDIS EI support for children with permanent hearing loss	27

About The Shepherd Centre – for deaf children

The vision of The Shepherd Centre is that:

Every child with hearing loss can achieve their full potential in the world through their listening, spoken language and social skills.

The Shepherd Centre is one of the world's leading services providing audiological, early intervention and family support for children with hearing loss. We are a specialist in working with these children, with a family- and person-centred approach, to enable them to achieve spoken language.

We assist over 450 children each year through both face-to-face and telepractice services. These children range from less than 1 month of age through to school-age and onwards; come from remote and metropolitan areas; all socioeconomic backgrounds; many cultural and linguistic backgrounds; and include many children with further needs and disabilities beyond hearing loss alone.

We focus on assisting these children to develop their listening, spoken language and social skills so that they can achieve their potential in life. **The outcomes achieved by the program are world leading, with the children typically developing spoken language at the same level as their peers without hearing loss.**

The children in our specialised early intervention service receive a transdisciplinary/interdisciplinary program incorporating specialist Listening and Spoken Language Specialists and therapists; Paediatric Audiologists; Child and Family Counsellors; and ENT Specialists (amongst other professionals). Our centres incorporate audiology booths designed for paediatric patients; individual therapy rooms; group clinical rooms; with videoconferencing facilities for remote service delivery. The program includes a cochlear implant program (integrated seamlessly within the early intervention program) for those children requiring this level of assistive hearing device. The early intervention children are aged up to 6 years; with hearing loss that may be bilateral or unilateral; and losses of all levels ranging from mild to profound. Further details on our program is provided in an appendix (**Error! Reference source not found.**, page **Error! Bookmark not defined.**).

Children 'graduate' from our early intervention program with the same profile of spoken language skill as other children of the same age. **More than 90% of all graduates go on to attend mainstream classes at a mainstream school.** The 'typical' (median) graduate has standardised language scores at the same level as the median child in the overall population. The statistics for the overall program – including the many children with additional needs, coming from a background other than English, with delayed diagnosis, etc – are outstanding, with the overall median language well within the normal range.

We also provide support for children at school and ongoing support for those children who have received a cochlear implant with us.

Our whole-program early intervention outcomes are published each year. The research we conduct and the outcomes we achieve are presented at multiple national and international conferences. In addition, the Shepherd Centre is:

- a member of First Voice (a globally-leading organisation joining together six like-minded charities from across Australia & New Zealand);
- a founding institution within the Australian Hearing Hub; and
- a member of the Hearing CRC.

Executive summary

Children with hearing loss are at severe risk of major disadvantage, compared to previous practice, due to the way the NDIS is being implemented. Childhood hearing loss can have dramatic effects, potentially to the extent of preventing a child from developing a functional language.

However, if appropriately supported with a specialised integrated early intervention program, children with permanent hearing loss (even profound deafness), can achieve spoken language that matches that of the general population. This outcome requires a significant up-front investment, however it results in outstanding improvements in the life course of these children, enabling them to go on and become an economically contributing and socially included member of society. As expected, these programs have been shown to have a positive benefit:cost ratio.

However, the current implementation of the NDIS does not support these programs so that they can continue to produce these outcomes.

Unless corrected, this will result in many of the 4,000 children with permanent hearing loss under 6 not achieving a good spoken or signed language prior to school entry. As well as having profound impacts on the individual child and family, this will lead to dramatic increases in costs to the NDIS (due to elevated needs for ongoing support) and to society (through the decreased capacity of these children to grow into adults that can fully participate academically, economically and socially).

The key issues with the current implementation of the NDIS that cause these unacceptable risks are:

- In assessing the appropriate level of funding for a service there is no apparent recognition of the benefit of the outcomes provided by the service. Current plans are funded based on specific inputs rather than on outcomes; and as a result do not deliver outcomes.
- The current planning approach is centred on the current functional deficits that a child has; rather than the longer term effects that their disability will cause. As a result funding is oriented towards a 'wait to fail' approach, rather than an early investment (prior to deficits appearing) to ensure future functioning is improved.
- The system is set up to wait until a child presents to the NDIS and then a lengthy planning process ensues. This has not been helped by the current ECEI approach, as for children with hearing loss it introduces even more steps that must be gone through before a child can receive appropriate specialist help.

As a result of the above, we are recommending major changes to the systems applied for children with permanent childhood hearing loss, including:

1. Funding that is oriented towards supporting specialised integrated early intervention services that are achieving outcomes. This requires a short-term increase in funding that is not driven by inputs such as direct service hours, but is instead driven by the costs of achieving the desired outcome. This will dramatically reduce mid- and long-term funding needs.
2. Ensuring that the longer-term effects of a disability are taken into account in determining the eligibility for early intervention services. In particular, recognising that early childhood unilateral hearing loss or mild bilateral hearing loss cause significant deficits during school age and that these can be prevented by appropriate early intervention.
3. Providing a guided referral pathway to ensure that parents of a child with permanent hearing loss are very quickly engaged with the services that they will need for their child to achieve their desired goals. Current systems are resulting in delays of many months; in a situation where it has been shown that every month of delay can cause permanent loss in language ability.

Context

This submission is provided in the context of the significant changes being planned for the provision of services and support to children with permanent hearing loss (permanent hearing impairment) in Australia, in particular the funding of the provision of therapy services and support currently moving to the NDIS (with resulting changes to referral pathways, eligibility criteria and support levels); and the subsequent transfer of most of the Community Service Obligation placed on Australian Hearing to the NDIS (with the subsequent services being provided by a number of entities on a competitive basis).

These changes offer the potential for improved outcomes for children with permanent hearing loss, but they also put at risk many of the unique features of the hearing services in Australia; and subsequently puts at risk the fantastic outcomes that these children can currently achieve.

This submission focusses on how the approach currently being taken by the NDIS, towards the support provided for children with hearing loss, affects the overall cost and cost-benefit of the scheme.

Overall, the thoughts and recommendations in this submission arise from the experience of hundreds of children with hearing loss being supported under the NDIS.

The profound impact of early childhood hearing loss

Children with early hearing loss face numerous challenges on their road to achieving full social inclusion. This document focusses on children who have a permanent hearing loss diagnosed in the first 5 years of life.

The effects of early childhood hearing loss are discussed further in *Appendix 1: The profound impact of early childhood hearing loss (page 19)*, however the key features are:

- **Incidence:** Up to 1 in 500 children born will have some degree of permanent hearing loss. Further children will develop hearing loss in the first few years of life and by the time they are of school age approximately 1 in 300 children will have permanent hearing loss. Overall there are approximately 4,000 children across Australia with permanent early childhood hearing loss. This number will not increase due to any changes to diagnosis etc; the rate has been constant for many years and is expected to stay constant.
- **Effect on speech and language:** permanent childhood hearing loss can cause profound communication difficulties, potentially preventing the development of any usable language. A review in 2008 reported that 67% of deaf children were taught outside of traditional mainstream classes; and historically the average oral language age of high school deaf graduates from the United States of America was at or below that of the average hearing seven to eight year old child.
- **Effect on literacy:** due to the close links between developing good spoken language and the development of literacy, significant literacy problems are reported in children with permanent childhood hearing loss. In 2007 the Journal of Deaf Studies and Deaf Education suggested that 30% of school graduates with severe/profound hearing loss were functionally illiterate.
- **Effect on socioeconomic outcomes:** as would be expected due to the effects of hearing loss on speech, language and literacy, negative socioeconomic outcomes are widely reported for children with permanent hearing loss. These include reduced employment, higher rates of depression and higher rates of marital breakdown.

Given the dramatic adverse life outcomes that can arise from childhood hearing loss, it is absolutely critical that these children are provided with the required specialised supports in a timely, effective and accessible way.

Critical aspects of support for children with hearing loss

Despite the challenges detailed above, and in contrast to the experience of the vast majority of children with hearing loss around the globe (as detailed in the published literature), it is feasible for children with hearing loss to routinely achieve spoken language at the same level as children without any loss.

However these excellent outcomes for children with hearing loss – the achievement of spoken language at the same level as if the child did not have a loss – are only possible if all of the following occur:

1. Early detection and diagnosis
2. Rapid provision of services
3. Optimised access to sound
4. Specialised early intervention through the child's caregivers
5. Ongoing support for the child and the caregivers

The outcomes achieved by children attending the early intervention program at The Shepherd Centre demonstrate this. These children, with all levels of hearing loss (including being profoundly deaf) and many with other disabilities or complications, typically develop the same level of language as their normally-hearing peers, with over 90% of children going on to a mainstream class in a mainstream school.

The children graduating from The Shepherd Centre achieve the same language as children without loss. **This enables them to go on and achieve the same level of socioeconomic participation as children in the general population**, as shown in a recently released survey of 18 to 29 year-olds who had received early intervention as a child:

- 95% attended a mainstream high school;
- 86% completed Year 12 (higher than the national average);
- 62% achieved a tertiary level qualification; and
- 77% had already been in paid employment.

The strong positive economic benefit arising from these outcomes, compared to what is normally seen for children with hearing loss, is completely in line with the findings of the Competition Commission in its study that originally recommended the development of the NDIS.

However the current implementation of the NDIS is not supporting these outcomes. The current implementation is focussed on providing a small number of hours of direct support; it is not funding the complex specialist and integrated programs that are required to achieve the above outcomes. As a result the NDIS is at risk of dramatically increasing the cost to society of children with hearing loss.

Responses to the study

QUESTIONS

- *Are there any cost drivers not identified above that should be considered in this study? If so:*
 - *how do they impact costs in the short and long term?*
 - *how, and to what extent, can government influence them?*

A missing cost driver is the assessment of the quality of the service provided (in terms of the ratio of outcomes achieved versus quantity of service) and the subsequent benefits provided (both in terms of improved function and avoided future support costs). By not including assessment of the ability of a service to deliver outcomes (and thus not facilitating their achievement) the government will dramatically reduce the overall benefit provided by the NDIS.

Proposal: An explicit assessment of the outcomes generated by a service must be made by Government, for each of the various types of support provided, so that appropriate types and levels of intervention can be funded. As part of the assessment of benefit the Government must value and account for the benefits, both economic and socioeconomic, arising from a participant's support.

A further cost driver is the complexity of the administrative system that has been developed, along with the attendant administrative burden on all of the groups involved – the participants (who now have to go through multiple administrative steps that were previously not required), the services (who now need to acquit for every activity for every individual participant, rather than a single bulk acquittal) and the government (which must administer a much more complex system). Currently only the government's administrative cost appears to be captured. For example, the incremental costs of the NDIS for The Shepherd Centre (which currently receives less than \$3 million in grant or NDIS funding) has exceeded \$300,000 during the transition phase (on system upgrades and extra labour) and is expected to stay at an incremental cost of over \$60,000 per year.

Proposal: A design-led approach must be taken to reduce the complexity and cost to participants and service providers of the administrative system that is being implemented.

QUESTIONS

- *Why are utilisation rates for plans so low? Are the supports not available for participants to purchase (or are there local or systemic gaps in markets)? Do participants not require all the support in their plans? Are they having difficulty implementing their plans? Are there other reasons for the low utilisation rates?*
- *Why are more participants entering the scheme from the trial sites than expected? Why are lower than expected participants exiting the scheme?*
- *What factors are contributing to increasing package costs?*
- *Why is there a mismatch between benchmark package costs and actual package costs?*

In our experience utilisation rates are low as often the supports that are funded are not those that are required or desired by the participant. A recent example in our service is for a 15-year old with combined hearing loss and physical disability. The approved plan provided a large amount of funding for social inclusion, which is not needed and will not be used; conversely there is a significant requirement for aids to assist with the physical disability but these aids were not appropriately funded. In this particular case these errors were corrected on plan review, however that may not happen with other participants.

Proposal: The planning of packages must incorporate the input of both the participant and of the relevant clinicians so that appropriate supports are funded; rather than the default supports that may not be relevant or helpful for the participant.

In the case of children with hearing loss (and possibly with other disabilities such as Autism Spectrum Disorder) the increased number of participants is likely due to unmet pre-existing demand, which as it was not supported by previous funding was not previously visible to the system. For example, there are approximately 4,000 children younger than school age who have permanent hearing loss. The previous system only funded approximately 1/3rd of these children, and only funded at significantly less than the actual cost of service.

Proposal: Once the 'missing' children are supported under the system, future increases will only be in proportion to population increase, so no government action is required.

The reduced number of exits from childhood EI may well be due to the fact that the NDIS is funding inputs and not outcomes. For instance, for children with hearing loss the plans provided are based on a set number of direct service hours, with the number of hours being driven by the severity of the hearing loss.

However the achievement of outcomes for these children (their ability to have a fluent spoken or signed language prior to reaching school age) is not dependent on the number of service hours; instead it is driven by the quality of the program and the large amount of non-direct effort that must be put in to achieve these outcomes. The current approach of the NDIS is actually incentivising service providers to find the minimum-cost way of providing many hours of direct service (which will not achieve outcomes) and disincentivises the provision of the complex programs that do achieve outcomes.

Given this, it is not surprising that outcomes are not being achieved and thus children have a high ongoing need for support (it is expected that with a permanent disability that there would be some ongoing need for support, however it would be at a much lower level than without effective EI). This high need for support will result in them staying in the program.

Proposal: It is imperative that the funding of supports be oriented towards the achievement of outcomes rather than funding of inputs. Specific proposals to address this for children with hearing loss have been made to the NDIS however they have not been taken up. A specific proposal is appended to this submission (Appendix 3: Proposed protocol for NDIS EI support for children with permanent hearing loss, page 27).

The variance between benchmark and actual costs could be expected and desired, as the benchmark is based on a single type of participant however the actual needs of participants (and their subsequently required package) can vary widely. However we believe that this is not the reason for the variance. In our experience the large variance in packages is due to large between-planner variations in what packages they provide for equivalent participants. Much of this variance is due to the lack of acceptance of clinical input into the required package for a participant, despite the clinicians being the individuals who are most informed of the needs of a participant.

Proposal: The planning of packages must incorporate the input of both the participant and of the relevant clinicians so that appropriate supports are funded; rather than the default supports that may not be relevant or helpful for the participant.

QUESTIONS

- *To what extent have the differences in the eligibility criteria in the NDIS and what was proposed by the Productivity Commission affected participant numbers and/or costs in the NDIS?*
- *Are there other aspects of the eligibility criteria of the NDIS that are affecting participation in the scheme (to a greater or lesser extent than what was expected)? If so, what changes could be made to improve the eligibility criteria?*
- *To what extent is the speed of the NDIS rollout affecting eligibility assessment processes?*

The eligibility criteria for children with permanent hearing loss does not take into account the risk of future disability, if the risk of that is not near 100%. For instance children who have a unilateral hearing loss (that is, they are deaf in one ear but they can hear normally through the other) are expected to be not eligible for the NDIS. The rationale for this is that their spoken language at 5 years of age is typically within the normal range. However, due to their disability, a high percentage of these children will have significantly reduced social and educational outcomes when they are at school (as discussed in *Appendix 1: The profound impact of early childhood hearing loss, Effects of unilateral or mild hearing loss*, page 20).

The risks and costs of these future disabilities are not being taken into account when assessing whether children with unilateral hearing loss should receive early intervention, prior to reaching school.

Proposal: The NDIS should take into account the combined effects of risk and future costs in setting eligibility criteria for early childhood early intervention. For children with permanent hearing loss, any diagnosed hearing loss should enable a child to be eligible for the NDIS.

QUESTIONS

- *Is the ECEI approach an effective way to ensure that those children with the highest need enter into the NDIS, while still providing appropriate information and referral services to families with children who have lesser needs?*
- *What impact will the ECEI approach have on the number of children entering the scheme and the long-term costs of the NDIS?*
- *Are there other early intervention programs that could reduce long-term scheme costs while still meeting the needs of participants?*

The ECEI approach is not effective for children who already have a diagnosed disability. Once a diagnosis has been made, rather than enter the generalist system of the ECEI approach, a child should immediately enter the specialist service tailored to their disability.

This issue is particularly critical for children born with hearing loss. As discussed in *Appendix 2: Critical aspects of support for children with hearing loss*, page 23, any delay to specialist service can result in

permanent impairment to language. The extra steps that the ECEI approach requires between diagnosis and specialist service are causing months of delay which will have major negative effects on the language that a child can develop. A similar situation will occur for other disabilities, due to critical short neonatal timeframe of high neuroplasticity.

Proposal: The ECEI approach should not apply for children with a specific diagnosis. Children with a diagnosis need immediate and rapid referral to the specialist service appropriate for their disability.

Early intervention programs that are designed to deliver outcomes, rather than provide set measures of input, will reduce the long-term cost to the scheme by ensuring that the intended benefits of early intervention are achieved.

Proposal: It is imperative that the funding of supports be oriented towards the achievement of outcomes rather than funding of inputs. Specific proposals to address this for children with hearing loss have been made to the NDIS however they have not been taken up. A specific proposal is appended to this submission (Appendix 3: Proposed protocol for NDIS EI support for children with permanent hearing loss, page 27).

QUESTIONS

- *Is the current split between the services agreed to be provided by the NDIS and those provided by mainstream services efficient and sufficiently clear? If not, how can arrangements be improved?*
- *Is there any evidence of cost-shifting, duplication of services or service gaps between the NDIS and mainstream services or scope creep in relation to services provided within the NDIS? If so, how should these be resolved?*
- *How has the interface between the NDIS and mainstream services been working? Can the way the NDIS interacts with mainstream services be improved?*

The interface between the health system and the NDIS is critical for children with hearing loss. Diagnostic audiology for children is funded medically, as is the provision of cochlear implants or other surgically implanted hearing devices; however hearing aids and early intervention services are transitioning onto the NDIS.

If this interface is not functioning effectively children may be lost to follow-up (they get diagnosed but then do not successfully seek services from an early intervention service) or there may be a significant delay between diagnosis and enrolment with an early intervention service.

Either of these issues can cause profoundly interfere with the ability of the child to develop spoken language. Delays result in progressively worse language outcomes and in extreme can completely prevent the development of language. Due to the highly specific nature of hearing loss, a specific referral pathway is required between the medical-funded services and the NDIS-funded services to ensure that children rapidly obtain the assistance they need.

Proposal: A guided referral pathway, funded by the NDIS, is required for children diagnosed with permanent hearing loss prior to 6 years of age.

QUESTIONS

- *Is the range and type of services proposed to be funded under the ILC program consistent with the goals of the program and the NDIS more generally?*
- *What, if anything, can be done to ensure the ILC and LAC initiatives remain useful and effective bridging tools between services for people with disability?*
- *Is the way the NDIS refers people who do not qualify for support under the scheme back to mainstream services effective? If not, how can this be improved?*

Specific cohort-based information and linkage services are critically important functions. The NDIS participant-choice model is only effective if participants have sufficient information to be informed consumers. This is particularly so for parents of children with hearing loss, as approximately 90% of these parents will not have had any exposure to childhood hearing loss prior to the birth of their child.

The selection of supports by parents for their disabled child is highly emotional and is taken at a time where they are pressured by all of the other demands of being a new parent. With their natural desire to do the best for their child, parents face a daunting task of choosing the best options. An incorrect choice at this early stage could result in their child never developing an effective language.

As a result it is imperative to have impartial expert advisors who can immediately assist parents in choosing the supports for their child. These advisors can be part of a referral process, but also need to be accessible to the parents throughout the early intervention period for their child, so that the parents can obtain the information they need to make the best ongoing choices for their child.

Proposal: The ILC process should fund independent advisory services for parents or carers of children with hearing loss, which will enable the parents to rapidly make the appropriate service choices for their child.

QUESTIONS

- *Is the planning process valid, cost effective, reliable, clear and accessible? If not, how could it be improved?*
- *How should the performance of planners be monitored and evaluated?*

The planning process is not appropriate. It is cumbersome, slow, and does not consistently result in appropriate plans. This is a critical area for improvement in the NDIS, along with the funding of services to enable achievement of outcomes.

There have already been many examples of poor execution of the planning function for children with hearing loss:

- Inconsistent plans – we have had children with equivalent needs and family characteristics, where one child has been provided with a plan 50% of the other.
- Inadequate plans – the vast majority of children with hearing loss are being given plans far below the cost of service. If these children do not receive the services they need they will not develop good spoken language, resulting in a life-long need for more intensive support and worse personal outcomes.
- Plans funded in proportion to current disabilities not risk of disability – in NSW children with hearing loss of school age (and who are demonstrating current deficits in language, social skills, etc) are averaging higher plans than newborn children (who as babies do not yet show evidence of their

disability). This is the reverse of what needs to be done – an intense investment in early intervention as a baby will dramatically reduce the future cost of support, reducing the overall cost to the NDIS by more than 50%.

- Planning is not accessible – the process is cumbersome and slow; often telephone calls are used in the planning process for families who are marginalised or from a non-English speaking background; there is no clarity on how decisions are made.

A structured planning process is required based on the established needs of the child; providing the funding required to achieve the outcomes required to reduce future support needs. A protocol suitable for children with hearing loss is appended.

Proposal: Adoption of the attached protocol (Appendix 3: Proposed protocol for NDIS EI support for children with permanent hearing loss, page 27) as the basis for plans for children with hearing loss.

QUESTIONS

- *Do NDIA assessment tools meet these criteria? What measures or evidence are available for evaluating the performance of assessment tools used by the NDIA?*
- *What are the likely challenges for monitoring and refining the assessment process and tools over time? What implications do these have for scheme costs?*

The NDIA is not basing its decisions on assessment tools that are appropriate for children with hearing loss.

The tool implemented for children is the PEDI-CAT, an assessment of the abilities of a child across a broad range of functional abilities. However for children with hearing loss, action is required when the children are very young – including *before* they have developed any communication abilities to exhibit deficits in. The whole aim of the early intervention program for these children is to ensure that they develop language at the same rate and same age as children without hearing loss; they should never exhibit any deficits. Waiting for failure, waiting for deficits to become apparent before therapy is funded, will ensure that these deficits are permanent and will ensure that the children will never be able to develop to their language potential.

Instead the therapy program must be established based on the known future effects of the hearing loss, and the program implemented early to ensure those deficits are prevented. There are well-established criteria for assessing the level of support required, based on: the severity of hearing loss, a child's age, their progress in developing their listening and language skills, and on risk factors that are known to affect the ability of children to develop spoken factors. These criteria are incorporated in the protocol proposed in *Appendix 3: Proposed protocol for NDIS EI support for children with permanent hearing loss, page 27.*

Proposal: Adoption of the attached protocol (Appendix 3: Proposed protocol for NDIS EI support for children with permanent hearing loss, page 27) as the basis for plans for children with hearing loss.

Ongoing refinement of the assessment criteria and the provision of supports in proportion to the needs and outcomes requires the regular collection of data on services. This system is currently partly developed for children with hearing loss, with Australian Hearing publishing an annual report on the children diagnosed with hearing loss who are supported by its services; and by the early intervention services that are members of First Voice, who report on the language outcomes of the children attending those services.

These systems need to be extended and integrated so that the NDIA is provided with appropriate data to assess whether the services funded are producing the outcomes expected. The NDIS is resulting in dramatic changes to the provision of supports for children with hearing loss. If appropriate data is collected it is feasible that the outcomes achieved by these children with dramatically decline, rather than improve.

A national data centre should be established (sub-contracted to an appropriate institution such as the National Acoustic Laboratories) to collect information from the various state' newborn hearing screen organisations; the national guided referral pathway; accredited providers of paediatric audiology services; and from accredited providers of paediatric early intervention services for children with hearing loss. This data centre would then provide the required information to the NDIA so that appropriate funding decisions can be made.

Proposal: Establishment of a national data centre to support ongoing quality assurance of services and research.

QUESTIONS

- *Are the criteria for participant supports clear and effective? Is there sufficient guidance for assessors about how these criteria should be applied? Are there any improvements that can be made, including where modifications to plans are required?*
- *To what extent does the NDIA's budget-based approach to planning create clear and effective criteria for determining participant supports? To what extent does it lead to equitable outcomes for participants? What improvements could be made?*
- *What implications do the criteria and processes for determining supports have for the sustainability of scheme costs?*
- *Are the avenues for resolving disagreements about participant supports appropriate? How could they be improved?*

The NDIS assembled the 'Early childhood intervention (hearing loss) expert reference group' in February 2015, of which I'm a member. One of the aims of this group was to establish the reference packages for children with hearing loss. The group has been called to meet only 3 times and no reports or recommendations have been produced. As a result there are no specific reference packages for children with hearing loss and planners are relying on unsuitable and insufficient generic packages; and these are not being applied consistently.

If a suitable reference package was used, such as those provided in *Appendix 3: Proposed protocol for NDIS EI support for children with permanent hearing loss*, the supports provided would be appropriate for the children.

In the absence of an appropriate reference package children with hearing loss are being provided with lower-cost ineffective packages. This substantially increases the ongoing cost to the NDIS. Whilst the number of children involved is too small for this cost to affect the sustainability of the scheme, the lost personal potential of these children and the increased cost should not be accepted.

Proposal: Adoption of the attached protocol (Appendix 3: Proposed protocol for NDIS EI support for children with permanent hearing loss, page 27) as the basis for plans for children with hearing loss.

Because of the inconsistent and insufficient plans being funded for children with hearing loss many are being appealed with the agency. These appeals take many months to resolve and if the therapy provided to the children was stopped during this time they would suffer unacceptable delays to their language development. Adoption of a clear planning framework (as above) is required to dramatically reduce the incidence of disagreements; and then for the remaining cases a mechanism must be put in place to enable a rapid resolution that will not cause a language delay for the children.

Proposal: Establish a triaged response protocol for disagreements, which will enable time-critical disagreements to be resolved rapidly.

QUESTIONS

- *What factors affect the supply and demand for disability care and support workers, including allied health professionals? How do these factors vary by type of disability, jurisdiction, and occupation? How will competition from other sectors affect demand (and wages) for carers? What evidence is there from the NDIS trial sites about these issues?*
- *How will an ageing population affect the supply and demand for disability carers (including informal carers)?*
- *Is increasing the NDIS workforce by 60 000-70 000 full time equivalent positions by 2019-20 feasible under present policy settings? If not, what policy settings would be necessary to achieve this goal, and what ramifications would that have for scheme costs?*
- *How might assistance for informal carers affect the need for formal carers supplied by the NDIS and affect scheme costs?*
- *To what extent is the supply of disability care and support services lessened by the perception that caring jobs are poorly valued? If such a perception does exist, how might it best be overcome?*
- *What scope is there to expand the disability care and support workforce by transitioning part-time or casual workers to full-time positions? What scope is there to improve the flexibility of working hours and payments to better provide services when participants may desire them?*
- *What role might technological improvements play in making care provision by the workforce more efficient?*
- *What are the advantages and disadvantages of making greater use of skilled migration to meet workforce targets? Are there particular roles where skilled migration would be more effective than others to meet such targets?*

The critical clinicians for the provision of services to children with hearing loss are specialist listening & spoken language therapists (most commonly speech pathologists with supplementary specialist training), audiologists and counsellors. There is increasing competition for these staff between service suppliers and this will intensify over the coming years.

It is feasible for the required number of staff to be trained and recruited, however this will be affected by the professional satisfaction these staff find in their roles. This adds weight to the importance of the NDIS supporting outcomes not inputs, so that these clinicians can see that they are making it possible for children with hearing loss to achieve their potential in life.

Proposal: It is imperative that the funding of supports be oriented towards the achievement of outcomes rather than funding of inputs.

Technological approaches can play a major part in the provision of services to children with hearing loss. For instance, approximately 15% of the children that The Shepherd Centre support are located in remote or regional locations where there is no local service available. These children are receiving their therapy via

online eLearning and video-based telepractice. These children achieve the same spoken language outcomes (matching children without hearing loss) as the children who receive face to face service. It is critical that the NDIS continue to be channel-neutral and not restrict the mode of service delivery.

Proposal: It is imperative that the funding of supports not restrict the mode of delivery but instead focus on the achievement of outcomes.

QUESTIONS

- *Are prices set by the NDIA at an efficient level? How ready is the disability sector for market prices?*
 - *How do 'in-kind' services affect the transition to the full scheme and ultimately scheme costs?*
 - *What is the capacity of providers to move to the full scheme? Does provider readiness and the quality of services vary across disabilities, jurisdictions, areas, participant age and types/range of supports?*
 - *How ready are providers for the shift from block-funding to fee-for-service?*
 - *What are the barriers to entry for new providers, how significant are they, and what can be done about them?*
 - *What are the best mechanisms for supplying thin markets, particularly rural/ remote areas and scheme participants with costly, complex, specialised or high intensity needs? Will providers also be able to deliver supports that meet the culturally and linguistically diverse needs of scheme participants, and Aboriginal and Torres Strait Islander Australians?*
 - *How will the changed market design affect the degree of collaboration or co-operation between providers? How will the full scheme rollout affect their fundraising and volunteering activities? How might this affect the costs of the scheme?*
-

The prices set by the NDIA need to reflect the costs of achieving the required outcome intended by the plan; not the minimum price required to achieve a particular input. Paying cheaply for inputs, but then those inputs not resulting in the required outcome, creates increased future costs for the NDIS.

The prices paid for early intervention for children with hearing loss is a clear example of this. The NDIA will only pay for the direct service hours for the child, which adds to about 60% of the cost of a specialised service. Direct therapy alone will not enable children to learn to speak well, as discussed in *Appendix 2: Critical aspects of support for children with hearing loss*, page 23. However, if the specialised integrated service is provided, the children should learn to speak as well as any other child, subsequently enabling them to achieve their academic, economic and social potential (as described in *Outstanding outcomes are possible*, page 24). This dramatically reduces the future cost to the NDIS with an overall very positive cost-benefit.

Proposal: The prices set by the NDIA should be calibrated to be the efficient prices for the achievement of the desired outcome; not the minimum cost to deliver a specific input.

The ability of providers to be able to document the achievement of economically relevant outcomes, and to demonstrate the cost-benefit of those outcomes, varies between disabilities and providers with a disability.

As a result outcomes-based funding should be used for those services that can demonstrate achievement of outcomes; but should not be paid to services that can't.

Proposal: Outcomes based funding should be used in those disabilities and with those providers that can demonstrate their outcomes and the cost-benefit of their programs.

QUESTION

- *How well-equipped are NDIS-eligible individuals (and their families and carers) to understand and interact with the scheme, negotiate plans, and find and negotiate supports with providers?*

Families of children with hearing loss are normally very poorly equipped to interact with the scheme. More than 90% of deaf children are born to speaking parents, who do not have experience with childhood deafness. As a result they are not informed consumers – they don't know what is required for their child, when it is needed, etc.

Also, the diagnosis of hearing loss is often made immediately after birth when the family is struggling with the changes and stresses of having a newborn; and approximately 30% of deaf children also have some other sort of additional disability.

As a result these parents are normally not in a situation where they are able to appropriately interact with the scheme, in a way that will enable them to achieve the outcomes they would want for their child. Experience in South Australia has already shown that in the absence of a guided referral pathway, it can take more than a year before a family engages with an appropriate provider of specialist early interventions services.

Proposal: A guided referral pathway is required to ensure that, following diagnosis of hearing loss, families are rapidly engaged with the services that they will need for their child to achieve the outcomes they hope for.

QUESTIONS

- *How should the financial sustainability of the NDIS be defined and measured?*
- *What are the major risks to the scheme's financial sustainability? What insights do the experiences from the trial sites provide on potential risks in the context of financial sustainability? How might the NDIA address these risks?*
- *Does the NDIA's definition of financial sustainability have implications for its management of risk? Are there risks that are beyond the NDIA's remit?*
- *How does the NDIA progress from identifying a risk to managing it through changes in the delivery of the scheme? Are there any barriers to the NDIA doing this effectively?*
- *Are there changes that could be made to improve the NDIA's management of risk? Should more details about the NDIA's risk management practices be publicly available?*
- *Does funding the NDIA on an annual basis affect its management of risk?*
- *Are there other ways the scheme could be modified to achieve efficiency gains and reduce costs?*
- *What are the likely longer-term impacts of any cost overruns? How should any cost overruns be funded?*

The current emphasis of plans are that they focus on the inputs that a participant receives, though they are intended to meet the goals that have been agreed. A move away from input measures to outcome measures and potentially funding of outcomes rather than inputs would enable further innovation and move towards lower costs and improved outcomes.

An example of this is with children with hearing loss, where a very tangible goal can be set (achievement of good spoken or signed language) and then achievement of that outcome being funded, rather than a pre-set number of therapy hours (which may well produce a nil outcome).

Proposal: incorporate an active pursuit of funding for outcomes rather than inputs, including an assessment of any improvements in effectiveness in producing outcomes.

Appendices

The following are appended:

1. The profound impact of early childhood hearing loss
 2. Critical aspects of support for children with hearing loss
 3. Proposed protocol for NDIS EI support for children with permanent hearing loss
-

Appendix 1: The profound impact of early childhood hearing loss

Children with early hearing loss face numerous challenges on their road to achieving full social inclusion. This document focusses on children who have a permanent hearing loss (which may be due to sensorineural, conductive, or be mixed in nature; or due to Auditory Neuropathy Spectrum Disorder; and which may affect one or both ears) diagnosed in the first 5 years of life.

Up to 1 in 500 children born will have some degree of permanent hearing loss. Further children will develop hearing loss in the first few years of life (due to progressive loss, disease, trauma, etc) and by the time they are of school age approximately 1 in 300 children will have permanent hearing loss (approximately 4,000 children across Australia). **More than 90% of these children are born to parents who use a spoken language in the home and who would normally want their child to speak their home language.**

Children diagnosed with hearing loss in both ears (bilateral hearing loss) have been demonstrated to have the most profound deficits in speech, language, literacy and social inclusion. However children with loss in one ear only (unilateral hearing loss or single-sided deafness) also suffer significant impacts. As listening through one year alone is often sufficient when a child is in a quiet environment, these impacts often only become evident once a child is in a challenging auditory environment such as day care or school. However at that time the same impacts as with bilateral loss then often become evident – poor development of language, speech and/or literacy; and poor social inclusion.

As with children with bilateral loss, an early investment into children with unilateral loss also prevents a significantly larger future cost to the child, their family and to society.

Speech and Language

Speech and language outcomes for children born with permanent childhood hearing loss (PCHL) have historically been compromised (Allen, 1986; Holt, 1994). Late diagnosis of PCHL has been associated with significant delays in speech and language, which has subsequently been associated with delays in literacy development (Francis, Koch, Wyatt, & Niparko, 1999; Lin & Niparko, 2006). For instance, a review in 2008 reported that **67% of deaf children were taught outside of traditional mainstream classes**; and historically the **average oral and written language age of high school deaf graduates from the United States of America was at or below that of the average hearing seven to eight year old child** (Durieux-Smith, Fitzpatrick, & Whittingham, 2008).

In recent years, a positive shift in the speech and language outcomes for children with early identified PCHL has occurred. However, international research data (not that on children graduating from The Shepherd Centre) continues to suggest that the **majority of these children are unable to achieve speech and language outcomes commensurate with their typically hearing peers**. (e.g., Forli et al., 2011; Niparko et al., 2010; Tait, De Raeve, & Nikolopoulos, 2007). Moreover, the limited research concerning speech development suggests that the acquisition of clear, intelligible speech for this population has been particularly challenging (e.g., Blamey, Barry, & Jacq, 2001).

Literacy

In 1979, Conrad stated that 92% of school leavers with severe-profound hearing loss were unable to achieve reading levels commensurate with their chronological age. For the children with profound PCHL, this figure increased to 99%. An editorial in the Journal of Deaf Studies and Deaf Education in 2007 suggested that **30% of school graduates with severe/profound SNHL were functionally illiterate** (Marschark, Archbold, Grimes, & O'Donoghue, 2007). Given the repeated reports of close links between long term literacy outcomes with early speech and language development success (e.g., Overby, Trainin, Smit, Bernthal, & Nelson, 2012; Pennington & Bishop, 2009), these poor literacy outcomes are of significant concern.

Socioeconomic Issues

Socioeconomic problems are well reported for children with severe-profound hearing loss, however the extensive issues documented for people with hearing loss in Australia (Hogan, 2012) indicate the likelihood of effects on children will all levels of loss.

A logical consequence of compromised speech, language and literacy outcomes has been the persistence of substantially unacceptable long term psychosocial problems as well as **reduced employment opportunities** particularly for those with congenital severe-profound PCHL (Kentish & Mance, 2009; Venail, Vieu, Artieres, Mondain, & Uziel, 2010).

Higher rates of self-reported depression are noted for these children (Theunissen et al., 2011). Parents of children with PCHL report high levels of stress (Meadow-Orlans, 1995) **as well as increased marital breakdowns**, particularly for those families where children have greater severities of PCHL (Henggeler, Watson, Whelan, & Malone, 1990). Significant delays in speech, language and literacy has been associated with consequent limits to educational, occupational and socio-economic options (Francis et al., 1999; Lin & Niparko, 2006).

Economic reports also identify significant financial burden. For example, according to the Access Economics Report, 2006, costs associated with hearing loss for the Australian economy were approximately \$11 billion per annum. These costs include the supply of personnel and equipment associated with diagnosis of hearing loss; ongoing supply and maintenance of paediatric audiological devices (hearing aids and/or cochlear implants); supply of specialised medical personnel, audiologists, and educational facilities/clinicians. **Long term lost earnings for individuals with hearing loss was listed as incurring the greatest costs**, accounting for more than half (57%) of all financial costs. An analysis of the cost-benefit of early intervention for children with hearing loss in Australia demonstrated significant benefits (First Voice, 2011). Governments have thus become progressively motivated to research and access solutions for congenital PCHL, ideally in early childhood, before these expensive long term consequences take effect.

More recently, the improvements to newborn hearing screening, diagnosis, therapy, and use of technologies such as cochlear implantation, has resulted in significant improvements in speech and language outcomes for children with all levels of hearing loss (Forli et al., 2011; Geers & Sedey, 2011; Sininger, Grimes, & Christensen, 2010).

Effects of unilateral or mild hearing loss

In decades past support for children with hearing loss was restricted to those with a moderate or worse loss in both ears (normally defined as a loss of more than 40dB in each ear). Children with a hearing loss in one ear (unilateral loss), or children with only a mild loss (21-40dB) were seen as not requiring support.

However extensive research over the last 3 decades has shown that these children do suffer significant functional loss in their communication capacities. This is evident from the first few months of life, where over 40% babies of around 9 months of age with unilateral loss had delays in babbling, an important developmental step for spoken language (Kishon-Rabin, 2015). This then leads on to significantly worse speech language scores in children and adolescents (Lieu et. al., 2010; Fisher & Lieu, 2014) and results in significant problems at school (Lieu, 2013).

A review of the literature on the effects of unilateral hearing loss (Krishnan & Van Hyfte, 2016) found that these children had:

- reduced spoken language competence (25-40% with poorer speech & language skills of a wide variety of domains);
- potentially reduced cognitive ability (lower performance on complex verbal IQ tasks);
- reduced educational progress (22-40% needed to repeat a grade at school and 41-54% required an individual education plan to support their learning); and

- poorer social & behavioural development (20-33% with behavioural problems, continuing into adulthood)

Given the dramatic adverse life outcomes that can arise from all levels of childhood hearing loss, it is absolutely critical that all of these children are provided with the required specialised supports in a timely, effective and accessible way.

References

- Access Economics. (2006). *The Economic Impact and Cost of Hearing Loss In Australia*. Melbourne.
- Allen, T. (1986). Patterns of academic achievement among hearing impaired students: 1974 and 1983. In Karchmer (Ed.), *Deaf Children in America* (pp. 161-206). Boston: College-Hill Press.
- Blamey, P. J., Barry, J. G., & Jacq, P. (2001). Phonetic inventory development in young cochlear implant users 6 years post operation. *Journal of Speech, Language, and Hearing Research*, 44(1), 73-79.
- Ching, T. (2015) Outcomes of early identified children with hearing impairment at 5 years: Update on the 5-year-old LOCHI Study data. *8th Australasian Newborn Hearing Screening Conference, Sydney Australia, 19-20 June 2015*.
- Conrad, R. (1979). *The Deaf Child*. London: Harper and Row.
- Durieux-Smith, A., Fitzpatrick, E., & Whittingham, J. (2008). Universal newborn hearing screening: A question of evidence. *International Journal of Audiology*, 47(1), 1 - 10.
- First Voice (2011). Early intervention programs to assist children with hearing loss develop spoken language. A social cost-benefit analysis (report by Econtext).
- First Voice (2016). Education, Employment & Social Outcomes of First Voice centre graduates (18-28 years).
- Fisher, C., & Lieu, J. (2014). Unilateral Hearing Loss is Associated with a Negative Effect on Language Scores in Adolescents. *International Journal of Pediatric Otorhinolaryngology*, 78(10), 1611-1617.
- Forli, F., Arslan, E., Bellelli, S., Burdo, S., Mancini, P., Martini, A., Miccoli, M., Quaranta, N., Berrettini, S. (2011). Systematic review of the literature on the clinical effectiveness of the cochlear implant procedure in paediatric patients. [Review]. *Acta Otorhinolaryngologica Italica*, 31(5), 281-298.
- Francis, H., Koch, M., Wyatt, J., & Niparko, J. (1999). Trends in educational placement and cost-benefit considerations in children with cochlear implants. *Archives of Otolaryngology-Head & Neck Surgery*, 125(5), 499-505.
- Geers, A. E., & Sedey, A. L. (2011). Language and verbal reasoning skills in adolescents with 10 or more years of cochlear implant experience. *Ear and Hearing*, 32(1), 39S-48S.
- Henggeler, S. W., Watson, S. M., Whelan, J. P., & Malone, C. M. (1990). The adaptation of hearing parents of hearing-impaired youths. *American Annals of the Deaf* (135), 211–216.
- Hogan, A. (2012). A report card on the social well-being of Deaf and hearing impaired people in Australia. *2012 Libby Harricks Memorial Oration, 7th National Deafness Sector Summit, Melbourne 2012*.
- Holt, J. (1994). Classroom attributes and achievement test scores for deaf and hard of hearing students. *American Annals of the Deaf*, 139(4), 430-437.
- Joint Committee on Infant Hearing (2007). Year 2007 position statement of the Joint Committee on Infant Hearing: Principles and guidelines for early hearing detection and intervention programs. *Pediatrics*, 120, 898-921.
- Kentish, R., & Mance, J. (Eds.). (2009). *Psychological effects of deafness and hearing impairment*. West Sussex, UK: Wiley-Blackwell.

- Kishon-Rabin, L., Kuint, J., Hildesheimer, M., & Roth, D. (2015). Delay in auditory behaviour and preverbal vocalisation in infants with unilateral hearing loss. *Developmental Medicine & Child Neurology*, *57*, 1129-1136.
- Krishnan, L., & Van Hyfte, S. (2016). Management of unilateral hearing loss. *International Journal of Pediatric Otorhinolaryngology*, *88*, 63-73.
- Lieu, J. (2013). Unilateral hearing loss in children: speech-language and school performance. *B-ENT, Suppl 21*, 107-115.
- Lieu, J., Tye-Murray, N., Karzon, R., & Piccirillo, J. (2010). Unilateral hearing loss is associated with worse speech-language scores in children: a case-control study. *Pediatrics*, *125*(6), 1348-1355.
- Lin, F., & Niparko, J. (2006). Measuring health-related quality of life after pediatric cochlear implantation: a systematic review. *International Journal of Pediatric Otorhinolaryngology*, *70*(10), 1695-1706.
- Marschark, M., Archbold, S., Grimes, M., & O'Donoghue, G. (2007). On language, education, and cochlear implants. *Journal of Deaf Studies and Deaf Education*, (Editorial), *12*(3), 257.
- Meadow-Orlans, K. P. (1995). Sources of stress for mothers and fathers of deaf and hard of hearing infants. *American Annals of the Deaf* (140), 352–357.
- Moeller, M.P., Carr, G., Seaver, L., Stredler-Brown, A., & Holzinger, D. (2013). Best practices in Family-Centred Early Intervention for Children Who Are Deaf or Hard of Hearing: An International Consensus Statement. *Journal of Deaf Studies and Deaf Education*, *18*(4), 429-445.
- National Deaf Children's Society (2016). NDCS note on Department for Education figures on attainment for deaf children in 2015 (England).
- Niparko, J. K., Tobey, E. A., Thal, D. J., Eisenberg, L. S., Wang, N.-Y., Quittner, A. L., Fink, N. E., CDaCI Investigative Team. (2010). Spoken language development in children following cochlear implantation. *Journal of the American Medical Association*, *303*(15), 1498-1506.
- Overby, M. S., Trainin, G., Smit, A. B., Bernthal, J. E., & Nelson, R. (2012). Preliteracy speech sound production skill and later literacy outcomes: A study using the Templin archive. *Language, Speech, and Hearing Services in Schools*, *43*(1), 97-115.
- Pennington, B. F., & Bishop, D. V. M. (2009). Relations among speech, language, and reading disorders. *Annual Review of Psychology*, *60*(1), 283-306.
- Sininger, Y. S., Grimes, A., & Christensen, E. (2010). Auditory development in early amplified children: Factors influencing auditory-based communication outcomes in children with hearing loss. *Ear and Hearing*, *31*(2), 166-185.
- Tait, M., De Raeve, T., & Nikolopoulos, T. (2007). Deaf children with cochlear implants before the age of one year: comparison of preverbal communication with normally hearing children. *International Journal of Pediatric Otorhinolaryngology*, *71*, 1605-1611.
- The Shepherd Centre (2016). 2015 Annual Report.
- Theunissen, S. C. P. M., Rieffe, C., Kouwenberg, M., Soede, W., Briare, J. J., & Frijns, J. H. M. (2011). Depression in hearing-impaired children. *International Journal of Pediatric Otorhinolaryngology*, *75*(10), 1313-1317.
- Venail, F., Vieu, A., Artieres, F., Mondain, M., & Uziel, A. (2010). Educational and employment achievements in prelingually deaf children who receive cochlear implants. *Archives of Otolaryngology Head and Neck Surgery*, *136*(4), 366-372.
- Yoshinaga-Itano, C. (2015) Outcomes of children identified through Universal Newborn Hearing Screening across the United States: Children with hearing loss only and those with special needs. *8th Australasian Newborn Hearing Screening Conference*, Sydney Australia, 19-20 June 2015.

Appendix 2: Critical aspects of support for children with hearing loss

Our brains have specialised areas for the processing of sound. These specialised areas are active from about half-way through pregnancy, so that a mid-term baby will start reacting to noise and by the time of birth they will already have a preference for the language and accent of their mother. The baby's ability to discern and interpret subtle sounds and tones continues to improve as they develop over the first few years of their life. This continually improving ability is critical for the baby to be able to learn a spoken language.

However the specialised parts of the brain will not develop and will actually regress if a child does not quickly receive sufficient high-quality auditory stimulation. In time the child's ability to ever understand sound may be effectively lost. This process of 'use it or lose it' is a key part of neuroplasticity, where the baby's brain is remodelling itself to maximise its abilities in the areas that are critical to it, whilst divesting itself of capabilities that aren't being used.

As a result of this dramatic process, 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.

Excellent outcomes for children with hearing loss – the achievement of spoken language at the same level as if the child did not have a loss – are possible if all of the following occur:

1. Early detection and diagnosis

A child must have its hearing loss diagnosed rapidly to enable the subsequent support to be able to be provided within the required timeframe. Across Australia the introduction of universal newborn hearing screening has meant that over 90% of children born with a hearing loss are diagnosed within the first few months of life. In contrast, there is no national approach for the detection and diagnosis of hearing loss developing after birth. As a result the diagnosis of these children is delayed and they are often not picked up until they are having problems at school.

2. Rapid provision of services

Following diagnosis the child must be rapidly referred to the specialised facilities and clinicians that are required. Direct referral pathways (without intervening steps) and active follow-up (to ensure at-risk families don't fail to attend) are critical for success. The structured pathway established prior to the NDIS resulted in over 90% of children diagnosed at birth being seen by Australian Hearing. However a standardised process was not established for children diagnosed after birth.

The NDIS has recently introduced its 'Early Childhood Early Intervention' approach which has introduced an extra 5 steps between the diagnosis of hearing loss and the provision of specialised service (**Error! Reference source not found.**, page **Error! Bookmark not defined.**).

3. Optimised access to sound

High-quality access to sound for a child with a hearing loss requires the child to be provided with the correct devices (specialised hearing aids, cochlear implants, etc), along with management of the devices, child education and carer education. This process is very different in young children than it is with adults, requiring audiologists with specialist paediatric training and specialist facilities.

Poorly fitted hearing devices will result in lower-quality sound input for the child. Without optimal access to sound it is incredibly difficult for the child to learn to produce clear speech – 'muddy in, muddy out'.

4. Specialised early intervention through the child's caregivers

Even with the best hearing devices available, the sound that children can access is not equivalent to what they would normally hear. This is due to both the quantity and quality of sound they receive. Children with 'normal' hearing are listening 24/7 – even when they are asleep they are perceiving sound and their brains are being stimulated. In contrast children with aids will normally only have them on for a maximum of 12 hours a day (due to taking them off during bathing, sleep, etc).

In addition, even the best devices do not match normal hearing – for example the outstanding cochlear implants produced in Australia, seen as the best in the world, only stimulate 22 separate regions in the cochlear (the part of the inner ear that detects sound and converts it into nerve impulses). This can be imagined as replacing a piano with thousands of keys (normal hearing) with one that only has 22 (the implant) and then requiring the pianist to try and reproduce the music of the original. It can be done, but it requires superb skill and a lot of effort.

As a result it is imperative that every opportunity is taken every day to practice the child's listening and language abilities. Normal exposure to sounds and language is not sufficient for a child with hearing loss to develop their language potential. Daily intense and individual therapy must be provided – which is only feasible and is best provided through the child's parents or caregivers, not through a therapist. As a result the parents must be taught, practised and supported in the specialised approaches they need to use to enable their child to develop spoken language in their natural environment. This requires a specialised, integrated transdisciplinary/interdisciplinary service that incorporates clinicians who have specialist knowledge in paediatric audiology, listening & spoken language, and emotional support.

As a substantial part of the clinician's work is individualised adult education, the level of support required for a child with a mild or moderate hearing loss is not substantially less than the level of support required with a severe or profound loss (the same level of adult education is required for the parents regardless of the child's level of loss).

5. Ongoing support for the child and the caregivers

The listening and language skills of a child naturally change as they develop, which requires adaptation of the listening and language interventions that the parents need to provide. In addition the hearing loss impacts on the development of normal social skills by the child and additional support is required to assist with this. As a result, support over all of the early years of life is required for the multiple challenges and transitions that these children face due to their disability.

These and other critical features of services supporting children with hearing loss are laid out in the "Best practices in Family-Centred Early Intervention for Children Who Are Deaf or Hard of Hearing: An International Consensus Statement", Moeller *et al* (2013).

Outstanding outcomes are possible

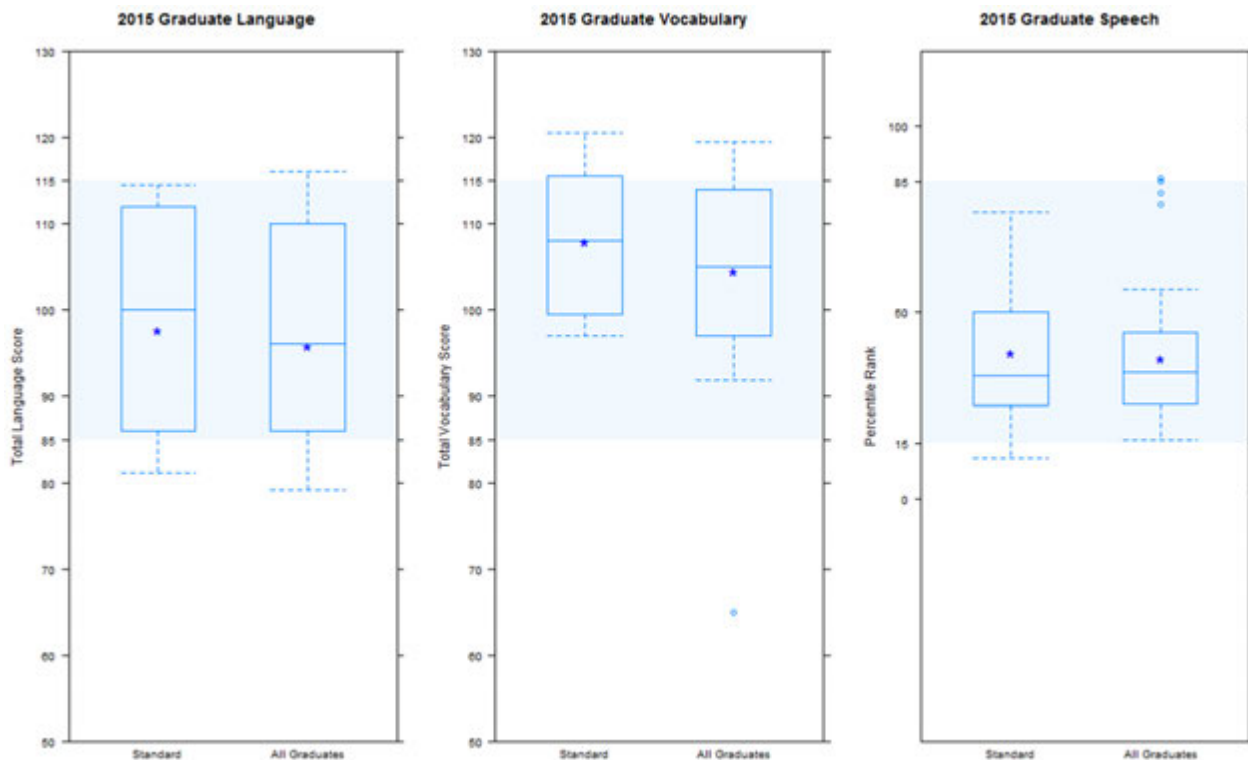
Despite the challenges detailed above, and in contrast to the experience of the vast majority of children with hearing loss around the globe (as detailed in the published literature), it is feasible for children with hearing loss to routinely achieve spoken language at the same level as children without any loss.

This is demonstrated by the outcomes achieved by children attending the early intervention program at The Shepherd Centre. These children, with all levels of hearing loss (including being profoundly deaf) and many with other disabilities or complications, typically develop the same level of language as their normally-hearing peers, with over 90% of children going on to a mainstream class in a mainstream school.

The children graduating from The Shepherd Centre achieved the same language as children without loss.

The following graph depicts the language of the children completing The Shepherd Centre early intervention program in 2015 (going on to school in 2016).

Three critical areas of spoken language are displayed (formal language skills, vocabulary and speech clarity), with the achievements of the graduates shown by the box & whiskers, compared to the normal range of children without hearing loss (blue shaded area). In each panel the results are shown for the children without any additional disabilities or other complications ('standard', which are about one-third of the children; left side) and also the results across all of the children (including those with multiple disabilities, coming from a non-English speaking background, delayed diagnosis, etc; right side):



These outcomes are attributable to a specialised, integrated transdisciplinary/interdisciplinary service that provides:

- Rapid provision of services, within a few months of diagnosis;
- Optimising access to sound for the child through management of hearing devices, child education and carer education;
- Teaching the child's caregivers the specialised approaches needed for them to enable their child to develop spoken language in the child's natural environments; and
- Supporting the child and the caregivers through the multiple challenges and transitions that these children face due to their disability.

Some of these services can be delivered through interaction with a single clinician and through face-to-face service. **However, the poor outcomes from services that only provide single-clinician and face-to-face service demonstrates that specialised integrated interdisciplinary/transdisciplinary services are required to deliver the required outcomes.** Success is critically dependent on other elements including:

- Provision of caregiver training outside of face-to-face sessions (such as through offline materials or online eLearning);
- Tracking of assessments of individual children versus program norms and development of individualised intervention programs;
- Refinement and implementation of specific interventions for each child based on their individual progress and circumstances; and
- Provision of extensive caregiver support and discussion channels to enable them to be effective language therapists in the child's natural environment.

These additional activities are essential within the clinical program, however they add an additional 2 hours of professional time for every hour of face-to-face intervention. Further details on this clinical program is provided in **Error! Reference source not found.**, page **Error! Bookmark not defined.**

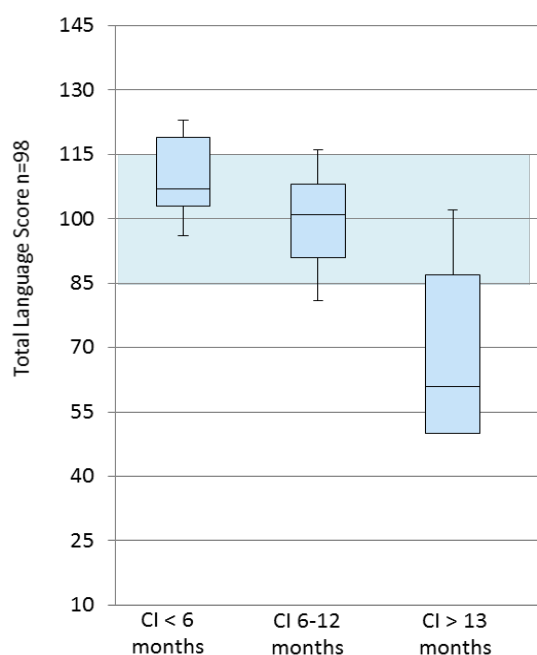
The ongoing benefit that children receive from participation in a specialised, integrated transdisciplinary/interdisciplinary program such as The Shepherd Centre's is demonstrated by the outcomes of children as they transition from high school to adult life. A survey of graduates from the programs of the First Voice centres (First Voice, 2016), which includes The Shepherd Centre along with 5 other centres with similar programs, showed outstanding results.

The respondents to this survey, children who graduated from these early intervention programs and were now aged 18-28 years, had academic and employment outcomes in line with those reported for mainstream young adults Australia (95% attending a mainstream high school; 82% accepted into tertiary education; and 77% in employment).

These findings contrast dramatically with the outcomes of children with hearing loss in the UK, where the number of children not achieving 5 GCSEs of at least grade C is almost double that of children without special education needs – 58.9% versus 35.8% (NDCS, 2016).

International experience also demonstrates that specialised services are able to deliver outcomes that other services do not (Yoshinaga-Itano, 2015). The importance of early provision of services, as quickly as possible after the emergence of the hearing loss, is emphasised by the Joint Committee on Infant Hearing (2007) which emphasised the need for intervention to be provided by 6 months of age.

This critical importance of rapid action is shown by the impact of any delay of cochlear implantation for children with congenital deafness. The largest prospective study of children with hearing loss, the Longitudinal Outcomes of Children with Hearing Impairment (LOCHI) study found any delay of implantation after six months of age results in progressively poorer language outcomes (Ching, 2015). This is emphasised by the outcomes found by infants within The Shepherd Centre early intervention program, with language ability of profoundly deaf infants who receive their cochlear implants early (before 6 months of age) being much better than those for children implanted later:



The outcomes of the children with hearing loss (and implanted either before 6 months; between 6 and 12 months; or 13 months and over) are shown by the box and whiskers, compared to the normal language range for children without hearing loss, shown by the blue shaded area.

Specific access requirement

A diagnosed permanent hearing loss of 21dB or greater (averaged over 3 or more frequencies) in one or both ears, including hearing loss due to ANSD.

Assessment of level of core program support required

The key aim of the core program (collaborative teamwork practice or transdisciplinary early childhood intervention) is to support the development of age appropriate communication & social skills by the child. The level of support required (Nil, Low, Med, High) is determined by the individual needs of the child.

All children require an initial 6 months of High level core program support. After this first six months, the default level of support is determined according to: whether the hearing loss affects both ears or one; age of child; level of hearing loss; level of current communication skill; and any additional risk factors (including delayed entry to early intervention). The appropriate level is determined as per the following tables:

Bilateral HL		0-36 months		37-72 months	
		Appropriate communication	Delayed communication	Appropriate communication	Delayed communication
Hearing loss in <u>less-</u> affected ear	Mild 21-40dB	- risk: Low + risk: Med	- risk: High + risk: High	- risk: Low + risk: Med	- risk: High + risk: High
	Moderate 41-70dB	- risk: High + risk: High	- risk: High + risk: High	- risk: Med + risk: High	- risk: High + risk: High
	Severe* 71-90dB	- risk: High + risk: High	- risk: High + risk: High	- risk: Med + risk: High	- risk: High + risk: High
	Profound 91+dB	- risk: High + risk: High	- risk: High + risk: High	- risk: Med + risk: High	- risk: High + risk: High
Unilateral HL		Appropriate communication	Delayed communication	Appropriate communication	Delayed communication
Hearing loss in the affected ear	Mild 21-40dB	- risk: Low + risk: Low	- risk: High + risk: High	- risk: Nil** + risk: Nil**	- risk: High + risk: High
	Moderate 41-70dB	- risk: Med + risk: Med	- risk: High + risk: High	- risk: Low + risk: Low	- risk: High + risk: High
	Severe* 71-90dB	- risk: High + risk: High	- risk: High + risk: High	- risk: Med + risk: Med	- risk: High + risk: High
	Profound 91+dB	- risk: High + risk: High	- risk: High + risk: High	- risk: Med + risk: High	- risk: High + risk: High

* children with Severe or Profound hearing loss are to be evaluated for cochlear implantation candidacy.

** no further core program support after the initial 6 months.

In the above tables:

Bilateral hearing loss: both ears with permanent hearing loss of 21dB or more (averaged over 3 or more frequencies), as diagnosed by a qualified paediatric audiologist. The level of hearing loss for use in the table is determined by the ear that has the better hearing.

Unilateral hearing loss: one ear does not have a permanent hearing loss.

Delayed communication: the level of communication (spoken or signed) of the children must be assessed according to a validated and standardised assessment tool. Delayed children are those that fall 1 SD or more below the population norm.

+ Risk factors: the presence additional risk factors that significantly increase the support needs of the child. Relevant risk factors are listed below.

Provision of the core support program

The core support program for hearing loss is funded in addition to the funding of any additional therapy provided due to any other disabilities (the presence of other disabilities does not decrease the funding need for hearing loss support).

All core support programs must include the following:

1. Therapy to support age-appropriate communication development (either spoken or signed) from a provider with specialist skills in supporting children with hearing loss and their families;
2. Intervention to support the development of age-appropriate play and social skills;
3. Audiological management where necessary to ensure assistive devices are being appropriately and effectively utilised;
4. Support and education for the family and for inclusion of the child into the family's community;
5. Assessments (at least annually) of communication (using a standardised tool), of any delay to play or social skills, and of support for the family; administered by a qualified individual.

All services providing core support programs must document the effectiveness of their program; such as through tabulation of the communication assessments of the children in their program, demonstrating that fewer than 35% of the children (excepting those affected by additional disabilities that affect learning) have delayed communication. Services unable to document the effectiveness of their program are eligible to provide specialised individual therapy on a per-hour basis but are not eligible to provide a core support program.

Services are to determine an appropriate individual support plan for each child, based on their needs and the goals established for them by their family. The maximum that can be funded for the core support program is:

- **Low** - \$12,000 per annum
- **Med** - \$16,000 per annum
- **High** - \$21,000 per annum

Provision of additional support beyond the core program

Further support in addition to the core program is required in specific situations:

1. Additional needs – if a child has further disabilities beyond hearing loss they will require additional therapy specific to that disability. The scope of that support is not part of this protocol.
2. If the child is learning sign language but the parents use spoken language – an additional \$6,000 per year for up to 3 years for sign language training of parents, caregivers and extended family.
3. If the child will be undergoing critical transitions between care environments (such as home to day care, or day care to school) – an additional \$6,000 for intensive support to the child, family and new care givers in preparation for and during each transition.
4. If the child is in the care of extended family members for 6 or more hours a week – an additional \$2,000 per year for up to 3 years for training of the extended family.

Risk factors

- Presence of additional needs
- Delayed fitting of devices
- Complex family needs
- Bilingual/multilingual environments
- Late diagnosis
- Delayed entry to Early Intervention
- Poor device compliance/reduced access to sound
- Recurrent middle ear pathology