

Parents of Deaf Children
and
Aussie Deaf Kids

Submission to the Joint Standing Committee on the
National Disability Insurance Scheme

On

The provision of hearing services under the National Disability
Insurance Scheme (NDIS)

January 2017



Thank you for the opportunity to make a submission to the provision of hearing services under the National Disability Insurance Scheme (NDIS) Inquiry (the Inquiry).

Aussie Deaf Kids (ADK) and Parents of Deaf Children (PODC) are both not-for-profit parent organisations that aim to empower parents raising a child with hearing loss through support, information and advocacy.

Over the past 12 months, ADK and PODC have addressed many of the Inquiry's terms of reference in correspondence to Ministers, Government Departments and the National Disability Insurance Agency (NDIA). ADK and PODC respectfully request that these be included in its formal submission and as such, have attached them as appendices to this (See Appendix 1 and 2).

1. The eligibility criteria for determining access to, and service needs of, deaf and hearing impaired people under the NDIS

Background brief

All babies, children and young people diagnosed with a permanent hearing loss require prioritised access to high-quality services and support to acquire and maintain age-appropriate language to maximise their academic and wellbeing potential.

The issues

- Eligibility criteria for children with permanent hearing loss have not been published.
- Children with all types and levels of hearing loss, irrespective of their eligibility for the NDIS, require access to high-quality assistive listening technology¹.

¹ Hearing devices (also known as assistive listening technology) includes hearing aids, cochlear implants, personal FM systems, and associated batteries and cords.

- Babies, children and young people who are d/Deaf or hard of hearing² require consistent, continuous access to assistive listening technology throughout their lives. These technologies are reasonable and necessary if babies, children and young people are to live “an ordinary life”.
- Consistent access to assistive hearing technology for babies, children and young people who are d/Deaf or hard of hearing is a protective of poor mental health.

Recommendations

- That all children diagnosed with permanent hearing loss be eligible for early intervention services under the NDIS.
- That all babies, children and young people who are d/Deaf or hard of hearing, irrespective of whether they are eligible for NDIS or not, receive access to high-quality hearing services³ and assistive listening technology⁴.
- That the eligibility criteria for the NDIS are released immediately. Hearing thresholds should guide a minimum support package framework but should not be the sole measure of impairment. Additional services and support for children with greater needs are recognised and funded.
- That every child client of the current hearing services program should continue to receive funded hearing services and assistive listening technology throughout their lives.

² *Deaf* refers to people who identify as culturally Deaf who typically use signed language to communicate; *deaf* refers to people who do not identify as culturally Deaf and who typically use both signed language and spoken language to communicate; *hard of hearing* refers to people who identify as having a hearing loss and use spoken language to communicate. This submission uses the term people who are d/Deaf or hard of hearing as an inclusive phrase.

³ Hearing services includes diagnostic audiology, regular comprehensive audiological monitoring

⁴ Hearing devices (also known as assistive listening technology) includes hearing aids, cochlear implants, personal FM systems, and associated batteries and cords

2. Delays in receiving services, with particular emphasis on early intervention services

Background brief

Children who are diagnosed with a hearing loss at birth and receive early and timely access to quality assistive listening technology and early intervention are more likely to achieve age-appropriate language and wellbeing outcomes by school age.

Successful early intervention fulfils the intent of the NDIS principle that emphasises investment in the child to facilitate the child's contribution to the economy and healthy wellbeing as an adult.

The issues

- Any delay in the pathway from diagnostic audiology to hearing services and early intervention has the potential to adversely affect child outcomes. Poor outcomes may lead to lifelong education, social, economic and psychological wellbeing disadvantages. Australia's current pathway from diagnosis to hearing services and early intervention results in less than one percent loss to follow up – the lowest in the world. Changes to the current pathway processes have the potential to compromise timely access to services resulting in less than optimal outcomes.
- Over 90% of parents of newly diagnosed babies who are d/Deaf or hard of hearing have no experience with deafness in their family. Parents initially lack knowledge and understanding about the potential consequences of hearing loss on their child and the assistive listening technology and early intervention options available. Parents require evidence-based and unbiased information to assist in making informed decisions regarding choices for hearing and early intervention providers for their child. With the introduction of the NDIS, to stay financially viable, service providers must attract new clients, and

information provided by service providers might not be unbiased or balanced in its approach.

Recommendations

- That clear pathways from diagnostic audiology to hearing services, assistive hearing technology, and early intervention that minimises time delays and parental stress are provided.
- That parents have access to independent advice and support to assist them to understand the implications of the child's hearing loss, the advantages and disadvantages of their options and the importance of timely intervention.
- That parents have access to counselling and support to build their capacity to undertake the additional requirements associated with a baby diagnosed with hearing loss.
- That disability-specific parent support organisations are funded to provide unbiased information to families as they navigate decisions required to receive services under the NDIS.

3. The adequacy of funding for hearing services under the NDIS;

Background brief

Not-for-profit early intervention service providers have had to subsidise service provision costs with charitable donations to deliver the level of service required. These charitable service providers were delivering services prior to the NDIS because of a desire to assist babies, children and young people who are d/Deaf or hard of hearing. With the advent of the NDIS, additional commercially-driven service providers may enter the market without the altruistic mission of best outcomes for children, but with a focus on shareholder profitability.

Provision of paediatric assistive listening technology via Australian Hearing has been of consistently high quality through a competitive tendering

process. This tender process and the bulk buying power of Australian Hearing provides high-quality equipment to clients resulting in better outcomes.

The issues

- Every child currently receives access to high-quality hearing services and assistive listening technology through Australian Hearing.
- Devices meet the individual needs of the child without parental financial contribution.
- The provision of high-quality assistive listening technology supplied must be maintained to maximise child developmental outcomes. If the current bulk-buying power of Australian Hearing is lost, operating costs for the Hearing Services Program will increase. The future potential for subsequent downward pressure on assistive listening technology quality will prevail, resulting in compromised outcomes for children.
- Hearing devices are classified in a range from Level 2 to Level 7, based on the capability and features of each model. Australian Hearing supplies Level 5 as standard. In the 'contestable' UK and NZ markets, customers are averaging Level 3.

Recommendations

- That equitable access to optimal assistive listening technology is maintained for all children.
- That the buying power for high-quality, high-specification assistive listening technology, through the competitive government tendering process is continued.
- That the provision of robust benchmarking processes (data collection) are implemented to ensure no reduction in child developmental outcomes related to the transition of hearing services to the NDIS. This data will inform funding levels required to maintain the world-leading outcomes experienced in Australia.

4. The accessibility of hearing services, including in rural and remote areas;

Background brief

Children in rural, remote and regional areas currently have access to similar hearing services as their metropolitan peers via Australian Hearing. Challenges with availability of service providers in rural and remote areas has been identified in NDIS trial sites and the government has identified these areas as problematic for the transition of hearing services to the NDIS. The risk of market failure in rural, remote and regional Australia is very high with cascading negative consequences for babies, children and young people.

The issues

- The ability of the private hearing services industry to meet the needs of paediatric clients has not been thoroughly investigated and published.
- The risk of market failure in rural regional and remote Australia and the potential detrimental consequences for children, their families and the Hearing Services Program has not been tested and published.
- Children require audiological services provided by appropriately trained audiologists with sufficient paediatric caseload to maintain competencies and skills. Providing appropriately trained audiologists in rural, remote and regional Australia is costly.
- Extensive and frequent travel time for appointments negatively influences family quality of life and the wellbeing.
- Children living in rural, remote and regional areas may be disadvantaged compared to their metropolitan peers in a contestable environment.

Recommendations

- That the government guarantee that children living in regional, rural and remote Australia have access to hearing services that are

commensurate with the services received by children living in metropolitan Australia.

- That hearing services in all areas are delivered by appropriately trained paediatric audiologists with sufficient caseload to ensure maintenance of paediatric competencies⁵.
- That service providers are required to comply with regular auditing of their services with immediate penalties for non-compliance.
- That service providers in rural, remote and regional areas are audited more frequently due to the greater risk of insufficient providers with the necessary paediatric competencies being available. Quality service provision must be available to all children.

5. The principle of choice of hearing service provider;

Background brief

Australian Hearing has been the sole provider for children's services through the Community Service Obligation (CSO) component of the Hearing Services Program. This has resulted in a service that is high quality, equitable and accessible for children and their families across the country. It has also resulted in a straightforward pathway from diagnostic audiology to the Hearing Services Program and then early intervention. Australian Hearing has been the source of balanced and unbiased information for families.

The issues

- Hearing service providers working with babies and young children require different equipment, knowledge and skills to those working with older children or young adults. The audiologist requires age specific knowledge and competencies to appropriately support the child and guide the family.
- ADK and PODC members prefer that Australian Hearing continue in its current iteration.

⁵ "Transforming Services for Children with Hearing Difficulty and their families: A Good Practice Guide." UK Department of Health August 2008.

- Hearing services should not be linked to an early intervention provider.
- Parents should be able to choose a hearing service provider that is not linked their early intervention provider and vice versa. Neither provider should be able to withhold services if parents choose a different provider for each, which is currently used for cochlear implantation and subsequent habilitation/early intervention by some providers. This results in less choice and potential market domination.
- If parents are to choose a hearing service provider, they need to know that the provider is appropriately qualified and has the expertise and skills to provide services to their child.
- Parents need to be told what incentive the provider will receive for providing one device over another.

Recommendations

- That a single provider continues to provide hearing services for children in through their growing years.
- That every NDIS hearing service provider must have the necessary skills and competencies to provide a paediatric service. ADK and PODC supports the Deafness Forum proposal that “expertise for working with children be identified against the following age groups: 0-6 months; 7 months – 3 years; 3 - 6 years; 7-12 years, 13+ years.”⁶
- That the NDIA apply a comprehensive vetting process to ensure all providers have appropriate expertise when providing hearing services to babies and children.
- That parents are provided with clear, balanced, independent information at each stage of the child’s development.
- That the choice of hearing service provider does not compromise the ability of the parents to choose early intervention providers or change providers.

⁶ Transition of the Australian Government Hearing Services Community Services obligation program to the National Disability Insurance Scheme” – Issues Paper June 2015.

- That a national database of all children diagnosed with a permanent hearing loss is established and maintained with an annual demographic report published.
- That the regulation of the hearing service industry should undergo a continual improvement process with ongoing community consultation.
- That non-compliance of hearing service providers results in clear and rapid consequences for providers to maintain the integrity of the system.

6. The liaison with key stakeholders in the design of NDIS hearing services, particularly in the development of reference packages;

Background brief

Representatives from parents and consumer groups were latecomers to the NDIS consultation process. ADK, PODC, and Deafness Forum have worked closely together to ensure the views and needs of parents and consumers are represented in an environment where service providers have a much larger representation.

The issues

- Parent groups appreciate the opportunity to participate in the design of NDIS hearing services. The process, however, has been protracted and lacks transparency.
- Parents and consumer groups must be included in the processes of developing and implementing changes to legislation and policy associated with hearing services. Improved outcomes for consumers is crucial for the success of the NDIS; this cannot be achieved without consideration of consumer view.
- Hearing sector providers and lobby groups have greater representation at consultations and therefore the potential for greater influence resulting in business priorities taking precedence over optimal outcomes for participants.

Recommendations

- That communication and consultation with key stakeholders is authentic, timely and facilitative of trust and continued collaboration.
- That the focus should be on child outcomes and minimising risks to the consumer or NDIS participant.

7. Investment in research and innovation in hearing services;

Background information

Australia has been fortunate to have the National Acoustic Laboratories (NAL) conduct valuable research for 70 years. NAL's research history is broad and impressive, leading to improved technology, assessment and the practical application of technology for the benefit of all people who are d/Deaf or hard of hearing.⁷

NAL has had collaboration with multiple national and international universities, hearing technology companies, deaf educational institutes, and early intervention service providers.

The issues

- The future of Australian Hearing and NAL has not been published. It is unclear how changes in ownership will impact on the world-leading research and projects currently undertaken by NAL.
- A current consortium proposal for the future ownership of Australian Hearing may affect the independence or direction of research, or who gains access to the research, as one of the consortium partners is a hearing technology manufacturer.

Recommendations

- That NAL continue as an independent research facility and maintains its important and collaborative work.
- That NAL undertake the benchmarking of outcomes under the NDIS if competitive service provision for hearing services occurs.
- That NAL manage a national database, as previously recommended, of all babies and children diagnosed with a permanent hearing loss.

⁷ NAL website project list - <https://www.nal.gov.au/projects/>

8. Any other related matters.

Information, Linkages and Capacity Building funding

Background brief

Two principles of family-centred practice highlight the need for parents to:

1. make informed decisions, and
2. receive information and support from other parents.

These principles require that parents have access to high-quality, balanced information about service options, which are not only disability specific but also nuanced for level and type of hearing loss. Parents also require contact with other parents to understand the implications of the hearing loss on their child and family. The ILC Framework would appear to be the mechanism by which these supports for families will be structured.

The issues

- The level of funding for the ILC Framework is minimal and cannot meet the needs of disability specific support and information provision.
- It remains unclear whether ADK and PODC, which have been providing these services for decades and developed the expertise to support families, will receive funding under the ILC.
- The sector cannot afford to lose the resources and expertise held by ADK and PODC; adequate funding is essential.
- The compliance requirements for ILC funding may preclude small but effective organisations from applying for and/or receiving funding.

Recommendations

- That in this critical period, with the roll out of the NDIS and the transition of hearing services to the NDIS, existing parent support groups receive funding to provide independent information and support to families raising children with hearing loss.
- That assistance and guidance is provided to smaller or state-based hearing disability specific groups, to combine or form

cooperatives/partnerships to enable national coverage and subsequently develop better and consistent interfacing of these groups with parents, children and the NDIS and NDIA.

The sale of Australian Hearing

Background brief

The future of Australian Hearing will influence the lives of all Australian d/Deaf and hard of hearing babies and children. This unresolved issue has plagued the sector for three years. Parents have unequivocally indicated that they want a government-run Australian Hearing to continue providing Hearing Services to babies, children and young people.

The government is considering a proposal by a consortium led by the Royal Institute for Deaf and Blind Children (RIDBC) but the outcome of this proposal is unknown and unsettling for parents.

Information from the scoping study by PwC into the potential sale of Australian Hearing, on market coverage and possibly other issues affecting clients, has never been shared by the government and remains “cabinet confidential”.

The issues

- Irrespective of what happens to Australian Hearing, hearing services will become contestable under the NDIS, unless the government decides to use Part 6 of the NDIS (Plan management) Rules 2013 which would allow the NDIS CEO to nominate a single provider of hearing services for children and young adults.
- The risks of market failure, particularly in rural, remote and regional Australia has not been investigated thoroughly. Market failure poses high risks to child developmental outcomes.
- The sale of Australian Hearing to the RIDBC Consortium (the Consortium) poses additional high risks. The Consortium would control

a significant portion of the market from hearing services to early intervention and cochlear implantation - a one-stop-shop - where choice is eroded. This is a conflict of interest. Other service providers, particularly early intervention providers, could become unviable in this environment resulting in less choice for parents.

- The roll out of new assistive listening technology currently occurs nationally in a fair and timely manner because Australian Hearing is the sole provider of hearing services for children and young adults. In a contestable environment, this may not occur, or may occur in an unfair or haphazard manner.
- The dissemination of the latest technical information in a contestable market will also be at risk and variable, leading to poor outcomes for children which may not be identified for years and which may result in lifelong disadvantage.
- Multiple brands or types of assistive listening technologies may make it difficult for teachers to use FM's in the classroom.
- Loss or reduction of school visits by Australian Hearing may influence the child's ability to hear in the classroom environment.
- State governments need to be aligned and a national approach undertaken for hearing services research and outcomes benchmarking.

Recommendations

- That Australian Hearing is retained as a government enterprise and NDIS designate Australian Hearing as the sole service provider for hearing services for babies, children and young people.
- That if the above recommendation is **not** undertaken and Australian Hearing is sold and the market for hearing services is contestable, the government address the following:
 - Details on how the government will prevent market failure at the initial roll out of the contestable environment, and subsequently monitor and assess for market failure once this system is fully operational.

- Details on how the government will prevent loss of choice due to contraction in the number of service providers if Australian Hearing is sold to the Consortium, creating a company with substantial market power in audiology, assistive hearing provision and early intervention services.
- Details on how the government will ensure new assistive listening technology and technical information will be fairly and broadly rolled-out or disseminated across the nation.
- Details on how the government will ensure hearing services are provided in an efficient and cost effective way to hearing units at schools under the NDIS and that ALL children will receive the same level of service.
- Details on how the government will nationally benchmark child outcomes to prove that service levels have not diminished since the transition of the CSO Program to the NDIS.

APPENDIX 1

Request for an independent study of risks & safeguards for the future delivery of hearing services through the NDIS.



REQUEST FOR AN INDEPENDENT STUDY OF RISKS & SAFEGUARDS FOR THE FUTURE DELIVERY OF HEARING SERVICES THROUGH THE NDIS

Submitted to: -
Parliamentary Joint Standing Committee on the
National Disability Insurance Scheme
Monday 7 March 2016

ABSTRACT

This submission highlights issues and risks regarding the future delivery of hearing services for deaf and hard of hearing children in association with the planned transition of the Community Service Obligation (CSO) to the NDIS, contestability in this area, and the potential change in Australian Hearing ownership. We do not have confidence that all the risks have been recognised, completely understood or focused on, through the current government processes, or if adequate safeguards and controls are in place. Our request is that a suitably qualified independent panel investigate the risks associated with these changes and evaluate the proposed safeguards and controls, benchmarking these against the existing arrangements & systems in the UK, USA & Canada.

These are the views of two organisations, Parents of Deaf Children (PODC) and Aussie Deaf Kids (ADK), representing parents of deaf and hard of hearing children. Our groups are run by parents with the lived experience of raising a child with hearing loss. We are confident that our issues speak for a wider community: national; regional and remote; culturally and linguistically diverse and representative of a wide range of socio-economic backgrounds.

Anna Messariti
President PODC

Ann Porter
CEO & Founder ADK

Mark Wyburn
Secretary PODC &
regional representative

1 OVERVIEW OF OUR CONCERNS

We strongly believe that the full range of issues and risks associated with the transition of the Community Service Obligation (CSO) to the NDIS, along with contestability in this sector and the possible changes to Australian Hearing ownership, have not been recognised, completely understood or focused on through current government processes, or if adequate safeguards and controls are in place.

The government has had the full capability of the public service and consultants to investigate and focus on the business opportunities and risks of the transition of the CSO to NDIS and the potential sale of Australian Hearing. The issues and risks to children and young adults associated with these changes, have largely been highlighted by volunteer and not-for-profit organisations.

Why is this so important to parent organisations? In brief, because for 70 years an excellent national system has been built around Australian Hearing. This system is currently totally reliant on Australian Hearing's quality, consistency, independence, and knowledge, in delivering world class hearing services, whilst also interacting with a diverse range of early intervention and other services. Changes cannot be made without first identifying, evaluating and implementing safeguards for these service parameters in a contestable NDIS environment that offers participant choice from a range of service providers.

Parents of Deaf Children (PODC) and Aussie Deaf Kids (ADK) recognise the enormous benefit of the NDIS. The two organisations fully support its general principles. However, the transition to the NDIS must be without a reduction in the quality and safeguards of existing services, or place at risk early intervention outcomes.

So that we can move forward on the issues that will be highlighted in this submission, we offer the following recommendation for an objective, non-partisan, open investigation as a method of delivering the required level of access, service delivery, safeguards and controls, for deaf and hard-of-hearing children participating in the NDIS.

Recommendation *We request that a suitably qualified independent panel: -*

- 1. Investigates the risks associated with the proposed changes from a consumer and parent or carer perspective;*
- 2. Identifies and evaluate current and proposed safeguards and controls;*
- 3. Benchmarks existing hearing services, service delivery safeguards and controls against the proposed arrangements and systems, as well as existing systems in the UK, USA & Canada.*
- 4. Recommends actions that must be undertaken to maintain and safeguard the quality of service delivery and consumer outcomes, for audiological services and early intervention pathways.*

All functions of the independent panel will be open to the public and inclusive of community input.

2 BACKGROUND

Since the Coalition Government first announced the scoping study into the potential sale of Australian Hearing in the May 2014 budget, parent groups have consistently voiced their opposition to the proposal through several submissions, representations and evidence.

When the Government reaffirmed that the Hearing Services Program would transition to the National Disability Insurance Scheme and that services would become contestable, parent groups again voiced strong concerns regarding the numerous risks of a contestable market to the outcomes of children and their families. Parent and consumer groups recommended that children from diagnosis to 18 years of age continue to receive services from Australian Hearing alone.

Replies from the government have been patronisingly reassuring, with nebulous statements such as *“an appropriate model will be adopted that continues to provide high quality hearing services for all eligible Australians.”*

The basis of the opposition of parent groups, is because there was and is no confidence in the existence of, or timely development of safeguards for, a nationally consistent quality delivery of hearing services and diversity of choice, unless Australian Hearing remains intact and continues to be the sole provider.

On 12/02/16, the government announced it was examining the transfer of ownership proposal by *“a consortium led by the Royal Institute for Deaf and Blind Children, alongside Cochlear Limited and Macquarie University,”*.

This proposal raises new issues of concern, including the potential loss of diversity of choice, unbiased information and market power. The proposal has been developed between the government and the consortium, without inviting any input from consumers, or engaging in a process of independent assessment.

The continued concern of parent groups, is that the business models and outcomes take precedence over the interests, safeguards, service delivery and long-term outcomes, for deaf and hard-of-hearing children, their families and the community.

3 SERVICE DELIVERY REQUIREMENTS

The following points outline the key service delivery requirements for a national system for hearing services.

Research and Application. The existing service has been built on evidence-based research, often undertaken by the National Acoustic Laboratories, and has provided equity of access to children, irrespective of where they live or their socio-economic status. It provides quality-accredited service across the whole nation, with consistent policies, procedures & training.

Evidence-based research must be collaborative and inclusive of all hearing service providers. Findings must be disseminated and improvements implemented, in a coordinated and consistent manner across the nation.

Data should be gathered nationally on diagnosis and hearing aid appliance efficacy in a consistent manner. The data needs to be analysed and its findings need to contribute to improvements in service.

A national database needs to be in place to track diagnosed children, follow-up attendance, and access to early intervention services. This provides information on the performance of the early intervention pathway on a national basis.

Prioritised entry to services. The system must ensure a smooth pathway from diagnosis through to the Hearing Services Program. Children must be given priority, so that the time between diagnosis and device fitting is kept to a minimum. Specialist medical practitioners refer to this period as being imperative, in order to deal with the 'neurological emergency'. All steps need to be taken to ensure that there are no delays and that the need for regular and frequent follow up in the first 2 years is prioritised.

The pathway must support parents in making decisions using unbiased, accurate information.

Consistent with the stated principles of the NDIS, the pathway must also assist families and parents who do not have the capacity or support to make good decisions on their own behalf.

Unbiased, independent information. The impact of a diagnosis of hearing loss cannot be underestimated. Parents frequently report an experience of grief and depression until they can see indications that interventions are having a positive impact. This can take a long time.

Parents need unbiased, independent information. Parents know the least about hearing loss and its complexities when their child is first diagnosed. During this time of incredible emotional stress, they have to make decisions about engagement with early intervention programs for their child without prior experience of these services. Parents will have varying degrees of capability to absorb and respond to information, either because of cultural or linguistic diversity, socio-economic factors, education, motivation, residential location or available support. Australian Hearing has been a buffer between parents and providers where parents feel they receive the independent information they need, particularly about communication options and early intervention.

Over 90% of Deaf and hard of hearing children are born to families with no previous experience of hearing loss. They can be easily influenced by suggestions from professionals. Sometimes these suggestions are not in the best interests of the child or family in the long term. Parents have to be 100% confident that the services and devices provided will allow their child to listen and learn. They also need to be confident that the devices provided will be of the highest standard and meet the needs of their child.

Technical competency & consistency. Audiologists and other service providers must have the specialist paediatric competencies for that area of service. This includes seeing a minimum number of paediatric clients per year to maintain these skills and competencies.

Approximately 300 new cases of hearing impairment are diagnosed in Australia each year as a result of newborn hearing screening programs.

The UK Department of Health recommends that *“To maintain competency and continually update skills in assessment and habilitation, individual audiologists need to assess 20 - 30 new cases per year to ensure best practice and improve expertise.”*

Additionally, 30-40% of these children will have additional disabilities which require consideration and accommodation.

Currently within Australian Hearing, specific paediatric training and supervision is required before a senior audiologist can undertake paediatric work. Specific paediatric qualifications and competency must be a pre-requisite for any audiology practitioners who offer and provide services to children.

The provision of hearing aids must meet the specific needs of the child. This needs to be consistently applied by all service providers in all locations. This requires an understanding of many kinds of aids and their technical capacities and complete independence from manufacturers.

Quality & Safeguards. The provision of services needs to be within a quality framework. Australian Hearing currently provides a service to the Australian and international quality standard AS/NZS ISO9001:2008.

Safeguards need to be in place to check that service delivery and quality parameters are met. Effective auditing for compliance to quality standards needs to occur.

Only appropriately qualified and competent service providers should deliver services and they should only operate within their scope of practice.

Practices and practitioners such as audiologists must be registered and regulated by national legislation that defines the scope of practice, ethics, quality and safeguards of practices and practitioners. It also needs to provide and implement consequences for non-compliance.

Service provision needs to be consistent across the nation, regardless of location. Measures need to be in place to benchmark service delivery.

Individuals and consumer groups must have avenues for local, state and national representation and input into the delivery of services.

Diversity of choice. The NDIS espouses Choice as a general principle for participants. Choice is seen to be central in the pursuit of participant goals and the planning and delivery of their support mechanisms. This needs to be upgraded to 'Informed Choice'. Without Informed Choice, it is difficult for the consumer to screen out charlatans and profiteers.

There need to be available and suitably specialised providers to allow for the genuine implementation of the principle of Choice.

Streamlining of services. Inconsistencies in the provision of health services and hearing services, the Community Service Obligation and NDIS are removed.

Examples as present are: -

- In the case of cochlear implants, the surgery and mapping services are paid for under Medicare, whereas the provision of hearing aids and associated programming, will fall under the NDIS for those who are eligible.
- Cases of clients who are eligible under the CSO Program, but who will not be eligible under the NDIS, such as an Aboriginal or Torres Strait Islander children, who are seen as part of the Indigenous Outreach Program that Australian Hearing currently provides in urban, rural and remote areas of Australia. A high percentage of these children have chronic conductive hearing loss which would not meet the eligibility criteria under the NDIS, as the loss is not 'permanent' in nature.

4 RISKS

The following points outline some of the key risks identified by PODC and ADK associated with the transition of the CSO to the NDIS, contestability in this sector, and the potential sale or transfer of Australian Hearing. All these risks potentially affect service delivery and optimised outcomes from early intervention.

The overriding risk, is that by the time poor service delivery is discovered, the window for optimal outcomes may have been missed, leading to life-long disadvantage. Parents of newly diagnosed children are unlikely to know what constitutes good or best practice, hence cannot recognise poor service delivery, as they are learning themselves.

The current equilibrium of a safe, trustworthy, quality service delivery of hearing services and interfacing with other agencies is totally reliant and built on the existence of Australian Hearing as the sole provider for the CSO. Transition of the CSO to the NDIS can only be done when regulatory safeguards and systems are in place that will maintain this balance. The focus on quality service delivery cannot be diminished as providers seek to minimize overheads by delivering minimal or below standard compliance. PODC and ADK do not believe that appropriate levels of safeguards for service and quality are adequately defined or even exist at present.

Research & application. In a contestable market it is difficult to imagine how a coordinated approach to data collection on hearing appliance efficacy and audiology practice can be maintained, so that collective learning can be used to improve technology and intervention.

It is also difficult to see how new technology, such as cochlear implant processors or hearing aids, or audiology techniques would be rolled out across the nation consistently and in a timely manner, so that all deaf and hard of hearing children benefit equally.

Contestability. A contestable market for the Community Service Obligation component of the Hearing Services Program is completely untested. The UK rejected

this approach and the US experience highlights the considerable risks of a contestable market to outcomes for children. Our knowledge suggests that no research has been undertaken in this area. It may have been done under the Department of Finance scoping study undertaken by PwC into the sale of Australian Hearing, however this has not been made public as it has been classified as cabinet in-confidence.

How will the level of functionality of hearing devices be consistently delivered, avoiding inadequate or inappropriate performance delivery, or without the risk of upselling? Under the current arrangement with Australian Hearing as the sole provider, these risks are not present.

Without an objective review of all of the risks of the contestability aspects of the proposed changes, the proposed shift is potentially a risky gamble, with any failure affecting deaf and hard-of-hearing children permanently. Mistakes made in this area of service provision will affect deaf and hard-of-hearing children for the rest of their lives.

Consumer and parent groups have suggested the use of the National Disability Insurance Scheme (Plan Management) Rules 2013 Part 6 Clause 6.6 - *“Describing supports where most efficient and effective to be provided by particular provider.”* This would allow Australian Hearing, or a tightly controlled number of specialised, suitably qualified and competent approved providers to deliver services to deaf and hard of hearing children.

Prioritised entry to services. Australian Hearing and existing early intervention providers know the importance of prioritised access to services. The NDIA is aware of this and parent groups know they are actively working on a pathway in cooperation with an expert reference group, which now includes parent representatives. This is appreciated and a model for other areas of concern.

New parents and potentially other new service providers may not appreciate this urgency. Safeguards and follow-up after diagnosis are required if “loss to follow-up” is to be maintained at the current low levels in Australia. Other countries such as the

USA do not have the same enviable record and the groups we represent do not want to go down that path.

Unbiased, independent information. Transition to the NDIS and changes to state and federal funding arrangements have meant that many disability specific volunteer organisations or associations struggle to exist or provide coverage and assistance to parents of newly diagnosed deaf or hard of hearing children.

New funding arrangements or organisational restructuring requirements for volunteer disability specific groups are still unclear to many as the NDIS develops the Information, Linkages and Capacity Building (ILC) framework. The knowledge gained by such groups and organisations, over decades of service may be lost in the NDIS transition, leaving families without support or information. This potential loss will occur at a time when families are inadequately prepared to decide on early intervention or NDIS funded supports and plans.

Parent groups have seen the robust marketing of early intervention services since the introduction of the *Better Start for Children with Disability* program. This kind of marketing masquerades as 'unbiased information.' During the pathway from diagnosis to early intervention, parents are under pressure, highly stressed and have the least knowledge of their child's disability or disabilities and their true needs.

Technical competency and consistency. In a contestable market it would be difficult to maintain technical competency consistently across the nation, especially in rural and remote areas.

Annually, there are around 2,600 children and young adults who are fitted with hearing aids for the first time, of which only approximately 300 are infants. As a result, the clinician's exposure level to paediatric clients is low, and would be even lower, if these children received services from multiple providers in a contestable environment.

A contestable market, may mean a very wide variety of hearing appliances are issued. These should always be of a high quality and specifically appropriate for the needs of the user. A lack of consistency in the provision of technology will make it

difficult to support children in the use of varied appliances. Examples of challenges include settings such as a school classroom, where a teacher or aide may have to deal with a variety of technologies and associated compatibility issues with devices, such as FM's, hearing loops, Sound Field Systems, DynaMics and so on. The teacher or aide may also have to deal with a variety of different service providers when school visits are required, to check hearing devices in the school setting.

Incompatibility of devices used by children need to be understood by practitioners in this space. If sales take precedence over excellent service delivery, this complex area of practice that is currently addressed very well by Australian Hearing, is at risk of complete failure.

Quality & Safeguards. A consistent approach with safeguards for quality service delivery will be lost in a contestable environment. It is difficult to see how an assurance of quality could be delivered.

The provision of Audiology services is currently unregulated – it needs to be.

There are no government legislated requirements – there need to be.

There is no registration system – there needs to be.

There is no single or legislatively enforceable code-of-ethics or code-of-conduct for the delivery of hearing services to paediatric clients – there needs to be.

There is no single, peak, professional practitioner body or board – there needs to be.

Audiology or audiometry does not come under a regulatory authority such as Australian Health Practitioner Regulation Agency (AHPRA) – these services should be regulated.

There is no enforceable minimum standard or good or best practice guidelines for paediatric audiology or early intervention service delivery. These exist in the UK, and are published by government departments. Australia needs to follow suit.

There is no required paediatric audiology qualification or competency standard, only the existing in-house training by Australian Hearing – it will be difficult for multiple,

small, service providers to match these kinds of standards in a contestable environment.

There is no legislatively enforceable scope-of-practice definition, or, regulation of scope-of-practice, between audiology and audiometry – it is imperative that this is developed.

There is no single or legislatively enforceable practice, clinical or competency standards for audiologists and audiometrists – there should be.

There has been no audit process proposed, for a contestable market, or, the requirements for key performance indicators. Evidence from the Senate Select Committee on Health on 10/07/16 stated that there are around 260 service providers to the Office of Hearing Services (OHS) with a workforce of 1,900 audiology professionals. The OHS has a team of six monitoring these practitioners. At that time no contracted service providers had ever been suspended. Industry or provider self- assessment or self-regulation is not a satisfactory or objective quality assurance or safeguard process either. This gives parents' very little confidence that there will be sufficient quality assurance oversight, or consequences for a poor service provider, through any audit process in a contestable market.

Australian Hearing had 16 key performance indicators for the delivery of the CSO along with the overview of the Australian National Audit Office. Equivalent safeguards for performance delivery must also be in place in a contestable market – in fact they those safeguards will need to be even more rigorous.

Poor delivery of audiology services will result in poor early intervention outcomes and life-long disadvantage. The timeframe for the most effective early intervention is very short and poor delivery takes time to discover. One only needs to compare a child diagnosed late prior to the implementation of newborn hearing screening programs to see clear evidence of the level of disadvantage that will ensue if the quality of paediatric audiology services and specialist early intervention provision is degraded in any way. The first years of a child's life, are also the period is when parents of children with hearing loss are at the least knowledgeable with regard to

their child's hearing needs. It is unfathomable as to why the Government would choose to risk our children's futures when we have a system that has worked so well. It is also unfathomable as to why the government would want to risk the ability of those people born with a hearing loss, to participate effectively in wider society in the long term.

Diversity of Choice. On the surface, a vertically integrated model, inclusive of audiology, appliance provision and fitting, and early intervention services, essentially a "*one-stop-shop*", looks efficient and engaging.

However, a vertically integrated service provider may not allow NDIS participants to exercise their power of choice, either intentionally or unintentionally: *Why even look at another service provider when everything is right here?*

The point is, will the customer even be told about other appropriate service providers?

Why look at another brand of hearing appliance when you've recommended your own brand? Will the customer be made aware of other brands, as is currently the case?

An arrangement where a vertically integrated group gets control of a large slice of the hearing services sector may mean it has "*substantial market power*" as defined by the ACCC. This may be detrimental in a number of areas: -

- A reduction in the diversity of choice as other service providers lose customers and close, down;
- Other hearing device manufacturers may not have sufficient access to customers and ultimately stop producing them;
- Customers who have a falling out with the vertically integrated group in one service area, will be obliged to continue to deal with that group for other services, due to the lack of availability of other service providers.

Other service providers, such as early intervention providers, may be discouraged from providing a vertically integrated service that includes audiology and hearing

appliance provision and fitting. This is because they have a lack of geographic coverage compared to another provider with substantial market power, a lack of buying power with hearing device manufacturers, and a lack of customers due to a lower public profile.

Not-for-profit service providers that rely on charitable donations to assist in funding services, may find that donations decrease due to the larger public profile of another service provider with substantial market power. Eventually, the small provider ceases trading, and the range of available providers diminishes rather than increases, resulting in further market dominance and concentration, and less choice for the consumer.

Multiple stakeholders. There is a plethora of departments, agencies and consultants involved in the current, transition, potential change, and future provision of hearing services and NDIS.

Department of Human Services
Department of Health
Department of Social Services
Department of Finance

Office of Hearing Services
National Disability Insurance Agency
Australian Hearing

Price Waterhouse Coopers (PwC)
Australian Healthcare Associates

Each of these stakeholders will have their own deliverables and conditioned view from a government, government directed, agency or political viewpoint.

Additionally, there are major service providers, retailers and professional practitioner bodies and lobby groups, trying to influence outcomes – all from a commercial provider viewpoint.

A transition plan for the CSO to the NDIS was released in February 2016 by the Office of Hearing Services. A proposal for the change in ownership of Australian Hearing

was released on 12 February 2016. The NDIS will commence national roll-out in July 2016. Many potential and actual changes are occurring concurrently.

An objective, independent, suitably qualified and open study from a consumer perspective is required to safeguard the service delivery through the NDIS, and deliver a satisfactory outcome for deaf and hard of hearing children and their families, now and into the future.

An independent, objective, consumer focussed study must be used as an audit benchmark to ensure future delivery of hearing and early intervention services will meet the necessary requirements to give our deaf and hard of hearing children the best possible outcomes.



PARENTS OF DEAF CHILDREN

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NORTH ROCKS NSW 2151

Email: info@podc.org.au Phone: 02 9871 3049

Parents of Deaf Children is the peak body for parents of deaf and hard-of-hearing children in New South Wales. The role of the organisation is to support families in NSW with unbiased information, referral and advocacy services.



AUSSIE DEAF KIDS

www.aussiedeafkids.org.au

PO Box 231 BRUNSWICK HEADS NSW 2483

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Aussie Deaf Kids is a not-for-profit organisation that provides online information and support to families raising child with hearing loss in Australia.

APPENDIX 2

Concerns about the future of Hearing Services for deaf and hard of hearing children



CONCERNS ABOUT THE FUTURE OF HEARING SERVICES FOR DEAF & HARD OF HEARING CHILDREN

Submitted to:-
Senate Select Committee on Health
10 JULY 2015

ABSTRACT

This submission raises issues regarding the future delivery of hearing services for deaf and hard of hearing children that must be addressed satisfactorily by the Government before any changes are made to the existing systems.

The future ownership options of Australian Hearing, and funding and support arrangements through the NDIS, should not diminish in any way the current world class delivery of the Community Service Obligation (CSO) by Australian Hearing, or the pathways to appropriate early intervention supports.

These are the views of Parents of Deaf Children (PODC) representing some of the NSW parents of deaf and hard of hearing children.

Our group is run by parents with the lived experience of raising a child with hearing loss.

We are confident that our concerns and experiences speak for a wider community: national; regional and remote; culturally and linguistically diverse and representative of a wide range of socio-economic backgrounds.

Anna Messariti
President PODC



Submission to:

**Senate Select Committee on Health
Hearing at Australian Hearing Hub
Macquarie University, NSW
10 July 2015**

Dear Senate Select Committee Members,

Thank you for providing an opportunity for *Parents of Deaf Children (PODC)* to participate in the *Senate Select Committee on Health*, to discuss the many and varied issues associated with the proposed privatisation of Australian Hearing. The invitation to discuss hearing impairment, deafness, and related health issues and in particular, access to healthcare and services for people who are deaf or have a hearing impairment, is greatly appreciated.

At the present time, high quality hearing services are delivered and made accessible to all eligible Australians, by expert practitioners. This high level of care must be maintained, so that the outcomes for deaf and hard-of-hearing children in Australia now and for future generations, can be maximized. Quality of care and outcomes must remain as the highest priorities. These should not be placed at risk by potentially short-sighted policies and practices that seek to explore “market forces” and “contestability” in the context of delivery models.

PODC is concerned about the financial models that are being considered by the federal *Department of Finance* in relation to the *Community Service Obligation (CSO)* program and Australian Hearing. Ultimately, what is at stake is a health and social issue that will affect disabled children and their families, not a financial issue. It needs to be addressed carefully.

The primary focus of a hearing services program and the pathway to early intervention, should always be on deaf and hard-of-hearing young Australians gaining specific and appropriate supports associated with their hearing disability. This is so that they can communicate and learn effectively, resulting in those young people achieving their optimal developmental potentials in social, educational and personal spheres.

At this time, PODC believes that ‘best practice’ for a national hearing services program and the pathway to early intervention supports, has NOT been clearly and unambiguously defined by suitably qualified and independent health professionals and academics. This needs to take place PRIOR to the implementation of a potentially massive change in available services, service delivery mode, and/or funding provisions.

The future of the most vulnerable in Australian society is currently at stake.

It will not be possible to reverse the poor outcomes that emerge, as a result of poor hearing services or pathways to early intervention supports.

Successful early intervention programs rely on correct audiological assessment and frequent revision in the early years, as well as the use of appropriate hearing appliances and fittings. Access to these hearing support programs and services is required promptly and must be continued throughout the development of a child's youth, otherwise ongoing issues that cannot be addressed, will be the end result.

Yours sincerely,

pp:

A handwritten signature in black ink, appearing to read 'Anna Messariti', with a stylized flourish at the end.

Anna Messariti
President PODC

1 OVERVIEW

With regard to the possible sale of *Australian Hearing* and the associated *National Acoustic Laboratories* and eventual integration of hearing services into *NDIS*, *Parents of Deaf Children* (PODC) ask: -

- “Why is the Government seeking to change an organisation and programs of support that are performing so well, and are recognised as world leading?”
- “Why is the Government making significant changes, when the full scope and functionality of an interconnected system involving: diagnosis; hearing appliances and equipment; medical services; client management; social and educational support and pathways to early intervention supports have not been: researched; defined; clearly understood and documented, in national policies and procedures?”

In 2014, the *Australian National Audit Office* (ANAO) reported that the *Community Service Obligation* (CSO) program, “is being effectively administered by *Australian Hearing*” [1].

Australian Hearing and *National Acoustic Laboratories* (NAL) are recognized as delivering world-leading hearing services to deaf and hard-of-hearing children [2].

The ANAO reported that the *Department of Health’s Memorandum of Agreement with Australian Hearing for the CSO Program*, has sixteen Key Performance Indicators (KPI’s), with which to monitor the achievement of the CSO’s objectives. This appears to be a significant number of performance metrics, but these 16 KPI’s only partly cover the full scope of the requirements of a good hearing services program. The lack of a full suite of KPI’s or a “best practice” benchmarking tool for a hearing services program, can presently be accommodated, because *Australian Hearing*, as the single service entity with national coverage, has been delivering a world-class service for many decades.

PODC’s investigations suggest that the *Department of Health* has not yet clearly, comprehensively, independently and unambiguously, defined - what is “best” or even “good” practice, with regard to hearing services delivery and pathways to early intervention supports for deaf or hard-of-hearing children. This is a matter of great concern.

In 2008, the *United Kingdom’s Department of Health* did define “good practice”, two years after the full introduction of the *Newborn Hearing Screening Programme* (NHSP). [3]. The UK organisation, *National Deaf Children’s Society* was a key contributor with regard to this UK Government document and also has a position statement on Audiology Service Provision in the UK [4].

There has been a negligible amount of consultation or information exchange with the most affected or at risk, deaf and hard-of-hearing children and their parents or carers, and their representatives [5]. The Federal Government has been determined to progress the Contestability Framework as applied to *Australian Hearing*, without fully considering and understanding the linkages, pathways and client management that exists between audiological diagnosis, CSO, medical interactions and early intervention supports.

The Contestability Programme, initiated and led by the Department of Finance, is primarily concerned with two major elements: cost and making an exit from government provided service delivery. The *Department of Finance* has noted that the Commonwealth Public Sector:

“..aims to continually improve its ability to utilise the skills and capacity of the private and not-for-profit sectors to deliver services at the same and better levels of quality at reduced cost.” [6].

PODC believes that the level of service delivery that is required from a hearing service program, is poorly understood by the Department of Finance. As a result, the Department of Finance, cannot deliver on its statement. Service and quality levels, should not be defined by the *Department of Finance*, but by the *Department of Health*. Again, hearing services to deaf and hard-of-hearing children, is and must remain a Health and Human Services issue, not a Finance issue.

The *Scoping Study on the Sale Options for Australian Hearing*, conducted for the *Department of Finance* by PwC, will not be released for public review, because of commercial-in-confidence information. This highlights the fact that the focus of the government, is on financial issues, not hearing service delivery. This is not appropriate.

The focus of the government must always be on the best possible short and long-term outcomes for young Australians who are deaf or hard-of-hearing. Any changes to Hearing Services under the *CSO* or *NDIS* must be risk assessed. Changes should not be implemented unless there is certainty that the changes will not affect client outcomes. Currently, under the *CSO* Program, service provision maintains a client outcome focus, rather than a profit focus.

“The lack of age appropriate language development and literacy skills have substantial negative effects on the child's cognitive and social development which, in turn, interferes with success in school and later life, especially in the development of reading and related activities.” [7]

PODC believes, that the balance of concern shown to date by the Federal Government, has been biased towards the current business operation and potential market models. The driving force has been around efficiencies and fiscal dividends, rather than the client outcomes that are achieved through service provision.

PODC requests that a national “best practice” model, and guidelines for a hearing services program and the pathways to early intervention supports, be clearly and unambiguously defined, by suitably qualified and independent health professionals and academics. This must take place PRIOR to any changes being made to available services, service delivery modes, pathways or funding provisions.

This submission details parents’ concerns and likely risks associated with possible changes being considered by the Government in relation to the sale options of *Australian Hearing* and *NDIS* integration of the current hearing services program through the *CSO*.

PODC's requirements, detailed in this submission, should form some of the metrics for the scope, quality, pathways and management of service delivery, to deaf and hard-of-hearing children. These requirements must inform the way in which a "best practice" system is defined and measured as well as how it will operate in practice.

The knowledge contained within this submission has been gained through the lived experience of parents and carers. As parents, we are engaged in managing our child's/children's' disability 24 hours a day, from birth. PODC believes that the parent concerns that it has highlighted in this submission are of the highest importance, as they are the concerns that truly reflect and champion, the best outcomes for children.

2 FUNDING

Any system should provide and prove to be ‘value for money’ in the context of services provided. PODC accepts that this should also be the case for the Hearing Services program through the existing CSO, or through any future funding arrangements made to provide hearing services through the *NDIS*. In striving to achieve the best “value for money”, it is important that a high standard of service delivery is always achieved, without sacrificing appropriate timeliness, type, quantity, or quality of supports. If these requirements are not met early in a child’s life, the future cost implications to the economy are significant, through additional or ongoing disability supports and welfare as an adult. Even more significantly, the future potential loss to the individual is lower socio-economic outcomes and quality of life.

“When children are not identified and do not receive early intervention, special education for a child with hearing loss costs schools an additional \$420,000 [USD], and has a lifetime cost of approximately \$1 million [USD] per individual. (Johnson et al., 1993)” [8]

“The Center for Disease Control and Prevention has estimated that the lifetime economic cost to the public for a child with hearing loss is over \$400,000 [USD], mostly for special education services. (Honeycutt et al., 2004; Mohr et al., 2000)” [8]

- a) *An open market will allow for providers to operate without constraints and create an opportunity for multiple providers to operate. As a result, there will be no longer be bulk purchasing arrangements for hearing aids. The current buying power and not-for-profit nature of Australian Hearing, ensures that its CSO clients have access to high quality hearing aids, with higher levels of technical capability and features. This excellent provision is because of this volume price reduction and the existing business model.*

Hearing devices are classified in a range from Level 2 to Level 7, based on the capability and features of each model. Australian Hearing supplies Level 5 as standard. In the ‘contestable’ UK and NZ markets, customers are averaging Level 3.

This current bulk-buying advantages of *Australian Hearing*, provides a higher level of equipment to clients and as a direct result, better outcomes. The higher level of hearing appliances supplied must be maintained. If bulk-buying power is lost, operating costs will increase. The future potential for subsequent downward pressure on appliance quality or features will prevail. It is therefore difficult to see any economic advantage in this aspect of a completely open market arrangement, given the low unit cost for hearing appliances that is now being achieved.

- b) *Families have expressed that they would rather forego having a choice of service provider, to ensure that they receive a high level of hearing aid technology as well as the maintenance of trusted, reliable, quality services.*

If an open market model is pursued, the Government must ensure, through meticulous regulation and auditing, that private companies will not try to maximize profit margins by reducing overheads. The risk that we are seeing is that a market model will trigger a “race to the bottom”, with regard to: the quality of service; the reach of services and the quality of hearing appliances and equipment.

- c) *The development of high quality technology has changed the educational outcomes achieved by deaf children. For these outcomes to occur, research has shown that children need **appropriate**, high quality listening devices. These include hearing aids, cochlear implants and FM systems. The system “should ensure that maximum audibility has been provide to the child, thus offering the child optimal access to spoken language.” [9].*

*The NDIS operational Guideline “Planning and Assessment – Supports in the Plan – Assistive Technology” states “...It is expected that the NDIS will generally only fund the **minimum necessary or standard level** of assistive technology.” The **minimum necessary or standard** level of technology will deliver very poor outcomes and is not the same as the “**appropriate**” level of technology. Each child is unique and some children have quite complex needs. It is not possible to recover lost early intervention time, if the technology issued for accessing listening and learning is inadequate. A degradation of the quality of hearing technologies that are made available to deaf and hard-of-hearing children will undoubtedly result in less than optimal developmental outcomes. PODC believes that:*

- i. Children must not be disadvantaged under the NDIS with lower levels of assistive technology, when under the current arrangements with *Australian Hearing*, appropriate levels of technology are provided based on each child’s specific, clinical needs.
 - ii. The financial needs for technology upgrades, will change for children from year to year. Funding models must be able to accommodate prompt delivery of improved or more appropriate technology, or devices with improved features, *as they are released*, all of which assist in delivering better outcomes for children. The change in funding costs associated with technology changes, should not affect other funding that the child may receive for Early Intervention supports.
- d) Cost items associated with the use of hearing appliances, such as assistive technology (e.g. FM’s), consumables such as batteries, cleaning, storage and testing equipment, repairs, and provision for lost or broken equipment, all need to be included as standard support items in any *NDIA* plan for a deaf or hard-of-hearing child. There does not appear to be a support item price for ear moulds in the *NDIS* price schedules. Ear moulds need to be replaced frequently in the first two years of life and regularly as a child grows. Newborn babies need ear-mould replacement, at two-weekly intervals. Fittings require a visit to a specialist paediatric audiologist for new impressions to be taken. [3]

- e) *The support and advice that is provided to schools, itinerant support teachers-of-the-deaf, Early Intervention support organisations and service providers and other groups such as PODC, around hearing aids and a child-specific technologies, is currently provided free of charge by Australian Hearing. This service can be provided to a whole classroom, school or group, in one visit by Australian Hearing.*

In a 'contestable' scenario, the Government must seriously consider how it will achieve "value for money" on a cost-per-visit basis, if multiple organisations provide these types of services to deaf children, their families, communities and support groups. The Government must also consider how it will deliver these types of services, outside of individually funded packages.

3 PATHWAY FOR GAINING ACCESS TO SUPPORT AND SERVICES

“Infants with hearing loss typically will not spontaneously develop language and literacy because most language development occurs before 18 months of life and lack of typical auditory and/or supplemental visual input during this critical period will irreversibly interfere with the healthy development of language and literacy skills.” [7]

Currently, the CSO program is embedded within diagnostic and Early Intervention pathways for babies and children. This process is streamlined. There is little delay when it comes to gaining access to services and appropriate devices. This is critically important because early detection and amplification is the key to good outcomes. In terms of accessibility, the NDIS process is slower and less responsive, involving confirmation of eligibility, developing a plan with an NDIS planner, choosing supports, implementing a plan and reviewing that plan.

Having Australian Hearing as a single reliable, organised, quality service provider, means that there is less risk of a child missing out on the vital Early Intervention that we know is critical for infants. There is also less risk of older children who are diagnosed later, becoming lost in the system and not receiving the necessary follow-up services in a manner that is timely and effective.

“The initial emotional response to a diagnosis of hearing loss for most hearing parents may cause increased stress, rendering them emotionally vulnerable and susceptible to bias that may be provided by ‘experts.’” [7]

Over 90% of deaf or hard-of-hearing children are born to hearing parents. These parents need a trustworthy and reliable system to support them and their child, as their pre-existing knowledge of what is required to achieve the best outcomes for their child in relation to a hearing disability, does not exist.

- a) Parents, medical and diagnostic services, NDIA planners and Early Intervention support providers, need to establish a “best practice” guideline to follow for the management and ongoing care, of a newly diagnosed deaf or hard-of-hearing child. The pathway needs to be clearly defined and documented and should not be left entirely to the parents to navigate, at a time when they are emotionally distressed.
- b) Under the NDIS, planning and funding pathways for infants and older children who are diagnosed with hearing loss, need to be prioritised to minimize any delays in accessing sound through hearing appliances.
- c) Assurances and systems must be in place so that clients will not become lost in a system, where there may be multiple service providers.
- d) Consistency of approach to appointment allocation is required, in order to ensure that sufficient time is provided for the audiologist to test and fit young babies and children with appropriate devices. Newborn babies need frequent ear-mould replacement, often two-weekly and they can be difficult to fit. [3]
- e) The NDIS must avoid the addition of another administrative layer that will inhibit timely access to Early Intervention services and support for newly diagnosed

families. Currently, access to the *Hearing Services CSO Program* via *Australian Hearing* is easy to manage with regard to administration and speed of delivery.

- f) Clients in rural and remote areas need to have access to an equivalent level of expertise and the quality of service that can be made available in urban areas. A coordinated approach to the screening of children, especially in remote locations, such as Aboriginal and Torres Strait Islander communities, must be continued.
- g) *Annually, there are around 2,000 children who are fitted with hearing aids for the first time, of which only approximately 250 are infants [10]. As a result, the clinician's exposure level to paediatric clients is low, and would be even lower, if these children received services from multiple providers. Special skills, specific training and a high level of experience in audiology, is required prior to servicing paediatric clients.*
 - i. If CSO services are delivered by multiple organisations, it is difficult to envisage how commercial hearing service providers will see enough paediatric clients per year to maintain this specialist competency. This is an even more challenging question in situations where rare or complex needs arise. The UK Department of Health states that: *"To maintain competence and continually update skills in assessment and habilitation, individual audiologists need to assess 20 – 30 new cases per year to ensure best practice and improve expertise."* [3]
 - ii. The audiology profession is self-regulating at the moment. Parents and carers of babies and children need to be completely assured, that the audiologists who are and will be delivering services to their children, are qualified and experienced enough to undertake the complex, specialised paediatric work that is involved. It is not as simple as a professional declaring that they have 'an interest in working with children'. Government regulatory measures must be in place around the audiology profession to ensure that audiologists will be qualified, competent and declared safe, to work with children from 0-18 years of age. Currently, there is no legislative system of registration which requires proof-of-experience (detailing caseloads within specific time-frames), capability and professional qualifications for audiologists. Staff in audiology clinics will need to undertake "Working with Children" checks and compliance will need to be strictly monitored.
 - iii. Private audiology service provider organisations, have indicated that there are a number of ex-*Australian Hearing* trained paediatric audiologists now operating in the private sector and that these individuals are ready to provide a service. This may provide a service now, but if the large training infrastructure facilitated by *Australian Hearing* is a casualty of privatisation, there is a future risk that the number of newly-trained paediatric specialists will decrease over time. The number of appropriately skilled paediatric audiologists may drop below the numbers that required to provide adequate services. Also, the standard of quality of in-house or on-the-job

training for paediatric specialists in the context of a contestable market, is obviously going to be very difficult sustain or validate, in an environment featuring multiple small, service providers.

- iv. *Australian Hearing* has developed a number of technologies, for example specialised, cutting-edge cortical testing equipment. It is difficult to see how the majority of commercial providers would be able to own and provide the expected range of appropriate equipment and expertise, needed to test newborn and infant clients, given the low number of newly-diagnosed paediatric clients each year. It is also difficult to see why commercial providers, would invest heavily in technologies that will only equip them to deal with 'thin markets'. Any alternate service providers offering paediatric services would need to be transparently ranked, assessed, approved and regulated.
- h) Audiology centres must have wheelchair and pram access and the capability and size to be child-friendly, including carers and siblings. Equipment and sound booths must be appropriate for paediatric requirements. Staffing levels also need to be adequate to ensure that testing is carried out to the highest standard. The current practice with regard to hearing tests for babies and children provided by *Australian Hearing*, requires the scheduling of *two* paediatric specialists to be present during a test. This is to ensure that the process is well-managed and to objectively confirm a diagnosis.
- i) Any new system or model must ensure that *all* children, (including those whose parents cannot be a strong advocate for them, due to factors such as having English as a second language, low socio-economic background or poor education), continue to receive appropriate paediatric services.
- j) Translation services will need to be provided as required, including AUSLAN. Parents from English as a second-language backgrounds, will require more time and understanding, when communicating with Audiologists during appointments.
- k) *Aboriginal and Torres Strait Islander* families, migrant families and Deaf families, require culturally appropriate services and interpreters, so that they are able to understand their child's hearing loss and needs. This is essential for them to be able to make informed decisions. Some families have to deal with cultural sensitivities, such as family and group acceptance surrounding the birth of a child with a hearing disability. This may have a significant impact on that child's development, if hearing aids are not worn as often as possible and Early Intervention is not undertaken regularly during the first 18 months of life. Service providers need to be aware of the full range of these issues, when they are dealing with paediatric clients.
- l) Children and adults who are diagnosed with complex hearing problems, require specialist testing and technical support currently received from NAL. This highly specialised service still needs to be provided, supported and funded in the future.

4 ACCESS AND QUALITY

The Government has noted in Senate Estimates and in recent press releases, that access and quality will be protected with any decisions regarding Australian Hearing and services.

This assurance is given even though there are no national “best practice” standards for: service quality; timeliness; quantity; accessibility; delivery; protocols; safeguards, or pathways.

- a) *The entire support structure for deaf and hard-of-hearing children in Australia, is built around the nationwide services provided by Australian Hearing. This includes liaison and interactions with not-for-profit deaf support and Early Intervention services, schools and other disability support organisations.*
 - i. The provision of hearing services and supply of hearing appliances is research-based and consistently applied across all of Australia, through *Australian Hearing*. This level of service and assurance of quality must be maintained.
 - ii. *Australian Hearing* interfaces with schools and other services, such as itinerant support teachers, Early Intervention supports and parents groups, in order to ensure that children’s access to their specific technology is well understood and functioning optimally in the classroom or home setting. This is currently provided free-of-charge and can be provided to a whole classroom or school, in one visit by *Australian Hearing*. This may not be initially considered or covered under a child’s individual NDIS support plan for Hearing Services, or be available from a private service provider. Potentially, multiple services providers may visit one classroom or school, rather than one provider, servicing all children in the class/school at once.
 - iii. *Australian Hearing* provides nationwide coverage through 127 hearing centres, as well as remote locations via 217 outreach sites. At a stakeholder meeting in Sydney on 19 June 2015, the *Department of Finance* provided very limited information from the PwC Scoping Study, detailing that *Australian Hearing* had a similar site profile to other providers when comparing metro, regional and remote locations. However, the basis of this analysis was not disclosed. The figures presented were decidedly odd. This lack of disclosure and explanation meant that the capability of the other provider sites to deliver or accommodate specialised paediatric service obligations, was also not disclosed. This analysis needs to be revisited.
 - iv. It is unlikely that providing hearing services to rural, remote and outreach areas will be as “cost effective” as city areas. There must be guarantees on the level of service delivery to ensure that all Australians receive an equitable national standard of service.

- b) *Currently, the pathway from diagnostic audiology to Australian Hearing, is both efficient and understandable for families, at a critical time. It is a time when families have minimal knowledge and are faced with maximum stress. This effective pathway reduces the burden of decision making. It also means that there is minimal delay in providing hearing aids to newly diagnosed babies. Australian Hearing prioritises access for newly-diagnosed families.*

NDIS administrative processes may have the potential to create administrative delays in the pathway to accessing hearing and Early Intervention services, slowing a child's access to assessment and hearing appliances. This could also increase the risk of poor outcomes in learning, language, and speech, because of the delays in accessing sound. Priority services are required for deaf and hard-of-hearing babies.

- c) *Parent counselling and support services at the time of hearing disability diagnosis varies from state-to-state. Often, Australian Hearing is the first source of comprehensive information, and the point at which families receive the 'Choices' booklet detailing aspects of a child's hearing loss, testing and contact details for support services.*

Parent support and information needs to be improved in terms of availability, timeliness of delivery, and consistency across the country. This will allow parents to start understanding the world that they have entered into *as well as* the pathway and decisions they need to take and make.

- d) *PODC knows that the current transition out of the CSO program for young adults, (i.e. under 26 years of age) is a daunting time even though they are experienced with hearing loss, hearing appliances and audiology testing, as they try to find a private audiologist who understands their hearing needs. If Australian Hearing is privatised or disaggregated, the 'search for an audiologist' is going to be infinitely more challenging for parents with a newly-diagnosed baby, as they have no experience in the hearing service provision world.*

Parents need to be provided with unbiased information when choosing Hearing Services providers. As previously stated, the quality, qualifications and capability of service providers, will need to be regulated, checked and controlled.

It is noted as a positive initiative that deaf and hard-of-hearing adults (those between 26 and 65 years of age) will now be able to apply for hearing services supports through participation in NDIS, and that legislative changes in 2013 expanded eligibility for CSO to NDIS participants.

- e) *The NDIA area coordinators have general disability knowledge and not specialist disability knowledge.*

Without a detailed, national Hearing Services and Early Intervention framework, or pathway for hearing impaired children, there is no system in place to ensure the NDIA coordinators fully understand, or include in an NDIS Plan, the complexity and requirements of a hearing services and Early Intervention program. This is essential

so that babies are quickly and appropriately referred, families are fully informed and available options are discussed and options considered, *prior* to an agreed *NDIS* Plan being finalised. The *NDIS ILC Framework* for supports outside of individually funded packages, is still being developed. As a result, the availability of information about hearing disability and support options, is reliant on existing services. Important information is currently not being delivered in a coordinated way, in association with *NDIS* processes.

- f) *Australian Hearing is currently the primary training ground for paediatric expertise in audiology. It has in-house training for audiologists to cover paediatric and special needs clients. **This is not covered by the university degree coursework.** It is estimated that up to 30 to 40% of hearing impaired children have additional disabilities [11].*
- i. Systems need to be in place to ensure that audiologists who decide to deliver paediatric services, are already experienced audiologists and that they receive comprehensive paediatric training, including dealing with children with additional disabilities. This system and training needs to be externally assessed and regulated. Showing '*an interest in children*' is not and should not be seen as an adequate level of competency or commitment with regard to delivering paediatric services.
 - ii. Recognized and approved *Continuing Professional Development (CPD)* and a minimum number of hours per year of delivered services in paediatric and special needs clients, needs to be part of a paediatric audiologist's qualifications, to permit continued delivery of these services.
 - iii. Given the low number of paediatric clients, as detailed in Section 3 g) above, it is difficult to envisage how non-*Australian Hearing* audiologists will maintain paediatric experience.
 - iv. Qualifications, experience, completion of approved training, competency, hours of specialised paediatric service delivery and *CPD*, will need to be checked and audited for compliance by a professional or Government body.
- g) *Australian Hearing* was reported to have an exceptionally low complaint rate of 0.02% for 2012-13 [1]. If the provision of a hearing services program is opened up to alternative providers, then an independent, national industry-wide standardized complaints system will need to be put in place. The system will require an open reporting system and a procedure for corrective actions.
- h) One third of private audiology clinics are owned by a hearing aid manufacturer. How will families receive independent and unbiased advice about: their child's unique hearing loss; the full spectrum of available options available to them and the comprehensive range of listening devices that are available and appropriate for their child's specific requirements and early intervention needs?

- i) A system of updating hearing appliances in a coordinated and fair way needs to be put in place, as technology changes, or the needs of the child change. The basis and rules associated with how frequently upgrades will occur, needs to be clearly established. *Australian Hearing* currently has an effective protocol around revisions and upgrades and this needs to be managed in any alternative scenario.
- j) Users of hearing appliances and associated equipment, such as FM devices, need to be assured of prompt delivery and capability when it comes to maintenance services for repair or replacement. This includes arrangements for a loan device whilst repairs are undertaken. Young children cannot be without access to sound and language. *Australian Hearing* currently has very effective systems in place to deal with these kinds of problems.
- k) *Australian Hearing* is accredited to AS/NZS ISO 9001:2008 and therefore has and provides a consistency of quality and systems across the nation. A recognised level of quality assurance delivery must be mandatory for any alternative service providers.
- l) *Service levels should not be based on a person's ability to pay.*
 - i. Safeguards must be in place to ensure that parents are not coerced into purchasing devices that have features that are not required by the child in a specific period of their life.
 - ii. The most vulnerable people must be protected against the practice of 'upselling', if there is an option for purchasing higher-level technology [12].
- m) Supplementary devices, such as FM's, must continue to be consistent in type. This is so that classroom technology aids can be easily operated by teachers and carers. The delivery of supplementary devices must be managed, including the roll out of new technology, and consistency of devices. The efficacy of these devices should be checked prior to issue by an independent body, such as the NAL, and outcomes measured.
- n) There needs to be regular auditing of service providers in order to ensure service and quality standards meet minimum delivery requirements. Consistency must be maintained, across all service providers and locations. Measures need to be in place to encourage and enforce compliance.
- o) Engagement, feedback, and input must continue between audiological service providers and parents, clients, and other user stakeholders. This ongoing dialogue is essential, so that service delivery meets expectations. This may be difficult within a fragmented service provider model. It may be reliant on the parents, clients and/or stakeholders, who are interfacing with a regulatory body that oversees the industry, such as the Government.

5 EVIDENCE BASED PRACTICE

- a) *Any changes to the Hearing Services program or pathways to Early Intervention supports will need close monitoring and evaluation. This attention to detail is to ensure that the outcomes for deaf and hard-of-hearing children and their families are not compromised. It will need to include monitoring across the entire cohort of hearing impaired children, including: documenting child and family outcomes; knowledge and skills of the interventionists and family benefits from services.*

The quality, outcomes and effectiveness of the Hearing Services Program, pathways and early intervention supports, must be defined and benchmarked, prior to the implementation of any changes. These features must subsequently be measured continually over time if and when changes are made, to ensure that the level of service and quality is at least maintained, or more desirably, that it improves.

- b) *Deaf children and their families currently benefit enormously from the conjoined nature of Australian Hearing as a service provider and the research functions carried out by the high calibre staff within NAL. Long-term projects that investigate aspects of Early Intervention, diagnostic testing and the efficacy of specific technologies, are carried out by Australian Hearing's research staff. These scientists work in close partnership with audiologists and their clients at the coalface.*

The National Acoustic Laboratories has been at the forefront of research into hearing aid prescription and features that optimise access to spoken language. It is a critical technical support for Australian Hearing's services. Children and young people have benefited from their research and use of the NAL prescription at Australian Hearing centres.

As clients of Australian Hearing, many children have been part of the world-first LOCHI study (Longitudinal Outcomes of Children with Hearing Impairment) – the largest longitudinal study of deaf and hard-of-hearing children in the world – undertaken by NAL. This study has provided evidence for best practice for services for deaf and hard-of-hearing children around the world [11].

Any separation or break-up of the current arrangements between *Australian Hearing* and *NAL*, places at risk the excellent marriage of service and research, delivering practical knowledge and expertise that benefits all deaf children. New technology and information is disseminated from *NAL* across Australia to all *Australian Hearing* centres in a consistent manner, so that all clients can take advantage of improvements.

It is difficult to imagine how this extraordinary advantage, made possible because of the conjoined nature of the two organisations, would be possible in a 'contestable' scenario, or with multiple service providers. This leadership in hearing service provision must continue, so that current and future generations benefit with the most appropriate hearing appliances.

At a briefing with hearing services stakeholders in Sydney on 19 June 2015, the *Department of Finance* revealed that the *Scoping Study* undertaken by PwC had found how vital a role the NAL played in technically supporting hearing services and hearing health research and recommended that this role continue. However, the feedback indicated a likely requirement for NAL to complete for funding, rather than receive it through *Australian Hearing* and the CSO. This finding was reported to stakeholders as “a greater opportunity to capture other research funding from having more experience in the broader contestable research funding environment.” This skewed feedback, neglected to state the downside risk of the proposed change: that if NAL was unsuccessful in attaining funding, it would as a consequence, most likely be less able to continue its research programs.

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Parents of Deaf Children is the peak body for parents of deaf and hard-of-hearing children in New South Wales. The role of the organisation is to support families in NSW with the provision of independent information, referral and advocacy services.