



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.

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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

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

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.

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



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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 unbiased information, referral and advocacy services.



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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.