

aussie deaf kids

QUESTIONS ON THE FUTURE OF HEARING SERVICES FOR DEAF & HARD OF HEARING CHILDREN

Submitted to:Minister for Finance
Minister for Health
Minister for Human Services
National Manager Office of Hearing Services
5 June 2015

ABSTRACT

This submission asks questions that must be answered satisfactorily by the Government regarding the future delivery of hearing services for deaf and hard of hearing children.

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.

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 questions 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

Ann Porter

President PODC

CEO & Founder ADK



Senator the Hon Mathias Cormann Minister for Finance

The Hon Sussan Ley MP Minister for Health

Senator Marise Payne Minister for Human Services

Ms. Tracey Duffy National Manager Office of Hearing Services

Dear Ministers and Ms. Duffy,

Thank you for the invitation and opportunity to participate in consultation between the Government and the deaf community and organisations that work to provide support services, before making a decision on the ownership options for *Australian Hearing*.

The Government has indicated that it is committed to the best possible outcome and that it will continue "to provide high quality hearing services for all eligible Australians." This was stated in a letter to PODC from Minister Cormann on 26 August 2014.

The Community Service Obligation (CSO) program "is being effectively administered by Australian Hearing" as noted in 2014 by the Australian National Audit Office [1]. Australian Hearing and National Acoustic Laboratories (NAL) are recognized as delivering world-leading hearing services to deaf and hard-of-hearing children [2].

This submission contains questions around and about what must be continued to be delivered through the CSO in order to maintain the current high level of quality hearing services delivered and accessible to all eligible Australians.

Further background reference documents are contained in Section 7 of this submission.

We look forward to discussing this submission with you or your representatives in the near future.

Yours sincerely,

pp: Anna Messariti President PODC Ann Porter CEO & Founder ADK

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1 OVERVIEW OF HEARING SERVICES

Minister Cormann's recent media release dated 8 May 2015 and letter to PODC reference MC15-000953 dated 18 May 2015 stated that the government intends to undertake further consultations before making a decision on the ownership options of Australian Hearing. This is the first invitation made by the Government for consultation with CSO clients and potential NDIS participants since the scoping study into ownership options was first announced in the May 2014. PODC, ADK and other organisations have made submissions to the scoping study and contacted politicians regarding hearing services [3], [4], [5]. Neither PODC and ADK, nor anyone else in the deaf community or general public, has been provided with any details of the PwC scoping study findings. PODC request for access to the scoping study under FOI has not been successful to date [6].

- a) Why is the Government changing a system recognized as world leading?
- b) Can you provide PODC & ADK with the detail of the PwC Scoping Study report?
- c) Please advise the current status of Australian Hearing within the 'contestability framework' process, as announced in the ministerial Statement and 2014-15 budget, including details of reviews, studies or assessments already completed.
- d) The National Manager, Office of Hearing Services, detailed in a letter to stakeholders that "in 2013, it was agreed that the hearing services program would be in scope of the NDIS and that this means by 2019 clients of the CSO who are eligible for the NDIS would transition..". We were not made aware of this decision at any time, formally or informally.
 - i. What was the background to this decision?
 - ii. Could we have copies of any relevant extracts from papers or minutes, relating to this decision?
 - iii. Were CSO clients and their families advised or consulted regarding this agreement?
- e) There has been little feedback on what is currently happening with Hearing Services within the NDIS trial sites.
 - i. Are some hearing services being delivered by agencies other than Australian Hearing now?
 - ii. What are those services?
 - iii. Has any feedback been provided about how those services compare with those of Australian Hearing?

- f) There has been no indication on the future of Australian Hearing and no feedback or information from the scoping study.
 - i. Will Australian Hearing remain a government organisation or be privatised?
 - ii. How would Australian Hearing look as a service provider within the NDIS model?
 - iii. Will Australian Hearing retain its reach and spread of locations?
 - iv. If there is privatisation, or the CSO delivery is opened to other providers, how will rural and remote areas, that are likely not to be as "profitable" as city areas, continue to have a level of service delivery that is equal, both in terms of access and quality assurance?
- g) 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.
 - i. How does the government propose to compensate for the loss of knowledge and expertise that currently benefits deaf children, because of the excellent marriage of service and research that is currently possible in the context of Australian Hearing?
 - ii. How would the extraordinary advantages that are possible because of the conjoined 'organisation' be possible in a 'contestable' scenario?
- h) What are the Government's Key Performance Indicators for the delivery of the requirements of the CSO program and how will this be managed in the future?
- i) How will services provided under the CSO Program maintain a client outcome focus rather than a profit focus?
- j) How will a coordinated approach to screening of children, especially in remote locations, such as Aboriginal and Torres Strait Islander communities, be continued?
- k) The support and advice that is provided to schools and itinerant support teachers around a specific child's technology, is currently provided free of charge and can be provided to a whole classroom or school in one visit by Australian Hearing.
 - In a 'contestable' scenario, has the government considered how it will fund, manage, and provide low cost-per-visit if multiple organisations provide these types of services currently provided by Australian Hearing to deaf children, their families and communities, that have no possibility of being profitable?

2 FUNDING

- a) What is the cost advantage to Government of moving funding arrangements to the NDIS?
- b) In 2012 -13 the CSO program was cross-subsidised by \$800,000 from the Voucher program. How will this funding shortfall be managed?
- c) We have seen recent confusion and distress about the decision to provide cochlear implant upgrades for some CSO Clients and not others. The financial needs for technology upgrades will change for children from year to year.
 - i. How will funding be increased as technology improves and better features on devices allow better outcomes for children?
 - ii. How will this be managed within the NDIS budget?
 - iii. Will there be allowances within the child's NDIS funding budget for newer and more appropriate technology when it becomes available?
 - iv. How will this impact on the other funding the child may receive for Early Intervention?
- d) An open market will allow for providers to operate without constraints and multiple providers to operate, therefore there will be no bulk purchasing arrangements. The 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 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 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.

- i. How will this current buy advantage and high level of equipment be maintained so that it continues to benefit clients?
- ii. What are the economic advantages in the open market arrangement, given that the low unit cost for hearing appliances that is now being achieved?
- e) Families have expressed that they would rather forego choice of service provider to ensure the level of hearing aids technology, and trusted, reliable, quality services are maintained.

How will the government ensure that private companies will not try to maximize

profit margins in a "race to the bottom" by reducing overheads, such as the quality of service, the reach of services and the quality of hearing aids?

f) The development of high quality technology has changed the educational outcomes of deaf children. For these outcomes to occur, research has shown that children need <u>appropriate</u> 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."
[7]

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 poorer outcomes and is not the same as the "appropriate" level of technology. Each child is unique and some children have quite complex needs. You cannot recover lost early intervention time if the technology issued for accessing listening and learning is inadequate and results in the less than optimal developmental outcomes.

Please explain why children may 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?

g) Funding services via the NDIS will add another layer of administration and thus additional costs to the existing direct funding arrangements to Australian Hearing under the CSO program.

How is this cost effective or efficient?

- h) What assurance is there that there will be no reduction in services and technology, in order to offset the increase in cost of transferring services from the CSO program to the NDIS?
- i) What will happen to the NAL and associated funding of that organisation if funding goes to the NDIS?
- j) How will funding for repairs and lost/broken equipment be managed under the NDIS?
- k) How will it be possible to provide quality on-the-job training for paediatric specialists in audiology in the context of a contestable environment featuring multiple small, service providers?

3 **ELIGIBILITY**

- a) The National Manager, Office of Hearing Services, noted in a letter to stakeholders that NDIS clients would include former CSO clients.
 - i. Does this refer to CSO clients who are over 26 years of age?
 - ii. Will those clients be able to access hearing services from Australian Hearing and other agencies, for example?
- b) Please clarify if children with a unilateral hearing loss who can access a hearing device from Australian Hearing at the moment will be eligible for the NDIS?

4 PATHWAY FOR GAINING ACCESS TO SUPPORT AND SERVICES

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, organized, 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 being lost in the system and being not receiving the necessary follow up in a manner that is timely and effective.

- a) What changes can be made to the NDIS pathway that will ensure that infants and older children who are diagnosed with hearing loss are prioritised and that they will not be lost in a system where there are multiple providers?
- b) How will consistency of approach to appointment allocation ensure that there is sufficient time provided for the audiologist to test and fit young babies and children with appropriate devices?
- c) Will the NDIS add another administrative layer that will inhibit timely access to Early Intervention services and support for newly diagnosed families?
- d) What arrangements will be put in place to ensure that clients in rural and remote areas will have access to an equivalent level of expertise and the quality of service that can be made available in urban areas?
- e) Annually, there are around 2,000 children who are fitted with hearing aids for the first time, of which only approximately 250 are infants [8]. 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.
 - i. Can parents and carers of babies and children be assured that the audiologists who are delivering services to their children are qualified and experienced enough to undertake this complex and specialized work?
 - ii. What regulatory measures will be put in place to ensure that audiologists in a contestable environment will be both qualified and competent to work with children from 0-18 years of age?
 - Australian Hearing has developed a number of technologies, for example specialised, cutting-edge cortical testing equipment. Will commercial

- providers be expected to have the appropriate equipment to test newborn and infant clients?
- iv. If a commercial service provider has very few paediatric clients, how will it be feasible for them to provide the necessary diagnostic testing technologies and the expertise to use those technologies?
- v. Will audiology centres be required to have wheelchair or pram access, and the capability and size to be child-friendly, including carers and siblings?
- vi. Will commercial hearing service providers see enough paediatric clients per year to maintain this specialist competency?
- vii. Can a range of service providers offer appropriate services, especially when rare or complex needs arise?
 - Will all staff in commercial audiology clinics need to undertake "Working with Children" checks?
- f) How will the new system or model, 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?
- g) Who will provide translation services, including AUSLAN?
- h) How will Aboriginal and Torres Strait Islander families, migrant families and Deaf families receive culturally appropriate services and interpreters, so that they are able to understand their child's hearing loss and needs and make informed decisions?
- i) Currently children and adults who are diagnosed with complex hearing problems that require specialist testing and technical support receive this from NAL. How will this be provided in the future?

5 Access and quality

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

- 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 services, schools and other disability support organisations. An example of this is an Australian Hearing audiologist attending public schools special hearing support unit classes, to ensure that FM systems and loop systems are in place and functioning well for the hearing impaired school children.
 - i. How will this consistency be maintained if a sale is to proceed?
 - ii. How will hearing services under the NDIS, interface with schools and other services, in order to ensure that children's' access to technology is functioning optimally in the classroom setting?
 - iii. The provision of hearing services and supply of hearing appliances is research based and applied consistently across all of Australia through Australian Hearing. How will this assurance of quality be maintained?
- 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.
 - i. Under NDIS processes there is the potential to create roadblocks in the pathway. It also could increase the risk factors when it comes to medical and other specialized follow-up services required for those babies.
 - Will families first need to apply to the NDIS for funding before they are able to access hearing services?
 - ii. How will the pathway from newborn hearing screening to the NDIS and hearing services be managed?
- c) Currently, Australian Hearing is the first source of comprehensive information and the point at which families receive the 'Choices' booklet.
 - i. Will parents still be receiving this kind of information to get them on the road to understanding *and* the pathway and decisions they need to make?

- ii. We know that the transition out of the CSO program for young adults is a daunting time, as they try to find an audiologist who understands their hearing needs. This 'search for an audiologist' is going to be infinitely more challenging for parents with a newly diagnosed baby.
 - Who will provide parents with unbiased information about the risks and benefits of choosing different hearing services providers?
- d) The NDIA area coordinators have general disability knowledge and not specialist disability knowledge.
 - What system will be in place to ensure the NDIS coordinators fully understand the complexity of the hearing services program, so that babies are quickly and appropriately referred and families fully informed, about the available options?
- e) The audiology profession is self-regulating at the moment.
 - How will NDIS providers demonstrate that they have the necessary expertise to deliver services to vulnerable groups, including babies and children?
- 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 [9].
 - i. What systems will be put in place to ensure that audiologists receive comprehensive paediatric training, including those with additional disabilities?
 - ii. How will there be ongoing professional development in paediatric and special needs clients if Australian Hearing is privatised?
 - iii. How will non-Australian Hearing audiologists have and maintain paediatric experience given the low number of paediatric clients?
 - iv. How will this experience and training competency be checked and audited for compliance?
- g) Australian Hearing was reported to have an exceptionally low complaint rate of 0.02% for 2012- 13 [1].
 - i. How would this be maintained under an alternative model?
 - What will the complaints process look like if there are multiple service providers?
 - ii. If there is an alternative model, will there be an ombudsman?

- h) How will services be maintained in rural and remote areas when services are transferred to the NDIS and what outreach services will be provided?
- i) Many private audiology clinics are owned by a hearing aid manufacturer. How will families receive independent and unbiased advice about their child's hearing loss, the options and range of listening devices that are available and appropriate for their child's requirements and early intervention needs?
- j) How will devices be updated in a coordinated and fair way, as technology changes or the needs of the child change and how frequently will upgrades occur?
- k) How will hearing device maintenance services deliver prompt repair or replacement capability, including arrangements for a loan device whilst repairs are undertaken?
- Australian Hearing is accredited to AS/NZS ISO 9001:2008 and therefore has consistency of quality and systems across the nation.
 - What quality assurance program requirements will be in place, if Australian Hearing does not deliver these services, or, if services are opened to other providers who may not have a quality assurance process in place?
- m) Service levels should not be based on a person's ability to pay.
 - i. What safeguards will 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. How will the most vulnerable people be protected against the practice of 'upselling', if there is an option for purchasing higher level technology [10]?
- n) 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.
 - How will supplementary devices be managed, including the roll out of new technology, and consistency of devices?
- o) Who will set the service and quality standards that have to be met and how will consistency of service delivery be maintained, across all service providers and/or locations?
- p) How will engagement and input continue with parent groups so that the service delivery meets expectations?

6 EVIDENCE BASED PRACTICE

a) Any changes to the system 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 cohort of hearing impaired children, including: documenting child and family outcomes; knowledge and skills of the interventionists and family benefit from services.

How will the quality, outcomes and effectiveness of the hearing services program be measured when services are transferred to the NDIS?

b) 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 benefitted 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].

- i. How will this leadership in hearing service provision continue, so that current and future generations benefit with the most appropriate hearing appliances?
- ii. The NDIS funding model is currently only directed to participants who choose their supports. There is currently no block funding from NDIS to organisations. How will funding be made available for NAL through NDIS?
- c) Why are we changing a system that is considered to be the best system in the world for the audiological management for children diagnosed with a hearing loss?
- d) How will continual improvement be implemented if multiple service providers enter the CSO Program?
- e) How will new technology information be disseminated across the industry consistently, so that all clients can take advantage of improvement?

7 REFERENCES AND FURTHER INFORMATION

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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 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.