

aussie deaf kids



SUBMISSION TO THE INQUIRY INTO HEARING HEALTH AND WELLBEING OF AUSTRALIA

Submitted to: -
The Standing Committee on Health, Aged Care and
Sport.
23 December 2016

ABSTRACT

This submission details the concerns of parents of deaf and hard of hearing children with respect to hearing health and wellbeing in Australia.

These are the views of two organisations, Aussie Deaf Kids (ADK) and Parents of Deaf Children (PODC), which represent and support 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 are representative of a wide range of socio-economic backgrounds.

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CEO & Founder ADK

Mark Wyburn
Secretary PODC

1 TERMS OF REFERENCE

The **bolded text** below indicates the points of the Terms of Reference that this submission will address.

“Taking into consideration the significant percentage of Australians experiencing hearing loss and the related social and economic impact of hearing impairment to the long-term health and wellbeing of Australia, the Standing Committee on Health, Aged Care and Sport will inquire into and report on:

- 1. The current causes and costs of hearing loss, and ear or balance disorder to the Australian health care system should existing arrangements remain in place;***
- 2. Community awareness, information, education and promotion about hearing loss and health care;*
- 3. Access to, and cost of services, which include hearing assessments, treatment and support, Auslan language services, and new hearing aid technology;***
- 4. Current access, support and cost of hearing health care for vulnerable populations, including: culturally and linguistically diverse people, the elderly, Aboriginal and Torres Strait Islanders and people living in rural and regional areas;***
- 5. Current demand and future need for hearing checks and screening, especially for children (12 years and younger) and older Australians at key life stages;***
- 6. Access, availability and cost of required drugs, treatments and support for chronic ear and balance disorders sufferers;*
- 7. Best practice and proposed innovative models of hearing health care to improve access, quality and affordability;***
- 8. Developments in research into hearing loss, including: prevention, causes, treatment regimes, and potential new technologies;*
- 9. Whether hearing health and wellbeing should be considered as the next National Health Priority for Australia; and*
- 10. Any other relevant matter.”***

2 INTRODUCTION

Aussie Deaf Kids (ADK) and Parents of Deaf Children (PODC) are writing as parent representatives of groups supporting parents whose child is deaf or hard of hearing. Many of the concerns we currently have are in regard to matters that we have previously addressed to government, namely the sale of Australian Hearing, the transition of Hearing Services to the National Disability Insurance Scheme (NDIS) and eligibility criteria for children and young people with regards to both Hearing Services and the NDIS. While these issues are still to be addressed and remain our primary concern for the long-term outcomes and wellbeing of our children with hearing loss and families, we do wish to address some of the issues outlined for this Inquiry into Hearing Health and Wellbeing in Australia.

3 BACKGROUND

Deaf and hard of hearing children and their families have been fortunate to receive comprehensive audiological and early intervention services over many years, thanks to early diagnosis through newborn hearing screening programs; the Community Service Obligation component of the Hearing Services program which ensures that all children with a hearing loss receive devices that will enable them to listen and learn throughout their education years; and a mature early intervention sector that supports the child and family. However, this is all changing and it remains unclear to us whether the changes will result in better outcomes for all children diagnosed with permanent childhood hearing loss.

This submission is written in the context that many of the issues of concern to parents with regards to the ongoing delivery of services and support for our children remain unanswered and are our primary concern. The wellbeing of our children depends on the effectiveness and efficacy of the services and programs providing these services.

4 ADDRESSING THE TERMS OF REFERENCE

“1. The current causes and costs of hearing loss, and ear and balance disorder to the Australian health care system should existing arrangements remain in place.”

The impact of hearing loss on the child and family

Permanent hearing loss in childhood impacts on all aspects of a child’s life – their ability to acquire meaningful language; their potential to learn effectively and readily; and their opportunity to enjoy and fully participate in family life and their local community. The success of the child will depend on many factors – early identification of hearing loss, appropriate access to hearing devices and early intervention and support at school. But the greatest source of success is the family that surrounds the child. But this also places a considerable burden on the family. The capacity of the family to take on this additional workload will depend on their resilience, their financial and social situation and the support they receive.

When considering the cost of hearing loss to the Australian health care system, the burden of this additional workload on families must be considered. Before parents are able to effectively take on the additional workload a number of issues need to be resolved.

Poverty, domestic violence, accommodation insecurity, mental health and drug and alcohol issues within the family require timely and appropriate intervention. The child’s hearing loss cannot be a priority when the family is experiencing problems that impact significantly on their daily lives. These issues impact on the mother-child bond, their ability to respond to the child’s needs, and the sense of security babies and young children need for their brains to develop (Hawley & Gunner, 2000). These issues impact on the ability of the family to attend appointments and provide the language-rich home environment children with hearing loss need to develop language. Early intervention provides a weekly appointment but the other 80 or so waking hours a week of the child requires parents who have the capacity to undertake the work required for their child to thrive. The National Disability

Insurance Scheme is person-centred but simply providing access to services for the child with hearing loss will not guarantee good outcomes. The wellbeing of the whole family must be considered alongside the needs of the child. They are inextricably linked. If a family is unable to undertake the work needed for their child to acquire language and learn, then the way the services are provided need to be modified to acknowledge and accommodate for this.

The mental wellbeing of carers, particularly mothers, within the sector has received little attention. Having a child with a hearing loss puts strain on relationships and marriages, frequently resulting in deaf and hard of hearing children being raised in single parent households. The disadvantages this places on all children is well-documented but the added burden mothers of deaf children face exacerbates the issues further.

Parents are reluctant to discuss their own mental health issues in our support groups but we have heard many stories one-on-one—mothers having problems bonding with their babies after diagnosis, significant post-natal depression and use of antidepressants as the child grows.

Recommendations

- 1. There is capacity within the system for services to ameliorate the obstacles to family wellbeing and the ability of the family to undertake the workload required to optimise the promise of early diagnosis and intervention.*
- 2. One-size does not fit all – the social circumstances, family wellbeing and maternal education must be considered when devising appropriate services for the child and the family.*
- 3. Mental health of carers, particularly mothers, is diagnosed and treated early so they are able to undertake the added workload of raising a child with a hearing loss.*

Mental health and deaf and hard of hearing children

As a result of anecdotal observations of parents, a systematic review of the literature was undertaken by Dr Paul Jacobs for Aussie Deaf Kids in 2013. Only four articles from Australia were retrieved (Cornes, Rohan, Napier, & Rey, 2006; Hogan, Shipley, Strazdins, Purcell, & Baker, 2011; Remine & Brown, 2010; Wake, Hughes, Collins, & Poulakis, 2004). There is little empirical data on this cohort of young Australians.

The wider literature reports that children with hearing loss are at greater risk of mental health problems than their hearing peers (Cornes & Brown, 2012; J Fellingner, Holzinger, Beitel, Laucht, & Goldberg, 2009; J Fellingner, Holzinger, Sattel, & Laucht, 2008; Hogan et al., 2011). Factors that affect poorer mental health status include the presence of additional disabilities (Hintermair, 2007) and external stressors particularly one parent families and lower parental education levels. Communication between the child and parents is crucial for mental wellbeing. Poor child-parent communication has been shown to increase mental health problems in children (van Eldik, Treffers, Veerman, & Verhulst, 2004), whereas fluent child-parent communication, whether spoken or signed, assists mental well-being and quality of life of the child (Kushalnagar et al., 2011; Wallis, Musselman, & Mackay, 2004).

Recommendations

- 1. Funding is provided for research into the mental health needs of children and young people with all levels of hearing loss.*
- 2. Training is provided for mental health practitioners to understand the unique needs of deaf and hard of hearing children and young people.*
- 3. Children and young people who are deaf or hard of hearing receive timely and appropriate mental health services.*

“3. Access to, and cost of services, which include hearing assessments, treatment and support, Auslan Language services, and new hearing aid technology.”

Children and young people have received world-leading access to hearing device technology for decades thanks to the Community Services Obligation component of the Hearing Services program. At this point in time, it is not clear to us whether the proposed changes to the system of delivering these services and the associated devices will continue to be the envy of parents around the world.

As parents, we recognise the unique opportunity our children have been provided through the Hearing Services program. Moving the age of eligibility for the Hearing Services Program to 26 years has meant that our children can complete their education and begin their working lives without the worry of paying for hearing devices and services.

However, once they turn 27 they are on their own. The system has provided them with the opportunity to access spoken language but then abandons them. People who are deaf or hard of hearing rely on their devices for their employment and participation in society. Hearing aids are costly and the refund from health funds is completely inadequate. Individuals with more severe hearing losses are better off getting a cochlear implant than persisting with hearing aids, which from a taxpayer perspective is absurd. We want our children to be independent taxpayers but without access to appropriate devices and assistive technology, there is a tendency for individuals with hearing loss to be unemployed or under-employed. This does not benefit the individual or society as a whole.

It remains unclear whether adults over the age of 26 will be eligible for the NDIS and ongoing support for the purchase of hearing aids and other listening devices.

Recommendations

1. *Our preferred option would be for adults who have been child clients of the Community Services Obligation component of the Hearing Services program*

continue to receive hearing services and listening devices throughout their lives through the Australian Government's Hearing Services program.

- 2. In the absence of ongoing support and device provision, hearing devices and other assistive technology must be tax deductible. They are essential for individuals with hearing loss to fully participate in the workforce.*
- 3. Urgently establish clarity around the levels of hearing loss to access the NDIS.*
- 4. A nationally consistent approach is undertaken for all aspects of hearing services.*

Delivery of hearing services

The model for the delivery of hearing services to children and young people is set to change with the transition of the Hearing Services program to the National Disability Insurance Scheme and a contestable environment. We have written to the Government previously about our concerns with these changes – there are few safeguards currently in place to ensure that children and young people receive services from appropriately trained audiologists with paediatric experience. Poor quality service delivery for children can have lifelong consequences but there is no system in place that will penalise providers who do not comply with proposed standards and guidelines. While this remains a work in progress, we want to reiterate our support for regulated services and appropriate governance to protect the rights of all children with hearing loss to services that are appropriate and timely without marketing pressures placed on parents to purchase devices and incentive schemes for audiologists to top-up devices unnecessarily.

There is also a risk with changes to hearing services as a result of the implementation of the NDIS, that less choice is an outcome due to vertical integration of services and subsequent market consolidation. One large vertically integrated service provider offering audiology and early intervention services, and even potentially including the manufacture of hearing devices, may hold substantial market power. This may lead to a loss of market share for other providers, who ultimately cannot sustain their business.

Recommendations

- 1. Regulation of audiologists and audiometrist and the hearing industry as a whole to safeguard consistent and appropriate levels of quality and service delivery.*
- 2. Clear guidelines around the provision of paediatric service in a contestable marketplace, i.e. babies and children should only receive services from a competent paediatric audiologist; full disclosure to consumers of the payment of commissions to audiologists and audiometrists; timely referral when the*

practitioner is unable to provide the support the child and family need for appropriate outcomes.

- 3. All children receive hearing devices that will allow them optimal access to sound in order to listen and learn without the need for parents to purchase top-up devices.*
- 4. Hearing device technology improvements are rolled out nationally to all children in a consistent, timely and equitable manner.*
- 5. The purchasing power of the government is used to deliver hearing devices with an appropriate level of technology for each child's specific clinical needs, rather than a minimum or standard level of assistive technology.*
- 6. The risks to clients and client outcomes in the provision of hearing services under the NDIS are fully researched, and any controls are in place prior to the implementation any changes.*

“4. Current access, support and cost of hearing health care for vulnerable populations, including: culturally and linguistically diverse people, the elderly, Aboriginal and Torres Strait Islanders and people living in rural and regional areas”

Guidelines and standards for family-centred services for deaf and hard of hearing children and evidence-based practice, require parents to make informed choices. To make an informed choice, parents need to know all their options – the advantages and disadvantages of each option – and they need to understand the information and what it will mean for their child and family in order to make an informed decision. Providing the information is not enough – parents need to be able to understand the information to make an informed decision.

The Australian Commission on Safety and Quality in Health Care indicates that only 40 percent of Australian adults have sufficient health literacy for everyday life (*National Statement on Health Literacy: Taking action to improve safety and quality*, 2014). At the greatest disadvantage for poor health literacy are people with low educational attainment, people whose first language is not English and people with disability. Parents whose first language is Auslan are another disadvantaged group when information is provided.

Parents who fall into these categories are often not provided with information in a format or manner that enables them to understand their options and the consequences of choosing an option and they are therefore unable to make any informed decision.

Disability specific information needs to be disseminated by people with experience in that disability area who are independent of service providers and any real or perceived bias and conflict of interest.

Recommendations

- 1. Additional time needed to assist parent to understand the necessary information in order to make an informed decision is provided and appropriately compensated.*

2. *When non-English speaking parents and culturally Deaf adults need to make decisions that will impact on the future of their child, they must have access to appropriately qualified interpreters.*
3. *Information provided to parents along the pathway meets readability guidelines and is available in community languages so all parents have the ability to make informed choices for their child.*
4. *Actions recommended in the National Statement on Health Literacy are addressed across the hearing health sector to improve understanding of all client groups and allow them to make good decisions about their hearing health.*
5. *Funding is provided for parent groups to provide disability specific information and peer to peer support for parents of newly diagnosed deaf and hard of hearing children, as well as ongoing support during life-critical events such as starting school.*

“5. Current demand and future need for hearing checks and screening, especially for children (12 years and younger) and older Australians at key life stages”

The introduction of newborn hearing screening in Australia has dramatically lowered the age of diagnosis and improved the speech and language outcomes in children with congenital hearing loss. Parents support the ongoing screening of babies to provide optimal opportunities in life to each baby born with hearing loss.

The National Framework for Neonatal Hearing Screening was endorsed by the Community Care and Population Health Principal Committee of the Australian Health Ministers Advisory Council in August 2013. While the implementation of newborn hearing screening programs is the jurisdiction of the States, a national approach to data collection, management and sharing and a national evaluation strategy has yet to be implemented. The lack of a national data set is particularly crucial with the changes that are underway within the provision of hearing services. Australian Hearing has provided a proxy data set over many years but this will no longer be possible when hearing services transitions to the NDIS and a contestable market. We are concerned that this will result in significantly greater numbers of babies being lost to follow up.

A national approach to the evaluation of newborn hearing screening programs is also crucial. The type and quality of service varies across the states and a national approach to ensure consistency and timeliness is needed.

There is an increase in the prevalence of hearing loss as children grow. The best way to ensure these children are identified early is not clear and a recent study in the UK suggests that school entry screening is “unlikely to be effective in increasing the identified number of cases with hearing impairment and lowering the average age at identification (Fortnum et al., 2016).” We are unable to comment whether this would be the case in Australia. It is nonetheless important that children whose hearing deteriorates in childhood have access to timely investigation and management for their hearing loss.

With a national data set, the results of their newborn hearing screening tests would provide a valuable source of longitudinal understanding of permanent hearing loss in childhood.

Recommendations

- 1. National data collection for newborn hearing screening programs becomes a priority before the introduction of any changes to Australian Hearing.*
- 2. Regular national evaluation strategy is implemented to ensure equality of access and timeliness across the country.*

“7. Best practice and proposed innovative models of hearing health care to improve access, quality and affordability;”

The UK Department of Health published a good practice guide in August 2008 on *“Transforming services for Children with hearing difficulty and their Families (Transforming Services for Children with Hearing Difficulty and their Families. A Good Practice Guide, 2008).”* To our knowledge no similar holistic review of hearing services has been undertaken in Australia. It is hoped that any outcomes of this inquiry deliver an approach that is a nationally consistent model of good practice for hearing services.

Recommendations

1. *A product of this inquiry is the delivery of good practice guidelines for national health and hearing services detailing the requirements for consistent and high quality service with appropriate safeguards and world-class outcomes.*

“10.Any other relevant matter.”

There has never be a time of greater change in the hearing services area. As a result there has never been greater risk of making changes that will deliver poor outcomes.

Current changes include: -

1. The national rollout of the NDIS.
2. The transition of the Community Service Obligation component of the Hearing Services program to the NDIS.
3. Competition for hearing services under the NDIS.
4. The unknown future of Australian Hearing.
5. The unknown market outcomes and resultant effect on services following 1 to 4 above, especially in regionally and remote locations.
6. The develop of some form of regulation of audiology services.
7. The lack of funding for the provision of information and funding for organisations that provide independent and unbiased information and peer-to-peer support.

Within each of these issues, many government departments, agencies and hearing sector professional associations and lobby groups are involved, each with their own drivers and deliverables.

No one group has addressed the interdependencies of each of these issues and the risks to consumers as a result of each of the proposed changes. An integrated approach is required with consistent and high level involvement of consumer groups assisted by research and quailified acedemics.

These risks should be identified and controls developed. Methods for benchmarking current performance against future performance need to be in place to assess the efficacy and outcomes of changes. Having a generation of children with poor outcomes is not the way this should be managed.

The focus **must always be** on the risks of services and outcomes to the Deaf of hard of hearing person through a holistic view of the services and supports.

The focus should not be on the individual deliverables of the larger entities such as the NDIS/NDIA, Department of Health, Department of Finance, Department of Social Services, Department of Human Services, existing or emerging early intervention and NDIS service providers, audiology professional bodies, and hearing appliance suppliers.

Recommendation

1. *An objective, independent, suitably qualified and open study is undertaken from a consumer perspective, which understands and considers the interdependencies of each aspect of hearing services, including data collection, research and its application. This study will benchmark current service delivery performance and provide safeguards to ensure that any changes will always deliver improved outcomes for deaf and hard of hearing children and their families, now and into the future.*

5 REFERENCES

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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 a child with hearing loss in Australia.