Inquiry into Hearing Health in Australia

Deaf Children Australia

Submission to the Senate Community Affairs References Committee

Deaf Children Australia February 2010

1. Introduction

Deaf Children Australia (DCA) welcomes the opportunity to make this submission to the Senate Community Affairs Committee for its inquiry into hearing health in Australia.

In our submission we provide an overview of information from families that is relevant to each of the terms of reference, references to research that has been undertaken on families' needs, and recommendations.

Deaf Children Australia welcomes the opportunity to answer any questions that the Senate Committee may have in relation to the content of this submission.

2. About Us

As a national service provider to deaf and hard of hearing children and their families we welcome the opportunity to provide the Senate with information and data in relation to each of the inquiry's terms of reference.

We work with families from diverse backgrounds, including those experiencing social disadvantage, culturally and linguistically diverse (CALD) members of our community and our indigenous population.

The children to whom we provide services communicate using a wide range of modalities. We provide services to children who :-

- are oral (use speech and lipreading) and may have a cochlear implant or use hearing aids
- have chosen Australian Sign Language (Auslan) as their language of choice.

Some of the children with whom we work employ a number of the above methods to ensure successful communication. We do not discriminate or select children on the basis of their communication modality, are unbiased in our service provision and are here for all children with a hearing loss. Attachment A provides information about Deaf Children Australia and its services www.deafchildren.org.au)

3. Executive Summary

In developing this submission, Deaf Children Australia aims to **promote the voice of deaf children and their carers.** Our organisation responds to the diversity of needs expressed by the families of deaf children. We are in contact with at least 1000 families across Australia at any one point in time. In addition to face to face contact, Deaf Children Australia provides information and reference for families, young people, health and education professionals, service providers and community members who regularly visit our website (7000 individual visitors each month).

Our submission references the qualitative and quantitative feedback received from families and deaf children in relation to their experience of deafness; their access to and navigation of the health, education and community service systems.

Deaf Children Australia embraces and works with all children regardless of communication modality, socio economic status, or cultural background.

From our involvement with a diverse range of families, we can report that:

- information they have received in relation to the health, communication or education options for their children continues to be poor, unbalanced or biased

- options and pathways were often not clearly explained by professionals or families were pressured to make decisions as “either or” choices, (families question the wisdom of this)

- early intervention, health/ medical, and education systems currently operate on a **failure model**

- their child has been “shut out” from mainstream Australia in many ways: for example: incomplete access to a full or quality educational curriculum; limited meaningful employment opportunities; an absence of meaningful community participation options.

The implications of deafness and the impact it has on the lives of the child and their family is significant. Inadequate provision for the social and economic inclusion of people with a hearing loss in the Australian community negatively impacts on all key areas of life: including **educational attainment** levels, **employment** opportunities, **mental health and wellbeing, community participation opportunities**, **access** to government, civic, and commercial services.

If we are to promote and enable the social inclusion and wellbeing of people with a hearing loss in our community, we believe that urgent improvement is needed in the areas of:

1. access to hearing services, assessment processes, technologies,
2. access to captioning in community settings: including commercial entertainment services; government services; public transport systems; educational environments; community events; workplaces etc
3. interpreting support for those people who are Auslan (Australian Sign Language) users and who also benefit from visual technologies.

In order to advance the idea of social inclusion in planning more responsive systems, we urge the Senate to seek feedback directly from families. We suggest this consultative approach because parents and young deaf people have first hand experience of dealing with the health, education and the community service system.

As a consumer, the parent interacts with and experiences the service systems on a daily basis. Parents frequently express their concerns to us in relation to their efforts to obtain balanced unbiased information, knowledge, skills, social support with the aim of achieving awareness, access and advancement for their deaf children.

We also urge the Senate Inquiry to seek feedback and to listen to the stories of young people who live the life of deafness and have direct experience of the challenges and struggles to gain an adequate education, and to obtain post school education and employment.

4. Recommendations

Recommendation 1: Australian research to comprehensively investigate and explore the implications of hearing loss on social and economic inclusion from the perspective of parents, families and from deaf people themselves.

Recommendation 2: The Federal Government commission an Inquiry into the type and range of resources required to ensure the full participation of people with a hearing loss in early education, primary and secondary education, tertiary options and workplaces as a means to **enabling more productive and meaningful outcomes for these citizens .**

Recommendation 3: The development of a new model of early intervention in Australia. Research should be undertaken into parents experience and models of service delivery that promote the best outcomes for the child. Particular attention needs to be given to international best practice and **models of early intervention that do not promote failure or place choice limitation on the child's development.**

Recommendation 4: The Federal Government to review the funding levels for deaf education in each state with the view to making a significant financial contribution, to ensure that every child with a hearing loss regardless of their location receives access to a quality curriculum and is socially included in their educational setting. This would mean ensuring that the child has access via their choice of communication methodology, that is through hearing technologies, visual technologies and/ or sign language, and advanced information technology options. Note this recommendation also has implications for teacher and support services staff resource levels

Recommendation 5: The Federal Government fund research exploring the reasons for low levels of participation of people with a hearing loss in meaningful employment and develop inclusive and meaningful training and workplace engagement strategies for deaf people

Recommendation 6: Consideration be given to the establishment of a National Strategy for Research and Information on Mental Health and Deafness

Recommendation 7: The Federal Government provide funding for a national summit for a 2020 vision on the inclusion of Deaf and Hard of Hearing people in community life, to address the question: *what can be done to stop the current social exclusion of people with a hearing loss and, what action can be taken to promote the social inclusion of people with hearing loss in all areas of daily living?*

Recommendation 8: The Federal Government examine the current inequality in service provision and identify strategies that would improve access to hearing technologies and reduce waiting times. In addition people over 21 years of age should be entitled to receive hearing aids at no cost to themselves. In addition, access via captioned technology needs to be addressed as does access to interpreter services.

5. The extent, causes and costs of hearing impairment in Australia

Data[1] available suggests that one in six Australians have a hearing loss, and this is likely to rise to one in four by 2050. In 2005, it was estimated that there were 3.5 million Australians (aged 15 plus) with a hearing loss and approximately 15,000 children under 18 years of age. The prevalence of hearing loss increases with an ageing population.

Hearing loss is not confined to a geographic region, a socio economic grouping or a particular cultural or linguistic group. However it is well known that hearing loss is more prevalent in the Australian indigenous community, with Aboriginal and Torres Strait Islanders making up 3% of the Australian population, and having 3 times the incidence of hearing loss as the non indigenous population.

One of the challenges in developing systemic and effective responses for people who have a hearing loss, is that deafness is a low incidence disability with a significant geographic spread. These factors together with the diverse range of hearing loss

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[1] Access Economics report "*Listen hear! The Economic Impact and Cost of Hearing Loss in Australia." 2006*,

categories means that the service system needs to be flexible, portable, and responsive to individual needs.

The causes of hearing loss are numerous. Hearing loss may occur at birth due to genetic factors, or due to congenital reasons; in early childhood, hearing loss may be acquired childhood illness or disease; or hearing loss may be acquired later in life through accident, injury, disease, or through normal ageing processes. Noise induced hearing loss is also a major hazard for some occupational groupings.

The Access Economics report "*Listen hear! The Economic Impact and Cost of Hearing Loss in Australia." 2006*, notes the significant costs of hearing loss to the community.

- $6.7 billion dollars in lost earnings
- $3.2 billion in the cost of carers
- $1 billion lost from taxation revenue
- $674 million cost of direct health/ medical intervention including the fitting of hearing aids and cochlear implants
- $191 million cost in education, communication aids and support services.

From this distribution of costs, we see that the biggest cost of deafness is related to **lost productivity** that is we have failed to facilitate the productive working lives for deaf people. The implications of this are that we have excluded a very large proportion of this group of people from workforce participation.

This situation could be reversed if we take corrective action to ensure that the communication and participation needs of people with a hearing loss whether they rely on hearing aid technology, visual technologies or sign language are comprehensively and urgently addressed. Communication and language options need to be enabled from the earliest possible time in the life of the child. Ensuring timely early intervention, appropriate education, post school training and employment options is essential.

Recommendation : the Federal Government identify the strategies and the resources required to ensure the full participation of people with a hearing loss in early education, primary and secondary education, tertiary options and workplaces, as a means to enabling more productive and meaningful quality of life outcomes for these citizens .

6. The implications of hearing impairment for individuals and the community

The implications of a hearing loss for an individual and for the community are profound. For the individual, there is clear evidence of lower employment participation (financial disadvantage), reduced educational attainment levels, greater risks of mental health problems, less opportunity for participation in local community and lack of access to basic community services. For the community, there is both a financial and a social cost if we continue to overlook the rights of people with a hearing loss, that is their right to lead productive lives with similar access opportunities to their hearing peers. This social and economic cost is evidenced by the aforementioned Access Economics report.

Early language development

Many parents report concern about language and speech delays in their child's early years. Parents report the "pressure of choice" is unhelpful. That is the pressure to choose a singular communication option. Parents express regret that "either"/"or" choices were put to them.

For some children, cochlear implantation greatly assists speech and language development, for other children the outcomes are somewhat successful, and for some the implant is not at all successful.

The challenge that parents and ultimately the deaf child face immediately following diagnosis is that currently the early intervention system **demands** the parents to make a choice. This is because services are frequently established with only one communication methodology to offer. If this methodology fails the child, then many months may have been spent focussed on one methodology that is then determined does not suit the child. This outcome is detrimental to the child's cognitive and linguistic development as valuable time has been lost.

This is why some parents refer to the early invention service system and the as the "failure model". It has failure built into it. We can reverse this negative scenario by asking early intervention service providers to offer all communication options to babies/children from the beginning.

If this scenario was developed and embraced, the situation would be reversed. An early intervention system that enables the participation of the child and family in a range of language and communication options would eliminate the failure model.

Many parents express the desire to embrace all communication methodologies, that is to encourage speech development at the same time as learning sign language and encouraging a visual language base. Their view is that if one methodology fails after many months of input then the alternatives provide a safety net. Embracing all communication styles also means that the child will never be excluded from an opportunity to communicate and learn language.

This multi - lingual approach in the early years for children with a hearing loss is also supported in international research. For example: A study by Preisler, Tvingstedt & Ahistrom 2002[2] demonstrates the benefits of bilingual programs.

Parents also report pressure from some professionals who suggest that bilingualism may severely impair their child's use of the cochlear implant or their child's development of spoken language. For example families have reported being told not to use visual language until after they have trialled a cochlear implant and been through an extensive habilitation process.

For some families, this has led to tragic results with the child at age three with no language capability. The child at age three and family then endeavour to progress onto learning sign language. However, a three year language delay has been built into this child's life, a delay that will have significant ramifications in all areas of the child's future functioning and prospects. These qualitative examples need to be explored and understood by policy makers.

This does not need to happen in Australia. Many other countries have already addressed this issue by enabling all options from the point of early diagnosis of

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[2] Preisler,G,Tvingstedt,A-L,&Ahistrom ,m. (2002) A Psychosocial follow up of deaf preschool children using cochlear implants *Child Care Health and Development 28(5) 403-418*

hearing loss. There appears to be no scientific justification for a limited one communication only option for children with hearing loss (Dr Donald Moores[3] 2008)

Recommendation: There is a need for a new model of early intervention in Australia. Research should be undertaken into parents experience and models of service delivery that promote the best outcomes for the child. Particular attention needs to be given to international best practice and models of early intervention that do not promote failure or place choice limitation on the child's development and that promote a multi faceted communication approach.

Education Participation

Recent studies[4] indicate that deaf children continue to emerge from the education system with unacceptably low levels of numeracy and literacy and poorer prospects of employment than their hearing peers. The comparative school results from the Australian Curriculum Assessment and reporting Authority is a valuable instrument in relation to the education of deaf children.

In 2007-2008, Deaf Children Australia participated in the Victorian Government's Review of Deaf Education. A key issue emerging from the review concerned the challenge to improve the attainment levels of children with a hearing loss.

As part of this Statewide review, Deaf Children Australia surveyed 147 parents of children with a hearing loss and facilitated 8 focus groups throughout rural and metropolitan Victoria. Data collected from the survey and focus groups was thematically coded.

The key implications of hearing loss within an educational setting that emerged from this consultation process were:

- Lack of access to curriculum (ie non provision of interpreters, or captioned technology or hearing loops or soundfield technology)

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[3] Moores, D (2008) Editorial: Cochlear failures. *American Annals of the Deaf 153.pg 423-424*
[4] Blamey, Melbourne University 2001, more recently supported in the review of Deaf Education Victoria, 2008.

- Inadequate learning assessment tools ie the assessment processes did not take account of the impact of the child’s hearing loss on their capacity to learn in a classroom setting or identify appropriate support resources to enable the child’s learning. Assessment tools were more suited to assessing children with intellectual or physical disabilities.)

- Shortage of qualified teachers of the deaf, speech and language coordinators, educational audiologists, interpreters, note takers and support staff. This was particularly inadequate in rural areas.

- The participation of children in national benchmarking programs (NAPLAN).The assessment of deaf students’ literacy and numeracy against benchmarks, which set out minimum acceptable standards at a particular year level, was one of the issues frequently raised by parents. They recognised the importance of assessing deaf children’s’ progress in literacy and numeracy against benchmarks and many reported that their deaf child had been excluded from the benchmarking process.

Parents often say they fear the real reason their children are granted immunity [from national benchmark monitoring] is that the results will reveal deaf children are not achieving results comparable with those of their hearing peers

- Social and Emotional development: some parents reported concern about their child’s social development. The negative stigma of deafness remains in Australian society, and together with communication difficulties, fosters a culture which “shuts out” the child with a hearing loss. Some students seek to meet their social needs through interaction with the predominately hearing population. They accomplish this by attempting to conceal or minimise signs of deafness, thus ‘normalising’ themselves. Not enough is yet known about the potential impact of such behaviour on a deaf child’s psychological wellbeing and identity formation. Parental concern, however, is largely on those children for whom interaction with hearing peers has become problematic, with reports of bullying, exclusion and isolation increasing, as mainstreaming becomes a more popular option. The level of concern and reporting of incidents suggest that more investigation into the issue is warranted.

Recommendation: The Federal Government review the funding models for deaf education in each state. The aim of this funding model would be to ensure that every child with a hearing loss regardless of their location receives access to a quality curriculum and an educational setting that is socially inclusive. This would mean ensuring that the child has access via their choice of communication methodology, that is through hearing technologies, visual technologies and/or sign language and advanced information technology options.

Employment participation

As emphasised earlier in this document, language delay and low educational attainment levels set the scene and pathway for negative employment outcomes for people with a hearing loss.

A survey undertaken by the Victorian Council of the Deaf (VCOD 2007) reported that 27% of people with a hearing loss had left school at or before the age of 16; only 39% of the deaf people surveyed were in fulltime work, 24% were not working and approximately 30% were in part time or casual work.

These results are of great concern and improved measures must be taken to ensure the meaningful participation of people with a hearing loss in productive work.

To reverse this situation, we must address communication access at work places either through greater availability of Auslan interpreters, portable devices which enable captioning, real time captioning as well as the installation of looped systems and sound amplification in building design.

Recommendation: The Federal Government research the reasons for the low levels of participation of people with a hearing loss in meaningful employment and develop employment inclusive strategies for deaf people

Mental wellbeing

Deaf and hard of hearing people experience greater risks of mental health problems such as anxiety and depression as compared to the hearing population because:
_ they experience increased social isolation (due to communication difference) and emotional vulnerability, leading to higher risk of abuse;
_ they encounter linguistic and cultural barriers to access and participate in existing mental health services and programs;
_ there is a lack of knowledge within the mental health sector of deaf specific considerations; and a lack of knowledge and acceptance of mental health issues within the deaf sector, the general community and by individuals.

Recommendation: Consideration be given to the establishment of a National Strategy for Research and Information on Mental Health and Deafness

Community participation and access to government and civic services

Shut Out reports on the cost of failing to deliver access to people with disabilities. Without access to the community, people with a hearing loss become excluded from the mainstream, and their quality of life suffers greatly. We need to reverse this and celebrate social inclusion and diversity.

It would appear that exclusion of people with a hearing loss is implicitly accepted as part of Australian community life. For example : Federal state and local Governments continue to produce information on DVDs without captions, Parliaments meet without ongoing provision for interpreters and most mainstream community events are neither Auslan interpreted or captioned. Other examples include public transport systems failing to address the fact that people standing on the train platform may have a hearing loss and therefore not hear public announcements and cinemas not allowing the screening of captions. All of these are simple examples of the widespread community exclusion of people with a hearing loss. The exclusion of children, young people and adults with a hearing loss appears to be widely accepted and endemic.

Recommendation: The Federal Government provide funding for a national summit for a 2020 vision on the inclusion of Deaf and Hard of Hearing people in community life, to address the question: *what can be done to stop the current social exclusion of people with a hearing loss and what action can be taken to promote the social inclusion of people with hearing loos in all areas of daily living?*

7. The adequacy of access to hearing services, including assessment and support services, and hearing technologies

Australia is in the fortunate situation of having a range of hearing technologies available. However, access to hearing services is currently limited by location, family resources, ability to pay, cultural background and awareness of the options available.

Families of children report difficulties in accessing appropriate services, and also report concern at waiting times for assessments and repair of hearing technologies.

Parents of older children also report that at age 21, their child will need to self fund hearing aids. This is clearly unacceptable and disadvantages financially an already economically disadvantaged group.

Recommendation: The Government examine the inequity in service provision and identify strategies that would improve access to hearing technologies and reduce waiting times. In addition people over 21 years of age should be entitled to receive hearing aids at no cost to themselves.

In addition, access via captioned technology needs to be addressed as does access to interpreter services.

8. The adequacy of current hearing health and research programs, including education and awareness programs

The documentation provided above highlights the need for further research. In particular, we would propose that this involves undertaking research into improved early intervention service models and strategies for improving education and employment outcomes, as well as a more socially inclusive environment for people with a hearing loss.

Most particularly in order to advance the idea of social inclusion in planning more responsive systems, we urge the Senate to seek feedback directly from families. We suggest this approach because parents and young deaf people have first hand experience of dealing with the health, education and community service system.

Research into strategies for more inclusive community and government practices for people with a hearing loss requires urgent investigation. The outcome of such an investigation would be action to more broadly make available Auslan interpreting services, real time captioning, and visual and hearing technologies in public spaces.

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