



Canberra Deaf Children's Association

Submission to the Senate Inquiry into Hearing Health in Australia

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The Canberra Deaf Children's Association (CDCA) is a non-profit community organisation that endeavours to provide support and information to parents and families on issues affecting deaf and hearing-impaired children. This includes all sorts of hearing loss such as sensorineural, conductive, and unilateral. It includes the ACT and surrounding NSW regions.

We also provide information to other interested people in the community, teachers and students.

CDCA acts as a lobby group to relevant government departments and other organisations on behalf of deaf and hearing impaired children, their parents and their families.

The following represents a sample of some of the concerns of our members. We represent the views of parents of children with hearing loss.

Newborn Hearing screening

- We welcome Newborn hearing screening programs that identify hearing loss present at birth. This provides timely access to early intervention services which aim to improve outcomes in our children.
- Screening needs to be universal – testing rates are not consistent nationally
- Hearing loss may develop after birth. Public awareness and education needs to address this to encourage investigation of possible hearing loss at any stage of a child's development.
- The process of diagnosis of hearing loss in a newborn baby can be a traumatic experience for families. There is inconsistency in the type of support available for families during the transition from screening to diagnosis to early intervention and onwards.
- A diagnosis of hearing loss and subsequent aiding or implantation does not 'fix' a child's hearing loss. They need continuing support to learn to use the hearing they do have. There are many situations where hearing aids or implants are ineffective. Not all children will benefit from hearing devices so alternative options for communication will always be required.
- We acknowledge that each child and family will have different needs and all services need to have a family based focus.
- The diagnosis of hearing loss in the majority of our children is permanent and lifelong, and services should reflect this.
- Hearing loss may be progressive so the needs of an individual child or family can change over time.

Transition to Early Intervention Services

- The coordination of accessing services is often left up to families without adequate support and guidance. There seems to be a concern around influencing people's choices about early intervention so services are not 'allowed' to refer families directly themselves – this may lead to some families not being aware of their choices whether due to lack of information, bias or in some cases, lack of motivation. Options to address this include parent mentoring programs and providing specifically trained counsellors that are able to provide all options in an unbiased manner.
- The main hearing loss support services for kids for example SCIC (Sydney Cochlear Implant Centre) and the Shepherd Centre providing early intervention, audiology, therapy and community support - are in the main privately funded. If the economic down turn had been more severe, a lot of children could have been without support.
- Access to services and support in rural and regional areas: There is not enough Government support of the early needs associated with hearing loss. This is particularly the case with country areas that are low income areas. The carers allowance will cover certain approved trips but other issues of support that we in the city take for granted such as Shepherd Centre play groups and parent support meetings etc are not covered.
- Access to Carers Allowance has improved however there are families who do as much care involved in a child with a hearing loss but miss out because of a few decibels.
- Access to Carers Allowance for regional families should be made available immediately on diagnosis for any degree of hearing loss – this would assist families to access the services that are required including travel.
- Many services such as speech therapy or occupational therapy that are available from ACT are not available to regional NSW residents. This would need a National policy that support services are delivered regardless of residency. This would possibly also apply in other cross border situations.
- Children with unilateral or conductive hearing loss may develop delays in speech and language. Without a hearing device, many of these children don't have access to early intervention services such as itinerant teachers of the deaf or The Shepherd centre. This defeats the purpose of early intervention – there are extremely long waiting times to access public speech therapy and this is after a problem develops rather than a preventative approach.

Preschool

- As per the findings of the Vinson Report into Preschool Education, there are many special needs (hearing impaired) and indigenous children missing out on a Preschool education and early intervention programs. NSW is the worst state affected by this with an identified need for an additional 10,500 places to cover the state. We reinforce the findings of this report and suggest that the recommendations put forward be implemented to provide access and affordability to hearing impaired children. As reported a \$1.00 investment can have a return of up to \$17.00 for the child, their family and society.

Transition to School

- Once early intervention is completed and school starts, many children still require additional services such as speech therapy. There are extremely long waiting times for public as well as private speech therapy.
- We acknowledge the value of the current Review of Special Education Services in ACT Public Schools. This type of review should be done on a national basis to provide a nationally consistent standard.
- There is no equity in choices for education. For example, catholic compared to public education system. A possible solution would be to have itinerant support for hearing impaired children through additional services provided by Australian Hearing or a separate body regardless of choice of school.
- Main stream school integration gives the child the opportunity to become a productive member of society. The support in the schools for inclusion and training for staff to support the integration is non existent. This needs training for all teaching staff and regular reinforcement of the qualifications and values so these children can be as much as possible productive (i.e. less burden in their adult lives) as the goal is intended. At the present it appears that main stream inclusion is to lessen the burden on current special needs support thus making a longer term issue.
- There is a concern from many parents with the trend for open plan classrooms which are not acoustically friendly. All teaching environments should be designed with consideration for the acoustic needs of hearing impaired children.

Teenage Years

- A significant issue facing our children is the teen years. This is where the support is lacking and most needed to address emotional and peer pressures that face a developing adult. This comes back to inclusion and acceptance being fostered in the early years of school.
- There is a concern with the use of current entertainment technology such as personal stereos and the subsequent damage to hearing of those individuals. There is a need for a national hearing prevention strategy to prevent noise induced hearing loss.
- We acknowledge there are many other issues facing teenagers with hearing loss that we are unable to address due to the lack of involvement in our services.

Australian Hearing Services

- Currently Australian Hearing services and technology are available to our children until age 21 years. Australian Hearing is a fantastic service. To have a national service that no matter where in the country you have an issue with hearing aids or hearing loss you can deal with the same organisation is great. This needs to be expanded to provide additional services. For example, regional Australian Hearing offices could also be an access point for early intervention services.
- Australian Hearing should be expanded to provide services for all hearing impaired Australians thus relieving the financial burden of hearing loss and deafness.

- It can be hard to get clear information about what is available from Australian Hearing - which hearing aids are on the free list, and which on the top-up as an example. A regular newsletter to clients of Australian Hearing would improve communication in this regard.
- Some technology available continues to be inaccessible to parents. For example, some children who are unable to use conventional hearing aids may benefit from a bone anchored hearing aid (BAHA). A soft band BAHA has been trialed by parents with positive results but they are currently unable to access them through Australian Hearing. Private purchase is out of reach of most families.

Over 21 years old

- We are concerned for the financial cost our children will be expected to meet once they turn 21 years old.
- Adults with hearing loss have to fund their own hearing aids. An adult may require upgrading of hearing aids every 5 or so years. It is not uncommon for adults to pay up to \$10,000 for hearing aids and an FM system to help them function more effectively at work – work place designs and meeting venues are not always acoustically friendly. Many are forced to take out personal loans to pay for the ability to function at home and work. These costs need to be addressed if the government wants our children to be fully integrated into main stream society.
- Ongoing costs include batteries, ear moulds, audiological services, repairs, and assisted hearing devices such as loop systems in the home to hear televisions. Other costs include special telephones or telecommunications to enable communication with family and friends.
- Cochlear implants have similar ongoing costs.
- Private health funds do not cover anywhere near the cost of hearing devices and people are required to pay top cover for that. There is no adequate insurance that covers broken, lost or stolen devices.
- It is essential that those with hearing loss have access to quality hearing devices. This will assist adults with hearing loss to be productive members of society as well as being socially active adults
- Captioning and loop systems are not consistently available – this isolates many deaf adults. For example, the new free to air ‘GO’ television programs do not have captioning. Another example, the ‘Hey hey it’s Saturday’ reunion shows also didn’t have captioning.
- For over 21 year olds, audiologist services should be available on Medicare. A basic level of hearing aid should be available for claiming on Medicare with an option for upgrades for hearing aids and FM systems to allow for individual needs.
- Other options include continuing services to those after 21 that have previously used Australian Hearing especially if students, or on a low income and for others to have all hearing related expenses to be fully tax deductible.

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