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8th October 2009

Elton Humphery
Committee Secretary
Senate Community Affairs References Committee
PO Box 6100
Parliament House
Canberra ACT 2600

Dear Mr Humphery

Re: The Senate Inquiry into Hearing Health in Australia

The North Shore Deaf Children's Association (NSDCA) is a support group for parents and families of children who are deaf or hearing impaired. The NSDCA has been an advocate on behalf of deaf children for over 40 years. Our members' children range in age from 0-21 years.

Our submission relates to the following terms of reference:
b) the implications of hearing impairment for individuals and the community;
c) the adequacy of access to hearing services, including assessment and support services, and hearing technologies;

Throughout this submission, the term "deaf" is used to mean all types and levels of deafness.

We would like to address these issues from a parent perspective:

- Newborn screening for hearing
- Early Intervention
- The effect of deafness on the family
- Hearing services for people over 21 years

Newborn hearing screening

Parent groups in Australia, including the North Shore Deaf Children's Association have been advocating for the introduction of newborn screening for hearing since the mid 1990's. There is now worldwide recognition of the importance of early detection and appropriate management of hearing loss, particularly in young children. Thanks to our Prime Minister's announcement in June this year, the universal newborn screening test for hearing offered in NSW, Queensland and parts of Victoria will become available in all other states by 2011. Newborn screening was not available to many of our members when their children were born. We welcome this initiative which has the potential to allow young deaf children to develop language skills that are age appropriate and to go on to become fully integrated members of the community.

However, early detection of hearing loss is only the beginning of the journey for our children. High quality support, which includes accurate, reliable and unbiased information, family counseling, and parent-to-parent support, must also be built in to the framework of any newborn screening program.

Recommendations:

1. NSDCA calls on the federal government to ensure that all newborn babies in Australia have access to the screen, regardless of where they live or their cultural background.

2. Families whose babies are identified with hearing loss through a newborn screening program must have access to appropriate support services until they are enrolled in a suitable early learning program.

3. NSDCA recommends that parents should be "at the table" during the design, management and evaluation of all hearing services (including newborn screening), to ensure that programs can deliver optimum outcomes for families, as well as effective support services.

Early Intervention

Our children need early and exemplary audition together with appropriate early learning programs to allow them to achieve their optimum language and educational potential, irrespective of the level of their hearing loss. High quality audiological management, including the timely selection and fitting of hearing aids and/or a cochlear implant, is essential.

Australian Hearing currently provides a level of expertise in audiological services that is world class. These services include: -

- Audiologists and ancillary staff who are trained to work with children, particularly with those who are pre-lingually deaf.
- Provision of reliable hearing testing and fitting of the most appropriate aids.
- Supply of well-fitting ear moulds, to enable the aids to operate without distorting sound.
- Same day repair service - for anyone (child or adult) to be able to function in everyday life it is important that he/she is not without hearing aids for more than a few hours.

In addition to audiological support, families need access to convenient, family-centred early learning services. These services must provide high quality professional support and programs that meet the needs of the individual child and family. Services should also include babies with unilateral hearing loss, many of whom go on to develop bilateral loss.

Some families have children with additional needs. Allied health services, such as speech therapy, physiotherapy and occupational therapy can be very expensive. One of our members gives an example of a recent course of speech therapy for her 7 year old son, "*We had to pay $300 for the initial consultation, and 12 follow-up sessions at $80 each*." Allied health services only attract a Medicare rebate under limited conditions. Low income families may not be able to afford private health insurance and only those with top extras cover are eligible to claim a refund for allied health services.

Recommendations:

1. Australian Hearing should continue to be the primary provider of hearing services for children under 21 years who have permanent hearing loss. In addition, the cost of hearing aids, moulds, batteries and repairs should continue to be fully funded.

2. NSDCA recommends the development of national standards for Early Intervention services and that parents participate during each phase of the development of such standards.

3. A review into the way that allied health services are provided to people with disabilities under the Medicare system should be undertaken.

The impact of deafness on the family

Discovering your child has a hearing loss is a devastating experience for every parent. Approximately 90% of children with a hearing loss are born to hearing parents with little or no experience of deafness. "Welcome to Holland" is a well known essay by Emily Perl Kingsley which many disability groups use as an introduction to new parents who have recently had a child diagnosed with a disability (copy attached).

This section of the submission aims to impart some of the issues that families need to consider after their child is diagnosed with permanent hearing loss. Deafness permeates all aspects of daily family life, in areas such as family and social relationships, child care, education, sport, and finances. We have listed some of the common challenges that many parents face in raising a child with a hearing loss. The points are intended to provide an overview and are in no particular order.

<u>Challenges in the early months</u>

- Coping with emotional aspects of hearing loss (e.g. feelings of grief, anger and guilt)
- Developing ways to communicate with their baby
- Impact on other family members (e.g. siblings, grandparents)
- Obtaining reliable, up-to-date and unbiased information to enable realistic choices
- Juggling numerous appointments - medical, audiological, early intervention, allied health
- Learning to understand the jargon of hearing loss (e.g. audiograms, dB, oral/aural, amplification, risk factors, otitis, Auslan, etc)
- Hearing-aid management - inserting and cleaning ear moulds, keeping the aids in position, monitoring hearing aid function
- Choosing interventions that will best suit their child and their family
- Finding appropriate intervention services
- Financial concerns, especially if a parent chooses to delay re-entry into the work force
- For approximately10% of families, exploring the pros and cons of cochlear implantation

<u>Challenges in the ensuing years</u>

- Helping their child to learn to communicate effectively
    - listening and speaking
    - and/or using sign language
- Sourcing reliable, up-to-date and unbiased information to enable realistic choices
- Maintaining strong and positive family relationships
    - Partner
    - Siblings
    - Extended family
- Deciding if/when to have another child
- Deciding which educational setting is best
    - Should he/she attend the same school as their siblings?
    - Mainstream education or specialised hearing unit?
    - What support is available?
    - How do we access support?
- Managing the emotional aspects of hearing loss as they ebb and flow throughout childhood, for both the child and the parents (many parents report the re-emergence of feelings of grief at key milestones during their child's life.)
- Access to support services such as family counseling, parent groups, deaf community
- Helping their child develop peer support and friendships that are important for social and emotional development
- Social isolation and sometimes bullying

- Cost of assistive listening devices such as FM's, specialised alarms, home loop systems
- Cost and access to allied health services, such as speech therapy
- Learning to become a confident advocate for your child
- Helping the child develop an appropriate level of independence
- Transition to high school
- Changing service providers
- Coping with a deaf teenager
- Teaching the child to learn how to manage their own hearing loss
- Maintaining access to services and upgrading technology (Governments and other service providers are always looking for ways to cut costs. Whilst understanding that monetary constraints are necessary, parents must be ever vigilant to ensure the needs of their children are being met.).

<u>Questions as our children become young adults</u>

- How will my deaf child cope in increasingly complex social situations?
- What support is available during post-school education and in the work place?
- How does my child access this support?
- Are there training programs in our local area for young people with hearing loss to prepare them for the work force? How do we access such programs?
- Should we continue to provide financial assistance for his/her hearing needs? How long are we prepared/able to continue with this assistance?
- Impact of deafness on a young adult, will they "pass on" their hearing loss to their children?

Families who have a deaf child experience many of the same successes and challenges as other families. However, every child and every family is different. As their choices and experiences will be individual, the level and types of support will also vary.

<u>All</u> parents want the best outcomes for their children. Our aim is to ensure our deaf children can grow into happy, well adjusted and financially independent young adults who are fully integrated in the wider community.

Hearing services and technology for people over 21 years

In Australia, we are fortunate that government provides newborn screening, early intervention and quality education programs for all our children. Children who are deaf or hearing impaired also have access to government funded hearing services. Parents see this as an investment, not only in their children's future but also the future of the Australian economy.

From a very young age, our children are encouraged to use their hearing devices at all times. They quickly become reliant on technology to help them communicate in a primarily hearing world. Throughout childhood they use these aids to learn and to develop the skills they need to become fully productive members of the community. A number of young deaf people remain in the education system beyond their 21st birthday. Why is it then, that access to essential hearing services and hearing devices is withdrawn at the time when young people are working hard to achieve independence and to gain employment?

Access to Australian Hearing services ceases for most child clients when they turn 21. The range of services and audiological expertise for deaf people with congenital hearing loss is not readily available outside of Australian Hearing, especially in country areas. Private audiologists are more accustomed to dealing with people who have acquired deafness or who have lost hearing due to age. Some private providers must fit hearing aids manufactured by their parent company; this may not necessarily be the aid of choice or the most appropriate aid for the client.

A related issue of concern to young deaf people is finding affordable private health insurance. Products differ from fund to fund so you cannot compare apples with apples. It is very difficult to find a suitable plan which includes cover for hearing aids & audiology services. These features are only available under top of the range products, with correspondently top price premiums. In general, funds do not allow for top extras cover in packages aimed at young people. Waiting periods range from 2-3 years before a claim for a hearing-aid can be lodged. This means young people must plan their health cover carefully, before they turn 21years. Extras cover costs approximately $720 -780 per year. Benefits range from fund to fund. For instance, HCF provides $600 per year per person, while MBF provides $1,000 per hearing aid, with a maximum of 2 hearing aids every 3 years. This means that even with the maximum return from the fund, it costs more over a 3 year period than the claimable benefit.

The current federal government espouses a policy of social inclusion. In a joint press release last month, Mark Habib and Bill Shorten stated, “Providing fulfilling work and economic independence for people with disability was a key to improving their inclusion in the community. There is no doubt that people with disability want to work, and can make a big contribution to businesses. We need to ensure that we remove the barriers and negative attitudes facing people with disability who want to work, and recognise their potential rather than their impairments.” For young deaf people, this cannot be achieved without continuing access to affordable hearing devices and appropriate hearing services, particularly through the years of tertiary education and early employment.

The provision of hearing aids, cochlear implants and associated audiology services is an essential health service. Whilst at first glance it may seem expensive to provide this level of support, the cost of not providing these services is far greater. People who are prevented from finding and maintaining employment because they cannot afford to pay for vital hearing devices are likely to end up being socially isolated and welfare dependant. Providing this assistance will result in far better outcomes not only for the people concerned, but also the wider community, in terms of financial, social and mental health well-being.

Recommendations:

1. Access to Australian Hearing services should be made available to all former child clients who wish to continue with Australian Hearing as their service provider.

2. Hearing services for people over 21 years who were child clients of Australian Hearing could be provided under a voucher system, similar to the one currently available to aged pensioners. The scheme should allow people to attend an approved service provider of their choice and should include audiological assessment and fitting of hearing devices.

3. Tax concessions should apply to assistive listening devices such as FM systems, specialised alarms and telecommunication equipment, and home loop systems.

Thank you for the opportunity to participate in this enquiry.

Sue Rayner

Secretary of the North Shore Deaf Children’s Association

WELCOME TO HOLLAND

by

Emily Perl Kingsley.

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this......

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.