SUBMISSION TO THE SENATE INQUIRY

INTO

HEARING HEALTH IN AUSTRALIA

ANZPOD
a coalition of parents of deaf children
across Australia

October 2009

ANZPOD represents families of children who are deaf or hearing impaired around Australia. Members of the group are all parents of deaf or hearing impaired children and represent most of the major parent organisations within Australia. The group is a loose collaboration of parents who wish to make a difference for the parents following in our footsteps. Participation is entirely voluntary and we receive no funding. Our children range in age from 1 to 21 years of age.

The initial focus of this group was to ensure parents of deaf and hearing impaired children have a voice in the development of the National Standards for Newborn Hearing Screening. However ANZPOD also aims to ensure parents of deaf and hearing impaired children have a voice in the development of policy initiatives such as those that may arise as a result of the Hearing Health in Australia inquiry by the Senate Community Affairs Committee.

ANZPOD's submission relates directly to the terms of reference as provided by the Senate Community Affairs Committee.

Within these terms of reference, we seek to address two main areas:

- Universal newborn hearing screening in Australia
- Access to hearing services and technology for all Australians but in particular our children when they turn 21.

In addition, we have briefly addressed the following issues:

- Noise-induced hearing loss
- Employment
- Captions

1. THE EXTENT, CAUSES AND COSTS OF HEARING IMPAIRMENT IN AUSTRALIA

1.1. The extent

Currently one in six Australians has some form of hearing impairment. Data provided by the 2006 Access Economics Report “Listen Hear! The Economic Impact and Cost of Hearing Loss in Australia” forecasts this figure will rise to one in four Australians by 2050.[1] Each of these Australians with hearing loss, does not exist in a vacuum but is part of a wider family unit. Figures that look at relative costs of hearing impairment relate mostly to the individual with the loss only and not at the whole family. So while the extent of hearing loss itself is currently at one in six, the extent of the impact of that individual’s hearing loss is much wider.

There is an increasing prevalence of hearing loss with age and this is true for children as well. Australian Hearing reports “In Australia, between 9 and 12 children per 10,000 live births will be born with a moderate or greater hearing loss in both ears and around a further 23 children per 10,000 will acquire a hearing impairment that requires hearing aids by the age of 17 through accident, illness or other causes.” [2]

1.2. Causes

Hearing loss in children can be congenital or acquired. Congenital causes can be genetic or non-genetic in origin. Acquired hearing loss occurs after birth and is usually associated with illness, such as meningitis, recurrent ear infections or injury. Increasingly, young people are exposing themselves to the significant and preventable risk of developing hearing loss from the use of portable stereo players (PSP).

Hearing loss can be sensorineural or conductive in nature. Most children born with a hearing loss have a sensorineural hearing loss as a result of damage to the inner ear or the nerve pathways to the brain. Sensorineural hearing loss is permanent.

Children can also suffer from conductive hearing loss which occurs when sound is not transmitted efficiently through the outer or middle ear.

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[1] *Listen Hear! The Economic Impact and Cost of Hearing Loss in Australia*. (2006). Access Economics. Retrieved 07/10/09 from http://www.accesseconomics.com.au/publicationsreports/getreport.php?report=71&id=81

[2] *Hearing loss in Australia - it’s more common than you think*. Australian Hearing. Retrieved 7/10/2009 from http://www.hearing.com.au/upload/media-room/Hearing-loss-in-Australia.pdf

Conductive hearing loss can often be medically or surgically treated. A significant number of children suffer from conductive losses, often as a result of otitis media. It should be noted that chronic otitis media is a significant issue in the Aboriginal and Torres Strait Islander populations and often times a major cause of hearing loss in these communities.

1.3. Costs

The financial burden of hearing loss has been well documented by the Access Economics in their 2006 report – costs largely attributed to lost productivity in the adult years.

Families receive financial assistance for their child with a hearing loss through:

- **Hearing services**
  Hearing services for children under 21 are well supported by the federal government. Our children have access to a full range of hearing services through Australian Hearing until age 21. This system uses technology, such as hearing-aids, that enables our children to use their residual hearing and assist them to develop speech and language skills.

- **Carer Allowance**
  Most families rely on financial assistance provided by government, such as the Carer Allowance and Child Disability Allowance, to help meet the additional costs of raising a child with a hearing loss. Although these allowances do not come close to covering all the relevant expenditure, ANZPOD welcomes this support and recommends that it should continue.

The financial costs of living with lifelong deafness are enormous – hearing aids and cochlear implants are high-end technology and are, therefore, very expensive. Added to this are the costs of necessary devices such as FM systems and specialised alarm systems – smoke detectors, doorbells, alarm clocks etc. None of these attract tax-deductibility status nor are there any subsidies available despite the fact they are essential for ‘normal’ day-to-day living.

Some children require services from Allied Health providers, for example, speech pathology, physiotherapy and occupational therapy, to help manage their hearing loss. These families may be eligible for Medicare rebates for these services, however, rebates are limited to a total of five Allied Health services per calendar year. Families may also recoup a small percentage of the fee from private health insurance.

The hidden cost with respect to hearing impairment is hard to quantify. The ability to communicate is the very essence of being. Poor communication skills very often means poor literacy and numeracy skills, poor educational achievements, poor employment prospects, limited income, social exclusion and a high incidence of mental and physical health issues.

2. IMPLICATIONS OF HEARING IMPAIRMENT ON INDIVIDUALS AND THE COMMUNITY

2.1. Individual implications

For the vast majority of deaf and hearing impaired children, the ability to communicate is solely dependent on the use of hearing augmentation devices – hearing aids and cochlear implants. Life without these devices is impossible. Education, social interaction, sport, daily life in general – all that the 'normal' hearing world takes for granted – becomes almost impossible for our deaf and hearing impaired children if their hearing aids or implants are not working properly or are missing. These devices represent an essential part of their 'being'. They are excellent users of their state-funded devices – their hearing aids do not end up in drawers unused.

Our children are fortunate to have access to hearing health services until age 21 through Australian Hearing. The present system (world's best practice) sets out to provide our children with the opportunities to be become fully functioning and contributing members of society only to trip them up at the final hurdle. Once they turn 21, this service is no longer available to them. Newborn hearing screening and free access to hearing services, hearing aids, cochlear implants and other assistive devices means that our children grow and learn in an environment where they are dependent on technology. At 21, many of them are still studying or starting out in the workforce, and they are faced with the prospect of having to find appropriate audiological services who understand congenital hearing loss and also fund the purchase of private health insurance, hearing aids and cochlear implants.

One of the members of ANZPOD cites her own personal story:
"I have 5 children all of whom have been afforded the same educational and social opportunities. They have all attended university and have

opted for different career paths. My deaf 21 year old son, however, must always factor extra ‘disability’ costs into his life – he must always have funds available for regular audiological and ENT assessment, hearing aid maintenance and replacement, hearing aid batteries and essential safety devices. It will always cost him more than his siblings to live and work ‘normally’”.

ANZPOD member, Jo Quayle, voiced the concern of parents and young adults alike at the 5th National Deafness Sector Summit in 2008, “Productivity and social inclusion for young deaf and hearing impaired people can’t happen if they can’t afford to replace or repair their hearing aids.”

2.2. Community implications

As parents of deaf children, we are very aware of the economic, educational and social effects of hearing loss. With increasing numbers of children being diagnosed as newborns and intervention provided at a younger age, we are encouraging these children to communicate and interact with the use of technology in the form of hearing aids, cochlear implants and other assistive devices. These individuals form their identity while wearing fully supported technology until age 21 when they become ineligible as previously highlighted.

Hearing aids and cochlear implant speech processors are extremely expensive and they do not have lifetime guarantees. They break down and need to be repaired and ultimately need to be replaced. At the age of 21 there are not many who can afford maintenance expenses of this magnitude. Some are still students, some have had only limited years in the workforce – if their devices break down or fail completely, their capacity to afford repairs and/or replacement is severely limited. Without these devices, it is almost impossible to study or work and therefore the capacity to earn the funds to repair/replace the devices let alone to provide for all other living expenses is almost non-existent. We also know of many individuals who are only able to afford one hearing aid, which is not adequate for their hearing needs. Where is the social justice ideal of equity of access for all when individuals are forced to make do with only one hearing aid because they cannot afford a second one?

The social costs of living with lifelong deafness are immeasurable – social isolation, limited access to captioned television, movies, public broadcasts (especially emergency broadcasts) just to name a few. If our deaf and hearing impaired children cannot afford the costs of repair/ maintenance to their devices then the social costs are compounded. Ultimately the cost to the community at large is enormous – rather than independent, tax-paying contributors to society, they become social welfare recipients.

Hearing impacts on the whole family not just the individual with the loss. There is a higher level of marriage breakdown where parents are dealing with the emotional and financial implications of raising a child with a disability. Similarly siblings of children with a hearing loss often resent the extra time and attention provided to their sibling which can lead to behavioural issues. The family as a whole needs to be supported throughout the journey with access to appropriate counselling at any point in time being a priority for families. This issue will be further discussed in terms of reference 3.2 - "Adequacy of access to assessment and support services".

3. THE ADEQUACY OF ACCESS TO HEARING SERVICES

3.1. Adequacy of access to hearing services and hearing technology

As previously noted there are issues of access to hearing services for children who have been supported through Australian Hearing from diagnosis until they turn 21. After turning 21 they cease to be eligible to access this service.

There are two main issues for our children when they turn 21:

3.1.1. Finding appropriately trained audiologist

Our children need to find an audiologist in the private sector who understands the issues of congenital deafness and has the knowledge and skills in the complexities of their needs. Most private audiologists are experienced in acquired hearing loss and the appropriate audiologist is almost impossible for our children to find.

An additional problem is that many private hearing clinics are staffed by audiometrists who are not university trained and do not understand congenital hearing loss. We are concerned that uninformed young adults may receive advice from these clinics which is inappropriate and potentially costly for our children.

3.1.2. Cost of ongoing technology needs

- **Hearing aids** – these costs around $3,000 each. Most of our children wear two hearing aids. A rebate is available from private health insurance but is only available on the extra cover and goes no way near meeting the cost of the hearing aids. Membership of a health insurance fund is also income-dependent – students and low-income earners are the least likely to be members of Health Insurance funds. Regardless of this, the rebate for hearing aids and speech processors is extremely small and is no incentive to join a fund.

- **Ear moulds** – hearing aids attach to ear moulds which fit into the ear canal. These need to fit well, otherwise the hearing aid produces feedback which is unpleasant for everybody. Ear moulds also deteriorate over time. The cost of replacing an ear mould is between $75 and $150.

- **Hearing aid batteries** - batteries cost around $1 each and last approximately two weeks.

- **Repairs** – this depends on the nature of the repair but can be several hundred dollars.

- **Cochlear implants** – Implantees with private health insurance can claim an upgrade on their processor but those without private insurance will need $8000 for a single processor. Many of our children now have two cochlear implants. We understand that two thirds of adult implantees are not privately insured.

- **Cochlear implant batteries** – each processor requires three heavy duty batteries which last 2 days. This is a cost of around $60 per processor per month.

As one of our members highlights:
"Of course we all know this one but for my daughter – 1 implant 1 hearing aid = $16,000 plus FM=$1,000 + batteries $500 so at 21 she will require (on today's rates) a job which give her approx $6,000 a year to maintain her battery addiction, and be able to put away money to upgrade in 3 years. That's without any technology issues that require servicing and a fee for that. All of this is without having a life.... Study, work and social life would all be affected."

In the United Kingdom, the National Health Service (NHS) provides hearing aids at no cost to those that require them . "NHS hearing aids, new earmoulds, tubing, batteries and repairs are free. On average, they last about five years. If you lose your hearing aid or damage it, you may be asked to pay towards the cost of repairing or replacing it." [3]

Currently audiological services are not available on the Medical Benefits Schedule. Medicare rebates for such services would assist in the financial costs associated with lifelong deafness.

Recommendations for former child clients of Australian Hearing

Preferred option

All former child clients of Australian Hearing over the age of 21 continue to be included in their Adult Eligibility list. This could be done via a voucher system where the individual could choose their provider of choice and receive their hearing aid at no cost, in the way that pensioners currently are entitled to a voucher to cover the costs of purchasing hearing aids. Vouchers should cover the cost of the aids which includes features that are clinically warranted for that individual – not just one model fits all. Individuals can choose to top-up aids with additional features if they wish and pay the gap. Similarly cochlear implant upgrades and repairs could also be funded under a voucher system.

Second option

All former child clients of Australian Hearing over the age of 21 be permitted to continue to be serviced by Australian Hearing until they reach a certain income threshold. For those young adults who also have HECS repayments, this threshold may need to be adjusted upwards to ensure an appropriate living wage.

Third option

Tax rebates on hearing services, hearing aids, cochlear implants and assistive listening devices. Assistive listening devices such as FM's, flashing door/smoke alarms, home loop systems etc should be tax deductible for all age groups. Parents should be able to claim for dependants.

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[3] *How do I get a hearing aid through NHS?* NHS Choices. retrieved 07/10/09 from http://217.64.234.89/chq/Pages/894.aspx?CategoryID=68&SubCategoryID=157

3.2. Adequacy of access to assessment and support services

The Prime Minister recently announced the introduction of universal newborn hearing screening throughout Australia by 2011. Newborn Hearing Screening is an initiative whole-heartedly supported by parents. The potential for improved outcomes for our children in terms of language development and the flow-on effects for education and socio-emotional development is an exciting and welcome prospect.

As parents of deaf and hearing impaired children, we want to ensure that newborn screening programs meet the needs of all families throughout the country, irrespective of the extent of the child's hearing loss, their geographic location or their ethnicity. We believe that current early diagnosis and referral services do not acknowledge the parent expert and do not fully reflect families' needs.

In July 2009, we outlined our vision for newborn hearing screening programs in a document titled "Quality Standards for Newborn Hearing Screening Services – supporting families" which is attached.

In brief, we believe that newborn hearing screening programs will meet the needs of families and improve outcomes for our children if:

- While acknowledging the important role played by professionals, parents need to be an integral part of the planning and decision-making stages of program development. Development of services should be the result of parent-professional partnerships.
- All babies in Australia have access to newborn hearing screening which is timely and minimises stress and disruption to the family
- The choices made by families need to be informed, meet the needs of the child and family and reflect their desires, beliefs and values. This requires accurate, reliable and unbiased information and appropriately trained professionals who support the notion of informed choice for families.
- Parents need family-friendly services which empower families and help them develop new strengths and competencies which meet the ongoing needs of their growing child.

Recommendations for universal newborn hearing screening

These are outlined in the attached document "Quality Standards for Newborn Hearing Screening Services – supporting families."

Assessment of hearing loss is only the first step; it is the intervention program that follows that makes the difference in the life of the child with a hearing loss. Intervention includes a range of services such as audiological, family, early learning and medical support. As part of any newborn screening program, there needs to be high quality, evidence based, early intervention programs that are available to all families on an individual needs basis. Empowering parents by providing them with information about all possible educational methodologies means little, if those same programs are not readily available. Early intervention services must provide personnel that have both the training and expertise to be able to deliver the program and ensure satisfactory outcomes for families.

When families first learn of their child's hearing loss, it can be a very difficult and emotional time. At that point, families need access to a range of support services, including meeting other parents who have children with a hearing loss, meeting Deaf and hearing impaired adults, and access to counselling services. Parents and families all cope in different ways with the diagnosis of a child with a hearing loss and as such counselling services need to accommodate those differences. Families need to be able to access counseling services at any point in the journey, not just in the early years.

4. ADEQUACY OF CURRENT HEARING HEALTH AND RESEARCH PROGRAMS

For many parents it is a difficult decision to choose specific interventions. This is in part due to a lack of detailed and easily accessible information that relates to outcomes demonstrated by specific intervention methodologies. Research into educational approaches and their outcomes is an area that needs further investigation.

ANZPOD awaits with interest the outcomes of the Longitudinal Outcomes of Children with Hearing Impairment (LOCHI) study currently being conducted by the research arm of Australian Hearing - National Acoustic Laboratories. [4]

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[4] Further information on the study, which began in 2005, can be found at www.outcomes.nal.gov.au

5. ADDITIONAL POINTS FOR CONSIDERATION

The major focus of ANZPOD's submission has been across two main areas that we feel most strongly about as parents of deaf and hearing impaired children. However, there are others areas that we believe also need to be a focus of the Senate Committee Inquiry and would like to briefly make reference to them here.

5.1. Noise induced hearing loss

Hearing loss can also be acquired later in life. We believe that for over one third of people with hearing loss, excessive noise is responsible for at least part of this loss. Excessive noise is present in many situations. Some of the more common sources include industrial machinery, nightclubs, movie theatres, lawn mowers, low flying jet aircraft and loud impulse noise, such as an explosion or gunfire. The effects of excessive noise on hearing are permanent.

Most developed countries, including Australia, have Occupational Health & Safety legislation designed to protect hearing in the work place. However, in some industries such as farming, hearing protection regulations are difficult to enforce. Furthermore, there seems to be little awareness in the general community of the risks associated with recreational noise, particularly amongst children and young adults. The "it won't happen to me" attitude prevails.

As parents of deaf children, we are very aware of the economic, educational and social impacts of hearing loss. We are particularly concerned at the number of young people who are exposing themselves to the significant and preventable risk of developing hearing loss from the use of portable stereo players (PSP).

In recent years sales of personal music players, which include mobile phones with such functions, have soared. The risk of noise induced hearing loss increases when PSP are used in environments where users raise the listening level to mask out background noise, such as on public transport.

There is ample scientific evidence that regular exposure to noise intensity above a level of 85 decibels (dB), can permanently damage hearing. For some people, hearing damage occurs at 75dB. The maximum volume setting on some personal music players can generate up to about 120dB, the equivalent of an airplane taking off nearby. According to a European Commission report in October 2008, around 10 percent of listeners risk permanent hearing loss or damage by listening to loud music every day for five years.[5]

In recent weeks, the European Commission ordered all makers of portable music players to add a default volume setting of around 80dB and a health warning to all new devices within the next two years. The new standard default setting on devices will not prevent users from overriding the default settings and pumping up the volume, but there will be clear warnings so they know the risks they are taking. The EC is also calling on standards bodies to change industry wide technical safety standards for other mobile devices to include the 80dB default setting.[6]

Recommendation for noise-induced hearing loss

ANZPOD recommendation is that the federal government introduces similar regulations in Australia.

5.2. Employment

An issue that effects both our children as they get older and adults with acquired hearing loss, is gaining employment. Employment levels are lower in those with hearing loss than their hearing counterparts. Part of this is the result of employers being wary or unsure of the implications of employing someone with a hearing loss.

The federal government funds a workplace modification scheme which is run through JobAccess. This scheme "aims to make accommodating employees with disability in the workplace easier."[7] Employers must employ a person with disability for at least eight hours a week in a job that is expected to last for at least three months and employees have to meet the eligibility criteria.

The information provided on the JobAccess website is very employer orientated. However the deaf person has to first secure a job. Employers

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[5] *Scientist warn of health risks from exposure to noise from personal music players.* (2008). Europa. Retrieved 07/10/09 from http://europa.eu/rapid/pressReleasesAction.do?reference=IP/08/1492&format=HTML&aged=0&language=EN&guiLanguage=en

[6] *Consumers: EU acts to limit health risks from exposure to noise from personal music players.* (2009). Europa. Retrieved 07/10/09 from http://europa.eu/rapid/pressReleasesAction.do?reference=IP/09/1364&format=HTML&aged=0&language=EN&guiLanguage=en

[7] *Workplace modifications.* JobAccess, Australian Government. Retrieved 07/10/09 from http://www.jobaccess.gov.au/JOAC/Workplace_modifications

must pay for the modifications up front and then apply for reimbursement. A far better alternative would if a young person could take information to a job interview which details their specific needs, e.g. modified telephone/alarm equipment and a guarantee that these needs will be met under the scheme. This way the young person can be assessed on their ability to perform the job and not their inability as perceived by an uninformed employer.

5.3. Captions

Many individuals with a hearing loss (including our children) rely on captioning to enable them to fully access the information being presented. Captions are used in television, movies and public broadcasts. Many people are working to improve captioning levels within Australia and move towards equity of access for Deaf and hearing impaired Australians.

Of particular importance to our children is the use of captions in schools. Captions provide a vital access tool for our children to ensure their inclusion in classroom activities using electronic media. Without captions, they do not have the same access to the curriculum as their hearing peers.

We applaud the Accessible Education Database being launched by Media Access Australia in late October 2009 and hope there will be a time when all electronic media needed by our children at school is available with captions.

The producers and distributors of movies, or the television stations themselves don’t always realise the impact that captioning their programs can have. They often have little idea of just how many Australians have a hearing loss and how they could widen their viewer audience by providing captions. Continued awareness campaigns targeted at producers, distributors and television station directors, and the wider community will help to educate every one of the benefits of captioning.

Equally a lot of people with a hearing loss do not know that they can speak up and highlight instances of lack of captioning and have their voices heard. An education campaign targeted towards people with a hearing loss, advising them of ways to bring attention to lack of captioning is also a necessary awareness campaign.

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QUALITY STANDARDS
FOR NEWBORN HEARING SCREENING SERVICES
Supporting families

Compiled by ANZPOD - a coalition of parents of deaf children across Australia

July 2009

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INTRODUCTION

ANZPOD represents families of children who are deaf or hearing impaired around Australia. Members of the group are all parents of deaf or hearing impaired children and represent most of the major parent organisations within Australia. The aim of the group is to ensure parents of deaf and hearing impaired children have a voice in the development of the National Standards for Newborn Hearing Screening.

How services are delivered is as important as what is delivered. The most important issue after screening is the response and support offered to families. It is the family who will bear the responsibility for the child with a hearing loss from the time of diagnosis through to their transition to adulthood. Parents are core stakeholders in ensuring optimal long-term outcomes for our deaf children and are, therefore, uniquely placed to contribute to the national newborn hearing screening initiative and ensure this develops into good public policy reflecting world's best practice for deaf and hearing impaired children and their families.

ANZPOD has compiled a set of family-centred, quality standards that we believe should sit within the management framework of all newborn hearing screening services across Australia. The rationale for family-centred practice indicates that when service providers work in partnership with families, there is a greater probability that the desired outcomes will be achieved.

In proposing these national standards, we draw your attention to the following unique practice features that we believe will lead to best practice in Australia:

1. The need for the standards and protocols to focus on family-centred outcomes and the provision of all communication options.
2. The need to ensure that all levels of hearing loss are incorporated in the care pathways, including babies with a unilateral hearing loss.
3. The provision for a fully funded skilled parent-to-parent mentor or parent-to-parent support model, that would be available from the earliest point of the care pathway.
4. The provision to ensure equal access to rural and remote families through the inclusion of rural parent representatives in policy development and through the provision of accommodation and travel allowances to enable rural and remote family access to services.
5. The need for a non-aligned linkage person (e.g. family support worker or skilled parent mentor) to facilitate the family's transition to early intervention services.

FORMAT OF STANDARDS

The standards focus on the needs of families and factors that have a high impact on quality care. They are evidence-based and take into account other recognised standards set by internationally renowned newborn hearing screening programs and the Population Based Screening Framework from the Screening Subcommittee of the Australian Population Health Development Principal Committee.

The standards were developed around four key areas that families have identified as essential components of a successful screening program:

1. Parent-professional partnerships
2. Equal access to newborn hearing screening for all babies
3. Informed choice
4. Family-centred services

Quality Standards give families an assurance of

- Equity in access to all aspects of the service
- Appropriate and adequate support
- Confidential and culturally appropriate care
- Well-trained, qualified and skilled professional staff and mentors
- Comprehensive unbiased information throughout the screening, diagnostic, and intervention stages to allow informed decision making
- Evaluation of service performance in terms of outcomes for deaf children and their families.

All standards follow a similar format:

- Each standard has a **title**, which summarises the area on which that standard focuses.
- This is followed by the standard **statement**, which explains what level of performance needs to be achieved.
- The **rationale** section provides the reasons why the standard is considered important.
- The standard statement is expanded in the section headed **criteria**, which details exactly what must be achieved for the standard to be reached and how the service will achieve this. The criteria are numbered for the sole reason of making the document easier to work with, particularly for the assessment process. The number of the criteria is not a reflection of priority.
- Each criterion is followed by a number of **indicators** that must be addressed in order for the service to demonstrate that it has achieved each criterion. There are indicators that require demonstration of the processes used to meet the criterion; others that require staff to be aware of those processes; still others that require documentation of the processes; and, finally, indicators that ask for consumer feedback on the processes.

Assessment of Performance Against the Standards

Assessment of performance against the Standards should be carried out by an independent review authority.

Services use the following means to demonstrate how they achieve the standards:

- Consumer feedback (such as conducting a parent survey or running a family focus group)
- Direct observation of the service
- Service documentation (such as policy and procedures manual, guidelines or protocols; information about the service; evidence of staff qualifications such as continuing professional development, in-service training programs; service evaluation reports)
- Review of information provided to families
- Interviews with staff who provide clinical care (such as screeners, audiologists, medical practitioners)
- Interviews with other staff in the service (such as family support workers, receptionists)
- Review of child & family health records

All criteria are expected to be met. Every indicator listed under each criterion must be addressed in order for the service to comply with the standard.

DEFINITION OF TERMINOLOGY

Deaf

This document uses the term ‘deaf’ is used to mean all types and levels of deafness, including unilateral hearing loss.

Parent/Family

This document uses the words ‘parent’ and ‘family’ to include the child’s carer with parental responsibility.

PARENT-PROFESSIONAL PARTNERSHIPS

STANDARD 1 – SYSTEMIC PARENT-PROFESSIONAL PARTNERSHIPS

Statement:

Professionals are experts in hearing loss. They have the education, the expertise and the experience. Parents are the experts on their child. They have the love, the lived experience and lifelong commitment to providing what is best for their child. The parent-professional relationship should be seen as a partnership of two experts.

Rationale:

Parent involvement provides motivated and personal commitment to improvement of the system, and services that are appropriate for and acceptable to families.

Optimum outcomes for a deaf child will occur when service providers work in partnership with families as valued and equal partners.

Criteria:

The planning and delivery of services needs to be a collaborative process between parents and the professionals and services supporting families. This is achieved by:

1.1 Parent representation in implementation, management and evaluation of national newborn hearing screening standards

1.1.1 Parents are appropriately represented during each phase of the development of national standards.

Indicators:

- ✦ Evidence of parent involvement in policy decisions such as advisory panel membership eg. Minutes of policy meetings.

1.2 Parent participation in strategic development, management and evaluation of newborn hearing screening services

1.2.1 Parents are centrally involved in developing services and reviewing plans.

1.2.2 Parents participate in on-going evaluation of all aspects of the service.

1.2.3 The service provider develops provisions that ensure that parents are able to participate on a level playing field with their professional counterparts. These could include direct staff support, stipends, travel expenses, and childcare.

1.2.4 The service provides convenient meeting times and locations for parent participation.

1.2.5 Parents from metropolitan, regional and rural organisations are all represented during consultations.

Indicators:

- Evidence of family inclusive policies
- Service evaluation protocols and reports
- Parent survey

1.3 Parent participation in education and training of service providers

1.3.1 Parents participate in the development of training programs for all staff in newborn hearing screening, including audiologists, family support workers and screeners

1.3.2 Parents are invited to contribute to in-service training of all staff including audiologists, family support workers and screeners.

Indicators:

- Evidence of parent involvement in development of family-centred modules for education and training programs
- Training program curriculum
- Interviews with staff including screeners, audiologists, family support workers and administration personnel

EQUAL ACCESS TO NEWBORN HEARING SCREENING FOR ALL BABIES

STANDARD 2 – ACCESS TO SCREENING

Statement:

All children should have equal access to newborn screening for hearing. Family support is an essential component of newborn hearing screening programs.

Rationale:

Early diagnosis together with appropriate intervention for children with permanent hearing loss can lead to improved outcomes for those children in language and communication acquisition, education and socio-emotional development.

Parents support the principles of early identification and intervention.

Criteria:

All children have access to newborn hearing screening in a timely fashion, with clearly defined pathways from screening to audiological assessment and on to engagement with early intervention services (where appropriate). Families must be able to access support at any point on the pathway, irrespective of the level of hearing loss of the child.

2.1 Care pathways are in place, clearly defined and monitored regularly

2.1.1 Easily accessible, written information is provided for families and the wider community that describes the pathway from screening to engagement with early intervention services, e.g. website, brochures

2.1.2 The service has policies and procedures in place that ensure all babies have access to newborn screening. Detailed protocols for each stage of the pathway, including family support, are documented.

2.1.3 Care pathways take account of:

- Well babies, including home births
- Infants in Neonatal Intensive Care or High Need Units
- Infants identified as having a risk factor, e.g. family history, medical condition
- Management of babies who miss or refuse screening
- All levels of hearing loss, including unilateral hearing loss.

2.1.4 The service monitors the care pathways and implements quality improvements on a regular basis.

Indicators:

- Annual survey of parent satisfaction
- Parent focus groups
- Service documentation details protocols for each stage of the pathway, including family support
- Review of child health records
- Care pathways are reviewed at least every 3 years

2.2 Speed of access to screening, diagnostic audiology and early intervention

2.2.1 All infants have access to hearing screening at no later than 1 month of age. Standard target is to screen minimum of 95% newborns prior to discharge from hospital.

2.2.2 The timeframe between refer and audiological assessment should not exceed 3 weeks.

2.2.3 Diagnosis of hearing loss should be confirmed by 3 months of age

2.2.4 All infants with confirmed permanent hearing loss should receive appropriate early intervention services as soon as possible after diagnosis but at no later than 6 months.

Indicators:

- Annual survey of parent satisfaction
- Evidence of referral outcomes at each stage of the pathway
- Waiting times for all stages of the referral pathway are collected and monitored in an effective manner.

2.3 Access to family support (see also Standard 5)

2.3.1 Families have access to a well trained family support worker at any point on the care pathway from the time of the first screen to engagement with an early intervention service; not just the first appointment with Australian Hearing.

2.3.2 Families have access to parent-to-parent support from the time the child has a confirmed diagnosis of hearing loss.

Indicators:

- Annual survey of parent satisfaction
- Parent focus groups
- Service protocols
- Staff can describe how families can access family support

2.4 Financial assistance for rural and remote families

2.4.1 The service funds travel and accommodation allowances to enable rural and remote family access to the service.

2.4.2 Information on eligibility and how to access travel assistance should be provided at each step of the program.

Indicators:

- Service protocols
- Service information brochures

STANDARD 3 – INFORMATION PROVISION AND COMMUNICATION WITH FAMILIES

Statement:

"Informed Choice means that families can make knowledgeable decisions, which reflect their own culture, values and views. It is based on access to comprehensive, unbiased and evidence-based information, about the full range of options.[1]"

Families have the right to be provided with unbiased, accurate and up-to-date information. Effective communication enables families to understand complex information and to make informed and appropriate choices for their child.

How deafness is presented to parents will influence their understanding as well as their expectations for their child. Service providers have a duty to ensure that deafness is not presented as only a medical or scientific issue and that they are positive in their approach to deafness.

It is not just information, but also experience that is crucial in making informed choices. Parent-to-parent contact and support are vital. They add context (both in the immediate and long term) to the realities and consequences of having made particular choices as a family. They are a source of knowledge and understanding that is of a totally different variety than that available from the printed word, or through the explanations of professionals.

Rationale:

Families need clear and timely information to facilitate attendance and reduce anxiety.

Newborn screening and subsequent audiological assessment (if required) can be a stressful experience for families. Information provided verbally may be overwhelming and difficult to understand. Providing written information at each stage of the process allows families to digest information in their own time and the materials can be used as a reference resource.

Presenting the same information on more than one occasion helps families understand and retain this information. It also creates multiple opportunities for the family to ask questions, as not all parents are comfortable in pro-actively seeking clarification.

Families who receive information in their preferred language are able to access the same information as members of the general community.

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[1] *Informed Choice, Families and Deaf Children: Professional Handbook* (2006). Retrieved June 4, 2009, from Early Support website: http://www.earlysupport.org.uk/)

Criteria:

Families must be provided with unbiased, accurate and up-to-date information about all their options in a format that is easy to understand.

Staff should be trained to communicate with families in a timely and appropriate fashion, particularly at critical times such as confirmation of deafness.

Providing information in a variety of formats, for example, written, verbal, video or audiotape ensures that families can access information in their preferred form of communication.

The professionals are experts in hearing loss and the parents are the experts on their child and his or her needs. The service provider's role is to help the parents think through the decision-making process, focus on the key issues and evaluate their options. Professionals should be empowering parents to choose, re-choose and change their minds when appropriate.

3.1 Information about the screening program

3.1.1 Parents must be given full information as to the purpose and nature of the screen as well as details of the results and how they will be used.

3.1.2 Written information that explains the reasons for screening and describes the screening process, is available to families during antenatal visits and parenting education programs.

3.1.3 Information that explains the reasons for screening and describes the screening process is provided immediately prior to screening, as part of the pre-screen protocol.

3.1.4 Written information regarding a diagnostic assessment appointment is provided as part of the appointment process. (directions, maps, parking facilities, appointment duration, procedures, facilities, desirable baby state).

Indicators:

- Parent survey of babies with a "pass" result
- Parent survey of babies with a "refer" result
- Direct observation of the service
- Service information sheet
- Program protocols
- Child health records

3.2 Explanation of results to parents

3.2.1 Families receive an explanation of the screen results as soon as the screen is completed.

3.2.2 Screeners are trained as to what information is given and how the information is delivered to ensure parents understand the message, particularly when there is a "Refer" result.

3.2.3 Written information is also provided regarding follow-up for either a "Pass" or "Refer" result.

3.2.4 Families receive an explanation of the diagnostic assessment results as soon as the assessment is completed. Information is provided by the audiologist who performs the assessment.

3.2.5 Families are provided with written copies of the results of any assessment and tests together with any supporting literature within 2 working days of the assessment.

Indicators:

- Family feedback
- Service information
- Program protocols
- Interviews with staff

3.3 Information after confirmed diagnosis of hearing loss

3.3.1 Parents are given accessible information that they can take away with them at the time of confirmation. This must include details about where they can obtain further information and advice.

3.3.2 Families are provided with unbiased and accurate information on all communication methods which comply with the principle of informed choice.

3.3.3 Families are provided with unbiased and accurate information on early intervention, including amplification and education options, which comply with the principle of informed choice.

3.3.4 Rural and remote families are provided with information about all travel and accommodation allowances available to them to allow them to access services.

3.3.5 At the time of confirmation of a hearing loss, information should include details about the next steps in the process, who will be contacting the parents, when this will be and where they can obtain further information and advice.

3.3.6 Families are offered the opportunity for their child to have aetiological investigations. These investigations must be carried out in accordance with local protocols based on nationally agreed standards. Families are offered counselling to understand these investigations and the implications.

3.3.7 All staff must receive training that will enable them to communicate positively about deafness.

Indicators:

- Family feedback
- Program policy and procedures
- Interviews with audiologists and family support workers
- Direct observation of the service
- Family resource kit

3.4 Access to information

3.4.1 Information is provided in a range of formats, e.g. brochures, books, websites, DVDs, audio tapes, face-to-face meetings etc.

3.4.2 Written information is available in English and other community languages.

3.4.3 Appointment schedules are arranged which allow parents time to ask questions and seek clarification.

3.4.4 Parents are able to obtain advice or information related to their child's audiological care by telephone or electronic means.

3.4.5 Staff need to be aware of alternative modes of communication used by the families, including those with a disability. Staff must be able to organise and provide support for the linguistic preference of parents, such as the provision of interpreters and use of the National Relay Service.

3.4.6 The service informs families of additional sources of reliable information, for example early intervention programs, parent support organisations, deaf organisations and internet resources.

Indicators:

- Evidence of the current range and format of information provided by the service
- Family feedback
- Staff can describe how they organise and provide support for with families who require sign interpreter or translation services.
- Review of appointment schedule protocols

3.5 Communicating with families

3.5.1 Clear guidelines must be developed on how confirmation of deafness is given.

3.5.2 Staff are trained to communicate appropriately, sensitively and effectively with families, particularly at critical times such as the time of confirmation of deafness.

3.5.3 The goal of professionals should be to support and guide families to make informed choices.

3.5.4 Service providers should not pressurise parents into making hasty decisions, but give them time to consider all options available.

3.5.5 Professionals should not make assumptions about the choices families will make. Families need to be told about all of their options.

3.5.6 Service providers should be honest, open and transparent about the services they can provide and what may be difficult for families to access.

Indicators:

- Family feedback
- Direct observation of the service
- Interviews with staff

3.6 Parent-to-parent support

3.6.1 Parents can access parent-to-parent support at any time in the care pathway.

3.6.2 Parent-to-parent support may be through trained parent mentors or parent support groups

3.6.3 Families are routinely offered parent-to-parent support at the time of confirmation of their child's deafness, regardless of the level or type of hearing loss.

3.6.4 The service funds training for appropriate parents who wish to become family mentors.

3.6.5 The trained parent mentor should contact the family within two working days of referral.

3.6.6 Should the family decline parent-to parent support at the time of diagnosis, the family is informed about how they can contact a parent mentor or parent support group should they desire this support at any time in the future.

Indicators:

- Annual parent survey
- Direct observation of the service
- Service protocols

FAMILY-CENTRED SERVICES

STANDARD 4 – PROFESSIONAL SKILLS AND COMPETENCE

Statement:

Young infants and their families who participate in newborn hearing screening programs must have access to high quality evidence based care, delivered by staff who have the skills for diagnosis, assessment, treatment and ongoing care and support.

All health services have a duty of care to children and families and must ensure that assessments and interventions are delivered by appropriately trained, qualified and registered clinicians. Through the clinical governance framework, services can manage their accountability for maintaining high standards.

Rationale:

Parents have a right to expect that all staff in the service will be well trained, skilled and experienced in working with families.

Criteria:

Professionals working with families must be able to demonstrate knowledge and skills commensurate with their position. All staff must have the clinical competencies necessary to support the assessments and interventions they undertake and to communicate effectively with families.

4.1 Assumed competencies

4.1.1 All staff have appropriate qualifications and have or are are provided with additional training, as required, prior to working with families. For example, audiologists possess a degree in audiology, supplemented by experience in paediatric audiology.

4.1.2 Competency is maintained and extended.

4.1.3 Staff do not practice beyond the scope of their expertise and do not misrepresent their training and competence.

Indicators:

- Personnel records
- Training protocols
- Staff assessment reports

4.2 Additional competencies for all staff working in newborn hearing screening

4.2.1 Staff have undertaken specific training in working with preschool deaf children and their families.

4.2.2 Staff are trained to present information without bias.

4.2.3 Staff are trained in communication skills.

4.2.4 Staff are trained to understand the importance of parent-to-parent support and have a knowledge on the support available in their local area and how to refer parents.

4.2.5 Training is provided for all staff in deaf awareness and different models of deafness, including how these models can impact upon the deaf child and their family.

Indicators:

- Evidence in personnel records
- Parent focus groups
- Interview with staff

4.3 Additional competencies for family support workers

4.3.1 Family support workers should possess a university degree or equivalent qualification/experience.

4.3.2 Prior to working with families, the family support worker must:

- be skilled in communication and counselling skills
- be able to demonstrate family-centred practices
- be trained in cross-cultural competence and inclusive practice
- be able to work in a team and to coordinate interdisciplinary service delivery.

4.3.3 Prior to undertaking the role of family support worker, he/she must have:

- specific training in working with preschool age deaf children and their families
- knowledge and understanding of different types of hearing loss
- knowledge and understanding of different communication methods
- knowledge of local, state and national services for deaf children and how to access them
- the ability to fully support a family in their choice of communication method
- knowledge and understanding of effect of hearing loss on the relationships within the family and
- be able to introduce families to other families with deaf children and to deaf people.

Indicators:

- Personnel records
- In-service training records
- Family feedback
- Interview with family support workers

STANDARD 5 – FAMILY SUPPORT & COUNSELLING

Statement:

Families vary greatly in their personal resources, levels of education, and confidence. When service providers and parents share and respect each other's knowledge and expertise, better solutions for the child and family are likely to be found.

Effective support services are individualised and responsive to particular family needs and circumstances. Individual Management Plans give parents the opportunity to participate fully in the planning of services, and to obtain support for the choices they make.

Rationale:

There are many common issues for parents of deaf children, but no two families are the same or have identical needs. Families can be diverse in terms of their experience, geographical location, resources and expectations, as well as their cultural, religious and linguistic influences. One-size-fits-all approaches fail to adapt to the needs of particular children and families.

The well-being of families depends upon the availability of high quality formal supports as well as informal social supports.

Families value a multi-disciplinary approach that reduces disruption to family life, avoids duplication and eliminates conflict of information.

The service provider's role is to help the parents think through the decision-making process, focus on the key issues and evaluate their options. Families who develop independence and advocacy skills are able to remain in control and can better manage their child's support needs.

Professional support should aim to empower parents to become confident decision-makers. An over-reliance on professional input can disempower parents, cause feelings of inadequacy, and encourage the tendency to problem-solve only when supported by professionals.

Criteria:

Continuity and coordination of support are essential components of a successful program

Having one independent and appropriately trained key support worker, from screening to engaging with early intervention services, provides a comprehensive and on-going partnership.

Well co-ordinated and seamless services will help to ensure that families receive coherent and consistent services and support. Support for a deaf child involves health, education and social services. The system developed to support deaf children and their families needs to provide integrated services across these three key service areas.

5.1 Support and counselling services

5.1.1 Planning and delivery of support & counselling services is done collaboratively involving the family and professionals as equal partners.

5.1.2 All staff are trained to treat families and family members with dignity and respect at all times.

5.1.3 The family support worker discusses with the family the support they wish to receive. Support is offered on a continuing basis and is accessible to the family all year round.

5.1.4 Family support workers are trained to take account of the needs of all family members as well as the needs of the family as a whole and to be responsive to family cultural, ethnic, and socio-economic diversity.

5.1.5 The family support worker provides information on a broad range of informal, community, and formal supports and resources to enable families to develop their own support systems. For example, local parent support and deaf community organisations, Auslan classes, access to financial assistance such as travel assistance and Carer Allowance.

Indicators:

- Support offered to families is tailored to meet their individual needs.
- The service is offered in a flexible fashion according to the evolving needs and circumstances of individual children and their families.
- Interview with family support worker
- Annual parent satisfaction survey

5.2 Access to family support worker

5.2.1 Parents can access family support at any point in the care pathway.

5.2.2 Families are routinely referred to the family support worker at the time of confirmation of their child’s deafness, regardless of their level or type of hearing loss.

5.2.3 The family support worker contacts the family within two working days of diagnosis.

5.2.4 The family is informed about how they can contact their family support worker and to whom that role has been delegated if their family support worker is not available.

Indicators:

- Feedback from families
- Individual management plan

5.3 Individualised support

5.3.1 The service prepares flexible management plans that are responsive to the child's and family's changing needs.

5.3.2 A preliminary individual management plan (IMP) is developed by the audiologist in collaboration with the family at the time of diagnosis.

5.3.3 The IMP is updated by the parents and family support worker during the first appointment and at subsequent meetings. A list of agreed needs and actions is recorded and a copy is given to the family at each revision.

5.3.4 The IMP details any requirements families have for information, family support and practical advice.

5.3.5 The IMP includes an assessment of current priorities including referral to appropriate services. These may include:

- Audiology
- Counselling service
- Assistance to access financial support
- Medical assessments
- Parent-to-parent mentoring programs

5.3.6 The IMP process should be used as a means to empower families to gain the skills they need to obtain, use and evaluate information. These skills foster independence and enable families to make informed decisions for themselves and their deaf child.

Indicators:

- Individual management plans are is in place and regularly reviewed
- The IMP includes a set of achievable objectives which are reviewed and updated regularly.
- Feedback from families

5.4 Multi-disciplinary team coordination

5.4.1 The family support worker assists the family to coordinate services for their child. The family support worker knows the key professionals who are working with the family and is able to contact them.

5.4.2 Parent must be given written copies of all assessments, test results and reports to ensure the parents are equal partners in the team and that up-to-date and accurate information is available to members of the team as required.

5.4.3 Confidentiality is a key element in a multi-disciplinary approach. Parents must know to whom information about their child and family is given.

5.4.4 The support worker is familiar with roles of multidisciplinary team members & involves families as equal partners in the team. Team members may include:

- Audiologist
- Specialist teacher
- medical practitioners, e.g. ENT, paediatrician, GP, geneticist
- Speech pathologist
- Allied health worker, e.g. physiotherapist, occupational therapist
- Parent mentor
- Deaf mentor

Indicators:

- The multi-disciplinary team includes the family and named individuals from all services supporting the child.
- Written and informed consent from the parent/guardian is obtained prior to the sharing of reports and information between professionals.
- The service encourages strong interagency networks that enable services to address the multiple needs of families in an integrated fashion.

STANDARD 6 - SERVICE EFFECTIVENESS AND IMPROVEMENT

Statement:

Service evaluation and continuous feedback, including the views of parents and families is critical to the development of good quality screening services. Audits should include all aspects of the service in relation to quality, safety, effectiveness, appropriateness, consumer participation, access and efficiency.

Rationale:

Implementing and embedding a continuous quality improvement cycle gradually improves standards.

The best quality services have a culture of learning continuously from families, children and service staff.

Criteria:

Services must carry out regular audits to evaluate the effectiveness and family-friendliness of their services, as well as identifying and implementing changes to improve service provision. As part of this audit, the views and experiences of parents of deaf children must be gathered.

Services must be capable of adapting to changes in technology and changes in other related services.

6.1 Service evaluation

6.1.1 The service undertakes regular audits to evaluate all aspects of the program.

6.1.2 Independent evaluation of all aspects of the service is undertaken every 5 years. Membership of the evaluation panel must include parents of deaf children.

6.1.3 The evaluation report is published.

Indicators:

- ✦ Feedback from families
- ✦ Audit reports
- ✦ Evaluation report

6.2 Quality improvement

6.2.1 The service has a documented, planned approach for improvements to all aspects of the service.

6.2.2 Quality review activities should be used to monitor progress. These activities may include audits, routine protocol reviews, staff assessment, parent surveys and health record reviews.

Indicators:

- Each area of the service has a process for continuous quality improvement in place.
- Evidence of quality review activities

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