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# Parent Perspectives and Newborn Hearing Screening

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**All families are different.**

**All families have strengths and competencies.**

**Parents know their child best and want the best for them.**



“The biggest needs [for parents] at the time of diagnosis were contact with other parents, unbiased information, help with their feelings and getting started with services...”

The key to the habilitation of young deaf children is the parents, and success in deafness habilitation does not reside in methodology or technology.”

(The Young Deaf Child by D M Luterman and E Kurtzer-White)

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## Parent Wish List for Newborn Hearing Screening Programs

### Parents wish for:

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

ANZPOD represents families of children who are deaf or hearing impaired around Australia. We believe that current early diagnosis and referral services do not acknowledge the parent expert and do not fully reflect families' needs.

## We wish for parent-professional partnerships

- 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.
- The planning and delivery of services needs to be a collaborative process between parents and the professionals and services supporting families.
- Parent mentors should be an integral part of the service provided to families post diagnosis. The feeling of understanding and knowledge that another parent who has been through a similar life experience provides has special meaning and importance for families.

“We [parents] are there for the duration! There is quite a reasonable level of staff turnover at most of the service providers. The one constant in the child's life is the parents. They are in fact the primary case worker for the child. That is why an equal partnership is a necessity.”

## We wish for equal access

- All babies in Australia should have access to newborn hearing screening.
- All babies, irrespective of the level of loss, need access to family-centred services which ensure optimal language, education and socio-emotional outcomes for the child.
- All babies and families need access to high quality evidence-based care.

“...until my daughter was two we lived in a small country town and there was no support and that was hard as even my gp had very little knowledge of hearing loss in children.”

## We wish to make informed choices

- The choices families make throughout the life of their child will be informed choices if they meet the needs of the child and family and reflect their desires, beliefs and values.
- Being informed is necessary to make a considered decision. Being informed is not sufficient – families also need choices, including access to different communication options, convenient service delivery, and the ability to change their decisions when necessary.
- The principle of informed choice means that professionals avoid bias and, instead, respect the family's preferences over their own.
- Families need accurate, reliable and unbiased information to make informed choices.
- Families need information about all their options, not just those readily available in their local area or those preferred by the professional or service provider.
- Simply providing information does not mean the family will understand it. Families need professionals who guide and support their decision-making.
- The need for information is ongoing. Family situations change. Children grow and develop. The family's choices may need to change.

"I can't stress enough how important it is for the information given out by the audiologist at the time of diagnosis to be done slowly and sensitively. There is a lot of information and it's quite overwhelming. Parents are often shocked numb by the diagnosis that any information given soon becomes quite foggy and missed. "

"...and ask why, in 2009, are parents still being asked to chose one method of communication over another, when it appears that oral and sign languages can both be learned??"

"Being given a book showing the options is not enough – we need someone who knows the options to talk to about them."

## We wish for a family-centred services

- Services should empower families and help them to develop new strengths and competencies and meet the ongoing needs of their child with a hearing loss.
- Family support services should provide families with breathing space to come to terms with their baby's hearing loss, become informed about all of their options and make appropriate decisions when they feel confident enough to make informed decisions.
- The well-being and development of a child with a hearing loss depends upon the well-being of the whole family.
- The well-being of families depends upon the availability of high quality professional support, as well as the quality of the support from other families with deaf and hearing impaired children.
- Support services should help families establish strong support networks with Deaf and hearing impaired adults.
- **Families should be an integral part of the planning, delivery and evaluation of family support services.**

"There needs to be something done between the time a child is diagnosed and the time before they have to be fitted with hearing aids. In my case, it was about 6 weeks. It was six weeks of hell. Not knowing was awful and I had so many questions to ask but had no one to ask... This period is incredibly tough on families and I think this period is one that needs to be addressed."

"Simply finding other parents is a help from a mental standpoint – you know you're not alone in this."

"In the early days, we were immersed in the medical model. It was 9 months later that I met a deaf adult – I wish this had happened in the first three months. It was 6 months before I met another family - after cold calling the family. This could have happened at 3 months also."

"I was very isolated at diagnosis with no information given to us until Australian Hearing confirmed the diagnosis – they were very good but the time between appointments was some weeks at which time we as a family had no idea what was happening, how to help our child or who to contact for more information."

## About ANZPOD

ANZPOD was formed after the 5th Australasian Newborn Hearing Screening Conference held in Adelaide in May 2009.

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.

Members of the group are all parents of deaf or hearing impaired children and represent most of the major parent organisations within Australia.

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