

Getting Started

Kei Te Timata



AN INTRODUCTION FOR THE
FAMILIES AND WHANAU
OF CHILDREN DIAGNOSED
WITH A HEARING LOSS.
THIS IS A JOINT PROJECT
BY DEAF EDUCATION AOTEAROA
NEW ZEALAND AND THE
NATIONAL AUDIOLOGY CENTRE.

GETTING STARTED is for families and whanau at the time a child's hearing loss is confirmed. It provides a brief overview and aims to answer immediate questions parents may have at the time of diagnosis. For more information please refer to **THE FAMILY BOOK** a comprehensive resource book about hearing loss, technology, education and with personal stories from other New Zealand families. This publication has current information (produced August 2004) and can be viewed or downloaded from www.deafed.co.nz/familybook or www.tki.org.nz/r/specialed/pdf/familybook.pdf

MY CHILD HAS A HEARING LOSS WHAT DOES THAT MEAN?



When parents are advised their child has a hearing impairment or deafness, their reaction can be as individual as the condition itself.

As there is often no previous experience of hearing loss, many parents find themselves moving into an area they know nothing about. For some parents the diagnosis brings a sense of relief as it may answer questions they have about their child's behaviour or development. Other parents may be deaf themselves, or are already familiar with someone who has a hearing loss.

It is quite natural for emotions to run high when your child's diagnosis is confirmed by an Audiologist. But the fact is: your child is still the same - it is the information you know about them that is different.

WHAT IS 'hearing impaired' 'deaf' or 'Deaf'?

Children whose hearing is outside the normal range, may be referred to as 'hearing impaired', 'deaf' or 'Deaf'. The small 'd' is often referred to as a medical term, but in the context of this booklet it can refer to all children with a 'hearing impairment' or hearing 'loss', including sign language users. The capitalised 'D' in 'Deaf' is used to indicate a group of people who identify with Deaf culture and are part of the Deaf community (see also page 6 'Sharing Deaf Experiences').

WHAT PROFESSIONAL SUPPORT IS AVAILABLE?

Under New Zealand's Public Health and Education systems, hearing services are provided free of charge

for your child until they leave school. The majority of parents make use of these public systems which are delivered through local hospitals and schools. However, sometimes parents choose private professional support, while others prefer a mix of the two.

ADVISERS

After a child's hearing loss has been diagnosed, the Audiologist usually notifies an Adviser ('Adviser on Deaf Children' or A.O.D.C.) who often becomes a main contact person between the family and the professionals who will assist them. An Adviser is usually a qualified teacher of the deaf, who has received additional specialist training in working with children and their families. Advisers help families to understand the implications of their child's hearing loss, and guide them as they consider the technology and communication options available to them. They also provide assessments and information about a child's development and behaviour to other professionals working with the family. After receiving a referral the Adviser will contact you.

If you haven't been contacted by an Adviser
Freephone Group Special Education on 0800
622 222 or see 'Education' in the blue pages
at the front of the phone book for your local
Group Special Education office.

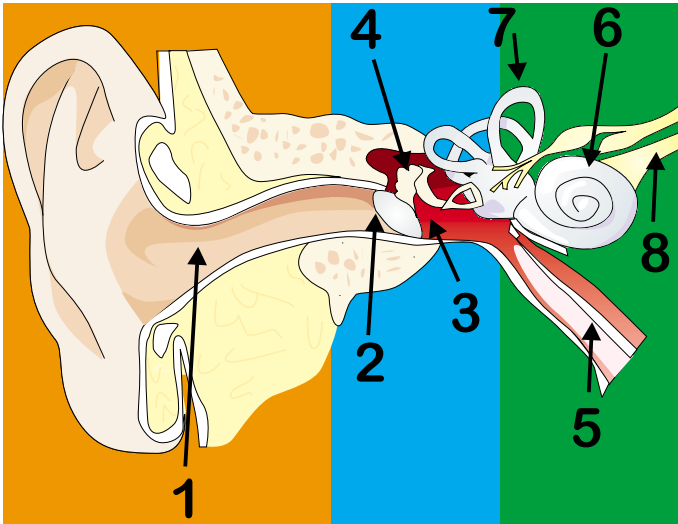
TALKING TO OTHER PARENTS AND CAREGIVERS

Sharing a common concern with others who are experiencing something similar can often be helpful. The New Zealand Federation for Deaf Children Inc. co-ordinates support groups for parents throughout New Zealand. Many groups have newsletters, social events, and can offer support and friendship for the parents and caregivers, and the children themselves.

Freephone 0800 332 324 for information
about a Parents' Support Group near you.

New Zealand is a multi-cultural society, where cultures can often respond to deafness in different ways. Ask your Adviser for any current information that will support your family's cultural needs, and ask about other families of similar culture who you can talk to in your area.

HOW DO WE HEAR?



- 1: Ear canal 2: Ear drum 3: Middle ear cavity
4: Middle ear bones 5: Eustachian tube 6: Cochlea
7: Semicircular Canals 8: Auditory Nerve.

Outer Ear

Air around us carries sound through sound waves. The outer ear collects these sound waves and sends them along the ear canal.

Middle Ear

At the end of the ear canal is the ear drum which bounces or vibrates, just like when you hit a real musical drum. Sound waves pass from the ear drum onto the three tiny ear bones in the middle ear called the hammer, the anvil and the stirrup (because that's what they look like). They are the smallest bones in your body. When these bones vibrate and move, they transport the sound waves into the inner ear.

Inner Ear

The inner ear contains the cochlea, the hearing organ which is spiral-shaped and looks like a snail's shell. It is filled with fluid and thousands of tiny sensory hair cells. These sensory hair cells convert all the sound vibrations which are passed from the middle ear into electrical signals which travel up the nerves of the auditory pathway to the brain for processing.

WHY ARE CHILDREN SOMETIMES UNABLE TO HEAR?

A child's hearing becomes impaired when sound waves or electrical signals from the hair cells are not able to travel freely from the outer ear to their brain, in a way that they usually would in a child with full hearing.

When a child's hearing loss has developed before or around the time of birth it is described as a 'congenital'

loss. When a child's hearing loss develops later it is described as an 'acquired' loss.

Often it is hard to pinpoint what has caused the hearing loss in a particular child. In fact, in 50-60% of New Zealand cases of permanent hearing loss, no known cause is identified. Where a cause has been identified, 20% are reported to have been genetic. Your Audiologist will refer you to an Otorhinolaryngologist (O.R.L. or Ear Nose and Throat Specialist) who will help you to understand the medical aspects of your child's hearing loss:

TYPES OF HEARING LOSS

Conductive Hearing Loss (C.H.L)

If the interruption happens in the outer or middle ear, this affects the way sound is carried or conducted through to the inner ear and the rest of the auditory system. This can be caused by problems such as fluid in the middle ear ('Glue Ear') or wax build up in the outer ear canal. A hearing loss in this part of the system can often be helped by medical or surgical means. It is not usually a 'severe' loss and is not often permanent.

Sensorineural Hearing Loss (S.N.H.L)

If the outer and middle ear are working effectively, the cause of the hearing loss is usually somewhere in the inner ear - the part of the auditory system which creates electrical signals (the cochlea) and sends them along the auditory nerve to the brain. This type of hearing loss usually means that a hearing aid (or occasionally a cochlear implant) is required. A sensorineural hearing loss is most likely to be permanent.

Mixed Hearing Loss

Some children may have a sensorineural loss and a conductive loss at the same time. In this case, they are described as having a 'mixed hearing loss'.

Auditory Processing Disorder

Sometimes when an Audiologist tests a child, they find the outer, middle and inner ear may be working well. Yet the parents are sure the child is not hearing well. In these cases, there may be a problem somewhere in the nerve pathway leading to the brain, or in the ability for the brain to process sound. These types of hearing problems are called auditory processing disorders.

Unilateral Hearing Loss

A unilateral hearing loss means only one ear has a degree of hearing impairment. It can be difficult to hear well in background noise and to 'localise' where sounds and voices are coming from. A unilateral loss can result from any of the above types of hearing loss. Most hearing loss is 'bilateral' or in both ears.

HOW DO WE MEASURE HEARING?

Audiologists are familiar with testing babies and younger children and usually want to make the child's experience as easy as possible. They are also mindful of the feelings of parents during a time when their child's hearing impairment is confirmed. When a child's hearing is assessed by an Audiologist, they use two basic test techniques. These tests do not cause any discomfort to the child. Hearing testing can be carried out at any age from birth.



Behavioural testing

Behavioural Testing

This relies on a baby or child responding to sound. For example, if they are about six months to two-and-a-half years old this may be a head turn response. Older children may carry out simple tasks in response to test sounds.

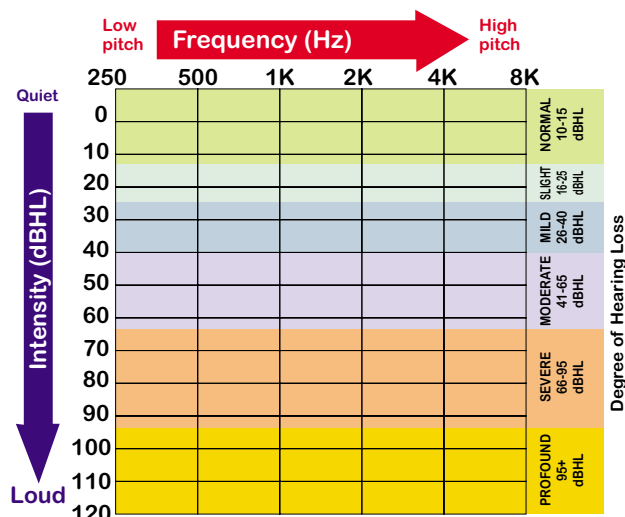
Physiological Testing

This is carried out to support the behavioural results. These are a whole range of tests such as tympanometry (test of the middle ear function); Otoacoustic Emission tests (test of the cochlear function); and Auditory Brainstem Response (A.B.R) testing (test of the auditory nerve function). The results of these tests allow the Audiologist to say more accurately what type of hearing loss a child has, and to confirm the behavioural results.

If your child doesn't co-operate during a hearing test, don't worry - we all have our off days! Try preparing your child for the next appointment by playing 'pretend hearing test' games at home in the days beforehand.

AUDIOGRAM

An audiogram is a 'map' of a person's hearing ability. It's a graphic way of showing the softest sound a person says they can hear (their hearing threshold), at different frequencies - or pitches - of sound.



SYMBOLS		
Pure tone Audiometry		
RIGHT		LEFT
○	Air	×
●	Masked Air	×
△	Bone	▽
∇	Masked Bone	▽
⊞	Soundfield	⊞
⊞	No response	⊞
⊞	LDL	⊞

If the information is available, you can ask your Audiologist to plot your child's hearing levels on the audiogram (above). The audiogram is used to identify the degree of hearing loss a child has. The degree and type of a child's hearing loss will often determine the hearing aids and services they will need.

The degrees of hearing loss are indicated on the right hand side of the graph above. Audiologists use terms which range from 'slight' meaning a very small degree of hearing loss, to 'profound' which indicates a very significant degree of hearing loss.

CHANGES IN HEARING LEVELS

The most common reason for hearing levels to change is when a child has a middle ear infection ('Glue Ear'). Wax build up can also affect hearing levels if the wax is completely blocking the ear canal.

Occasionally a child's hearing will deteriorate and there will be no sign of a middle ear problem or wax. Seek advice urgently from your Audiologist or O.R.L. Specialist if this happens.

WHAT ARE HEARING AIDS?

When a child's hearing impairment is confirmed as permanent, generally the child is fitted with hearing aids. Hearing aids are like mini microphone-and-speaker-systems that amplify sound into the ear, or increase sound and make it louder, so the child can make use of the hearing they have left.

However, it is important to realise that hearing aids can't permanently correct the hearing nor can they restore the child's hearing to levels regarded as normal. What they can do is make more sounds loud enough for the child to hear them. Hearing aids are not like glasses: it is not just a case of wearing them to hear better. Hearing aids increase noise levels which then need to be processed by the brain. In time, when worn consistently every day, and with the right therapy or teaching support, children of any age can usually learn to use and make sense of the new sounds they hear through their hearing aids.

HOW ARE HEARING AIDS FITTED?



Behind-the-ear hearing aid

A Behind-the-Ear hearing aid is most commonly used for younger New Zealand children. An ear mould is created from an impression of the outer ear; one is needed for each ear that is fitted with a hearing aid. The moulds are replaced as the child grows. The process of taking an ear impression is quite painless but may feel a little uncomfortable for the child. Ask your Audiologist to explain the procedure to you and your child first.

FUNDS FOR HEARING AIDS

Most children's hearing aids are fitted for free through the public hospital system. A small number of private audiology clinics also fit children's hearing aids. Hearing aids for children are paid for by the Ministry of Health, through the Children's Hearing Aid Fund.

WHAT IS A COCHLEAR IMPLANT?

A cochlear implant is a type of hearing aid; however it operates to deliver sound in a different way, bypassing the traditional hearing route and stimulating the auditory nerve directly. A cochlear implant is usually recommended only for children with a severe to profound hearing loss. Extensive assessments and a significant trial with hearing aids usually takes place before a cochlear implant is considered.

Other technology

In addition to hearing aids there are other devices which can assist hearing, such as a Personal FM (radio aids) and classroom amplification systems. Ask your Adviser.

If you are a member of a Parents' group belonging to the New Zealand Federation for Deaf Children Inc. you can often get a partial refund on assistive technology. Freephone on 0800 332 324.

RESOURCES & FINANCIAL SUPPORT AVAILABLE

Teacher Support when your child starts pre-school, kindergarten or school they may receive some teacher assistance. Ask your advisor.

Funding Allowances are available from a number of government agencies, such as:

Carer Support Subsidy - Full-time parents or caregivers of a child or person with a disability can apply for funding to pay for an alternative caregiver to give you 'time out'. This allowance is not means tested. Contact Ministry of Health, Ph 0800 281 222 (then '1')

Child Disability Allowance - A payment (weekly rate, non-taxable) is made directly to the parent or guardian when the child lives at home and requires constant care and attention. Not means tested. Contact Work and Income New Zealand, Ph 0800 559 009 Deaf Link free-fax 0800 621 621

Childcare and O.S.C.A.R. Subsidy - Available to provide financial assistance to low-income families. Means tested. Contact Work and Income New Zealand (see details above).

Travel Assistance - For hospital or treatment visits related to the disability, assistance may be claimed under some circumstances, if your child needs to travel more than 8kms each way. Ask your hospital specialist for details.

COMMUNICATION AND EDUCATION

Babies usually start to hear (in the womb) before they are born. Then, once they enter our world they use their eyes and ears to start communicating. This is when parents and caregivers become a young child's first teachers of language. Long before they can communicate, your baby will have absorbed many hundreds of thousands of signals from you and your family. It is never too early to communicate; in fact this is the best time for us all to take in information.

Methods of Communication

For a child with a hearing loss, the development of effective communication skills is important. This becomes the key to your child's ability to progress well educationally, and be emotionally healthy.

Most people take communication for granted. However it is a complex process made up of many parts. There are two main ways people communicate in NZ:

Spoken Communication - has three components: speech; listening; and lip-reading or learning lip patterns that relate to speech.

New Zealand Sign Language (N.Z.S.L.) – is a visual socio-cultural language with its own grammar structure conveyed through hand movements combined with facial grammar, expression, lip patterns and a system of body postures.

The full spectrum of communication options are available in New Zealand - from auditory (or listening) only, to a visual (or signing) only approach. Some parents are strong advocates of one particular education approach while others prefer a mix of strategies. Sometimes parents say they have begun with one approach and added or incorporated another to meet the child's needs. Others combine both methods from a young age.

AUDITORY MIX OF STRATEGIES VISUAL

WHAT ABOUT MY CHILD'S SCHOOLING?

The majority of deaf and hearing impaired New Zealand children attend mainstream pre-schools and schools in their local neighbourhood, some supported by one-on-one teacher assistance. There are also schools specifically for deaf and hearing impaired children: van Asch Deaf Education Centre, Christchurch; and Kelston Deaf Education Centre, Auckland. The Hearing House operates a private pre-school facility in Auckland.

SHARING DEAF EXPERIENCES



The Deaf community is a wide network of people who share a culture that is based on a long tradition of common experience. The New Zealand Deaf community includes a network of social, sporting, religious and political organisations all over the country. What particularly makes them distinct is their strong sense of identity and a shared use of sign language. New Zealand Sign Language (or N.Z.S.L.) is one of New Zealand's community languages, unique to our country and soon to be recognised as the third official language of New Zealand, after English and Maori .

To find out about your local Deaf community, the Deaf Association has a full list of organisations at www.deaf.co.nz or check your local telephone book under 'Deaf Association' or 'Deaf Society'.

Other parents have their say...

“Your child's greatest challenges often turn out to be their greatest strengths or gifts. You yourself will find your own reserves of patience, courage and commitment. You will discover the hero within yourself.”

“We are confident that Anahera will be able to choose her own career path and as parents, we know we do not need to worry. Luckily for us, we had a beautiful healthy happy baby. She has grown into a bubbly outgoing child who loves interacting with other people.”

ACKNOWLEDGEMENTS: 'GETTING STARTED' and 'THE FAMILY BOOK' were inspired by "Choices", a publication by the Australian Hearing Services. 'The Family Book' has been undertaken by Deaf Education Aotearoa New Zealand and the National Audiology Centre. This is a joint project supported by the Ministry of Education and the Ministry of Health. This publication is endorsed by the New Zealand Audiological Society.

Thank you to: Auckland Parents of Deaf Children Inc., Campbell Photography, Canterbury Parents of Deaf Children Inc., Deaf Association of N.Z., Flat Bush Kindergarten, Great Things Communications, Group Special Education, Hearing House, Kelston Deaf Education Centre, National Foundation for the Deaf, N.Z. Federation for Deaf Children Incorporated, Project HIEDI and van Asch Deaf Education Centre.

