

Working with families when a Hearing Loss is Confirmed

This fact sheet uses the terms deaf, deafness and hearing loss interchangeably. They are not used to imply level or type of deafness and include children with mild, one-sided, or temporary deafness.

In other publications and websites the reader will find other definitions that some groups of people identify themselves with, for example “Deaf” (with an upper -case D) is used by people who have had a significant hearing loss since birth, usually use sign language, and identify with being part of the Deaf community. A “deaf” person (with a lower-case d) is likely to be somebody who has lost their hearing after they were born and were brought up in the hearing community.

Hearing loss can happen at any time during childhood:

- Hearing loss can be present at birth or develop at any time during childhood (NDCS 2013)
- More than 90% of deaf children have hearing parents who have no previous experience of deafness (Mitchell & Karchmer 2004)

Hearing loss can be permanent or temporary (NDCS 2013):

- Hearing loss can be described as mild (21-40 dB Hearing Level), moderate (41-70 dBHL), severe (71-95 dBHL) or profound (95+ dBHL) in nature, and can affect 1 or both ears
- Permanent hearing loss can be caused by genetics, complications at the time of birth (e.g. lack of oxygen, severe jaundice, extreme prematurity), congenital infection (e.g. cytomegalovirus), childhood illness (e.g. meningitis) or head injury

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- Temporary hearing loss is caused by otitis media with effusion (commonly known as 'glue ear'). Children with glue ear are usually monitored over time. Most cases of glue ear resolve spontaneously in a short space of time (within 3 months) but for those children where it lasts longer and is having a negative impact on their development the family will be offered surgery to insert grommets in the eardrums, or temporary hearing aids (NICE 2009). Some groups of children have craniofacial abnormalities or differences which mean they are likely to have long-standing glue ear that does not resolve spontaneously. This includes children with Down's syndrome and those born with cleft palate.

Use your knowledge and positive attitude to reassure families with recently diagnosed children:

- The news that a child is deaf can come as a great shock to their parents. Some parents will be upset, others will be relieved that their suspicions have finally been confirmed. Deaf parents may feel confident in the knowledge that they can share their culture and experience with their child. Every parent will have their own reactions, and there is no right or wrong way to feel.
- With the right support, deaf children can participate in all the same activities as their hearing peers, and can achieve in school as well as other children with the same cognitive ability.
- Deaf children can learn to communicate through sign or spoken language, or a combination of both. Some parents feel under a lot of pressure when making choices about communication, but it is important to remember that they do not have to make a choice for life. They may want to change their approach as they learn more about their child's needs and preferences. A common concern about sign language is that it delays or prevents speech development. There is no evidence that shows this is the case provided a rich spoken language environment is still available for the child.

Using sign language early may in fact be beneficial in language and later speech development. Hand-eye coordination develops earlier than speech skills and babies are able to use simple signs such as milk, eat, sleep, nappy and teddy, before they are able to say these words. Children will communicate in the way that is easiest for them at the time and it is therefore natural for children to drop using signs as they begin to talk. Using sign language may remain an important way to reinforce the learning of new language for some families, for communication at times when hearing equipment is faulty or can't be used, and for mixing with deaf friends and the Deaf community.

- Families often benefit from talking to and meeting other families in the same situation. Parents may also benefit from signing up to the National Deaf Children's Society's (NDCS) Parent Place forum bit.ly/1pvkbTB or join the NDCS Facebook page on.fb.me/1ywiYQ7 to share experiences with other parents online, or choose to meet other families at a local NDCS group bit.ly/1rjk90h
- The NHS provides a range of good quality hearing aids and cochlear implants free of charge to families. Hearing aids help children hear as much as possible with the hearing they have. If a child is still unable to hear the full range of speech sounds with the most powerful hearing aids the audiologist will offer a referral for the family to have an assessment with a specialist implant team. A cochlear implant is an electronic device that stimulates hearing in children who are severely or profoundly deaf and who gain little or no benefit from hearing aids. The implants are fitted during an operation. A wide range of other useful equipment is available to deaf children, some of it from the local authority, which helps them hear and listen easier in difficult listening environments (such as when there is lots of background noise) or to listen to other electronic equipment instead of headphones (such as TV, games consoles, mobile phones etc).
- Families who have a child with a hearing loss are entitled to claim Disability Living Allowance to help with additional costs and extra care needs associated with raising a child who has a disability (e.g. purchasing equipment, transport costs to hospital appointments etc).

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Specialist support is available from the child's wider multidisciplinary team which includes:

- An audiologist from a local NHS Trust, and a Teacher of the Deaf from the local authority's specialist sensory support team. An ENT GP, paediatrician who specialises in audiology or audiovestibular physician who is responsible for the medical management of the child. The GP will also order any aetiological investigations needed to identify the cause of the hearing loss and refer the family for genetic counseling if wanted. They may also see, speech and language therapists, and other professionals depending on their needs. Some areas have a HV who specialises in working with deaf children and their families.

Simple steps can make communication easier with deaf children or deaf parents:

- To help a deaf child or adult understand what's being said it's important to get their attention before starting to talk to them. Make sure you face the person and keep eye contact. Lip-reading is easiest and hearing aids work best at a distance of 1-3 metres from the person speaking. Do not cover your mouth when speaking. Check that background noise is kept to a minimum (e.g. ask that the family turn off the TV or pause the washing machine in the background), speak clearly without shouting, and maintain your normal rhythm of speech. Use gestures and facial

expressions to help communication. Make sure the room is well lit and avoid sitting in front of a window which will put your face in shadow and make it harder to lip-read.

- If you are working with a family whose first language is British Sign Language (BSL) find out what the local procedure for booking interpreters is and ensure that appropriate communication support with a qualified interpreter is booked. This may be available in person or by video relay. It is not usually acceptable to ask family members to interpret.

HVs and families can access further support plus free, up-to-date, clear, unbiased and balanced information on all aspects of childhood deafness and supporting deaf children at:

All NDCS services and publications are available free-of-charge to members. Membership is also free and registration via the website or Helpline just takes a few minutes:

bit.ly/1kOEzc4

Early Support: Information about deafness and hearing loss (2013):

bit.ly/1kOEwx6

Action for Deafness:

bit.ly/1iaOQoE

References

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