Good Practice Points for Health Visitors

Institute of Health Visiting
Excellence in Practice

Working with families when hearing loss is confirmed

Hearing loss can happen at any time during childhood:

- Around 1 to 2 babies in every 1,000 are born with permanent hearing loss. This increases to about 1 in every 100 for babies who have spent more than 48 hours in intensive care[1]
- 50% of deaf children will be identified through the newborn hearing screening programme (NHSP) and 50% will become deaf during childhood[2]
- More than 90% of deaf children have hearing parents who have no previous experience of deafness[3]. **Between 23% and 40% of deaf children are more likely to have other needs additional to their deafness**[4]. Sometimes these needs are not recognised, or they are attributed to the deafness, for example moderate learning difficulties or autism
- Some deaf babies and children have acute medical and developmental needs which may overshadow their deafness. Having access to sound and communication can make a big difference to children with complex needs

This resource 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 terms to describe deafness, such as hearing impaired, hard of hearing and partially hearing. “Deaf” (with an upper-case D) is used by people who usually use sign language and identify with being part of the Deaf community.

The iHV has also published a GPP on working with families where a hearing loss is suspected which can be accessed here.

Common terminology used

Our ear and hearing are made up of many parts:

- The outer ear
- The middle ear
- The inner ear
- The ear (auditory) Nerve – the hearing (auditory) System pathway in the brain

These terms describe hearing loss where part of the hearing system is not working in a usual way:

- **A conductive loss** - hearing loss caused by something that stops sounds from getting through the outer or middle ear
- **A sensorineural loss** - hearing loss that occurs when there is a problem in the way the inner ear or hearing nerve works
- **A mixed hearing loss** - hearing loss that includes a conductive and a sensorineural hearing loss
- **Auditory Neuropathy Spectrum Disorder** - hearing loss that occurs when sound enters the ear normally, but because of damage to the inner ear or the hearing nerve, sound isn’t organised in a way that the brain can understand

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The information in this resource was updated on 13/09/2022.

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These terms describe the degree or the amount of hearing loss a baby or child has:

- **Mild Hearing Loss** - a person with a mild hearing loss may hear some speech sounds but soft sounds are hard to hear
- **Moderate Hearing Loss** - a person with a moderate hearing loss may hear almost no speech when another person is talking at a normal level
- **Severe Hearing Loss** - a person with severe hearing loss will hear no speech of a person talking at a normal level and only some loud sounds
- **Profound Hearing Loss -** a person with a profound hearing loss will not hear any speech and only very loud sounds

Every baby and child responds differently to a hearing loss according to their makeup and their environment. Even a mild loss, or single-sided deafness, can have a significant impact on a baby and child's development.

Causes of hearing loss

A **Permanent hearing loss** can be caused by genetics, complications at the time of birth (for example: lack of oxygen, severe jaundice, extreme prematurity), congenital infection (for example: cytomegalovirus), childhood illness (for example: meningitis), or head injury.

Temporary hearing loss usually occurs because of problems with the middle or outer ear. The most common cause is otitis media with effusion (OME) (commonly known as 'glue ear'). Babies and children with OME are usually monitored, and most cases resolve spontaneously in a short space of time (within three months). If OME lasts for longer or is having a negative impact on the baby or child's development, they may be offered surgery to insert grommets in the eardrums, or temporary hearing aids[5].

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 a cleft palate.

Good practice points for health visitors

- **Deafness will impact babies, children, and their families in different ways. Use your knowledge and strengths-based approach to support families with recently diagnosed children.**
- **Families will experience a range of emotions when they receive a diagnosis of deafness**, there is no right or wrong way to feel. Some parents will be upset or feel responsible for the deafness. Others will be relieved that their suspicions have finally been confirmed and support can be put in place for their child. Deaf parents may feel confident in the knowledge that they can share their culture and experience with their child.
- **Families benefit from high quality support from those who are knowledgeable about deafness**, as soon as possible after diagnosis. This should include audiological support and support from a Teacher of the Deaf.
- **Support with learning and transition into early years settings and education**: With the right support, deaf children can participate in all the same activities as their hearing peers and can achieve as well in school as other children with the same cognitive ability.
- **Meeting other deaf babies, children and adults** and having access to deaf role models can help to promote positive attitudes to deafness and help to develop a child's deaf identity.
- **Most deaf children use spoken language** if they have access to enough speech, but many will also use some sign language and natural gesture.
- Some deaf babies and children will learn British Sign Language (BSL) either as their first language or alongside speech. Parents do not have to make a choice for life, and they can change their approach as they learn more about their child's needs and preferences. There is no evidence that choosing to use some signing with a baby or child delays or prevents speech development.
- **Deaf babies and children do best when they have access to a rich language environment**, spoken or signed or both. To learn spoken language, they will need good access to speech, usually through a personal hearing device. They will also benefit from lots of visual information, for example facial expressions, lip patterns and natural gesture.
- **Using sign language early may in fact help early communication and bonding**. Hand-eye coordination develops earlier than speech skills and babies can use simple signs such as milk, eat, sleep, nappy, and teddy, before they are able to say these words.
- Using sign language can help families when mixing with deaf friends and the Deaf community, or when hearing equipment is faulty or can't be used.

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Working with families when hearing loss is confirmed

Good practice points continued

- **The NHS provides a range of good quality hearing aids and implants** free of charge to families. Hearing devices amplify the sounds a baby or child cannot hear as well, but they cannot replace normal hearing. They work best when they are close to the speaker and there are low levels of competing noise.
- **A cochlear implant maybe offered to babies and children who are unable to hear the full range of speech sounds** even with the most powerful hearing aids. A cochlear implant is a type of implanted hearing device that converts sound into electrical signals. It has two parts – an internal receiver which is implanted surgically under the skin behind the ear, and an external part which is worn like a hearing aid. This part is known as a speech processor and includes the microphone.
- **Other hearing technology and equipment can help children** hear and take part in everyday activities in difficult listening environments (such as when there is lots of background noise). These include radio aids, devices which can stream sound directly to personal hearing technology, and equipment such as vibrating alarm clocks.

Getting support

Many families benefit from meeting other families of deaf children. The National Deaf Children's Society (NDCS) (Facebook Page) is an online forum in which parents can share experiences and tips. Many local authorities run groups for the families of deaf pre-school children. There are also local deaf children's society groups. To find the nearest group/place, visit: https://bit.ly/3aChjRK.

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 (such as purchasing equipment and transport costs to hospital appointments).

Specialist support may include:

- An audiologist or a consultant from the implant centre.
- An ear, nose and throat (ENT) consultant.
- A medical team who will work to identify the cause of the hearing loss and offer a referral for genetic counselling.
- Teacher of the Deaf (ToD) are qualified teachers who have taken further training and qualified to teach children with a hearing loss. They provide support to deaf children, their parents and family, and to other professionals who are involved with a child's education. They offer support after the diagnosis and with transition into early years settings and education.
- A speech and language therapist and specialist disability health visitors.

Further resources

The National Deaf Children's Society (NDCS) is the leading charity for deaf children. They are there for every deaf child and their family no matter what their level or type of deafness or how they communicate.

The NDCS has a helpline and they offer free independent information, advice, and guidance on a range of topics relating to childhood deafness. 0808 800 8880

All NDCS services and publications are free of charge to members and membership is free. Registration via the website or helpline takes a few minutes.

Further information on UK-wide newborn hearing screening:

England

- Guidance Newborn hearing screening programme: standards: https://bit.ly/3dg2vh4

Wales

- Newborn hearing screening Wales: https://bit.ly/3P9nbV5

Scotland

- Newborn hearing test: https://bit.ly/3P7zod8

Northern Ireland

- Newborn hearing screening: https://bit.ly/3zBySya

References

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2. NDCS (2017) Early identification of deafness in childhood (following newborn hearing screen) position statement https://bit.ly/3RUkZ5I
3. National Institute on Deafness and Other Communication Disorders (2021) Quick Statistics About Hearing. https://bit.ly/3vNPTEh
4. Consortium for Research in Deaf Education (CRIDE) (2017) CRIDE report on 2017 survey on educational provision for deaf children https://bit.ly/3SElyBJ
5. NICE (2021) Otitis media with effusion Last revised June 2021. https://bit.ly/3p1B39m

This GPP was originally written by Vicki Kirwin, Audiology Specialist, and has been updated by Emma Fraser, Teacher of the Deaf, Policy and Campaigns, National Children's Deaf Society.

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