

The newborn hearing screening journey

The NHS Newborn Hearing Screening Programme aims to identify all children born with moderate to profound permanent deafness* within 4-5 weeks of birth and to ensure the provision of high quality and appropriate assessment and support for deaf children and their families. This article set out an infant's journey from screening to early support.

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The NHS Newborn Hearing Screening Programme (NHSP) gives every parent in England the opportunity to have their newborn baby screened for hearing loss. The NHSP was introduced following a Health Technology Assessment¹ commissioned by the Department of Health. Since NHSP started in 2001, more than three million newborn babies have been screened and approximately 3,500 babies with a permanent hearing loss have been detected by the programme. Over 99% of parents offered the opportunity to have their child's hearing screened accept.

Each year, some 840 children are born in the UK with a permanent hearing loss of 40dB or more in both ears**. Most of these babies are born into families with no experience or history of childhood hearing loss and this is why systematic screening is so important. The screening test itself is not diagnostic but identifies where further testing or investigation may be needed. It usually takes place before leaving the maternity unit, but can also be carried out at home or in a community setting.

Screening methods

Two screening methods may be used: the Automated Otoacoustic Emissions test (AOAE) and the Automated Auditory Brainstem Response (AABR) (FIGURES 1 and 2).

The AOAE involves placing a small, soft tipped ear-piece in the baby's outer ear; soft 'clicking' sounds are then played. When a hearing ear receives sound the cochlea produces a response which can be picked up by a tiny microphone in the earpiece.

The AABR involves three small sensors being placed on the baby's head and neck. Soft headphones are then put over the baby's ears and a series of clicking sounds are played, with the sensors measuring the brain's response.

Types of deafness

There are different types of deafness. Conductive deafness is when sound cannot pass efficiently through the outer and middle ear to the cochlea and auditory nerve. The most common type of

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Key points

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1. The NHSP is highly effective in detecting newborn babies with a permanent hearing loss.
2. Outcomes for every child can be improved through a high quality hearing screening programme, effective assessment and early intervention.
3. Early intervention to develop communication is the key to long-term outcomes for children.



FIGURE 1 Infant undergoing the Automated Auditory Brainstem Response hearing screening test.



FIGURE 2 Infant undergoing the Automated Otoacoustic Emissions hearing screening test.

conductive deafness in children is caused by 'glue ear', which is a build-up of fluid in the middle ear. Whilst the NHSP does pick up some cases of conductive deafness the programme aims to identify children with a permanent hearing loss. Children may also have sensori-neural (or nerve) deafness. This deafness is permanent and affects the inner ear or auditory nerve. Children who have a sensori-neural deafness can also have a conductive deafness and this is known as a mixed hearing loss.

Causes of deafness

There are many reasons why a child can be born deaf or become deaf in infancy. Genetic reasons account for around half of all cases of newborn deafness in the UK. Other causes of newborn hearing loss are unknown but may include: infections such as maternal rubella, cytomegalovirus (CMV) and toxoplasmosis amongst others.

Premature birth can also increase the risk and three in every 1,000 babies who have spent more than 48 hours in a neonatal intensive care unit are diagnosed with a permanent hearing loss¹. Severe jaundice or a temporary lack of oxygen can contribute to a child becoming deaf. In addition, the use of essential treatments in neonatal intensive care can negatively affect hearing².

The importance of early identification

Deafness can significantly affect a child's language, communication and social development. By the age of three, a hearing child will generally enjoy a vocabulary of approximately 700 words, whilst a deaf child the same age with undetected hearing loss will know less than 25³. A delay in identification means a delay in establishing

21. All families of babies with confirmed deafness are provided with an explanation of the full range of support available and given the Early Support publications.
- 21a. Families are given the opportunity to meet other families of deaf children and also make contact with older deaf children and adults.
22. Families are offered a main professional contact to provide ongoing regular support and ensure a co-ordinated and coherent service.
- 23c. Robust ongoing audiological care including regular checking of hearing aids, hearing aid settings, and use in the home is carried out. This information is shared with colleagues to form part of each baby's audiology care plan.
24. Families are given information about the full range of communication approaches and supported in their choices, in accordance with the principle of informed choice.
25. The social care needs of all families with a deaf child should be reviewed as part of an initial assessment by the lead professional. In all areas there should be available a member of Social Care staff, with appropriate expertise in working with deaf children and their families, to respond to the identified needs.
26. When a baby has additional needs they are supported by professionals with appropriate expertise. These additional needs are responded to within one week of their identification.

FIGURE 3 Selected standards for the provision of support post-diagnosis. Standards 21-26 of the NHSP Quality Assurance standards, June 2008⁴.

effective communication with the child. This in turn can have a long term impact on their social, emotional and educational development. The impact on the family is also substantial. Identifying deafness or a hearing loss at birth is critical to ensure the best possible life chances for a child.

Early support for families

The introduction of the NHSP has been a catalyst for change in the ongoing support services for deaf children. Parents have the time to research different options to support the best development for their child. This may include fitting hearing aids at an age much earlier than possible, prior to the NHSP, or a cochlear implant. Parents may also choose sign language for their child. Effective information enabling informed choice is vital for parents. Early Support (www.earlysupport.org.uk) is about improving services for families with young disabled children.

It provides a standard framework and set of materials that can be used in many different circumstances and a set of expectations about how services should work with families. It is a way that keeps

families at the heart of discussion and decision-making about their child. <http://www.earlysupport.org.uk/>

Despite huge progress since the introduction of Early Support, there is still much work to be done to facilitate joint working between health, education and social care. There is arguably limited advantage in newborn hearing screening and early identification of deafness unless Primary Care can provide appropriate empowering support and services for families. Most importantly, parents must be given the support to make informed decisions about their child's development, which reflect their own culture, values and views.

The NHSP works within the Early Support framework and has a series of national Quality Standards (26 in all) which relate to the entire pathway; screening, diagnostics and ongoing support. There are six Quality Standards that relate to ensuring families and children get the support they need following their early diagnosis. **FIGURE 3** refers to some of those standards.

In the initial months of a baby's life, it is

important to parents that they are supported in establishing good communication between them and their child. It is essential for families to communicate in a way that feels natural and comfortable for them and parents will be led by their child and their natural communication strengths. Sounds, gestures, touches, facial expressions, hugs and games are all important in early communication, as is the use of voice or sign according to parental choice. During this time, parents also have the opportunity to learn about a range of options for communication with their deaf child and where to get the support in evaluating and developing those options. Ideally, in an informed choice context, families will be able to explore and choose from a range of different options. However, they fall into two main approaches which are predominately manual (sign based), or auditory-oral (hearing and speaking based).

British Sign Language (BSL) is the language of the British Deaf Community. It is estimated that over 70,000 people use BSL as their first or preferred language⁵. BSL is a visual language using hand shapes, facial expressions, gestures and body language to communicate. It has a structure and grammar different from that of written and spoken English. Families choosing this option will need support to develop their own skills and can also benefit from the richness of deaf culture. The involvement of native BSL users and deaf people is important in the support for families who choose this approach.

Auditory-oral approaches, of which there are a range of variations, aim to develop listening skills and spoken language in deaf children. The emphasis is on the use of hearing aids, radio aids and cochlear implants to maximise the use of any hearing a deaf child has. Most auditory-oral approaches also use lipreading to support the child's understanding. These approaches are used by children with all levels of deafness, from mild to profound. Auditory-oral approaches do not use sign language but many incorporate natural gestures.

Early support in practice – case study

Wandsworth Hearing Impaired-Service

As a Hearing-impaired Service our work is underpinned by informed choice and the Early Support materials.

Families are placed at the heart of decision making. We offer families a range of approaches based on the choice they make. Two important principles of informed choice for us, is that decisions are not set in stone. We review choices every three months through a Family Plan meeting that we hold in our centre for deaf children and their families. It is important for us as a team that we do not make judgements but respect the choices families make. For families who wish to follow a signing route we ensure the teacher of the deaf working with the family holds a sign language qualification, and provide baby sign classes. For families wishing to follow an oral route we again consider carefully how we can support the family and child. Families tell us that they value support from the professionals around them in making their decision.

Our approach in Wandsworth is to ensure that families fully understand the diagnosis and its implications. We have an Early Support library in our centre which holds the latest books and journals on deafness and we support families in accessing high quality up-to-date information. We ensure families can access high quality, relevant information and can meet other families of deaf children so they have full awareness of the choices available.

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Head of Service

It is important to recognise that what a child and family need may change with time or with increased knowledge and experience. Parents must be supported to understand that a decision made in infancy is not permanent and professionals should always support a family in the process of making choices.

The NHSP is involved in delivering services to support parents in making an informed choice. This includes working in partnership with a number of voluntary agencies, in particular the National Deaf Children's Society (NDCS). The NDCS offers a range of opportunities for parents to support each other. One of these opportunities is the Parent2Parent Network, which is a joint venture between the NHSP and NDCS. It is a vital support service which helps parents of deaf children find other parents in similar positions with whom to share their experiences (www.parentsnetwork.org.uk).

The NHSP works closely with the national Early Support programme which has developed a range of materials to support both families and professionals. Two key documents developed by the Early Support programme relate specifically to the practice of informed choice.

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* *The term 'deafness' is used to cover all types of hearing loss.*

***The Newborn Hearing Screening Programme defines this as being a hearing impairment on the better ear of ≥ 40 dB HL over the frequencies 0.5, 1, 2 and 4 kHz.*

References

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