

Early identification of deafness in childhood (following newborn hearing screen) position statement

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1. National Deaf Children's Society's position

- 1.1. Parental or professional concern about hearing should always be taken seriously and acted on.
- 1.2. Care pathways must be commissioned which allow for timely hearing assessment and referrals from multiple routes, including screening services, GP, health visitors, speech and language therapists, parents, etcetera.
- 1.3. In addition, until such time as the UK NSC make alternative recommendations, the National Deaf Children's Society supports government policy in England, Wales and Northern Ireland to ensure all children receive hearing screening at school between the ages of 4-7 years.

2. Introduction

Permanent hearing loss

- 2.1. Newborn hearing screening completed roll-out across the UK by 2006. During its period of implementation the programme has proved very successful in reducing the age of diagnosis for babies born deaf, and provides the opportunity for early intervention before the age of 6 months. However, 50% of children with a permanent deafness require identification after the newborn screening period, including those born with mild deafness which may be missed by newborn hearing screening, those who have progressive, later-onset or acquired deafness, and those who were born deaf but who missed newborn hearing screening and later moved into the country.^{1 2 3 4} Prevalence of permanent deafness in children increases with age⁵ to approximately 4/1000 at the age of 18 years⁶.

Temporary hearing loss

- 2.2. Temporary deafness caused by 'otitis media with effusion' (a common childhood condition known as 'glue ear') affects up to 80% of children before the age of 10 years at some point⁷. Glue ear usually resolves spontaneously within three months. However, 30-40% of children have recurrent episodes and 5-10% of these episodes last for more than a year. During this time, and without appropriate awareness and support, glue ear can also have a significant impact on a child's language development and educational attainment.
- 2.3. Some groups of children are known to be at risk of:
 - a) Having long-term glue ear (such as those born with a cleft palate, Primary Ciliary Dyskinesia or Down's syndrome).
 - b) Developing permanent deafness (such as those children born with Down's

¹ Bamford J, Fortnum H, Bristow K, Smith J, Vamvakas G, Davies L, *et al*. Current practice, accuracy, effectiveness and cost-effectiveness of the school entry hearing screen. *Health Technol Assess* 2007;**11**(32).

² Watkins, P. & Baldwin, M. Identifying deafness in early childhood: requirements after the newborn hearing screen. *Arch Dis Child* 2011;**96**:62-66

³ Watkins, P. & Baldwin, M. The longitudinal follow up of a universal neonatal hearing screen: The implications for confirming deafness in childhood. *International Journal of Audiology* 2012;**51**:519-528

⁴ Walker, A. & Nassas, G. The role of the school entry hearing screen in identifying childhood hearing impairment in reception age children. *Audacity Magazine* December 2014

⁵ Fortnum, H.M., Summerfield, A.Q., Marchall, D.H, Davis, A.C., & Bamford, J.M. Prevalence of permanent childhood hearing impairment in the United Kingdom and implications for universal neonatal hearing screening: questionnaire based ascertainment study. *BMJ* 2001 Vol 323

⁶ The National Deaf Children's Society estimates based on current research and epidemiological data, 2012

⁷ Surgical management of otitis media with effusion in children, Clinical Guideline, National Institute of Health and Clinical Excellence, 2008 <https://www.nice.org.uk/guidance/cg60>

syndrome or another genetic syndrome associated with deafness).

- 2.4. Other children may be deafened following illness (such as meningitis, or following chemotherapy), etcetera.
- 2.5. Later-onset deafness can therefore happen at any time and there is no optimum time for further screening, although children may be screened soon after they start school with the aim of identifying any permanent hearing difficulties that may impact on their education.
- 2.6. Whilst it is still government policy that children receive this hearing screening between the ages of 4 and 5 (England and Northern Ireland)⁸⁹ and 5-7 years (Wales)¹⁰, more than 10% of services across the UK had been found to be no longer providing hearing screening at school entry in 2007¹¹. Scotland no longer carries out school entry hearing screening¹² and we understand further areas across England have gradually withdrawn services.

3. Background

Commissioning school entry hearing screening

- 3.1. England, Wales, Scotland and Northern Ireland all have early intervention and prevention public child health programmes. In England the commissioning of the child health programme is the responsibility of local authorities^{13 14}. The child health programmes are each led by health visitors and their teams for pre-school children before handover to a school nursing-led service on school entry¹⁵.
- 3.2. Included in the universal offer it is recommended in England, Wales and Northern Ireland that hearing screening is carried out as part of the health assessment at school entry during ages 4 and 5 in England and Northern Ireland, and between ages 5 and 7 in Wales. In addition, parental concern about hearing should always be noted and acted on at any stage.

NSC guidelines

- 3.3. The UK NSC advises ministers and the NHS in the four UK countries about all aspects of screening and supports implementation of screening programmes¹⁶. The Child Health Sub-Group of the UK NSC made recommendations that screening for hearing loss in school age children should continue until a review of new Health Technology Assessment (HTA) research was undertaken¹⁷. This research was published in May 2016 and we welcomed consultation during the

⁸ The Healthy Child Programme (England) 2009 <https://www.gov.uk/government/publications/healthy-child-programme-pregnancy-and-the-first-5-years-of-life>

⁹ Healthy Child, Healthy Futures (Northern Ireland) 2010 <https://www.health-ni.gov.uk/publications/healthy-child-healthy-future>

¹⁰ Healthy Child Wales Programme 2016 <http://gov.wales/topics/health/publications/health/reports/healthy-child/?lang=en>

¹¹ Bamford J, Fortnum H, Bristow K, Smith J, Vamvakas G, Davies L, *et al*. Current practice, accuracy, effectiveness and cost-effectiveness of the school entry hearing screen. *Health Technol Assess* 2007;**11**(32).

¹² Child Health Programme Scotland 2005 <http://www.isdscotland.org/Health-Topics/Child-Health/Child-Health-Programme/Child-Health-Systems-Programme-Pre-School.asp>

¹³ Health and Social Care Act 2012 <http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted>

¹⁴ Guidance to support the commissioning of the Healthy Child Programme 0-19: health visiting and school nursing services, PHE, Jan 2016 <https://www.gov.uk/government/publications/healthy-child-programme-0-to-19-health-visitor-and-school-nurse-commissioning>

¹⁵ Getting it right for children, young people and families; Maximising the contribution of the school nursing team: Vision and Call to Action, DH 2012 https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216464/dh_133352.pdf

¹⁶ <https://www.gov.uk/government/groups/uk-national-screening-committee-uk-nsc>

¹⁷ <http://legacy.screening.nhs.uk/hearing-child>

NSC review of their recommendations as registered stakeholders¹⁸.

HTA 2016¹⁹

- 3.4. The HTA research compared an area that has a school hearing screening programme (Nottingham) with an area that does not (Cambridge). The research found that 36% more children were referred for further testing in the area that did not have the screen. The mean age of referral and numbers of children identified with deafness was nearly identical, but for those children who were subsequently confirmed as being deaf, there was strong evidence that the children from the site with a screening programme were older at referral.
- 3.5. Whilst the research suggests that school entry hearing screening was not found to be cost-effective for the areas studied, the researchers highlighted aspects of their results that suggest caution is exercised before a local area withdraws its own programme. In particular the identification of deaf children is highly dependent on the effectiveness of parents, schools and health professionals noticing promptly when a child might have hearing problems and referring them to audiology, which tends to be highly variable across areas.

Local arrangements

- 3.6. Until such time as the UK NSC make alternative recommendations, the National Deaf Children's Society supports government policy to ensure all children receive hearing screening as part of the health assessment at school entry during ages 4-7 years.
- 3.7. In those areas with school entry hearing screening currently in place, we expect that:
 - a) A pathway and clear guidelines for onwards referral to audiology are developed and implemented from the school entry hearing screen.
 - b) Pathways are additionally developed that enable timely review by audiology services for:
 - children identified as requiring hearing surveillance following the newborn hearing screen^{20,21}
 - children known to be at risk of developing deafness
 - children in response to parental concern about their hearing
 - children referred from other professionals, such as health visitors, school nurses, speech and language therapists etc. without the need for families to have to seek further referral from their GP or wait until hearing screening takes place.
 - c) Data should be collected locally and nationally on coverage, referral rates, age of confirmation of deafness, and prevalence of deafness. Information is reported annually to the local Children's Hearing Services Working Group (CHSWG). Information systems should be capable of identifying those children who should be offered screening, managing them through the pathway, and ensuring that the best outcomes are reached for the child and family.

¹⁸ <http://legacy.screening.nhs.uk/hearing-child>

¹⁹ Fortnum H, Ukoumunne OC, Hyde C, Taylor RS, Ozolins M, Errington S, et al. A programme of studies including assessment of diagnostic accuracy of school hearing screening tests and a cost-effectiveness model of school entry hearing screening programmes. *Health Technol Assess* 2016; 20(36). <http://www.journalslibrary.nihr.ac.uk/hta/volume-20/issue-36#abstract>

²⁰ Guidelines for surveillance and audiological referral of infants & children following the newborn hearing screen, NHSP 2012 <https://www.gov.uk/government/publications/surveillance-and-audiological-referral-guidelines>

²¹ Guidelines for surveillance and audiology referral of infants & children following the newborn hearing screen, NHS Scotland 2012 <http://www.nsd.scot.nhs.uk/Documents/UNHStargetedFollowUpGuide2012.pdf>

- d) School entry hearing screening is included in local audit and clinical governance arrangements. The information and IT systems should also enable adequate fail-safe systems and support performance management of the screening programme.
- e) Informed parental consent is gained before hearing screening. The recommendation of the UK NSC is that the explicit informed consent of parents should be obtained before any screening test is carried out.
- 3.8. In those areas where there is no hearing screening currently in place, we expect that:
- a) Pathways are additionally developed that enable timely review by audiology services for:
- children identified as requiring hearing surveillance following the newborn hearing screen^{22, 23},
 - children known to be at risk of developing deafness
 - children in response to parental concern about their hearing, and
 - children referred from other professionals, such as health visitors, school nurses, speech and language therapists etc., without the need for families to have to seek further referral from their GP or wait until hearing screening takes place.
- b) Data should be collected locally and nationally on coverage, referral rates, age of confirmation of deafness, and prevalence of deafness. Information is reported annually to the local Children's Hearing Services Working Group (CHSWG).
- c) Appropriate commissioning arrangements are in place to ensure that audiology services have adequate capacity should referrals be higher than areas with school entry hearing screening in place.
- d) Local professionals (including and especially GPs) have been made aware of referral criteria and pathways so that they are able to proactively refer children when there are concerns about their hearing, rather than waiting for the child's routine school screen which is not available locally.
- e) In places where there is high movement of at risk populations (such as some immigrant populations) into the area, that there is targeted screening/referral in place to ensure children who would not previously have newborn hearing screening or otherwise been in the NHS system are not missed.
- f) Parents, teachers and other professionals are given information about signs to look out for and are able to understand/act on it (e.g. through the local offer, information from their Health Visitor before the child starts school, early years settings etc.).

²² Guidelines for surveillance and audiological referral of infants & children following the newborn hearing screen, NHSP 2012
<https://www.gov.uk/government/publications/surveillance-and-audiological-referral-guidelines>

²³ Guidelines for surveillance and audiology referral of infants & children following the newborn hearing screen, NHS Scotland 2012
<http://www.nsd.scot.nhs.uk/Documents/UNHStargetedFollowUpGuide2012.pdf>