

# Audiology services provision in the UK position statement

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# **Contents**

		Page
1.	Purpose of the position statement	2
2.	<ul> <li>NDCS expectations on audiology services</li> <li>Holistic team approach (paragraphs 2.3-2.5)</li> <li>Transitions (paragraph 2.6-2.7)</li> <li>Audiology test facilities (paragraph 2.8)</li> <li>Timescales for treatment (paragraphs 2.9-2.12)</li> <li>Hearing aid availability and batteries (paragraphs 2.13-2.14)</li> <li>Children with additional or complex needs (paragraph 2.15)</li> <li>Hearing aid reviews (paragraph 2.16)</li> <li>Loss of hearing equipment and insurance (paragraph 2.17)</li> <li>Participation of parents, children and young people (paragraphs 2.18-2.19)</li> <li>Information for parents, children and young people (paragraphs 2.20-2.23)</li> <li>Qualifications of staff and professional competence (paragraphs 2.24-2.26)</li> <li>Quality Assurance and Quality Standards (paragraphs 2.27-2.28)</li> </ul>	2
3.	Commissioning of audiology services from the private, independent, or third sector	7
4.	Private provision of hearing aids	8
5.	Auditory implants	8
6.	Aetiological investigations	9
7.	Data and recording	9
8.	NDCS services and audiology	9

#### 1. Purpose of the position statement

- 1.1. Audiology services are responsible for assessment, diagnosis and rehabilitative support of deaf children (including hearing aid fitting and maintenance). This paper details NDCS position on audiology service provision throughout the UK. It sets out our position as a partner organisation supporting deaf children and their families, and in terms of driving up service standards with the expectation of improving outcomes for deaf children and their families. The paper highlights and records NDCS position on specific issues common to audiology practice. For further detail on specific issues refer to NDCS position statements on *Genetics* and deafness, *Insurance* and replacement hearing aids, informed choice, and implantable hearing devices.<sup>1</sup>
- 1.2. Further information for families on their rights and what they can expect from their audiology service is available <u>here</u>.

#### 2. NDCS expectations on audiology services

- 2.1. In England, Scotland and Wales, good practice guidance, standards and quality audit tools have been developed for paediatric audiology services. NDCS has participated in these developments and expects to see their implementation and widespread use throughout services. At 2016 Northern Ireland does not have a quality standards framework. NDCS will continue to work with local and national partners to get standards developed and implemented.
- 2.2. NDCS believes that an effective audiology service that meets the needs of deaf children will have the following characteristics.

#### A holistic and team approach

- 2.3. Audiology should be a key element of a holistic approach to supporting deaf children where their education, health, social and personal needs and their human right to participation and communication<sup>8</sup> are met in a coordinated and family-friendly way.
- 2.4. NDCS believes that the family is the most important influence on the deaf child's life. Deaf children and young people must be fully supported in participating and influencing decisions and issues that affect their lives. The child, young person and family should be central and equal members of the multi-disciplinary team supporting them.
- 2.5. NDCS believes that every tertiary audiology service should belong to a local multi-disciplinary and multi-agency Children's Hearing Services Working Group (CHSWG) or similar group. The group must have terms of reference, aims and objectives and publish an annual report. Membership of the group must include representatives from local professionals, service users (parents and young deaf people), funders or purchasers and be enabled to make changes at a strategic level<sup>4</sup>.

UN Convention on the Rights of the Child

Audiology Services UK Position Statement-June 2016-Director PaC

NDCS Position Statements

Transforming Services for Children with Hearing Difficulties and their Families, DH, 2008

Improving Quality In Physiological diagnostic Services (IQIPS), RCP/UKAS, 2012

<sup>&</sup>lt;sup>4</sup> Quality Standards in Paediatric Audiology - Guidelines for the early identification and audiological management of children with hearing loss, NDCS, 2000

<sup>&</sup>lt;sup>5</sup> Quality Standards for Paediatric Audiology Services Scotland, NHSQIS, April 2009

<sup>&</sup>lt;sup>6</sup> Quality Standards for Paediatric Audiology (Wales), NHS Wales & Welsh Assembly Government, March 2010

<sup>&</sup>lt;sup>7</sup> NDCS Listen Up! campaign report, 2015

#### An effective transition to adult services

- 2.6. Every audiology service should have a clear written and accessible protocol on managing the transition of young people to adult services. Policies should be flexible enough to enable transition plans to meet the needs of the young person and their family. As young deaf people move into adulthood the objectives of the services providing care for them should be:
  - a) To ensure continuity of care and support for the young person and their family.
  - b) To provide equality of opportunity in order to enable all deaf young people to participate equally in education, training and employment.
- 2.7. Further information and guidance is available in Quality Standards and good practice guidelines. Transition from paediatric to adult audiology services and Commissioning audiology services for young adults. 10

#### Audiology test facilities that are fit for purpose

Modern digital hearing aids are programmed to fit prescription targets and 2.8. verified using real-ear measurements. The introduction of even a small error in the original hearing test results (e.g. caused by ambient noise) will mean that the hearing aids aren't optimally fitted for the child's hearing loss. Therefore, NDCS believes that paediatric diagnostic hearing testing must be undertaken in soundproofed facilities that "conform to standards outlined in the Department of Health Building Note (1994): Audiological testing must be performed in soundproofed accommodation built to ISO 8253-1 (1998) and ISO 8253-2 (1998) standards for acoustic test methods and suitable for children." 1112

"Care should be provided in an appropriate location and in an environment that is safe and well-suited to the age and stage of development of the child or young person."<sup>13</sup>

#### **Prompt access to treatment (Timescales)**

- 2.9. Good quality access to sound is critical to a child's development of language and learning. NDCS believes that the impact of hearing loss on children is such that hearing aid fitting should be done as a matter of priority.
- The maximum waiting time from 'referral to treatment' in England 14, Scotland 15 and Northern Ireland is 18 weeks, and Wales 26 weeks. NDCS believes these waiting times are too long for children to be diagnosed with a hearing loss and fitted with hearing aids. NDCS expects hearing assessments to take place within four weeks of referral into the service.
- 2.11. Hearing aids must be fitted within 4 weeks of confirmation of deafness, unless deliberately delayed for management reasons. 181920

Audiology Services UK Position Statement-June 2016-Director PaC

Quality Standards and good practice guidelines: Transition from children's to adult audiology services, NDCS, 2011 Commissioning audiology services for young adults, NDCS, 2012

Quality Standards in Paediatric Audiology - Guidelines for the early identification and audiological management of children with hearing loss, NDCS, 2000

12 ISO 8253-1 and BS EN ISO 8253-2 Standards for Acoustic Audiometric Test Methods (updated in 1998) and Department of

Health (1994) Building Note 12, Supp 3 ENT and Audiology Clinics/Hearing Aid Centres, NHS Estates

Getting the right start: National Service Framework for Children, Standard for Hospital Services, 2003

<sup>14</sup> NHS Choices

<sup>15</sup> You health, your rights, NHS Scotland

<sup>&</sup>lt;sup>16</sup> Waiting Lists Crisis' Private Members' Business – in the Northern Ireland Assembly, September 2015 17 Welsh Government

Transforming Services for Children with Hearing Difficulties and their Families, DH, 2008

2.12. Earmoulds are an integral part of the hearing aid system and need to be replaced frequently as children grow. When earmoulds become loose the hearing aid does not work optimally because some sound will escape around the edge of the mould. Additionally this escaping sound can re-enter the hearing aid microphone and cause feedback (whistling). Appointments for impressions should be made within 48 hours of being notified of the need. The family should receive the new moulds within 5 working days.<sup>2122</sup>

#### Hearing aid availability and batteries

- 2.13. Bilateral/binaural hearing: NDCS believes that children should always be fitted with bilateral hearing aids unless clinically contraindicated NDCS believes that children should always be given the opportunity to benefit from binaural hearing unless clinically contraindicated<sup>23</sup> (e.g. by fitting two hearing aids, one cochlear implant and one hearing aid, or two cochlear implants). Evidence suggests that for a significant proportion of children unilateral deafness can have an adverse impact on their development and how well they do at school if their hearing needs are not supported.<sup>24</sup> NDCS therefore believes that children with unilateral deafness should be assessed carefully and given the opportunity to trial a hearing device if clinically indicated.
- 2.14. Batteries and accessories: NDCS believes all batteries, leads and accessories that are required should be provided free of charge and be easily accessible.

"All the batteries for your hearing aid will be supplied to you free of charge." 25

"Equipment, leads and batteries must be provided free of charge and despatched by the implant team on the day they receive the request for replacement."26

## Children with complex needs, including language and communication disorders and learning disability

2.15. There is a high prevalence of hearing loss in children with multiple needs.<sup>27</sup> Deaf children with other complex needs should receive the best audiological care that takes account of their other needs. Effective processes and protocols should be in place to ensure that children with complex needs are not missed from routine audiological care. Children with complex needs should be considered for an implantable hearing device, such as a cochlear implant, if they fit the audiological selection criteria and the parents wish an assessment to be undertaken.

#### Hearing aid reviews

2.16. NDCS recommends hearing aid review appointments at least every 3 months for children aged up to 18 months, every 6 months aged from 18 months to 5 years and annually for older children.

"Babies, infants and children with hearing aids should be offered regular hearing

<sup>19</sup> Quality Standards in Paediatric Audiology - Guidelines for the early identification and audiological management of children with hearing loss, NDCS, 2000

Quality Standards in the NHS Newborn Hearing Screening Programme, NHSP, 2010
 Transforming Services for Children with Hearing Difficulties and their Families, DH, 2008

Guidelines for the Taking of Impressions and Provision of Ear Moulds within a Children's Hearing Aid Service, MCHAS, 2005 <sup>23</sup> Quality Standards in Paediatric Audiology - Guidelines for the early identification and audiological management of children with hearing loss, NDCS, 2000

Lieu, J. E. (2004). Speech-language and educational consequences of unilateral hearing loss in children. Archives of Otolaryngology—Head and Neck Surgery, 130(5), 524-530.

How to use your hearing aid, DH, 2008

Quality Standards in Cochlear Implants for Children and Young People, NDCS/BCIG, 2010 Prevalence of additional disabilities with deafness: A review of the literature, NDCS 2012

aid reviews. Such reviews should be scheduled for one and a half hours or more and involve two experienced audiologists. Parents should be able to be present throughout, and the support teacher of the deaf should be invited to attend and /or to send a summary report on the child's progress with reference to the outcome measures described above."

"Hearing aid reviews will need to be very frequent in the early stages of fitting when information is only partial and the child and family are adjusting to the aid. They should never be less than annual."

"Hearing aid fitting and assessment must be reviewed (weekly for newly diagnosed babies, to every few months once hearing aid provision has been established) as required. Children who are established hearing aid users must be reviewed at least annually by the providing service."28

#### Loss of hearing equipment and insurance:

2.17. NDCS has a separate position statement on insurance and replacement of hearing equipment. NDCS expects that young people and parents will take every reasonable care of their hearing aids and that they will be replaced or repaired free of charge when lost or damaged during the course of normal family life. Families should be provided with information about the implications of failing to take all reasonable care of their hearing equipment.

"Your hearing aid is provided free on loan. It is yours for as long as you need it, but it remains the property of the NHS... Your audiology service will repair or replace it free of charge if it goes wrong. However, there may be a charge if it is damaged or lost through misuse or neglect."<sup>29</sup>

#### Participation of parents, children and young people in service improvement initiatives

- 2.18. NDCS believes that the family is the most important influence on the deaf child's life. Parents must be considered as equal members of the team that supports the child.
- 2.19. Participation and communication are basic human rights.<sup>30</sup> Deaf children and young people must be fully supported in participating and influencing decisions and issues that affect their lives. The views of children and young people should influence the development of services as well as their treatment and care. 31

#### Information for deaf children, young people and their parents and families

- 2.20. Services should have effective ways of communicating with children, young people and their families. Services should provide:
  - a) Information about the appointments (times, directions, public transport, facilities, what happens).
  - b) A clear explanation of the assessment results on the day they are carried out.
  - c) Clear written information within one working week of the assessment setting out what happens next.
  - d) Information on what the diagnosis means in terms of enabling the child/young

Children and Families Act 2014

<sup>&</sup>lt;sup>28</sup> Guidelines for the Fitting, Verification and Evaluation of digital signal processing hearing aids within a Children's Hearing Aid ervice, MCHAS, 2005

How to use your hearing aid, DH, 2008 UN Convention on the Rights of the Child

- person to manage their hearing loss more effectively.
- e) Sources of local and national support (e.g. local deaf children's society group, details of NDCS services).
- f) Direct communication and conversation with children and young people themselves in age appropriate ways, taking account of communication preference and any learning difficulties a person may have.
- 2.21. Information should be available to children and parents in their preferred language.
- 2.22. NDCS believes that patients/carers should be offered copies of all letters written about their child.<sup>32</sup> Copies of letters should be written in such a way that they are easily understandable by the recipient. All test results should be clearly explained. Parents should never receive letters that contain information that has not previously been discussed with them.
- 2.23. Deaf children and young people should be helped to understand and manage their hearing loss and influence their treatment and care.

## Qualifications of staff/professional competence

- 2.24. Assessing the hearing of young children can be complex and requires specialist skills. The fitting of hearing aids and the expected outcomes are fundamentally different for adults and children. The issues relating to paediatric fitting are complex:
  - a) Pre-lingually born-deaf or deafened children have very specific audiological needs in order that they are provided with every opportunity to develop speech and language skills.
  - b) Hearing aids must be fitted, regularly re-programmed/updated to take account of their growth and changing hearing development and environmental needs. Staff must be fully trained in understanding the differences between a child's clinical, education and home listening environments.
  - c) A large proportion of deaf children (up to 40%) have additional or complex needs in addition to their deafness<sup>33</sup> and may present with a spectrum of developmental and medical concerns which require consultant-led medical management undertaken by a physician with specialist accreditation through the Royal Colleges. The medical management of deaf children should also include the offer of relevant aetiological investigations around the time of diagnosis (see 6.1–6.2).34
  - d) It is therefore important that children are seen as part of an experienced multidisciplinary team which includes a paediatrician.
- 2.25. For the above reasons, NDCS believe that key staff must be appropriately trained at postgraduate level (for example MSc or equivalent) as the minimum level for paediatric practice. 35 Each service should be able to demonstrate it has the clinical competencies required to undertake reliable assessments and interventions.
- 2.26. NDCS recommends that all staff, including reception and administrative staff, should receive deaf awareness and communication training which is updated at

<sup>&</sup>lt;sup>32</sup> NH<u>S Plan</u>, DH, 2000

NHS Plan, DH, 2000

Prevalence of additional disabilities with deafness: A review of the literature, NDCS 2012

Role of the Doctor in the NHSP Team. BAAP and BAPA July 2008

Quality Standards in Paediatric Audiology - Guidelines for the early identification and audiological management of children with hearing loss, NDCS, 2000

least every 3 years.

#### **Quality Assurance and Quality Standards**

- 2.27. Each service should apply robust clinical audit and quality assurance procedures. NDCS believes that each country of the UK should assist this process by:
  - a) developing, implementing and reviewing minimum and best practice standards
  - b) regularly assessing the quality of services against minimum and best practice standards.
- 2.28. NDCS recommends a national programme of audit of services with reference to national standards. Information on the performance of services should be publicly available for benchmarking purposes as well as informing service users.

# 3. Commissioning of audiology services from the private, independent or third sector

- 3.1. There are different commissioning models in use across NHS England and Clinical Commissioning Groups (CCGs). CCGs are routinely commissioning using 'Any Qualified Provider' (AQP) for routine adult hearing services (assessment of hearing and fitting of hearing aids to adults with age-related hearing loss) to purchase services from private hearing aid dispensers and independent high-street providers.
- 3.2. Assessing the hearing of young children can be complex and requires specialist skills. The fitting of hearing aids and the expected outcomes are fundamentally different for adults and children. The issues relating to paediatric fitting are complex (see paragraph 2.24 above).
- 3.3. At the current time (2016) the private and independent sector consists mostly of HCPC registered hearing aid dispensers<sup>36</sup> who would not meet the minimum qualification for paediatric practice. The vast majority of hearing aid dispensers work from high street premises and most will not see children and young people under the age of 16-18. They:
  - a) receive no training in paediatrics
  - b) work from premises and test suites that are predominantly suited to the older generation.
- 3.4. There are a few paediatric audiologists who are dual qualified but they normally work from hospitals (e.g. the hospital can then legally sell hearing aids to private paediatric patients) or in private practice.
- 3.5. NDCS therefore believes that the needs of deaf children are generally supported better within an established and consistent multi-disciplinary NHS clinic based audiology service.
- 3.6. If paediatric audiology services are to be commissioned from the private, independent, or third sector then NDCS believes that these organisations must be able to provide the equivalent or better quality audiology service assessed against the same standards as NHS audiology services using the RCP/UKAS accreditation programme Improving Quality In Physiological Diagnostic

<sup>&</sup>lt;sup>36</sup> Health and Care Professions Council - Register of Professions

Services (IQIPS).37

3.7. Any NHS or other provider must be staffed by appropriately qualified and skilled audiological professionals and supported with appropriate Service Level Agreements and referral protocols to other members of the multi-disciplinary team (e.g. paediatricians, speech and language therapy, etc.). These requirements should be set out clearly in the specification, contract documents and service compliance monitoring arrangements.

## 4. Private provision of hearing aids

4.1. The NHS currently (2016) uses a range of good quality digital hearing aids and the vast majority of deaf children are fitted with NHS hearing aids. However, a small number of families may see a private hearing aid dispenser and purchase hearing aids; these include children of parents who have chosen private care for their child as well as children who are not eligible for NHS care (those not normally resident in the UK but who choose to obtain private treatment from the UK). NDCS acknowledges this situation and supports any family that chooses this option.

#### 5. Auditory implants

- 5.1. For many years cochlear implants and bone anchored hearing aids were the only implantable options for deaf children who did not benefit from conventional hearing aids. In recent years the range of implantable devices has rapidly expanded and is set to continue in this trend. The range of implantable devices available currently include:
  - a) Bone conduction hearing implants (BCHI), including bone anchored hearing aids (BAHA).
  - b) Active middle ear implants.
  - c) Cochlear implants.
  - d) Auditory brainstem implants (ABI).

NDCS has a separate position statement on implantable hearing devices.<sup>38</sup> NDCS expects a holistic approach to supporting children with implantable devices.

For example, "It is essential to consider the entire patient pathway when commissioning a cochlear implant service. The patient pathway may start in the community, then enter the acute system, and then return to the community. The funding streams for the service must recognise this. The national tariff covers the in-patient spell of the procedure, but excludes the costs of assessment, rehabilitation/habilitation in year 1, and ongoing lifelong costs thereafter. These costs must be factored in when commissioning the service."

5.2. NDCS believes that funding for bone conduction hearing implants should be available for all children who are suitable and whose family chooses this option. The same system worn on a soft headband should always be considered for young children and those in who surgery is not possible rather than traditional

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<sup>&</sup>lt;sup>37</sup> Improving Quality in Physiological Services (IQIPS)

<sup>38</sup> NDCS Position Statements

<sup>&</sup>lt;sup>39</sup> Cochlear Implant Services: Commissioning Guidelines, RNID, NDCS, DH et al, 2007

- bone-conduction hearing aids. 404142
- 5.3. NDCS will work locally with purchasers and funders to ensure that adequate and complete referral pathways are commissioned whether from one or multiple providers.

#### 6. **Aetiological investigations**

- Aetiological investigations are medical tests carried out to determine the cause of 6.1. a child's deafness. 43 These tests include blood and urine tests, imaging techniques, ECG, and genetic testing. As well as being used to determine the cause of the deafness they are used to rule out medical problems that may be associated with syndromal deafness. At the current time it is only possible to determine the exact cause in approximately 50% of cases of permanent sensorineural deafness.
- 6.2. NDCS believes that families should be given clear information about the aetiological tests, what the tests may show and the implications of having tests done. Families should be offered relevant aetiological investigations around the time of diagnosis 44 and at other occasions during a child's development as new tests/test techniques become available or when a child or young person wishes them to be done.

#### 7. Data: Numbers of deaf children

- 7.1. The absence of a national register of hearing impaired children and accurate estimates on the prevalence of childhood deafness makes it difficult to plan and commission services and monitor outcomes.
- 7.2. NDCS recommends the establishment of accurate national records capable of producing data on numbers by area, age, ethnicity and whether children have additional needs and levels of hearing loss within the 4 countries of the UK. This would require all services to collect reliable data in a consistent way.

#### 8. NDCS services and audiology

- NDCS will support families in making informed choices for their child by: 8.1.
  - a) Providing clear, unbiased, factual information for families.
  - b) Encouraging honest and open discussion of the key issues about which parents need to be aware and that professionals need to address.
  - c) Work with other organisations to promote relevant translational research and ensure that the results are accessible to families.
  - d) Provide opportunities for parents to contact other parents, deaf adults and professionals.
- 8.2. NDCS will continue to work with professionals developing good practice guidance and guality standards. Through our guality standards documents and

<sup>44</sup> <u>Aetiological investigations guidelines</u>, BAAP, 2015

Audiology Services UK Position Statement-June 2016-Director PaC

<sup>&</sup>lt;sup>40</sup> Quality Standards in Bone Anchored Hearing Aids for children and young people, NDCS, 2010 (reprint as Quality Standards in Bone Conduction Hearing Implants expected late 2016)

Clinical Commissioning Policy: Bone Anchored Hearing Aids, NHS CB, April 2013 (Ref: NHSCB/D09/P/a)

Consultation document - Clinical Commissioning Policy Proposition: Bone conducting hearing implants (BCHIs) for hearing loss (all ages), NHS England, March 2016 – expected to be published later in 2016

Understanding your child's hearing tests, NDCS, 2013

working with professionals in the field of audiology, NDCS advocates on behalf of families so that audiology teams working with children:

- a) Provide information which is clear, jargon-free and accessible.
- b) Ensure a multi-disciplinary approach.
- c) Provide parents and children with effective counselling and support.
- d) Ensure parents and children are given appropriate time and space, particularly after confirmation of deafness, to consider all the information and implications and opportunities to ask questions.
- e) Ensure that parents are not put under pressure to change communication methods that work for them and their child.
- f) Encourage families to meet other deaf children and deaf adults.
- g) Ensure the child is, wherever possible, fully involved in decision making processes.
- h) Ensure that deaf children receive the highest possible standards of care with smooth transition to adult audiology services.
- 8.3. NDCS will continue to work with government advisory groups, external agencies, other organisations and charities in the development of good practice guidelines. For example, the NHS England and the Chief Scientific Officer's work-streams on audiology (England), Audiology Services Advisory Group (Scotland), Audiology Standing Specialist Advisory Group (Wales), IQIPS Clinical Advisory Group, NICE, commissioning guidelines groups, etc.
- 8.4. NDCS will challenge decisions within the health service that restrict informed choice for the family or young person or prevent early intervention or/and may simply pass costs from one provider to another. One example of this might be failing to commission grommet surgery recommended for children with glue ear. Although glue ear does usually resolve without treatment in the long-term, most parents find it unacceptable to leave the problem untreated with the potential that their child falls behind with speech, language, educational and social development in the meantime. As a consequence there is increased pressure on hearing aid and educational support services. 46
- 8.5. NDCS will work locally with local funders and purchasers of services (e.g. Clinical Commissioning Groups (CCGs), commissioners, health boards) to ensure that the quality audit tools are used and adequate referral pathways are purchased for families of deaf children.

<sup>46</sup> OME (Glue Ear) / Adenoid and Grommet Position Paper, ENTUK, 2009

<sup>&</sup>lt;sup>45</sup> Surgical management of children with otitis media with effusion (OME), NICE, 2008