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## Quality Standards in Paediatric Audiology

Guidelines for the Early Identification  
and the Audiological Management  
of Children with Hearing Loss

# NDCS Quality Standards in Paediatric Audiology

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Guidelines for the Early Identification  
and the Audiological Management  
of Children with Hearing Loss

VOLUME IV

The National Deaf Children's Society is an organisation of families, parents and carers which exists to enable all deaf children and young deaf people to maximise their skills and abilities and works to facilitate this process by every possible means.

REVISION OF

NDCS Quality Standards in Paediatric Audiology: Volume I (1994)

Guidelines for the Early Identification of Hearing Impairment in Children

NDCS Quality Standards in Paediatric Audiology: Volume II (1996)

The Audiological Management of the Child with Permanent Hearing Loss



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# 1 SUMMARY

*"Identification of hearing loss by six months of age, followed by appropriate intervention, is the most effective strategy for the normal development of language in deaf and hard-of-hearing infants and toddlers." (Yoshinaga-Itano, 1998).*

Approximately 840 children with bilateral moderate or greater permanent hearing loss are born in the UK each year (Davis et al, 1997) at a prevalence of 1 to 2 per 1000 births. Around 40% of these children will have additional needs, such as visual problems (Guy et al, Presentation at 'Vision Impairment in Deaf Children', Nottingham, 1999) or developmental delay.

The identification of hearing loss in babies throughout the UK has been poor, relying where appropriate on targeted screening for babies seen to be at risk of hearing loss, and on the health visitor (universal infant) distraction test at age 7-8 months. The age of identification for hearing loss has usually been greater than 12 months, with many more children not being identified until they are 2 years of age or more (Davis & Wood, 1992; Davis et al, 1997).

Early identification and appropriate management will lessen the impact of deafness on the child, the child's family and on society (Markides, 1986; Meadow-Orlans, 1987; Ramkalawan & Davis, 1992; Kuhl et al, 1992; Yoshinaga-Itano et al, 1998).

Following a critical review (Davis et al, 1997), the UK is moving towards implementation of universal neonatal hearing screening (UNHS). This is expected to improve significantly the age of identification. However, the need to ensure good, accurate family-friendly hearing services (FFHS), to meet each child's needs, becomes more critical. This document highlights the importance of screening for hearing loss within the context of paediatric audiology service provision.

Screening is the beginning of the process. Screening is reliant upon paediatric audiology services being in place that meet the individual needs and provide optimum support to **all** deaf children and their parents.

In June 2000, at the National Deaf Children's Society's (NDCS) *Paediatric Audiology Healthcare Conference: what constitutes a quality service?*, the government announced the piloting of UNHS at 20 sites in England. The NDCS expects Scotland, Northern Ireland and Wales to implement their own UNHS programmes. The evaluation process must be time-limited. Therefore, the NDCS believes it is realistic to expect a UK-wide UNHS programme will be in situ by 2003.

This document is based on that assumption and outlines good practice in local audiology services that considers the needs of babies, children and young people through to transfer to an adult service. It highlights, where relevant, 'Quality Standards' which are both realistic and achievable.

## Identified targets and timescales:

### Immediate:

***Services must rectify the present inadequacies in service provision for deaf children. In particular there is an urgent need to ensure that the health visitor distraction test is functioning according to recommended standards and that comprehensive follow up audiological services are appropriately staffed and resourced.***

### By 2001:

***Services must be at an advanced stage of preparation for the introduction of UNHS. Attention must be given to ensure that services are well co-ordinated at a multi-disciplinary level (eg by setting up local audiology working groups) and that they function in a family-friendly context.***

### By 2003:

***There should be nationwide introduction and full implementation of UNHS so that all babies born with deafness are identified and supported within the first weeks of life. There must be sensitive follow-up care and appropriate habilitation available for all deaf children and their families.***

**It is vital that all services recognise and comply with the NDCS quality standards. It is recognised that extra effort will be needed.**

The NDCS will revise this document in the light of full implementation of UNHS by 2003.

## 2 INTRODUCTION

2.1 This revised document supersedes the NDCS Quality Standards in Paediatric Audiology Volume I – *Guidelines for the Early Identification of Hearing Impairment* (1994), and Volume II – *The Audiological Management of the Child with Permanent Hearing Loss* (1996). It provides comprehensive guidelines and quality standards for paediatric audiology in the UK, from diagnosis and ongoing management of hearing loss, through to transfer to an adult service.

This document is aimed primarily at commissioners (health authorities, primary care groups, primary care trusts, NHS trusts), education services, professionals working within those services (providers) and others with a professional interest in providing services for deaf children throughout the UK. The objective is to provide a framework for audit with realistic and attainable standards within paediatric audiology services.

2.2 The contents of this publication are interim. These guidelines will be revised following the outcome of the piloting of UNHS throughout England. It is expected that Scotland, Wales and Northern Ireland will, during this period, be piloting and implementing UNHS in order that outcome measures are nationwide.

2.3 For UNHS to be successful there must be an effective and efficient screening programme and quality authoritative diagnostic paediatric audiology services in place that work in partnership with the family, with the wider health services, and with educational, voluntary and social service provision.

2.4 It is important that commissioners and providers recognise that the management of a deaf child involves local health, education and social services. The Health Act (HMSO 1999) enables health, education and social services to pool funds with integrated provision of services that can focus on the needs of the deaf child and their family.

2.5 Paediatric audiology services throughout the UK must meet the real needs of all deaf babies, children, young people and their families. The introduction of a comprehensive system of quality control will enhance this process.

2.6 To ensure families are fully informed, and to minimise parental anxiety, the NDCS strongly recommends that paediatric audiology services develop services and strategies to support all deaf children. This should

include children with mild, fluctuating, sudden, progressive, late onset, unilateral hearing losses and also children with auditory neuropathy (ie children who have normal peripheral hearing but who may have neurological deficits resulting in central auditory processing disorders).

2.7 The health district must have access to one or more centres with specialist staff providing screening, confirmation, assessment and hearing aid management, for babies, children and young deaf people.

2.8 It is essential that professionals providing services and support to children, seek wherever possible to obtain the views of the child.

Age-appropriate information must be available for use with children.

2.9 Information must be available in other languages and interpreters must be provided when required.

2.10 Professionals have a duty to ensure that a deaf child's and their family's views are respected. Professionals must help the family understand their child's deafness, and help them to feel supported at each stage of their child's development.

2.11 Professionals have a responsibility to encourage the child and their family to develop a positive attitude towards deafness.

2.12 The NDCS believes there is a need for further research to identify outcomes for different groups of children, with different degrees of hearing loss, different intervention methods, and over a range of intervention times.

2.13 This document uses the words 'parent' and 'family' to include the child's carer with parental responsibility. If the child is a ward of court, or in the care of a social services department, appropriate permission must be sought before any medical or surgical procedure takes place.

The NDCS uses the word 'deaf' to mean the full range of hearing loss. The phrase 'all deaf children' includes children with complex needs, ethnic minority children, and children from difficult to reach families.

2.14 The abbreviation 'QS' is used throughout to define quality standards that must be monitored and audited.



### 3 FAMILY-FRIENDLY HEARING SERVICES

The FFHS must provide hearing screening programmes and authoritative paediatric audiology services that work in partnership with the family and health, education, social, voluntary and private sector services to provide support for children and their families.

From a survey carried out by NDCS in 1999, parents identified the following issues that must be considered at the time of and following diagnosis:

- Early accurate diagnosis in an appropriate setting
- Quality time with professionals to understand the implications of diagnosis and to come to terms with this
- An early follow-up appointment to address parental concerns
- Provision of clear accessible and balanced information, with details of self-help support groups
- Well trained and qualified staff who are deaf aware and who have empathy with and understanding of child and family
- A positive and encouraging attitude towards deafness
- Respect for the child and the child's family
- Inclusion/partnership in the development plan for their child
- Co-ordination between services to eliminate conflicting advice
- Long term local quality services and support

Parents have a right to expect professionals to acknowledge their expertise as parents, and to share information. Parents must be involved in the decision-making process.

**QS** It is the role of the paediatric audiologist to work with family support workers who must specialise in early years support for deaf babies and children. Together they must help parents to help their child acquire communication skills through the mode(s) of communication chosen by the parents.

Parents must be well informed and receive information without bias if they are to make informed choices.

Optimum habilitation for the child will only occur when parents are considered valued and equal members of a well co-ordinated and accessible team.

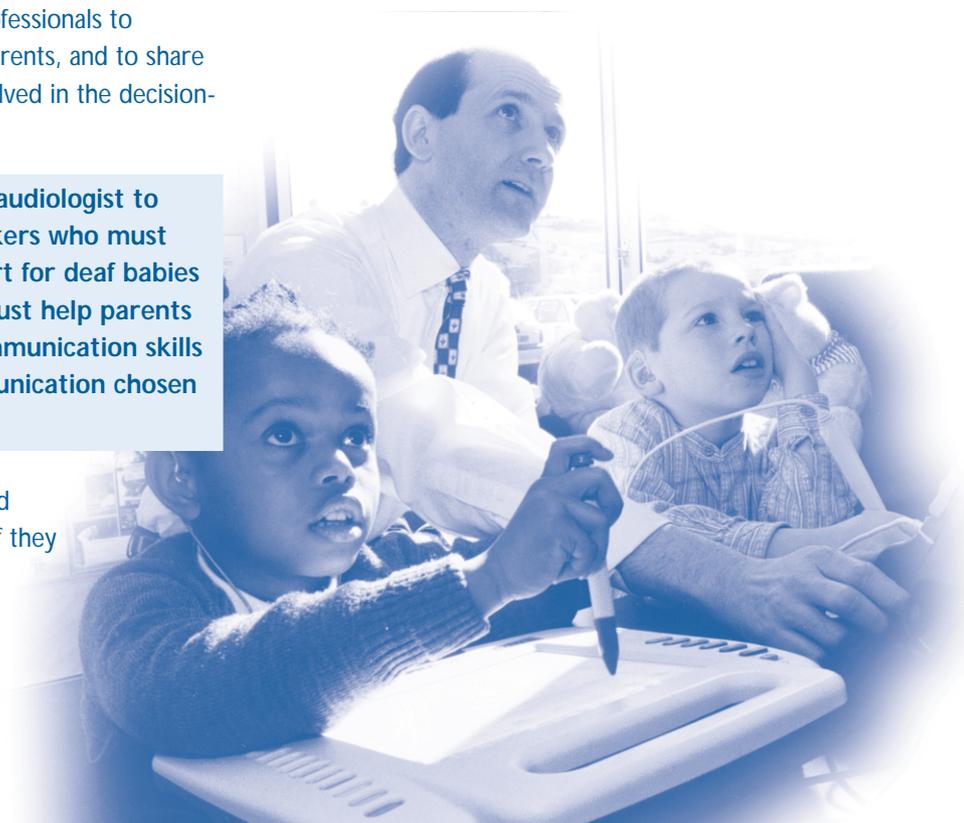
Parents must be fully involved in helping professionals to decide upon appropriate habilitation and implementation of procedures, in monitoring the effectiveness, and evaluating success.

#### 3.1 Open access

Parental concern about their baby's hearing must be treated seriously with prompt referral to the paediatric audiology centre. Such referrals must be accepted from parents. Open access audiology services have proven to be effective and desirable (McCormick et al, 1984).

#### 3.2 Baguley et al (2000) identified principles of FFHS for children. From these principles there are four main elements identified:

- Collaboration
- Responsiveness of services to meet the real needs of families
- Optimal provision of information
- A culture of service evaluation including the use of peer review and parent, family and service user perspectives



## 4 COLLABORATION AND RESPONSIVENESS OF SERVICES TO MEET THE REAL NEEDS OF FAMILIES

All services working for the child must be well co-ordinated. Local audiological, educational and social services must work closely together in the developmental management of the child.

### 4.1 The audiology working group (AWG)

**OS** District-wide AWGs must be set up across the UK by April 2001, with a named co-ordinator (Hall, 1996) to act as a contact and reference point for AWG policies and audit.

It is the responsibility of the health services to set up the AWG ensuring appropriate representation is sought from all those supporting deaf children.

- OS**
- AWGs must meet at least twice a year
  - Records must be made of AWG meetings
  - A record of attendance must be made including the sectors represented
  - There must be representation from all those supporting deaf children in health, education, social services and the voluntary sector
  - Membership must include service users, for example one or more parents of deaf children, the local co-ordinator/service manager of the neonatal and infant hearing screening programmes and the early years specialist
  - An annual survey of client satisfaction must be carried out

The AWG must take responsibility for ensuring that paediatric audiology services work in a co-ordinated way, whether provided through health or education, and that all services work seamlessly to avoid conflicting provision and information.

The AWG must take responsibility for developing policies and strategies that allow for the development of good quality FFHS that have well trained staff and well resourced facilities.

Strategies must be in place to enable services to be responsive to families needs at each stage of:

- pre-screening
- screening
- follow-up assessment
- early identification
- diagnosis

- ongoing care and service provision
- meeting children's complex needs
- transfer to an adult service

It is the responsibility of the AWG to agree the setting of local quality standard targets and the implementation, monitoring and audit of quality standards in paediatric audiology.

Health services have a responsibility to ensure that adequate resources are available to support the AWG and to reimburse parents for their time, travel expenses, and any child care costs incurred to enable them to participate in the development of local services.

It is the responsibility of the AWG to ensure that sign language classes are made available for families (including siblings) and professionals.

## 5 LOCAL SERVICES AND SUPPORT

### 5.1 Local audiology, education and social services

Local services must ensure that the family is given every opportunity to discuss and explore issues relating to their child's deafness.

Local services must:

- promote equal opportunities for all children supported by the service
- ensure children have the opportunity to develop their full potential
- raise the level of awareness of deafness with the child's teachers and peer groups to maximise the child's potential
- encourage opportunities for deaf children and their families to meet other deaf children and their families, and deaf adults

Personnel must be fully conversant with new technologies, and current policy and practice.

### 5.2 Support groups and voluntary organisations

It is the role of support groups and voluntary organisations to provide parents with information on all aspects of deafness, in order that the child (wherever possible) and their family can make informed choices.

**OS** In accordance with The Education Act (1996); The Code of Practice, Northern Ireland (1996); and Circular No. 4/96, SOEID (1996) local health and education services must provide parents with information about relevant support groups and voluntary organisations.



## 6 KEY PERSONNEL AND FACILITIES

### 6.1 Staffing and training

Audiological assessment of children requires a high level of skill, training and background knowledge.

**QS** Assessment and audiological support must be undertaken by staff capable of performing and interpreting such testing. Key staff must be appropriately trained at postgraduate level (for example MSc, or equivalent, in audiology or audiological medicine supplemented by suitably assessed practical experience).

No audiological member of the team with less than 3 years experience in paediatric audiology, will work without the supervision of an experienced audiologist.

Staff must be able to communicate effectively and sensitively with deaf children and their parents.

### 6.2 Staff training

**QS** All staff within the audiology service must be trained in:

- deaf awareness with an introduction to sign language through an approved course
- disability and cultural awareness
- customer care, including listening skills
- text phone use

Additionally, clinical staff must receive training in sign language to a minimum of CACDP Stage I.

### 6.3 The early years specialist

The early years personnel and key (link) worker will be dealt with in detail in the NDCS Quality Standards on The Early Years and Support (in publication, 2001). The document will also highlight issues relating to joint funding.

**QS** Each district must allocate specific responsibility for very young deaf infants to an early years specialist. This may be a teacher of the deaf or a speech and language therapist.

The early years specialist specific to the 0-2 age group should be the first "key worker" assigned to the child and family. They must have the knowledge and skills as outlined in the NDCS Quality Standards on Early Years and Support (in publication, 2001).

The early years specialist must work with parents to help the baby acquire appropriate communication skills. They have a duty to provide parents with

balanced and unbiased information, advice and guidance.

### 6.4 The key (link) worker

**QS** Each child, from diagnosis and during their development, must have assigned a key (link) worker.

The key (link) worker must work with the child's family and local professionals to ensure there is a seamless and efficient service in place. The key (link) worker must be:

- a facilitator and link person
- accessible to the family
- flexible in their approach to the needs of the family

### 6.5 The early years personnel

The early years specialist, paediatric audiologist and paediatric audiology medical specialists will have overlapping knowledge and skills. The early years team must work closely together to ensure a seamless service to the child and family.

### 6.6 Facilities

Facilities for the provision of quality paediatric audiology services, as outlined in this document, must be available. Such facilities must be designed so that the environment is child and family-friendly in order to optimise service provision.

**QS** Facilities must be available for:

- otoscopy
- behavioural observation audiometry
- visual reinforcement audiometry: soundfield, insert earphone and bone conduction
- distraction testing
- performance testing
- speech discrimination testing
- pure tone audiometry
- auditory brainstem evoked response measurement (air and bone conduction)
- otoacoustic emissions
- otoadmittance testing (including high frequency probe tones)
- soundfield aided threshold measurement
- electro-acoustic testing of hearing aid
- probe-tube microphone measurements

## 6.7 Testing

- OS** • Each district must carry out testing according to professionally accepted protocols (eg British Society of Audiology (BSA) recommended procedures) and the Recommended Protocols for Neonatal Hearing Screening and Assessment (BSA, 2000)
- All equipment must be calibrated at least annually using acceptable methods on equipment whose own calibration is traceable to national standards (BSA 2000)
- Rooms provided for the above testing must conform to standards outlined in the Department of Health Building Note (1994)
- Audiological testing must be performed in soundproofed accommodation to ISO 8253-1 (1987) and ISO 8253-2 (1992) standards for acoustic test methods suitable for children.
- Equipment must not be more than 5 years old

- provision of information to child and family at time of visit
- monitoring of policy, procedures, service and auditing outcomes
- liaison with relevant agencies, including voluntary groups

## 8 SCREENING

It is critical that hearing screening programmes are implemented without delay and effective support services made available for all deaf babies, as outlined in the NDCS, Quality Standards on Early Years and Support (in publication, 2001).

- OS** There must be a quality UNHS programme in place throughout the UK by 2003. In the interim, there must be efficient and effective targeted neonatal hearing screening (TNHS) and universal infant distraction testing (IDT) in each health authority.

Until such time that commissioners and providers can be sure that all babies are covered by the UNHS programme in their area, it is essential that current and interim hearing screening systems, such as the universal IDT and TNHS, are optimised and maintained at their highest level.

It is the responsibility of the lead clinician/audiologist to ensure that audiology and screening services work closely together. Those carrying out the screening of babies hearing must recognise the care they must take in approaching babies and families at this sensitive time so shortly after birth. Care must be taken to work in partnership with other medical professionals involved with babies and families at this time.

Families must be given the opportunity to contact local support groups, such as the local NDCS group. Families must also be provided with written details of their local and regional NDCS representatives.

Information provided to parents must reflect the stage of the screening process reached by the parents (ie graduated information).

## 7 DEVELOPMENT OF LOCAL PROTOCOLS

- OS** All protocols must adhere to local and nationally agreed standards, eg health and safety, staff conduct, confidentiality, equal opportunities, discrimination and infection control.

Written protocols must be in place to include:

- calibration of equipment to nationally recognised standards
- test methods and procedures, including test equipment required, test duration
- location of testing
- clinical facilities
- effective reporting and results, including data collection analysis
- optimum staffing levels
- minimum qualifications (see page 6)
- sufficient time to ensure the child and family's needs are met
- waiting times (as laid out in the NHS Patients Charter and National Plan HMSO, 1991; HMSO 2000; Dyke, 1998)
- facilities that are child and family-friendly



### 8.1 Pre-birth

Parents must receive appropriate and sensitive written information on:

- the screening process
- the likelihood of their child having a hearing loss and the benefits of early diagnosis
- outcome of the screening process
- follow up procedures
- management and support
- the need for ongoing surveillance

### 8.2 At the time of screening

Parents must have detailed written information on the above including what the screen and test results mean and why it is important to attend follow up appointments.

Parents must be invited to be present during the test. Testing must be undertaken in a quiet and appropriate environment.

### 8.3 Post-screen

Post screening information must be provided and will vary depending upon the part of the process reached by the family. Services must base locally agreed information on any nationally agreed templates and use valid ways of assessing the quality of written information, such as 'DISCERN' (Charnock et al, 1999).



**Screening and assessment must be carried out by well trained staff (see page 6) with good baby-handling skills and be sensitive to the needs of the parents.**

Babies in a neonatal intensive care unit (NICU) and/or a special care baby unit (SCBU) must not be tested until they have graduated to the low dependency part of the unit and are preferably close to discharge.

Professionals must be aware that babies in NICU/SCBU, seen as a part of a UNHS or TNHS programme, remain at higher risk of delayed onset deafness and further monitoring is essential.

### 8.4 UNHS

At the time of writing, a national protocol for UNHS has been agreed by the UNHS Steering Group and recommended to the National Screening Committee (NSC) (Appendix Ia).

### 8.5 Children with mild or unilateral hearing loss or auditory neuropathy

In order to minimise parental anxiety, to ensure families are fully informed, and that all children



receive an optimum service to meet their individual needs, the NDCS recommends that paediatric audiology services develop strategies to support all deaf children and their families. This should include children with mild or unilateral hearing losses and auditory neuropathy.

8.5.1 The NDCS believes that it is essential to refer for further assessment any baby who does not pass screening tests in one ear, including well babies.

### 8.6 Protocols for UNHS

The majority of newborn babies will be full term and well. However, approximately 7% of all newborn babies will require care in a NICU and/or SCBU for longer than 48 hours, and it is these babies that are recognised to be at high risk of deafness.

Approximately 13% of babies are discharged on the day they are born. The majority of these are testable with only a high false alarm rate recorded for babies less than 4 hours old (Davis et al, 2000).

The flow-charts recommended by the NSC's Steering Group on UNHS are based on evidence of screening all babies in hospital prior to transfer home (Appendix Ib). Full coverage is only gained by following up those babies who miss all or part of the screen either in the community or in the outpatient department.

### 8.7 Performance standards for UNHS



- All positive cases must be followed up with audiological assessment by 3 months of age unless deliberately delayed for diagnostic reasons, or if follow up is refused
- The NDCS recommends that the true state of hearing must be confirmed by 4-6 months of corrected age for each child
- The NDCS recommends that education services must be informed by the paediatric audiologist of all true cases within 1 working day of confirmation
- Hearing aids must be fitted for all true cases within 4 weeks of confirmation, unless deliberately delayed for management reasons

## 8.8 Performance standards for TNHS and universal IDT

- OS**
  - All positive cases followed up with audiological assessment within 1 month unless deliberately delayed for diagnostic reasons or follow up refused
  - True state of hearing confirmed within 2 months
  - 80% of bilateral congenital deafness in excess of 40dBHL (averaged across the frequencies 500Hz, 1kHz, 2kHz and 4kHz) confirmed within the first year of life and 40% by the age of 6 months
  - Education services informed for all true cases within 1 working day of confirmation
  - Hearing aids must be fitted for all true cases within 4 weeks of confirmation unless deliberately delayed for management reasons
  - Audiological assessment provided within 4 weeks of referral or fitness to test for children at high risk of acquired hearing loss, eg following meningitis
  - All children resident in the district must benefit from either a formal screen or a specific surveillance procedure to assess risk of hearing loss by 12 months of age

## 8.9 TNHS

- OS** When no UNHS programme is in place, neonates with any of the following risk factors must be tested:
  - admitted to NICU/SCBU for a total of 48 hours or more
  - family history of congenital or early acquired deafness
  - abnormalities of the head and neck
  - suspicion of significant intra-uterine infection during pregnancy
  - consanguineous marriage, eg cousin

The flowchart for TNHS is shown in Appendix Ib, 'In-patient screen for babies in neonatal intensive care'.

## 8.10 Performance standards for TNHS

- OS**
  - Screening for risk factors must cover all babies resident in the district
  - Vigilance on the part of the primary health care team is essential to this process

- TNHS programme coverage by discharge >90% of all live birth at risk neonates determined before discharge from maternity unit
- Where initial TNHS is carried out as an outpatient, it is recommended that it be carried out as soon as possible, preferably within 6 weeks of expected date of delivery
- Parents must be invited to be present during the test whenever possible
- The test must be carried out in an appropriate environment

## 8.11 Non high-risk/normal birth neonates

For the majority of neonates there will be no known risk factors associated with deafness. For these, a surveillance approach must be adopted to include:

- The questioning of parents at the antenatal stage about family history of sensorineural deafness in childhood
- The issuing of a handout/checklist (along the lines of the "Can your baby hear you?" form McCormick, 1983), on discharge from the maternity unit or during the health visitor's birth visit
- Acting on parental concern about their baby's hearing with prompt referral to the paediatric audiology centre. Such referrals must be accepted from parents, health visitors, GPs or other relevant professional

## 8.12 If UNHS and TNHS is passed

- OS** Parents must be given an explanation of the test results and a written record. They must be given a handout such as the 'Can your baby hear you?' form (McCormick, 1983).

Parents must be made aware that if they become concerned they must contact their health visitor, community doctor or GP to arrange for an early appointment at the paediatric audiology centre.

- OS** The neonatal screening test results must be forwarded to the GP and child health service by the screening programme within 5 working days.



**8.13 If UNHS and TNHS is not passed**

Parents must receive sensitive counselling and guidance about test results.

Parents must also be given written details of the local and regional NDCS representative for the area.

**QS** The GP must be notified and informed of all follow-up action by the UNHS/TNHS programme within 5 working days.

Parents must be given clear information about planned follow-up which must include full ABR testing to estimate auditory thresholds (this may include air and bone conduction, click evoked and tone pip stimulation, or steady state evoked potentials).

Such testing may be performed in the neonatal unit or as an outpatient appointment within 6 weeks from the expected date of delivery.

Beyond this age sedation might be needed. Sedation must be supported by paediatric anaesthetic expertise. Tympanometry should be undertaken at the same time if required.

**8.13.1**

**QS** If the ABR identifies permanent childhood hearing impairment (PCHI), at the same time or shortly after the ABR testing, full audiological assessment must be undertaken at the paediatric audiology centre to include:

- the taking of a full history
- behavioural testing (according to the level of maturity) to observe auditory sensitivity and tolerance levels
- middle ear impedance and stapedia reflex testing
- recording startle and auro-palpebral reflex activity
- full diagnostic otoacoustic emission testing (where indicated)

The results of these investigations must be discussed and explained to parents. Reports with interpreted results must be sent to the GP, child health service, paediatrician, and other relevant professionals.

**8.13.2** Contact must be made with families who fail to attend for follow-up appointments. If parents do not take advantage of the facilities offered it is essential to be vigilant within the normal surveillance programme.

**8.13.3** The clinical management and quality care issues highlighted in the NHS Patient's Charter must be satisfied.

**8.14 When audiological assessment indicates normal hearing**  
Action is the same as if the screen is passed.

**8.15 Babies who miss the UNHS or TNHS**

**QS** Babies who miss the initial screen must be recalled within 4-6 weeks to have their hearing screened within the community or outpatient department. For babies still missed, or who do not attend, it is the responsibility of the paediatric audiology service to make continuous attempts to attain a hearing assessment of that child.

**8.16 Universal IDT programme**

**QS** All babies must receive a hearing screening test at 7-8 months. This must be undertaken by two well trained community health staff, at least one of whom is a health visitor.

Testing must conform to recognised standard procedures (McCormick 1991)

There must be regular updating of procedures and facilities for testing the hearing of testers every 2 years (BSA News, 1994)

Coverage of this test must be >95% and results subject to regular monitoring by the health visitor management, the audiological scientist/physician, and the community paediatrician (Appendix Ia)

**8.17 First universal IDT is passed**

Parents must be provided with a copy of the document "Can Your Baby Hear You?" (McCormick, 1983), or, issued with a similar document. The health visitor must guide them through the document.

Parents must be advised that although the baby has passed the screening test, if they become concerned about their child's hearing in the future they must request another test or an appointment at the paediatric audiology centre.

**8.17.1** The procedure for routine developmental checks and further hearing tests must be explained to parents.

**8.18 First universal IDT is not passed**

The need for a second screening test must be explained in the light of the test results.

**OS** The timing for the second test must be:

- Within 7-10 days if parents are concerned about their baby's hearing or the baby has not responded to sound, or
- Between 6-8 weeks if the parents are not concerned and the baby shows some evidence of responding to sound

**8.19 Second universal IDT is passed**

Action is the same as if the first distraction test is passed.

**8.20 Second universal IDT is not passed****OS** An immediate referral must be made to the paediatric audiology centre and treated urgently if the parents express particular concern. Such urgent referrals must be given an appointment to be seen within 2 weeks.

All other cases must be seen within 1 month.

**8.21 Monitoring of non at-risk children****OS** Facilities must be in place to test an infant at any stage, either in the community (health visitor, practice nurse, clinic nurse) or at a secondary or tertiary level audiology clinic, if there are concerns about the child's hearing (Smith & Evans, 2000).**8.22 Follow up of referred babies**

All referred screens must be investigated in order to minimise parental anxiety and to reach a correct diagnosis.

Once identification of significant permanent hearing loss has been made, there must be seamless provision of care. Educational support services must provide regular home and nursery visits for pre-school children as outlined in the NDCS Quality Standard on Early Years and Support (in publication, 2001).

**9 CHILDREN AT RISK****OS** For children considered to be at risk of acquired hearing loss, eg following meningitis, audiological assessment must be provided within 4 weeks of referral or fitness to test (see Appendix II).**10 MEETING THE REAL NEEDS OF FAMILIES AT DIAGNOSIS AND REVIEW**

(see *NDCS Quality Standards on Early Years and Support (in publication, 2001)*)

It is the responsibility of the health service to detect and confirm hearing loss.

**OS** The early years support services must be available immediately hearing loss is confirmed. Early years support and education services must be informed of confirmation of deafness within 1 working day.

The family must be contacted within 1 day and visited within 2 days (Kural et al, 1999).

The family must be provided with information, advice and guidance on deaf awareness.

10.1 It is essential that health and education provide services to families and children throughout the year.



## 11 PROVISION OF INFORMATION

It is the responsibility of the audiology service to provide parents with accessible information that is unbiased. Parents, and when possible the child, have a right to be fully informed in order that they can make an informed choice with regard to the health and educational management they consider to be most appropriate for their child.

Parents must be provided with unbiased information detailing **all** modes of communication and **all** methods of amplification.

- 11.1 Audiogy and education services must work together to ensure parents are provided with balanced and unbiased information to ensure parents and children can make an informed choice.
- 11.2 At the time of confirmation of hearing loss, parents must be given time to ask questions and discuss their views. A private area must be made available to them.

**QS** At the time of diagnosis, parents must be offered a follow up appointment to discuss the implications of their child's deafness within 5 working days.

11.3

**QS** Parents must be given copies of audiograms, and any other audiological assessments, with a full explanation.

Parents must be provided with a parent-held folder for all audiograms, correspondence, reports, written management plans, etc, relating to their child. All letters relating to the child must be copied to parents.

The same information, and full explanation, must be given to the older child or young person in order for him/her to better understand their own hearing loss and its implications.

**QS** Clear written summaries of assessments, diagnostic opinions, and agreed plans for the ongoing management of the child's development must be given to parents within 5 working days.

- 11.4 Interpreters must be provided for all appointments as required.

11.5

**QS** Parents must be given information about relevant support groups or charities (HMSO Education Act, section 332, 1996; HMSO Code of Practice, Northern Ireland 1996; SOEID Circular No. 4/96, 1996)

## 12 AETIOLOGICAL INVESTIGATIONS

**QS** Children diagnosed with a hearing loss must have aetiological investigations in accordance with local protocols based on nationally agreed standards.

Aetiological investigations must be carefully overseen by an appropriately medically qualified person to optimise the information and support for families and children.

### 12.1 Genetic services

Parents must be informed of genetic screening and counselling services. Such services must be made available when the family and, where relevant the child, chooses to access them. These genetic services must be well informed on all issues relating to deafness.

## 13 HEARING ASSESSMENT

**QS** There must be accurate and clearly defined audiological assessment (including assessment of hearing thresholds across frequency, and assessment of middle ear function).

Prior to their visit, parents must be provided with information, such as 'A visit to the hearing clinic' (Dighe, 2000), which can be adapted to local circumstances.

### 13.1 Hearing assessment targets

- QS** Once a child has been identified as having a PCHI, the following assessment targets must apply:
- To determine minimal response levels (and hence hearing thresholds) in sound-field from 0.5 to 4kHz by 4-6 months for those identified through neonatal screening, and by 12 months developmental age for all other babies

- To determine thresholds for each ear from 0.25 to 4kHz by 6-8 months developmental age for babies identified through UNHS (e.g. with insert earphone VRA)
- For all other babies, to determine thresholds for each ear from 0.25 to 4kHz by 12 months
- To determine the upper dynamic range of hearing (loudness tolerance limits), or any indicators of it, by 6 to 12 months developmental age
- Auditory brainstem response (ABR) testing with clicks and tone-pips, ac and bc, is essential for assessment of babies under 6 months of age, and for difficult-to-test children of other ages
- ABR may require sedation or general anaesthetic and this facility must be available if necessary
- To determine middle ear status using otoadmittance testing and (for babies below 4 months of age) high-frequency probe tones

### 13.2 Standards for testing

**OS** Guidelines, recommendations and nationally agreed protocols relating to electrophysiological testing, behavioural testing, and acoustic impedance measures are given in the Recommended Protocols for Neonatal Hearing Screening and Assessment, (2000).

### 13.3 Children with conductive hearing loss

**OS** Where there is a mild hearing loss with evidence of Otitis Media with Effusion (OME) further testing must be carried out to check for persistence within 3 months.

Children with PCHI who acquire an additional level of conductive hearing loss must have rapid access to paediatric otological opinion at consultant level, and be seen as a priority if required.

### 13.4 Hearing assessment of children with complex needs

It is the responsibility of both health and education to ensure that staff are well informed as to good practice guidelines produced by other agencies and organisations to support such children.

Strategies and protocols must be developed to provide seamless services for children with complex needs.

### 13.5 Eye assessment

Health professionals working with young deaf children are in a key position to ensure good vision care in this high-risk population.

When deafness is confirmed, the child must be referred to an ophthalmologist with experience of working with children, in order that an eye examination can be carried out.

During the child's development, subsequent checks must be made (NDCS/SENSE guidelines on working with deaf children with vision impairment, in production)



## 14 HEARING AID PROVISION, AUDIOLOGICAL ASSESSMENT AND MANAGEMENT

### 14.1 Criteria for hearing aid fitting

**QS** Protocols must be in place to identify approaches to the different audiological management needs of children with:

- bilateral sensorineural hearing loss
- unilateral hearing loss
- conductive hearing loss
- minimal hearing loss
- fluctuating hearing loss
- mixed hearing loss
- sudden hearing loss
- progressive hearing loss
- children with auditory neuropathy

**14.1.1** Hearing aids must be selected for the child according to standard prescriptive procedures designed for children (eg Seewald, 1992; Byrne & Dillon 1986), and staff must be appropriately and specifically trained in the provision of advanced hearing aid systems to children.

Hearing aids for babies and children must:

- be manageable for the family and child,
- have childproof battery locks,
- prove beneficial to the child (Stokes, 1999)

### 14.2 Choice of aids to hearing - appropriateness and compatibility

Babies and children will have different requirements to those of adults. Therefore, no single choice of technology will provide all that is required. It can be expected that a range of technological solutions, taking into consideration developmental changes, must be available to meet each child's individual and diverse needs.

**14.2.1** Audiology services must ensure continuity of hearing aid provision from childhood to adulthood. Hearing aid provision to children and young people must not be marginalised on the grounds of cost.

#### 14.2.2

**QS** Children with permanent bilateral hearing loss must be provided with two hearing aids, unless there are justifiable contraindications.

#### 14.2.3

**QS** Hearing aids must be supplied within 4 weeks of the time of confirmation of hearing loss, other than in exceptional circumstances.

**14.2.4** At the time of fitting hearing aids, a thorough evaluation must be undertaken to ensure that:

- hearing aids have sufficient gain (with varying inputs)
- ear moulds permit the use of desired gain
- hearing aids do not cause loudness discomfort
- frequency response is appropriate
- hearing aids, ear moulds, elbows, and leads are appropriate and of a comfortable fit
- size, shape and colour are appropriate and the hearing aids are compatible with any other equipment with which they will be used (eg radio FM systems, induction loop systems, etc)

### 14.3 Ongoing hearing aid provision and assessment

The child (and family) must have:

- frequent reviews to establish benefit
- information and support on maintenance of the hearing aid
- information and support to optimise the use of hearing aids and ear moulds

**QS** 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.



14.3.1 Each child's records must be up-dated following each hearing aid/audiological review.

#### 14.4 Ear impressions and ear mould fitting

Child-appropriate techniques must be used when taking ear mould impressions.

**OS** Guidelines for ear mould impression-taking in babies and children, ear mould types and material, and manufacturing procedures must be followed (BSA, 1986; Nolan, 1993).

Ear moulds must be replaced as required. In babies and very young children this could be between 2 and 4 weeks. The ear mould service used must be capable of meeting these requirements.

14.4.1 Ear mould clinics must be available outside school hours.

#### 14.5 Provision of batteries and spare/loan hearing aids

**OS** Hearing aid departments must carry sufficient stocks of hearing aids and hearing aid batteries to provide immediate replacements to the child and family. Hearing aids to the child must be replaced within 1 working day.

- Replacement aids must be of the same make and model
- Replacement aids must be set to the internal and external settings recorded on the child's audiological files

#### 14.6 Replacement following loss or damage

**OS** Following loss or damage of a child's hearing aid(s), replacement instruments of the same make, model and settings must be issued free of charge within 1 working day of notification.

If the child is provided with a spare hearing aid, then the urgency for replacement is less acute.

#### 14.7 New spare/loan hearing aids

The audiology service must ensure that parents and the child's teacher of the deaf (and other support staff) receive updated information on hearing aid settings.

**OS** If the child's hearing aid settings are changed, this information must be given to the child's parents immediately. The teacher of the deaf and other support staff must be informed within 2 working days.

#### 14.8 Monitoring progress

Following initial fitting babies and young children must be reviewed frequently to meet their rapidly changing requirements.

**OS** In the paediatric audiology centre, electroacoustic performance measurements and evaluations must be repeated at least annually during the child's audiological evaluation.

For older children, audiological evaluations must be carried out during their hearing aid review.

Electroacoustic performance of the hearing aid must be checked every 6 weeks (in between paediatric audiology hearing aid reviews), in accordance with current British and IEC standards. This monitoring is usually carried out by the education service.

14.8.1 Flexibility may be required as to where such assessments and reviews are held.

14.8.2 Verification of appropriateness of amplification characteristics must be undertaken at regular intervals using functional measures (aided sound-field thresholds to warble tone stimuli, aided speech testing), and probe-tube microphone measures (real ear aided responses, real ear saturation SPL).

#### 14.9 Daily maintenance

**OS** Parents and teachers must be provided with a hearing aid kit that must include at least a stetoclip and air puffer for daily maintenance (NDCS Hearing Aid Booklet, 2000).

#### 14.10 Insurance

All aids issued by the NHS, regardless of whether these are from the commercial range or the NHS range, remain Crown property, and as such do not require insurance. Parents must not be pressurised or encouraged to insure their child's hearing aids (Department of Health Guidelines ref. C101, 1983).

## 15 DETERIORATION OF HEARING LOSS

**OS** A child with a sudden deterioration in hearing thresholds must be referred for full audiological and ENT investigation as a matter of urgency. They must be referred within 1 working day and seen within 2 days.



## 16 REFERRAL FOR THE USE OF COCHLEAR IMPLANTS AND OTHER AIDS

Consideration must be given to the provision and funding of other aids to hearing, such as cochlear implants (NDCS/BCIG Quality Standards, 1999), vibrotactile aids, environmental aids and FM radio systems. Procedures and protocols must be in place to ensure that provision and support for these devices are suitable to meet the needs of the individual child and the child's family.

Identification of hearing loss through UNHS will mean that cochlear implants can be considered sooner. It is, therefore, vital that all babies and children, who might be considered for a cochlear implant, are appropriately and thoroughly assessed. This assessment must include a consistent trial of the most appropriate hearing aids, regardless of cost, over a substantial period of time. This assessment must take into account the child's age-related development (NDCS/BCIG Quality Standards, 1999).

Parents must be given sufficient time to make an informed choice on behalf of their child.

Appropriate balanced information must be given to parents to ensure that they can make an informed choice (NDCS/NPCIP/Cochlear (Europe) Ltd, 1999).

### 16.1 Cochlear implants

**QS** Services for such children must be guided by the NDCS/BCIG Quality Standards Cochlear Implants for Children (1999).

### 16.2 Radio FM systems

Radio FM systems are used extensively by school age children who wear hearing aids and cochlear implants. The fitting of FM systems can improve signal to noise ratio and therefore help to reduce some of the adverse effects of the acoustic environment. With the increase in the use of day care and nursery facilities, the listening environment may be less than ideal. Young children, as well as school age children, may benefit from the use of FM systems (ASHA, 1991).

### 16.3 Soundfield FM systems

These systems have proven to be effective in the signal to noise ratio particularly by children who are mild to moderately deaf, children with fluctuating deafness and children who wear cochlear implants (Arnold & Canning, 1999).

**QS** The paediatric audiology and educational services must work collaboratively to ensure provision of equipment and effective use by the child and the transmitter user.

### 16.4 Assistive devices

**QS** Strategies and protocols must be developed to determine children's requirements for assistive devices and a review of these requirements must be made regularly. The paediatric audiology service must work collaboratively with the provider of the equipment (for example, social services) to ensure appropriate provision and effective use by the child and the child's family (ADSS et al, in publication, 2001).

## 17 SUPPORTING CHILDREN, YOUNG PEOPLE AND FAMILIES

As they develop, children need to gain an understanding of their hearing loss, their hearing aids, and their aided abilities. They will need to learn how to manage their own device, learn what resources are available to them, and understand how service commissioners and providers operate.

Local health, education and social services have a responsibility to ensure they work in partnership to provide support and accessible and age-appropriate information to children.

### 17.1 Local and national support

Family support and youth groups are useful and effective in providing information and self help to families, children and young people. They can provide opportunities for the child and the child's family to meet and provide positive support to each other.

The AWG must identify availability of funding to support these groups.

## 17.2 School leavers

School leavers must be informed about services and resources and what support they will require when they move into further study and employment. School leavers must have a full assessment of their requirements for assistive listening devices based on any changing circumstances, such as moving accommodation.

17.2.1 It is the responsibility of the AWG to agree and develop policies and strategies for the transition to adult services.

## 17.3 Sign language opportunities

It is the responsibility of audiology services to identify and direct families towards the availability of sign language classes.

It is the responsibility of health and education to provide parents and professionals with information, advice and guidance on deaf awareness and good communication.

# 18 SERVICE EVALUATION AND AUDIT

## 18.1 Peer review and parent, family and service user perspectives

There must be locally agreed policies and strategies in place for the development, provision and evaluation of local audiology services.

A paediatric audiology service must:

- ensure continuous service evaluation using the nationally agreed standards recommended in this document
- include families and the views of consumers in the strategic management of their service

Internal and external evaluation of services and audit is essential to enable continued service improvement.

Local, regional and national structures must be in place that take strategic responsibility for planning and implementing hearing screening programmes and ongoing paediatric audiology services.

## 18.2 Regional/country

**OS** A nominated person must be responsible for monitoring paediatric audiology on behalf of each health authority. They must be responsible for publishing an annual written report of performance against standards. The following must be monitored and included in the annual report:

- the mean ages of confirmation, including standard deviations, ages of confirmation, levels of deafness
- hearing aid fitting for moderate, severe and profound hearing loss for each annual birth cohort, and for 3 years retrospectively
- all false negative cases identified during the preceding year, including possible or known children with progressive hearing loss

## 18.3 National

- The NSC to fund 5-yearly surveys and report based on local audits
- The NSC to fund an annual survey and sample (minimum of 10%) of local audits
- Local registers to be aggregated into ongoing national register
- The NSC to fund 5-yearly surveys of sample of parents, sample of parents of children with PCHI, clinical managers, education services and voluntary bodies

## 18.4 IT in screening and paediatric audiology

Data collection and audit systems in screening and paediatric audiology must be computerised, utilising a minimum data sheet approach for every child considered at risk.

There must be a local register of deaf children (to include late onset and progressive deafness) available for the use of education and social services. To divulge this information to a third party, parental consent must be obtained.



## 19 ADMINISTRATION

Appointment protocols must be developed for the organisation of scheduling and prioritisation of appointments, as well as failure to attend issues.

Staff must be familiar with agreed local health authority standards for case records, reporting issues, distributing information to all parties, and provision of information to families before, during and following the child's visit to the paediatric audiology centre.

There must be agreed standards for staff within the local audiology service, including reception staff, regarding telephone contact and direct access with families and other team members working and supporting deaf children and their families.

There must be a policy in practice that deals with issues relating to failure to attend by any family.

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