

Transforming Services for Children with Hearing Difficulty and their Families

A Good Practice Guide

Transforming Services for Children with Hearing Difficulty and their Families: A Good Practice Guide

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Foreword

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We are delighted to see the publication of this Good Practice Guide for children's hearing services, at a time when there is rightly a national focus on the delivery of excellent services for children, and on improving the quality and availability of audiology services.

The ability to hear is critical, not just for communication and social interaction, but to enable an individual to fulfil their learning and development potential. The early detection, assessment and management of hearing problems in children is therefore key to their personal, educational and social achievement.

We are launching this document to support local services in ensuring that children with hearing difficulty have improved access to high quality hearing services, which will be delivered in networks and in line with the target of a maximum wait of 18 weeks from GP referral to initiation of consultant-led treatment. This should enable as much care as possible to be delivered close to the child's home, with rapid access to more specialist expertise when needed. This guide provides practical advice on how to improve access to, and experience of, hearing services for children with hearing difficulty and their families, and suggests how to reduce waits and unnecessary steps in care.

A wide range of professionals, managers and voluntary sector organisations, most notably the National Deaf Children's Society, have contributed to the development of this document, and we are very grateful to them. We are especially grateful to Maggie Pearson who worked with this wide range of stakeholders and the DH Audiology Clinical Champions to ensure this document provided clarity and outlined the issues that need to be addressed.

We hope that practitioners, managers and commissioners will use this good practice guide to shape local decisions about services and support for children with hearing difficulty and their families, and in doing so enable these young people to fully achieve their potential.



Professor Sue Hill



Dr Sheila Shribman

Executive Summary: The Vision for Children's Hearing Services

1. The vision for children who are deaf or have hearing difficulty¹ is for them to be identified, assessed and receive appropriate intervention as early as possible. They and their families need to receive early support from high quality, efficient and integrated services across agencies, which respond well to their changing needs.² Children's hearing services need to be delivered as locally as possible, and to have low waits at every stage of the pathway, recognising the potential impact of unmanaged hearing loss on learning and development. These services will be delivered by a wide range of professionals working collaboratively in a multidisciplinary team and in a network arrangement. They will involve a number of different healthcare providers in partnership with professionals from other agencies including the third sector,³ which plays a key role in supporting parents, through providing unbiased information and peer support.

the child's home, with rapid access to more specialist expertise when needed. It provides practical advice on the characteristics and qualities locally determined paediatric audiology networks need so that they can improve access to, and experience of, hearing services for children with hearing difficulty and their families. It suggests how to reduce waits and unnecessary steps in care.
3. The paediatric audiology networks will need to provide high quality services in which:
 - parents are regarded as full and equal partners in the team;
 - there is a clear clinical and where appropriate managerial lead for the network, liaising with relevant regional or sub-regional specialist commissioned children's services (eg cochlear implants, bone anchored hearing aids, cleft lip and palate);
 - Children's Hearing Services Working Groups play a key role in shaping services, forming the basis of the service network and informing commissioning;
 - there is early identification of hearing difficulty and rapid, definitive
2. This guide supports local services in implementing the vision to reduce variability in quality and to provide a critical mass of clinical skills and competences so that as much care as possible can be delivered close to

A Good Practice Guide to Achieving the Vision

1 From here on referred to as 'children with hearing difficulty' and including children with permanent hearing loss and those with temporary but prolonged hearing loss.
2 See <http://www.earlysupport.org.uk/> for details of the Government's Early Support initiative.
3 Formerly known as the voluntary sector.

assessment and differential diagnosis in high quality facilities by specialist staff with the appropriate skills and competences, accompanied by clear accessible information about communication, amplification, and educational placement options, and about the role of health, education and social care in the provision of support to the family;

- there is rapid referral to the hearing support service provided by the local education authority for all babies and children diagnosed with permanent childhood hearing impairment and there is timely and appropriate referral for investigations into possible causes of the impairment;
- there are clear referral criteria, direct care pathways with minimal steps and rapid referral to specialist or sub-specialist care, such as paediatric cochlear implant teams as required;
- the children's network is 'vertically' integrated into a wider hearing services network for adults which is particularly important to ensure a seamless transition for young people as they leave the children's service.

Part one: The Current Challenge in Children's Hearing Services

Permanent hearing impairment in children: an uncommon condition requiring vigilant detection

4. Effective commissioning and provision of high quality children's hearing services requires accurate information about the scale and nature of permanent and temporary hearing loss. There is a good evidence base about moderate, severe and profound deafness,⁴ but data are less robust around children with mild and unilateral permanent childhood hearing impairment (PCHI). Otitis media with effusion (OME), or glue ear, is common in children, and is the most common cause of temporary hearing loss which may fluctuate and be prolonged.⁵ All hearing difficulties are more common in disadvantaged and ethnic minority populations.⁶ This is due to a combination of factors, including the impact of poverty and social deprivation on the health of the mother in pregnancy, and some genetic conditions. Approximately half the cases of PCHI have a genetic cause.⁷

5. From published epidemiological evidence⁸ we know that:

- **about 1,000 babies are born each year in England** with PCHI, two thirds of whom will be affected bilaterally. In 40 per cent of those children, the hearing loss will be severe or profound. Bilateral PCHI can have a major impact on these children and their families, and is often associated with a life of consistent underachievement. This means that approximately 1.6 per thousand babies born will have a permanent hearing disorder: a rare event which an average maternity unit (3-4,000 births per annum) will encounter about five times a year. A GP with an average list size will look after one deaf child in their entire career, and an average GP practice with five GPs may see only one deaf child in ten years. In a Primary Care Trust with a population of 500,000, there will be about ten new cases of PCHI per year, with about 40 pre school and 160 school age deaf children in the population. In some areas this can be up to twice the expected prevalence, due to population variations;

4 Davis et al 1997; Fortnum et al 2001.

5 Maw 1988.

6 Fortnum and Davis, 1988.

7 Morton 1991.

8 Whilst Permanent Hearing Impairment (PCHI) is technically defined as bilateral hearing impairment exceeding 40 dB (http://www.who.int/pbd/deafness/hearing_impairment_grades), this document also addresses services needed by children with milder and/or temporary hearing loss. Some studies reported here include milder and/or temporary hearing loss.

- **an estimated further 600 children develop or acquire PCHI by the age of ten.** This may be the result of either congenital or genetic causes which become manifest after a period of time, such as exposure *in utero* to certain viruses such as cytomegalovirus (CMV), or there is genetic progressive hearing loss. The principal causes of acquired hearing loss are mumps; meningitis; head injury; autoimmune ear disease; and drugs which are toxic to the ear, such as chemotherapeutic agents. There may also be unexplained individual causes.
6. By the age of ten, therefore, in each year's cohort of children in England, there will be up to 1,200 children with congenital or late onset bilateral hearing impairment and between 600 to 800 with unilateral deafness. At any one time, there are about 16,000-20,000 children aged 18 or under who have bilateral moderate, severe or profound hearing impairment, a high proportion of whom routinely use hearing aids, cochlear implants and other implantable devices to hear sounds. An average Primary Care Trust may therefore have about 150 children under the age of 18 with a hearing impairment who would benefit from a joint care plan, and 35 children under the age of five affected by PCHI. The small numbers of children with PCHI mean that highly specialist facilities and services will necessarily be concentrated in urban conurbations, serving a large population.
 7. 30-40 percent of children with hearing difficulty have additional health needs or development problems, and 20 percent have more than two.⁹ There is evidence that children with hearing impairment are more likely to experience mental health problems or to be abused.¹⁰
 8. Given the relative infrequency of PCHI, which may present as behavioural and developmental problems or educational underachievement, the challenge is to ensure that all practitioners working routinely with young children are alert and vigilant to its possibility. Any child about whose hearing there are concerns needs to be referred rapidly for assessment and diagnosis.
 9. OME is a condition which fluctuates, causing hearing loss which may be prolonged, although transient, and in some children may have a detrimental impact on behaviour, development and achievement through to late teenage years, particularly if it was untreated in childhood.¹¹ 80 percent of children have

⁹ Fortnum and Davis, 1987,1988.

¹⁰ Hindley and Kitson, 2002.

¹¹ Bennett and Haggard 1999; Bennett et al 2001.

had an episode of glue ear by the age of ten and require assessment and monitoring by paediatric audiology services or in a children's Ear, Nose and Throat (ENT) clinic if it gives cause for concern, or is affecting their health or development. A small sub-set of children with glue ear and another condition (eg Down's Syndrome, cleft palate) are more likely to have the condition for longer periods of time, and their hearing may be monitored and managed by local children's hearing services or by the cleft lip and palate multi-disciplinary team, depending on service accessibility to families and on local arrangements. The local hearing services provided collaboratively with children's ENT clinics and which are needed by these children, who represent a significant part of the workload, are included in the scope of this document.

Variable children's hearing services

10. There is significant variability in the quality of commissioning and of co-ordination of children's hearing services across England. In some places, this has resulted in inefficient pathways through multiple steps of care. Until the full introduction in 2006 of the Newborn Hearing Screening Programme (NHSP), identification of childhood hearing impairment was dependent upon the vigilance of parents

and practitioners in health, education and social care. Prior to the introduction of the NHSP, routine child health screening tests identified less than 20 percent of cases, and almost a quarter of children born with PCHI were not identified until they were over 3.5 years of age.¹²

11. Currently, child hearing services across England are provided as:
 - 121 newborn screening programmes;
 - approximately 150 children's hearing services which assess, diagnose and habilitate children with hearing impairment; and
 - 14 cochlear implant services.
12. Despite the major service improvements and good practice which have been stimulated by the NHSP and the Modernising Children's Hearing Aid Services (MCHAS) initiative, there is still a long way to go to ensure equity of access to high quality services. The major problems which need addressing are:¹³
 - the organisation and delivery of children's hearing services are not always well co-ordinated or child and family-centred;
 - provision is uneven and inconsistent in quality and quantity, including the

¹² Fortnum and Davis 1997.

¹³ List includes problems identified by QA visits for the NHSP and MCHAS feedback. See: MRC Hearing and Communication Group 2007.

adoption of new technology and digital aids;

- children's hearing services are not always well aligned with other children's services and interagency working;
- education services have generally responded well to the challenge of providing good early support, but health and social care support for babies, children and young people with PCHI and their families does not have the same coverage;
- the provision of interpreters is poor;
- there are long waits in some places for initial assessments and ongoing review, often after rapid identification by the newborn screening programme;
- fundamental audiological testing methods are lacking in many services, particularly for young babies;
- the lack of training for audiologists to work with tiny babies and their families, such that they are particularly uncertain about the audiological management and amplification of babies under six months of age, and the application of real ear measurements;
- data recording, quality assurance and IT systems are in need of improvement and monitoring to ensure that accurate information is shared with parents and between different parts of the service;
- plans and arrangements for the transition of young people to adult services are not always explicit.

Transforming Children's Hearing Services

13. The implementation in 2006 of the universal NHSP has been a major catalyst for change in children's hearing services. Now focus is needed on the service transformation required to support children with hearing difficulty identified at birth or at a later stage and to ensure that this continues into adulthood.

Networks of services for children with hearing difficulty

14. The vision for good practice in children's hearing services is therefore to provide locally determined networks of high quality services in which:

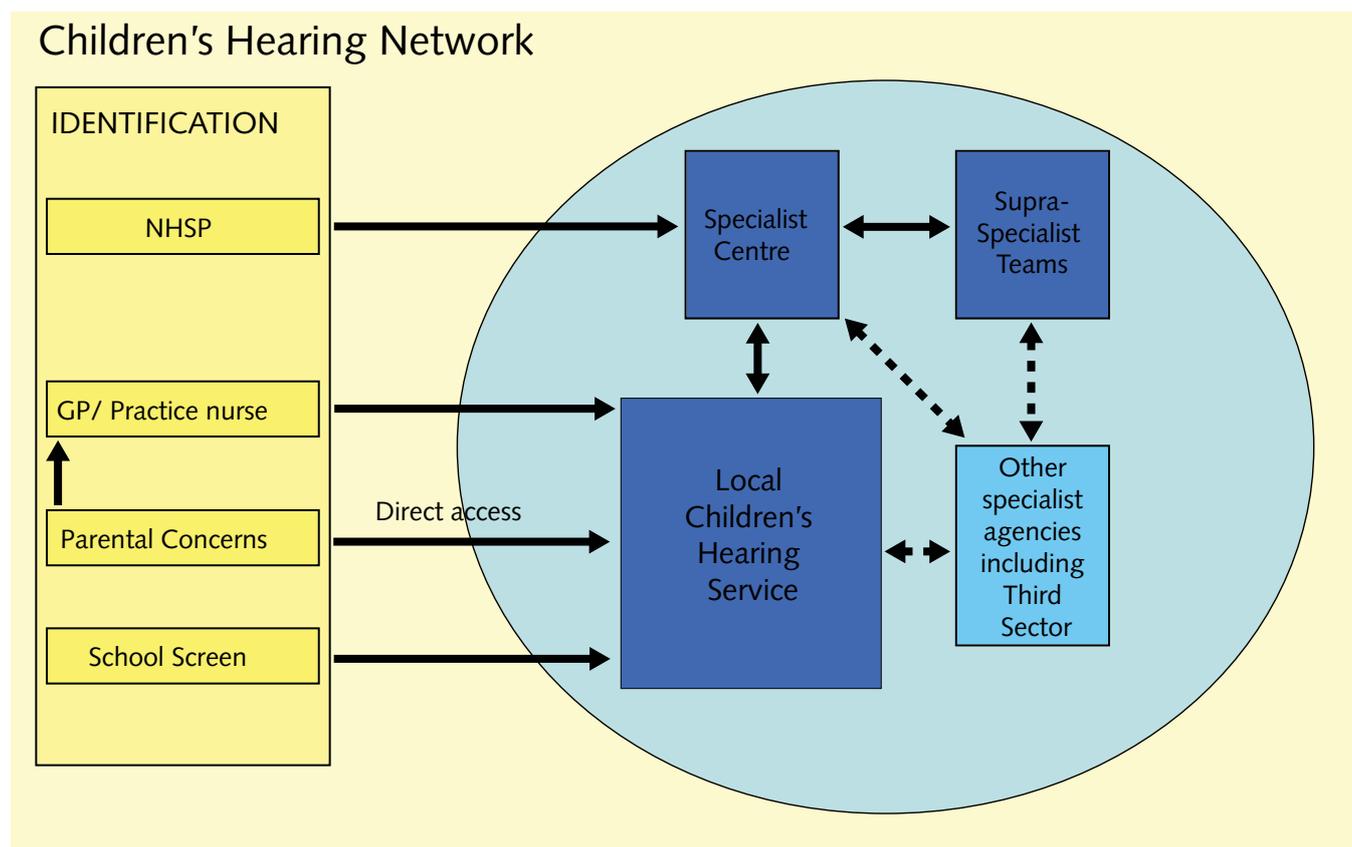
- parents are regarded as full and equal partners in the team;
- there is a clear clinical and managerial lead for the network, liaising with relevant regional or sub-regional specialist commissioned children's services (eg cochlear implants, bone anchored hearing aids, cleft lip and palate)
- children's Hearing Services Working Groups play a key role in shaping services, forming the basis of the service network and informing commissioning;
- there is early identification of hearing difficulty:
 - at birth, via the NHSP
 - through ongoing monitoring of high risk cases (eg children with complex

disabilities, children with conditions known to be associated with hearing loss, children on ototoxic drugs, including platinum cytotoxics)

- as early as possible following serious infection or injury or suspicion of impairment of hearing, following referral to specialist audiology services by vigilant professionals and parents
- at school entry via school screening (if the policy is implemented)
- following routine referral of children with speech and language delay
- at any age if there is parental or professional concern;
- there is rapid, definitive assessment and differential diagnosis in high quality facilities by specialist paediatric staff, accompanied by clear accessible information about communication, amplification, and educational placement options, and the role of health, education and social care in the provision of support to the family;
- there is rapid referral to the hearing support service provided by the local education authority for all babies and children diagnosed with PCHI;
- in discussion with parents, there will be timely referral for investigations into possible causes of PCHI

- those who have persistent OME/glue ear are appropriately and uniformly referred for specialist ENT treatment and follow up until the hearing and ears are normal. Those who have ongoing hearing difficulty should be expertly assessed for any underlying permanent impairment;
- there is early multidisciplinary, multi-agency support for the child and parents including education, speech and language therapy and social care if appropriate;
- there is agreement with parents and across agencies on a multidisciplinary management plan for each child;
- there is early access to, and expert fitting of, digital hearing aids where indicated;
- there are clear referral criteria, direct care pathways with minimal steps and rapid referral to specialist or sub-specialist care, as required;
- children with permanent hearing impairment receive ongoing care as close to home as possible by multi-disciplinary teams around the child

Figure 1



which are aware of safeguarding issues and mental health needs of children with hearing loss;

- the progress of children with permanent hearing impairment is systematically monitored to ensure that support services, including education, speech and language therapy, and any equipment provided (such as hearing aids, FM systems, implants) are appropriate;
- for the 40 percent of children with hearing impairment who have additional health needs, as well as those at particular risk of mental health problems or abuse,¹⁴ there is close liaison with other specialist children's service networks;
- the children's network is 'vertically' integrated into a wider hearing services network for adults. This is particularly important to ensure a seamless transition for young people as they become adults and leave the children's service.

15. The precise configuration of children's hearing service networks will vary, depending on local epidemiology, geography and service configurations. The challenge is to provide an effective network of services in which the more common, milder hearing difficulty can be

treated in local children's hearing services with specialist input, whilst also ensuring rapid referral of more complex cases to specialist centres with more diagnostic equipment and services for further assessment and diagnosis. Depending on population density and geographical scope of the service, a single specialist team¹⁵ may provide both local children's hearing services and a more centralised specialist service. The need for highly expensive specialist equipment may inevitably require some centralisation and physical concentration of certain specialist facilities. Some staff may work with both children and adults in separately timed clinics, but all must be specifically trained to work with children and have fully compliant child protection training and CRB screening.

16. The basis of the networks of services will be local children's hearing services, led by a consultant community paediatrician with expertise in developmental paediatrics and training and a special interest in audiology. Paediatric audiology teams will conduct the initial phase of all assessment, diagnosis (including differential medical diagnosis) and hearing aid fitting, and monitor the child's progress with hearing aids. Those teams will triage cases and refer complex cases on to specialist centres and supra-specialist centres (see Table 1 and Annex 1 for more detail).

¹⁴ Hindley and Kitson 2000.

¹⁵ Including audiologists trained to work with children, paediatricians with training and a special interest in audiology and ENT specialists as appropriate.

Table 1: Network of Children's Hearing Services

(See Annex 1 for more detail)

Network Component	Function	Workforce	Facilities
Primary care	Identify children whose hearing is cause for concern Refer to local children's hearing service or specialist centre, according to agreed criteria Long term support to families	GP Practice nurse Health visitor	None specialist for hearing
Local children's hearing service	Assessment and surveillance of hearing in children about whose hearing there is concern, including cleft lip and palate ¹⁶ Actively monitor children with OME, and refer for paediatric ENT and other specialist care if required Hearing aid fitting and replacement over 3 years of age in straightforward cases Refer children needing specialist or supra specialist care Long term support to families	May be shared with specialist centre Multi-disciplinary and multi-agency team, including: Community paediatrician with expertise in audiology and developmental paediatrics Audiologist trained to work with children Speech therapist Teacher of the deaf Social care (if required) Outreach ENT and audiovestibular physician from specialist centre, depending on geography Third sector support	Soundproofed test room Specialist equipment (see Annex 1)

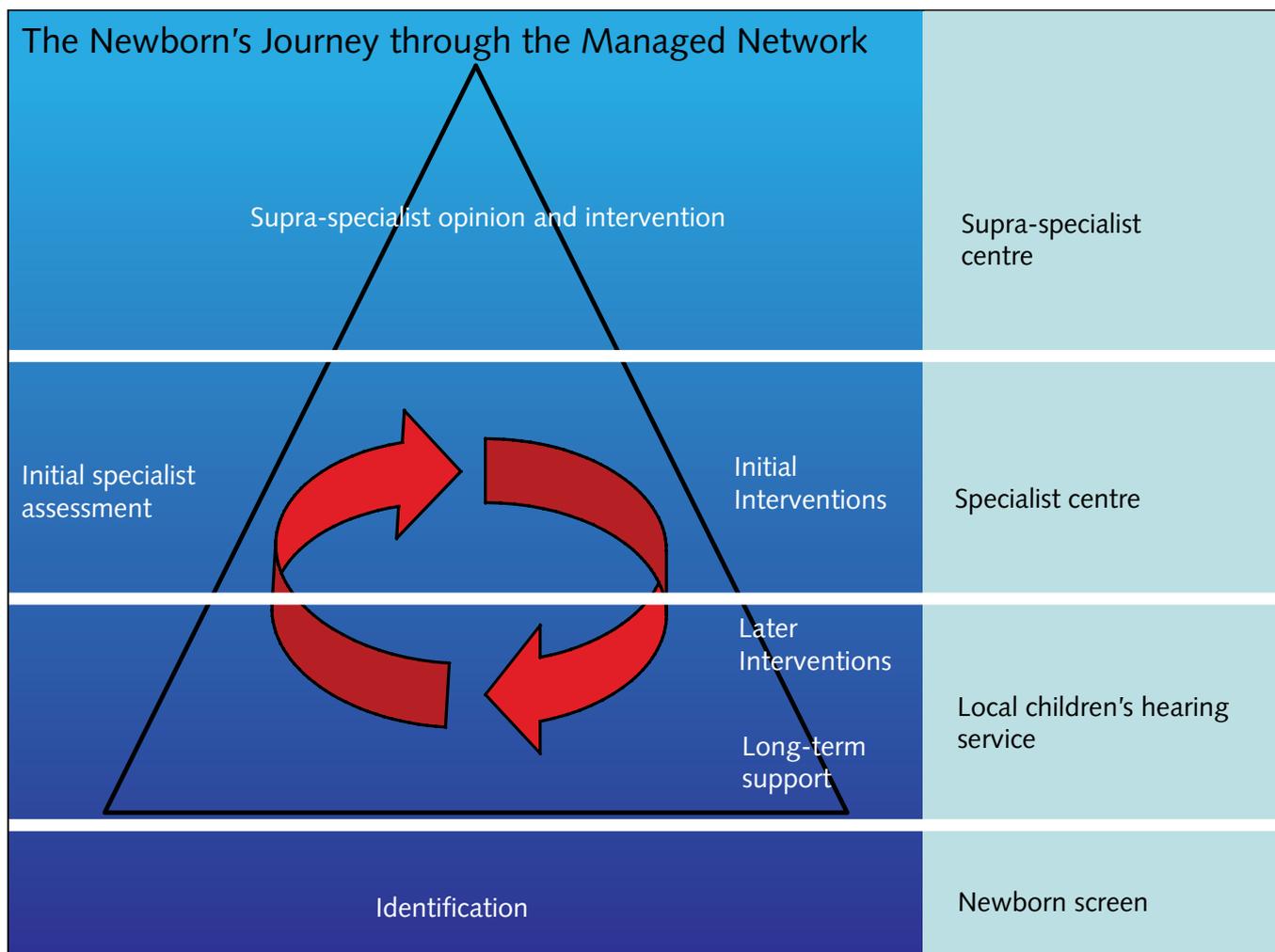
¹⁶ In some places, hearing in children with cleft lip and palate may be assessed and monitored by the regional cleft lip and palate multi-disciplinary team.

Network Component	Function	Workforce	Facilities
Specialist centre	<p>Assessment of babies identified by Newborn Hearing Screening Programme</p> <p>Children with more serious or complex hearing loss, needing wider clinical input (eg ENT, AVP)</p> <p>Hearing aid fitting and replacement for complex cases</p> <p>Joint clinics with ENT and clinical genetics</p> <p>Long term support to families</p>	<p>May be shared with local children's hearing service</p> <p>Specialist team including:</p> <ul style="list-style-type: none"> audiologist trained to work with children; children's ENT; audiovestibular physician clinical genetics 	<p>Vestibular testing Facilities</p> <p>Sound proofed test room</p>
Supra-specialist centre	<p>Provision of specialised hearing aids including cochlear implants and bone anchored hearing aids</p>	<p>As specialist centre plus</p> <p>Supra-specialist medical staff,</p> <p>Clinical psychologists</p>	<p>As specialist centre plus supra specialist Equipment (see Annex 1)</p>

17. Local children's hearing services and specialist centres in secondary care will work in hub and spoke arrangements, led by the paediatrician in the local service, managing those children whose needs fall within their sphere of expertise. Referrals to the local hearing service will be by GP or other primary care professionals, and by direct access as parents should be able to refer their own child if they have concerns about his or her hearing.

18. Children needing more specialist expertise will be referred to specialist centres, either directly by the GP or by the local hearing services, according to agreed local referral criteria (see Figure 1). Within the network, children with PCHI need to be managed long term, after assessment, diagnosis and hearing aid fitting, in clinics and services provided jointly across agencies, as close to the child's home as possible, possibly in generic local children's centres (depending

Figure 2

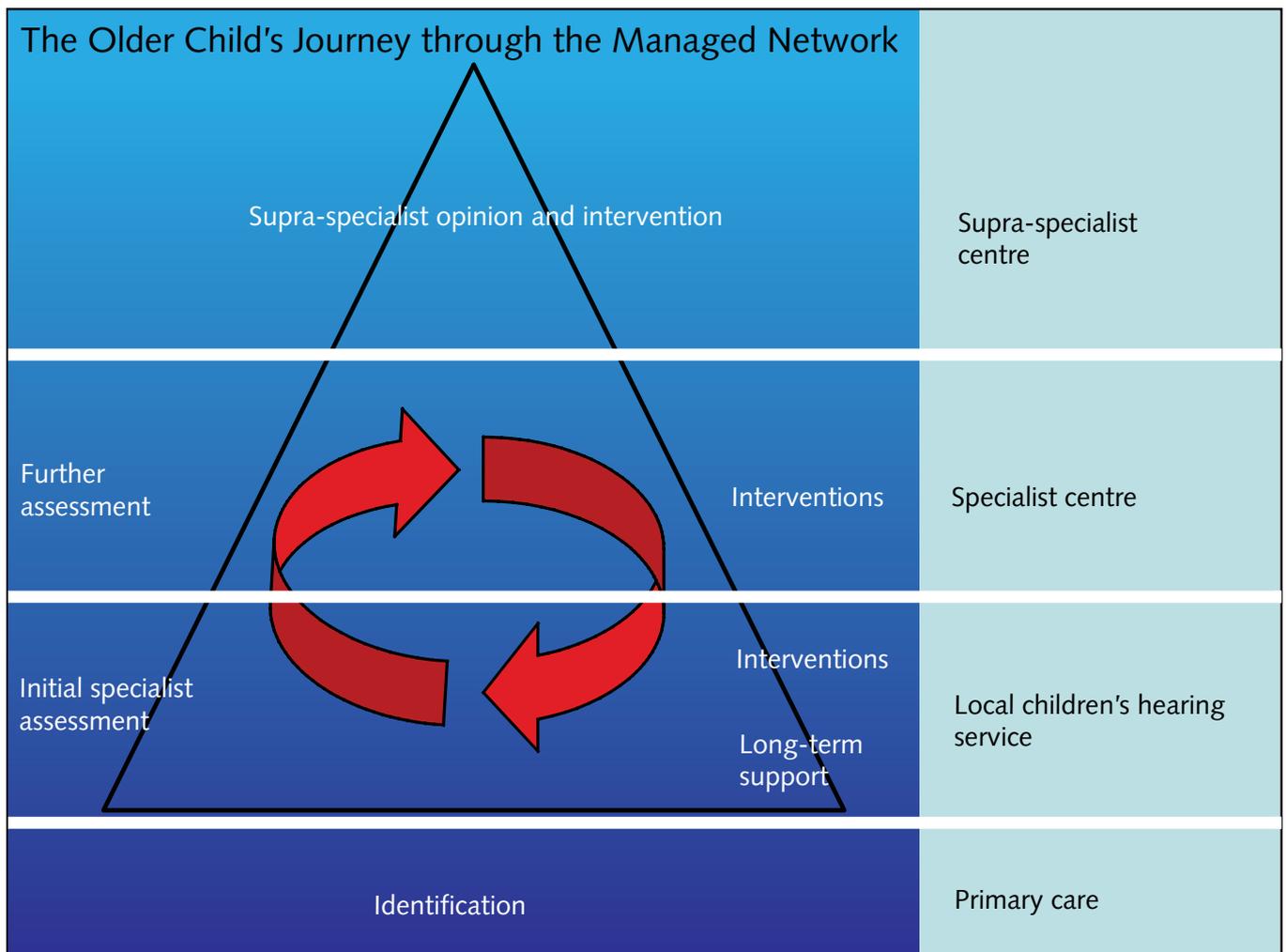


on local services) to enable multi-agency working.

19. To work effectively and ensure that children move along care pathways with a minimum number of steps and to receive consultant-led treatment¹⁷ as soon as possible to minimise the impact

on education and development (within a maximum wait of 18 weeks, but for many children it will need to be much lower), the constituent parts of the network will need to work efficiently together. There will need to be strong and clear managerial and clinical leadership from within the specialist paediatric hearing team.

Figure 2



¹⁷ For children with OME, there may be no intervention, but active monitoring.

Achieving the Vision

20. Over the last decade there have been significant technological developments which can improve potential outcomes for children with hearing impairment, but their full benefits will not be routinely delivered across the NHS unless the networks, systems and processes within which they are delivered are efficiently organised and the workforce is appropriately skilled. An integrated approach is therefore required to transform paediatric audiology services, tackling the following inter-related components (see Figure 4):

- involving children, young people and parents;
- improved cross sector working;
- systems and processes;
- technology;
- workforce.

Involving Children, Young People and Parents

21. The fundamental principle of listening to children, young people and their parents is central to children's policy. Children, young people and their families should be involved in shaping services at the strategic and individual levels and their feedback sought regularly and in a meaningful fashion.¹⁸ This means their involvement in groups such as local Children's Hearing

Services Working Groups (CHSWGs), which have parent representation, and are intended to encourage further modernisation and quality assurance. The NHSP Quality Assurance visits inspect local CHSWGs against standards based on recommendations of the National Deaf Children's Society. In 2006, the NHSP commissioned a consultation of parents and children, which had a variety of communication modes, including signed support and British Sign Language (BSL), to meet the needs of all participants.¹⁹

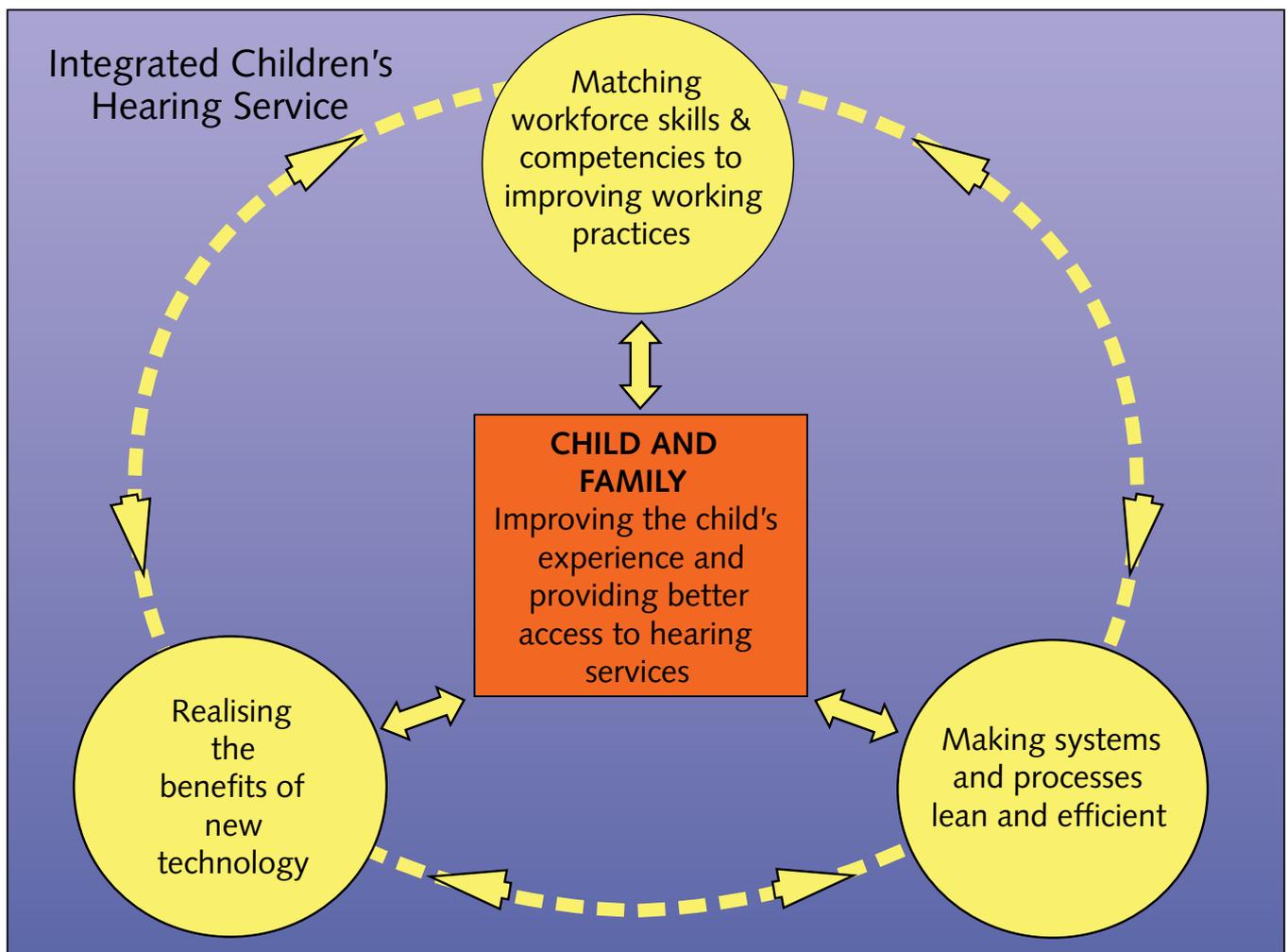
22. If the input of children and their families is to be meaningful, it is crucial that meetings and events are conducted in a manner which caters for their communication needs and encourages their involvement. Lipspeakers, palantypists, signed support and BSL interpretation may be required, and other members of the group will need to be communicating in such a way that deaf members can be fully involved, that is, speaking one at a time, and not too rapidly. The NHSP Children's Consultation event identified several issues about children's audiology services, including a lack of books and toys in waiting areas, many of which were felt to be drab, a lack of audiologists who could sign, and the need for more communication with the child as well as the parents.

¹⁸ Several helpful publications aimed at parents and professionals on improving family involvement are available from Contact a Family. See: <http://www.cafamily.org.uk>. See also Participation Works, <http://www.participationworks.org.uk>

¹⁹ MRC Hearing and Communication Group 2007.

23. It is crucial that children, young people and their families are involved in shaping both the strategic direction of services and their individual packages of care. The ability of audiologists to communicate with deaf children competently in the child's preferred mode, and to focus on the child rather than the parent, is crucial to this.
24. It is particularly important to involve the young person and his/her parents in plans for the transition from children's to adult services. Given the difference between services and sector in the age at which a 'child' becomes an adult (16, 18 or 19 years of age), it is critical that plans are centred around the young person, and they are able to exercise choice. Furthermore, as the young person progresses, new agencies (eg Further Education) may need to become involved. Careful co-ordination will be required

Figure 4



to ensure that young people do not get 'lost' as they move between services. Practitioners need to be mindful that the young person may find it hard to have to create new relationships with colleagues in adult services, and transfers need to be handled sensitively.

Improved cross-sector working

25. Central to the provision of high quality hearing services for children is the involvement of practitioners from a wide range of professions and agencies, and the involvement of the third sector. There are excellent examples of good practice in multi-professional, cross-agency working, but equally, despite decades of policy emphasis, there is also poor co-operation between agencies and professions in some places. Commissioners should ensure that new providers of health services, such as Specialist Providers of Medical Services are fully aware of hearing service network arrangements and provide facilities to specified standards.
26. The development of networks of services will require the involvement of partner agencies in multi-professional teams. There will need to be clear leadership, governance and accountability arrangements, so that there is clarity

about roles, responsibilities and reporting arrangements. A common feature of high performing managed networks is that there is a clearly identified lead agency and a specific person to lead the collaborative process.²⁰ Multi-professional, cross agency teams need to acknowledge and address professional and organisational cultural differences, including the use of terminology (eg 'patients' or 'clients') and differing service priorities.

27. Cross-agency team work requires pooling and sharing of data for planning purposes and for the delivery of care and support to individuals. These issues are dealt with in the section on systems and processes below, but it is important to recognise that different professions and agencies may have different traditions, policies and practices in respect of holding and sharing data. Information technology has a key part to play. Consent is required at all times for health information to be shared with third parties, with consent from the child when s/he has capacity to understand (ie is Gillick competent),²¹ or by the child's parent(s) or legal guardian where s/he lacks capacity. It is particularly important that data about individual young people are shared with their consent at the point of transition to adult services:

²⁰ See DCSF/DH 2007 for examples of high performing cancer and cardiac networks.

²¹ *Gillick v West Norfolk & Wisbech AHA & DHSS* [1983] 3 WLR (QBD) *Gillick v West Norfolk and Wisbech Area Health Authority* [1985] 3 All ER 402 (HL).

²² *ibid.*

by developing a common assessment framework and sharing information, agencies can avoid multiple but partial assessments.²²

28. Strategic Health Authorities and Primary Care Trusts have a duty, set out in the Children Act 2004, to co-operate in drawing up arrangements with Local Authorities which produce integrated working for children's services at all levels. *Every Child Matters* recommended these arrangements should be in place by 2008.²³ It is also good practice for children's health services to be planned and commissioned with reference to the Children and Young People's Plan, which forms part of a broader Local Area Agreement, on which the Local Authority will take the lead, and which gives strategic direction for all children's services in a local area. The inclusion of children's hearing services in the Children's and Young People's Plan should ensure that the needs of deaf and hearing-impaired children and their families are properly considered when developing local services.
29. There is already good partnership working between the NHS and local government, in particular around Local Area Agreements, in many places. The NHS Operating Framework²⁴ confirms that to transform local services further, the NHS will need

to build on these local partnerships, and recognise the value and critical contribution of partner agencies before and after NHS treatment. Joint Strategic Needs Assessments will be a crucial tool for PCTs and Local Authorities to identify the priorities for health and well-being that should be included in the Local Area Agreement.

Systems and processes

30. The earlier good practice guide *Transforming Adult Hearing Services for Patients with Hearing Difficulty* set out the key aspects of systems and process reform which will also be important in transforming waiting times and access to children's hearing services:
 - understanding the scale of the local challenge and collecting information to plan capacity;
 - improving referral criteria and ensuring that they are consistently applied by well informed primary care practitioners;
 - better waiting list management and efficient scheduling, including managing patients who do not attend (DNAs);
 - managing variation in capacity and demand, and maximising the clinical value of steps in the patient pathway;

23 <http://www.everychildmatters.gov.uk/aims/childrenstrusts/>

24 http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081094

- utilising all benefits of the audiology Patient Management Systems and linking where possible with broader NHS Patient Management Systems;
- adopting lean processes and other service improvement technologies through a systematic approach to understanding local services.

Understanding the scale of the local challenge for services

31. Given the relatively small numbers of children with hearing or associated problems in any local area, it is critical that service commissioners and providers have robust data from screening programmes and child health services, to ensure that babies and children identified with hearing loss receive high quality continuous services. In addition, high quality information systems which enable children to be tracked across agencies are crucial to ensure a seamless journey across complex pathways. With parents' consent, lists or registers of deaf and hearing-impaired children should be shared in strict confidence between local partner agencies and any third sector organisations contracted to provide support and services to children. It is essential that lists of children identified at an early stage as having congenital deafness are continually updated to include children who later

acquire deafness or hearing impairment. The shared lists should be used to estimate the need for services, and to enable monitoring of:

- the accuracy of the newborn and later screens;
- monitoring of progress and actions taken; and
- the appropriateness of professional concerns and responses.

32. Information technology can enable effective monitoring and is critical to the delivery of high quality continuous care, both in clinical assessment and diagnosis, and in the organisation of clinics and efficient record keeping.

33. The Department of Health has collected data on audiology diagnostic assessments since January 2006. Monthly data on all audiology assessments are collected on a monthly basis and published by the Department.²⁵ The quarterly census data collection provides a more detailed breakdown of the data by test, and separates out data on waits for paediatric hearing services following newborn screening, pre-school and school-age audiological assessment at specialist and supra-specialist tier clinics, and paediatric referrals for cochlear implant candidacy assessment.

25 <http://www.performance.doh.gov.uk/rtt/index.htm>

34. Patients referred for surgical or medical consultant-led care are included in the 18-week referral-to-treatment data return. From April 2008, the Department is also collecting information on waits for direct access audiology treatment, ie for patients who are referred directly to audiologists or clinical scientists in audiological medicine. Further information about this data collection is available on the 18-week website.²⁶

35. All audiology services should ensure that:

- the Department of Health data returns are completed fully and accurately, referring where necessary to the document *What is Physiological Measurement?*²⁷ for assessment definitions;
- data are collected to understand fully the demand and capacity of the different parts of their services;
- commissioners are supplied with up to date activity data and any variations over time in demand.

Planning service capacity

36. PCHI is a low-incidence condition, but newborn babies with PCHI require intensive professional support, including frequent (often two-weekly) ear-mould

replacement. The need for services can be highly variable, depending on social and economic circumstances. Service networks need to be organised across a sufficiently large population to absorb fluctuations in incidence, whilst enabling good local access. To maintain competence and continually update skills in assessment and habilitation, individual audiologists need to assess 20-30 new cases per year to ensure best practice and improve expertise. This has a key impact on the quality of the service provided and is particularly important in low volume specialist activity such as early electrophysiological assessment of babies, early hearing aid fitting and habilitation. Paediatric audiology services should be planned to cover sufficient population to generate the requisite critical mass of patients, and areas with low birth rates need to take account of this. Each specialist clinic in community based and hospital settings needs to be staffed by specialist practitioners trained in paediatrics who between them have all the requisite skills to undertake the assessment, diagnostic tests (see Annex 1 and 18-week website for details), treatments and counselling required.

37. Computerised databases, possibly of audit data, or comprehensive data collected by service providers on whom they have

²⁶ <http://www.18weeks.nhs.uk/content.aspx?path=/achieve-and-sustain/Specialty-focused-areas/Audiology>

²⁷ <http://www.18weeks.nhs.uk/content.aspx?path=achieve-and-sustain/Diagnostics/Physiological-measurement#28047>

seen, and for what purpose, can enable understanding of referral trends and patterns from which the capacity needed can be predicted. Careful planning of space and staffing are also necessary if appointments involve a more comprehensive assessment than previously separate ones. Regular review of the use of capacity (staff, rooms and equipment) will enable changes to be identified, which can increase efficiency. If more resources are needed, senior management needs to be engaged.

Improving and consistently applying referral criteria

38. Clear and consistently applied referral criteria are a key element in service transformation, ensuring not only that there is equity of access to services for children who need them, but also that children with symptoms which may be related to a hearing problem reach the most appropriate service in a timely manner.
39. For babies identified through the newborn screening programme, there are clear criteria for referral following a 'no clear response' outcome on either ear for the newborn hearing screen. The NHSP website has details.²⁸ If there is concern about the child's hearing and speech

development in the first few years of life, practitioners in primary care should make an appropriate referral to the local children's hearing service for assessment, using the NHSP checklist.

40. After the first few years of life, if there is concern about the child's hearing, communication behaviour or auditory development, then an appropriate referral should be made to assess hearing function and pathology. The most likely cause will be Otitis Media with Effusion (OME). Parental concern about hearing should always be taken seriously, and an onward referral made for audiological and/or ENT assessment, which will be in the local children's hearing service or the secondary care specialist centre, depending on local arrangements. Given the range of different ways in which acquired hearing difficulty may present (eg suddenly after meningitis or insidiously as in a high frequency loss after medication which is toxic to the ear), it is crucial that all those working with children are aware of the pathways along which any child with a suspected hearing problem or predisposing condition should be referred, and the criteria for referral.

28 <http://hearing.screening.nhs.uk/cms.php?folder=1247>

41. There should be clear criteria for:

- referral of children whose OME is affecting their health or development to a glue ear pathway. This should be as closely in line with the 18-week pathway,²⁹ and recent NICE guidance,³⁰ as is feasible. In this way their condition can be rapidly assessed by practitioners who are competent in the detection and management of OME. No 'long term' OME should go unmanaged, and OME that is persistent for more than three months duration should be referred to a children's ENT clinic;
- rapid referral for assessment by a paediatric audiologist of children treated with ototoxic medications (eg gentamicin and during and after chemotherapy), discharged from hospital after meningitis, or following a severe head injury, (especially those involving fracture);
- referral for diagnostic assessment by a paediatric audiologist after failing the school audiometric screen. A recent review of school screening indicated there was a need to ensure that the school screen used a standard method and that data were recorded;³¹
- specialist paediatric assessment of children with complex medical, genetic and/or developmental conditions, especially those known to be associated with hearing loss;
- surveillance of unilateral hearing difficulty so that any deterioration of hearing in either ear is detected early, with the normally hearing ear also being monitored;
- rapid, direct access for emergency specialist hearing assessment if parents of children with a permanent childhood hearing impairment (including parents of children with a unilateral hearing loss) believe their child has symptoms suggesting that the hearing loss is worsening;
- rapid emergency referral by GP (best practice recommendation would be within 24 hours) to audiology or ENT (on call service if necessary, out of hours) for specialist hearing assessment for children thought to have suffered a sudden sensorineural hearing loss in one or both ears.

Waiting list management and scheduling

42. To minimise waiting times for children and their parents, and to meet the waiting time

29 See: <http://www.18weeks.nhs.uk/Content.aspx?path=/achieve-and-sustain/Specialty-focused-areas/Audiology/audiology>

30 NICE 2008. <http://www.nice.nhs.uk/guidance/index.jsp?action=byID&o=11928>

31 Bamford et al 2007.

targets, it is important that systems are as efficient as possible to identify the need for audiology services, and to manage the workflow as shown in *Transforming Adult Hearing Services*.

43. The employment of administrative and clerical staff who are empowered to manage appointments can improve the efficiency of clinics significantly, particularly if parents are contacted close to an appointment to check that they will be attending. This can be done by text message from computerised systems to mobile phones. Such measures have been shown to reduce the number of people who do not attend appointments. Contacting new referrals by phone to arrange an appointment at a time convenient for them can improve first attendance rates. Where possible, efforts should be made to give school age children appointments outside school times, so that they do not miss school.
44. The workflow through audiology clinics can be improved by teams of practitioners being well prepared and ensuring that all equipment is to hand, to prevent delays or repeat attendances. All assessment tests required should be undertaken in one visit if possible. This will:

- minimise inconvenience for the family (and thereby ensure maximum attendance);
- maximise workflow throughput; and
- minimise wait times.

45. However, some babies and young children have very complex needs, for which more than one assessment visit may be required. Streaming cases according to complexity can improve the efficiency and effectiveness of clinics, as different members of the team work to their maximum skill and competency levels.
46. Clinics which are known to be family and parent-friendly will have higher attendance rates, thus maximising the efficiency of the service and reducing wait times. The Children's Consultation undertaken by the NHSP highlighted the importance to children of attractive clinics, toys and play areas.³²

Technology

47. There have been significant technical innovations in diagnostic tests and in interventions for children with hearing difficulty, including the type of aids and support now available. All children with confirmed hearing impairment should be offered digital hearing aids, unless contraindicated.

Assessment

- Screening tests will continue to improve, based on our knowledge of diagnostic tests and their application to populations;
- New electrophysiological testing techniques, eg Auditory Steady State Responses (ASSR), are being developed to complement those that exist, but will need interpretation by experienced practitioners;
- New electrophysiology recording methods and noise rejection techniques may allow better success in testing on non-sleeping and older babies.

Hearing aids

- Digital hearing aid technology is developing rapidly, and audiologists and services need to keep abreast of the latest developments. Digital signal processing (DSP) hearing aids have a number of features that may be of increasing benefit to children. These need to be tested and adopted if found to be helpful;
- Behind the ear (BTE) hearing aids are used for children and young people, who will readily accept these, however there is a need for some children to use smaller in the canal (ITC) or in the ear (ITE) hearing aids so that they will continue to use them, providing the signal processing strategies and power are appropriate;

- FM systems have the greatest benefit in improving signal to noise ratios and should be routinely made available without undue delay for those children (including pre-school children) who are judged to benefit. There needs to be close joint working between health and education services, and potentially, pooling of currently separate budgets for ear-moulds, digital aids and FM systems;
- It is crucial that there is consistency in the precise type of digital aids that are supplied by the NHS, and that practitioners influence the procurement;
- Bone anchored hearing aids are surgically attached to the skull and transmit sound directly to the cochlea, giving a clear signal through the bone, and are used in some forms of permanent conductive hearing loss;
- Cochlear implants are surgically implanted aids to hearing which directly stimulate the auditory nerve via an array of electrodes which are surgically implanted inside the inner ear (cochlea). Use of these devices is increasing rapidly as technologies and surgical techniques evolve;
- Cortical evoked potentials can help monitor progress in habilitation by monitoring the effects of sound on the brain's processing of signals, and are helpful in very young children.

Workforce

Audiology workforce profile

48. Throughout the NHS, the workforce is critical in delivering effective services and plans which are affordable, supported by significant role redesign, skill mix and productivity gains. Given the relatively small workforce currently competent to work with children in respect of their hearing, it is vital that these specialist skills are deployed efficiently and to best effect, to minimise waits and ensure that children with hearing difficulty are seen as soon as possible. It is also vital that local workforce plans ensure a suitable supply of all staff groups involved to meet future needs, including audiologists and audiovestibular physicians trained to work with children where current workforce numbers are low.
49. The delivery of child hearing services will require a paediatric audiology workforce spanning the whole career framework, including specialist paediatric medical practitioners. The specialist and supra-specialist components of the network will need to include ENT and clinical genetics specialists. It is essential that the local children's hearing services and specialist centres have both medical and scientific expertise with appropriate competence in working with children with PCHI and their families. Staff trained to work with children are essential to the delivery of a high quality service. In some areas, depending on population density and case load, staff trained to work with children may also work with adults, but in clinics held at different times. Continuing Professional Development and peer review of case studies are crucial to the maintenance of high clinical standards, not least given the pace of technological development.
50. The skills involved in the processes of delivering child hearing services should be mapped into a workforce profile, which will enable more efficient deployment of highly specialist medical and audiological skills to work with children with more complex needs. Other staff such as audiology assistants and associate audiologists can work with more straightforward cases, undertaking less expert, routine clinical tasks, with appropriate training within competency frameworks. This will increase clinical capacity and maximise the number of patients who can be seen, thereby reducing waits.
51. The transformation of services and reduction of waiting times will require the development of new roles to support specialist audiology staff. Some routine tasks such as screening can be carried out by well-trained non-graduate staff. An audiological scientist can be supported by a range of staff in assessment, diagnosis and intervention.
52. The need to ensure that specialist expertise is deployed to maximum effect may

require the concentration of specific tasks with specific professional roles, and there may be a critical mass of procedures which need to be undertaken by a practitioner each year, to ensure competence. For example, early assessment, particularly Auditory Brainstem Responses (ABR) and its interpretation and decisions on contingent testing is a highly skilled area.

53. The administrative load of all clinical staff should be kept to a minimum, to ensure maximum availability of their clinical skills for assessment and treatment. High quality administrative and clerical staff are essential for the efficient running of clinics and management of waiting lists.

Effective teamworking and networking

54. The importance of effective multi-agency working for high quality children's services cannot be over-stated. A specific workforce development programme may be required to ensure that all practitioners can work in this way. This will involve:

- the facilitation of peer support and networking between professional groups and teams;
- participation in regional networks where they exist, and the stimulation of new ones where they are not already established;
- recognition of and participation in multi-agency working practice

(including inter-agency referral, information sharing, training etc);

- regarding parents as full and equal partners in the team.

Leadership

55. Within the NHS, strong clinical leadership across audiology, paediatrics, audiovestibular physicians and ENT services is required to ensure the transformation of services, efficient pathways, and the maintenance of standards across the network. The leadership needs to have vision, and to foster networking across service and agencies, and to enable the multi-agency team, including the third sector, to identify opportunities for service improvements and to respond to them. Furthermore, strong leadership and accountability is required across multi-agency working. Strong clinical and professional leadership is needed to secure the safety and quality of services and it is important that the leadership is approachable, so that colleagues can raise any concerns which they may have. There need to be clear and explicit management arrangements across the networks, to support accountable leadership.

Part Two: Good Practice Commissioning Specification

56. A number of care pathways for children with hearing difficulty have already been published.³³ A new 18-week commissioning pathway for children with hearing difficulty is being developed and it is recommended best practice to deliver these pathways, within the network of children's hearing services. Given the complexity of multi-agency arrangements for children's service commissioning and provision, local partners should have a clear and agreed vision and plan, with clarity about respective roles, responsibilities and accountabilities.
57. A network of children's hearing services is the most efficient way of delivering the vision and service transformation required (see Figure 1). Local children's hearing services, staffed by specialist paediatric multi-disciplinary teams, are the basis of the network. The network's role is to provide ongoing assessment and management of all children with hearing difficulty, and to ensure that appropriate reviews and re-assessments are carried out in association with the other parts of the network, as children are transferred seamlessly to supra-specialist services for more complex assessment or management, as required. For children with multiple and complex problems, there will need to be effective liaison with other children's service networks. The functions and features of different components of the network are set out in Annex 1, as a guide for commissioners. There will be local nuances, and the functions discharged in specific components of the network will depend on local circumstances and facilities. Commissioning arrangements for the network of children's hearing services should be understood by all agencies, funding for the various components should be clearly identified, and there should be specific arrangements to ensure the smooth transition of children into adult services.
58. In responding to their local population's needs, commissioners should ensure that they have identified and addressed the diverse range of children and families' circumstances, in terms of race, first language and other cultural considerations, gender and disability, in order to promote equal access to services and reduce health inequalities. They should consider the impact of any proposed changes in terms of whether they will have a different impact on different groups, and whether there might be an unexpected negative effect. The nature and diversity of the hearing service workforce may need to be addressed to ensure that all service users' needs and requirements, including

33 For glue ear, see: <http://www.18weeks.nhs.uk/Content.aspx?path=/achieve-and-sustain/Specialty-focused-areas/Audiology/audiology> For newborn screening, see: <http://www.mrchear.info/cms/Resource.aspx?ResourceID=400> For early audiological assessment and support, see: <http://www.mrchear.info/cms/Resource.aspx?ResourceID=393>

language spoken, can be met. All NHS staff are required to undertake diversity and equality training.

59. Local children's hearing services will often share staff (and, in some cases, facilities) with specialist children's hearing centres, in which expensive equipment and facilities are centralised to maximise clinical quality and value for money. Clinical and managerial leadership for the network would normally come from within the local children's hearing service.
60. This model incorporates a number of modernisation elements, including:
 - putting the child and his/her family at the heart of service design and delivery;
 - multi-disciplinary and cross-sector working;
 - increased provision of care local to the child and his/her family;
 - expanded roles for audiologists and audiology assistants/associate audiologists;
 - seamless referral and provision from primary care, across local specialist services to supra-specialist care;
 - ability to deliver rapid treatment following initial presentation, to meet the target of a maximum patient

wait of 18 weeks from GP referral to initiation of hospital based treatment.

Primary care

61. Within the network, primary care teams will refer to the local children's hearing service those children whose hearing, language, speech or behavioural development is identified as a cause for concern by the parent, school, or a health service professional. Children with OME which is affecting their health or development should be seen by practitioners who are competent in the detection and management of OME. At the primary assessment level, this is likely to mean referral to the local children's hearing service for assessment and active monitoring by a paediatrician with expertise in developmental paediatrics and a special interest in audiology, and an audiologist trained to work with children. Until local hearing services are fully developed, this may require collaboration with ENT services for access to expertise and facilities. It is hoped that over time, the requisite skills and expertise will be developed in primary care clinicians.³⁴ The child may be referred for an ENT opinion, as appropriate and according to local referral criteria in line with NICE guidance. The majority of children with unproblematic glue ear which is self-limiting and of three months' or less duration will be managed in primary care,

³⁴ Buchanan and Pothier, 2008.

following specialist assessment and active monitoring by the local hearing service to rule out a permanent hearing loss. General practitioners will be notified of babies with hearing difficulty who have been identified by the NHSP and referred to the specialist children's hearing centre in secondary care.

The local children's hearing service

62. All children with hearing difficulty will be seen by the local children's hearing service, in which all clinical practitioners, including audiology assistants, have training in paediatrics. The initial hearing assessment will be undertaken in the local hearing service. Where possible all care will be delivered in the local hearing service, but some complex tests and procedures may need to be undertaken in the specialist centre. There will be protocol based follow up, review and monitoring, and digital hearing aids may be fitted on children over the age of three years who do not have significant additional needs. Geography, population density and current service configuration will influence how locally accessible these services can be, and in some places they may be provided from the specialist children's hearing centre, sometimes on an outreach basis. Long-term support will be provided by the local children's hearing service and partner agencies, possibly in local generic children's centres. All staff involved in long term support for children with PCHI and their

families should be alert to mental health and safeguarding issues.

Specialist children's hearing centre

63. The specialist children's hearing centre may be staffed by practitioners delivering the local specialist services, and in some cases may be co-located with them. It will normally be part of a secondary care provider's specialist services. The Centre will also have direct access to more specialist and technical diagnostic equipment including imaging, will be able to undertake audiovestibular assessment, and will have the ability to undertake hearing assessments under anaesthetic. In addition, there will be access to medical investigations and a wider range of paediatric medical expertise, including clinical genetics and ENT, enabling joint clinics, as suggested in Annex 1. Depending on geography, cleft lip and palate services may be provided. In some places, joint clinics are offered between ENT and the local children's hearing service, depending on geography.

Supra-specialist centres

64. The network will include a series of supra-specialist teams, which ideally would be co-located in one centre, to maximise the number of tests and interventions which can be undertaken in a single visit. Supra-specialist services and centres will provide specialised hearing aids (cochlear implants; bone anchored hearing aids) and

medical expertise for children with very complex care needs, cleft palate services and auditory processing disorder (APD). They will contribute the supra-specialist component of the child's individual care plan, which should be co-ordinated by the referring local children's hearing service.

Configuration of the network

65. The precise arrangement of the different components of the network and employment arrangements of the practitioners within the network should be flexible and managed according to local needs, resources and circumstances. In urban areas with dense population, it may be possible for the local hearing service to be provided from the specialist centre, yet still be acceptably accessible to local families. In more rural areas with

a dispersed population, specialist teams may need to be peripatetic for some of their care, but the need to provide expensive state of the art technical equipment and facilities means that there is a delicate balance to be struck between local access and best possible care. High quality facilities and expert staff need to be provided, so that a correct diagnosis can be made at the first visit, rather than families having to attend several visits to poorer quality services before a correct diagnosis is made.

Indicators of high quality care

66. These can be used by commissioners and providers in local self-assessments, which will identify gaps or duplication in service provision and underpin a local commissioning strategy.

1 IDENTIFICATION

- All newborn children are screened by specifically trained staff either in hospital, or at the primary home visit (10 to 14 days after birth);
- all professionals working with children and families are vigilant to the possibility of hearing loss;
- where there is concern about a child's hearing, speech and language development or behaviour, they receive a timely hearing assessment;
- all children who have recovered from meningitis are referred for hearing assessment;
- school screen.

2 REFERRAL AND ACCESS

- All children have timely access to the audiological services which they require;
- there are clearly defined referral pathways which are widely disseminated, and are monitored and reviewed to ensure compliance;
- routine and urgent referrals are seen within time limits according to locally agreed 18-week pathway.
- waiting times for assessment are monitored effectively (eg using IT systems) and there are sustainable strategies to reduce waiting times.

3 INITIAL ASSESSMENT (in children's hearing service except for newborns, who go straight to the specialist centre)

- All children are assessed by audiologists trained to work with children, from a multidisciplinary team (MDT), and receive audiological assessment commensurate with their age and stage of development. Parents are recognised as key members of the team;
- testing is carried out in appropriately sound treated paediatric test rooms;
- accurate and complete audiological information is gathered to inform decisions about aetiology and prognosis and discussions about further management;
- all audiological procedures use equipment which is calibrated at least annually, and meets national and international standards;
- the outcome of the assessment should inform a clearly defined care management plan;
- parents are given an appropriate verbal explanation of the audiological assessment result on the day of the assessment;
- after the assessment, parents are given appropriate written information;
- results of the audiological assessment are reported to the parents, referrer, GP, child health department and any other relevant professionals within seven days;
- there are written local protocols and care pathways which define appropriate management options arising from assessment, and comply with national guidance.

4 MANAGEMENT: INDIVIDUAL CARE PLANS AND MULTI-AGENCY WORKING FOR CHILDREN WITH PCHI (spanning the network of services as appropriate)

- An individual care plan (ICP), which encourages holistic discussion of needs, agreement of priorities and regular reviews of support provided, will be developed and documented within three months of diagnosis of PCHI, by the MDT and the parents for each child with a significant hearing loss;
- families are enabled to participate in the development of the ICP, to understand information and to make informed decisions;
- the ICP should span the constituent parts of the network which provide care and support to the child and parents;
- outcome measures are used to evaluate the effectiveness and benefit of the service provided and to shape the ICP;
- the intended and actual outcome of any intervention is recorded in the clinical records, along with any variance from the ICP;
- copies of the ICP and of care plan meetings are given to the parents and all other members of the MDT;
- formal arrangements are in place for sharing information between agencies and with the parents;
- the local children's hearing service MDT includes the parents, who are central to it, and expertise in paediatric audiological assessment, development of language and speech skills, medical aspects of audiology, child development and family support, education. There will be liaison with a wider team, including paediatric otologist, social services and educational psychologist;
- the MDT has an appointed co-ordinator and a key worker for each case;
- the ICP is delivered effectively by the MDT and is reviewed and revised at regular intervals (at least six-monthly for pre-school children and annually for school age children) to ensure that objectives have been achieved, it responds to the child's changing needs and is flexible enough to incorporate additional information as required;
- accurate and unbiased information is shared between members of the MDT including the parents, to ensure that care is co-ordinated;
- parents are given information about the role of the voluntary sector.

5 MANAGEMENT: HEARING AIDS

Specialist centre

- The selection, fitting and verification of hearing aids should follow accepted best practice guidelines;³⁵
- hearing aids should be fitted within four weeks of diagnosis and programmed to the hearing loss, taking the child's age and needs into account to ensure effective amplification. This may take longer for a new born baby, until the precise nature of the hearing loss is understood.

Local children's hearing service

- For children wearing hearing aids, there is same day access to a repair service, and a quick turn around postal service (three working days) for replacement batteries. Moulds are returned or replaced within five working days;
- service users' satisfaction with repair and replacement services is monitored.

6 FAMILY-CENTRED CARE

- Each service has in place processes and structures to facilitate communication with families;
- services are family friendly, with good play areas for children attending appointments and siblings;
- families are given clear information to facilitate attendance and reduce anxiety;
- children and young people's views are sought and listened to in respect of amplification options and their impact, and information about their hearing loss is provided to them at age-appropriate levels
- views of service users are sought in an annual survey of families and children;
- systems are in place to manage transition to adult services.

Annex 1: Suggested Components of the Children’s Hearing Service Network

Local configurations may vary, depending on population density and service history

Primary Care	Local Children’s Hearing Service	Specialist Centre	Supra-Specialist Centre
<p>Casemix</p> <ul style="list-style-type: none"> Children whose hearing, language, speech or behavioural development is identified as cause for concern by parent, HV, GP or other Management of acute otitis media without effusion 	<p>Casemix</p> <ul style="list-style-type: none"> Assessment of children whose hearing is giving cause for concern, referred from primary care, parents and other professionals according to locally agreed criteria Children with speech and language delay Children referred from school entry screen Children ‘at risk’ of deafness through meningitis, ototoxic drugs or head injury, etc Children identified by NHSP as being at risk of late onset deafness All cases of OME: actively monitor hearing loss for 3 months Children with cleft lip and palate, for routine surveillance and management of hearing loss Some with complex problems 	<p>Casemix</p> <ul style="list-style-type: none"> All babies identified in Newborn Hearing Screening Programme Others referred from children’s hearing service OME which requires vigilance and intervention (not watchful waiting) Complex external or middle ear disease eg as in Microtia, Down’s syndrome Syndromic conditions with possible hearing and balance disorders Cleft lip and palate specialist care (if CLaP Centre at this level) Fast track referrals of complex cases from GP All permanent sensorineural, conductive or mixed hearing losses Auditory processing disorder Auditory neuropathy Balance problems Dysacusis requiring investigations 	<p>Casemix</p> <ul style="list-style-type: none"> Specialised hearing aids (Cochlear implants, Bone anchored hearing aids etc) Complex children (complex syndromes, children with multiple medical problems – these may be part of a national service) Cleft Palate (seen in CLaP centres) <p><i>Also, depending on critical mass in specialist centre:</i></p> <ul style="list-style-type: none"> auditory processing disorder auditory neuropathy/ dyssynchrony

Primary Care	Local Children's Hearing Service	Specialist Centre	Supra-Specialist Centre
<p>Functions</p> <p><i>Initial suspicion</i></p> <ul style="list-style-type: none"> Refer to local children's hearing service if suspicion about hearing 	<p>Functions</p> <p><i>Initial specialist assessment post 6 months</i></p> <ul style="list-style-type: none"> First assessment (post 6/12) Auditory Brain Stem Response test (ABR), several modalities AC inerts/BC/Tone burst Visual Reinforcement Audiometry (VRA) in the soundfield VRA inserts VRA BC Distraction testing Performance testing Play audiometry Toy tests, several modalities Full PTA Speech audiometry, several modalities Tympanometry High Frequency Tympanometry Active monitoring of OME once other causes of hearing loss have been excluded. Monitoring of some permanent conductive or sensorineural hearing losses 	<p>Functions</p> <p><i>Assessment/investigations</i></p> <p><i>All the tests in the Children's assessment centre plus</i></p> <ul style="list-style-type: none"> ABR tests under anaesthetic for babies under 6 months and older children requiring sedation or anaesthetic ABR, Tone Pip ABR Bone conduction Cortical evoked potentials Transient Evoked Otoacoustic Emissions (TOAE) Distortion Product Otoacoustic Emissions (DPOAE) Auditory Steady State Responses (ASSR) Cochlear microphonic Specific Tests for further investigating auditory neuropathy/dyssynchrony Assessment of children who are 'difficult to test' Medical investigations for aetiology of hearing loss and investigation for associated medical problems Paediatric vestibular assessment Paediatric tinnitus assessment Clinical genetics opinion ENT opinion Imaging (CT/MRI/Renal US) with facility for anaesthetic Other examinations under anaesthetic or sedation 	<p>Functions</p> <p><i>Assessment/investigations</i></p> <p><i>Assessment or the following as appropriate</i></p> <ul style="list-style-type: none"> Cochlear implants Bone anchored hearing aids Cleft lip and palate if provided at this level As a part of a national/regional service eg cranio-facial, metabolic medicine, tumours

Primary Care	Local Children's Hearing Service	Specialist Centre	Supra-Specialist Centre
<p><i>Diagnosis</i></p> <ul style="list-style-type: none"> Alert to mental health and safeguarding issues 	<p><i>Diagnosis</i></p> <ul style="list-style-type: none"> Differential diagnosis of other conditions presenting as hearing difficulties (eg autism, unilateral symptoms, balance problems, unusual presentations, hearing difficulties with normal PTA) Evaluate degree of hearing loss and type Recognise presence of other conditions which may present as hearing loss and refer onwards for further evaluation Alert to mental health and safeguarding issues 	<p><i>Diagnosis</i></p> <ul style="list-style-type: none"> Paediatric audiovestibular medicine Auditory processing disorders (multi-disciplinary, SLT/ Psychology/Audiology/ Medical) Joint ENT/Audiological medicine/audiology clinics Joint clinical genetics/ Audiology/Audiological Medicine clinics 	<p><i>Diagnosis</i></p> <ul style="list-style-type: none"> Further evaluation of the degree and type of deafness in relation to type of surgery required and in relation to any associated medical condition Clinical genetics ENT
<p><i>Treatment/Management</i></p> <ul style="list-style-type: none"> Primary management of external ear infections Primary management of middle ear infections 	<p><i>Treatment/Management</i></p> <ul style="list-style-type: none"> Manage and actively monitor OME referred from primary care, and onward referral to ENT according to agreed criteria or temporary amplification (parental choice) NICE guidelines Protocol driven follow up, review and monitoring of Grommets High risk groups identified through NHSP Children with documented hearing loss 	<p><i>Treatment/Management</i></p> <ul style="list-style-type: none"> Hearing aid fitting and reviews for complex cases Provision of ear moulds and replacement digital hearing aids for complex cases 	<p><i>Treatment/Management</i></p> <ul style="list-style-type: none"> Cochlear implant insertion and review Bone anchored hearing aids

Primary Care	Local Children's Hearing Service	Specialist Centre	Supra-Specialist Centre
	<ul style="list-style-type: none"> • Children with hearing aids • Rehabilitation of hearing loss • Digital hearing aid fitting for children over 3 years of age without significant additional needs • Provision of ear moulds and replacement digital hearing aids • Monitoring of some sensorineural hearing losses where hearing aids not required 		
<p><i>Long term support</i></p> <ul style="list-style-type: none"> • Support for child and family • Alert to mental health and safeguarding issues 	<p><i>Long term support</i></p> <ul style="list-style-type: none"> • Liaison with teachers of the deaf and multi-agency team (incl. education, social care, third sector) • Ideally near to community paediatric services and child development centre • Alert to mental health and safeguarding issues • Transition to adult services 	<p><i>Long term support</i></p> <ul style="list-style-type: none"> • Transition to adult services • Liaison with teachers of the deaf and multi-agency team (incl. education, social care, third sector) • Multidisciplinary review with appropriate professionals 	<p><i>Long term support</i></p> <ul style="list-style-type: none"> • Transition to adult services
<p>Workforce skills</p> <ul style="list-style-type: none"> • Basic training to be alert to common hearing problems and how they present 	<p>Workforce skills possibly shared with specialist centre, depending on geography and population coverage</p> <ul style="list-style-type: none"> • Multi-agency team (incl. education, social care, speech therapy, third sector) 	<p>Workforce skills possibly shared with local hearing service, depending on geography and population coverage</p> <ul style="list-style-type: none"> • Multi-agency team (incl. education, psychology, social care, specialist speech and language therapy) 	<p>Workforce skills</p> <ul style="list-style-type: none"> • Paediatric ENT surgeon • Paediatric audiovestibular physician • Clinical genetics • Paediatrically trained Audiologists

Primary Care	Local Children's Hearing Service	Specialist Centre	Supra-Specialist Centre
	<ul style="list-style-type: none"> • Paediatrically trained audiologists • Paediatrically trained audiology assistant/ associate practitioner • Paediatrician with special interest in audiology (with adequate training) • GP with Special Interest with appropriate training • Admin staff • Trained in safeguarding • CRB checked • Know about mental health issues 	<ul style="list-style-type: none"> • Paediatrically trained audiologists • Paediatrically trained audiology assistant • Paediatric audiovestibular physician • Developmental paediatricians • Paediatric ENT surgeon • Clinical genetics • Trained in safeguarding • CRB checked • Know about mental health issues 	<ul style="list-style-type: none"> • Specialist speech and language therapists • Teachers of the deaf • Clinical Psychologists • Admin & Clerical • Links to social services • Anaesthetic support • Trained in safeguarding • CRB checked • Know about mental health issues
<p>Facilities/technology</p> <ul style="list-style-type: none"> • None specific 	<p>Facilities/technology</p> <ul style="list-style-type: none"> • 5m x 5m soundproofed test room to ISO 8253 • equipment to do the tests listed above • family friendly, children's play area • data collection facilities and IT support, access eSP, and other NHS relevant databases eg PIMS/PAS 	<p>Facilities/technology</p> <ul style="list-style-type: none"> • 5m x 5m soundproofed test room to ISO 8253 • Vestibular testing facilities • Equipment for tests listed above • Equipment for multi-disciplinary work eg APD tests, speech in noise, localisation tests etc 	<p>Facilities/technology</p> <ul style="list-style-type: none"> • 5m x 5m soundproofed test room to ISO 8253 • Specialist equipment, tests, software to assess and manage children referred for cochlear implants and bone anchored hearing aids • Equipment/training and facilities for specialised tests eg EABR, CM etc • Test equipment specific to supra-specialism

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