

Rapid Review into Paediatric Audiology in England

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In association with:



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National Deaf Childrens Society

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Executive Summary

The Covid 19 pandemic has brutally exposed the lack of national clinical leadership within the Newborn Hearing Screening Programme. As a consequence, this has highlighted a lack of oversight at a national level of service provision within paediatric audiology.

Children learn and socialise through hearing. Having a hearing loss therefore presents considerable challenges to a child's progress at school as well as their ability to make friends and develop socially. Good audiology services therefore make a critical contribution to a deaf child's success in life, ensuring a deaf child is able to use their remaining hearing to the fullest extent possible.

This report outlines the case for urgent action to ensure that every deaf child can achieve their potential, setting out ways of eliminating possible variation in quality and access to paediatric audiology services across England. It should be seen as the basis to build quality paediatric audiology services for the future, to ensure each child achieves their full potential

The recommendations for NHS England are:

1. There should be one national body responsible for oversight of the whole of paediatric audiology, from birth to the point of transfer to adult services. This should have clinical knowledge of audiology embedded into it and include oversight of newborn hearing screening, medical and scientific diagnostics, school screen, behavioural audiology, and hearing aid services for children and their families.
2. This body should then define;
 - clear operational standards for services delivering paediatric audiology, with clarity of responsibilities including working with other sectors across boundaries
 - specific targets for paediatric audiology services with reporting separate from the RTT and DM01 returns for adult audiology.
 - staff training requirements
3. There should be clear, joined up, commissioning of paediatric audiology services, with the newborn hearing screening programme payment unbundled, if possible, from the Maternity Payment Pathway and a realistic national tariff established for all procedures / pathways.
4. A quality assurance scheme such as IQIPS should be mandated but this scheme needs to offer both process and clinical level quality assurance to be more relevant to services.

The authors and professional bodies within the associated professions stand ready to offer NHS England the needed advice, support and expertise to refine and implement these actions.

Introduction

The right to effective language and communication is enshrined in Article 19 of the UN's Universal Declaration on Human Rights. Furthermore, the UN Convention on the Rights of the Child recognises the right of every child to "the highest attainable standard of health" and to the development of "mental and physical abilities to their fullest potential", two key areas also prioritised in the WHO's sustainable development goals.

Undiagnosed or late-diagnosed hearing loss can have severe negative impact on child development, affecting not only speech, language and communication, but also social, emotional and cognitive development, mental health and family relationships. It can lead to significant educational underachievement and an economic burden to society.

Newborn hearing screening aims to enable identification of hearing loss in the earliest weeks of life so that babies, and their families, can receive the interventions they need in order to develop optimally. Hearing screening for newborns, successfully fully implemented in England since 2006, is only the first step in a care pathway which crucially includes timely diagnosis and interventions. There is now a wealth of compelling international research evidence that newborn hearing screening, **when followed up by rapid and appropriate diagnostic assessment, medical and audiological management (both through hearing aids and via Cochlear Implantation) and family-centred support for communication development**, radically improves outcomes and life chances for children with hearing loss. Arguably there is little benefit in screening without the ability to offer the other essential elements of the care pathway in a speedy and coordinated manner. Delay and service fragmentation compromise child outcomes, and where these result in children with confirmed deafness not being speedily referred onwards for medical evaluation, may also lead to failure in diagnosing and addressing additional, preventable, developmental disability.

Internationally recognised guidelines (US Joint Committee on Infant Hearing, 2009, 2013, 2019) and Global Coalition for Hearing Health (2020 – in preparation) emphasise the importance of a seamless pathway from screen to early intervention, overseen by audiological specialty with co-ordinated multi-disciplinary expertise in the assessment, treatment and management of deaf children and family support. In recent years, this pathway has become fragmented and inconsistent for deaf children in England, giving concern to professionals and parents alike. The COVID pandemic has further exposed weaknesses and failings in the system, despite the best efforts of clinicians, statutory support services and the voluntary sector to provide the response babies and families urgently need.

This highlights a totally unacceptable regional variation which cannot meet the NHS Long Term Plan's commitment to be equitable and "more joined up and coordinated in its care."

The Current Situation

Covid-19 highlights a lack of leadership

With the onset of the Covid-19 pandemic and its effects in the UK, issues arose with the ongoing provision of some newborn hearing screening and diagnostic services at a regional level due to operational restrictions on outpatient activity. It quickly became apparent that the national response provided to local services was not sufficient to meet local need in managing the situation.

At a time where all professionals needed good, clear, timely, joined up guidance, this was lacking with PHE and NHSE issuing apparently conflicting guidance (e.g. NHS England's

initial advice of 'all stop' to all audiology services whilst PHE's advice was that services should continue to screen and assess babies within audiology).

As events unfolded, a letter from the BAA, signed by over 15 different clinical leads from across the UK was sent to PHE to highlight the issues being experienced. As a response, PHE requested the formation of an advisory group from the professions, which whilst welcomed, came as a surprise as this suggested a lack of appropriate audiology clinical knowledge or experience embedded at the top of NHSP within PHE.

The experience of the advisory group was they then not only had to overcome this barrier to explain the adverse clinical implications for what was being suggested by PHE but also that the operational mechanisms within the PHE / NHSE structure appeared not to be able to operate in a timely manner which led to delays in the dissemination of guidance which caused confusion for services. In the absence of national guidance, services took local decisions which appear to have further fragmented the whole NHSP and paediatric audiology service, for example this quote from an NHSP team leader:

“We haven't heard a word from the top – nothing! We've just worked with Audiology to do our own protocols during Covid-19”

This instigated this review into the whole of paediatric audiology and NHSP across England.

Hearing loss – a fragmented journey

Thanks to the Newborn Hearing Screening Programme (NHSP), every baby born in the UK is offered a hearing screen within weeks of birth. Those who refer from the screen are then seen by services for diagnostic audiology assessment and if necessary, management. The Action Plan on Hearing Loss emphasises a whole system approach to the delivery of integrated public services, to work collaboratively, and focuses upon the individual needs of the child with hearing loss¹. This is mirrored by NHS England's Long Term Plan² which emphasises the need to give children the best start in life, address health inequalities and deliver integrated care. Despite this, since 2014, NHSP has been administered and run as a separate entity from audiology services by Public Health England (PHE). Despite having audiology data tabs within the national IT system for NHSP and a key performance indicator (KPI) for the programme still being that 95% of babies referred from screening are seen in Audiology within 4 weeks of referral or by 4 weeks corrected age (NH2), because quality assurance of NHSP no longer covers audiology services and PHE have no oversight over that part of the process, data and quality beyond 'has the baby been seen' is not assessed.

A significant proportion of children, once diagnosed with a hearing loss have a range of additional and complex needs and so may enter many different services in their early years (2-88% depending on the additional need or disability)³. Working together across education, health and social care to improve outcomes for children with special educational needs and disabilities and improve the services they receive is central to the SEND Code of Practice (2015)⁴ Whilst most paediatric audiology services have good working relationships with their council and hence local sensory support teams, in some areas the lines between services of

¹ The Action Plan on Hearing Loss, NHS England and Department of Health, 2015

² NHS England (2019) The Long Term Plan

³ The Ear Foundation: Literature review into the prevalence of additional disabilities with deafness, 2012
https://www.ndcs.org.uk/media/1829/ear_foundation_additional_disabilities-literature_review.pdf

⁴ Special educational needs and disability code of practice: 0 to 25 years; Statutory guidance for organisations which work with and support children and young people who have special educational needs or disabilities, DfE and DH (January 2015)

'who delivers what' have become blurred over time. With no national oversight and few defined roles and responsibilities detailed within specification documents, in some areas can lead to difficulties within services as to who is responsible for what provision and the likely consequence is that services do not work in a joined up manner across health, social care and educational services. This will then have an adverse impact on children's learning and ability to develop independent living skills, for example this quote from a parent whose son has been affected by the absence of support during covid:

"I can see my son regressing with no access to therapies. The total absence could be very damaging. There's a limit to what I can do as a parent." (Parent)

Access to Services

While up to 50% of deaf children are deaf at birth and identified via the newborn hearing screen, the other 50% develop deafness during childhood, often in the first three years of life. Sadly, access for children into later audiology services is also varied with families regularly reporting that they wait longer than the 4 week recommended waiting time^{5,6}. There is growing and emerging evidence that the outcomes for children identified with later onset, developmental and acquired hearing losses (i.e. those not identified from NHSP) do not match the good outcomes of those identified through NHSP, however with no national oversight, it is difficult to be sure.

Access to services for older children is different across England:

- Some areas of the UK still run the school entry screen of hearing, others do not.
- In some areas of the UK, school screening and assessment for initial referrals from GPs and health visitors are delivered by a community healthcare trust, with referral mechanisms into the acute trust provider if a hearing loss is suspected, in other areas, referrals are direct to the acute trust.
- Some areas of the UK run a self-referral system directly to the acute trust, so that parent or health professionals with concerns about a child's hearing other than the GP can refer into them, however this is not widespread and in areas without this or school screening, could potentially lead to access difficulties for families.

With no national oversight to pull these strands together, these current different ways of working would suggest that children and families could be referred to the wrong provider, particularly in areas where services overlap, causing unnecessary duplication of appointments or miss out on being referred at all, leading to likely increased anxiety for the family and unnecessary additional cost to the NHS.

Commissioning of paediatric audiology services and NHSP

This fragmentation and mixed modelling has continued into commissioning. NHS England guidance states that the reduction of inequalities in access and outcomes should be central to the development of children's hearing services. Local commissioners should make explicit

⁵ *Transforming Services for Children with Hearing Difficulties and their Families*, Department of Health 2008

⁶ 252 of 1057 surveyed waited over 4 weeks, 214 of 1057 surveyed waited over 8 weeks. Listen Up! Campaigning to improve the quality of children's audiology services, National Deaf Children's Society (Oct 2014)

in their plans how they have taken into account the duties placed on them under the Equality Act 2010, and their duties with regard to reducing health inequalities as set out in the Health and Social Care Act 2012. Service design and communications should be appropriate and accessible to meet the needs of diverse communities. However, NHSP is commissioned outside of audiology, within the Maternity Payment Pathway. This means the place where the child is born gets the money for the screen, which in a number of cases, isn't the centre which actually performs the screen. This leaves centres with higher level neonatal units than the hospitals which surround them significantly underfunded and because the formula for newborn hearing screening staff is calculated according to birth rate, not on number of screens performed, under-staffed.

There is evidence that CCGs and maternity services have used service reference cost data inappropriately to infer what the cost the newborn hearing screen is and anecdotally this can be as low as £5 rather than the typical £35-40 when properly costed - this can then influence the proportion of the MPP which then gets attributed to the NHSP provider. Where multiple Trusts, delivery units, screening sites and audiology services are involved with a single baby, this becomes increasingly complex.

Within paediatric audiology commissioning, with no central guidance on tariff or specification, large variations in tariffs and access pathways have persisted and become embedded - for example:

- some services receiving no income at all for their NHSP follow up diagnostic work whilst others receive in excess of £500 per patient.
- Some parts of audiology are commissioned directly by NHS England, but with most, responsibility for commissioning is with the local CCGs.
- Some services are jointly commissioned with their adult audiology service on one, single block contract, with oversight limited to that of the whole contract, meaning that the much bigger adult service dominates the data returns, resulting in a lack of even local oversight of the paediatric service.
- Some services are separated, with separate block or payment by results contracts for their respective services.

This variation in tariff and service specifications has led to a variation in the services being offered by each department and the ability of services to offer assistive technology to those children who may benefit from it, for example the fitting of assistive listening devices such as Bluetooth streamers or the fitting of FM enabled hearing aids to pre-school children is not routinely and consistently funded despite considerable evidence that they improve children's outcomes.

As part of the Modernising Children's Hearing Aid Service Project (2004-5) there was a move to include this assistive devices provision but this did not become embedded in practice. A national body would be able to revisit this, influence commissioning and help improve deaf children's quality of life.

Waiting times

These differences in service specification, tariff and oversight also leads to a wide variation in waiting times within paediatric audiology and this situation is apparently worsening. NHS RTT diagnostic waiting time target for referrals to first assessment for older children (not

identified through newborn screening) is 42 days. Whilst this is not nationally collected outside of DM01 which includes adult figures, a FOI request showed that in 2018, 10 services (9%) did not meet this target. Children at the worst performing service were waiting more than six months for an initial appointment⁷. In 2019 this had risen to 15 services that did not meet the RTT target.

The variation in waiting times in services had also widened with children at the worst performing service waiting more than 18 months for an initial appointment⁸. 62% of services also reported that they were missing the routine follow up time identified as clinically appropriate for those with hearing aids.

With no national oversight of these figures, issues cannot be identified and services supported. A service with an increased waiting time is going to lead to a delay in identification of hearing loss and so poorer outcomes for the children affected. Despite the fact that deafness in itself is not a learning disability, deaf children underachieve throughout their education. In their GCSEs, deaf children achieve, on average, a whole grade less in each subject than other children⁹. This example of delays comes from a parent of a deaf child who urgently needs to see audiology:

“Audiology not seeing any outpatients for 2 months at least. My son was due there the week they stopped seeing patients. He desperately needs new moulds as the feedback is horrendous. He also has a faulty aid. We have been told to send his moulds to them and they’ll send them to the manufacturer which will mean no access to speech for 2 weeks minimum with a high risk that the moulds won’t fit anyway. He is 14, is oral only, and would feel even more isolated if he had no hearing aids. It’s awful, it’s having a major impact on his mental health.”¹⁰(Parent)

As the NHS and other services enter a recovery phase from the Covid-19 Pandemic and going forward, those services who faced varying degrees of service provision disruption as a consequence of local covid related restrictions will have to manage what could be significant backlogs in addition to their everyday working. With no national oversight to pull all these strands together, no separate national reporting of paediatric audiology, a national picture of the waiting times and ‘health’ of paediatric audiology is impossible to achieve and thus it is impossible to support services with issues with their backlogs. Without this oversight and support for services, deaf children will be adversely affected:

“My daughter was under assessment for Cochlear Implants, we were hoping it would be weeks until her operation date but now it’s on hold, just like other services. She used to have weekly visits from specialist speech and language as well as a teacher of the deaf, she also visited a deaf preschool once a week and had a one to one support in a mainstream preschool twice a week. Now the services can’t visit face to face, her progress has massively declined. (Parent)

⁷ Listen Up! The state of children’s audiology in 2018, National Deaf Children’s Society <https://www.ndcs.org.uk/get-involved/campaigning/campaigns-england/listen-up/>

⁸ Paediatric audiology provision in England (2019), National Deaf Children’ Society (unpublished at time of writing)

⁹ v The National Deaf Children’s Society’s summary of government statistics on deaf children’s attainment data is published at: <https://www.ndcs.org.uk/media/3468/ndcs-note-on-attainment-data-2018.pdf>

¹⁰ Survey of 82 families and 12 deaf young people asking about the impact of the COVID-19 lockdown, NDCS April 2020

Aetiology and Monitoring of Hearing

Diagnosing the cause of the hearing loss in a deaf child is as important as the management and rehabilitation of the deafness itself. At present however, timely aetiological investigation does not appear to be consistently provided across the country.

It can be months before a baby gets seen for aetiological investigations. Early diagnosis of the cause of the deafness can have significant benefits as in the case of congenital CMV (cCMV), where diagnosis and initiation of early treatment for this can prevent the progression of hearing loss and thus reduce hearing disability. As current evidence stands, to be effective, antiviral therapy for cCMV has to be started within 1 month of birth. However, diagnosing cCMV before this period and further appropriate management needs clear pathways and protocols. Without national oversight to commission a service and mandate a protocol, the opportunity for treating a preventable cause of progressive hearing loss is likely being lost in parts of the country.

Diagnosing other conditions associated with hearing loss is also important for the child's health and well-being. The incidence of vestibular or inner ear balance problems can be significantly higher in children with sensorineural deafness and this can vary with the aetiology of the deafness. Vestibular loss may manifest in children as motor developmental delay and this may be mistakenly attributed to developmental delay.

The role of the doctor in the multidisciplinary team looking after a deaf child is crucial in establishing the aetiology of deafness. This is important, as it not only helps in better management of the hearing loss but can also play a pivotal role in preventing the progression and any underlying genetic cause of the deafness. However, at the moment there appears to be a wide variability of professionals undertaking aetiological investigations for hearing loss in children with marked differences in protocols followed in different regions for carrying out investigations to diagnose the cause of the deafness. Since the NHSP QA was abolished for aetiological investigations, currently there is no oversight of the quality of these services with IQIPS not covering this aspect and no national guidance on appropriate training for the professionals involved.

There are many recognised conditions, such as Down Syndrome or children with a cleft lip and palate, where hearing loss can fluctuate or progress. In such cases it is vital to offer regular audiology review to ensure these children are able to access sounds and hear speech to help with their communication and development. Again there is wide variability across the country in monitoring of such children which the establishing a national body with oversight of the entire range of paediatric audiology services including medical aspects, aetiology and monitoring will help to improve outcomes.

What is quality?

At the present time, the only compulsory quality assurance (QA) that is mandatory within paediatric audiology is the QA undertaken by PHE on behalf of the Newborn Hearing Screening Programme. This however, is now of limited scope. Previously the QA process for NHSP followed a child through the pathway and assessed screening, diagnostic assessment, hearing aid fitting and aetiological investigation, as well as ongoing support services from education and speech and language therapy. Since the change to PHE, the QA scope for NHSP does not go beyond the point of referral from the screen, despite a KPI

for the programme being beyond this and so, no compulsory quality assurance of paediatric audiology is undertaken and paediatric audiology services are now no longer routinely involved in the NHSP QA process.

A particular issue is that a Newborn Hearing Screening Programme may cover more than one Audiology service. Whilst there is an NHSP Local Director/Team Leader role associated with each programme there is a limitation as to what influence they may have on Audiology services provided by other Trusts, even though the NH2 performance for those services are reflected and reported for the specific screening programme. This is a reason why NH2 should be removed from the screening programme KPIs and robustly monitored separately as part of the specification of each paediatric audiology service.

The commissioning specification for NHSP does include a sentence that 'audiology departments undertaking audiological assessments on babies referred from screening should participate in a scheme for external peer-review process of auditory brainstem response (ABR)' and that 'commissioners should make sure that audiology services participate in and maintain accreditation to defined quality standards operating under the umbrella of the United Kingdom Accreditation Schemes (UKAS) / Improving Quality in Physiological Services (IQIPS)' however in practice, this is not enforced and is not within the scope of NHSP QA. Whilst most centres are part of an external peer review process for ABR, the peer review groups structures and remit differs across the country, again making determination of quality difficult and could lead to worrying misdiagnosis.

IQIPS, whilst a useful quality management system, is seen by many services as more of a process audit than clinically beneficial and because of this many services do not see the overall benefits of being registered and accredited. This, coupled with the fact that it is time consuming, costly (especially for Trusts running across multiple sites) and not mandatory in a profession with staffing problems has meant that most paediatric services are not accredited (as of September 2020, approx. 71% are not accredited). Unless the organisation providing paediatric audiology services has clear guidance from NHS England and the local CCGs that accreditation is mandatory then Trust support for individual services seeking accreditation may be limited.

Overall, this means that whilst services may be meeting the only nationally assessed wait time, NH2 of NHSP, there is no assurance on the quality of their intervention. The fact that PHE have no say on how NH2 is met was again exposed during the covid-19 pandemic, where some services were reported to consider the target to be met simply by phoning and speaking to the parents. This is clearly not what was intended by the standard, but a quality assurance indicator which in itself is outside the scope of the programme, is very difficult to police.

Without national oversight and a form of quality assurance for paediatric audiology services it is very difficult to be assured that each child is achieving the best possible outcome they can at this present time.

Staffing problems stifling innovation

Fragmentation of commissioning and tariffs has also led to problems with staffing. Despite the establishment of a 4 year BSc with paediatric audiology modules, this was, in 2013 amalgamated to a 3 year 'health science' degree with many of the paediatric audiology elements removed. With no national oversight on staffing and its effects, it is difficult to assess the current situation, however NDCS 2019 recently reported that 48% of paediatric

services across England had seen a reduction in permanent staff since 2017, with 30% of those reporting that they were unable to recruit suitable candidate to NHS AfC band 6 or below. Perhaps most worryingly with this lack of ability to recruit to the start of the profession, the majority of posts which have been lost are within AfC payband 8, indicating a likely lack of strategic leadership within services. Job roles and bandings within NHSP and paediatric audiology are not well defined however, for example, there is no nationally agreed AfC job description for either an NHSP screener or NHSP Local Manager which has led to a large variation in job role and job grading.

This reduction in staffing has led to issues with CPD, with 15% of services reporting problems accessing the CPD necessary for their roles¹¹. Lack of staff is likely to be in turn affecting waiting times for patients and families as well as making it difficult for services to release staff to access training on the latest developments within the field.

This inability to recruit suitable new staff has resulted in a number of paediatric audiology staff 'learning on the job', by appointing staff as apprentices or asking members of their adult audiology team to assist rather than accessing external courses and learning. With no quality oversight, there is no national standard on the level of training for paediatric audiologists. It is therefore difficult to be assured on the level of this in house training and if a consistent approach is being applied nationally across the profession. This, again, is likely to lead to variations in outcomes for children.

With no national approach to training, this has implications for the continued and appropriate provision of schemes such as the BAA Higher Training Scheme, specifically in paediatric assessment and rehabilitation to allow development of these staff.

The recent review into the Practitioner Training Programme (PTP) is welcome, however the recommendations are yet to be implemented and will take some time to come to fruition. Along with the Scientist Training Programme (STP) there is a continuing need to ensure that these entry routes into the profession are funded appropriately and are delivering the required audiology workforce at the appropriate level.

A lack of clinical knowledge embedded within the PHE structure for NHSP has also appeared to stifle innovation within hearing screening. No significant changes to the screen have been made since 2015 and despite significant improvements in manufacturers algorithms and stimuli for screening, changes to the commissioning and specification of devices have made it difficult to bring new devices into the service. To drive innovation, clinical leadership within the national NHSP programme should be explicit and transparent, provided by personnel who are active clinical practitioners or who are active researchers in the field of audiology and/or hearing impairment in infants.

The way forward

An opportunity to build the Paediatric Audiology Services of the future

The lack of national oversight of paediatric audiology has been brutally exposed by the Covid-19 pandemic. The government announcement to disband PHE presents the opportunity to ensure that the whole of paediatric audiology including NHSP can have specific strategic leadership under one organisation through the following recommendations;

¹¹ Paediatric audiology provision in England (2019), National Deaf Children' Society (unpublished at time of writing)

- One national body is responsible for oversight of the whole of paediatric audiology, from birth to the point of transfer to adult services and include oversight of newborn hearing screening, diagnostics, school screen, behavioural audiology and hearing aid services to children. The responsible group should have clinical knowledge of audiology embedded into it.
- This national body should then define;
 - clear operational standards for local services delivering paediatric audiology, with clarity of responsibilities including working with other sectors across boundaries and with a robust QA of all services.
 - specific targets for paediatric audiology service reporting separate from the RTT and DM01 returns for adult audiology.
 - staff training requirements.
- There should be clear, joined up, commissioning of paediatric audiology services, with the newborn hearing screening programme payment unbundled from the Maternity Payment Pathway and a realistic national tariff established for procedures / pathways with reporting separate from adult audiology. Robust, supportive commissioning will drive up quality.
- Quality assurance schemes such as IQIPS should be mandated and these schemes should evolve to become more clinically led and thus more relevant to services.

This will immediately allow high level clinical input into NHSP and paediatric audiology, and embed NHSP into the clinical audiology pathway.

This national oversight is essential to determine the situation in paediatric audiology. The Covid-19 situation and shut down of most routine services within the NHS for 3+ months has caused many waiting times to grow. With national oversight, this can be monitored, an action plan agreed and struggling services can show a target against which to drive support. This should, in turn, allow for the sector to recover and eliminate the significant variation in waiting times which is holding back timely diagnosis and vital intervention for deaf children.

Along with timely appointments however, must come consistent quality and this should be supported through robust, yet supportive commissioning. Services would be encouraged and supported to take part in schemes such as IQIPS and these schemes should evolve to become more clinically led and thus more relevant to services.

The aim of paediatric audiology services across England must be one of consistently good outcomes. These changes, if implemented, would allow the best life chances for all deaf children across England.