1. Executive summary
Newborn hearing screening has allowed the early diagnosis of thousands of deaf babies. Screening is vital to ensure that effective support can be put in place as soon as possible so it can have the greatest impact on deaf children’s development.

However, recent changes following the Health and Social Care Act mean that the quality assurance cycle, that inspected each service every 18 months to ensure standards were being met, now stops after screening and doesn’t cover follow up services. This is despite the final round of inspections finding that 29% of paediatric audiology services were not meeting minimum standards.

A new accreditation programme has been introduced to monitor the quality of paediatric audiology services. However, as the accreditation is not mandatory and is costly for services to gain, take up is very low. Since the scheme began in 2012 only 19 out of 134 paediatric audiology services have achieved accreditation (14%). Most parents now have no information about the quality of the audiology service their child uses.

Considering the Government’s commitment to patient choice and transparency in the NHS, a number of actions are needed to address this situation:

1. A return to mandatory inspections of paediatric audiology services
2. Greater transparency about the accreditation process
3. Clarifying who is responsible for service improvement

Without widespread accreditation, the majority of parents will have no information about the quality of the audiological support their child receives and services themselves will have no incentive to improve. As a third were failing to meet government standards for care when the last inspections happened in 2013, action is needed to address these problems and ensure that every deaf child, regardless of where they live in England, receives high quality audiology support.

2. Introduction
In 2006, the newborn hearing screening programme was fully rolled out across England. Nearly 6.7 million babies have been screened since the newborn hearing screening programme was introduced, leading to the early identification of nearly 13,000 deaf babies. Every week, an average of 12,645 babies are screened, of which 34 will be identified as deaf.¹

Research has found that there is a significant relationship between early identification and the child’s development, including in language development and socio-emotional development. Early diagnosis means that effective support can

¹ National Deaf Children’s Society analysis of figures from the newborn hearing screening programme and the Office of National Statistics.
be put in place right from the start where it will have the most impact on their development.

Prior to the newborn hearing screening programme, more than half of children born deaf had not been identified by the age of 18 months and a quarter had not been identified by the age of three-and-a-half\(^2\), well past the critical ages for language and communication development. Research has shown that an undiagnosed deaf child at age three will not know more than 25 words, compared to 700 in a hearing child of the same age.\(^3\)

The provision of audiology services is therefore absolutely vital for the long term health and well-being of deaf children and young people. High quality audiology services unlock educational and developmental opportunities that are otherwise denied to the deaf child. At a time, when only 41% of deaf children are achieving five GCSEs (including English and Maths) at grades A* to C (compared to 64% of children with no identified SEN), we must ensure that early and effective diagnosis and intervention is of the highest and most consistent quality.

3. Newborn hearing screening and paediatric audiology

The Newborn Hearing Screening Programme (NHSP) automatically offers all parents in England the opportunity to have their baby's hearing tested shortly after birth. NHSP aims to identify moderate, severe and profound deafness and hearing impairment in newborn babies. Early identification, via the programme, gives babies a better 'life chance' of developing speech and language skills, and of making the most of social and emotional interaction from an early age.

The screen involves two tests: an Otoacoustic Emissions Test (OAE) and an Automated Auditory Brainstem Response (AABR) Test. Babies who do not show strong responses to the two screening tests will be referred on for a full diagnostic assessment of the hearing.

4. Changes since 2013

Since implementation of the Health and Social Care Act 2013, the NHSP has undergone some fundamental changes to the way it is delivered and funded. Before the Act came into force, the NHSP was commissioned directly by the Department of Health. It is now funded by NHS England whilst service delivery is overseen by Public Health England.

Even though the NHSP has never “managed” services beyond screening, since its inception, NHSP quality assured services beyond screening, in audiology and other areas. There were four strands to the NHSP quality assurance programme encompassing 26 standards in total:

1. Screening
2. Audiology
3. Medicine
4. Early intervention

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The standards that relate directly to screening have been reviewed by Public Health England and have reduced from 15 to 6 – these 6 are still measured. The rest are ‘still in force’ and fall under the jurisdiction of NHS England, but whether or not they are being met is no longer measured as was the case under the old NHSP QA programme.

When NHSP was introduced in 2006 it was based on a holistic, multi-agency, pathway which included screening, audiology, medicine and early intervention. In many respects, the NHSP and its corresponding QA programme was a very good example of the aspirations of the Children and Families Act 2014 about better joined-up working between different services and child-centred working, and in Open Public Services, about standards, regulations and transparency.

**Case study – Referral to follow up services – Speech and Language Therapy (SALT)**

A parent of a 9 month old with baby with temporary hearing loss and possible underlying hearing loss recently contacted her local speech and language therapy service, run by Lewisham Health Care Trust on one of their community sites, to get advice on activities she could do with her baby to encourage his speech and language development.

She asked if the audiology service her baby was seeing could refer her while his hearing problems were being investigated further. She was told that as her baby's audiology service was operated by Guys and St Thomas’ NHS Trust, they could not refer her baby. She was then told that as the SALT service was a community health service, her baby's paediatrician, based at Lewisham Hospital, was also not able to refer her baby.

The only referral route available was self-referral at a drop-in clinic that would have no record of the baby's hearing problems or investigations to date. This requires a pro-active parent to not only know what services their deaf child needs but to pursue a number of different pathways in order to obtain them.

Before the Health and Social Care Act came into force there was a quality assurance cycle that ensured that NHSP QA standards were being met. The last quality assurance cycle (round four - QA4) was undertaken from June 2012 to March 2013. It was a three step process including:

a) Self-assessment; sites were asked to include their action plans arising from previous QA cycle to allow the QA team to assess progress.

b) Desktop review by QA team; followed by recommendations detailing which services should receive a visit

c) 20 services were visited by a peer reviewer from the QA team to make a further assessment/gain clarification.

Following implementation of the Health and Social Care Act, and post reconfiguration of services, we had concerns that screening would suffer. Data and reports from the latest NHSP quality assurance programme show that 98% of
screening services are meeting or exceeding the standard for screening coverage.

However, this data also shows that in most regions of England the time between referral from screening to audiological assessment is not being met, falling below the level regarded as ‘acceptable’ by NHS England.\(^4\) In addition, the Action Plan on Hearing Loss by NHS England and the Department for Health has identified large geographical variations in the time taken from referral to assessment of newborn deaf children.\(^5\)

In the final round of NHSP QA inspections the reports identified that 29% of paediatric audiology services were not meeting minimum standards. Some of the key shortcomings that were identified were:

- There were some audiology tests, hearing aid fitting and evaluation measures that should have been routinely used but that hadn’t been introduced by many services. These are not new and were introduced as far back as 2005.

- There was poor diagnosis: despite additional training and introduction of peer review networks for Auditory Brainstem Response (ABR) tests, less than half of audiology services were meeting satisfactory or better standards for diagnostic ABR testing and interpretation.

- A fifth of services were still not able to get new ear moulds to families within 36 hours of impression. The reasons for this are unclear, given that no technical or audiological expertise is needed, just an efficient administrative and postal system.

- Less than two-thirds of services had the necessary equipment available or a sound-proofed room to test the 6-9 month age group for targeted screening. This means that babies were being tested in poor conditions and audiologists were using outdated methods (e.g. distraction testing. When NHSP was introduced, distraction testing with the health visitor was supposed to stop, yet audiology departments continue to use this method as they lack the facilities for more robust testing techniques).

The ending of inspections for all paediatric audiology services

At about the same time that we learned that one third of audiology services were failing to meet standards, the scope of the Newborn Hearing Screening Programme and the Quality Assurance programme was drastically scaled back.

The screening programme now finishes at the point of referral to audiology, as does the Quality Assurance programme. The natural successor to the NHSP QA programme is the Improving Quality in Physiological diagnostic Services (IQIPS) accreditation programme. However, as the accreditation is not mandatory and is costly for services to gain, take up of IQIPS is very low. Since the scheme began in 2012 only 19 out of 134 paediatric audiology services have achieved accreditation (14%).


Children’s Hearing Services Working Groups (CHSWGs)
CHSWGs are usually based in health authority areas, and are a way for services to work together to make sure that deaf children and their families have good quality local support which meets their needs.

Each group usually includes representatives from health (e.g. audiologists and paediatricians), education, local charities, local authority services, the National Deaf Children’s Society (NDCS) and parents of deaf children, who have a unique overview and experience of those services.

Primary Care Trusts (PCTs) used to support CHSWGs but since the reorganisation of the NHS CHSWGs are no longer connected to local health decision-makers and commissioners. Although the NHSP service specification says that providers must still participate in CHSWGs there is no mechanism for ensuring this happens, that the groups are effective or that feedback of service users has been taken on board.

Case study – Hearing tests not being appropriately adapted

A 6 month old baby was referred to his local audiology service for testing after the parent repeatedly reported the baby's lack of response to noises and failure to babble. The baby had passed the newborn screen at birth but had subsequently been treated for a serious infection with antibiotics that put the baby in a high risk category for hearing problems.

Over the next 4 months, the baby had three hearing appointments and is due to have his fourth soon. The parent was told the results have been inconclusive, due to the baby being 'developmentally too young' for the tests available. An underlying permanent hearing loss has not yet been ruled out a crucial time in the baby's speech and language development.

This parent is a long standing member of NDCS staff with a good understanding of hearing loss and audiology services. She felt reasonably confident she was receiving a good quality service, despite not being able to verify this independently. The service is not IQIPs accredited and the parent has no way of knowing if they are trying for accreditation or have tried and failed.

After speaking to NDCS’s own independent audiologist and sharing her baby's test results, the parent has discovered that the service could be adapting the tests so they were developmentally appropriate for his age. It is possible that a conclusive diagnosis could have been achieved some time ago; giving the baby the chance to get the support he needs to develop and achieve.

Like the parent in this case study, most parents now have no information about the quality of the service their child uses. In addition, many may not know what they are entitled to so may not be able to make a judgement of whether what they receive is acceptable or comparable to other services. For this reason independent inspections by experts, are vital.
5. The impact of these changes

Lack of transparency
Despite the Government’s promises of patient choice and transparency in the NHS, families do not have access to the information that helps them make choices about service providers and are frequently unaware whether they are receiving a good - or inadequate - level of service.

From our involvement in the Accreditation Clinical Advisory Group (ACAG), we are aware that in April 2015 there were 60 children’s services registered with IQIPS and forty-one were actively completing the initial stages of accreditation.

However, this information is not publically available and we don’t know which services they are. Of the 60 services, we have no idea how many have reached accreditation standard but are unable to go forward due to cost or lack of management support locally, how many don’t achieve the standard, and how many have applied for accreditation but failed.

An un-level playing field
Although the forthcoming commissioning guidance for CCGs states that they should be commissioning an accredited service, this is only guidance and NHS England is unable to force CCGs to do this. It is unclear if the Government can either mandate that all services become accredited or mandate CCGs to only commission accredited services.

As a result of the non-mandatory nature of the inspections families in the 86% of areas which have not been accredited will have no information about how their service is performing. There are also other issues with stopping mandatory inspections:

- Unlike Ofsted or the CQC, when IQIPS inspectors find that a service is failing, they are bound by the terms and conditions of the programme to keep it secret. This runs counter to quality assurance which must shine a light on failures and poor practice. CCGs and NHS England could be paying for a service that is poor quality and therefore poor value for money for patients.

- Transparency is important for patients but any moves to make either IQIPS inspection reports or the outcome of failed inspections public, is likely to further put services off becoming accredited. This emphasises the need to make sure all paediatric audiology services are accredited.

- It’s highly likely that only the best audiology services will attempt accreditation as they will want to be confident they can achieve the standard before spending time and money to gain accreditation. However, this means that those which are most in need of monitoring and improvement are least likely to apply and the status quo will remain.
• Some trusts may be tempted to divert money away from paediatric audiology towards specialisms and departments that are independently audited and therefore under greater public scrutiny.

What happens when services fail?
We know of one paediatric audiology service, so far that has failed to gain accreditation – however there may be more that neither the NDCS, local parents, commissioners nor other health professionals know about. There is no compulsion for services to publically disclose that they are trying to gain accreditation or indeed that they have failed. It’s also possible that those that have attempted accreditation but failed are running a better service than those that have made no attempt to start the process.

It does not appear that this situation has been planned for by policy-makers – going through the IQIPS process should improve services - but when departments are very far from achieving accreditation what support is there to help them improve and who is responsible for making sure that they do?

If a service is openly failing and is no longer commissioned to provide audiology services, the knock-on effect this will have could be detrimental to other services which may have to see more patients than they can cope with.

If one of the reasons for IQIPS accreditation failure is financial, then having to pay additional accreditation expenses will cause further problems for a service that is already struggling.

It’s important to remember that all these issues could already be happening - behind closed doors without patients, commissioners, the CQC or the Department for Health knowing that there is a problem.

6. What needs to happen now

1. **A return to mandatory inspections of paediatric audiology services**
The most obvious way of making sure all paediatric audiology services are good quality and consistent across England is to make IQIPS accreditation mandatory. NHS England has told us that they are unable to force CCGs to commission accredited services beyond writing guidance to suggest that they should.

However, NHS England have told us that they could require the services which they are directly responsible for commissioning, to be IQIPS accredited. As they commission services for the 0-5 year’s age group this would mean that the majority of services would become accredited and those that weren’t would face increasing pressure to become so.

2. **Greater transparency about the accreditation process**
In the past, the NHSP QA programme published reports of its inspections detailing how well the service was meeting expectations and what needed to improve if standards were falling short. There is significantly less information available about inspected services for commissioners, service users or other
health professionals under IQIPS. For services that are not accredited there is no information at all.

More importantly, it is not made public that a service has started the accreditation process, where it is within the process or if it fails to reach the standard required for accreditation. If a service gains accreditation a report is published with basic details about the sites included, the patient groups served and the tests that are carried out. Very few details about the inspection are released.

3. **Clarifying who is responsible for service improvement**

It is unclear who is responsible for making sure a service improves if it fails accreditation. It should not be possible for a Trust to fail IQIPS accreditation and still continue to provide paediatric audiology services, as this service has been proved to be unsafe and inadequate. However, in the current situation, the CQC, the Department of Health, service commissioners and patients are unlikely to be aware that a service does not meet expectations and has failed their accreditation.

Without support to improve, services may be unable to achieve accreditation, will not be able to provide the quality of service that patients need and are even less likely to be transparent about service failures in the future. As well as support to improve, the service also needs to be monitored to ensure that shortcomings are addressed quickly. There needs to be a clear line of accountability to ensure the status quo does not persist and changes are made.

7. **About the National Deaf Children’s Society**

The National Deaf Children’s Society (NDCS) is the national charity dedicated to creating a world without barriers for deaf children and young people. We represent the interests and campaign for the rights of all deaf children and young people from birth until they reach independence. There are over 45,000 deaf children in the UK and three more are born every day.

By deaf, we mean anyone with a permanent or temporary hearing loss. This could be a mild, moderate, severe or profound hearing loss. The term deaf does not presuppose the use of any one communication method and could refer to children who communicate orally or through sign language. We also include children who have a hearing loss in just one ear.

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