



**BRITISH ACADEMY
OF AUDIOLOGY**

Review into NHS Lothian Paediatric Audiology Summary Report

Confidential

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With thanks to:

The Senior Management Team at NHS Lothian for their openness and candour throughout the process and their continuing desire to support and implement improvements

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Overall Summary

1. The independent audit and governance review into the Paediatric Audiology service at NHS Lothian (the Health Board) was established following the Scottish Public Services Ombudsman Investigative report into Child A's audiology care at the Health Board¹. Following publication, the British Academy of Audiology (BAA) was commissioned by the Health Board to help it fulfil recommendations 2 and 3 of that report. The BAA was also asked by the Health Board to perform a full governance review of the department to establish the governance structure within the Health Board and advise on any issues.

2. A thorough audit of the Health Board's Paediatric Audiology case load from 2009 to 2018 was carried out. Following communication with the Health Board (detailed within the audit report), the time period to be reviewed was extended to cover until the end of August 2021, in specific areas. The initial audit involved 12 professionals with expertise in the field of Paediatric Audiology reviewing 1,113 patient records. The governance review was completed by two professionals who visited the Health Board for a week of clinical visits, observations and interviews, and a review of written procedures and guidelines. The findings from the audit and governance review are detailed within the individual reports

3. Children learn and socialise through hearing. Early identification and management of a hearing loss present at birth or acquired later is essential, both for the acquisition of spoken language and cognitive development of the child. It is now widely accepted and internationally recognised that delays to identification / management have significant detrimental effects on children's lives in terms of speech and language development, literacy, mental health, educational performance, employment and social economic performance^{2,3,4}. Children need early identification and effective management together with quality Paediatric Audiology services to attain their full potential⁵.

4. The review identified that the team are friendly, hardworking and supportive of each other. They are keen to offer the best service they possibly can to children within the area. The department has a clear structure of roles and responsibilities, with evidence of regular team and multidisciplinary meetings and evidence of good communication both internally and with other departments. Departmental facilities were found to be good, with excellent new soundproof facilities. Many elements of good practice were seen during clinical observation and most appointments and audiological procedures were carried out in accordance with appropriate guidelines.

5. Audit findings have identified a series of serious, significant issues particularly within the early years (under 5) age groups of the Paediatric Audiology service. These have led to significant failings which have adversely impacted the early years spoken language acquisition of numerous children, affecting a number of these children for life. Of the 1,113 patient records in the audit 155 children were identified as having significant failures, and during the onsite visit, 3 areas of the service were identified as containing a very high risk of significant failure. The 155 children identified with serious failures included:

- 5 children who were not suitable for cochlear implantation due to the delay in hearing loss identification

- 2 children who were being assessed as normal by the Health Board at the point a 2nd opinion was sought from which they were referred for cochlear implantation (and implanted)
- 5 children who had their cochlear implantation delayed due to the delay in hearing loss identification
- 49 children where identification and management of a hearing loss was significantly delayed

6. There is no evidence that at any point since 2009 any form of up-to-date British Society of Audiology (BSA) or Newborn Hearing Screening Programme (NHSP) protocol for Auditory Brainstem Response Testing (ABR) on newborns or older children has been followed or consistently applied. The head of department reported being aware of this failing; however there was no evidence this was raised at a more senior Health Board level, no evidence of any mitigation having been enacted or that any action plans had been put in place to correct this. Therefore children with a permanent sensorineural hearing loss at birth were often not diagnosed in a timely manner and not managed effectively in line with early assessment and intervention guidance. These children have missed out on the early years benefit of appropriate hearing aid management.

7. Failures in ABR testing were compounded by a poor standard of early years behavioural testing at the Health Board. The most serious of failures included the incorrect acceptance of a wide variety of behavioural responses, such as stares, twitches or eye-movement during visual reinforcement audiometry (VRA) and distraction testing. This incorrect practice was widespread throughout the team. Clinical observations indicated a tendency to reduce distracting play when the sound stimuli was about to be presented and therefore cue the child to the presentation of sound. Audit findings showed the recurrent incorrect selection of behavioural assessment tests / techniques for the child's chronological age without evidence of justification (e.g. developmental status of the child requiring the use of such tests) in a large number of children. This resulted in a significant failure to accurately establish children's behavioural hearing thresholds in the under 5 age group.

8. These failures in ABR and behavioural testing combined have resulted in many children where their other audiological results were clinically incompatible. These should have raised clear red flags about the quality of testing. Evidence of this includes absent distortion product or transient otoacoustic emissions (OAE) in the presence of peaked tympanometry or significantly raised air conduction thresholds on ABR, being discharged or managed as having normal hearing by the service. Subsequently these children were often not diagnosed with a hearing loss they had at birth (as evidenced on ABR) until they were able to behaviourally test using performance or pure-tone audiometry (PTA), much later in life. They were then incorrectly labelled as having a progressive hearing loss and no form of reflection of the child's records and results appears to have taken place. The audit highlighted 3 examples where children were still being assessed as normal at the Health Board despite being sent for a 2nd opinion at a different centre, where they were immediately diagnosed as having a profound hearing loss.

9. The inadequate level of assessment, interpretation and management of children resulted in the service taking several years to diagnose and appropriately manage with amplification a significant number of children with evidence of permanent childhood hearing impairment at birth.

10. The benefits of early amplification in children are widely accepted² and this delay in identification has highly likely impacted significantly on the auditory, speech and cognitive

development of the children involved. At its most serious, 5 profoundly deaf children were diagnosed too late to be considered for cochlear implantation. The audit team identified 155 children (15.7% of those reviewed) with serious concerns. These are detailed in the audit report and the names of the children have been identified to the Health Board.

11. These failings led to a significant increase in the average age of diagnosis at the Health Board which appears to have gone unreported and un-noticed. An audit of the Permanent Childhood Hearing Impairment (PCHI) register showed that from 2009-2018 the average age of diagnosis at the Health Board was 4.53 years (1,653 days) of age. The comparison figure for England for 2018 was 109 days.

12. In addition, the audit and governance teams found other areas of practice which raised concerns and are detailed in the individual reports. These include:

- The incorrect interpretation of objective test results, such as acoustic reflexes being reported as present despite being artefactual upon review
- A poor standard of record keeping which did not allow children with risk-factors for hearing losses to be clearly identified and monitored or clear clinical pathways to be followed
- No clear protocols for the selection of testing on developmental age and the requirements for that test, which often resulted in inappropriate tests for the child's developmental age being selected and performed with no documented reason
- Inappropriate management of children with risk factors for hearing impairment, for example the inappropriate discharge of children with Down's Syndrome or cCMV
- No good evidence that guidelines on glue ear management were followed which appears to have led to a high rate of mastoidectomy
- The tone of reports and journal entries was on occasion dismissive, both of other professionals and of the children within the service
- Whilst overall the (re)habilitation part of the service appeared better run, there was, however, several incidents where inappropriate verification and outcome measures (such as RECD measurements on hearing aids with open ear moulds & live voice speech testing in the soundfield for unilateral hearing losses) or inappropriate selection of hearing aids had been made in the cases reviewed
- There was evidence of a general reluctance to discuss the benefits of hearing aids for children with mild, unilateral and high frequency losses, despite clearly documented concerns from parents, other professionals and impacted speech development
- There was substantial evidence of an overreliance on parental perception of hearing ability. This was especially true where parents were not concerned regarding their child's hearing. This likely led to attitudinal and confirmation bias i.e. looking for evidence to support a diagnosis of hearing within normal limits, rather than actually trying to understand the true nature of the child's hearing ability by cross referencing objective and subjective tests
- There was evidence of a widespread lack of critical appraisal of individual test results, especially when results were conflicting

13. The audit team found good evidence that multiple opportunities for the department to reflect and change practice had been missed or dismissed by the head of department. These include:

- Seven children were once identified as having a hearing loss, the Cochlear Implant team had written back to the department to say the child would not be a candidate due to the delay in identification and subsequent referral
- One occasion where the National Deaf Children's Society (NDCS) contacted the health board due to concerns from a parent
- One occasion where a private paediatric audiologist raised concerns about a child whom they referred directly for cochlear implantation
- Three complaints from parents to the Health Board relating to late or misdiagnosis

In all cases, there is clear evidence that the individuals' audiological care had been mis-managed and each child misdiagnosed. In each case there was opportunity for the service to undertake critical reflection and put in place actions to reduce risk of future incidents. In all cases, the complaint or enquiry was dismissed.

14. The audit team were so concerned with the level of ABR testing that on the 6th September 2021, the Health Board gave permission to review the previous 12 weeks of ABR tests. The concerns remained and the Health Board were advised to stop ABR testing, which they did immediately, sending the children to a neighbouring Health Board. A mitigation strategy was written and implemented across the Health Board for the behavioural testing of infants, which allowed the continuation of the service whilst minimising the risk.

15. The root cause of these failures is identified as a lack of scientific leadership, knowledge, reflection and enquiry in the presence of a lack of routine and robust quality assurance processes.

Nearly all staff had been trained in-house, inaccurately, in both ABR and behavioural testing with no form of external competency assessment. Fundamental audiological tests for early years assessment were carried out incorrectly and no staff members have applied the knowledge base to identify or correct this.

The lack of scientific leadership, knowledge, reflection and enquiry has meant that there is no critical appraisal oversight on the evidence base for guidelines, assessments, tests and results which should have raised clear and obvious issues / concerns with the service. These have not been identified or action plans put in place.

A lack of a routine and robust quality assurance process within the sector, coupled with a lack of national oversight of the outcomes from the Newborn Hearing Screening Programme (NHSP) in Scotland has allowed this to continue without being identified until a significant number of children have been adversely affected.

16. Throughout the audit process and review visit, the panel wish to state that the Executive of NHS Lothian and the department have been open and welcoming of the team. They have expressed a clear desire to support and implement improvements to the service and this should be commended.

Recommendations

The panel have made 36 recommendations to improve the Paediatric Audiology Service to ensure it is both safe and fit for purpose

Urgent – to address immediately

- 1) Update mitigation strategy in light of onsite observational findings (*Completed 8th October 2021*)
- 2) Debrief this report to the Audiology staff in a supportive manner and offer ongoing support to the team
- 3) Share this report with the Scottish Public Services Ombudsman by 19th November 2021
- 4) Commence onsite visual reinforcement audiometry training, covering test technique with case studies incorporated for illustration
- 5) Commence training for 2 members of staff to perform ABR to BSA recommended procedures including for complex cases such as Auditory Neuropathy Spectrum Disorder (ANSD), Unilateral hearing loss and special cases
- 6) Commence training of the 2 members of staff performing ABR testing in sharing the news with parents and appropriate ongoing management options for infants diagnosed at ABR
- 7) Ensure there are adequate toys available during behavioural testing meeting current Health and Safety guidance
- 8) Ensure there is adequate funding for equipment and spares for the Newborn Hearing Screening Programme
- 9) Establish audiological scientific knowledge and leadership skills in the leadership roles within the department, seconding to post if necessary. This will enable the staff undergoing VRA and ABR training to be supported and to embed this new practice across the department, ensuring that the incorrect practice does not continue

High – to be addressed within 12 weeks

- 10) Consider under duty of candour the need to communicate the findings of this report to the children and families identified within it
- 11) Consider the need to share this report with other health boards who refer children for Paediatric Audiology testing at NHS Lothian or where NHS Lothian paediatric audiology staff have conducted testing at their premises
- 12) Consider the need to share this report more widely, for greater professional learning both within Scotland and across the United Kingdom
- 13) Share the findings of this review within the multidisciplinary team at the Health Board to ensure clinicians are aware that there could be children within their caseloads who may have been tested inaccurately and therefore have a misdiagnosed hearing loss, and the need to review the full clinical picture, so that repeat testing can be arranged as needed
- 14) Review all protocols / guidelines, consolidating them where appropriate, and update using full referencing and version numbers to facilitate document control. New protocols written if they don't currently exist or adopt and amend guidelines from other departments to reduce workload

- 15) Train all clinical staff in all new protocols to ensure they are understood and the importance of following them is highlighted
- 16) Implement theoretical and practical training for all staff covering:
 - The importance of following protocols and guidelines
 - Review of the evidence base to include:
 - Accuracy of parental reports of hearing ability
 - Test techniques to include scientific rationale and understanding of child development
 - Effects of mild and high frequency hearing losses
 - The impact of delayed diagnosis of permanent childhood hearing impairment
 - Test techniques
 - Test selection
 - Result integration and critical review
 - Management of inconclusive and complex patients
 - The importance of early cochlear implant referral
- 17) Implement training for staff undertaking regular hearing aid work on the selection and fitting of hearing aids to children under the age of 3-years-old, including the use of Real Ear to Coupler Difference (RECD) measurements
- 18) Ensure all staff are familiar with the correct child protection reporting procedures, and recognise when concerns should be highlighted, including some children who fail to attend
- 19) Review management of the Newborn Hearing Screening Team to ensure the team are supported as needed
- 20) Improve administration systems to ensure that information from appointments is recorded contemporaneously in the Journal, using appropriate keywords; in the paediatric module where appropriate and is not confined solely to patient documents. Use of standard templates (Hotkeys) should be encouraged
- 21) Improve scanning of documents to ensure legibility
- 22) Begin to review the Newborn Hearing Screening records of all children for the last 3 years to ensure that those which have referred the screen have been offered an audiology diagnostic appointment. Where any child is identified which have not been assessed by ABR at birth, recall these for testing.
- 23) Establish or join an existing external ABR peer review network for ongoing support and advice for the professionals
- 24) Commission a review of the ABR recordings of all children seen by the service for ABR testing during the last 5 years, recall for behavioural testing those where significant concern is raised
- 25) Begin to recall children of clinical concern identified at the audit stage for retesting and new management
- 26) Begin to review children known to the service who have risk factors for hearing loss and recall these children in line with national guidance
- 27) Ensure that Stage A checks are being completed daily on equipment that is in use on that day and that these are documented, recorded and audited

Medium – to be addressed within 6 months

- 28) Review the long term structure of the department to ensure:
 - Adequate senior staffing with the appropriate scientific approach and critical appraisal skills in each of the three areas: screening, diagnostic assessment and (re)habilitation, to enable appropriate service development and leadership
 - Adequate senior staffing to enable more management functions to be delegated to ensure robust leadership and management in the absence of the head of department.
 - Staff grading is reflective of the specialist roles and training
- 29) Develop a comprehensive quality assurance programme for the clinical aspects of the service, to include peer review, and reporting / oversight mechanism to Director. Suitable peer reviewer to be identified, which may be external
- 30) Implement further training for staff in Clinical audit so they are able to support the quality assurance programme, and recognise the importance and benefits of accurate self-assessment
- 31) Implement further training for senior staff on critical appraisal and reflection, root cause analysis, action planning and investigation such that in the future issues should be identified and acted upon earlier
- 32) Review complaint management processes to consider:
 - Regular recording of all complaints received by the Paediatric Audiology Department, to include informal complaints
 - Monitoring of complaints at departmental level to look for patterns and themes, and agreeing appropriate action plans
- 33) Review use of aids for trials and as loan aids in line with infection control guidance
- 34) Consider sending staff to observe other large paediatric audiology departments, with priority given to those with clear scientific leadership
- 35) Perform a full review into the hyperacusis and tinnitus service in order to ascertain and ensure:
 - the best management approach
 - families are receiving the information provided.
 - That all referrals to the service are appropriate
- 36) Review and update the PCHI record so that it is an accurate reflection of all children with hearing aids for a permanent childhood hearing impairment known to the department

References

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