

Tommie Denman had eight hearing tests before a correct diagnosis

'I had to beg for hearing tests': the children failed by the NHS

Thousands of babies born with hearing problems may have been misdiagnosed and denied vital support because of errors

NEW

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Kirstie Denman knew something was wrong with her baby son but no one in the health service seemed to want to help.

The dog would bark, the doorbell would ring, the volume on the television would change dramatically but Tommie would not flinch. "He became increasingly frustrated. He'd lash out at me, bang his head on cupboard doors and claw at his legs in fits of tears," she said.

Tommie was seen by paediatricians every few months and failed his initial newborn hearing test but NHS staff told Denman just to wait and see in a few months. He then failed another hearing test and then another.



Tommie, now eight, has caught up but remains behind where he should be

"They kept telling me everything was fine, we'll review him again in a few months," she said. "I practically had to beg for hearing tests. I knew something was just not right. I work in early years so I had quite a good understanding of children's developmental milestones and he was very, very delayed."

Eventually she was told Tommie, who was born prematurely at 29 weeks, would probably have to be in a special needs school and would struggle for the rest of his life as a disabled child.

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In reality, he was deaf, but his hearing problems had been missed by the NHS. He had eight tests before being properly diagnosed in October 2018. This was only after Denman, 31, had sought a private assessment and a referral to a different hospital.

Until then Tommie, now eight, had been denied the stimulation of sound and language that his developing brain needed, which was why he was showing similarities to children with learning difficulties.

Tommie's story is not unique. It can be revealed that NHS officials have begun an urgent review of hearing services for children in England amid fears thousands who need help have been missed.

At least three NHS hospitals have had their audiology departments closed because some children and their parents have been incorrectly given the all-clear because of poor testing and misinterpretation of test results.

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Tommie was under the care of audiology services at the Diana, Princess of Wales Hospital in Grimsby, one of the hospitals whose services have been shut by NHS England. The others include Scunthorpe Hospital and services at Warrington Hospital in Cheshire, although this has since reopened.

North West Anglia NHS Foundation Trust and the East and North Hertfordshire NHS Trust have also been told to make improvements.

The nationwide review was prompted by an inquiry into serious failings at the NHS Lothian health board in Scotland, where profoundly deaf children were diagnosed so late they could no longer have implants they needed.

In the past six months, health officials in England have reviewed the records of babies born since 2018 and the levels of diagnosed hearing problems. They found some areas had much lower diagnosis rates than would normally be expected.

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Some of the problems uncovered include inadequate training and supervision of staff, failure to follow clinical guidelines and the incorrect interpretation of the auditory brainstem response (ABR) test.

This is used to assess the hearing level of babies who are referred after failing the newborn hearing test.

The National Deaf Children's Society fears there could be other deaf children who were missed before 2018. A new report from the charity reveals eight out of ten paediatric audiology services struggle to review children fitted with hearing aids on time, and that staffing levels dropped by a fifth between 2019 and last year.

There are 50,000 deaf children in the UK, with three deaf babies born every day. While around 50 per cent of deaf children are born deaf, the other 50 per cent will become deaf during childhood. Other youngsters affected by the NHS failings will include not just children who are profoundly deaf but others who have a less severe hearing loss but who would have needed tests to determine what help they needed such as hearing aids and implants.

Mike Hobday, chief policy officer at the society, said the problems were likely to be widespread and were a consequence of a lack of oversight by the NHS, which stopped quality checks on audiology services in 2013.

He said: "What's critical in the life and prospects of deaf children is that the deafness is identified early. Babies' brains develop more in the first year or two of life than at any other point.

"It is astonishing, and appalling that at a number of sites around England the quality of the ABR testing and the interpretation of the results wasn't up to clinical standards, and as a consequence deaf babies were not provided with any support and are in some cases going to be affected for life."

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In a survey of 114 NHS services the society found the total number of children with permanent deafness had fallen by 7 per cent, about 3,000 since 2019.

Hobday warned: "We do know the number of deaf children in the population is pretty constant, it hasn't suddenly improved. So that indicates that some deaf children are missing and not being picked up."

He said some children could end up being mislabelled as severely autistic because they display similar behaviour.

Tommie, who now has cochlear implants in both ears, is developing well and making progress, although he is still behind where he should be.



A number of children have been recalled for further hearing tests

Denman said she was haunted by the knowledge that had she not pushed for a second opinion her son could have been classed as special needs.

"It really upsets me to think this little boy that we have got now would never have existed. It terrifies me.

"He'd just be sat in a room unable to communicate. What sort of life is that? I don't doubt there are hundreds if not thousands of children in that position.

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"No one was listening at all. Everybody said to me, come back in six months, we'll review him in six months.

"If I had a pound for every time a professional told me he was premature and boys were just lazy, I wouldn't have to work now."

Denman urged worried parents to keep pushing and asking for help saying: "If you feel something's wrong you need to batter down every door until somebody listens."

Dr Kate Wood, chief medical officer at Northern Lincolnshire and Goole Trust, which runs the Grimsby site, said: "We are reviewing our paediatric audiology service and have temporarily suspended ABR testing after a review of patient results showed some of them have been misinterpreted.

"We have already written to a number of families about this review to let them know what is happening. Many of the results are fine and we have let those families know that.

"We are working with an external team of specialist audiologists to determine whether children need to have their hearing retested. A number of children have been recalled."

NHS England said: "Following serious concerns highlighted in Scotland, NHS England proactively set up a national paediatric hearing service review, initially looking at four trusts that have been identified as requiring improvements in their children's hearing services.

"It's vital we get this right, which is why we are working closely with local teams, clinical experts, professional bodies and patient groups, including the National Children's Deaf Society, to develop a comprehensive understanding of the issues and to find immediate and longer-term solutions.

"Families that are affected are being contacted by their local hospital if their child needs their hearing reassessed."

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