

Listen Up!

**Campaigning to improve the quality
of children's audiology services**



October 2014
The National Deaf Children's Society

ndcs
every deaf child

NHS report shows **one-third** of audiology services are failing deaf children

This shocking statistic prompted the National Deaf Children's Society to take action and find out more about the quality of children's audiology services in England. We carried out an in-depth analysis of each NHS audiology service quality report looking closely at the most critical quality standards. Taking evidence¹ from the NHS and deaf children and their families it is clear that too many audiology services are:

- Failing to see a child when deafness is suspected within government time frames
- Failing to use the most up-to-date tests and interpret results correctly
- Failing to ensure hearing aids are set-up correctly
- Failing to ensure earmoulds are provided according to government time frames
- Seeing too many deaf children in school time
- Lacking deaf awareness



1. For more information on the evidence, methodology and analysis behind this report please visit www.ndcs.org.uk/ListenUp

Far too many deaf children have been losing crucial listening time and their learning and development is suffering as a result.

Now is the time to ‘listen up!’ **Yet the Government plans to stop listening.** Despite the failures identified by its own reports, the Government is planning to stop assessing the quality of children’s audiology services.

This report sets out:

- 1** The problems deaf children and their parents experience
- 2** Government plans to stop assessing the quality of children’s audiology services
- 3** What action is needed now

Why do deaf children need good quality audiology services?

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 can make a critical contribution to a deaf child’s success in life as they are responsible for ensuring a deaf child is able to use their remaining hearing to the fullest extent possible.

It is particularly shocking therefore that the NHS revealed that **one third of children’s audiology services are failing to meet required quality standards.**

1

The problems deaf children and their parents experience

Waiting too long for the first audiology appointment

If initial tests show that a child may be deaf, they will be referred to an audiologist to be tested again and diagnosed.

As hearing is critical to a child's development of language and learning, early diagnosis and support is vital as it will reduce the risk of delays in language, educational and social development.

The government therefore recommends that newborn babies should receive an audiology appointment within four weeks² of referral and older children should be seen within six weeks.³

Too many parents told us they waited longer than this for their child to receive their first appointment.

The evidence

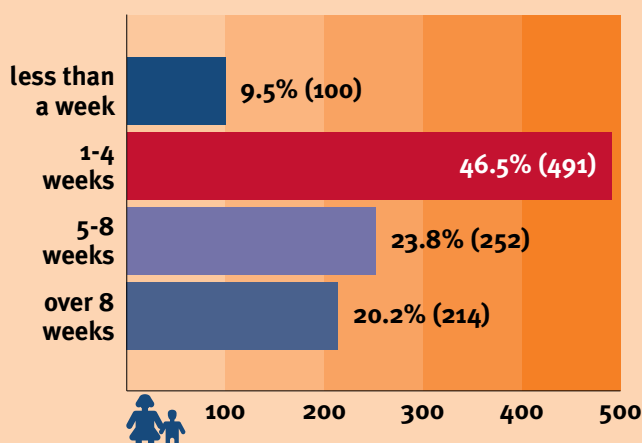
In July 2014, we asked parents to tell us their story. 1,057 parents responded to our question: **'How long did it take to get an audiology appointment from the point your child was referred?'**

44%

(466) of parents told us they had to wait five weeks and longer for their child's first audiology appointment.

20.2%

(214) of parents told us they had to wait over eight weeks for their child's first audiology appointment.



2. KPI NH2 Newborn Hearing Screening Programme 'Test within 4 weeks of referral' www.screening.nhs.uk/kpi [Accessed 20th August 2014]

3. www.england.nhs.uk/statistics/statistical-work-areas/diagnostics-waiting-times-and-activity/ [Accessed 20th August 2014]

The evidence

“It took us three months to get an audiology appointment for our second son. This was despite the fact that we knew that he had had hearing difficulties, and despite the fact he had an older brother with a genetic sensori-neural loss. We explained this to our local audiology service – they couldn’t have cared less. Our second son was eventually also diagnosed as deaf – three months later than he should have been, at a time of peak language learning. He’ll never get that time back.”

– Parent of deaf boy

“Despite calling hospital several times, audiology appointment could not be arranged any sooner – waited three months.”

– Parent of deaf child

Three months is almost a whole term of school. Imagine how much an undiagnosed deaf child is missing out on in language, education and social development in that time.

If a child is not diagnosed quickly following referral, families report feeling left in limbo and frustrated that their child is not receiving the support they need.

Long waiting times = lost listening time

Listen Up!

Audiology services must ensure they see every child within government time frames.

Oliver's story

Like all babies, Oliver's hearing was tested when he was born. The results showed there might be a problem but his parents had to wait three months for his first audiology appointment to check it out further.

Early communication with the family is the strongest influence on language development. In those first three months of his life Oliver would have missed out on hearing vital sounds such as mummy and daddy's voices.



Poor hearing tests and diagnosis

Assessing the hearing of young children is complex and requires specialist skills. It is vital deaf children are tested correctly and get accurate results so that the right course of action is taken. However, the NHS report⁴ and parents have told us that too many children are being inadequately tested and are receiving the wrong results. It is completely unacceptable that services are continuing to fail in this area.

The evidence

Parents told us:

“The audiologist who originally completed my daughter’s first hearing test was rushed and told us things looked ok, subsequent tests showed differently. If she had had an accurate test in the first place it would have meant that the severity of her hearing loss would have been picked up sooner.”

– Parent of deaf girl

“It took 12 months and repeated hearing tests for my son to get the correct diagnosis. During those 12 months his teachers thought he was misbehaving at school, now it’s clear he was frustrated and missing out on important information. We’ve really noticed a difference in him since he starting wearing a hearing aid, especially in the car and at home with his younger siblings.”

– Parent of deaf boy

“They’ve left my [one-and-a-half – two] year old hearing 16% speech in her right ear for months on end with no resolution, dismissing my concerns and not getting any test results from my child. We trust them so little we had to pay £150 and travel to London to get someone to actually test my daughter’s hearing properly which was a dead easy process when I saw it being done right. When they had a mother telling them her daughter’s right ear had been worse for months [and] that the hearing aid was doing nothing, they said come back in 3 months!”

– Parent of deaf toddler

If a child is not diagnosed correctly at an early stage they risk delays in their speech and language development during this crucial stage in their lives.

Poor diagnosis = lost listening time

4. Report of the Fourth Cycle of the Newborn Hearing Screening Quality Assurance Programme (NHSP QA4) 2012–2013:18

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Audiology services must use the most up-to-date testing methods and improve the accuracy of their interpretation immediately.

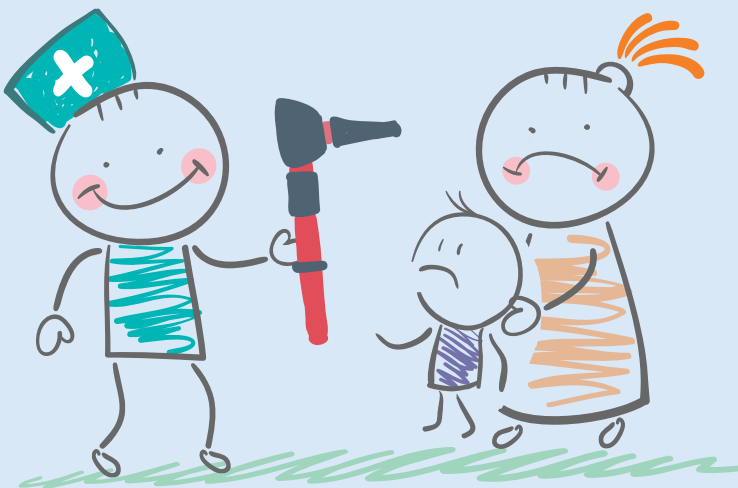
Audiology services must actively participate in and learn from peer review⁵ to ensure diagnostic testing is accurately carried out and interpreted.

Oliver's story

At his audiology appointment, Oliver's parents were told he was moderately deaf and offered hearing aids. Oliver was fitted with his first set of hearing aids when he was six months old.

Even with the hearing aids in, Oliver's parents still didn't think he could hear. They took him for a second opinion and found he was severely deaf.

Oliver was 12 months old when he got an accurate diagnosis and hearing aids that were programmed to match his true hearing levels. That's a year of listening time that Oliver lost in his development. Oliver didn't babble like other babies in his playgroup.



5. Peer review is a quality control system providing opportunities for learning where children's hearing test results are evaluated by experts and other audiologists. Using this method potential problems with the way a test was carried out or interpreted are highlighted, addressed and learned from.

Incorrectly set-up hearing aids

A deaf child needs their hearing aids to be programmed to closely match their type and level of hearing loss. Unfortunately, the NHS report revealed that too many audiology services are failing to do this and parents have also reported the same issue.

The evidence

The NHS report highlighted the setting-up of hearing aids to match different types and levels of hearing loss as one of the lowest rated standards overall. It revealed that 50% of services only met some elements or about half of the elements of the standard to ensure that hearing aids are set-up to match amplification needs⁶.

It is completely unacceptable that half of children's audiology services do not fully meet this quality standard. How will a child know that they are not hearing all that they should be? Parents may not be aware that their child is losing listening time.

Parents told us:

"They managed to set my child's hearing aids wrong three times one after another, it's only because I know my child and her hearing aids so well we got it sorted in just over a week, still very poor attention to detail and timescale."

– Parent of deaf baby

"...she was once given a faulty hearing aid which my daughter said didn't work at the time of fitting, her comments were dismissed as being overly picky."

– Parent of deaf girl

If a child's hearing aid is not set-up correctly they won't hear as well as they could and may start to feel isolated and withdraw from their family.

**Incorrectly set-up hearing aids
= lost listening time**

6. Report of the Fourth Cycle of the Newborn Hearing Screening Quality Assurance Programme (NHSP QA4) 2012–2013:18

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Audiology services must ensure every child's hearing aid is set-up correctly and should regularly check the settings.



Oliver's story

After receiving the correct diagnosis Oliver was fitted with hearing aids to help him make the most of the hearing that he does have — but when they broke and had to be replaced, they were not set-up correctly.

Oliver's parents weren't shown how to check his hearing aids and as a toddler Oliver was unable to explain something was wrong, so the family did not know there was a problem until his next routine appointment.

Oliver missed out on three further months of hearing words clearly. This meant he didn't begin to learn new words and build his vocabulary like other toddlers. By the time he started nursery school Oliver had only learnt 25 words whereas his friends knew around 700.

Waiting too long for earmoulds

An earmould is a vital part of a hearing aid that fits into the ear and needs to be replaced frequently as a child's ear grows. It should fit tightly to make sure that all the amplified sound from the hearing aid travels into the ear. If the earmould becomes loose, the hearing aid will not work properly because some sound escapes around the edges. Sometimes this sound can re-enter the hearing aid and cause feedback and whistling.

With children growing out of their earmoulds as often as they do their shoes, a pre-school child may need new ones every few weeks and by school-age, every few months. Therefore if a child experiences a delay every time they need an earmould replacing, or if they receive their earmould and it does not fit correctly, they will be losing out on significant amounts of listening time.

Professional standards for audiologists and manufacturers⁷ say that children should get an appointment for new earmould impressions within two working days and receive their new earmoulds back from the manufacturer within three days.⁸

The NHS report and parents revealed that too many services are not meeting these standards.

The evidence

The NHS report revealed that 35% of audiology services do not meet the standards to provide earmoulds within the set time frames.⁹

We also asked parents **'How long does it take to get an appointment for your child to have new earmould impressions when needed?'**

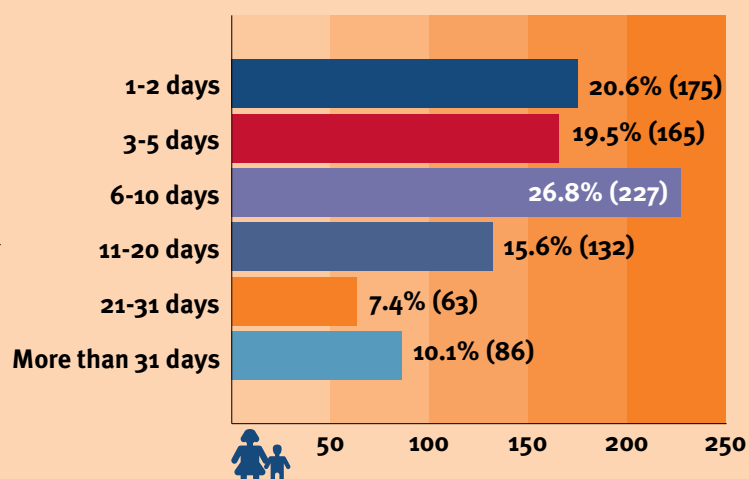
848 parents responded and the majority told us they had to wait longer than two days for their child's earmould impression appointment:

79.4%

(673) of parents told us they had to wait **three days and beyond** for an earmould impression appointment.

10.1%

(86) of parents told us they had to wait **more than 31 days** for an earmould impression appointment.



7. *Guidelines for the Taking of Impressions and Provision of Ear Moulds within a Children's Hearing Aid Service*, MCHAS 2005

8. Government guidance specify that children should wait no longer than 5 days in total to receive new earmoulds: *Transforming Services for Children with Hearing Difficulties and their Families*, Department of Health 2008

9. *Report of the Fourth Cycle of the Newborn Hearing Screening Quality Assurance Programme (NHSP QA4) 2012-2013:18*

The evidence

We asked parents ‘How long does it take for you to receive your child’s new earmoulds after the impression appointment?’

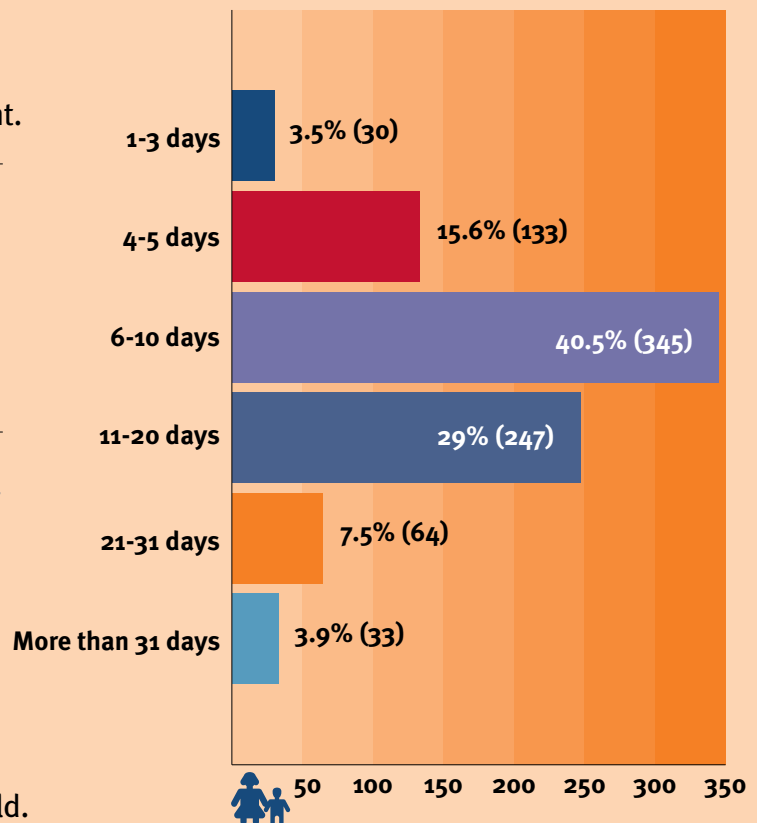
852 parents responded and almost all told us they had to wait over three days for their child’s new earmould following their impression appointment:

Only **3.5%**
(30) of parents told us their child received their earmoulds within 1-3 days after their impression appointment.

96.5%
(822) of parents told us they had to wait over three days for their child’s new earmoulds.

Shockingly, more parents told us they waited over 31 days for earmoulds than those that told us they waited between 1-3 days.

3.9%
(33) of parents had to wait more than 31 days for new earmoulds for their child.



Those children waiting more than 31 days for new earmoulds are losing out on large chunks of good quality listening at a time when every day counts in their hearing, listening and language development.

The delays are often not as a result of a demand on the service but because of administrative failures, such as staff booking an impression appointment in a routine slot (which means a longer wait) rather than an urgent slot and earmould boxes labelled inaccurately and not marked as urgent.

Children should not be losing vital listening time because of unnecessary administrative problems that can be easily fixed.



The evidence

Parents and deaf young people told us:

“There were many times where the moulds did not fit correctly, or in the time that it took for the moulds to get to us my son’s ear had changed in shape so we would be back to square one!”

– Parent of deaf toddler

“Getting the moulds back are a nightmare. Usually too small when come back as over 2-3 weeks to get back.”

– Parent of deaf baby

“...they’re unable to make ear moulds that actually fit my ears. They’re often a bit wonky, and I’ve had to have them replaced a lot because they don’t fit quite right, or cause pains in my ears, etc... About 1 in every 3 attempts the school makes, they get my ear moulds right.”

– Deaf young person

“Just waited 3 weeks for new moulds, he was having to struggle with his split moulds.”

– Parent of deaf boy

Whilst a young person waits for new earmoulds they could miss out on key information in the classroom.

Long wait for earmoulds
= lost listening time

Listen Up!

All audiology services must ensure adequate administrative systems are in place so that professional standards and government guidelines are met.



Oliver's story

Oliver was growing up and started school. His ear moulds needed to be replaced four times a year to ensure they still fitted as his ears grew.

Each time he went to the hospital it took 30 days to get new earmoulds back, rather than the recommended three days. This meant that by the time the earmoulds arrived it was almost time for his next fitting.

Oliver spent a quarter of his first year at school being unable to hear his classmates and teachers due to the sound from his hearing aids escaping from his ears.

Appointment times in school hours

Deaf children must be given every opportunity to achieve their potential at school. The GCSE attainment gap between deaf children and their hearing peers is already too wide.¹⁰ Audiology appointments that are made in school hours could widen this gap even further by regularly taking children away from vital opportunities to learn.

It is extremely concerning therefore that many parents and young people told us they missed out on school time because of their audiology appointments.

The Children and Families Act 2014 requires education and health bodies to work together to improve services for children with special educational needs and disabilities – this should include working together to minimise disruption to a child’s education.

The evidence

“The appointments are also in school time, which is hard as I already do extra work and then I’m missing lessons.”

– Deaf young person

“[I now tend to go] either during the evening or holidays... Last year my attendance was poor because of the appointments I had.”

– Deaf young person

“I would like to choose [a time] that suit[s] my son. I prefer after school and he doesn’t like to take away from school hours and doesn’t want to miss his lessons. This is upsetting him.”

– Parent of deaf child

“Not enough appointments made available for children outside of school hours, very limited and extremely busy.”

– Parent of deaf child

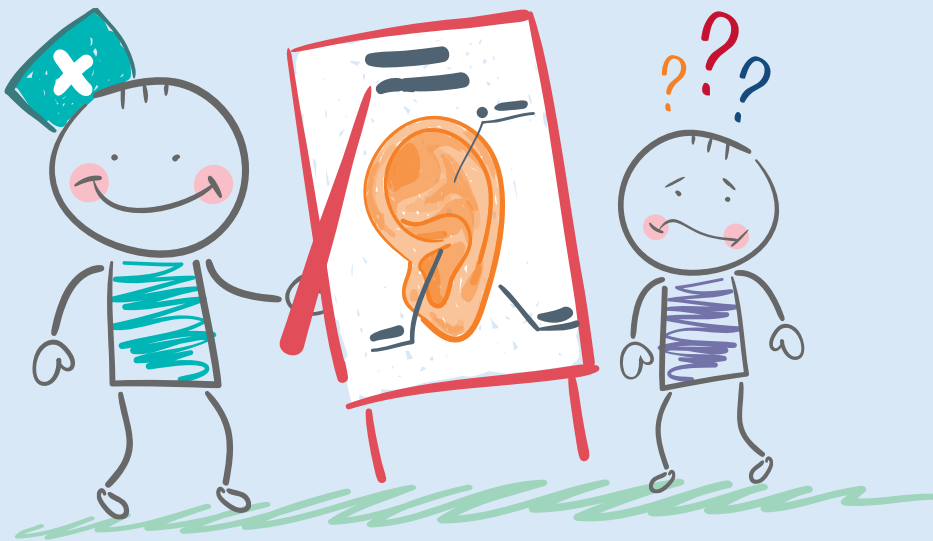
Reducing a child’s time at school, reduces their listening time at school and could result in a child failing their GCSEs.

**Appointment times in school hours
= lost listening time**

10. <http://www.ndcs.org.uk/data> [Accessed 21 August 2014]

Listen Up!

Audiologists must try to see deaf children and young people out of school time. They must work with educational professionals to minimise disruption to a child's education as the Children and Families Act 2014 stipulates.



Oliver's story

Oliver's audiology service did not offer appointments outside of school hours so he had to attend appointments during school time.

Oliver needed to see his audiologist twice a year for check-ups plus extra visits for hearing aid repairs and to get new parts, meaning he missed out on a further three days of school a year.

Lack of deaf awareness

A service that deals with deaf children and young people every day should be deaf aware – ensuring that all staff know how to communicate properly with a deaf child or young person so that they have a full understanding of what they are being told at their audiology appointment.

If staff are not deaf aware a deaf young person could miss out on key information about their hearing and the equipment they use. They will also have to rely on family members to relay information during appointments. Audiology services must ensure deaf young people are empowered, supported and encouraged to ask questions.

Many deaf young people also depend on their family to book audiology appointments on their behalf because telephone booking systems are not accessible to them. As a result they lose their independence. Ensuring deaf young people can book their own audiology appointments and that staff are deaf aware are vital preconditions to understanding and independence.

Unfortunately some deaf young people and their parents have told us their audiology staff are not deaf aware, that they are unable to book their own audiology appointment and that they were not able to communicate with their audiologist in the way that they preferred.

The evidence

“My son’s been going for 10 years, the staff still talk to him when he has his aids out. Some deaf awareness training wouldn’t hurt.”

– Parent of deaf boy

“...nobody prepared to talk the procedure through with us or answer our daughter’s questions, she is now old enough to ask them for herself, it’s like she has no voice or say in her treatment...”

– Parent of deaf girl

“No [they don’t have a text service], you just get told and then you have to turn up for it. But, if it gets cancelled they call, which is stupid because a deaf person struggles via phone call... My mum’s the one who sorts things out for me.”

– Deaf young person

“Most audiologists I’ve had don’t know how to sign. It’s weird, considering they work with hearing-impaired people, and most likely, lots of BSL users too...”

– Deaf young person

“The audiologists just orally communicate with me, I have understanding of what is said to me but not necessarily hearing all of that is said.”

– Deaf young person

“On one occasion there was a woman who didn’t look at me when she was talking and I got annoyed with that so I never had her again.”

– Deaf young person

Listen Up!

Audiology services must ensure that their staff undergo deaf awareness training as part of their induction, and receive refresher training as part of their ongoing professional development.

Audiology services should refer to NDCS's *My Life, My Health*¹¹ resources to improve the deaf awareness of their staff.

Audiology services must ask deaf children and young people what their preferred method of communication is and ensure that communication support is available to them for their audiology appointments.

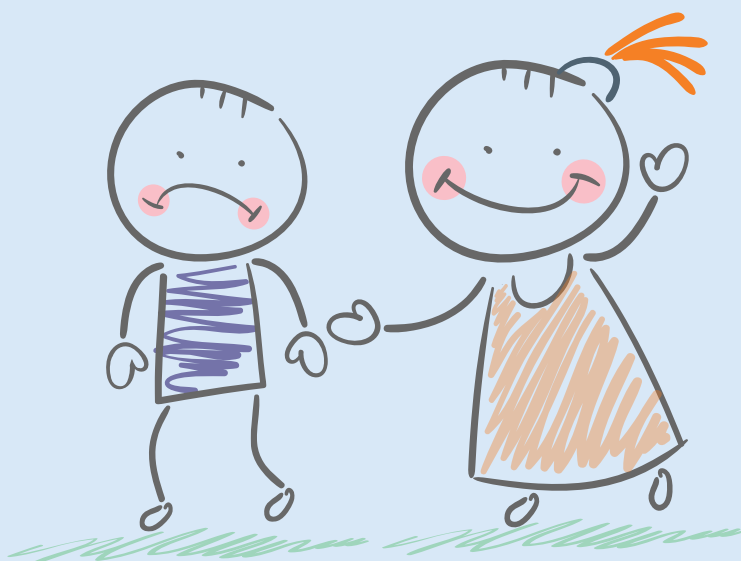
Audiology services must ensure that deaf children and young people fully understand what is communicated to them during their audiology appointments, are spoken to directly, and are actively encouraged to ask questions.

Audiology services should have a range of accessible systems in place to enable deaf children and young people to book their own appointments, including email, online booking and/or text messages. They should also have visual alert systems in the waiting area or vibrating pagers available so that deaf children and young people know when it is their turn.

Oliver's story

As Oliver grows up he could continue to face challenges with his audiology service. His audiologist has poor deaf awareness, often removing Oliver's hearing aids before speaking so Oliver can't understand what is being said to him and his mum.

If nothing changes as he grows up, Oliver will have to take one of his parents with him to appointments, rather than going on his own, to ensure he does not miss any vital information.



11. *My life, My health* is an NDCS campaign to improve deaf young people's experience of healthcare services: www.youngpeople.ndcsbuzz.org.uk/mylifemyhealth/

2

Government plans to stop assessing the quality of children's audiology services

Despite the fact that **one in three audiology services are failing deaf children**, the Government plans to stop assessing the quality of these services and providing support to help them improve.

This decision is being made before the problems have been solved and before a suitable new system is in place, meaning:

- there will be little incentive or support for audiology services to improve
- services with dangerously low standards will continue to operate
- parents will not know if their child is using a good quality service.

The Government says the Improving Quality in Physiological Services (IQIPS) accreditation programme¹² for audiology services is an adequate replacement to the current programme.¹³ However:

- it is not mandatory. Only six out of 134 services that provide hearing aid services for children have achieved IQIPS accreditation so far.¹⁴
- not enough information is published. IQIPS does not publish information about services that have signed up to the process but have not yet achieved accreditation.
- parents will only know about services that are accredited. They will not know if other services are poor quality and can't reach the standard, or if they are good quality and simply not participating. As a result they are left with little choice.

12. www.rcplondon.ac.uk/projects/IQIPS [Accessed 28th August 2014]

13. <http://hearing.screening.nhs.uk/quality> [Accessed 28th August 2014]

14. As of 28th August 2014. www.ukas.com/about-accreditation/accredited-bodies/IQIPS_Schedules.asp [Accessed 28th August 2014]

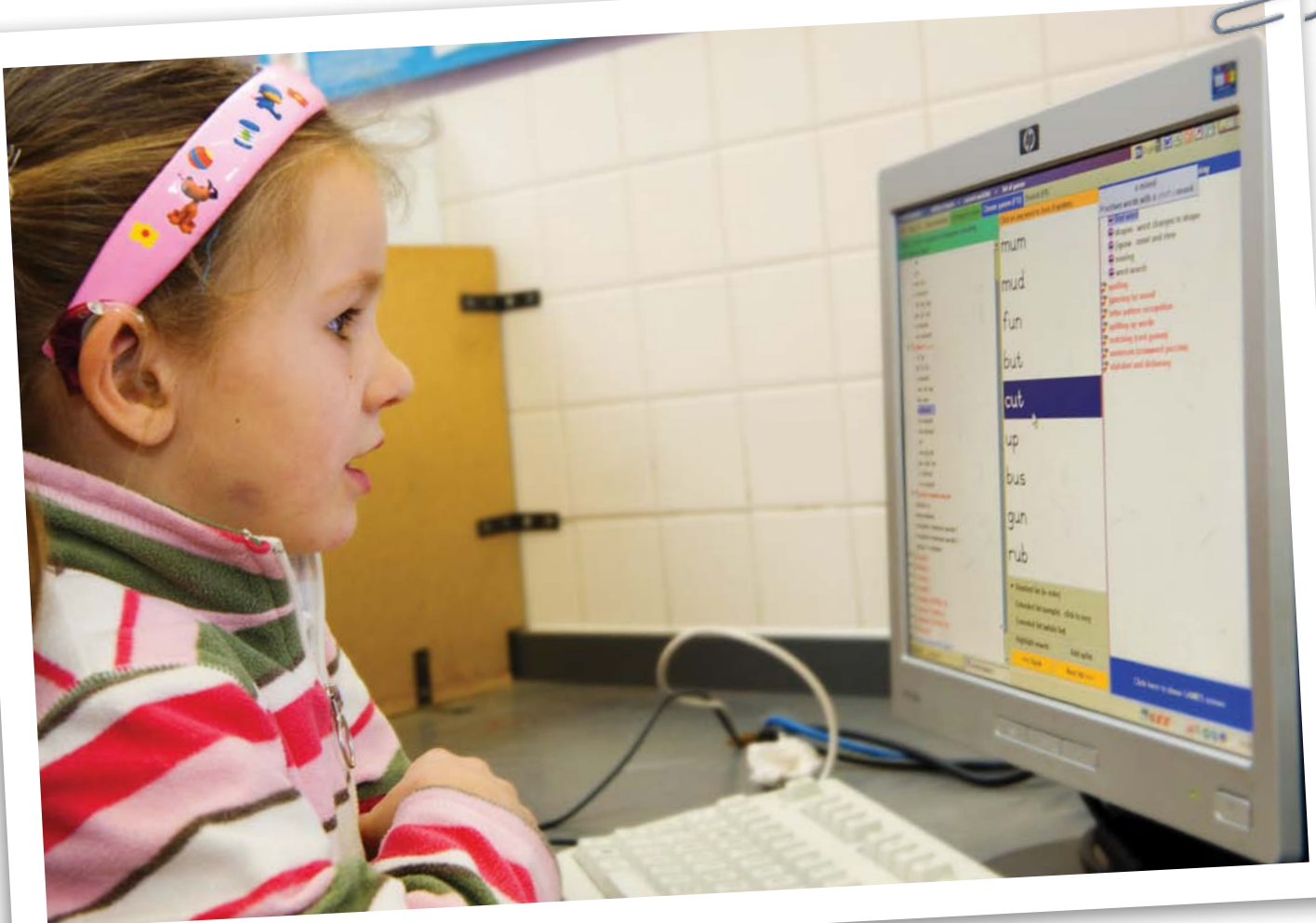
Listen Up!

The Government must immediately take action to improve the one-third of audiology services that are failing deaf children.

The Government must commit to continuing the existing quality assurance programme until the IQIPs accreditation system offers families transparency, accountability and choice.

The Government must ensure 75% of children's audiology services are IQIPs accredited by 2016 and 100% by 2017.

The Government must make it mandatory for all children's audiology services to sign-up to the IQIPS process and all assessment information must be publicly available.



How it should be

Whilst too many parents and children told us about the problems with their audiology service, others told us about their positive experiences. The following services all exceeded government quality standards:

Southend

“The people there were God’s gift to deaf people. Every time I had an earmould replaced, it was perfect. They never bugged me about getting implants, ever! I’d rate my experience there at a definite 10!”

– Deaf young person

Chesterfield

Any problem I have with my son’s hearing or hearing aids is sorted straight away, they are always very kind and helpful.”

– Parent of deaf child

Norfolk

“They are fast, thorough and approachable and welcoming. We are seen straight away, with no waiting for appointments, and given all the time we need during appointments. We have had very quick referrals for scans, ENT and Genetics consultants, development assessments and to a Teacher of the Deaf. We have been offered a trial of a radio aid. The audiologists keep on top of what’s happening.”

– Parent of deaf baby

It is vital that every deaf child receives a good quality audiology service and it is important that every parent and child knows what kind of service they should expect.¹⁵ If families know that their service is not up to standard they can tell them to ‘listen up’ and improve.

15. www.ndcs.org.uk/family_support/audiology/audiology_service.html [Accessed 28th August 2014]

3

What action is needed now

Listen Up!

We want to see every deaf child and young person and their families receive quality support from children's audiology services. For this to become a reality the following needs to happen as a matter of urgency:

Government

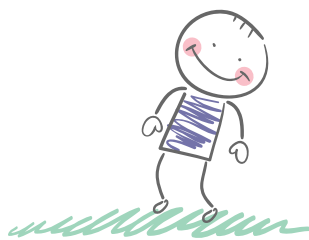
- The Government must immediately take action to improve the one-third of audiology services that are failing deaf children.
- The Government must commit to continuing the existing quality assurance programme until the IQIPs accreditation system offers families transparency, accountability and choice.
- The Government must ensure 75% of children's audiology services are IQIPs accredited by 2016 and 100% by 2017.
- The Government must make it mandatory for all children's audiology services to sign up to the IQIPS process and all assessment information must be publicly available.



Audiology services

- Audiology services must ensure they see every child within government time frames.
- Audiology services must use the most up-to-date testing methods and improve the accuracy of their interpretation immediately.
- Audiology services must actively participate in and learn from peer review to ensure diagnostic testing is accurately carried out and interpreted.
- Audiology services must ensure every child's hearing aid is set-up correctly and should regularly check the settings.
- Audiology services must ensure adequate administrative systems are in place so that professional standards and government guidelines are met.
- Audiologists must try to see deaf children and young people out of school time. They must work with educational professionals to minimise disruption to a child's education as the Children and Families Act 2014 stipulates.
- Audiology services must ensure that their staff undergo deaf awareness training as part of their induction, and receive refresher training as part of their ongoing professional development.
- Audiology services should refer to NDCS's *My Life, My Health* resources to improve the deaf awareness of their staff.
- Audiology services must ask deaf children and young people what their preferred method of communication is and ensure that communication support is available to them for their audiology appointments.
- Audiology services must ensure that deaf children and young people fully understand what is communicated to them during their audiology appointments, are spoken to directly, and are actively encouraged to ask questions.
- Audiology services should have a range of accessible systems in place to enable deaf children and young people to book their own appointments, including email, online booking and/or text messages. They should also have visual alert systems in the waiting area or vibrating pagers available so that deaf children and young people know when it is their turn.

Join the campaign



Visit our Listen Up! web page for more information on the campaign and how you can take action.
www.ndcs.org.uk/ListenUp

Join our Campaigns Network to be kept fully up-to-date about this campaign.
www.ndcs.org.uk/network

Keep informed

Know what kind of audiology service you and your child should be receiving.
www.ndcs.org.uk/family_support/audiology/audiology_service.html

Be vigilant and get in contact

Get in contact with the National Deaf Children's Society's Helpline team if you are concerned about the quality of your child's audiology service. Please call the Freephone number 0808 800 8880 or email helpline@ndcs.org.uk

NDCS is the leading charity dedicated to creating a world without barriers for deaf children and young people.

**NDCS Freephone Helpline:
0808 800 8880 (voice and text)**

helpline@ndcs.org.uk

www.ndcs.org.uk

Published by the National Deaf Children's Society © NDCS October 2014
37-45 Paul Street, London EC2A 4LS
Tel: 020 7490 8656 (voice and text) Fax: 020 7251 5020
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in Scotland no. SC040779.
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