Parent lived experience insights report

October 2025

National
Deaf Children's
Society

A report by National
Deaf Children's
Society

Paediatric Hearing Services Improvement Programme: Embedding lived experience to improve the review and recall process in England

Introduction

The National Deaf Children's Society is represented on the NHS England Paediatric Hearing Services Improvement Programme (PHSIP).

PHSIP is working on the ***review and recall process** in paediatric audiology clinics across England. The National Deaf Children's Society is leading the parent lived experience work (including parents and carers who have had their child's hearing retested as part of this review). We feed back to NHS England through the Task and Finish Group, incident management meetings and directly with services to improve the review and recall process for families.

The aim of this work is to embed lived experiences into the design of parent and carer feedback questions and methodology, and to capture meaningful insights to improve the review and recall process and inform the provision of support.

What is *review and recall?

Some audiology services in England are checking some children's hearing tests to make sure they were accurate. This is called 'review and recall'.

If a child had a hearing test at a service that's part of this review, their parents/carers may be contacted by phone or letter to be:

- sent a new appointment (or be invited to book a retest appointment), or
- be told that their child's hearing test has been reviewed and no further testing is needed

This is part of a national programme called the Paediatric Hearing Services Improvement Programme (PHSIP). It was set up after some services were found to have identified fewer deaf children than expected in the Newborn Hearing Screening Programme

Methodology

Phase 1: Co-designed parent feedback questions and methodology

We worked alongside one audiology service to build an understanding of the review and recall process that it had completed. Following this, we worked with parents with lived experience to design the feedback questions and methodology.

Phase 2: Piloting the questions, approach and refinement

The audiology service contacted parents and carers involved in the review and recall process directly via letter. The survey was promoted along with the letter using a National Deaf Children's Society flyer with a QR code, which led to an online survey. We promoted other methods of providing feedback to ensure the opportunity was accessible, including the option of a one-to-one interview or telephone call. We also offered communication support (for example, an interpreter).

Phase 3: Roll-out of feedback opportunity

The National Deaf Children's Society contacted sites that had completed the review and recall process to disseminate the parent feedback opportunity. Five sites disseminated the feedback opportunity to parents and carers involved in the review and recall process.

Phase 4: Gathering actionable insights centring lived experience

We've taken a qualitative reflexive thematic analysis approach to explore and interpret patterns and meaning from the data collected across the different involvement activities. This has generated actionable insights to inform practical guidance for sites starting the review and recall process. These insights are also informing provision of information and support as well as recommendations to improve routine feedback mechanisms for future service improvements.

We have established a lived experience group to co-create and inform the development of this guidance for services and to identify the right support families need.

Participants

Audiology services promoted the opportunity to families who had completed the review and recall process to feedback on their experience.

- **Phase 1:** Four parents and carers took part in the co-design from one service.
- **Phase 2:** Eight parents and carers participated in the pilot feedback survey from one service.
- **Phase 3:** Eight parents and carers completed the feedback survey from across 5 services, and one requested to take part in a one-to-one conversation.
- **Phase 4:** Three parents are taking part in the Parent Experience Group, which aims to inform recommendations and improvements to the review and recall process and support offer for families. The National Deaf Children's Society also supports this group through our involvement officer, audiology advisor and early intervention advice and guidance officer. This group convened in September, meeting monthly until March 2026 and feeding into the monthly Paediatric Hearing Services Improvement Programme (PHSIP) Task and Finish Group on Lived Experience.

Findings

The feedback generated at each stage has provided rich insights on how to make tangible improvements to the review and recall process. Due to the small number of participants involved, we combined all qualitative responses gathered through the involvement activities and analysed them collectively. This approach allowed for a more holistic understanding of the feedback, ensuring our insights were drawn from a range of participant contributions rather than from individual activities in isolation.

We employed qualitative reflexive thematic analysis to explore and interpret patterns of meaning across the data collected from the different involvement activities.

We followed the 6-stage approach described by Braun and Clarke (2019), which comprises:

1. familiarising with the data through immersion in the anonymised survey responses and interview transcripts
2. generating initial codes in the data to reflect potentially interesting data of relevance to the area of focus
3. generating initial themes to illustrate patterns of shared meaning across the responses
4. developing and reviewing themes to consider how well the initial themes fit the data and how well the analyses work
5. refining, defining and naming themes to ensure that individual themes are stand-alone and built around a single defining concept
6. writing up findings using an iterative writing and rewriting process. We selected illustrative quotes to support and demonstrate key points for each theme.

Overall themes and insights

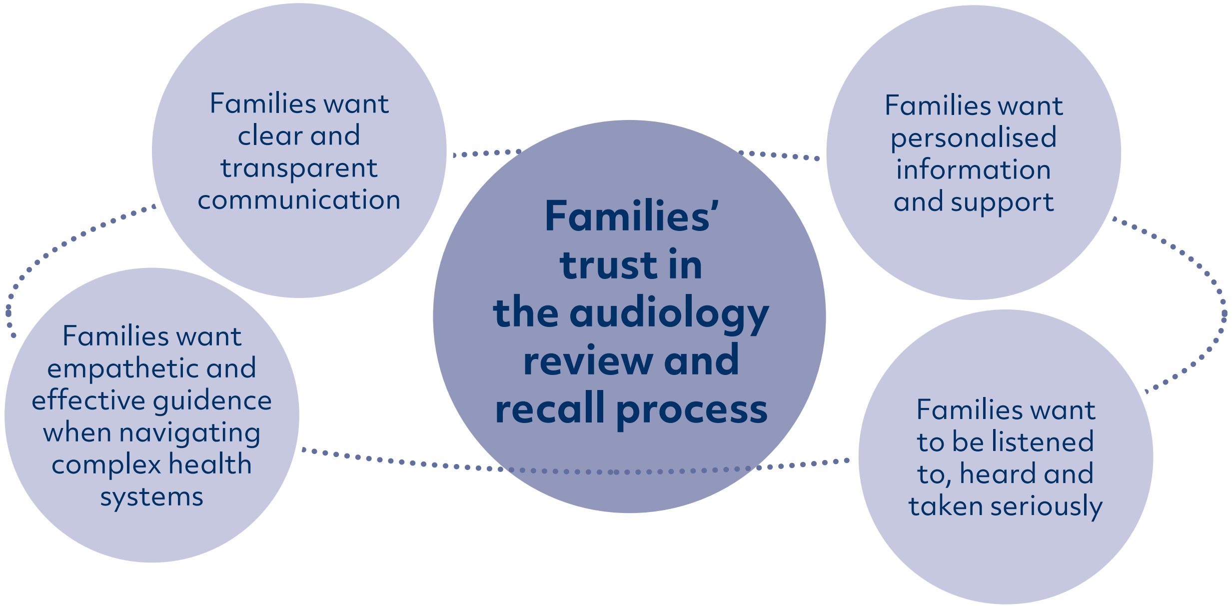
Across the different involvement activities, we identified trust in the audiology review and recall process as a central concept in families' experiences (Fig. 1).

The building of trust appeared to be shaped by 4 interlinked themes, which influenced how confident and supported parents felt in making decisions about their child's care. Families consistently valued:

- clear, transparent information – Parents wanted clear, honest information that helped them understand what was happening and why
- personalised information – Parents wanted personalised support that reflected their child's situation, provided by someone with relevant knowledge and expertise
- being listened to – Parents wanted to feel listened to and taken seriously, with their concerns acknowledged and respected
- empathetic guidance in navigating the health system – Parents wanted empathetic and effective guidance through complex systems, especially when services were constrained by wider challenges

Together, these elements helped to build trust in the process and the professionals delivering and supporting their child's care.

Fig1. Themes identified



Theme 1: Clear, transparent information

"They should have told us from the start there was an incident. We did receive a phone call, but they weren't sure if it [the hearing test] was his or not, so they needed to retest him"

Theme 2: Personalised information

"[We wanted] a guide to explain step-by-step, what is going to happen... Stages on what is going to happen during the recall process"

Theme 3: Being listened to

"I felt like I was being heard so it was brilliant"

Theme 4: Empatheic guidance navigating health system

"The first appointment was fine as it came as an online letter. Follow-up appointments were supposed to come within 3 months, but we have had to chase every appointment as they had not been scheduled. We are now a year overdue for our next appointment."

Families want clear and transparent communication

Families consistently highlighted the need for clear, transparent communication throughout the review and recall process, particularly in explaining the seriousness and urgency of the incident. They stressed the importance of receiving honest, straightforward information from the review team to avoid confusion and build trust.

> "I feel the trust haven't been open about this incident; why has it not been publicised locally but has made national news? People I have spoken to have asked for hearing tests and been told that the machine is broken rather than the reason for the tests being cancelled because of the review – it doesn't feel transparent."

> "The first I saw on it was a solicitor's post on Facebook about the whole thing."

Families described uncertainty about why a review was taking place and noted that this was not made transparent or publicised (for example, whether it was triggered by faulty equipment or was part of routine checks by the trust).

They also emphasised the value of clear explanations about what the review involved and possible outcomes, so they could feel fully informed and supported at every stage.

> "They should have told us from the start there was an incident. We did receive a phone call, but they weren't sure if it [the hearing test] was his or not, so they needed to retest him."

> "It could have been better. The only way I found out about any of the details is statements they released on Facebook. I haven't had an explanation of what equipment was faulty and how and if my son was affected. So, whilst a review did take place it might have used the same equipment, and they didn't notice my son at all."

> "I wouldn't really say a lot of it was very clear to what had happened to begin with."

Several families perceived the initial phone call and letter as routine rather than a clinical review process and as lacking in context about their child's specific situation. Some parents thought it was going to be a standard follow-up appointment and expected a routine check-up. There seemed to be little indication of urgency or seriousness, which led to a sense of shock when the nature of the appointment became apparent. The absence of clear communication about the potential implications – such as identification of deafness – meant they were emotionally unprepared during appointments.

"There was no sense of seriousness or concern. There was no clear indication of the scale of the issue. The letter should've been clear. It felt like a box ticking thing. We were blindsided by what appeared at first to be a routine appointment and it was upsetting and distressing for our family to be so underprepared for this. I thought it was just a formality; I was not aware of all of the poor practice and misdiagnosed children."

"They told us at first that it was a review, not [hearing] loss information. I was told it was [hearing] loss at an appointment."

A few parents expressed their gratitude for the recall and retesting process. They appreciated the opportunity for further assessment as reassurance for them that their child's case was being taken seriously.

"I felt happy he was getting investigated."

"It was a good thing we got my child retested. If they didn't send a review, I wouldn't have known that my child is partially deaf."

Families want personalised information and support

Parents emphasised the need for personalised information and support to help them make sense of their child's situation. They described how initial communication felt too generic and not tailored to their child's situation. After initial contact, families described waiting for a long time before their recall appointment took place. Families wanted to know what might happen next and have the opportunity to speak with someone knowledgeable about their child's case and be able to ask any questions.

> "The initial call-taker had no idea about the recall and was just calling people up; they asked if my child had any issues I was concerned about, but they weren't a clinician and gave no indication of any urgency or that this was anything other than a paper exercise or double check."

Parents remembered phone calls where staff did not appear trained to break difficult news or answer questions, and where staff conveyed that appointments were routine without explaining their significance. The limited information and absence of seriousness left families feeling dismissed and uninformed.

> "Each clinician has been great but it's always different people and we get mixed messages about her ability and future. I am constantly sceptical of what I am being told as I have no trust and get conflicting information."

> "I wonder if the liaison should be done by an independent person as I lost trust in the entire health trust, so to have a liaison who is unreliable and employed by the trust isn't really fit for purpose."

Following identification, families wanted clear details about the type and level of their child's deafness, what will happen next, possible options for intervention, a named point of contact, and information about other professionals involved in their child's care. Where parents referred to having a point of contact working well for them, they reported that it made communication easier, they received help with any problems, and they received appointments on time.

> "Having someone as a point of contact now works; it has made it easier with communication."

> "[Name of point of contact redacted] was very helpful and easy to reach and sorted any problems quickly. Got our appointments on time."

Some families felt their child’s care was not given sufficient priority, both at the point of identification and during subsequent reviews. They felt that a clearer, more coordinated pathway was needed with automatic referral to Ear, Nose and Throat (ENT). When asked what additional support they might need, parents said:

> “A guide to explain step by step what is going to happen. Stages on what is going to happen during the recall process.”
>
> “Doctors to actually do their job and provide all the information and explain when the next appointment is going to be and with who.”
>
> “A clear proper pathway so parents know what will happen next. Children should have an automatic review arranged with ENT and if they are part of a review their care should be expedited.”
>
> “We haven’t heard about next steps; contact for us is very slow and limited.”

Families wanted to make sense of their child’s hearing and identification and develop an understanding of what the identification might mean for their child’s everyday life and in the future. They also stressed the importance of holistic care – seeing and supporting the whole child, not just as a number. This included recognising the child’s feelings and needs before audiology appointments.

> “My child is often fed up and can get very distressed; it is a hard day that we do not look forward to.”
>
> “[Name of child redacted] was scheduled for an appointment with an audiologist after his treatment for serous otitis media (glue ear)’. As he was scared, even though his dad explained that he is autistic, the doctor didn’t see him and did not reschedule.”

One parent highlighted that deafness is not a uniform experience, and therefore information and support should reflect each child's lived experience. For those with little prior exposure to deafness, this process felt like navigating the unknown.

> "It's not just a small issue, it's a massive, huge issue, not just as a parent, but [for] him as a child and as an individual. No one in my family is deaf at all. Where did this come from? So obviously [child] is still going through all of these appointments and these checks and everything. Not each deafness is exactly the same. I feel it's going to really impact him going about the world and about his life."

> "You are responsible for people's lives and my child is a human being, not a number."

For some, services reinforced trust through positive interactions, such as when staff demonstrated professionalism and checked practical details like whether families had transport and childcare or offered timely reminders of their appointment. These acts of attentiveness reassured families that staff were supporting them. When asked what they found most helpful about the initial information provided by the review team, one parent responded:

> "They rang and then sent a letter with appointment details. Also rang to check we [were] attending."

Families want to be listened to, feel heard and taken seriously

Families described the emotional burden of the review and recall process, including feelings of anger, confusion, devastation, disbelief, exhaustion, sadness and worry. Families spoke of feeling guilty for missing signs of deafness and stressed the importance of supportive professionals that validate their experiences and feelings. Their responses highlighted the emotional toll, compounded by frustrations due to missed opportunities for earlier intervention and support.

> "I cried. I was in a massive, massive shock. I was like, are you serious? My child can't hear. I've adjusted to it. It's his genes. But it's just, it's just a sad journey."
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> ---
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> "It was a shock; the fact he had gone the first 4 years of his life thinking he could hear fine. There was no indication that this was the case. If it wasn't for his reception hearing check in school, I'm unsure when we would have found out that he only had hearing in one ear."
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> "Very frustrated, worried and annoyed."
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>
> "Worried about the possible needs of our child."

Central to families' experiences was the importance of being listened to, taken seriously and treated with dignity and respect. Feeling validated seemed to provide a foundation for support as they made sense of the process. For some, the process brought a sense of relief and reassurance.

> "I felt like I was being heard so it was brilliant."
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>
> "Relieved, as we had spoken to the GP who did not believe there was a problem."

Families also emphasised the value of compassionate, family-centred communication that included the child, prioritised their needs, and encouraged parents to advocate, knowing their input was valued.

"Spoke to both parents and child, especially as he got older, to explain what was happening and what the results of any tests meant."

"The nurse at every appointment was excellent and made my child feel at ease."

"Their openness and honesty and the confidence they gave us during the appointment."

"Fabulous staff, amazing with our child, and despite this review, we still feel very confident in their work."

Conversely, when parents were made to feel like an inconvenience or burden, this eroded trust and deepened distress.

"Parents should be supported in their feelings and anger at what has happened; they should not be made to feel a burden or a nuisance because they advocate for their child."

"They could have cared. They didn't tell me any results; I was just an inconvenience."

Families want empathetic and effective guidance when navigating complex health systems

Families described the difficulty of navigating complex health systems while managing other responsibilities in their lives. Some parents seemed to carry the burden of organising their child's care to minimise further delays and uncertainty. Chasing appointments, repeatedly sharing medical histories and coordinating care across multiple services were all part of the hidden work of managing their child's care. They spoke of the need to continually advocate for their child. This effort was characterised as a battle, leaving some families feeling frustrated.

> "I had to contact PALS [Patient Advice and Liaison Service] to get any sort of appointment or recognising that my son's hearing had been affected."

> "We were referred to the wrong area for Teacher [of] the Deaf initially, then the follow up referral was blank, so I had to do it myself. I had to arrange community speech and language myself. I had to chase all appointments and support for my child and [it] felt like a constant battle. I asked for copies of reports. At the start, one clinician told me I can't have them as I won't understand them as I'm not an audiologist; others have since said I can have reports and they just don't turn up. I have felt angry and frustrated at the lack of priority treatment for my child given what she has been through."

> "There was no information provided. I called the hospital back but no one provided any information or scheduled another appointment/redirected us to another hospital."

> "Make appointments within the agreed timeframe, don't cancel appointments, make sure referrals actually happen, talk to each other and make sure a full history is provided and referenced."

When asked about what could have been better about the support provided by the review team, one parent said:

> "Appointments are tricky to get so do not cancel or rearrange months later. Point of contact who returns calls."

Concerns about professional competency also influenced trust. Parents described poor practice that left them feeling let down, such as delayed incident reports with no explanation, inaccessible documentation, misinformation about broken equipment and confusion over results. Some reported conflicting information between professionals, or lack of clarity over referral pathways and expected timelines.

> "After the incident it has put us off [name of hospital] and tend to get appointments at [name of hospital]."

Despite these challenges, some families seemed to maintain trust in the wider system. Compassionate care seemed to act as a buffer, helping parents reconcile mistakes with their broader interactions with professionals and services.

> "Not worried at all – full faith in the hospital and the audiologists involved."

For other families, negative experiences seemed to erode confidence in the system. One parent described missed opportunities for their child's hearing loss to be identified when engaging with other health professionals. They felt these oversights not only delayed intervention but also reshaped the child's communication pathways, social and education experiences. They reflected on what could have been, had identification and intervention occurred earlier.

> "It had failed, the one [Newborn Hearing Screening test when child was born]. There was no recall. Nothing. So obviously life is just going on. There were no interventions, no nothing. But when I look back now, as much as I have helped my child now, I wish I knew it sooner, but it is what it is. Had they done that at the age of 2, 100% I feel he would have had hearing aids and he would have got to the level that he is with his peers."

A few parents reported using their own personal financial resources to ensure their child received timely care or to confirm an identification of deafness with a second opinion.

> “I said to her, how can you tell me my son is deaf when at the age of 3, before lockdown, the woman passed him. I said, go back to your records please. It took me a while to understand my child was deaf. I paid for 2 private tests with paediatricians. The results were the same. Then they were worried about his speech and everything. So, this is what I’m paying for with this private speech therapist.”

> “After checking his hearing in [another country] privately where it was discovered that he had serous otitis media (glue ear) and he needed treatment.”

Families mentioned delays in waiting for appointments following identification of deafness and experiencing inflexible booking systems and last-minute cancellations without explanation. These systemic constraints seemed to increase a sense of frustration given the seriousness of the situation.

> “The first appointment was fine as it came as an online letter. Follow-up appointments were supposed to come within 3 months, but we have had to chase every appointment as they had not been scheduled. We are now a year overdue for our next appointment.”

> “I think the time frame was probably 3 to 4 months, but my point here is why does it take so long for a referral? Why does it take so long to get an appointment when you know it’s important?”

Fragmentation of care, particularly poor coordination between departments such as ENT and audiology, seemed to add to the strain.

> “Our child attended several [appointments] with audiology and was then referred to ENT as the audiologist didn’t think the issue was glue ear after all – however, ENT went straight back to glue ear, without seeming to reference previous notes/medical history, meaning that we have started again.”

A few parents highlighted the practical burdens of attending appointments. They described the travel, time, parking and organisation required as part of the hidden/invisible work involved in managing their child's care.

> "Appointments are always on a weekend; I have another child and my husband works weekends at times. Attending [name of town redacted] is over 50 miles each way and the appointment and travel take up the majority of the day. My child is often fed up and can get very distressed; it is a hard day that we do not look forward to."

> "Parking around [name of hospital town redacted] is awful."

A few spoke about the hospital environment itself. Respondents described clinical spaces as unwelcoming to children, with parents suggesting more child-friendly design to reduce stress and create a supportive atmosphere for families.

> "Finding where I needed to go was difficult; the area itself was dark, gloomy and not particularly child-friendly. The location of the department needs better signage and some improvements made to the waiting area/room; quite daunting, especially for children."

Families offered constructive suggestions for improvement. They felt review teams should take responsibility for contacting parents, rather than requiring parents to initiate follow-up, and stressed that appointments should never be cancelled without rescheduling or explanation. Respondents suggest peer-to-peer support as a valuable resource for families navigating similar experiences.

> "It was a lonely process; as a parent you want someone to talk to who is in the same situation as you: peer support perhaps."

Respondents also recommended that hearing screening is embedded into routine child health pathways, making use of existing touchpoints with early childhood services. Prioritising urgent needs through effective triage was seen as important to avoid delays and ensure children access support during key developmental windows. Respondents also highlighted providing clear information for families on the signs of hearing loss as a priority.

> "I think there needs to be a small some-sort-of A5-clear-as-day information. If your child can't talk or if it has not got his voice, look out for the silent letters. Look out for this, look out for that. Can he hear what you're saying in a busy environment? Put the TV on, make some noises in the background with the music. Can the child hear what you're saying? If not, go to the doctors for referral. So simple and basic as that."

Parents need a range of options to engage in routine feedback to services, following the care provided to their child

We explored routine feedback mechanisms within the pilot and wider survey with parents, to identify ways they would like to provide feedback and find out the difference their feedback had made.

Most parents that took part in the involvement activity said they were likely or fairly likely to give feedback to their local service in the future (12 parents). Two were unsure and 2 stated they were unlikely to provide feedback in the future. One parent noted that they had used the complaints process several times.

Of those that answered the question on how they would like to give feedback to their local service, responses included:

- scan QR code with phone to access a short survey (8 parents)
- complete a short survey using a tablet issued at reception (3 parents)
- digital push button (3 parents)
- parent liaison at service (1 parent)
- all the above (1 parent)

Of those that answered the question about how they would like to find out about service improvements, responses included:

- appointment letters (10 parents)
- clinic noticeboard at local service (7 parents)

Impact of embedding lived experiences

The involvement of parents and carers with lived experience at each stage had a significant impact on our work within the Paediatric Hearing Services Improvement Programme (PHSIP).

- We were able to make immediate alterations to designed questions and methodology to reach parents and carers. Those who participated provided useful insights to deepen our understanding of the review and recall process and highlight what families need.
- We worked with NHS England to develop a practical communications toolkit that contains the review and recall process timeline, advice for services, letter templates, phone call scripts and information and support for signposting families to early intervention advice and guidance officers (EIAGO) at the National Deaf Children's Society.
- Early intervention advice and guidance officers provide specialist one-to-one support for families of children who have been newly identified as deaf following the review and recall process. We were better able to prepare our officers to support families affected by the review, refine the support offer and the National Deaf Children's Society website page: Review and recall in England.
- Continuity of care has been a key area raised in the Parent Experience Group and within this report. It is important to ensure families experience consistent, transparent and supportive care through and beyond review and recall, even when different external subject matter experts (SMEs) are involved in the process. We have been able to create a briefing on continuity of care for PHSIP based on lived experiences and professional quality practice.

Similar projects in future should explore the factors that facilitate or prevent families providing routine feedback about the care provided to their child. Developing guidance on routine feedback, centred on lived experiences, should ensure services are continuing to respond to feedback, improving services for families and rebuilding their trust.

Challenges and learning

There were challenges involved in gathering feedback from parents with lived experience of the review and recall process, which merit further exploration. Most services routinely communicate with families by post, rather than electronically. To complement this communication approach we provided a flyer with a QR code leading to the survey. This flyer was to be included with the letters sent by the local service. Our intention was to enable services to share the feedback opportunity with as many families as possible, in a timely and cost-effective way. However, the flyer generated low engagement from parents and carers.

As a benchmark, we would typically expect a flyer to generate an engagement rate of between 1% and 3%. However, in this instance, the flyer generated a lower level of engagement. There may be different factors that contributed to the low level of engagement which we are unable to evidence at this stage. These factors may have included:

- delayed or lost post
- lost flyers
- unclear messaging leading to low understanding of terms used
- low levels of language and literacy, and of digital literacy amongst families who received the flyers
- limited capacity of parents and carers to share feedback before the closing date
- requesting feedback over the summer holiday period
- the length of time that elapsed between a child being recalled and their family receiving the review and recall survey

Conclusion

The insights and learning gained from the project have highlighted the importance of embedding lived experience feedback from the start of any project aimed at service improvements. This project has generated continuous feedback loops centring lived experience and making tangible recommendations that have been put straight into practice by NHS England, Integrated Care Boards and by services starting the review and recall process.

This work has highlighted the need to further explore the mechanisms by which families are made aware of opportunities to provide feedback, how to make feedback opportunities accessible to families with different levels of medical and digital literacy, and to ensure services communicate the difference feedback has made. These efforts would help to improve services and build trust with families.

Recommendation

1. **NHS England's practical guidance for services beginning the review and recall process should be informed by lived experience. This should include:**

   a. a detailed timeline for services to communicate and deliver on the review and recall process with families

   b. additional communications for other professionals including GPs, health visitors and teachers, to promote consistent messaging about the serious incident and importance of families attending review appointments

   c. clear and transparent scripts and templates to communicate with all families in response to the outcome of the review of each child

   d. clear levels of responsibility to communicate with families, with particular focus on conducting duty of candour by senior clinicians

   e. accessible and inclusive communications for all families affected which focus on promoting the importance of attending the review appointments and removing barriers

   f. providing communications via phone or letter that promote what support is available to families from the start. This means offering support at each stage including initial communications, preparing for the review appointment and following the appointment. All communications should promote the National Deaf Children's Society's early intervention advice and guidance offer.

2. **The National Deaf Children's Society will promote consistent messages, information and support to families informed by parent lived experiences. This will include:**

   a. developing a **web page** on the National Deaf Children's Society website to communicate consistent messages to families about the Paediatric Hearing Services Improvement Programme (PHSIP), the review and recall process, access to appropriate information and one-to-one early intervention advice and guidance support

   b. the National Deaf Children's Society working with audiology sites undertaking review and recall to provide direct support to families from the outset of the process through a small team of Early Intervention Advice and Guidance Officers (EIAGOs)

   c. EIAGOs developing relationships with sites to establish ways of working to provide specialist one-to-one support for families at the right stage of the review and recall process

   d. EIAGOs providing specialist one-to-one support for families going through review and recall

   e. offering EIAGOs to all families going through review and recall. They will prepare families to attend review appointments to reduce was not brought (WNB) or did not attend (DNA).

3. **The learning and insights should inform the development of future work centring lived experiences, including:**

   a. opportunities for parent lived experience to improve the support pathways of families across paediatric audiology services

   b. investigating the effective mechanisms for families engaging with effective routine feedback

Authors:

Emma Papakyriakou
Angela Decket
Dr. Sian Lickess
Alison Worsley

Contact:

Emma Papakyriakou
Involvement and Engagement
National Deaf Children's Society
Emma.Papakyriakou@ndcs.org.uk

National
Deaf Children's
Society

We're the National Deaf Children's Society, the charity for deaf children with any level of hearing loss.

Helpline
0808 800 8880 (voice and text)
helpline@ndcs.org.uk

ndcs.org.uk

Published by the National Deaf Children's Society
167-169 Great Portland Street, 5th Floor, London W1W 5PF

Tel: 020 7490 8656 (voice and text) Fax: 020 7251 5020

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