## **Temporary hearing loss**

## Results of surveys to parents and professionals



## 1. Summary

- 1.1 Between August and October 2019, we surveyed parents and professionals for their views on support to children with temporary hearing loss. This was part of a wider piece of work to improve our understanding of the experiences of parents of children with temporary hearing loss, as well as the challenges they may face.
- 1.2 This paper provides a high-level summary of the findings from these surveys. More detailed reports are included in Annex A and B. A literature review has also separately been produced and is available online at <a href="https://www.ndcs.org.uk/research">www.ndcs.org.uk/research</a>.

## 2. Background

- 2.1 We received responses from 125 parents and 154 professionals to our surveys. In both cases, the responses we received were thoughtful and rich in detail we would like to thank all those who took the time to share their views.
- 2.2 In terms of possible limitations, it should be noted that:
  - a. Responses to both surveys were self-selected. This means they may not be fully representative of the views of parents and professionals.
  - b. Responses to the parent survey included parents whose children were now older 28% were over the age of 11 than the age beyond which temporary hearing loss is typically experienced. This means that responses to the parent may include a mix of comments on both existing and historical provision.

## 3. Summary of key findings

- 3.1 49% of parents reported that their child's temporary hearing loss was confirmed within a year of it first being suspected. 32% waited a year for confirmation whilst 19% waited two years or more.
- 3.2 Parents reported that temporary hearing loss impacted on their child in a range of ways most common responses were around speech (47%), language and communication (38%) and behaviour (31%).
- 3.3 Parents' perceptions and experiences of local support are often negative. There was a mismatch between what families and professionals report.

#### Table 1:

	% of Professionals saying they agree	% of Parents saying they agree
"Where I live, temporary hearing loss is identified quickly"	68%	30%
"Where I live, children with temporary hearing loss and their families receive high quality support that meets their needs"	61%	18%

3.4 There was also a mismatch in terms of what professionals say is available and what support parents were offered.

## Table 2:

	% of Professionals saying their service provides this support	% of Parents saying they were offered this support
Leaflets	86%	50%
Signposting to websites	60%	21%
One-off meeting	26%	7%
Poster	18%	N/a
Annual review meetings	12%	12%
Coffee mornings	9%	14%
Other	35%	27%

- 3.5 Over a third of parents (36%) stated that they had not received any of the support options listed above.
- 3.6 The parent survey results indicated that audiologists are a key audience for reaching parents with temporary hearing loss.
  - a. Audiologists are most likely to identify temporary hearing loss in a child (58%), compared to other professionals
  - b. Audiologists are most likely to be identified as a provider of information 74% of parents saying they'd received support from an audiologist.
  - c. Audiologists had 2<sup>nd</sup> highest rating in terms of helpfulness of support 75%. Only NDCS was higher at 88%, whilst Teachers of the Deaf were at 74%. School nurses, health visitors and GPs were rated least helpful.

## Annex A: Summary of results to survey of parents

### Scope

125 parents participated in our survey. When asked how old their child is now: 54% were between the ages of 5-10 and 23% were between the ages of 11-16 (although nearly half of this group are aged 11). 18% were between the ages of 0-4, and 5% were over 16.

83% were from England, 9% from Wales, 6% from Scotland, and 2% from Northern Ireland.

### Methodology

The survey was disseminated by email to NDCS members whose records showed that their child had a temporary hearing loss.

Separately, the survey was also promoted via our local groups and social media channels. Professionals who received the survey for professionals were also asked to disseminate the parent survey to families in their area.

#### Who first suspected that your child may have a problem with their ears or hearing?

125 parents answered this question. 62% indicated that they were the first to suspect this followed by someone in a medical role (22%). This was most likely to be a health visitor (13%) followed by an audiologist (3%) or a paediatrician (2%) or doctor (2%).

Other responses indicated that the school (10%), nursery (7%), and the newborn screening (4%) first suspected a problem with their child's hearing.

2% indicated other family members, 1% indicated their speech and language therapist, while 4% of parents were unclear in their response.

#### How old was your child when you or someone else first suspect a problem with their ears or hearing?

125 parents answered this question. 54% of parents stated that their child was suspected of having a temporary hearing loss between the ages of 0-2. 40% indicated that they were between the ages of 3-5 when they were suspected of having temporary hearing loss. 6% were between the ages of 6-10 with two being detected as late as 10. No responses indicated that temporary hearing loss was suspected at the age of 11 years and older.

#### Who identified your child as having a hearing loss?

125 parents responded to this question. 58% indicated that their audiologist identified their child as having a hearing loss. 11% indicated that an ENT doctor identified their child as having a hearing loss, 9% indicated their GP, and 7% indicated the school nurse. 2% said their paediatrician made the identification.

12% indicated that someone not listed in our survey made the identification. Responses in this category were the nursery, health visitor, hospital, and the newborn hearing screening. The following all received one response: parents, paediatrician, nurse, and midwife.

## How old was your child when their temporary hearing loss was confirmed?

125 parents responded to this question. 25% of parents indicated that their child was 3 years old when their temporary hearing loss was confirmed. 18% indicated that their child was 4 years old. 13% said their

child was 5 years old. 13% also indicated their child was 2 years old. 11% indicated their child was under 1 year old, and 8% indicated one year old.

When grouped together, 56% of responses indicated that their child was aged between 3-5 years old when temporary hearing loss was confirmed. 32% indicated that their child was between the ages of 0-2 and 12% indicated their child was between the ages of 6-11.

When the confirmation year is compared to how old the child was when temporary hearing loss was first suspected, 49% of respondents appear to have had confirmation of temporary hearing loss in the same year it was suspected. 32% received confirmation one year later while 13% received confirmation two years later. The remaining 7% received confirmation at least three years later.

Difference between suspected and confirmed temporary hearing loss	Count	Percentage
0	61	49%
1	40	32%
2	16	13%
3	2	2%
4	3	2%
5	2	2%
11	1	1%
Total	125	100%

## Does your child still have a temporary hearing loss?

66% of parents confirmed that their child still has a temporary hearing loss. 23% said this was not the case while 11% were unsure. The table below indicates that 48% of children who still have a temporary hearing loss in our survey are between the ages of six and ten. 23% are 11 and above and 17% are below the age of five.

Age	Count		Percentage
1		1	1%
2		3	4%
3		3	4%
4		2	2%
5		5	6%
6		13	16%
7		12	15%
8		7	9%
9		5	6%
10		2	2%
11		10	12%
12		4	5%
13		4	5%
14		1	1%
15		1	1%
16		4	5%
17		2	2%
18		3	4%
<b>Grand Tota</b>	al	82	100%

## In what way, if any, has temporary hearing loss affected your child?

119 parents responded to this question. Most of the responses here are concerned with language development in particular. (Percentages in this section do not add up to 100% as responses could be grouped into multiple categories.)

47% of responses indicated issues with speech. Some responses in this category have been selected below:

- Speech very delayed. Also missing starts and ends of words.
- His speech quality is very poor, up until he was given hearing aids.
- Found phonics at school harder to grasp.
- Her speech is poor and she misses the endings of words.

38% of responses also mentioned general issues with language and communication. Some of these responses refer specifically to issues with grammar and vocabulary while some indicate listening problems.

- He only began to communicate properly after it was fixed. Before then, very basic language skills.
- Significant impact on language development.
- Just not catching some word when he's having a conversation.
- Reduced vocabulary.
- Slow language development. Still cannot accurately compose sentences sometimes.

31% also referred to problems with behaviour with some indicating that their child feels frustrated and angry. In some cases, problems with behaviour are said to have arisen because they are unable to interact with others effectively.

- Behaviour due to not being able to communicate with each other.
- His behaviour has been really bad and challenging ... Lots of hitting and violence.
- Mishearing conversations causing frustration and anger.
- Frustrating and generally unexplained poor behaviour which changed almost immediately when she
  got her hearing aid.
- Behaviour is challenging with his peers as he gets fed up trying to join in.
- She is often frustrated with herself for the mistakes she makes and feels useless

24% of responses refer to issues with hearing.

- He struggles in class and can't concentrate very well on tasks if he doesn't quite hear what is going on.
- ... struggling to hear the teacher in school so was labelled as 'bad' on a few occasions for 'ignoring' the teacher.
- She doesn't hear when there is background noise.
- He becomes withdrawn when his hearing deteriorates and is prone to outbursts

18% indicated that temporary hearing loss made it difficult for their child to interact with others.

- Lacks confidence with peers and often backs down in social situations. Never puts herself forward or asks questions in public.
- Reduce social skills and disengaged from learning in school to a degree.
- Her confidence around people she doesn't know including other children has dropped as she is afraid to answer them incorrectly.
- In primary school, the main impact was on her ability to socialise

10% indicated that having temporary hearing loss has led to low-confidence/self-esteem (10% responses). In addition to a lack of confidence in socialising with others (as above), children can also lack confidence about their ability; this is often stated in general terms without specific examples.

- She still has low self-esteem and thinks of herself as being less capable.
- Lack of confidence, lack of self-belief in capability
- Very shy/no confidence

12% indicated that their child now had an issue with reading and writing and 12% felt their child had difficulty at school due to their hearing loss.

- Learning in reading/writing due to speech delay
- Falling behind with his reading too.
- She struggles to read yet she is bright.
- When he started school and was learning to read he was behind his peers as he struggled with phonics and learning the sounds that go with letters as he couldn't hear the sound.
- Missed a lot of information at school
- He also ended up behind where he should have been in other areas of his schooling due to his hearing loss.
- He is currently 2 years behind his peers

8% indicated their child was inattentive as a consequence of having temporary hearing loss.

- · ... disengaged from learning in school to a degree
- Poor attention span
- Huge impact on attention
- Concentration level really low

Many other issues were mentioned by a small number of parents. These included the following: tiredness (7%), tinnitus (2%), being sensitive to noise (3%), problems sleeping (3%), pain (2%), being loud (3%), ear infections (2%), dyslexia (1%), being bullied (2%), auditory processing disorder (1%).

## Have you received any information or support from any of the following professionals?

113 parents responded to this question. 74% of parents have received information or support from audiologists. 49% have received information or support from ENT doctors and 33% have received information or support from Teachers of the Deaf. 31% said that someone from the NDCS had provided them with information or support. Responses which received fewer than 17% of responses include GPs, health visitors, paediatrician, and school nurses.

18% of parents indicated that they had received support from other areas. This includes speech and language therapists, hearing services, SEN staff, private healthcare system, teachers, parents, Dorset Deaf Children Society.

## And were you offered any of the following support?

113 parents answered this question. 50% indicated that they were offered leaflets as support; this was the most frequent support option offered. 36% indicated that they were not offered any of the support options listed.

21% indicated that they were signposted to websites and 14% were invited to coffee mornings with other families. 12% received an annual review meeting and 7% only had a one-off meeting to provide information and advice.

27% parents indicated that they had received other forms of support such as a follow-up hospital appointment, support from hearing support services, local support groups, NDCS support, regular hospital visits, regular visits from a Teacher of the Deaf, as well as a school visit from an audiologist, and in the form of a social events.

## How helpful or not did you find this support?

More than half (where applicable) stated that they found the support from NDCS, audiologists, Teachers of the Deaf, and ENT doctors helpful.

49 parents responded when asked how they found the support from NDCS. 88% thought NDCS's support was helpful. 6% thought it was unhelpful while 6% were unsure. No clarification was provided as to why NDCS's support was unhelpful.

72 parents responded when asked how they found the support from audiologists. 75% thought this support was helpful. 18% thought it was unhelpful while 7% were unsure. When asked why they considered audiologists unhelpful, they cited the lack of advice and information given, the fact that regular appointments were unlikely and that audiologists were sometimes slow to refer or to offer hearing aids.

38 parents responded when asked how they found the support from Teachers of the Deaf. 74% thought support from Teachers of the Deaf was helpful. 16% thought it was unhelpful while 11% were unsure. When asked why it was unhelpful, one parent indicated that this service was not available to them. Another parent indicated that visits from (peripatetic) Teachers of the Deaf were not frequent enough to have any value.

51 parents responded when asked how they found support from ENT doctors. 57% thought the support from ENT doctors was helpful. 34% thought they were unhelpful while 10% were unsure. When asked why ENT doctors were unhelpful, the following responses were provided:

- Lack of advice and information; unhelpful; sometimes, they seemed ill informed.
- Surgery is presented as the only option
- Kept saying it would resolve itself despite this not being the case after 6 months

18 parents responded when asked how they found support from their paediatrician. 50% thought this support was helpful, 28% were unsure, and 22% thought it was unhelpful. Little feedback was provided as to why this was unhelpful. One response offered suggests that one paediatrician only wanted to prescribe antibiotics initially which was unhelpful. A second response suggests a lack of advice and delay in diagnosing the condition as possible reasons.

In contrast to the above services, fewer than 50% of parents thought that support from the school nurse, health visitor, and the GP was helpful.

11 parents responded when asked how they found support from the school nurse. 45% thought this was helpful and 54% thought this was unhelpful. No feedback is provided as to why this was unhelpful.

24 parents responded when asked how they found support from health visitors. 46% thought this was helpful. 42% thought the support was unhelpful. 13% were unsure. When asked why this was unhelpful, responses indicated that the health visitor seemed to lack knowledge or insight into the issue and how

provide support. One respondent said that the health visitor kept saying it would resolve itself despite this not being the case.

36 parents responded when asked how they found support from their GP. 34% thought this was helpful, 44% thought this was unhelpful while 22% were unsure. When asked why the GP's support was unhelpful, responses indicate that GPs do not always take the issue seriously and appear to be dismissive at times. They are also unable to provide adequate support or information on temporary hearing loss. In some cases, they are not willing to, or are slow to, refer children to a specialist.

## If your child's hearing loss was caused by glue ear, were they provided with any of the following?

113 parents responded to this question. The most frequent treatment options were grommets and hearing aids. 58% indicated that they were provided with grommets and 58% indicated that they were provided with hearing aids. Otovent treatment was only available to 17% of parents.

14% indicated that these three options were not made available to them.

## If yes, can you tell us how happy or unhappy you were with the length of time for these treatments to be provided?

Parents are more likely to be unhappy with waiting times associated with grommets surgery than for hearing aids. Views on Otovent treatment elicited the most uncertainty although most were happy with this treatment.

Grommets: 61 parents responded to this question. 61% were unhappy with the length of time for grommets to be provided. 29% were happy while 10% were sure. When asked to clarify why they were unhappy, responses indicate that parents were unhappy with wait times (36%). These long waiting times (or repeat appointments with no treatment) would then have an impact on their child's progress at school and their well-being overall. In a small number of cases, grommets were ineffective (21%) and sometimes had to be re-inserted.

Hearing aids: 64 parents responded to this question. 50% were happy with the length of time for hearing aids to be provided. 37% were unhappy while 13% were unsure. 22 parents responded to our request to clarify why they were unhappy. 41% indicated that they had to be very proactive to get hearing aids. Some services are not keen on supplying hearing aids and parental requests are often refused (27%). As with grommets surgery, 59% parents stated that the wait times for hearing aids were too long.

Otovent treatment: 22 parents responded to this question. 36% were happy with the length of time for this treatment to be provided while 33% were unhappy. 32% were unsure. 10 parents responded to our request to clarify why they were unhappy. The following responses were provided:

- We were only told about that option a few months and we had to buy the equipment ourselves
- Tried the Otovent treatment it was no use.
- We weren't shown how to use it and had to buy it ourselves
- I'm really disappointed that Otovent treatment was never even suggested

## Please tell us if you agree or disagree with the following statements.

Where I live, temporary hearing loss is identified quickly

112 parents responded to this statement. 30% agreed with this statement while 21% were unsure. 50% disagreed.

Where I live, children with temporary hearing loss and their families receive high quality support that meets their needs.

113 parents responded to this statement. 18% agreed with this statement while 20% were not sure. 61% disagreed.

#### Looking back, what information or support do you think was most helpful to you at the time?

83 parents responded to this question.

27% of responses referred to the NDCS and referred to our leaflet on glue ear covering the behaviour and emotional impact of the condition as well as our website.

20% mentioned general advice and support as being useful. These include the following:

- Don't give up
- Help with what my rights are
- Speech and language input
- That tubes can damage a child's eardrums and can cause permanent damage and scarring
- The advice regarding hearing aids and the benefits this can have for a child with temporary hearing loss.
- Being able to understand the hearing loss and knowing what to do to help her speech at home
- How hearing loss affects speech and development

10% mentioned audiologists being helpful and supportive throughout the process.

- The audiology department have been a great support to us. Never rushed and explained everything.
- One very supportive audiologist who really took parents' view and opinion into account.

8% also valued the support received from Teachers of the Deaf.

- The Teacher of the Deaf was amazing to meet. She was able to confirm that he was relying on lip reading in the classroom and recognised the difficulties this would raise. She was able to explain this to the school.
- The support of the Teacher of the Deaf was invaluable.
- Our Teacher of the Deaf was amazing, her support was the only thing that got us through our original diagnosis.

7% said they found the internet helpful.

- The information I found myself online was the most helpful. Only medical facts given by hospital.
- Google
- Internet and self-searches

6% suggest that the importance of a diagnosis as being helpful.

- Knowing that there was a hearing loss, we could tell the nursery what was happening
- Someone actually listening and realising that my son could not hear and it was affecting his development.

A number of aspects were cited as being helpful which received a small number of responses. These include support from individuals (e.g. health visitor, friend, speech and language therapist, teachers,

support worker, peripatetic teacher, SEN coordinator) as well as organisations and educational settings (e.g. Phoenix deaf charity, Dorset Deaf Children Society, nursery, and school)

Although small, 4% indicated that they found value in reading about other people's stories and experiences with temporary hearing loss (found on the internet or via NDCS's website).

# Looking back, is there any additional information or support that you didn't receive but that you think would have been helpful to you then?

72 parents responded to this question.

21% suggested that there was a lack of information on various aspects related to temporary hearing loss at different stages of the process.

- More advice on looking after hearing aids and useful things we could do in everyday life to help him.
- Would have been nice for someone to explain the hearing results, more support at school.
- It would have been helpful to know the impacts on speech and behaviour so that we were prepared and could let the school know instead of having to learn as we went along.
- More information on treatment choices would have been helpful.
- Information about Otovent treatment would have been useful.
- I wish I'd realised more about how hearing aids work and how he still doesn't have total bearing with them.

18% mentioned that information on how adjustments could be made to meet the child's need could have been more forthcoming. In addition, support on ensuring these adjustments were in place would have also been helpful. 10% mentioned this when discussing the school.

- What I could do to help
- I think all parents should be given written information as well as information to pass on to the teacher
- We were given no information as to strategies that we could use to support him or things we should tell the nursery
- Advice for school on how to ensure she could hear properly in class
- More help with getting school to take it seriously

14% suggested that a prompt referral and treatment would have been helpful.

- Quicker referral by GP who wanted to 'watch and wait'
- Being diagnosed and sorted before impact of language delay
- Earlier intensive speech therapy
- Diagnosis is quick but after that you don't get seen in the right timescales (6 months is really a 14 month wait)
- It would have been more supportive if the GP had questioned our son's ability to speak when glue ear had been spotted initially ... this might have helped him get some support from a younger age

7% indicated that a support network would have been helpful.

- Details of a support group would have been nice. We have tried and failed to find parents locally... meeting parents of children with glue ear would have been helpful.
- Meeting other parents and children with similar issues.
- More local groups for people who have children with similar conditions to compare notes, stories, etc.

6% also underlined the value of being listened to.

- To be listened to as the expert on my child and his needs.
- Maybe listen to the parents and my concerns a little more? All the information received by the deaf society fell on deaf ears (sic)

6% indicated that they would have appreciated signposting.

• We would have like a meeting with healthcare professionals to take time to talk through what to expect and where to go for help. We stumbled across things more by accident than anything else.

Many other aspects were also suggested by 2 or 1 respondents. These include more regular check-ups, information about time scales/milestones, sign language, school visits, and having information in a clear format.

## Still looking back, what information or support did you think was least helpful?

61 parents responded to this question.

20% referred to unhelpful comments (most often from a health professional) which were dismissive or not very supportive.

- GP telling me she would grow out of it even though we noted nursery said her speech was affected
- Consultant's comments on the physical appearance of my daughter
- "She'll grow out of it"
- Being told it would get better when it is impacting their life

12% instead referred to the lack of support rather than indicating something they considered unhelpful.

- No unhelpful support but a lack of support
- Professionals giving no hearing support
- We just weren't really told anything

10% considered the GP unhelpful.

- The GP was least helpful
- Our initial visit to the GP was disappointing as they were not interested as the school had not noted any hearing problems
- GP was awful

7% stated that they found the wait and see approach the least helpful.

- Wait and see
- Wait and watch periods weren't particularly helpful because my son's hearing didn't change and nothing was being done to help this.
- The wait and see approach seemed a waste of time
- Going back every 6 months for 3 years

5% indicated that the Teacher of the Deaf service was not helpful (although two comments appear to indicate that it is the unavailability of this service that is the problem).

The following aspects were also considered unhelpful but mentioned fewer than 3 times: being denied or not offered hearing aids, the lack of a prompt diagnosis, speech therapy, otovent, ENT doctors, behavioural testing, school, being pressured to choose surgery, and a lack of compassion.

## Is there anything else you'd like to tell us about your experiences in this area?

56 parents responded to this question.

25% mentioned problems with long wait times.

- Very slow
- The ENT wait times are completely out of this world, leaving a child a year to wait to be able to hear properly is a disgrace.
- We were not referred to ENT and then had to wait 9 months for an appointment. Process took over two years...
- The wait to see ENT specialists is far too long and referrals back don't happen quickly enough

16% discussed aspects related to the school. These responses were a mixture of positive and negative comments.

- Schools are not aware how much of a disability it is to the child suffering.
- School teachers have little or no understanding of this area.
- I informed the school regarding my daughter wearing hearing aids and gave the letter... luckily her teachers were amazing and very supportive
- The lack of knowledge the school had about this common childhood condition is scary. Even now teachers still say hello to the back of my son's head and wonder why he ignores them.

16% also discussed how their concerns and queries were not taken seriously.

- Glue ear is not taken seriously
- Our local speech therapy isn't working at all. They don't care about the individual child just box ticking
- ... you find that people think 'it's not so bad' and 'he will grow out of it' and that, especially educational settings have no or very little understanding of the condition and its effects
- You get misinformed and brushed off
- The ENT consultant was rather dismissive about Otovent treatment
- Feel very let down and fobbed off... just told glue ear very common.

13% provided some positive aspects. These covered several aspects and praised specific support received

- We would like to praise the work of the Teacher of the Deaf and would only wish they were able to come in more and follow up more.
- Wonderful support from the audiology and the Teacher of the Deaf who helped at a time when I was really upset about my daughter's hearing issues and having to wear hearing aids
- I think it was dealt with quite quickly once the audiologist referred us to ENT.
- All treatment we have received has been fantastic but the waiting times are frustrating...

The followings points were also raised: poor facilities and services (9%), having to be proactive and chase up queries (9%), issues related to diagnosing the condition (9%), the need for emotional support (7%), the lack of awareness surrounding the condition (7%), provision of equipment such as hearing aids (7%), the low quality of support provided by speech and language therapists (7%), and the lack of support (5%).

## Finally do you have any other thoughts, comments, or suggestions on this issue?

25 parents responded to this question.

As with the previous question, most responses (36%) stressed the importance of improving awareness of temporary hearing loss – particularly within services such as schools.

- Make schools aware. The first school, the headmaster said she was not that deaf so didn't warrant any support.
- More awareness needed with professionals and the public.
- I don't think it's taken seriously. When my daughter started school, we pushed for a speech assessment but have had to use the local university language centre for speech therapy.
- We have experienced families of children with cochlear implants saying that our daughter shouldn't be included in deaf playgroups as she isn't really deaf. There is a lack of understanding of the impact of temporary deafness on a child and their family.
- I would like to see more training/awareness of glue ear within schools.

24% drew attention to the need for more support. Some responses have also indicated that emotional support is needed.

- Helping children feel worthwhile before they show signs of depression
- I'm just upset and disappointed that my boy was just told to wait and see which hindered development.
- I feel like we have been left and there is very little support in-between appointments which can be months
- Not enough help for children to get hearing tests without a long wait or having to go private

## 4. Temporary Hearing Loss: summary of response to survey of professionals

### Scope

154 professionals responded to our survey. The majority of professionals were audiologists (51%) and Teachers of the Deaf (31%). The third largest category was "other" (9%) and included clinical (e.g. audiovestibular physician, speech and language therapist, ENT nurse, psychologist) and educational roles (e.g. Communication Support Worker). Paediatricians (4%), teachers (2%), early-years practitioners (1%), health visitors (1%), and ENT doctors (1%) made up the rest of this group.

86% of professionals were from England and 9% were from Scotland; the remaining number was from Northern Ireland and Wales (2.5% each).

## Methodology

The survey was disseminated in a range of different ways:

- Targeted emails to heads of audiology services and to NDCS professional members working in health.
- Via the British Association of Teachers of the Deaf and the Heads of Sensory Services email forums
- Within the NDCS Professionals Update to all professional members.

## Does your service provide any of the following forms of information or support to families with children experiencing temporary hearing loss?

We had 131 responses to this question. Professionals could select more than one answer. Results indicate that information and support is provided in a range of forms with some more frequent than others.

- Most professionals provide information in the form of leaflets (86%) followed by signposting to websites (60%).
- Few services provide coffee mornings with other families (9%) and annual review meetings (12%).
- A quarter of professionals (26%) stated they provide a one-off meeting to provide information and advice to families. 18% provided information in a poster format.
- 35% indicated that they provided information in other means such as:
  - A school visit in which information is provided to the school and assessment is carried out.
  - o A home visit
  - Ongoing meetings arranged every three months.

# Are there any particular organisations or websites that you signpost families to for information about temporary hearing loss? If so, please say below what these are:

105 professionals answered this question. 90% professionals mentioned that they would signpost families to NDCS. 6% recommended the NHS and 4% would signpost Otovent. Other resources mentioned were Cleveland Clinic, Ear Foundation, and Action on Hearing Loss (all mentioned once).

## Tell us to what extent you agree or disagree with the following statements.

Where I live, temporary hearing loss is identified quickly.

123 professionals answered this question. 68% agreed with this statement while 16% disagreed. 16% were unsure.

Where I live, children with temporary hearing loss and their families receive high-quality support that meets their needs.

132 professionals answered this question. 61% agreed with this statement while 21% disagreed. 19% were unsure.

The majority of professionals agreed with the two statements above. Most professionals believe that temporary hearing loss is identified quickly and that children and their families receive high-quality support. While disagreements were in the minority, comments from 40 professionals as to why they disagreed with the above statement indicate a number of issues such as:

- No routine screening to identify temporary hearing loss
- Parents may have to visit GP several times before a referral is made.
- The number of children with temporary hearing loss is likely to be high; resources are not in place to support this.
- Long waiting list for review/initial ENT appointments (no government targets for review times) and for surgery if required. Treatment is not considered until after a period of watchful waiting.
- There is a lack of support and information for nurseries, schools, and families
- Some parents have resorted to private healthcare
- Parents and the school have to be forceful before any treatment is given for glue ear
- Temporary hearing loss is difficult to diagnose. Children are often not identified until school age.
- Lack of awareness (new parents are not given information in maternity wards on this common problem)
- There is a lack of signposting. GPs and other healthcare professionals are not referring families because they 'passed' the screen; No referral made to sensory support service from school
- Appropriate equipment is not provided; some feel that bone conduction hearing aids would be beneficial. However, this is too expensive/funding is not available.
- Teachers of the Deaf or local hearing support services do not always support these children (even if they have a hearing aid and the loss is long term)

## Finally, do you have any other thoughts or comments, suggestions on the issue

24 professionals responded to this question with the following comments. Only comments that have not been covered previously are listed here.

- Continue providing the glue ear booklet
- Create a Glue Ear app (could include a hearing loss stimulation)
- Compare costs of watchful waiting/grommets surgery in relation to bone conductor hearing aids
- Get health professionals to run clinics that parents would attend to get support
- We (Teachers of the Deaf) provide advice for families and settings for when children have a temporary hearing loss, but this may not always be the case due to a lack of resources or funding. If funding is cut again this would have to be reviewed.
- There seems to be a push for education services not to have much involvement with temporary hearing loss and that it will be left to health professionals. Schools and families do not agree with this.
- Bone conduction aids have been really successful. Hearing aids are unreliable and bone anchored hearing aids are too expensive. The funding for this resource is not in place however.
- Grommets surgery seems to be becoming less popular. Without this intervention, children need help
  with fluctuating hearing loss and bone conduction aids offer a good solution. No one seems keen to
  address this issue.
- Send information to mainstream primary schools (e.g. posters and leaflets) to promote awareness on temporary hearing loss.
- Used to fit hearing aids for children with temporary hearing loss but families didn't look after the aids (lost them or did not return them. This was too costly to maintain so hearing aids have been

withdrawn from our audiology service despite growing numbers of children with temporary hearing loss.

- Campaign to get all reception classrooms fitted with a soundfield system might be helpful
- Very little research published for audiologists on how best to fit amplification for temporary hearing loss.
- An increased waiting time for grommets has a knock on effect to the number of children being seen in audiology and fitted with temporary hearing aids, and therefore on audiology waiting times.
- I'm not sure that we can term middle ear problems as temporary when sometimes they are not. We have many children on our register who have ongoing middle ear problems throughout their school life. They are supported equally to the children who have a permanent HL.
- GPs tend to dismiss parental concerns about the reduced hearing especially if otoscopy reveals no inflammation of the outer ear or tympanic membrane.
- Ensure families get enough support from local services following diagnosis. A questionnaire or monitoring protocol regarding glue ear for families to monitor children would be useful.