Experiences of young people with mild to moderate hearing loss:

Views of parents and teachers

May 2015

Sue Archbold, PhD, Zheng Yen Ng, MA, Suzanne Harrigan, BSc, Sue Gregory, PhD, Tina Wakefield, BSc PGCE, Lynda Holland B Ed, Imran Mulla, PhD

There were no conflicts of interest to declare.

Acknowledgements: This study was funded by National Deaf Children’s Society (NDCS). We would like to thank the parents of children with mild to moderate hearing loss and professionals who work with them for their help and participation.

Ethical considerations: this study asked the views of parents and professionals, not patients, and did not ask for clinical data. Data was kept in compliance with the Data Protection Act.
Executive summary

This research explored the experiences and views on children and young people with mild or moderate hearing loss from the viewpoints of parents and teachers using online questionnaires with open and closed questions, and interviews. 614 parents of children and young people with mild or moderate hearing loss responded to the survey. The children and young people represented a range of ages, educational and communication backgrounds and needs. 166 teachers who are involved with the education of children and young people with mild or moderate hearing loss responded to the survey.

For both groups, a high level of thoughtful open responses were given, which underwent analysis. Many respondents indicated that they would be willing to take part in further research. Following this, 12 parents and 14 professionals were interviewed.

The main issues which arose were:

- The terms “mild” and “moderate” used to describe the hearing loss do not describe the impact described by parents and professionals at home and school.
- There is a bigger impact of mild/moderate hearing loss on family and education than generally recognised by others.
- Children and young people with mild/moderate hearing losses in school have to use greater levels of effort than generally realised.
- Mild/moderate hearing loss frequently has a social and emotional impact on the child or young person.
- Family adjustments are often required to meet the needs of the child or young person with mild/moderate hearing loss.
- 60% of parents felt that they wanted more support for their child: they most commonly wanted more individual 1-1 support in education.
- When asked about information, 66% of parents considered that the child’s teacher or form tutor had sufficient information about hearing loss.
- There is a major lack of deaf awareness in mainstream schools for children and young people with mild/moderate hearing loss in particular.
- Children with mild/moderate hearing loss experience diagnosis and fitting of aids later than in other groups, with an apparent lack of care pathway and liaison between professionals.
- There is a need for parents of children and young people with mild/moderate hearing loss to be particularly pro-active: parents were unaware of the roles of teachers of the deaf and teaching assistants.
- There is an increasing use of technology, including bone-conducting hearing implants, for children and young people with mild/moderate hearing loss and there is a need for up to date information and training for those working with them, including audiologists.
- While hearing technologies are very effective in this group, they may appear not to need them, and appear to “hear” without them. This can lead to confusion for them and their parents and teachers and possible non-use in later years.
• The impact of fluctuating, conductive losses and unilateral losses are often not recognised.
• Parents and young people valued support groups for families and young people with mild/moderate hearing losses; their needs may be different to those of the profoundly deaf.
• With financial and service cutbacks and prioritisation of services, there appears to be a particular impact on support for children and young people with mild/moderate hearing loss.

This report demonstrates a need for:
• Parents and young people to have access to more information about the potential impact of mild and moderate hearing loss and the support that may be available to support them and how it can be accessed.
• Teachers to have greater awareness of the impact that mild and moderate hearing loss can have and the steps that they need to take to, for example, improve listening environments and deaf awareness within the classroom and ensure better access to hearing technology.
• Local authorities to ensure that services are sufficiently resourced to provide the necessary support for children with mild and moderate hearing loss.
• NHS England to ensure that there is a clear care pathway for children with mild/moderate hearing loss and that families receive appropriate, timely support and are signposted to support groups and specialist education services for deaf children.
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1. Background

The implications of mild or moderate hearing loss may be underestimated in spite of an increasing amount of evidence to illustrate its impact on educational performance (Bess, Murphy, & Parker, 1998; Cone, Wake, Tobin, Poulakis, and Rickards, 2010; Most, 2004). Evidence, including from NatSIP (2013) suggests that in some cases, children with severe/profound hearing losses may be achieving better educational attainments than those with mild or moderate losses or that children with mild or moderate loss are not doing as well as expected compared to other deaf children. This is borne out by anecdotal evidence from some specialist education services for deaf children.

Children with a mild or moderate hearing loss may be seen as having only minor difficulties, and thereby risk being overlooked. O’Neill, Arendt & Marschark, 2014 found that these children are likely to develop spoken language, and to be intelligible to their teachers and hence not to be identified as having major issues related to hearing loss. They may mishear at times in the classroom, have smaller vocabularies, and have greater difficulties in listening over distance and in noise than their hearing peers to understand the information; all of which may have a significant impact on the learning experiences and educational achievements (Moeller et al, 2007; Cone, Wake, Tobin, Poulaki, & Rickards, 2010; O’Neill, Arendt, & Marschark, 2014; Marschark et al 2015). The impact of hearing loss has been shown to affect the language and reading (Dellage & Tuller, 2010; Moeller, Tomblin, Yoshinaga-Itano, Connor, & Jerger, 2007), particularly the vocabulary development (Davis, Stelmachowicz, Shepherd, & Gorga, 1981; David, Elfenbein, Schum, & Bentler, 1986; Wake, Hughes, Poulakis, Collins, & Rickards, 2004), and also pragmatic and social skills (Most & Peled, 2007; Wolters, Knoors, Cillessen, & Verhoeven, 2011).

In addition, there are difficulties in identification and they may be more likely to be later diagnosed, or not at all. Research has suggested that this group is under-researched as compared to groups with more considerable losses, because they have not been the focus of early intervention, and there are technical difficulties with regard to the identification of the more mild losses (Cone-Wesson et al. 2000; Russ et al., 2002; Bamford et al., 2005; Johnson et al. 2005). Furthermore, there have been concerns that those with milder hearing losses are not being identified in the universal new-born hearing screening (UNHS) programmes (White & Muñoz, 2008), although UNHS does contribute to the identification of many children with mild hearing losses and increasingly children are younger identified (Fitzpatrick et al., 2014). After children with mild to moderate hearing losses have been provided for their basic management
such as hearing aid fitting, Antia et al. (2009) found that there often seems to be a lack of support for these children. In their Scottish study, O’Neill, Arendt, and Marschark (2014) found that more support is given on average per week to those with severe hearing loss and profound hearing loss than those with mild to moderate losses. They also found that communication between the school, including teachers, and the parents is often very little or inadequate.

In times of financial challenges for educational services, and where services are being prioritised, evidence is required from their parents and teachers on their perspectives and experiences of the impact of a mild/moderate hearing loss at home and in the classroom, and how these children and young people can best be supported. This study addresses these issues, through questionnaires and interviews of parents and teachers. The findings of the study can inform parents, teachers and other professionals about the impact of mild to moderate hearing loss on the lives of children or young people with mild to moderate hearing loss, their needs, the support they receive and their views and recommendations for the future.
2. Methodology

The current study consisted of two parts: online questionnaires and interviews. The study was conducted by a team of three Teachers of the Deaf (ToDs) and a speech and language therapist (SLT), a neuro-linguist researcher and advised by a psychologist and an audiologist. The first part of the study entailed online questionnaires to investigate the experiences of children and young people with mild or moderate hearing loss; one questionnaire for parents and one questionnaire for professionals: Teachers of the Deaf including Heads of Services (HoS). The surveys were designed to explore the impact of a mild or moderate hearing loss at home and school, ways in which children and young people with mild to moderate hearing loss, parents and teachers are currently supported, their views on their needs and their views on future support for the children and themselves. The surveys contained both open and closed questions. Before dissemination, the surveys underwent several iterations; these were carefully drafted, piloted, reviewed and revised to account for balanced questions and to remove ambiguous questions. Parents from across the United Kingdom were approached through National Deaf Children’s Society (NDCS) database, and teachers from across the United Kingdom were approached through The Ear Foundation Research Forum database, NDCS database, The British Association of Teachers of the Deaf (BATOD) ToD list, notice board and Facebook page, and the Heads of VI and HI Support Services (HOSS) forum. Parents and professionals were asked to complete the questionnaires on Survey Monkey. The surveys were placed online for approximately two weeks to be digitally completed within this timeframe. 614 parents and 166 professionals filled in the online questionnaires.

The second part of the study consisted of in-depth interviews with 12 parents and 14 professionals. The aim of the interviews was to explore further specific issues which emerged in the questionnaires, with probes, but also to give the interviewees the possibility of bringing up fresh perspectives into their experiences at home and in education, and what is needed to facilitate educational progress. One interview schedule was developed for the parents, and a different interview schedule for teachers. The interview schedules were developed by professionals in the fields of education, research, and speech and language therapy. The schedules were reviewed by experienced researchers and other professionals. The participants were selected from those who volunteered to be interviewed in the survey and agreed to be involved in further research. A prerequisite for the interviews was that the parents and professionals had completed the online survey, to allow for in-depth responses. The interviews were carried out by two professionals in the field of education and one professional in the field.
of speech language therapy. Care was taken by discussing the methodology and the interview schedules in order to minimise variation in interview techniques. Audio recordings and copious notes were made during the interviews. Furthermore, information sheets, informed consent forms and assent forms were collected. Parents were interviewed at home, and professionals were interviewed in places of work.

The data was collected online and from the interviews. The responses of the online questionnaires were exported from Survey Monkey and analysed in Excel. The audio files of the interviews were transcribed for analysis, and combined with the notes for analysis. The quantitative responses were analysed, and the qualitative responses were analysed with the transcripts from the interviews. The qualitative responses were analysed for themes and subthemes in order to find the emergent issues from the data, using Grounded Theory methodology (Glaser and Strauss, 1967). These themes were discussed and were refined. Finally, research member of the team who had not carried out the interviews read the transcripts and the emergent themes were further refined. Some questions gave the parents and professionals the opportunity to identify differences between the groups (mild; moderate), but for clarity we report the groups together, unless there were clear differences to report. The definitions given for the degree of hearing loss were: 1) mild hearing loss is considered an average loss of 25-40 dB and 2) moderate hearing loss is considered an average loss of 41-70 dB. The option of a category of mild-moderate was requested and used where there was uncertainty about the loss, or in unusual configurations. The definitions given for type of hearing loss were: 1) conductive hearing loss is considered hearing loss due to blockage, rupture or difference in structure in the middle ear, ear canal or outer ear; 2) sensori-neural hearing loss is considered hearing loss due to damage in the inner ear or central processing centres of the brain.
3. Results

3.1. Demographic information
The mean age of the children at the time of the questionnaire was reported by parents to be 8 years 2 months with a range from 2 months to 18 years 3 months. 48% of the children were female and 52% male. Mean reported age at identification of hearing loss was 2 years, 10 months with a range of birth (0) to 16 years.

Parents were asked about their child’s specific hearing loss and the following tables (1-4) summarise their responses.

Table 1. Degree of hearing loss (n = 577)

<table>
<thead>
<tr>
<th>Degree of Hearing Loss</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>10%</td>
</tr>
<tr>
<td>Mild-moderate</td>
<td>43%</td>
</tr>
<tr>
<td>Moderate</td>
<td>46%</td>
</tr>
<tr>
<td>Do not know</td>
<td>1%</td>
</tr>
</tbody>
</table>

Table 2. Type of hearing loss (n = 581)

<table>
<thead>
<tr>
<th>Type of Hearing Loss</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conductive</td>
<td>25%</td>
</tr>
<tr>
<td>Sensorineural</td>
<td>49%</td>
</tr>
<tr>
<td>Mixed</td>
<td>11%</td>
</tr>
<tr>
<td>Do not know</td>
<td>15%</td>
</tr>
</tbody>
</table>

Table 3. Is the hearing loss permanent or temporary? (n = 579)

<table>
<thead>
<tr>
<th>Status</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Permanent</td>
<td>78%</td>
</tr>
<tr>
<td>Temporary</td>
<td>9%</td>
</tr>
<tr>
<td>Do not know</td>
<td>13%</td>
</tr>
</tbody>
</table>

Table 4. Condition of hearing loss (n = 580)

<table>
<thead>
<tr>
<th>Condition</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stable</td>
<td>55%</td>
</tr>
<tr>
<td>Deteriorating</td>
<td>9%</td>
</tr>
<tr>
<td>Fluctuating</td>
<td>29%</td>
</tr>
<tr>
<td>Do not know</td>
<td>10%</td>
</tr>
</tbody>
</table>

With regard to grommets, 9% had grommets currently, and 33% had had grommets in the past. 88% of the children were fitted with hearing aids, with 84% of those having two. The average age of fitting hearing aids was 3 years and 10 months with a range from 1 month to 16 years. 7% had bone conducting hearing implants (BCHIs), but often called BAHA, or soft band, with 40% of those having two. The average age of fitting of BCHI was 4 years 2 months with the oldest being 12 years of age.
11% were reported to use another language at home: 12 used British Sign Language and the rest other spoken languages. Thinking about education, parents were asked about where their child attended school and the following table provides details (see Table 5). The majority of children attended mainstream provision.

Table 5. Education provision (n = 557)

<table>
<thead>
<tr>
<th>Provision</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mainstream</td>
<td>86%</td>
</tr>
<tr>
<td>Resource Base in mainstream school</td>
<td>4%</td>
</tr>
<tr>
<td>School for the Deaf</td>
<td>1%</td>
</tr>
<tr>
<td>Other Special School</td>
<td>3%</td>
</tr>
<tr>
<td>At home</td>
<td>6%</td>
</tr>
</tbody>
</table>

When asked whether their child had disabilities or any special educational needs other than a hearing loss (n = 574), 35% responded yes, which is in line with the known figures. Of these, the most common difficulties were learning difficulties (46%), and language and speech difficulties (46%), see Figure 1.

Figure 1. Reported additional difficulties (n = 210)

The professional questionnaire was distributed to teachers, and of the 166 respondents, 93% were qualified Teachers of the Deaf, and 72% were peripatetic/visiting Teachers of the Deaf. Other roles included heads of services, other special school teachers, and mainstream
teachers. The respondents had a wide range of experience, with an even distribution of contact over the entire age range, and range of mild and moderate hearing losses. When asked if they worked with children with fluctuating conductive hearing losses, 82% answered that they did.

The information from the questionnaires of parents and teachers, of both the open and closed questions, and the analysis of the interview transcripts of both parents and teachers led to the following themes and subthemes (please see Table 6).

Table 6. Themes and subthemes of the impact of mild-moderate hearing loss from the perspectives of parents and professionals.

<table>
<thead>
<tr>
<th>Themes</th>
<th>Subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impact on family</td>
<td>Diagnosis</td>
</tr>
<tr>
<td></td>
<td>Lack of recognition and impact</td>
</tr>
<tr>
<td></td>
<td>Emotional impact: on family and child</td>
</tr>
<tr>
<td></td>
<td>Challenging situations</td>
</tr>
<tr>
<td></td>
<td>Family adjustments</td>
</tr>
<tr>
<td></td>
<td>Managing the technology</td>
</tr>
<tr>
<td>Impact on education</td>
<td>Listening in difficult conditions</td>
</tr>
<tr>
<td></td>
<td>Lack of recognition and awareness</td>
</tr>
<tr>
<td></td>
<td>Speech, language and learning</td>
</tr>
<tr>
<td></td>
<td>Social and Emotional impact</td>
</tr>
<tr>
<td></td>
<td>Educational assessment and outcomes</td>
</tr>
<tr>
<td></td>
<td>Family and professional roles and relations</td>
</tr>
<tr>
<td>Educational support</td>
<td>Referral to educational support</td>
</tr>
<tr>
<td></td>
<td>Support in school</td>
</tr>
<tr>
<td></td>
<td>Support by ToD</td>
</tr>
<tr>
<td></td>
<td>Support by Teaching Assistant</td>
</tr>
<tr>
<td>Audiology and technology</td>
<td>Referral to audiology</td>
</tr>
<tr>
<td>management</td>
<td>Audiology visits</td>
</tr>
<tr>
<td></td>
<td>Fluctuating losses</td>
</tr>
<tr>
<td></td>
<td>Use of aids</td>
</tr>
<tr>
<td></td>
<td>Use of Assistive devices</td>
</tr>
<tr>
<td>Looking to the future</td>
<td>Deaf awareness training</td>
</tr>
<tr>
<td></td>
<td>Peer group support</td>
</tr>
<tr>
<td></td>
<td>Information and resources</td>
</tr>
<tr>
<td></td>
<td>Technology training and management</td>
</tr>
</tbody>
</table>
The results of the questionnaires and interviews are now provided under these themes. Where quotes are used, it is indicated whether it was a parent or teacher, and whether it was from a questionnaire open response, or by in-depth interview.

3.2. Impact on family

3.2.1. Impact of diagnosis

The average age of diagnosis of these children was 2 years 10 months, with some being diagnosed as teenagers, the oldest being 16 years. Wood et al. (2015) report the mean age of confirmation of deafness in the 2012/13 cohort of children screened (and likely to be born deaf) as being 49 days, and the mean age of hearing aid fitting in that group being 82 days. For the mild/moderate group we explored, parents reported the mean age of hearing aid fitting to be 3 years 10 months, a considerable difference. About half of deaf children are born deaf, and half have acquired deafness; this can create uncertainty about when children may become deaf and this may account for some of the delays.

Those whose child hadn’t been aided earlier often wished that they had:

- “I wish [name] was aided from a toddler!! He is now very behind in his learning at least 3-4yrs. We just never knew he couldn't really hear.” (Parent Survey)

When parents were asked if they were aware of the hearing loss before diagnosis, 39% commented that they were, but 61% did not realise their child was deaf. When asked about cause of hearing loss, the majority (20%) of the 488 respondents did not answer, and the next largest category was unknown (15.5%). Thus there was no response for the cause of deafness for 35.5% of the respondents. Whether this is because there was no diagnosis possible, or whether parents did not know what it was, is not clear. Otherwise, glue ear, followed be genetic causes, premature birth and syndromes were the most common causes.

Experiences of confirmation and diagnosis were varied; some children had passed the newborn hearing screen and diagnosis had taken longer, whereas others had failed screening but still the route had not been straight forward, and there appeared to be no clear pathway for these children. For some parents, where the child had acquired deafness, it had been difficult to convince professionals that their child had a hearing loss, when they had passed the screening test.

- “Failed newborn test and 15 subsequent hearing tests but people said he wasn't concentrating on test....” (Parent Survey)
- “I had always assumed that they had just passed it because their hearing was good enough.” (Parent Interview)
- “From birth she never startled, failed her newborn test twice before passing.” (Parent Survey)
- “Since birth I had concerns even though he passed the newborn tests.” (Parent Survey)
In the interviews of parents, the responses to the question about diagnosis received the longest and fullest responses, often revealing a great deal of frustration, and the need for parents of these children to be proactive, particularly as many had passed newborn hearing screening.

- “He was identified at birth as having a hearing loss but we didn’t know about the hearing loss level until he was 8 months old. .... we were pretty much told to go away and interact with him as a baby and ....we will see how he is doing....he was 8 months and... fitted when he was 9 months old.... with his hearing aids in he is pretty much on par, he is really good because he keeps them in all the time.” (Parent Interview)
- “From birth my son never passed newborn screening after repeated screening and my husband and I getting angry it was confirmed.” (Parent Survey)
- “I would say you have to push and push and inform yourself unfortunately. You have to do all the reading and you have to advocate for your child. It is unlikely that any one else will do it. You will be lucky if you find someone who does.” (Parent Interview)

This appeared particularly true if the child had a fluctuating hearing loss.

- “since [name] was born he never passed a hearing test but they were saying not to worry because he’s got glue ear. Then when he was 15 months old they said it isn’t going to be fixed!” (Parent Survey)

For parents, the diagnosis remained fresh in their minds:

- “I cried my eyes out and it was on mine and my husband 10th wedding anniversary. .... and it was just a shock, that your baby is partially deaf, but once you get over the initial shock we were fine... and make sure he has a good time growing up and is treated the same as the rest of the children.” (Parent Interview)
- “Grieve, have a grieving moment, because if you don’t you are still going to be in that shock state for a long time. Grieve, have your moment and then just carry on really.” (Parent Interview)
- “I was sat in a plastic chair and they broke the news that my child was deaf in one ear... the surgeon was lovely, but there was nowhere for me to take her to.....” (Parent Interview)

For another mother, the shock was so great that she felt it all happened too quickly:

- “So we were told very quickly about her hearing loss by the audiology consultant and were told she had to wear hearing aids. It was permanent. It was the biggest smack in my face.” (Parent Interview)

Being given too much information too quickly was also not always helpful:

- “What on earth were these pictorial audiograms? .......I was definitely in denial at this point....” (Parent Interview)
Some emotional support would have been helpful, and to be put in touch with organisations such as the National Deaf Children’s Society (NDCS) or the Ear Foundation. Those parents with conductive losses particularly felt “abandoned”:

- “Just more on the emotional, practical side, ....You go into hospital and they tell you ‘yes she has got this hearing loss, but there is not much we can do about it’ and then you are sent home for 3 months... It would have been lovely if the hospital had put us onto the NDCS or The Ear Foundation” (Parent Interview)

It may be that for professionals working with the range of hearing losses regularly, a mild to moderate loss does not seem so significant, but it clearly was for these parents. However, parents gave the message that it was important to get on with it.

- “It’s not as bad as it might feel and it’s ok to feel, even with a mild or moderate hearing loss, that your world has come to an end, but as a parent you are at the mercy of your child. It means as a parent you have to work harder and just accept that it’s going to require some very proactive parenting, but it gets easier. It gets so much easier.” (Parent Interview)

Where diagnosis came after a long time of parental suspicion, it could come as a relief, particularly when hearing aids were seen to make a huge difference (as in this case, fitted at aged three):

- “I was relieved. As I say I suspected for a while, and it was nice once she had got hearing aids to be able to communicate much more with her, because she would get so cross because she couldn’t hear thing properly.” (Parent Interview)

And for another parent:

- “Well I wish they had been diagnosed earlier. Going back to that GP who said they are fine. I think if there was some more education about the fact that you might have a moderate hearing loss, that doesn’t present obviously and is picked up at birth - I don’t know if most GPs know about that.” (Parent Interview)

However sometimes a moderate loss, and the child apparently “hearing”, could complicate adjustment for the family. One teacher commented that:

- “family acceptance of hearing loss and the need for amplification can be a challenge for some families...” (Professional Survey)

For another parent, who had two profoundly deaf children, having a child with a moderate loss had been different, and she felt he didn’t quite “fit”, as she discussed in her interview, and she felt this problem was greater now that he was a teenager.

For those who are diagnosed later, as an older child or young person, this can mean a difficult adjustment, as the young person is unlikely to relate to deafness, although actually having a
hearing loss, and apparently being able to “hear” can lead to the misunderstanding that their issues are not real.

3.2.2. Lack of recognition and impact

The terms mild and moderate imply little impact of the hearing loss, but the results of both questionnaires and interviews repeatedly reveal that this is far from the truth. Both parents and teachers gave many examples of this, both from the family perspective and from the educational perspective. One parent explored this in her interview:

- “I would say we were most vulnerable when we thought it’s mild to moderate, its only little, and we did think... its nothing, and we were only told its only mild to moderate you will be fine. No, mild to moderate deafness, he is still deaf.” (Parent Interview)

Others said:
- “The term mild - does not reflect the difficulties some children have. Needs can be over looked in schools especially if not aided. Poor acoustics and listening conditions. Often acceptance issues, child does not want to identify with deafness.” (Professional Survey)
- “There is an assumption with many that mild deafness is not a big problem which is contrary to the truth” (Professional Survey)
- “It is difficult because it is not a disability that people see or understand....” (Parent Survey)
- “Most people don’t get it. They think because she responds that her hearing is fine (she heard that being a favourite comment).” (Parent Survey)

Another teacher explained in an interview the dangers of looking just at the audiogram:

- “Well again, you can look at an audiogram on a mild or moderate ..... and you might think it makes very little difference, and I have had children where I have thought that’s not going to make a difference at all, and actually it has made a huge difference, and I think the hardest thing is to convince the parents...... because these children do hear, they will hear clattering, banging doors, .... they say they can hear their name, but it might not be their name they are hearing, it might be the intonation....” (Professional Interview)

3.2.3. Emotional impact on the family and child

Many parents reported challenges with low self-esteem and lack of confidence, in playing with friends and siblings, and with isolation experienced. Comments included:

- “Lowered self esteem” (Parent Survey)
- “Find it difficult to ... keep up with play with other children.” (Parent Survey)
- “He gets frustrated if he misunderstands what people say” (Parent Survey)
- “She has a significant delay in speech and language. Her social behavioural skills are not so good too. We find it difficult to go to public leisure centres for example as my
daughter is weary of unfamiliar people. Really difficult on public transport. She gets frustrated when she is not understood at home.” (Parent Survey)

- “Can’t always contribute to conversations, finds hard to concentrate if background noise, affects moods if doesn’t have aids in.” (Parent Survey)
- “He gets very frustrated and extremely emotional…” (Parent Survey)
- “She finds it hard sometimes to listen and understand instruction she finds it very hard to calmly deal with her younger brother and sister.” (Parent Survey)

Further examples are given in the next section about challenging situations.

### 3.2.4. Challenging situations

When parents were asked about the impact of mild/moderate hearing loss on their child at home or when engaging in leisure activities, they clearly differentiated between the scenarios given (see Figure 2).

![Impact at home or in leisure](image)

**Figure 2. Impact of hearing loss at home or in leisure in different situations**

The greatest impact of hearing loss was felt in sporting activities, joining in family conversation or group activities, and when playing with friends. Most of the respondents considered the impact was moderate. The parents’ 489 open responses support this, with many thoughtful responses, illustrating the impact and adjustments by families, including siblings.
3.2.5. Family Adjustments

Parents gave examples of where they made adjustments in their family activities to address these challenges, recognising that the child with a hearing loss may miss out in some situations. The majority of parents gave examples as to how they had adjusted family life and addressed the “Huge impact on daily life...” as one parent put it (Parent Survey).

- “normal activities need to be adjusted to accommodate him especially if its something new we are doing.” (Parent Interview)
- “I think we shout as a family as the volume has gone up over the years. TV is loud. We can all get frustrated we can’t hear each other. Thankfully hearing aids make a difference.” (Parent Survey)
- “We are very aware of background noise, particularly in the kitchen. We invested in the quietest dishwasher, the quietest oven, because you know those are things that constantly go on in everyday life, and we are very aware that whenever there is a television on as well, we need to make sure that [she] has heard us.” (Parent Interview)
- There are frustrations with her sister, her sister gets frustrated if [she] doesn’t hear and that ends up in siblings’ arguments. Sometimes to be spiteful her older sister will shout at her and [she] will get very cross and she says ‘you don’t need to shout at me’ but generally we have all taken it on board.” (Parent Interview)
- “We make sure the washing machine or dishwasher is done at a different time when he is home and awake. .....and the tv is not on in the background.” (Parent Interview)
- “as he is our third child this limits his ability to do activities with other children....” (Parent Survey)

The difficulties in following family conversations and needing to remember this:

- “he relies on family members to relay messages to him if he’s out of sight or upstairs... can’t just shout up to him.” (Parent Survey)
- “Difficult for him to follow group conversations eg round the dinner table.” (Parent Survey)

With regard to sporting activities, swimming was the most commonly mentioned, with the problems experienced when hearing aids are removed. For example:

- “we don’t go swimming as she can’t hear and becomes frustrated...” (Parent Survey)
- “swimming is the biggest challenge....” (Parent Survey)

It is interesting to note, that while there has been huge effort to make cochlear implants waterproof, little or no attention has been paid to this issue for hearing aids.

3.2.6. Managing the technology

Where children seemed to have little impact from their hearing loss at home, it was often related to the effective use of hearing aids:
• “Very little (impact) as my child has worn hearing aids from being a baby.” (Parent Survey)
• “Hearing aids must be fully working....” (Parent Survey)
• “I think the impact of the moderate hearing loss of my child at home is not good if she hasn't got her hearing aid on.” (Parent Survey)
• “Only issues are in activities where she cannot wear her hearing aids eg swimming...” (Parent Survey)
• “Not much, only in a practical sense, e.g. batteries running out or fear of damaging hearing aids” (Parent Survey)
• “I would say embrace hearing aids they are your friends.” (Parent Interview)

For this group, hearing aids were cited as extremely helpful in the majority of cases. However, as children grew older wearing them was reported as more of an issue, particularly as the children could “hear” without them. Where Teachers of the Deaf had demonstrated the value of the hearing aids to children and young people with functional hearing tests, this was considered of immense value.

When parents were asked what use they made of additional technology at home or in leisure, Only 12.7% of the respondents commented that a radio aid was in use at home; why this was the case is not certain. However, the majority used radio aids at school, and there appeared to be a problem of funding for FM systems at home, for example:

• “No, but do need a radio aid. I have to somehow find the money for this....” (Parent Survey)

Other technology commented on were loop systems, flashing doorbells and alarms, vibrating clocks.

3.3. Impact on education
Parents’ questionnaires and interviews indicate that they feel the impact of their child’s hearing loss is greater on education than at home. We asked parents their views about the impact of mild/moderate hearing loss on their child’s education.

The following figure illustrates that they consider the only area where there is little impact is in talking one to one, which is the least common situation in school. Over 40% of respondents rated there being a major impact in all other areas, including both in work and in social situations and they rated the impact on education as being greater than that at home.
Figure 3. Impact of hearing loss in education in different situations

Some children learned to hide their difficulties, “going along with things” or “using her cleverness to disguise it”, adding to the lack of recognition of its impact. 459 parents provided very full open responses and the most common words used were: huge, massive, and significant. Typical comments included:

- “It impacts massively on his education as he is unable to tell that he has not heard properly or has missed something.” (Parent Survey)
- “Profound. Starting nursery at three was a nightmare. My daughter’s behaviour can be disruptive. .....entering play with others is fraught with difficulty when you can’t hear what is going on.” (Parent Survey)
- “Major. Has had to be taken out of two schools as he couldn’t keep up in background noise....” (Parent Survey)
- “Huge. She has to concentrate extra hard to hear which is very tiring.” (Parent Survey)
- “Big impact. which is how we picked up severity and why he has aids...” (Parent Survey)
- “Huge. The ToD visits and supports with seating arrangements etc, but my daughter feels very different due to the need to wear aids and hates this....” (Parent Survey)
- “I have felt my daughter spent a long time at the start of her education just being lost in the crowd.” (Parent Survey)
- “Massive. He is underachieving academically and socially in the school environment.” (Parent Survey)
For several parents home tuition or a change of school had been required, but one parent in particular commented on how specific teaching strategies had had a positive impact on her son:

- “a year ago he would not even look people in the face. But now with one-to-one at school and some superb teaching he is standing up in class and presenting in large groups and enjoying it.” (Parent Survey)

For a few parents, they did not consider the hearing loss had caused a massive impact on education; this seemed to be the case where hearing aids were worn and seen to make a difference, where parents were pro-active, and school and teachers working together.

- “At the moment not much (of an impact). She has great teachers, who in turn get good support from the visiting school service.” (Parent Survey)
- “We do extra work at home to ensure he keeps up.” (Parent Survey)

When we asked teachers what the main challenges were for these children, we gave them the option of open responses, and received thoughtful responses. Analysis of the 135 respondents revealed the most commonly mentioned challenge was poor acoustics and background noise and understanding speech at a distance (spontaneously mentioned by 69%), followed by staff deaf awareness (33%) and speech, language and literacy development (23%). Other issues mentioned were child and parents’ deaf awareness, language access in the classroom, seating arrangements, social and emotional development and fluctuating hearing losses. One teacher summarised it thus:

- “children with mild/moderate hearing loss can be lost in the school system as they don’t always outwardly appear to have a learning need.” (Professional Survey)

### 3.3.1. Listening in difficult conditions

While the value of hearing aids came through strongly in the responses, parents were aware of the difficulties of listening in difficult conditions in school and it was the major issue. Listening in background noise and in groups were the most commonly mentioned with recognition of the limitation of hearing aids in groups and in noise. These examples, from parents, highlight that hearing aids can be both helpful and unhelpful:

- “In any situation where she is unable to lipread i.e. several people talking at once, or in a noisy environment her hearing aids become more a negative than a positive.” (Parent Survey)
- “When everyone is in a group it is difficult to hear.” (Parent Survey)
- “Assembly overwhelming and switches off hearing aids as he can’t cope.” (Parent Survey)
- “Learning is very difficult as the classroom is noisy, lots of chattering. My daughter relies heavily on lip reading making group work difficult.” (Parent Survey)
- “unable to follow teaching properly especially with background noise disturbance - even with using radio aids and sound field mishears and often misunderstands what is said” (Parent Survey)
• “struggles in even moderately noisy classroom environment due to background noise. Can’t manage to keep up in classroom discussions due to impossibility of lipreading more than one person at a time” (Parent Survey)

When teachers were asked what the main challenges were for these children, listening in background noise and in poor acoustic conditions were also most commonly mentioned by the respondents. For example:

• “Accessing teaching in a noisy environment.” (Professional Survey))
• “background noise with more than one person talking....” (Professional Survey)

The physical arrangements of classrooms were mentioned too; for example, teachers providing support in mainstream schools commented on unsatisfactory acoustics, even in new buildings:

• “Open plan classrooms...” (Professional Survey)

The classroom organisations didn’t always lend itself to satisfactory access to the curriculum:

• “noisy classes, not always being seated appropriately because of swapping around in groups.” (Professional Survey)
• “Working in physical environments that are not always suitable for children with a hearing loss, staff not always remembering strategies advised - so children missing instructions & key language” (Professional Survey)
• “Many of them will have had experience of parents and teachers telling them “they can hear when they want to” because people are ignorant of the effect of different acoustics and also the level of concentration required to listen with a hearing loss. .... The child in this situation, who thinks they are hearing ok, but need to concentrate hard to hear, may just think they are not good academically. Sadly the adults in their lives might come to that conclusion too. It is a hidden problem often so people jump to the most obvious conclusion that the child’s potential is below the norm. That becomes a self fulfilling prophecy.” (Professional Survey)
• “Accessing speech in the noise of a classroom. Levels of cognitive demand required to listen to learn in various listening conditions of classrooms” (Professional Survey)

3.3.2. Lack of recognition and awareness

Lack of recognition of the impact of mild/moderate deafness in school occurs again and again in the responses from both parents and teachers, with the terms themselves causing difficulties: one teacher in her interview commented “mild and moderate disguises the difficulties that some of these young people can have.” Another teacher commented that “the amount of hearing loss does not define the child.”

• “The term mild – does not reflect the difficulties some children have. Needs can be overlooked in schools especially if not aided. ..... often acceptance issues, child does not want to identify with deafness.” (Professional Survey)
• “There is an assumption with many that mild deafness is not a big problem which is contrary to the truth....” (Professional Survey)
• “Yes, but even more so for children who may be struggling, and all those people who may be undiagnosed mild losses, so I think it’s a group that are often overlooked and I think it needs some form of additional or different descriptor and people will appreciate the problems that these young people can have.” (Professional Interview)

The fact that the children can appear to hear without their aids adds to the lack of recognition of their issues in school: comments by teachers included “Wearing their hearing aids and feeling that they don't need to, in many cases” and “mild moderate loss children often don't wear their aids as they see it as unhelpful, they can 'hear' without it”. This can make it challenging for parents and teachers of the deaf to ensure that mainstream teachers are aware of the child’s needs. One teacher expanded in an interview:

• “If they are not wearing aids, then even if the young person and the school were aware, often the description that is used – so we are talking about the mild and moderates – I think that actually causes its own problem when mainstream class teachers are now dealing with so many different groups of young people with additional educational needs in their mainstream school and when they are told that a child has a mild hearing loss it gives the wrong impression. Sometimes we really have to promote the difficulties that that young person may experience to help class teachers realise the significance.” (Professional Interview)

The lack of understanding of the mainstream teachers, the lack of deaf awareness, and of recognition of a mild/moderate hearing loss were also cited as real issues in schools by teachers. Communication challenges with the potential for mishearing and misunderstanding without it being obvious were all mentioned.

• “May not realise they are missing out information...” (Professional Survey)
• “He is doing very well but think his school is quite supportive. It could be so different if his school wasn't as good.” (Parent Survey)
• “She is a very bright child, and is often overlooked by some teachers at school because she 'seems to be coping'.” (Parent Survey)
• “Again we are told that she copes so well - and she does...but I feel that her hearing loss is minimized and I am the one that notices her struggle to keep up and I am the one that hears her tell me "she felt lonely today". She is in preschool and I worry about how school will be (as she will start at just turned 4)” (Parent Survey)

Another teacher expanded in her interview that because the benefits of hearing aids may not be apparent, the challenges of difficult listening situations may be overlooked. For example:

• “Just because one day they don’t wear their hearing aids this is what I find from some teachers and TAs with the children with mild and moderate losses and they will say..oh she didn’t have her hearing aids yesterday but she was fine, she reacted the same way.” (Professional Interview)
One teacher in interview commented how useful it had been to make educational psychologists experience mild hearing loss, wearing ear defenders, and how that simple training had changed their perspective. For another parent, the best training she had witnessed was to give teachers and assistants the experience of having a mild hearing loss for a day, which changed their views on the impact of the hearing loss.

### 3.3.3. Speech, language and learning

Both parents and teachers commented on the impact, often unrecognised, that mild/moderate losses have on the development of speech and language, and on learning. A mild/moderate hearing loss affects the ability to ‘overhear’ and to acquire language informally, and the difficulty in picking up information this causes was mentioned: “lack of indirect learning - this has a major impact on education.”

- “I think even if they come across as having good language and being good communicators that you will always find gaps in their language. Often, even the bright ones, even the ones I have who have got good language levels and good literacy skills, if you are working closely with them, you will still come across lots of language that they will not know that hearing children will have more of an idea of it, even if they don’t know exactly they will have more of an idea of it because, particularly those who don’t wear their hearing aids, they are not picking it up incidentally.” (Professional Interview)

For parents, there was a great awareness of the current emphasis on teaching using a phonic approach, and it was mentioned frequently that their children might be at a disadvantage:

- “Difficult spelling, spells as she hears, difficulty following teacher” (Parent Survey)
- “[Name] is a very bright boy but is actually below average in literacy due to the difficulty he has hearing certain sounds/ phonics etc.” (Parent Survey)
- “Phonics a nightmare but no flexibility in teaching.” (Parent Survey)
- “He struggles with reading spelling and his education is not that great but he struggles along” (Parent Survey)
- “I believe he has had some difficulty in hearing initial sounds when learning phonics.” (Parent Survey)
- “His vocabulary isn’t as large as some children his age and he is definitely a visual learner. He isn’t in main stream school but if he was he would struggle with background noise.” (Parent Survey)

Language delay and difficulties in vocabulary, in accessing demanding curriculum language were all challenges these teachers reported in questionnaire and interview. The fast pace of delivery and expected learning at secondary level and “the pace of lessons and vocabulary” were noted as real areas of difficulty for these children.

- “Working in physical environments that are not always suitable for children with a hearing loss, staff not always remembering strategies advised - so children missing instructions and key language, older children feeling self-conscious about using equipment.” (Professional Survey)
- “Language, phonics work and understanding/ hearing what is being asked of them” (Professional Survey)
In interviews, parents had a lot of advice for teachers about having higher expectations of their children:

- “To teachers I would say, just don’t assume that they are reaching their natural level. Always remember that the child does have a disability, and always try to see if you can – not necessarily push them – move them on a step and think they could be doing more. Give them a little bit of thought because they might be no trouble and I think the problem with being a teacher is that you have got so much to worry about you don’t really think about the children who don’t give you much trouble.” (Parent Interview)

3.3.4. Social and Emotional impact

Parents commented strongly on the impact of their child’s hearing loss on the social and emotional aspects of education. Social difficulties and school trips in particular were mentioned:

- “Does not socialise with peers, prefers younger children.” (Parent Survey)
- “lunchtimes and breaks are the most difficult part of her day... she doesn’t mix.” (Parent Survey)
- “she doesn’t mix outside in the playground.” (Parent Survey)
- “misses out on girly whispers...” (Parent Survey)
- “He doesn't make friends easily as he tends to keep himself because other children can’t understand him some times as his speech is not as good as his friends. He’s about 12 months behind on average compared to his class friends. He misses out on things due to him hanging on the outside rather than interacting.” (Parent Survey)

For many, bullying was a major issue, with parents feeling strongly about their child’s experiences and needing to intervene:

- “our daughter was badly bullied and had to change school....” (Parent Survey)
- “My son is beaten up at lunch time everyday.” (Parent Survey)
- “Participating in class, misses out on instructions, low self esteem, bullying from other children.” (Parent Survey)

The very strategies which are encouraged, and maybe fought for by parents and teachers of the deaf to overcome the problems of deafness, can have social and emotional consequences:

- “He feels ostracized for having to sit near the front of the class so that he can hear the teacher” (Parent Survey)
- “I believe that the hearing loss causes a slight lack of freedom.” (Parent Survey)

Tiredness and fatigue due to the amount of effort the child needs to do to keep up with peers, and to follow in class was mentioned by parents in their free responses:

- “Dramatic, in terms of actual hearing, cognitive processing, fatigue, confidence, not receiving additional help in class, peer/group work, vocab.” (Parent Survey)
• “He is often confused about instructions in the classroom and becomes panicked or worried. He relies of following what others are doing and is embarrassed that he cannot hear as well as his classmates.” (Parent Survey)

• “She also has to concentrate so hard she is very tired at the end of the day. Forming friendships is also hard and following what’s going on.” (Parent Survey)

• “On an emotional level her low confidence and self-esteem has an impact on her willingness to, for instance, ask questions. Physically, she has to be positioned well in a classroom so she can lip read as well as listen to teachers.” (Parent Survey)

• “Some have speech and language delay. With some school staff feel the child can hear better than they can - deceptive disability.” (Professional Survey)

Issues with self-esteem came up from both parents and teachers:

• “how would you feel if you went in to pick up your child from school and found her sitting under a table saying “she was no good” just because she knew that she wasn’t the same as others and couldn’t catch up.” (Parent Survey)

• “These children are also more vulnerable to self-esteem issues, as they often struggle with wearing hearing aids (seeing them as something that grandma wears). One of the strategies that seems to help is referring to them as sophisticated technology, like an iphone and making sure they know there is nothing ‘wrong’ with them. They are fine. They just need some new strategies such as wearing a hearing aid or changing position in class.” (Professional Survey)

• “His knowledge is not fully recognised as he is reluctant to speak up during group questions, and he gets frustrated quite quickly when trying to learn something new. Homework always gets stressful no matter how positively we approach it with him.” (Parent Survey)

There were examples where the impact of hearing loss is becoming extreme:

• “Cannot join in all activities, misses out on hearing correct conversations so gets frustrated and has been suspended from school at least 10 times” (Parent Survey)

3.3.5. Educational assessment and outcomes

When parents were asked how they considered their children were doing compared with other children, the majority considered they were behind for their age (Table 7).

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behind their age</td>
<td>47%</td>
</tr>
<tr>
<td>Right for their age</td>
<td>35%</td>
</tr>
<tr>
<td>Advanced for their age</td>
<td>18%</td>
</tr>
</tbody>
</table>

Teachers were asked how the children in the groups compare to hearing children in their area; teachers also considered that this group were performing less well than hearing children.
Increasingly, there is a perception that children with severe/profound hearing loss are achieving better educational attainments than children with mild/moderate hearing loss and teachers were asked for their opinions. Many felt that those with profound losses were provided with greater levels of support and that the needs of those with lesser losses were overlooked and not recognised. Some saw it as being linked to early intervention and early cochlear implantation. In addition there were comments about those with mild/moderate losses being detected later.

Typical comments included:

- “greater input from professionals, great technology, more support.” (Professional Survey)
- “More awareness of the impact of the loss and so more attention given in both in school and at home. May be detected later.” (Professional Survey)
- “I am not surprised...” (Professional survey)
- “Because their needs [profoundly deaf] are easier to define – and there is more statutory requirements regarding support for their learning” (Professional Survey)
- “Cochlear implants and more support.” (Professional Survey)

There was comparatively little in the responses by Teachers of the Deaf about actual assessment or how monitoring was carried out, but where parents had received assessments and advice based on them, they found it helpful, and suggested that more of it would be helpful, particularly in functional listening and in the classroom. Parents felt that this may identify other issues which may be present:

- “I would like a proper assessment of his learning needs by them and others in order to have a more informed view of why he’s falling behind. At the moment, everyone is assuming it’s all because of his hearing loss.....” (Parent Survey)

As one teacher said:

- “An assessment in school by a skilled Teacher of the Deaf who talks to the child, parents and staff and gives appropriate advice and support. The aim should be to get the child to a place where they have well developed skills and good self esteem, so that they are thriving and self sufficient.” (Professional Survey)

However, assessment and outcomes were rarely mentioned in teachers’ free responses and interviews, and one interviewee reported that their service did not keep curricular outcomes on their caseloads.

3.3.6. Family and professional roles and relations

Parents considered it very important that their role was recognised and valued good working relationships. For example, working with a good Teacher of the Deaf, but the parent needed to be proactive:

- “She is there when needed, I recently needed to find out if [name] was entitled to additional time in her mocks and GCSEs. The teacher found this all out and confirmed she was and forwarded this to the relevant persons at the school. However, I had to
"initiate this and chase this and it was not in place as a standard which I rather think it should be. Not all children have a parent who can advocate for them.....” (Parent Survey)

Parents gave many examples where they needed to be proactive and the school had not recognised their child’s difficulties:

For example:

- “School said she was fine, when in fact she was struggling with background noise.....” (Parent Survey)
- “we have spent a lot of time on deaf awareness training from my wife with staff and pupils...” (Parent Survey)
- “they try but don't get it...” (Parent Survey)

Parents also commented on their role in bringing together different professionals, and the importance of finding a professional who listened to them:

- “Generally I find the audiology service very good but audiology had to refer us to the ENT nurse who also was very good, but the communication between departments was horrendous......so basically it took me about 18 phone calls to the hospital to get to this nurse and now she has given me her mobile number......” (Parent Interview)

A teacher in an interview reported the value of the audiologist coming into school to take ear moulds and check technology: there was a value in the mainstream staff meeting the person who managed the child’s hearing loss.

The challenges for parents of bringing together different professionals were true even if the child’s difficulties were apparent, as with microtia. A mother of an 11 month old:

- “I can't even remember the complexities of our trying to chase this, it was like trying to get ourselves referred to the right department of ** and not getting anywhere, and *** weren't doing anything at all. .......so she forwarded to the consultant who said the clinics were full. .....it was supposed to be early intervention is best....” (Parent Interview)

There were a few comments about speech and language therapy for this group, but where there were, it was usually due to parents’ being pro-active:

- “.... (I) kept on being annoying really. The other speech and language therapists didn’t seem to get it.” (Parent Interview)

For many parents, the numbers of appointments could be challenging, particularly when they needed to be proactive:

- “They forget I have to see a doctor, I have to see the audiologist, I have got to get his ear moulds done then there is a follow up to getting his hearing aids reviewed, so every month you are not free to do anything really because it is just appointments, appointments, appointments.” (Parent Interview)
Parents also valued working with Teachers of the Deaf and others, and learning how to help their child:

- “I do sit and watch what they are doing, I take note when they are talking with him and the sounds that they do with him, and see whether he is looking here or what sort of body language that he does. I tend to practise it at home once they have gone, and do the different sounds with him and it seems to be working, so I find whatever they do or whatever they say I take on board.” (Parent Interview)

### 3.4. Educational support

#### 3.4.1. Referral to educational support

The majority of referrals to educational services came from audiologists (over 60%), with very few coming from parents (2%) or schools (4%). The next largest category of response (25%) was “varies”; explanations clarified that referrals were largely from health services in this category. 59% of teachers thought that there were children with mild/moderate losses who hadn’t been referred to them. The reasons they gave for this were varied but included those with temporary conductive losses, those not identified by parents or schools, those being seen by ENT but not aided, and those with complex needs. For example:

- “statistics show that there is a high percentage of SLD children with hearing loss - this percentage is not reflected in pupils who are referred to sensory support and thence to myself. Downs children with conductive losses are often not referred.” (Professional Survey)
- “If they are diagnosed as a profound deafness then it is clear cut that the children will need extensive support from a ToD. However, the mild/moderate children are ones that aren't always referred to us. (Professional Survey)
- “maybe down to money and funding. The greater the loss the greater the need so those who have a greater loss are seen as most needing specialist support.” (Professional Survey)

Teachers considered that if children with mild and/or moderate losses were not usually referred that they should be, with 94% responding yes. However, there were many comments about the challenges for services if all these children were referred. Many are already seeing these children:

- “they all are, and we cope (just!)” (Professional Survey)
- They are referred to me. However, considerable pressure is being placed on the service to reduce this support as the authority has decided to massively cut our budget. (Professional Survey)

Many felt that these children deserved services:

- “A more equal system” (Professional Survey)
“They are (referred)! It is a false economy to ignore them as they can, with a little support develop confidence and skills to thrive.” (Professional Survey)

However, for others more referrals would put a strain on stretched services:

- “Complete overload!” (Professional Survey)
- “implications on staffing/time...” (Professional Survey)
- “not enough staff” (Professional Survey)

Many teachers highlighted the lack of recognition of the difficulties of these children led to their not being seen as a priority for support:

- “Being seen as a low priority by education services and not allocated resources for support.” (Professional Survey)
- “Because children with mild/moderate losses don’t get as much input. Those with a profound loss have earlier intervention and previously had statements. Children with profound losses get prioritised over mild/moderate cases and thus when short staffed they are the ones who are still seen.” (Professional Survey)
- “No support as need is not recognised.....” (Professional Survey)

However, many services appeared to have systems in place for prioritising or for providing support by letter or information if visits were impossible. Additionally, services were differentiating between those with mild and those with moderate losses, often by sending out information or letters to those with mild losses. In interviews, teachers expanded on the challenges they face in prioritisation:

- “They (children with mild losses) just don’t come onto case load. They are screened, they see their teachers who screen, .... and an advice sheet will be sent out to parents and to the school, ...saying ... we won't come out and do a visit, you won't be going on a caseload. .....Our moderates, we generally go out and see them.....and we would NatSIP criteria them.” (Professional Interview)

Another teacher talked about “Information only service”, she described the challenges for the service with the numbers of referrals from ENT:

- I can have referral envelopes that contain 24 referrals all in one go, in one week, and we can't begin to meet their needs, so we supply an information only service. I deal with this and write to the SENCOs in each school, giving an outline of the child’s hearing loss......and there is an advice sheet in there...and an invitation.... to get back to me personally. (Professional interview)

Teachers were at pains to point out that there may be other difficulties, that a child may have a deteriorating loss, and several teachers brought up the challenges of children with unilateral losses. As one commented:

- “we need to differentiate between hearing and understanding”.

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When asked if there are mild to moderate children who have not been referred to the service, 59% responded yes; teachers considered that these children may be referred to audiology or ENT but not on to education, particularly if not fitted with aids. In addition, as one commented:

- “If you are clever you don’t realise the hearing problem”

Over 80% of teachers saw children with fluctuating conductive losses, and of those who didn’t, 65% thought that they should. The majority of teachers considered they should see those with fluctuating losses, as they have specific issues to deal with, and need help in managing it.

There were only two references anywhere to those children with progressive losses, and how they were referred or monitored, in spite of 9% of the children were reported by parents to have progressive losses.

3.4.2. Support in school

When parents were asked in the questionnaire if the school did anything to help their child with regard to their hearing loss 464 responded, and 73% responded yes. When asked what kind of support, 351 provided very full answers. Only 18 of the responses to this question could be considered negative and many examples of good practice were given and were valued:

- “the school is fantastic and is in constant contact with ways to support my child.” (Parent Survey)
- “A HUGE amount of support. .....His teacher checks throughout the day that he hasn’t just heard what has been said but that he understands it too. Otherwise he is treated no differently to the other kids in the class, which I believe is very important.” (Parent Survey)
- “The school could not be better so fortunately I do not think there has been an impact. The only thing that may have had an impact is the amount of time off for audiology appointments, Teacher of the Deaf sessions, fiddling with audio equipment etc.” (Parent Survey)
- “[The school] implement all the recommendations from the teacher of the deaf.” (Parent Survey)
- “I have a lot of support from my child’s school and I have close contact with the ToD” (Parent Survey)
- “regular reviews with the visiting deaf teacher. She liaises with the school and attends audiology review with the multi-disciplinary team. The class teacher keeps in touch with any issues as they arise.” (Parent Survey)

Many examples were given of the use of the technology, including radio aids, sound field systems, and much of it positive. For example:

- “all staff have been given training in radio aids, even teachers that don’t teach my son.” (Parent Survey)
- “recently had alterations to improve acoustics.” (Parent Survey)
However, an emphasis on technology was not enough....

- “radio aid – that’s it.” (Parent survey)

However, for some parents, fighting for support was a major issue, particularly when others didn’t see the problem:

- “Yes and the schools don’t see it as a problem... they don’t think its a serious problem to warrant them having any extra help in school. ..... I had to teach them and get booklets and stuff..... and it was like oh ok – and still things weren’t getting done. It was like banging my head against a brick wall.” (Parent Interview)
- “Kick the school staff every now and again to stop complacency!” (Parent Survey)
- “To be honest, we have found our child’s teachers very unsupported (unsupportive) and the school itself have only ever been concerned about any extra funding they may be entitled to. My child has no SEN (Special Educational Needs) co-coordinator and the school nurse has had very little impact as the general consensus is that as our child is in Year 6, it will be a problem inherited by her secondary school to help with.” (Parent Survey)

Several parents and teachers raised the importance of ensuring the school SENCO (Special Educational Needs Coordinator) was involved fully in information and discussions.

3.4.3. Support by Teachers of the Deaf

When asked more specifically about Teacher of the Deaf support, only 72% of children were reported by parents to be seen by a Teacher of the Deaf (n = 502); 18% were visited monthly, 40% termly 40%, and 12% annually with 30% being seen according to need. When asked why their child did not see a Teacher of the Deaf, 104 parents responded; the three most common responses in order were:

- Didn’t know they existed
- Don’t know
- Not necessary

Other issues included having had a Teacher of the Deaf when younger, the school or service not considering it necessary, and being at independent school. The high level of lack of awareness of Teachers of the Deaf was striking:

- “I am not sure what a 'Teacher of the Deaf is’” (Parent Survey)
- “Don't have an awareness of Teacher of the Deaf.” (Parent Survey)
- “Not offered and didn't know they existed.” (Parent Survey)
- “Didn't know about it.” (Parent Survey)
- “Audiology referred but we have never heard anything from them although on the grapevine they dont see children with a conductive loss.” (Parent Survey)
• “It has never been offered and any attempts to ask if its available for our child have only caused hostility from the school.” (Parent Survey)

Parents were asked what kind of support their child received from the Teacher of the Deaf, with 361 responses. Positive experiences outweighed negative ones, and included:

• “Help with technology aids and does classroom observations. Really good at getting supporting language programmes implemented and also does these sessions herself. Pushes school to acknowledge that HI does need support. Would not want to be without her.” (Parent Survey)
• “She is brilliant. She visits once a week/fortnight depending on her case load. She provides support for her in the form of signing, getting her level with her age group, checks her aids, provides us with information, checks her level of understanding, etc.” (Parent Survey)

In interviews parents explained the value further:

• “It’s fundamental because the Teacher of the Deaf is not only there to teach A, but the Teacher of the Deaf is there to support the classroom teacher, so from my perspective it is so crucial that the relationship between the classroom teacher and as Teacher of the Deaf works, because if that doesn’t work then you don’t have harmony, and the classroom teacher absolutely values the Teacher of the Deaf because it is an opportunity for her to say ‘I noticed the other day A was slightly distracted, could it be X, Y, Z etc?’” (Parent Interview)

Other experiences were not so positive when asked about the support provided by the Teacher of the Deaf:

• “not a lot.” (Parent Survey)
• “None – she’s ineffective. Does not really see him as having issues.” (Parent Survey)
• “The Teacher of the Deaf has done nothing for us, to be honest. I felt like I have been battling with her to get anything all the way. She has been so unhelpful.” (Parent Interview)

For a few parents, the input had been out of date advice:

• “…there has been no advice to the school on approaches to learning just criticism of her having a radio aid at the age of 5. The Teacher of the Deaf tells anyone who will listen that she is too young to have one….” (Parent Survey)

Some parents had turned to the National Deaf Children’s Society (NDCS) for support in seeking Teacher of the Deaf help, and clearly had had to fight for recognition of their child’s needs:

• “We have never been able to tell what kind of support she is entitled to, even after repeatedly asking. For 3 years she never received a visit, and we were told she was not
entitled to visits. Once we complained the teacher of the deaf started visiting, but clearly felt put out by this, even after it was clearly demonstrated that my daughter was struggling with some aspects of school.” (Parent Survey)

However, there was an awareness that services were under pressure and needed to prioritise:

- “My Teacher of the Deaf offers fantastic support on the occasions he sees him .... regrettably he is only able to see my child occasionally as the service is significantly understaffed.” (Parent Survey)
- “No, they have made it very clear we are not on their priority list. To be honest because we go to the playgroup they can tick the box they are seeing us.” (Parent Interview)
- “Minimal due to service cuts.” (Parent Interview)

When teachers were asked how much contact they had with these children (monthly, termly annually, varies); 147 responded they gave their answers according to level of hearing loss. Table 8 shows the percentages, and illustrates that as the hearing loss increases from mild to moderate, the frequency of visits increases. Open responses revealed the huge variation in the amount of support to these children: from daily visits to annual, or only on request.

Table 8. The amount of contact of the teacher with the children

<table>
<thead>
<tr>
<th></th>
<th>Monthly</th>
<th>Termly</th>
<th>Annually</th>
<th>Varies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild (n = 122)</td>
<td>11%</td>
<td>30%</td>
<td>20%</td>
<td>39%</td>
</tr>
<tr>
<td>Mild-moderate (n = 113)</td>
<td>23%</td>
<td>35%</td>
<td>7%</td>
<td>35%</td>
</tr>
<tr>
<td>Moderate (n = 141)</td>
<td>37%</td>
<td>12%</td>
<td>2%</td>
<td>49%</td>
</tr>
</tbody>
</table>

The frequency of visits was largely determined by the NatSIP (National Sensory Impairment Partnership: www.natsip.org.uk) criteria. Of the 151 respondents to this question, 40% said it was in line with NatSIP criteria, followed by child’s needs 25%, varies 20%, service policy 15% and funding given little weight. NatSIP criteria use a scoring system including deafness categories: for some this is too restrictive:

- “I’d like the opportunity to give teaching according to pupil’s needs rather than be restricted by the scoring on the NatSIP criteria.” (Professional Survey)

However, most, when discussing the use of NatSIP criteria, commented that they considered the child and family needs. For example:

- “child’s needs, using NATSIP as starting point.” (Professional Survey)

Teachers were asked the nature of their support professionals responded whether the support provided was: “Advisory”, “Direct Teaching”, “Hearing Aid Management”, and “Varies/Other” (see Table 9). More advice is given for those children with mild hearing loss, and significantly more direct teaching is given to those children with moderate hearing loss.
Table 9. The nature of the support provided by the professionals

<table>
<thead>
<tr>
<th></th>
<th>Advisory</th>
<th>Direct Teaching</th>
<th>Hearing aid management</th>
<th>Varies/Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild (n = 128)</td>
<td>78%</td>
<td>13%</td>
<td>62%</td>
<td>24%</td>
</tr>
<tr>
<td>Mild-moderate (n = 117)</td>
<td>76%</td>
<td>32%</td>
<td>74%</td>
<td>24%</td>
</tr>
<tr>
<td>Moderate (n = 147)</td>
<td>63%</td>
<td>58%</td>
<td>69%</td>
<td>31%</td>
</tr>
</tbody>
</table>

When asked about what should be provided, once more the common response was that it varied and depended on need. Provision required included:

- Deaf awareness training for staff
- Support for parents
- Hearing aid management
- Teaching and learning strategy advice

Teachers provided a wide range of contributions in thinking about their management of these children. Deaf awareness was the most commonly mentioned issue which they felt they needed to address with these children in school. They could bring:

- “knowledge of hearing loss and prior experience of the situation…” (Professional Survey)
- “making other teachers aware, giving additional knowledge for the students/parents to understand the implications on learning…” (Professional Survey)

Teachers wanted to provide training in technology, in liaison with other services, particularly audiology and the ability to assess progress and advise on strategies. One teacher in an interview commented that many of the classroom strategies suggested were good for all children not just those with hearing impairment.

When parents were asked if they felt their child needed more support in future, 60% of the 470 respondents felt that they did, and when asked what they would like, 281 responded. The greatest request was for individual support, with 48 of the 281 spontaneously using the words “one to one” support, and others implying it in their answers. This emphasis on “one to one” support appeared in their suggestions about what a Teacher of the Deaf should provide in 'an ideal world.' There was a wide range of other requests, arising from greater awareness in school of the implications, and the importance of managing the technology. This meant that parents wanted to be informed and involved, and wanted more visits to schools.

- “In an ideal world, i would prefer more regular contact although I know I can reach her anytime. ... I want all who are involved with my child to liaise more so that we all aware what is going on where we all stand, and what can be improved or worked on.” (Parent Survey)
- “Just ensure she is OK within the classroom setting and school environment and that she is performing to the best of her ability. As I am not at school with her I cannot assess whether she is OK and her needs are met as well as they need to be.” (Parent Survey)
- “If students have a mild/moderate hearing loss that is impacting on their ability to access the curriculum, they should receive support appropriate to their needs in order that they
are able to fulfil their potential and ultimately fully participate in education, work and society.” (Professional Survey)

- “Children with a mild and/or moderate loss need staff in schools to be aware of their loss and receive training in order to enable them to access the curriculum, equipment needs to be checked at least on a half termly basis by a ToD as well as staff in schools who are trained to do basic checks, functional listening assessments completed prior to annual audiology reviews, children given support in hearing aid management, direct teaching by ToDs may be appropriate focussing on language.” (Professional Survey)

- “Well trained support staff, deaf awareness; understanding the importance of the audiology equipment (including testing, troubleshooting), pre/post-tutoring of key vocabulary, tailored support.” (Professional Survey)

The following comment from a parent in capital letters appears to summarise what parents wanted:

- “HELP HIM LEARN AND UNDERSTAND SO THAT HE CAN HAVE A PROPER EDUCATION.” (Parent Survey)

3.3.4. Support by Teaching Assistant

Only 15% of children saw a specialist Teaching Assistant; (n = 475); of these 54% daily, 24% weekly, 3% monthly and 19% according to need. A quarter of the 293 parents whose children did not see a specialist Teaching Assistant did not know about their existence. For example:

- “Never heard of them” (Parent Survey)
- “We were not informed of this service.” (Parent Survey)
- “I did not know this service was available.” (Parent Survey)
- “Was not even aware that she might be able to have one.” (Parent Survey)
- “I do not know but perhaps this is my missing link.” (Parent Survey)
- “I don't know what I need to do to get this.” (Parent Survey)
- “No awareness of this position either.” (Parent Survey)

For some children it was felt that it wasn’t needed... “she doesn’t need one!” However, some parents pointed out that their child needed to fail before help was offered, and again funding emerged as an issue:

- “Because she is bright and her grades are satisfactory for her age? No funding? She is not deaf enough? Its not for the want of asking!” (Parent Survey)
- “Never been discussed as he “copes” ” (Parent Survey)
- “Turned down for additional support as ahead of age-appropriate. We have been told to wait until he starts falling behind his peers then he can be re-assessed.” (Parent Survey)

When asked what kind of support they received from their child's Teaching Assistant, there was a wide range of responses from the 77 respondents, but most of them related to supporting learning in the classroom:
“English and maths, reading when they can” (Parent Survey)
“Help with his hand writing and English language” (Parent Survey)
“Language support” (Parent Survey)
“Helps to clarify work” (Parent Survey)

Only five of the 77 mentioned looking after hearing aids or FM systems and there was little description of “specialist” support.

3.4. Audiology and technology management

3.4.1. Referral to audiology
Parents were asked who suggested he/she should have a hearing aid(s) or BCHI’s) (n=272). Referrals came largely from the audiologist (81%), with other being 19%. Teachers and health visitors were both 0% in responses. The majority of other responses were clarified as being either ENT-consultant (n=33) or the Parent (n= 9).

“I have felt my daughter spent a long time at the start of her education just lost in the crowd. She struggled hugely settling at school daily from nursery right up to year 2. She was in year 1 when a teacher questioned whether she had a hearing problem. Up until that time my feelings that there was a problem were not acknowledged. Thankfully because the teacher had noticed, when I went to the doctor he actioned a referral quickly because it was affecting her education.” (Parent Survey)

3.4.2. Audiology visits
When asked how often their child visited an audiology clinic or saw an audiologist for hearing testing/review 580 parents responded. 18% attended 3-monthly, 39% 6-monthly, 24% annually and 9% according to need with 10% answering other.

These areas were explored further in interviews, where the importance of good relationships is clear. For example:

“We had a really good couple (of audiologists) to start with who were really just fun and they made it all really good fun, which is very important I think.” (Parent Interview)

3.4.3. Fluctuating hearing losses
Fluctuating losses were mentioned as causing particular difficulty by many teachers and parents, as the children have varying levels of hearing, and the need for aids may change from day to day. One parent commented:

“Significant - because it's fluctuating it's taken less seriously than a permanent loss. I have had to educate the school on the impact and how to support him. He struggles to hear in the classroom. But teachers do not always try to tell the difference between not or mishearing and not listening. Poor behaviour is assumed”. (Parent Survey)
• “The impact fluctuates with his loss.” (Parent Survey)

Comments from teachers on the impact included:

• “fluctuating loss gives inconsistent listening experiences. The child or young person frequently doesn't realise that they have missed information. Lack of understanding from others that acoustic environment really affects what has been heard.” (Professional Survey)

• “I think the children with fluctuating hearing loss often struggle more than others, because they do not have an established identity and do not have a good set of skills for when their hearing goes down. They are often reluctant hearing aid wearers. .....they need some new strategies such as wearing a hearing aid or changing position in class.” (Professional Survey)

• “vulnerable to self esteem issues...” (Parent Survey)

3.4.4. Use of aids

The group of mild/moderate children is a group for whom hearing aids or bone conducting hearing implants or soft bands can make a huge difference. In the responses from both parents and teachers a common theme of increasing use of technology for this group emerges both at school and at home.

Figure 4 shows the parents' response when they were asked how much their child wears their hearing aids or BCHIs. The vast majority of the children and young people are reported to be wearing their devices all the time (81%). This is slightly at odds with the emergent theme that the wearing of aids can be an issue with this group.

![Figure 4. How much the children wear their hearing aids or BCHIs (n = 530)](image)

Many parents commented on the value of hearing aids or bone conducting hearing implants, often called BAHAs) to their child, and the difference it made. In the words of one mother, the difference it made was:
• “..her ability to be able to learn.” (Parent Interview)

It seems, however, as if this was sometimes achieved at a cost to the family – for example:

• “He wears it (soft band) the majority of the time. Basically he has zero tolerance not wearing it, apart from letting him leave it off when he is eating. Sometimes he keeps pulling it off and I put it back on, then pulling it off and putting it on, but some days I just leave it off for a bit, but he has zero tolerance but he has to wear it all the time so I just stick it back on all the time, so he does wear it.” (Parent Interview)

Parents needed to be tenacious with equipment:

• “The big thing that has worked so far, touch wood, is making sure that you get hearing aids as soon as you can, even if that means doing what we have done, which is going through stressful times like arguing with various people through the whole system, because now we are at the stage where his speech, touch wood, does seem to be developing fine and he really doesn't seem to be missing out on anything because he has got the hearing aid and what he would be like if he didn't, because you can tell the difference when he is wearing it.” (Parent Interview)

The management of equipment, and hearing aid wearing and management rated highly as a challenge, particularly at secondary stage, where frustration might lead to non wearing of hearing aids. These levels of hearing loss lead to particular difficulty; for example,

• “establishing good hearing aid use (is a challenge) as they can be seen to respond to sounds when not aided.” (Professional Survey)
• “they often struggle with wearing hearing aids (seeing them as something that grandma wears).” (Professional Survey)
• “refusing to wear their hearing aids...” (Professional Survey)
• “seeing the need to wear their aid...” (Professional)

For one parent, her son had particular difficulty now he was at college, and she felt he was confused about his aids, not seeing himself as deaf.

• “He knows he has a hearing problem but he is more into the hearing world.” (Parent Interview)

3.4.5. Use of assistive technology

Teachers were asked about FM/radio microphone systems usage with these groups of children and their responses are given in Table 10. It can be seen that as hearing loss increases, the use of FM systems increases.
Table 10. Use of FM/radio microphone systems with these groups of children

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>Some</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild (n = 109)</td>
<td>6%</td>
<td>32%</td>
<td>61%</td>
</tr>
<tr>
<td>Mild-moderate (n = 102)</td>
<td>13%</td>
<td>59%</td>
<td>28%</td>
</tr>
<tr>
<td>Moderate (n=146)</td>
<td>42%</td>
<td>52%</td>
<td>5%</td>
</tr>
</tbody>
</table>

Parents responded that the major technology support children had in school was a radio aid, with sound field systems also being mentioned. However, in interviews, once more the importance of parents being proactive emerged.

- “I just did some research, about what they needed when they went to school, and the sound field came up, so we went to the school and I said we need a sound field and actually, to be fair to the school, they just bought it straight away.” (Parent Interview)

There were particular difficulties in encouraging older children and young people to wear radio (FM) systems:

- “Even if they have hearing aids not all teenage pupils will wear them. Some pupils with hearing aids do not want a radio aid as well.” (Professional Survey)
- “Very much as said it’s very hard to get teacher to wear fm system and Robert hates wearing it too.” (Parent Survey)
- “not all teenagers will recognise the value of a radio aid. Care of radio aid at school can also be problematic.” (Professional Survey)

3.4.6. Information accessibility

Parents commented on the need for information and the information from the National Deaf Children’s Society (NDCS) was the most commonly mentioned and very much valued, both for families and for teachers.

- “When I found out about what his diagnosis was I read up so much because I wanted to know everything about it, so yes lots of reading was done in the first week.” (Parent Interview)

When asked about information, 66% of parents considered that the child’s teacher or form tutor had sufficient information about hearing loss, and many had been pro-active in ensuring that the information got to the right place. Web-based information was also valued, and those who had been to NDCS weekends also valued these.

- “Not sure if all teachers have the correct information” (Parent Survey)
- “info re acoustics and listening and auditory discrimination info on possible impact of her loss and use of HAs” (Professional Survey)
- “as a parent of a deaf child and children’s nurse I have shared all the info I have and an happy that the relevant teachers understand it. The school have been very supportive to us as a family and have helped our daughter hugely.” (Parent Survey)
• “All NDCS info is useful but cannot expect class teacher to be fully engaged when only 1 child has hearing problems in the class, she is bound to aim teaching at the majority, not the minority” (Parent Survey)

Several parents commented that they had found it useful to listen to simulations of hearing loss, to help them understand the implications. For example:

• “most useful bits of info have been things I’ve found on line that describe how/what a children might hear in a typical sentence with a moderate hearing loss eg show that parts of words might be missing so that the sense isn’t clear etc. Along with descriptions regarding the sound experience eg hearing with both fingers in your ear, underwater etc. Think this really helps to show how frustrating and disorientating glue ear can be for a child. NDCS material has also been useful, as has the telephone support they provide.” (Parent Survey)

Information for the young people themselves as they got older was brought up by parents in interviews:

• “I keep forgetting that as [name] got older she needed some information about her own condition, so actually last year I could get a diagram out and show her what is going on with her ears……she has no idea what all this is about.” (Parent Interview)

### 3.5. Looking to the future

Parents and teachers were invited to make suggestions as to what they had found helpful and what they would like in the future, to provide advice for others, and finally to make any other comments they wished. 168 parents and 42 teachers provided additional comments, and many of them used the opportunity to re-iterate how important it is to make people aware of the needs of these children, summarised by one teacher:

• “I think the effects of mild and moderate hearing loss are frequently underestimated”

Looking to the future, we provide a summary of their thoughts and suggestions.

#### 3.5.1. Deaf awareness training

Although the terms mild and moderate are used for these children, for both teachers and parents, deaf awareness training for schools and teachers was the most common theme to emerge. It is interesting that although these children are often not considered “deaf”, “deaf awareness” was the term most often used by both parents and teachers.

A major theme in the research was the lack of deaf awareness in mainstream or other special schools, and in general, for example with GPs. Training for all student teachers on deaf awareness was suggested:

• “All teachers undertake training in deaf awareness.” (Professional survey)
• “Providing deaf awareness training to teachers in the schools. Providing advice and in service around the management of equipment.” (Professional Survey)
• “Teacher training colleges to have appropriate training around deafness....” (Professional Survey)

Other suggestions were that simple leaflets or posters were designed for staff rooms: highlighting key strategies and tips to be aware of whether a pupil could hear them.

3.5.2. Addressing the use of the technology and acoustic conditions

Linked to deaf awareness training, a common theme for both parents and teachers was improved acoustic conditions in schools, and better use and management of technology, including hearing aids, bone-conducting hearing implants, FM systems, and sound field systems. As reported, for this group, the technology can be very effective, and addressing acoustics in the classroom extremely beneficial.

• “a sound field system in every classroom and a law that ensures every teacher makes use of the system! Improved acoustics in schools – especially in the more modern, fancier designs!” (Professional Survey)

Some parents had written their own advice for teachers in the absence of anything they found useful:

• “we write our own instructions on how to look after the hearing aids and change batteries etc which we give to the teacher at the beginning of each year....” (Parent Survey)

3.5.3. Peer groups for families and young people

Where peer groups for parents and for children and young people had been provided, parents had really valued these, particularly as their child’s needs may not be obvious to others.

• “The sensory group is a lifesaver, because you get to meet other parents with the same sort of hearing loss, and there are others there... you can just sit and talk to others who understand.” (Parent Interview)

They commented that often these children did not meet others with a hearing loss or hearing aids, as they were in mainstream schools:

• “For deaf children in general, some sort of emotional support would be good, especially as they get older and realize they are different from other children” (Parent Survey)

• “More opportunities for teens to meet up” (Professional Survey)

• “We used to have lots of children at this picnic every year from all the different schools and they could bring a friend. ....just blown away by seeing others with hearing aids.” (Professional Interview)

One parent, comparing the social needs of her son with a moderate loss felt that deaf events didn’t meet his needs: Even though he is a deaf person he doesn’t relate to them.... A teacher commented similarly:

• “Children can feel they don’t "fit" in with hearing peers nor with profoundly deaf BSL users - issues with self perception” (Professional Survey)
Both parents and teachers recognised that young people with a mild to moderate loss may have greater difficulties as they progress to secondary level, and suggested resources and information for this group. There appears to be increasing difficulty in accessing the curriculum, but also in social and emotional issues:

- “I think that it is important for the child’s peers to be educated about the implications of the hearing loss and how they can help their friend in different situations. My son has gone through primary school with no academic problems (nothing out of the ordinary) and I think that due to this his friends do not understand the extent of his hearing loss. This is now becoming apparent as they are ignoring, leaving him out because communication is becoming more important in their relationships. My son I think needs support from the ToD to help him cope socially as much as academically, give him strategies to get the most from his education and from his interactions with peers” (Parent Interview)

For older children and young people, parents suggested more thought be given to preparation for the future: “opportunities to practice social interactions eg interviews, meeting someone for the first time”.

One service had developed a support group for these families which was proving helpful:

- “We provide a monthly support group for parents with unilateral loss, chronic conductive loss and unaided mild losses. The feedback has been overwhelmingly supportive from the parents who feel they have more information and feel better equipped to move forward with helping their child progress their language and listening skills.” (Professional Survey)

Some services commented on a Buddy system for these young people, where contact was facilitated between them. Parents and teachers suggested specialist groups such as music groups, Sensory integration groups, where these children could benefit from the skills of other specialists.

3.5.4. Information and resources for parents, young people and teachers

There was a great deal of useful information mentioned by both parents and teachers, and National Deaf Children’s Society (NDCS) information and resources were particularly mentioned. NDCS resources were the most common source of support – and being free and easily available valued. They were used by parents and Teachers of the Deaf to give to schools.

It was of interest that a significant numbers of parents did not know about Teachers of the Deaf or about teaching assistants. Information needs to be provided in audiology and ENT clinics about the support services available. The parents who responded to this survey were a self selecting group, and there are likely to be an even greater proportion of parents unaware of the services available in the wider population.

A recurrent theme was the increasing use and benefits of technology for these children, and its rapid development. There was mention of the increased use of bone conducting hearing
implants for this group, and the need for parents and teachers to be kept up to date. Regularly updated information was required and “short and snappy!” to ensure it was used:

- “....there is a wealth of it (information) out there. I am not sure how accessible it is if you are very, very busy teacher. I did see something recently... where they had made it really accessible in terms of contents, how to find information, a lot of it was cartoon-based, and it was a one or two minute read. ......class teachers are assailed by hearing loss, visual impairment, autism, Down’s syndrome.....” (Professional Interview)

Parents and teachers both commented on the use of web-based information, such as Sounding Board (The Ear Foundation) were considered valuable, where monthly updates and regular advice can be accessed.

4. Conclusions

The terms mild and moderate may describe the hearing loss in audiological terms but they in no way describe the impact of the hearing loss on the child, young person, family and their education that this research uncovered. As one teacher commented, the terms themselves are misleading when making the case for support services:

- “Unless the government, local authorities, heads of services etc understand the impact hearing losses have on children’s overall development nothing will change. How hearing loss is labelled can be misleading to those unfamiliar with the impact. “mild” does not suggest the real impact that this type of loss can have on a child’s development.” (Professional Survey)

Another teacher in interview summarised:

- “...careful consideration needs to be given all of the time to their listening and their speaking, and opportunities to do those things with their peer groups and support with their peer group to be able to do that, and its a lot about social and emotional and the understanding and knowledge of the world, and not taking for granted that these children are picking up things as they go along, because they are not, and that is presenting all sorts of difficulties for them” (Professional Interview)

The main issues which arose were:

- The terms “mild” and “moderate” to describe the hearing loss do not describe its impact
- A bigger impact of the hearing loss on family and education than generally recognised by others
- Greater levels of effort for the children and young people in school
- Social and emotional impact on child or young person
- Family adjustments required to meet the needs of the child or young person
- Parental recognition of a greater impact on education: parents wanting 1-1 support
- Lack of deaf awareness in mainstream schools
• Diagnosis and fitting of aids later than in other groups, with an apparent lack of care pathway and liaison between professionals
• Need for parents to be pro-active: parents unaware of roles of Teachers of the Deaf and teaching assistants
• Increasing use of technology, including bone-conducting hearing implants, for these children and need for up to date information and training
• Technology very useful for this group, but they may appear not to need it, and “hear” without it, leading to confusion and possible non-use in later years
• Impact of fluctuating, conductive losses, unilateral losses
• Value of support groups for families and young people
• Impact of cutbacks and prioritisation of services on support for this group

Far from having mild or moderate impact on the child and family, mild or moderate hearing loss has a major, often unrecognised impact, as reported by these parents and teachers. It would be useful to talk to the children and young people themselves about their experiences. There is an urgent need to address the challenges that mild and moderate hearing loss bring to a home and at school, and which may be overlooked as they are often not apparent, particularly at a time of financial challenges for services. It is also a time where the latest hearing technologies can have a great impact on minimising the effect of the hearing loss and our knowledge of how to address acoustics has never been greater.

This survey of parents and teachers about the group of children with mild/moderate deafness and their needs clearly tapped an area of great interest for both. The open responses from both groups were very full and thoughtful, and contained unusual messages of support for the research, such as:

• “In the current climate we are under pressure to cut wherever possible. Thank you for tackling this issue” (Professional survey).
• “Will be interested to read the report.”

The last words – a quote from a teacher, and one from a parent, respectively:

• “It is important to stand up for children with mild and moderate losses”.
• “I would say we were most vulnerable when we thought it’s mild to moderate, its only little, and we did think... its nothing , and we were only told its only mild to moderate you will be fine. No, mild to moderate deafness, he is still deaf.”
References


