Audiology Services and Hearing Technologies: The Experiences of Deafblind Individuals

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Sense estimates that the number of deafblind people in the UK in 2010 was around 250,000; 222,000 aged over 70 and 33,000 aged 20-69. It is likely that this population already use, or will need to use, audiology services and hearing technologies. Sense receives a high rate of enquiries from their members and commissioned this study to qualify the needs, experiences and expectations of deafblind people in order to make recommendations for clinicians and commissioners.

The views of 37 deafblind adults were collected using questionnaires and interviews. Participants varied in communication preferences, age, gender, geographical location, type/severity of deafblindness and use of hearing technology.

Recommendations based on the results of this study have been produced relating to: technology self-efficacy, access to information and service provision. It is essential that services and clinicians are aware of these recommendations in order to meet the needs of this ever increasing population.
About

Sense

Sense is a national charity that supports and campaigns for children and adults who are deafblind. We provide tailored support, advice and information as well as specialist services to all deafblind people, their families, carers and the professionals who work with them. We also support people who have a single-sensory impairment with additional needs.

Our services include on-going support for deafblind people and their families. These range from day services, where deafblind people have the opportunity to learn new skills to Sense-run houses in the community, where people are supported to live as independently as possible. Our communicator-guides offer support to deafblind people living in their own homes and our dedicated Information & Advice Team provide support and guidance on all issues relating to deafblindness.

The Ear Foundation

The Ear Foundation, formed in February 1989, is an independent registered charity that supports deaf children, young people, adults and their families to ensure they make the best use of the latest hearing technology to improve communication and spoken language. It brought cochlear implants for children to the UK in 1989, funding the first ten, until the service was established by the National Health Service. The impact of hearing loss, whether in childhood or adulthood, is devastating, leading to communication difficulties, educational and employment underachievement and linked to isolation, depression and dementia.

Today’s hearing technologies can address this, but all too often their potential is not reached. This is where The Ear Foundation comes in. Our aim is to bridge the gap where hearing technologies are fitted and home, school and work where they are used. We do this through our: Family Programme – supporting deaf people of all ages; Education Programme – training professionals working with deaf people; Clinical Services – enabling users to make the most of their hearing technologies; Research Programme – researching important issues related to deafness and using the findings to influence Government policy and practice; and advocacy and lobbying.
List of Abbreviations

AoHL: Action on Hearing Loss
AQP: Any Qualified Provider
BCHI: Bone Conducting Hearing Implants
BSL: British Sign Language
CCG: Clinical Commissioning Group
CI: Cochlear Implant
CROS: Contralateral Routing of Sound
DoH: Department of Health
GHABP: Glasgow Hearing Aid Benefit Profile
GP: General Practitioner
HA: Hearing Aids
NHS: National Health Service
NICE: National Institute for Health and Care Excellence
UK: United Kingdom
WHO: World Health Organisation
YLD: years lived with disability
Hearing loss and vision loss each remain a leading cause of global disease burden and there is a marked increase in the prevalence of both with age. The number of years lived with disability (YLD) because of hearing or vision loss is increased substantially and remains a growing burden of ill health particularly amongst older adults. Sense estimates the number of deafblind people in the UK in 2010 to be around 250,000: 222,000 aged over 70 years, 33,000 between the age of 20-69 and 4,000 estimated to be children (0-19 years).

For all ages, deafness or blindness can have a significant impact on quality of life and when combined have a greater impact still, frequently affecting mobility, communication and access to information. As a result an individual can then experience further negative consequences such as poorer health, increased risk of depression, poorer quality of life and reduced independence and wellbeing.

Hearing technologies including hearing aids, cochlear implants, bone conducting hearing instruments, FM systems and loop systems have been found to improve adults’ health-related quality of life by reducing the psychological, social and emotional effects of hearing loss. Despite the benefits that hearing technologies offer, the uptake is low, with only one in seven hearing impaired adults aged 50 years or older reporting using a hearing aid; other studies have reported 80% of adults who would benefit from a hearing aid do not use them.

Research has highlighted the added difficulties deafblind individuals have in managing their hearing needs. Individuals who reported having visual disability were less likely to report adequate hearing aid self-efficacy. Very little has been previously documented on deafblind peoples’ perspectives and experiences of audiological services and hearing technologies. The purpose of this study was to explore in depth, deafblind adults’ views and experiences of their hearing care pathway and hearing technology use. A two phase approach to this study was employed. The first phase of the study was a questionnaire survey which was disseminated to individuals in touch with Sense resulting in 37 completed surveys. The survey was analysed and the findings were used to develop a semi-structured interview schedule, where 10 qualitative interviews formed the second phase of the study. Findings from the survey highlighted patients’ experiences of obtaining hearing technology, long term care and maintenance.
issues and responses for the Glasgow Hearing Aid Benefit Profile (GHABP). This study highlights some important findings on the access to and use of hearing technologies. This group attribute very high importance to their hearing technologies, because they enable them to perform everyday activities and maintain independence. Their hearing technologies are integral to their quality of life and the loss, even temporarily, of this technology can have a much stronger impact on their health, ability to function and activity engagement and further compound the effects of their dual sensory deficits. Audiology services and commissioners need to be sensitive to the combined effects of dual sensory loss and the value hearing technologies can hold for deafblind individuals. Improvements in professional awareness, quality and accessibility of information and long term support would help to provide an optimal hearing aid service and the potential to maximise the benefits deafblind people gain from their hearing technologies.

**Key findings**

- Professionals and services frequently lack deafblind awareness resulting in low patient satisfaction regarding both verbal and written communication.

- In the current study satisfaction with aftercare was low, with 29-48% expressing not being satisfied with repair services, ongoing support, upgrade opportunities and service information.

- Waiting times experienced by participants for a repair appointment were varied: 44% reported being seen within 48 hours, 39% within a week to two weeks and 17% being seen after two weeks; a significant cause for concern given the importance participants place on hearing aid use and that 58% reported not having access to spare aids.

- 41% of participants reported that they had not been offered a follow-up appointment to receive post fitting support or were unaware that this type of appointment was available – and therefore they had not had the opportunity to discuss the set up of their aid with a professional.

- Participants reported how the sound required from their hearing devices differs from those who have a single sensory hearing deficit, and specifically that professionals should ascertain details about the environments and sounds the individual needs or wants to hear. A frequent comment received was the need to hear background sounds to aid personal safety.
• Participants were confident with their technology and over 90% were able to manage with inserting earmoulds, replacing batteries, identifying left and right and hearing aid controls. Cleaning aids was deemed more difficult with 28% not able to manage and 16% being able to manage with support.

• The majority of participants (55%) made use of additional hearing technologies to use with their hearing aid.

• A substantial improvement in listening ability and a reduction in residual disability was noted by all participants with the use of their hearing technology.

• 97% of participants use their hearing aids all the time when in a one to one situation, 94% also use their hearing aids all the time when in background noise and in group situations.
1. Introduction

Age related hearing loss and vision loss remain a leading cause of global disease burden with a marked increase in prevalence with age (Vos et al., 2012). In the UK, the number of years lived with disability (YLD) because of hearing or vision loss are increasing in absolute terms (Murray et al., 2013) and generate a substantial and growing burden of ill health particularly amongst older adults (Murray et al., 2013). It is likely that the reported numbers on the prevalence of sensory loss in adults are substantially underestimated (Davis, 2012).

In a recent GP Patient Survey for England approximately 5% of all adults reported deafness or blindness. This increased to approximately 11% for those aged 55 years and over with approximately 9% reporting deafness, 2% blindness and 1% both (Davis, 2012). Sense estimates for the number of deafblind people in the UK in 2010 were around 250,000. Among those, around 222,000 were aged over 70 years, 33,000 were between the age of 20-69 and 4,000 were estimated to be children (0-19 years).

For all ages having deafness or blindness can have a significant impact on quality of life, when experienced in combination, deafblindness has a greater impact still. Deafblindness, commonly referred to as dual sensory loss in research (Wittich et al, 2013), has substantial and wide ranging impacts. For example, activity limitations and participation restrictions (Crews and Campbell, 2001), poorer health and functioning (Crews and Campbell, 2004), less optimal everyday functioning (Ciamarelli and Jopp, 2014), poorer quality of life (Chia et al., 2006), increased risk of falls, injuries from falls, mortality and poorer health related quality of life (Lopez et al. 2011).

A number of studies have also shown a strong link between dual sensory loss and depression (see for example: Kiely et al, 2013). Around 69% of those reporting deafblindness have at least four long term additional conditions. People with deafness and blindness, compared to those without, are less confident in managing their own health (Davis, 2012). Additionally, the impact of sensory impairment on cognitive function has been reported to be substantially greater for those with deafness or blindness compared to those without sensory loss (Davis, 2012; Lin, 2012).
Despite the above, the uptake of available interventions remains low (Davis, 2012). The primary clinical management intervention for people with hearing loss is the fitting and use of hearing technologies (McCormack and Fortnum, 2013). Hearing technologies including hearing aids (see for example Kochkin, 2012), cochlear implants (see for example NICE, 2009) and bone conducting hearing instruments (see for example Ho et al., 2009) have been found to improve adults’ health-related quality of life by reducing the psychological, social and emotional effects of hearing loss. Yet, the uptake of hearing technologies has been low with only one in seven adults aged 50 years or older with a hearing loss reported to be using a hearing aid (Chien and Lin, 2012). Other studies have reported 80% of adults who would benefit from a hearing aid do not use them (WHO, 2006, Dawes et al., 2014).

Recent research on hearing aid self-efficacy in owners and non-owners of hearing aids found that those who also reported visual disability were less likely to report adequate hearing aid self-efficacy (Meyer et al. 2014). Hearing aid self-efficacy refers to the individual’s level of confidence in their ability to use a hearing aid (Smith and West, 2006). For hearing aid owners, self-reported visual disability was a key factor influencing confidence in the ability to manage the ‘advanced handling’ (West and Smith, 2007; e.g. the ability to troubleshoot a hearing aid when it stops working). Low levels of hearing aid self-efficacy were reported by 81% of hearing aid owners who had reported a
visual disability as well (Meyer et al., 2014). These findings highlight the added difficulties deafblind individuals have in managing their hearing needs. Sense frequently receives enquiries from deafblind people and their families relating to hearing technologies and audiological service provision. Since April 2012, the government has been rolling out the ‘Any Qualified Provider’ (AQP) scheme to include NHS Adult Hearing Services (Audiology). Many areas have opted to use the AQP process to commission their audiology services. AQP incorporates a tariff and pathway for a ‘direct access adult patient’ which constitutes someone with a routine bilateral age related hearing loss and no additional contraindications. There have been some local discussions on what constitutes routine and what defines a ‘non AQP’ patient and how to manage their care pathway. This is relevant for deafblind people who may receive a service via a routine or alternative pathway. Whatever the pathway, specific consideration is needed on the impact a visual impairment has on their hearing, if their needs are to be met effectively.

To our knowledge, there has been no in-depth mixed methods investigation into deafblind adults’ views and experiences of hearing technologies and audiological service provision. The purpose of this study was to explore in depth deafblind adults’ views and experiences of their hearing care pathway and hearing technology use.
This study aimed to explore deafblind adults’ views and experiences of their hearing care pathway and hearing technology use. The research had two phases:

1. Questionnaire survey
2. Follow up qualitative interviews

2.1. Questionnaire Survey (n=37)

2.1.1. Recruitment and data collection

A questionnaire was developed by researchers and audiologists to gain basic information about a wide range of aspects of deafblind individuals’ experiences of audiology services and hearing technologies. It captured both quantitative and qualitative data and was made available in a range of accessible formats that included; an online version available via Survey Monkey, a word document accessible for those using screen reading and braille technology (where Survey Monkey was not accessible) and hard copy format in the individuals’ chosen font type, font size and colour preferences. Individuals also completed this questionnaire by telephone or face to face interview upon request.

The recruitment of participants for phase 1 took place over a 16 week period; this was extended from the original 14 weeks to incorporate a Sense membership event. A request for participation was distributed via:

- The Sense website (web pages and social media)
- The Ear Foundation website
- Sense membership e-bulletin
- Sense membership magazine “Talking Sense”
- Sense forum and branch group facilitators
- Sense Assessment and Advice Officers
- The membership of the Sense Hearing and Sight Impaired (HSI) group
- A network of individuals in contact with Sense with a known interest in this topic
- The Sense “Growing Stronger Together” event

Purposeful sampling was used targeting existing recruitment pools to achieve a better response rate. While the vast majority of participants were recruited through their contact with Sense, the self selected participants varied in; age, gender, location, type and severity of deafblindness and communication preferences.
Phase 1 was initially piloted on 4 deafblind adults and their feedback was used to further refine the survey prior to its final dissemination, however their responses were not included in the final collation of Phase 1 responses. The survey contained questions which aimed to elicit both numerical and narrative data. Open ended questions were used to allow for exploration of deafblind adults’ narratives and issues related to specific questions. Any identifiable details were removed from the data to protect the anonymity of the participants and the services. Participants who did not complete the survey were removed from the analysis (n=5).

Details of participants can be found in Table 1.

<table>
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<th>Hearing Technology</th>
<th>Communication Method</th>
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The Glasgow Hearing Aid Benefit Profile (GHABP; Gatehouse, 1999) questionnaire was included at the end of the survey. The GHABP is very commonly used within audiology clinics and aims to establish differences in hearing ability in different situations before and after audiological intervention. For the purpose of this survey, participants were asked to consider their experience without their hearing technology when completing the disability and handicap section.

The rest of the GHABP was completed with participants sharing their experiences with their hearing technology. As explained in the GHABP information package (www.ihr.mrc.ac.uk) one of the advantages of this approach is that participants, having had some experience with hearing aid use, can now realise the difficulties that they did have prior to fitting (a concept often called “revealed disability”).

The GHABP accesses four pre-specified listening circumstances which commonly occur in the lives of hearing-impaired people:

1. Listening to the television with family or friends when the volume is adjusted to suit other people
2. Having a conversation with one other person when there is no background noise
3. Carrying out a conversation in a busy street or shop
4. Having a conversation with several people in a group

Each of the situations are assessed separately. Firstly the occurrence of the
listening circumstance in the hearing technology user’s life is established.
If the particular situation does not occur in the participant’s life they would
move on to the next circumstance. For each of the circumstances the following
questions are asked:
1. The degree of difficulty experienced by the listener (initial disability
   without hearing aids),
2. The effect or impact on the hearing-impaired listener’s life (handicap
   without hearing aids),
3. The extent to which the hearing aid is used in that listening circumstance,
4. The extent to which hearing is improved in that listening circumstance
   (hearing aid benefit),
5. The hearing difficulty experienced by the listener after the fitting of the
   hearing aid (residual disability) and
6. The client’s satisfaction with their hearing aid for that listening
   circumstance.

2.1.2. Data analysis
Descriptive statistics were used to summarise the quantitative data using
Microsoft Excel. Percentages were used to describe distribution across
individual question options, rather than raw counts, as they provided a more
consistent measure across all questions. Open ended responses were treated as
separate transcripts for each question and were analysed independently. The
analysis of narratives were summarised and included under the corresponding
quantitative question.

Thereafter, individual narratives for each question were thematically analysed
and together with quantitative findings were used to guide the development
of the semi-structured interview transcript for the second phase of the project
(Section 4).

2.2. Follow up qualitative interviews (n=10)
A qualitative methodological approach was used to gain more in depth
insight into the quantitative questionnaire responses where participants
responded to a set of predefined questions. During this stage, participants
had the opportunity to discuss their own perspectives highlighting events and
experiences they felt were meaningful and important to them. The advantage
of this approach was that it allowed participants to evaluate their experiences of services and use of hearing technologies. This approach identifies what is meaningful from the participants personal experience rather than being decided by the researcher when developing a closed set of quantitative questions (Silverman, 2005; Smith, 2003; Willig, 2001). As the purpose of this part of the study was to explore participants’ in depth perspectives of their experiences accessing audiological services, the qualitative approach was well suited for this

2.2.1. Participants

Participants for the interview study were identified from their survey responses. Twenty two participants from the survey expressed an interest in follow up interviews. Maximum variation purposive sampling was used to select 10 participants, covering a range of demographics including age, sex, onset of hearing loss, hearing technology use and communication method. One of the interviewees was a Sense support worker who also shared her experiences of supporting a large group of elderly deaf blind individuals.

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2.2.2. Data collection
Participants were given the choice of where they wanted the interviews to take place; seven chose to be interviewed in their own home, two interviews were conducted at a Sense facilitated branch group and one participant asked to be interviewed at a local cafe. Interviews lasted between approximately 45 and 90 minutes and were audio recorded. The BSL user was accompanied at her interview by an interpreter, who interpreted the questions for her and voiced over her responses for the audio recording. Notes and reflections were also documented separately by the interviewer. Each interview was transcribed verbatim and treated as an individual case.

2.2.3. Data analysis
Thematic content analysis was carried out in a series of stages. Initially, the transcripts were read in full to obtain a sense of the narrative. Next, each transcript was read in detail to generate meaningful units. These units were generated independently by the first two authors. This was followed up by regular discussions to consolidate and group units into meaningful codes based on similarities and differences. An emphasis on preserving the original context in which the statements were made was maintained during this process. Cross sectional analysis techniques were used to analyse both within case and cross case perspectives (Silverman, 2005). This recursive iterative process produced overarching themes and lead to the final coding framework, which explained the qualitative dataset as a whole. The analysis process resulted in four main themes and 14 sub themes relating to deafblind adults experiences of hearing loss and access to and use of hearing technologies.
The questionnaire received 37 responses (n=37) and the results from the survey are presented in this section with the findings divided into three parts:

- Experience of obtaining hearing technology
- Long term care and maintenance
- GHABP

### 3.1. Experience of obtaining hearing technology

Participants were asked a series of questions relating to their experience of accessing audiology services to get their hearing technology. Topics included satisfaction with appointments, information sharing and time allocation. Figure 1 shows the participants experience of their audiology appointments: referral, assessment, fitting and follow up. Overall, the majority of participants expressed being satisfied or very satisfied with all four appointments. The highest satisfaction rates were given for the fitting process with only 9% expressing “not satisfied” for this stage. Dissatisfaction for the other three processes ranged from 19-23%.

![Patient Experience (%)](chart)

**Figure 1: Satisfaction feedback for different audiology appointments.**

Participants were able to provide open ended feedback with their survey choices. Overall, comments were positive about the processes.

“Assessment brilliant, good checks. GP got nurse to check and clear ears before referral”
However, some responses did highlight reasons for selecting ‘not satisfied’. One participant explained how the communication methods both in writing and at the clinic were inadequate, making it difficult to understand the letter sent from the audiology department and comprehend instructions at the clinic:

“She was unable to read the referral letter herself, she would have wanted this in large print or even better an email. The audiology department not very approachable using phrases like come this way or follow me and talking away from [Patient] so it is even harder to understand people.”

The methods of information sharing used by clinics were explored for this group of patients in relation to their hearing condition, hearing technology options, hearing technology model and aftercare services. The participants were asked how the information was shared with them and were able to select all the options that applied. Responses are illustrated in Figure 2. The hearing condition and hearing technology options were mostly described verbally to participants. Information relating to hearing technology model and aftercare services were also provided through written information (13-14 %). Sharing of information through electronic means (internet/email) was limited in all cases (0-4 %).

Figure 2: Methods of information sharing used with deafblind patients.

Open ended responses provided far more insight into the process of information sharing between clinicians and patients. Participants were clear when they felt the process was not being handled as well as they felt it should:

“No explanation about hearing loss and any changes to it/not given any options. After being tested in a very small booth they roughly took her out
of the booth and then took her current aids away to be adjusted but no info about what actually happened with the aids”

“Literature too small to read at all”

“Given a pack but as [Patient] cannot see print and husband is dyslexic they have really struggled to understand the information/Hearing therapist has given much better information especially verbally very full information”

“Verbally, but still struggled to hear as now unable to lip read as well. Audiology advised that their info was not accessible for [Patient]”

“Unable to read leaflet/Only advised to attend repairs if problems - the repairs do not offer the opportunity to discuss the aids properly.”

Others described how they would prefer the information to be shared through electronic means:

“I would prefer to receive my appointments via email”

The participant who was fitted with a cochlear implant mentioned how she had received information through all three means:

“I was also given leaflets and information via email regarding my cochlear implant.”

Participants were asked to consider whether they felt the information they had received was sufficient for them. Figure 3 describes their responses on the level of information they felt was shared with them regarding their technology options, how to use the hearing technology and aftercare services. Approximately half (51%) of the participants felt that the technology options available were not shared with them. The majority (72%) of participants felt information on their hearing technology and how to use it was shared in some or a lot of detail. Views on the level of information on aftercare services were split evenly with 50% feeling that the information shared was either brief or not shared at all.
Figure 3: Perceived level of information shared with patients.

Open ended responses were clear in emphasising how participants felt about the hearing technology options available to them and their lack of involvement in the decision making process:

“No (technology) options discussion: ‘we can offer hearing aid’”

“It took approximately 9 months of liaising with the audiology department before further equipment options were discussed and initiated.”

“Was offered another type of digital hearing aid but was told it would take him at least 3 months to get used to. [Patient] continually asks for the background noise to be given but the audiologist keeps saying that background needs removing”

“Over the years I have been given different hearing aids. On each occasion there was no discussion. The audiology department representatives made it clear that there was very little option.”

“Audiologist turned off audible jingles without asking if she would like it. Said people find it annoying.”

Participants were asked to consider whether the amount of time allocated to them for their assessment, fitting and follow up appointments were sufficient in their view. The majority of participants (74 %, 85 %, 70 %) felt sufficient time had been allocated to them for their appointments. Figure 4 shows participants responses for each of the appointments.
Many of the open ended responses were in agreement with the closed set data with participants explaining how they were pleased with the time allocated to them:

“Seen on a Saturday over time clinic, quiet clinic plenty of time.”

“CI assessment very thorough”

“Extra time was given.”

“The service is excellent probably because hearing is one of the main symptoms of the rare set of disorders I have”

“Very kind audiology department and very patient”

However, this view was not shared by all and some did feel the time allocated was not sufficient or that the appointment was rushed:

“Not always enough time given”

“Feels that Audiologist are clock watching”

As mentioned in the methodology the data illustrated in the Figures are in percentages, rather than raw counts, as they provide a more consistent measure across all questions. As a result, it is important to note data on follow up/aftercare in Figures 1-4 are based on the responses of participants who
had received a follow up. Many participants (9) reported not being offered a follow up or explained that they felt there was no system in place for follow up appointments.

“There doesn’t seem to be a follow up appointment system”

“No follow up appointment offered”

3.2. Long term care and maintenance

Patients were asked about their experience with aftercare: Figure 5 illustrates the levels of satisfaction with repair services, ongoing support, upgrade opportunities and service information and shows a shift in levels of satisfaction, with more participants expressing some dissatisfaction with long term care and maintenance. The previous responses on the process of obtaining their hearing technology highlighted dissatisfaction levels of between 9-23% (Figure 1), however when reporting on aftercare, dissatisfaction levels increased considerably ranging from 29% to 48% (Figure 5).

The participants were also asked to respond to a series of questions relating to their hearing technology aftercare requiring Yes/No answers. When they were queried on whether they felt the audiologists were able to answer their questions 72% replied ‘Yes’ and 28% ‘No’. Open ended comments from the participants provided more information:

“In general yes”
“Never had problems”

“Audiologists don’t listen to what I am saying”

“There is not enough time to answer the questions”

“Some can. One person in particular now starting to understand”

“Depends on the individual Audiologist – inconsistent”

“The complexities of being both Blind and Deaf does make it much more difficult to explain why certain hearing aids do not work! The people are not trained to the issue of deafblind. The answer above is a mixture of Yes and No because the hearing aids were handled just fine but the choice of aids was not. But to be fair there was a limited choice anyway.”

“I have discovered that it is beneficial to ensure that I always book to see the same audiologist at the Hospital, this continuity has proved invaluable.”

The last open ended response identified the participant’s perceived benefit of having a named audiologist to ensure continuity of care. The following question on the survey highlighted the issue of having the same audiologist and asked participants if this was something they would like to have. The vast majority, 90%, selected ‘Yes’ for this question. Although the wish to have a named audiologist was very popular with the participants the open ended responses provided clarity on this choice:

“Yes if I could choose the Audiologist”

“They vary considerably in their bedside manner; If there was someone he could identify an audiologist that was confident with communication and answering [Patient]’s questions.”

“In the past she saw the same person but more recently has seen the same few people. There does seem to be a difference in the ability of those audiologists that deal with her care some are better than others.”

Simply having the same audiologist each time was not their main requirement but being able to have a named audiologist of their choosing who could meet their needs was what they most wanted.
Participants were asked to share their experiences of repair options specific to them in light of their dual sensory impairment. Participants were asked if they were given the option of domiciliary visits for repairs and servicing to their hearing device. Only 11% said this option was available to them. The remaining 89% said this was not an option for them. Open ended responses explained how some of the patients were not aware that this could be an option:

“Never been asked if I wanted this”

“I am sure not! I have never requested it.”

One participant described how previously a home repair service was an option but this was no longer available:

“No, not these days which is rather disappointing”

Another explained how they could access the repair service through the post:

“Yes, via the post.”

The follow up question asked about the options available to the participants for having a spare device whilst theirs was being repaired. There was close to an even split here in the feedback with slightly more saying they did have access to a spare device, whilst 47% did not. Open ended feedback explained in more detail the nature of this service:

“Yes but it’s a very old one!”

“Previous old aid”

“This facility took time to negotiate, it was not an automatic solution offered.”

“Has two spare sets - 1 x old set 1 x a whole new set including moulds.”

When asked whether they had access to a spare on a permanent basis, more participants (58%) said this was not an option for them and 42% said they did have access to a permanent loan. The open ended feedback explained both experiences of having and not having a spare device on permanent loan:

“Never!”
“Had a spare analogue aid years ago but never been offered one. There have been so many times this would have been useful”

“That would be really useful and has never been offered”

“Sometimes I have been offered especially during testing of new latest models! I find this very, very valuable so that I can fall back to my trusty old ones if I cannot get on with the newest ‘all singing all dancing’ aids!”

Participants were asked about the length of time it took for them to be seen by the audiology department once they asked for a repair appointment. Figure 6 shows the spread of the responses with 31% of participants being seen within 24 hours, but 39% waiting 2 weeks or more.

Figure 6: Bar graph illustrating the duration of time taken to arrange repair appointment.

The open ended responses provide more insight into the reasons for the different lengths of time taken to be seen for a repair appointment:

“Local hospital is Tuesday AM only for 3 hours. Aids haven’t broken down completely yet. Slight problem (didn’t sound right) took 4 weeks to get an appointment.”

“Has to attend with her support worker as she cannot go out alone but sometimes she cannot get the appointment on the day that she has the support so has to wait much longer for an appointment”
“I can send in an email to my man directly and will get an appointment within a day (most of the time)!”

Others described longer waiting times for a repair appointment as an unfortunate drawback to having a named audiologist:

“Named Audiologist only works once a week. Has just waited 4 weeks for an appointment”

“Regularly told there is a long wait as Mike is away, no one else able to see him”

Surprisingly some participants were not aware of the process to book a repair appointment:

“You’ve not been told what to do if your aid breaks down”

“Not sure as not used yet.”

![Management of Technology (%)](image)

**Figure 7: Participants’ feedback on ability to manage with different aspects of their hearing technology.**

The survey participants were also asked to consider how they managed with their equipment on a range of different activities including inserting earmoulds, replacing batteries, cleaning aids, identifying left/right and hearing technology controls. Figure 7 (above) illustrates the responses for each of the activities. The majority of participants (91-97%) were able to manage their technology on their own without any support for the all activities mentioned except for the cleaning of the aid. For cleaning of the aid 28% explained how they could not manage and 16% explained how they could manage with support.
The follow up question asked participants who did they receive support from for the management of their hearing technology with these activities? The majority of participants, 82%, selected the option ‘I use my aids without support from others’. The remaining responses were 22% received support from family members and 4% from their carer. Open ended responses further emphasised the cleaning of the device to be the main difficulty:

“Hearing aid clinic clean and maintain as I unable to see”

“Changing the tube on the hearing aid will be difficult to do without help”

Participants were asked to consider what they found the most useful in helping them to make use of their hearing technologies in an open ended question. The majority of participants highlighted the instructions given to them by the audiologist coupled with the opportunity to practically use the device either as part of the instructions within the appointment or even at home was invaluable:

“Instruction and being shown”

“Playing around with the technology; Instructions at hearing aid clinic wife reads instructions as additional help”

“Experience, reading what instructions there are and the internet”

“Practical usage after spending time reading the manual, looking on the internet at supportive documentation and spending time with my hearing care professional”

“The physical, practical hands on instructions given at appointments have meant that I am fully able to manage both my hearing aid and my cochlear implant, as I am totally blind.”

One participant identified the Action on Hearing Loss service ‘Hear to Help’ as something they found most useful in getting used to their device. Another explained being able to access the internet about their device and receiving emails from their audiologist was what helped them the most:

“Internet; emails from my audiologist”
Accessories related to their specific hearing device were also mentioned:

“Oticon connect line”

In the next question, participants were asked whether they made use of accessories with their hearing device. The majority of participants (55%) selected ‘Yes’ and the open ended responses provided considerable detail into the range of devices used. Loop systems were very popular amongst participants. Many also used accessories specific to their hearing device:

“Has Phonak CROS System (wireless) has iCom system (personal loop system only as back up now as quality is poor compared to iCom)”

“Oticon connect line and other room loops and personal loops”

“Com pilot providing wireless connectivity to Bluetooth and hard wired sound sources”

“Personal Listeners, one is loop and one not.”

“Senheisser infrared headset for watching TV.”

Finally, the participants were asked to consider what advice they would give to other deafblind individuals considering the use of hearing technologies. All the responses were positive saying that individuals should give this option a try:

“Go and have a test. Hearing aids are not perfect (but) with them isolation is reduced; Nothing to lose, far more to gain by trying, help to avoid isolation and exclusion by being able to hear better; The benefits gained from any form of hearing (even damaged or diminished) is an incredible benefit to a blind person. It increases communication, independence and an overall ability to function.”

Others described how individuals should ensure they get the best possible service so that they can benefit from their technology:

“Ask for someone in the department who has dealt with deafblind patients before!!! The “expert” must be gentle and give you lots of time to explain things.”

“Make sure the person fitting the technology understands that the needs
of someone who is using hearing in the context of visual impairment are very different from those who can see. Explain clearly how it’s important to have clear audibility of sounds other than speech, like traffic, and other environmental sounds”

3.3. GHABP (Glasgow Hearing Aid Benefit Profile) responses
After completing the survey responses, participants were asked to complete the GHABP taking into consideration their experiences with and without their hearing technologies. The self-report questionnaire assesses aspects of auditory disability, auditory handicap, and hearing-aid benefit and covers scales of initial disability, handicap, hearing aid use, hearing aid benefit, satisfaction, and residual disability.

3.3.1. Situational listening
Participants were asked to confirm whether each of the pre-defined circumstances from the GHABP occurred in their life. Figure 8 illustrates the number of participants who completed the GHABP and whether any of the four circumstances occurred in their life:
- Listening to the television with family or friends when the volume is adjusted to suit other people (TV)
- Having a conversation with one other person when there is no background noise (C1)
- Having a conversation in a busy street or shop (C BN)
- Having a conversation with several people in a group. (C Group)

![GHABP Responses (n)](image)

Figure 8: Number of participants who completed the GHABP for each of the four pre-defined circumstances.
‘Listening to the television when the volume was adjusted to suit others’, for this group of participants was not as common as the other circumstances because of the impact that the visual and hearing impairment together have on the ability to access the television.

The following results describe the number of responses received for each of the circumstances (Figure 8) and are presented in percentages to make responses more comparable.

3.3.2. Hearing technology use

Figure 9 highlights the amount of time the participants used their hearing technology in each of the circumstances. Apart from when viewing the television the majority of the participants (94-97%) used their hearing device all the time.

![Usage of Hearing Technology (%)](chart)

**Figure 9:** The amount of time participants used their hearing technology in each of the four circumstances.

3.3.3. Listening Benefit and Residual Disability

For each of the listening situations participants were asked to consider how much difficulty they have listening in that situation without their hearing technology and the amount of difficulty they perceive to have in the same situations when using their hearing technology. Figure 10 illustrates their perceived difficulties without their hearing technologies and Figure 11 with their hearing technology.
Without their hearing technology, when watching television with the volume adjusted to suit others, the majority of participants selected ‘Cannot manage at all’ (35\%) and ‘Great difficulty’ (31\%). In comparison, with their hearing technology, 23\% selected ‘Only slight difficulty’ and ‘Great difficulty’ with the most popular response being ‘Moderate difficulty’ (32\%) when using hearing technologies. The number who selected ‘No difficulty’ was 9\% and 13\% felt they ‘Cannot manage at all’ even when using their hearing device.

The most popular response for a conversation with one other person with or
without the use of the hearing technology, was ‘Only slight difficulty’, with 37% selecting this choice when not using their hearing device and 42% when using their hearing device. However, 27% of participants felt they ‘Cannot manage at all’ without their hearing device in this situation. In comparison, none of the participants selected ‘Cannot manage at all’ when using their hearing device. The numbers who found ‘No difficulty’ in this situation were 13% and 17% without and with their hearing technology respectively.

Results for having a ‘Conversation in a busy street or shop’ illustrated a large portion of participants (41%) felt they ‘Cannot manage at all’ without their hearing technologies. With the use of their technology 48% of the participants felt they had ‘Moderate difficulty’. Even when using hearing technologies 23% felt they had ‘Great difficulty’ and 13% felt they ‘Cannot manage at all’.

Difficulties in group conversations showed the majority of participants felt they had ‘Great difficulty’ (40%) or ‘Cannot manage at all’ (44%) without their hearing technology. Although 41% of the participants still had ‘Great difficulty’ in group conversations even with their hearing device, and 13% felt they ‘Cannot manage at all’ even when using their hearing device. When using their hearing device 31% indicated having ‘Moderate difficulty’ and 14% ‘Only slight difficulty’. None of the participants selected ‘No difficulty’ with or without their hearing device for this situation.

3.3.4. Help and satisfaction

For each of the four situations participants were asked to rate how helpful they found and how satisfied they were with their hearing technology.

Figure 12: How much help participants felt their hearing technology gave them for each of the four situations.
Figure 12 illustrates responses regarding how helpful participants felt their hearing technology was in each situation.

The greatest help perceived with their hearing device was for ‘conversations with one person’, where 56% of participants felt their hearing technology was ‘a great help’. For the rest of the situations the feedback was mainly towards their hearing technology being ‘some help’ or ‘quite helpful’. Some participants (4-14%) did feel their hearing was ‘perfect’ with their hearing device.

Participants expressed their satisfaction with their hearing device in each of the four pre-defined situations (Figure 13). Some participants did feel they weren’t satisfied at all with their hearing device when ‘listening to the television’ (19%) and having a ‘conversation in background noise’ 25%. A large portion of participants, 38% and 31%, were only ‘a little satisfied’ with their hearing device when watching television and having a group conversation respectively. Between 17-36% were ‘reasonably satisfied’ with their device in all four situations. Interestingly, 38% of participants were ‘very satisfied’ with their hearing device in group conversations. Some of the participants (5-17%) did say they were ‘delighted’ with their hearing technology.

Figure 13: How satisfied participants were with their hearing technology in each of the four situations.
4. Phase 2: Qualitative interviews

We interviewed 10 deafblind people for the detailed qualitative aspect of this study. During the interviews, the participants spoke movingly about living with a dual sensory impairment and had strong views about their hearing technologies, and about audiology services in particular, which they were keen to share.

4.1. Living with deafblindness

4.1.1. Managing in daily situations

“Because the blindness is really bad, but the deafness is isolating” [5]

We asked the participants to talk about how their lives have been affected by deafblindness and the interviewees described the difficulties that they encounter on a daily basis. In some respects, it felt as if the difficulties they encounter were not so different from those described by many adults with hearing loss. Like all people with hearing loss they struggle in noisy situations for example, or to participate in group activities and conversation:

“I’m still really struggling with the distortion, clarity, going out in the community...yes, shopping at the supermarket, I can’t cope with it” [8]

“I am experiencing extreme difficulties in going about my daily business. One to one conversations can be difficult especially if the person talking to me does not direct their voice. When there are a number of people in conversation I understand 10% of what is being said”. [6]

“Pubs are not very good but I get used to it. If I’m in the group I find it difficult to talk to the whole lot of them, because either they are too far away, or there is so much noise, it’s just not worth it.” [1]

But when the topic was explored in more detail, it appeared that this group is very different from the much larger group of deaf adults, crucially in the area of personal safety. The interviewees emphasised the difficulties and dangers they experience when going outdoors. They talked about the importance of making sure they have enough hearing to monitor their environment, whilst not being so overwhelmed with sound that they become disorientated:

“Yes I need the environmental noise to know what’s going on behind me. I was in the post office and I knew someone was holding the door open for
me because I could hear the noise from outside. And that’s because I had the extra power in the hearing aid. It’s something that audiologist don’t realise with blind people that often they need that extra bit of noise.” [4]

“Sometimes I just have to take them off, I say, I don’t know how you can live in a world as noisy as this- it’s a jungle out there!” [9]

“When I’m outside, it was like listening to a thunderstorm. The road you came down is really busy, so if I walked towards town, it was like listening to a thunderstorm, because of the traffic, the magnification, the sound quality is probably better with these hearing aids outside that it is in, but if you had vision you would probably use, you need to use your sight to cross, say you had peripheral vision for instance, they would miss bits round the corners, so they would try and use their hearing for it, so, I find if I go outside, the sound of the birds and whatever is magnifies, sometimes I have to turn it down!” [1]

Six of the participants recognised that going outdoors was particularly frightening, and one interviewee felt that her guide dog was invaluable in that respect, by acting as her ears as well as her eyes:

“I have a guide dog because she can hear too! I can’t hear traffic and I have never had a directional sense of hearing ever, so I’ve always made mistakes working out where sounds are coming from- she keeps me safe in so many ways!” [9]

Another participant spoke movingly about how his lack of ability to monitor his environment through either sight or sound was restricting his independence:

“I’m not allowed out on my own at all- my wife always has to come with me. Walking out of my front door down the path, there is a big housing estate just passed me and there are vehicles going up there all the time- noisy ones I can hear! It’s the new cars that are so quiet- I just can’t hear them” [10]

4.1.2. Psychological-emotional well being

During the interviews, five of the participants talked about the emotional and psychological impact of living with a dual sensory impairment. They talked about the effort and energy it takes to make sense of the world when you struggle to both hear and see, and described becoming socially isolated from other people as they struggle to take in and process information. The amount of effort and planning needed to function on a daily basis was described by
all the participants, whether they had been deaf and blind for many years, or just a few, and several of them talked about how much they rely on family members, carers and support workers just to get through the day:

“I can still function, but I do get very tired and I’ve lost my depth perception, so when I reach out for something, I don’t quite grab it- yes, I do get very tired—the eyesight and the hearing together. I do get tired and frustrated.”[8]

“I have struggled cos I can’t lip read- I was beginning to become really isolated in that way- you have to concentrate so hard, you have to work so much harder than other people to receive information.” [9]

The one interviewee who had suddenly lost both her sight and her hearing did say that she felt her whole personality had changed:

“I had a health specialist in year 2 and half and I saw her again earlier this year. She said to me “You’re really subdued now” and I wasn’t like that before. But it’s hard work! Trying to process sound and what people are saying all the time. And I’m really looking forward to meeting up and seeing my son again, but at the same time I’m dreading it. Because my sons and my husband all banter really fast and I just feel really left out. And I don’t want to be grumpy and things but it is really very hard. And you get really fed up saying “What? What? Sorry?” and in the end I’m finding myself withdrawing more and more.” [5]

4.2. Confidence and Competency

“And I insisted, because I knew my rights [4]

While participants spoke about the challenges they often experience living with a dual sensory impairment, this particular group demonstrated high levels of confidence and competence, especially regarding two crucial areas; communication and technology.

4.2.1. Communication

Five of the participants gave examples which demonstrated their abilities to assert themselves in potentially tricky communication situations and showed enthusiasm for new challenges:

“The meetings I go to I’m very good at asserting myself now though the church meetings and the governing body meetings those I always insist that they talk one at a time that they speak up. And I must admit at the meetings
with the governing body they’ve really caught on with how to use the loop system...Church when I first started to go, they were thrilled to bits when I first phoned up and said “I’d like to come but I can’t hear and I can’t see and I’m worried” “Oh I’m so glad I’ve just had an induction loop put in!”.” [4]

“But yes it would be embarrassing if I didn’t say to people “can you sit on the right of me?” And if I have to have people sitting on this side of me I just say “I hope you don’t mind if I turn my head round like this but I have no hearing on that side”.” [2]

The eldest participant for example displayed a degree of communicative confidence which illustrates that it need not be limited to those who are younger:

“I am a trustee director, and we go to meetings every 5 to 6 weeks. I’m computer literate, use talking books from the RNIB and my eyes and ears are sitting opposite me, [pointing to his Sense worker] we go out 2 to 3 times a week don’t we?” [6]

One participant in particular showed a courage and tenacity to try and maintain her independence, even under very challenging circumstances:

“Coming back you go to the bus station which is a terribly noisy environment. The b*****d buses they swap, there are two bays and they don’t always come into the same one. So my solution was I did an A4 sign which I have. I have it double sided. And it says “I’m blind and profoundly deaf, please could you help me to get on the 86 thank you very much”.” [5]

But it was also good to note that the same interviewee demonstrated a realistic attitude towards her communication needs:

“I have a friend who I met at university within the last 8 years or whatever, and she has a hereditary deafness. And it’s declining all the time. And she is struggling with life. And she said “Oh well as a family I think we’re going to go to sign language classes” and I said “Oh well that’s great but do you think the lady who works in Marks and Spencer’s can sign?” I said “I don’t want to be a killjoy but you’ve also got to learn to take control of the situation yourself whether its lip reading to the best of your ability or whatever. You need a combination of things. Signing is not just the solution” [5]
The interviewees also demonstrated a formidable degree of communication confidence and assertiveness when it came to accessing services:

“But nobody tells you, you see if you don’t know and you don’t make enquiries. For us of course we got a sort of rebuff you know. “This is what the NHS provides and that’s it”. Everybody’s the same. And I said “Well no not everybody is the same! A lot of people are sighted. And that’s different. They can see traffic coming they don’t have to listen to it. They can see it! So I think anyway we’ve put over a good case.” [6]

4.2.2. Technology

“I love my gadgets!” [8]

All the participants talked about their use of and attitudes towards technology and enthused about it, recognising that it helped them to maintain independence and improved their quality of life:

“So getting around the flat is easy, and of course I’ve got my gadgets, I have a talking microwave, talking computer and bell.” [1]

Interviewees were proactive in finding out about new technologies that might help them; 6 participants described attending private clinics, conferences and exhibitions to find out more about technologies that might help their hearing and vision loss.

4.2.3. Hearing technologies

Passion for technology was most clearly demonstrated when participants were asked to talk about their hearing technologies. All the interviewees talked about hearing technology with informed enthusiasm:

“I totally rely on my hearing aids because I can’t lip read anymore because my visual acuity has gone. I have no measurable field of vision left- I am so reliant on my hearing aids now, I don’t know what I would do without them!” [9]

“My hearing aids- couldn’t manage without it- it’s the first thing I put on and the last thing I take off!” [8]

“Oh they are fantastic- they’re far clearer- I can hear more conversation!” [6]
However, they also recognised that both for themselves and for other users, hearing technology was far from perfect. Six of the participants commented on the difficulties they have trying to work out where sounds are coming from and two criticised their current hearing aids for not providing them with better directionality:

“I can’t hear traffic and I have never had a directional sense of hearing ever, so I’ve always made mistakes working out where sounds are coming from- she keeps me safe in so many ways!” [9]

“Yeah because they [the hearing aids] are only in 1 direction so I always find it confusing to be honest. I prefer to take them off rather than wear them” [1]

“You get a distortion and you can’t hear anything that’s going on. Which was quite serious really because then I didn’t know, without being able to hear traffic, to cross roads you see. And the other thing with the NHS standard hearing aids, the microphones are not sufficiently orientated to receive signals from way behind you know. Not directly behind. So again that’s another problem.” [6]

One participant expressed her excitement at the possibility of trialling new hearing aids which might help her to locate where sounds are coming from:

“I think the next lot of hearing aids I’ll be trialling if they let me, I’ve been asked if I’ll do it and I’m really keen. They’ve got directional hearing. So I’m really keen to try those. Because like I was saying, me going out with my guide dog it’s so important to know which direction the traffic’s coming from. Or if I’m in conversation which direction the person who’s talking to me is.” [4]

Four interviewees talked about the difficulties of handling and managing hearing aids when you can’t see and are struggling with manual dexterity— even the simple tasks of cleaning and maintain hearing aids are so much worse when you can’t see, and the perils of dropping hearing aids on the floor and then spending hours trying to find pieces were mentioned by a number of the interviewees:

“They are quite durable, they are better than the analogue ones, but the problems I have with them they come apart very easily. You know there are 3 bits to them, the mould, the tubing and the battery compartment. Well the batteries are fine, I used to have a problem with putting them in at one time
but you find a method, you find a method to do everything and you stick to it—
that’s the easy bit! But sometimes you get where the hook is starting to wear out it tends to fall off the tubing and then the tubing itself tends to wear out
very quickly, build-up of wax and because I get very hot, I tend to have waxy ears—now that is something they could improve I think” [1]

“Going back to the design, I really dislike having to open the drawer of the hearing aid to turn it off at night. When I take my hearing aids off there isn’t an off switch! I can manage because I have small fingers but I know people who have real problems!” [4]

“Well of course the other problem we have is cleaning the moulds. There’s nothing that’s been invented for a blind person to clean these hearing aids. And because the very fact that you wear hearing aids produces more wax than if you didn’t have them. So that’s another big problem. And I put mine in hot water to clean them but it must have been boiling because it melted! There all a funny a shape and I thought no wonder I can’t get them back in my ear! I thought well I must have the wrong one, this is the left 1 or something.” [6]

“Because I mean especially blind people, you put things down and you can spend an hour on your hands and knees feeling where you’ve put them.” [6]

Because of these practical issues, all of the participants felt that deafblind people should be allocated spare sets of hearing aids or speech processors to keep at home as a matter of routine, and not just as a favour from a particularly concerned audiologist:

“Actually what my situation highlighted for the implant centre was that anybody who is deafblind should be entitled to a spare processor” [5]

“ And I insisted, because I knew my rights, I’ve made sure that I’ve got spare hearing aids because I’m deafblind, because I’m blind as well I’m entitled to spares.” [4]

There was also a feeling from the interviewees that NHS hearing aids, although better than ever before, were starting to fall behind those offered by the private dispensers:

“I feel that the private hearing aids are getting more sophisticated, more technological and the NHS ones are lagging behind— they are using the older sort, the older digitals and the cheaper ones” [1]
One participant talked about his delight at being fitted with new state of the art hearing aids from a private dispenser, whilst also expressing his frustration about not being informed that such technology was available:

“Oh fantastic. I mean they’re far clearer, I can hear more conversation, there’s no wind problems at the moment... they’re brilliant. But I mean the fact that they’re there and you’ve got to fight to get them...If I hadn’t gone to that private clinic with that private showing I would never have known.” [6]

This enthusiasm for their hearing technology, coupled with communicative confidence allowed this group of individuals to articulate their hearing needs very clearly in the audiology clinic, which tended to make them popular patients:

“The reason they like me is that they don’t have many people who can cope with the new technology and I’m like “what have you got? what’s newest?”” [5]

Crucially the group of interviewees did recognise that within the deafblind community they were a particularly special and proactive group. Of the people we interviewed, six were active members of groups and committees associated with sensory impairments or other disabilities and six participants recognised that not all deafblind people are as happy or comfortable wearing hearing aids as they are:

“And the other thing, because we used to have a blind club, half the people who were there didn’t wear hearing aids. Because there was a bit of a stigma attached to them. And I could never understand that. Because you know when you had a meeting and they’re all saying “What did she say?” and it disturbs the whole thing.” [6]

One who had been deaf since childhood stressed how valuable her lifetime experience of deafness and using hearing aids could be, and expressed a strong desire to pass on her knowledge to others:

“But most of what I know I’ve picked up over a lifetime. This is why I’m so keen to pass on all that I know to other people. A lot of the things I’ve found out are from people telling me you know, word of mouth, recommendation. Not from the experts, all that I’ve found out about hearing aids I haven’t found out a damn thing from them. It’s only a small percentage is what I’ve been told by hearing services. It’s all my own experience of using them.” [4]
Another participant had already gone ahead and set up a support group:

“cos we’ve set up a group which is working with people with hearing loss and we have a lot of people referred to us, but we are only a voluntary group, we are just a group of people who meet up once a month and get together, but the social services are referring people to us for equipment advice and we are not people who can give equipment advice, we can only say what we have got” [8]

4.2.4. Assistive Technologies

The participants were not only passionate about their hearing technologies but also about using assistive technology to help their hearing losses- even the slightly more mature participants felt that age was not an excuse for engaging with new devices.

“And this is connected to my mobile phone, the landline the television and a microphone that my companion can wear and it just Bluetooth’s it. And I’ve got this cord that plugs into it so I can use it on my talking books and my computer- it’s absolutely brilliant!” [8]

“Because I am a technology junkie I borrowed this thing from the implant centre- a digital portable loop system- it was brilliant! In restaurants, the way I had it set up, rather than 80 % gadget I had 100% gadget so that I could literally communicate with who was there, cut out all background noise” [5]

“I think I need to learn so much more about hearing aids and new technology and just because you are getting older, they think you are not capable, but you have to try and keep up with it!” [9]

Four of the participants did express dissatisfaction with access to assistive technologies, especially as in some cases, the expense of such equipment was an issue:

“I know my streamer and my blue tooth mic is way out of date now. And [audiologist] said to me about the Phonak thing “Oh well of course you’ll need to get this and you’ll need to get that” and I was just like “It’s all extra accessory packs that I don’t think I can afford it” I’m going to get this great new processor and great new hearing aid and ‘I’m going to struggle to afford the accessory pack.” [5]

Five of the interviewees felt strongly that more assistive technologies should be available for loan; as one participant mentioned, this already happens with guide dogs:
“I just think there should be more facilities for even renting the equipment... Well I mean I rent a guide dog? He’s 50p a year.” [5]

4.3. Deafblind awareness

“It’s an invisible issue- not like being an amputee! [5]

4.3.1. Health Services

The perceived lack of patient focused care was linked with another strong theme to emerge from the interviews; the lack of awareness of the needs of deafblind people. Unfortunately, the interviewees talked about this most strongly when they described a range of bad experiences of health services. One who had suddenly lost both her sight and hearing talked at length about her bad experiences as an NHS inpatient:

“We were having to put signs on stuff. But when they’re coming to try and tell you what medication they’re going to give you...just because I’m deaf and blind does not mean I’m stupid. And they would give me something to take and I’d ask what it was and they’d say “Why do you need to know?” and I’d say “Because I’d like to know what I’m swallowing please”. I just found it... they’re preconceived ideas I suppose. And I know it’s difficult because this particular situation is very rare. And therefore how many people will really have come into contact with it. But it’s lack of common sense. Lack of courtesy. It wouldn’t take a rocket scientist in the nurses’ room to put a sign on the wall, “Patient in bed bla bla is...” And I find that quite astounding. Stupid things like they’ll put the menu card and no one will tell me it’s there and so it won’t get filled in so there’s no food for you. So I dread having to go into hospital. I don’t like doctors, I don’t like hospitals, I don’t trust many of them.” [5]

An older participant described the experience of feeling abandoned in an NHS outpatient clinic:

“I used to be in the hands of the driver of the car and they just put me into the clinic and leave you there. And then when your name’s called you can’t hear it. And you sit there and you sit there and the clinic’s nearly finished. And someone comes up to and says “What’s your name? Oh you should have been seen a long time ago!” now you’ll have to wait until the end of the clinic. I mean this is another thing really... Well again you see when you report into the clinic the person who’s taking you in should note that you can’t see and draws attention to whoever’s going to call you to say “Look go and get him.” [6]
4.3.2. Opticians

All of the participants had regular contact with services to support them with their sight loss as well as their hearing. There was a feeling from the majority of the interviewees that the 2 departments operated very separately and didn’t work together to provide services to deafblind people. There was also a feeling that the professionals in the two areas had very little understanding of the other sensory impairment. For example:

“I guess audiologists just concentrate on the ears and opticians just concentrate on the eyes- but say you go to the audiologist and you have an eye problem I don’t think they understand, you can’t lip read and things like that. I do notice that when I take a lady to the eye hospital and I say she is deaf, she can’t hear what you are saying, they just carry on talking” [8]

One talked about an issue she had when she attended a local opticians, which highlights the need for deaf awareness training for this group - it’s possible that even small changes in service delivery or raising awareness of the needs of deaf people when they attend sight tests could improve services:

“It’s like when you go to the opticians, you are in a dark room. And then they start talking to you! You can’t lip read them! And they don’t seem to take on board that I have a hearing loss! So it’s difficult! There was a time when I was off to the opticians, quickly put my hood up and dropped my hearing aid in a puddle! I felt I had to go to the appointment, it was too late to cancel it, I was there! So I told them. I’ve broken my hearing aid, it fell in a puddle and they just put me in a dark room and I didn’t hear anything! She just disappeared! Luckily my friend works there and she told them, you are talking to her, but she can’t hear you” [8]

4.3.3. Audiology and ENT

The majority of interviewees spoke about the lack of deafblind awareness within audiology services. A typical comment was:

“I do remember because of my sight impairment- there was 1 incident of sitting in the waiting room after I’d had the hearing test, they told me to go and sit in the waiting room and everybody seemed to have gone, and left the building and I was still sitting there- and the person came out, the audiologist and said “ what are you still here for?” and I said “you told me to wait!” and she said, “well, I’ve given you your hearing aids!” “No you haven’t!” “I put them on the chair next to you!” literally you need to take my hand and put it in because I can’t see!” [9]
A support worker also described how an elderly woman she supports almost missed her appointment completely:

“Well I have one client who’s an older deafblind lady. She’s aged around 86 I think...I’ve actually forgotten the exact age... so she has to wait and wait and wait at reception for a long time because she couldn’t hear it. You know, audiology should know that deaf people are going to be going there!” [7]

Of the 9 deafblind people interviewed, 4 felt that training and support for audiologists working with deafblind people was lacking:

“Top of the priority is training around sensory awareness and if they get that right then we shouldn’t be having these problems” [9]

The most striking example of lack of deafblind awareness came from the only cochlear implant user who we interviewed, who said that even as an inpatient on an ENT ward, deafblind awareness was lacking:

“They didn’t know I was blind 3 times. You have a cochlear operation as you know you’ve got the b****y great bandage, they’re standing on that side of the bed trying to talk to me and I’m going “Sorry?” They should know I’ve had an ear operation...I was in the ENT ward but I didn’t feel they had the skills.” [5]

4.4. The journey through hearing services

4.4.1. Good practice

We asked the interviewees for their opinions of audiology services in some detail, and also asked how services might improve for deafblind people in the future and where others might learn from good practice.

Five interviewees described examples of good practice within their current audiology services, where simple changes in administration have made a big impact on deafblind peoples’ ability to access the services. These included some departments making sure the deafblind adults had spare hearing aids at home, as mentioned previously and departments improving waiting times so patients don’t have to wait so long:

“In October 2010 I got my new hearing aids and I got a spare set of hearing aids, but they also let me keep my old ones- so I now have 3 sets! But I’ve never gone back to my old ones cos these have been the best I’ve ever had.” [9]
“The staff are really good there. They’ve now got an appointment system which means you don’t have to wait so long when you’re there. – it’s not like the eye department where you can wait for 4 hours” [3]

“Well, I have a really good service when I have had hearing aid problems. I’ve e-mailed and they have come straightaway or they send the hearing aid through the post special delivery and I get it the next day, so that is an excellent service. And when my screw came loose for the BAHA attachment I e-mailed, I was frantic and they said come straight over!” [8]

4.4.2. Information sharing

A person centred approach utilising tools such as the ‘individual management plan’ (IMP) to improve the quality of audiological care and patient experience is essential given that NHS services are now in direct competition with alternative providers. Part of this approach means that sharing information with patients about their hearing loss and its management is a crucial, therefore we were interested to find out how the participants receive information. One interviewee had been impressed by the audiology department’s willingness to think flexibly and adapt materials for him to access information:

“They sent me away with the book for my hearing aid and they tried really hard to photocopy it up and everything” [3]
But on the whole, the interviewees were dissatisfied with the lack of accessible information for deafblind people. They expressed concern about the lack of appropriate generic materials for deafblind people around hearing and assistive technology and management. Interviewees felt that there was a link between the lack of appropriate and accessible information and professionals’ lack of deafblind awareness:

“I think a lot of it is just lack of awareness, like they give a blind person a printed manual!” [4]

“There is nothing at all for hearing. You never get any guidance. Sensory impairment is very neglected” [2]

“I think information about maintenance. Somebody ought to have devised some system where people with poor sight are given some method of maintaining their hearing aid- actual information” [2]

“I think I tried to get large print- they tried to get it from the supplier and they couldn’t get it. but that’s across the board I think, if you go to the supplier they won’t provide it, but if you go to the government their regulations say that everybody should be providing accessible information, but they don’t” [3]

It wasn’t just the inaccessibility of written information that the participants were concerned about, they also expressed concerns about how information is conveyed verbally to deafblind people by audiologists in clinic appointments:

“I think it’s criminal. That they’re sending people out with hearing aids and not giving them the time to explain things quietly in a way that an elderly person who’s upset anyway because they’ve got to have an hearing aid will understand. And they’re just not giving people time. It’s always a rush. I’ve often thought the audiologists do the hearing tests they fit the hearing aids and then send people away who are confused, upset, stressed, perhaps been on their own, perhaps a family member’s with them but doesn’t understand it either...And yes they need to get the hearing aids fitted but perhaps, even if it’s not the same day, a week later maybe, just have somebody to explain in a quiet environment how to use it.” [4]

“But when they give you the information to say what to do next, at the audiology clinic, I still didn’t pick it up, you have a lot to retain, and of course, I can’t see to read. For example, I taught myself to use the computer, I’m a computer user, if they gave me a link to look at so I could look and hear on the computer in my own time and speed, to read the instructions” [9]
One gave an example where poor communication in the clinic had resulted in her struggling with her hearing aids for two years:

“This time what they did was, I went into another room and the person who gives you the hearing aids sits there and does it on the computer straightaway, and he said “well you are never going to be able to read the instructions, so I will take you through the instruction. He wanted to make sure I could change the batteries on the hearing aid because I can’t see to do that- I still make mistakes and some days are worse than others, but what I didn’t realise and he told me- it’s just a rocker switch and if you bring it up a bit, if you touch it once it will get louder- it never did! I struggled in meetings- I needed to use the hearing loop- always do- but I was really struggling, the concentration, I’m sure I have frown marks- you are not going to believe this- I’d had my hearing aid for over 2 years- I was so frustrated and my finger, it was almost like a twitch I went 1, 2, 3 [shows twitch of finger] and the sound that came through my hearing aid- I nearly fell over backwards! And I’d gone for 2 years living with hearing aids I could barely hear anything with” [9]

4.4.3. Person centred approach - partnership

Despite this group being confident and competent around both communication and technology there was a feeling that hearing professionals did not always appreciate them as individuals and listen to their needs and expertise. When the participants were asked to talk about their experiences of audiology services, participants conveyed the impression that the professionals were firmly in charge and that they were expected to be passive receivers of audiological care, rather than the active partners in their hearing management that they wanted to, and had the capability of being. One described her frustration at not being treated as an individual:

“I don’t think in my current experience it has gotten better at all, I just feel like I am just being given some tests that come up on the computer and that’s it- there’s no relating to me” [2]

She and her husband commented ruefully that:

“we’ve learnt more about what goes on from audiologists that we’ve met on consultancy groups than we’ve learnt from the audiologists that we’ve met in appointments” [2]

Another participant expressed his dissatisfaction when he consulted the audiology department about his severe tinnitus- it seems as if his disagreement
with the audiologist over his hearing technology led to a loss of confidence in the service:

“I had problems with the white sound, they had to send it away. Then it came back and the audiologist said “it’s working perfectly” and I said “well not in my ears it isn’t!” and they did nothing about it” [10]

Three experienced hearing aid users described situations where their own expertise around managing their hearing needs were either ignored or not sought. One felt that her safety had been compromised when making the switch over from analogue to digital hearing aids:

“When I had analogue they gave me a spare hearing aid- when I got digital, they wouldn’t let me keep my analogue so that I got used to my digital- what it did cause me was to place me into danger by doing that- because I could hear sounds that I’d never heard in my life, and when I went out, I nearly got run over because I don’t know what direction to look in and I couldn’t rely on my eyes either to give me that information- I got lost in very familiar places just because of my hearing aids- I feel they didn’t give me that time to transition from analogue to digital- they took the analogues away and I was really lost. I got used to the digital aids but it took a long time- I would say it took 18 months to 2 years” [9]

Whilst another who had been deaf since early childhood expressed annoyance with some audiologists who tended to make assumptions about her hearing needs rather than asking for her opinion:

“And another thing I get a bit cross about is very often I think audiologists find it easier to just say “We’ll set your hearing aids so it’s automatic so you won’t have to touch them at all” so basically its things like they can’t alter the volume, if they want to use program three to talk on the phone the other hearing aid goes on program three as well so you can’t hear if anyone in the room is talking to them.. A lot of it is down to personal choice. It’s just taking away that person’s right to choose how they’re going to use their hearing aid and often the person will agree to it because they think it will make life easier because they haven’t had it explained to them.” [4]

This man who had taken a real interest in the development of hearing technology through his career as an industrial designer felt insulted when he visited the clinic for new moulds:
“For example I had to go last week because I had a mould that broke and they got me a new mould. One of the problems is that every time you go to audiology you meet a different technician. They’re all sorts of ages etc. Just as I was going in, my battery failed. I did the usual thing and opened the battery casing. I went in and saw her, gave it to her and she put the new mould on and the rest of it. And I said “I shall need new batteries and I shall want one in this because it’s just failed” and she said “Well of course it has because you’ve opened it!” And I said “I opened it because it failed!” But I don’t think she understood the point I was making at all. That’s typical of the kind of rapport you get with these people all the time.” [2]

There was one notable exception. The only BCHI user to be interviewed talked at length about her great partnership with both the audiology service and the manufacturers. She commented on how much she appreciated being listened to and treated as a partner in her hearing management:

“And they do listen to me, they don’t say this is how a hearing aid is, that’s it, wear it. They listen to my needs and adjust it accordingly. So understanding and listening to your needs is very important!” [4]

Interviewees also made it clear that their experience of attending appointments for audiology were completely influenced by who they happened to see on the day:

“It’s the right people to be honest, you hear all this talk about the NHS and this and that- there are good people out there, you just have to meet them!” [1]

“I really think it depends on who you get. If you get a really good audiologist then it’s brilliant. You get the right hearing aid and the right device. But if you get someone who doesn’t really understand, or they are in a rush or can’t be bothered, it’s awful! But I think a lot of it is that they are just too pushed for time.” [4]

The interviewees also agreed with the other participants who completed the online questionnaire that having named audiologists with better awareness of the needs of deafblind patients would be beneficial, providing the professional was right for the job:

“This was a question in the questionnaire I remember, to actually choose which audiologist I want to see. But then of course you could get the wrong person doing that job, someone who’s no good at it. And people like myself would have no choice but to see that person.” [4]
4.4.4. Access to services

The interviewees were asked to talk about their experiences of accessing audiology services and they described some of the difficulties they encountered, particularly when trying to book follow up appointments. There seemed to be little understanding within this group of how often they should be going back to audiology for follow up hearing checks which was in marked contrast to the appointment system for routine eye check-ups for example,

“I’m not sure if I’ve got to go back for a hearing test again, I don’t know, how it works. Do you have hearing tests like eye tests” [3]

“And the optician of course, I go every 2 years now for an eye test [Interviewer; “how often is it you go back to audiology?”] Well, that’s up to the individual to sort out” [6]

Even if the participants wanted to go back, there was uncertainty about how to go about that; some felt that they needed to be re-referred via their GP, others felt it could be done via a phone call- easier said than done with visual and hearing impairment:

“They said [the audiology department] that they would recall me every 2 years, but I never got any recalls I had to keep re referring back through the GP- it’s been over 2 years and I know I desperately need to go back because something has happened to me hearing- so I don’t know if it’s every 2 years or every 3 years and I’ve not had a recall” [9]

One of the oldest interviewees summed the access issue up particularly clearly:

“One of the things I would change would be the appointment system. I’ve seen four different consultants at the hospital and every time I’ve seen either consultant I’m given a note for my next appointment that day at the appointment. That never happens with audiology and as far as I’m concerned it’s a blank. I’ve never actually been called back or made an appointment in advance. It may well be that nothing has changed and everything is fine and I don’t need a call back. But it’s not for me to decide that. That is for the audiologist to decide” [2]

The one participant who spoke about the length of time she had to wait for first fitting, rather than follow up appointments, was the only cochlear implant user in the study:
“It was disappointing going back to the length of time I had to wait. A hell of a wait. An unforgiveable wait. For somebody like me who really has bust a gut, who tried to rebuild their life, I do think it could have made a profound difference if I could have had it sooner” [5]

The interviewees also talked about difficulties having to travel, often many miles, for repair services based within hospitals even when the problems were minor ones. The eldest in the study described his most recent contact with hearing services:

“This is what we had to do this morning; we called the audiologist in [places name] and we actually have got to go and see them tomorrow to get the tube to go back in the ,mould- that’s a 30 mile drive for tubing. I’ve waited a week for tubing” [6]

His experiences were echoed by another gentleman, who commented on the wisdom of using expensive hospital based services to solve problems which could be sorted out much more expediently:

“Hearing aids are wonderful things, but they’re horribly fiddly. And the only place you can really get anything done to them is at a hospital. Or if you’re lucky specsavers. If you’re hearing aid fails because it’s got a bubble in it or something. If it’s somebody who can’t see or someone with less dexterity than required, you just go deaf until somebody rescues you. And when you get in
touch with the hospital and say “My hearing aid needs replacing”, they say “Ok we’ll give you an appointment next week”. What are you supposed to do until next week?” [2]

One interviewee had most recently lost her sight and hearing through illness. She described a situation in which equipment was withdrawn from her, purely on the basis of her postcode, illustrating how a patient’s urgent needs may be overshadowed by financial pressures:

“I had started to notice I could hear these sounds. But he sent me to audiology at [clinic name] and they were arranging to lend me this set of headphones with a power box. And she went through it all, showed me how it worked and she looked at my address and took it off me and said you can’t have it. You need to drive to [other clinic] and get one off [other clinic] not [this clinic]. And that was last year. And she even...they took a mould of my ear to get a mould made for the hearing aid and because of funding she wasn’t going to pay to send it to the mould company she was going to send it in the internal post to [place name] so they could pay the postage.” [5]

4.4.5. Service improvements

We asked all the interviewees for their views on how audiological services could be improved. One interviewee felt that the NHS should no longer be the provider of hearing services to deafblind people:

“I think they should be taken over by a private company, with brand new sets of hearing aids having done research on a random set of deaf people, either sell their products at a cheaper price, or find some way of loaning them out” [1]

Others felt that services could improve if audiologists were provided with better support and training around the needs of deafblind people:

“Well my wish for the audiology department would be for them to have a better service for deafblind people. To show some empathy, also make their services better. They need to think about deafblind people and how they give their services to them. They should be aware of deafblind people they should have some training! My wish is to see a fantastic service, for them to improve appointment booking systems and think who they’re going to see in emergency.” [7]
And finally, one gentleman described his experiences through hearing services as:

“Rocket science subjected to peasant servicing” [2]

A very strong statement but one worthy of scrutiny and debate.
5. Discussion

Very little has been previously documented about deafblind people’s perspectives of audiological services and experiences of hearing technologies. This study employed a mixed methodology including quantitative and qualitative measures of enquiry. The findings have provided an in depth description of the effects of hearing loss on deafblind individuals and the wide range of impact on their everyday lives. The interviewees spoke in detail about the challenges they face to maintain connections with the world, and described the psychological and emotional toll deafblindness has had on their health and emotional wellbeing. The range of experiences shared highlight the significant impact deafblindness had on all facets of their daily activities, consistent with findings from previous studies (e.g. Ciamorelli and Jopp, 2014).

5.1. Technological self-efficacy

The participants in this study embraced a range of advanced assistive technologies which enabled them to improve their quality of life and reduce the impact of deafblindness on their everyday living. In particular, the quantitative results highlighted good use of hearing technologies amongst participants. The interviewees were all passionate users of their hearing technologies and in some case other assistive hearing devices. Their increased use of many forms of advanced and everyday technologies seemed to influence their confidence and competency with their hearing technologies.

This supported the findings of Gonsalves and Pichora-Fuller (2008) who reported that the cohort of participants who used technology (computer, internet, email, fax, ATM) used their hearing aids significantly more. In contrast, Ham et al. (2014) reported the that use of everyday and advanced technology is not a factor in the uptake and use of hearing aids in older adults. Influencing factors reported in their study were age, gender and whether participants lived alone or with others. Their finding that technological competency had no influence on hearing aid use was counterintuitive, however their focus was on older adults with an age range of 60-95 years (mean age 72 years).

In comparison, the participants in this study had an age range of 29-94 (mean age 59 years) which may have a bearing on the reported technological confidence in the current study and explain the differences between the two results. It would be interesting to further establish the findings reported by
Meyer et al. (2014), specifically in relation to deafblind hearing aid users and non hearing aid users, on the influence the added sensory deficit had on the factors they associated with the uptake and use of hearing technologies.

Visual deficits alongside hearing loss have been reported as a large contributing factor for individuals with hearing loss choosing not to adopt hearing aids (Kochkin, 2007). Hearing aid management includes tasks such as earmould insertion, battery replacement, identification of hearing aids and controls. Previous research has identified each of these tasks as daunting for older adults with visual disability (Erber, 2003; Jennings, 2005). Meyer et al (2014) reported participants who were hearing aid owners were less likely to report adequate hearing aid self-efficacy if they also reported visual disability. They reported visual disability as the key factor influencing confidence in the ability to manage the ‘advanced handling’ of their hearing aid (Meyer et al. 2014).

In comparison the majority (90%+) of participants in the current study reported being able to manage ‘inserting earmould’; ‘replacing batteries’, ‘identifying left and right’ and managing the ‘controls’ of their hearing aid on their own without any support. The majority of participants in this study were established hearing aid users and reported good management of their devices indicating better hearing technology competency compared to the participants from the Meyer et al. study (2014). Consistent with findings from Meyer et al. (2014) this group of participants did report some difficulties with hearing aid management but this was only reported for the cleaning of their aids, where 28% reported not being able to manage and 16% felt they could manage with support.

Hearing technologies are not without their limitations and the quantitative findings from the GHABP responses in this study highlighted the difficulties associated with listening in background noise and following group conversations. Situations particularly difficult for all users of hearing technology are expectedly even more difficult for deafblind people who are unable to use their sight to monitor the environment and utilise visual cues. Consequently, careful consideration is needed regarding the hearing device settings, especially with regard to noise management strategies. To our knowledge there has been no research into hearing technology programming for those with deafblindness. Information gained in this study indicates that devices may require programming very differently to those with hearing impairment only and this should therefore be investigated further.
The participants in this study enjoyed trialling new technologies to improve their listening experiences and had strong opinions about how their hearing needs were different to those without sight loss. More than half (55%) of participants to the survey reported using assistive devices and accessories with their hearing device. These devices weren’t restricted to the basic assistive devices such as alarm clocks or doorbells but included a wide range of advanced hearing technologies including proprietary devices used with their model of hearing aid e.g. ComPilot with Phonak devices and ConnectLine with Oticon devices. The use of loop systems, both personal and room based, were very popular amongst those surveyed.

These findings help to alleviate some of the concerns reported by Jennings (2005) of vision problems making it more difficult to handle assistive devices. It would be expected that visual deficits would make the management of additional devices more difficult, however in this study the benefits perceived from such technologies for those with deafblindness outweighed the common difficulties associated with them. The findings from the current study are consistent with the recommendations by Kricos (2008) who reviewed the need for hearing assistive technology for older individuals with dual sensory loss. The potential benefits she suggested included improved speech perception, connection and orientation with the environment and enabling greater mobility.

All these benefits were reported by the participants in our study who had made use of assistive technologies. It was clear from the interviewees that in their opinion, deafblind people need as much access to hearing technology as possible and they need that technology to be well fitted, to ensure that they can use audition to monitor their environment, help them locate where sounds are coming from and cope in a variety of different listening conditions. Deafblind individuals reported attending conferences, exhibitions and private hearing clinics to find as much as possible about hearing technologies.

5.2. Access to information

Accessible and appropriate information about hearing technology and services is an important component of good audiological practice and there is clearly a greater need when dealing with deafblind people. Survey responses identified that information sharing with this group of individuals in all aspects of audiological care was mainly done verbally. The provision of written information was limited (13-14%) and where provided was not always accessible and did not take into consideration the group’s visual needs.
The use of electronic means (internet/email) of information sharing was further limited with only 3-4% of participants reporting this method of information sharing being employed by their audiologist. The lack of electronic means of communication was deemed a missed opportunity by some as many deafblind individuals were better able to access information electronically through the use of assistive software and devices. Half the participants felt the level of information shared regarding technology options and aftercare services was insufficient by being either brief or not shared at all. Interviewees further emphasised their dissatisfaction with the lack of accessible information and appropriate generic materials for deafblind individuals.

Recent evidence on the suitability of hearing aid user guides has emphasised similar concerns. Caposecco et al. (2014) analysed the suitability of 36 hearing aid user guides for older adults and rated 69% as unsuitable and 31% as adequate, with many scoring poorly on scope, vocabulary, aspects of layout and typography, learning stimulation and motivation, and too high reading grade levels. They concluded that hearing aid user guides are not optimal for older adults, require a great deal of improvement and they raised concerns that this may impact the successful use of hearing aids. This concern would be expectedly greater for deafblind individuals who may also require different formatting such as larger font sizes, use of matte paper, black text on white background, greater between line spacing and particular fonts (sans-serif) to make it easier to access text (see for example Caposecco et al, 2014; Kricos, 2008).

Similar concerns were found for the quality and readability of internet information on hearing loss and hearing aids. Laplante-Levesque et al. (2012) assessed 66 websites searched through the most commonly used search engines and found the readability and quality of the websites was highly variable. The reading age of the majority of websites was too high and only 14% had Health On the Net (HON) certification. Non-profit organisation websites were found to have the highest DISCERN (www.discern.org.uk) scores compared to commercial or government websites. Reichow et al. (2013) compared the quality of websites related to developmental disabilities in general. They evaluated 10 characteristics of 208 unique websites of which only 104 (50%) were found to provide relevant information about the disability being searched.

The websites found to be of the highest quality were those from non-profit organisations, contained references from peer reviewed publications, had
a domain of .gov or .org, were not a sponsored result and did not contain advertisements. Almost half the participants (49%) from a survey of over 6000 adults (Hesse et al., 2005) reported seeking information from internet sources first, compared to 11% going to their clinician first, highlighting the importance that internet resources hold for health related information seeking. Clinicians would benefit from selecting internet health information of high quality and readability and ideally guiding deafblind individuals to reliable non-profit websites and useful rehabilitation sites for intervention purposes. Reliable and accessible internet information should be monitored regularly by clinicians for the benefit of deafblind individuals who may find it easier to access information through electronic means.

A recent review of health websites found many were not accessible by individuals with visual impairment (Davis J., 2002). Deafblind individuals would be expected to encounter accessibility barriers more often than those reported in studies of individuals with visual impairments alone. As such clinicians could help by ensuring internet resources they suggest to patients are accessible and compatible with the assistive technologies the deafblind individual may use. Similarly, manufacturers of hearing devices would benefit from working closely with non-profit organisations on the content, design and readability of their guides and the accessibility of internet information.

A good example of working with non-profit organisations has been seen recently with NHS England (NHS England, 2014) who have been working towards developing an Information Standard for accessible information which health and social care organisations must follow. They have worked in partnership with key national charities including Action on Hearing Loss, CHANGE, RNIB, Sense and SignHealth. A series of workshop discussion events with different groups of people supported by these charities were also included. The findings from the Sense Accessible Information Workshop (NHS England, 2014) highlighted the many difficulties deafblind individuals had in accessing information through NHS and social care services and corroborated the findings from this study.

5.3. Service provision

A strong link between the lack of appropriate and accessible information and professionals’ lack of deafblind awareness emerged from the participants in this study which directly impacted service provision. Overall, the questionnaire results demonstrated encouraging levels of satisfaction with audiological services in particular for the process of obtaining hearing technologies
e.g. referral, assessment and fitting services. The majority of participants also reported satisfaction with the amount of time they were given for appointments.

However a noticeable deterioration in levels of satisfaction was reported with regard to aftercare. Dissatisfaction was reported by 29 - 36% of the participants for repair services, ongoing support, upgrade opportunities and service information. The option of domiciliary visits for repairs was only available to 11% of participants yet 39% of participants reported being seen after 2 weeks or more for a repair in clinic. The delay in repair service provision raises genuine concerns, especially for this group of individuals who as a result of their deafblindness are more reliant on their technology and 58% reported not having access to a spare device. The findings highlight for many participants the service they received fell below the specifications of the AQP implementation pack (DoH, 2012) which state “Patients should be able to access aftercare services (via face to face or non face to face methods) within 2 working days of the request”. This evidence raises significant concerns that services are failing to provide deafblind people with follow up opportunities and aftercare that would support and improve essential use of hearing technologies.

Interviewees were able to highlight specific incidents and reported a general lack of deafblind awareness within audiology services. A lack of training and support for audiologists working with deafblind people was expressed. These concerns were supported by the findings from NHS England workshops (NHS England, 2014) where a need for improved training for health professionals was expressed. In the case of audiologists these concerns hold much more weight compared to general health and social care practitioners.

In recent years, there have been significant contributions to the literature on the need for adopting a person centred approach to hearing rehabilitation (for example Laplante-Levesque et al., 2012). Although a clear definition of what exactly person centred audiological rehabilitation should be considered (Grennes et al., 2014a), in general an emphasis on trust in their therapeutic relationship with their audiologist was a key factor (Grennes et al., 2014b).

Person centred communication characteristics are also a core component of the audiological counselling workshops developed by English and Archbold (2014). Unfortunately, for the participants in this study there was a feeling that a person centred approach, which values the opinions and experiences of the deafblind individual, was lacking in some audiological practice. This
combined with a lack of awareness of the needs of deafblind people lead to disillusionment amongst some interviewees who felt that they needed to opt out of NHS services entirely or fight to access the services they needed.

Appropriate support has been shown to significantly improve scores on outcome measures and demonstrate a substantial impact on quality of life for individuals with sensory deficits (Davis, 2012). The reported lack of follow up appointments being offered to many of the deafblind participants in this study was concerning. Current AQP specifications require follow-up appointments be undertaken within 10 weeks of fitting and that patients should be offered a choice of a face to face or non-face to face follow-up (DoH, 2012). Meyer et al (2014) report the importance of working in collaboration with individuals with dual sensory loss to determine their hearing technology needs to facilitate optimal hearing aid self-efficacy. Kricos (2008) provides detailed considerations that audiologists should focus on including, pre-fitting and fitting of technology, post-fitting support and changes to practice settings that would benefit deafblind individuals and older adults.

Improved room illumination, increased contrast and reduction in glare are simple steps that can have a positive impact on the visual environment in which deafblind individuals are offered services. Similarly, collaboration with vision specialists was recommended in the best audiological practice for patients with dual sensory loss (Kricos, 2008). This would help provide useful information for the audiologists regarding the patient, for example on their visual acuity and contrast sensitivity.

The importance of helping professionals develop good working practice has been a concern of Sense for some time. Snow and Telling (2011) conducted
research with Sense investigating the use of video analysis to improve skills development and expertise of Sense staff working with deafblind individuals. The findings highlighted that the training, which included video analysis to analyse practice, improved staff practice, raised staff confidence, improved staff recognition of participants’ expressive communication and developed participants’ independence. Similar training tools could be used with audiology professionals to aid their skill development and improve the quality of service for deafblind people. Furthermore as interviewees in this study expressed, many deafblind adults can be an excellent resource and source of support for others in a similar situation and this potential should be maximised and where possible facilitated.

As a study limitation, the findings from this research may not represent the complete views and experiences of those with deafblindness. A concerted effort was made to recruit as many deafblind individuals as possible. Our sample mainly included those who were using hearing technologies and who during the process often expressed an interest in this subject. Given this interest, their opinions could vary from those who have less interest in this subject and therefore chose not to participate.

5.4. Conclusion

In summary, very little is known about deafblind peoples’ perspectives and experiences of audiological services and hearing technologies. This study, through questionnaires and interviews, highlights some important findings on the access to and use of hearing technologies. The combination of hearing and visual impairment often causes difficulties with mobility, access to information and ability to maintain independence even with everyday tasks.

Given these difficulties, this group attribute very high importance to their hearing technologies because they enable them to perform everyday activities and help maintain a level of independence. Their hearing technologies are integral to their quality of life and the loss, even temporarily, of this technology can have a much stronger impact on their health, functioning and activity engagement and further compound the effects of their dual sensory deficits. Audiology services and commissioners need to be sensitive to the combined effects of dual sensory loss and the value hearing technologies can hold for deafblind individuals. Improvements in professional awareness, quality and accessibility of information and long term support would help to provide an optimal hearing aid service and the potential to maximise the benefits deafblind people gain from their hearing technologies.
6. Recommendations

Technology self-efficacy

- Audiologists need to carefully consider the setup of deafblind patients’ hearing technology to help them to monitor their surroundings and access environmental sounds. Hearing aid features such as adaptive directionality and noise management strategies should be carefully considered for this population.
- Spare aid(s) should be offered and any spares must be of an equal quality to those usually worn. If older models are given as spares the settings must be updated according to the latest audiological needs.
- Assistive hearing technologies should be considered more often for deafblind individuals and encouraged where appropriate. Audiologists should be able to signpost towards accessible information sources if not held in house.
- Regular appointments for cleaning of hearing aids should be scheduled in or an alternative support mechanism sought i.e. local volunteer service, such as the national ‘Hear to Help’ scheme run by Action on Hearing Loss.

Access to information

- Deafblind people can learn so much from each other and clinics should try and facilitate, either within the department or through local non-profit organisations, opportunities for them to meet and learn from each other.
- Audiologists should be able to signpost deafblind people to alternative support mechanisms in line with Deafblind guidance, such as onward referral for specialist assessment provided by sensory teams.
- Manufacturers of hearing devices and those that set the criteria for information booklets such as NHS supply chain would benefit from working closely with non-profit organisations on the content, design and readability of their guides and the accessibility of internet information to create user friendly, workable and cost effective solutions. A good example of partnership working with non-profit organisations can be seen with NHS England (NHS England, 2014). Manufacturers should make an effort to follow the Information Standard for accessible information which health and social care organisations must follow.

Service provision

- Audiologists, audiology receptionists and clerical staff should increase their deafblind awareness. Training must enable staff to identify deafblindness
as one condition and understand the impact that this has on the individual both from a clinical perspective i.e. when attending the department and from a daily living perspective i.e. when they are in their own environment. Deafblind awareness should encourage audiology staff to ask the individual what their specific needs are and then help them to achieve them.

• More consideration should be given to the needs of deafblind patients during and around appointments (increased deafblind awareness will assist with this). Services should consult with deafblind patients on the best method of information sharing on services and the layout of materials for technology guides. Some help can be taken on these from their opticians and carers. Alternative methods of communicating with these patients to suit their needs should be considered, for example appointments could be sent by email.

• Audiologists and Opticians may benefit from gaining a basic awareness of the others profession to help the respective professions have a better clinical understanding of hearing or vision loss. It may also assist each to improve their service delivery with respect to the other impairment, professionals could share information and suggest improvements that will ultimately benefit deafblind individuals in their overall care.

• Audiologists need to incorporate a person centred approach and professional training around counselling infused audiological care should be emphasised.

• Where appropriate, the provision of named audiologists who could answer patients’ queries and are aware of their needs should be considered. Audiologists with the knowledge, skills and desire to work with this group should be supported. More than one named audiologist should be available for these patients in case the main named audiologist is not available to ensure repair times are not delayed.

• Follow up appointments must take place to provide the opportunity to discuss the setup of hearing devices and ascertain that they are appropriate and meet the needs of the individual. AQP specifications for follow ups must be adhered to.

• Waiting times for repairs services need to be improved and prioritised for this group of individuals. The impact of hearing aid breakdown may isolate and risk personal safety. Repairs should be prioritised and be within two working days as specified in AQP contracts. Given the immediate impact of breakdown this group should not be expected to wait two weeks for repair appointments.
7. References


DISCERN. Background to Discern. Available from: http://www.discern.org.uk/background_to_discern.php


IHR, GHABP Information Package. Available from: http://www.ihr.mrc.ac.uk/products/display/questionnaires


About Sense

Sense is a national charity that supports and campaigns for children and adults who are deafblind. We provide tailored support, advice and information as well as specialist services to all deafblind people, their families, carers and the professionals who work with them. We also support people who have a single-sensory impairment with additional needs.

Technology can be key to enabling deafblind people to communicate, access information and become more independent. Technology@Sense works with deafblind people and organisations to improve the accessibility of existing technology, to support the development of new technology and to help people make use of the opportunities available to them. Sense Public Policy campaign for the rights of deafblind people, and work to influence public policy to ensure it meets the needs of deafblind people.

About the Ear Foundation

The Ear Foundation is an independent registered charity that supports deaf children, young people, adults and their families to ensure they make the best use of the latest hearing technology to improve communication and spoken language.

Sense have worked collaboratively with the Ear Foundation to complete this research project.

To find out more about this project please contact;
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