



Seen but not heard

People with hearing loss are not receiving the support they need

Laura Matthews
March 2011

Content

Acknowledgements	3
Foreword	4
Summary	5
Introduction	15
Chapter 1: The journey to getting help with hearing loss	17
Problems experienced prior to getting help with hearing loss	17
Taking action on hearing loss	19
Chapter 2: Experiences of health services	22
Experience with the GP	22
Initial experiences with NHS audiologist	25
The private sector	27
Follow-up and ongoing reviews	29
Information	34
Accessibility of services	42
Chapter 3: Hearing aids	44
Expectations	44
Difficulties and problems	46
Benefits of hearing aids	50
Frequency of wearing hearing aids	52
Chapter 4: Other technology and equipment	54
Equipment at home	54
Loop systems	57
Work	61
Chapter 5: Additional support	62
Lipreading	62
Other support	63
Chapter 6: Impact of hearing loss	65
Relationships, family and social situations	65
Work	66
Chapter 7: Personal attitudes to hearing loss	68
Pre hearing assessment	68
Post diagnosis	69
Telling others	71
Chapter 8: Conclusions and recommendations	73
Bibliography	78
Annex: Research methodology	80

Acknowledgements

I would like to thank the participants who kindly gave up their time to be interviewed for this research. I would also like to thank the audiology departments who completed our questionnaire. Finally, I would like to thank my colleagues, and in particular Melissa Echaliier and Madeleine Clark, who assisted with the interviews.

Foreword

Hearing services have a powerful impact on helping people to address their hearing loss, and continue active social and working lives.

The personal and social impact of hearing services is often undervalued and underplayed. With the implementation of substantial changes in health care services, it is now more important than ever that we encourage better recognition of the value of the care and support services for hearing loss. More efficient use of resources and services delivered in the right place at the right time will help to achieve the best outcomes possible for service users.

This new report is timely. It will help GPs, audiologists, commissioners and the government to understand better the importance of high-quality, personalised care and support for people with hearing loss, and the measures that need to be taken to achieve this.

The report throws a spotlight on current trends and patterns within audiology services, and the experiences of patients diagnosed with hearing loss, helping to show what really matters to them. Its findings and recommendations should underpin the thinking of health professionals and commissioners, whose decisions are crucial in determining the outcomes for people with hearing loss.

Ultimately, as increasing numbers of people live longer and live with hearing loss, our whole society will benefit from more timely and more accessible services.

Best wishes



Chief Executive, RNID

Jackie Ballard

Summary



This summary sets out the key findings from research looking at the experiences of people when addressing their hearing loss. One in seven of the adult UK population has hearing loss and we know that hearing loss can have a serious impact on quality of life (Weinstein and Ventry 1982; Mulrow et al 1992). Hearing loss also impacts on relationships, with both the person with hearing loss and their partner feeling a sense of isolation and frustration (Echalier 2010).

It is therefore important that people are encouraged and supported to take action on their hearing loss in order to minimise the impact it has. The medical and social care professions refer to the support they provide as 'hearing rehabilitation'. The aim of rehabilitation is to reduce or eliminate the impact that hearing loss has on someone's life. In 1975 a Department for Health and Social Services (DHSS) report highlighted the issue that fitting hearing aids is not enough; people need further support to ensure that they get the best out of their hearing aids. NHS audiology services have improved since 1975, however this research set out to discover if people are effectively supported with their hearing loss and what other methods of support people with hearing loss have available to them.

Interviews were conducted with 27 people with hearing loss, who have had hearing aids fitted in the last five years. A questionnaire was also sent to audiology departments to establish what services they offer. We received over 100 completed questionnaires from audiology departments throughout the UK.

Findings

The findings cover each stage of the patient's journey, from recognising they have a hearing loss, to going to their GP, referral to the audiology department and getting hearing aids fitted. The research also looks at aftercare, assistive equipment and the support people with hearing loss make use of. For details of the full findings please refer to the main report at www.rnid.org.uk



Journey to getting help with hearing loss

Unsurprisingly, communication was the major difficulty for people prior to getting help with their hearing loss. Early identification would in many cases reduce the time people struggle with their hearing loss. Friends and family play a key role in making people aware of their hearing loss and for those in employment work was a key area of motivation for people to take action on their hearing loss.

“I kept saying to my wife – pardon, pardon – and she said ‘Are you going deaf?’ I said ‘I am not.’”

Man with hearing loss, North West England

Experiences of health services

People must first visit their GP for a referral to audiology services. However, this research found some GPs did not refer participants on to audiology departments when they presented with hearing loss. This reinforces research which showed GPs failed to refer 45% of people who reported hearing difficulties (Davis et al 2007).

A lack of clear and comprehensive information is a key issue for many participants. In particular, limited information is provided about hearing aids, assistive equipment and organisations that can provide support. In our survey of audiology departments, less than half provide written information.

Participants did not feel they have sufficient time in audiology appointments to ask questions and for thorough explanations to be given. Not all participants were given a follow-up appointment after their hearing aids were fitted, and the majority received no ongoing review. This trend was confirmed by the survey of audiology departments, with just over half (**53%**) stating they always offer a follow-up appointment after the initial fitting of hearing aids, and only a quarter (**25%**) have a procedure in place to automatically review the needs of their patients.

“She put it in and said ‘How does that feel, fine? Well that’s alright then. Goodbye,’ and that was it.”

Man with hearing loss, Scotland



The facilities at audiology departments and the attitude of staff were viewed as important by participants. The location and accessibility of audiology services was also an issue for participants with some reporting poor public transport links or limited parking.

The private sector was used by some participants to initially identify their hearing loss, but then participants were deterred from buying hearing aids due to the high cost. They did however think that the private sector offers greater choice and better design of hearing aids than the NHS.

“You can get much nicer ones now, but they are so expensive. They are too much for me to buy.”

Woman with hearing loss, South East England



Hearing aids

Hearing aids are not able to restore natural hearing, however some did expect this to happen. Participants had numerous problems with them, including the aids feeling uncomfortable to wear, difficulties with noise, problems with the sound quality, and issues around design. Some problems could be easily resolved through better information, provision of a troubleshooting guide, and people being encouraged to return to their audiology department.

Most participants received benefit from their hearing aids, including improved communication, being able to watch the television at a lower volume and as a signal to other people that they have a hearing loss. The frequency and length of time people wear their hearing aids varies depending on the benefit they get from them and the comfort of the hearing aids.

“They’re not very comfortable. It’s just literally like you’ve got someone’s finger in your ears... So they’re not very comfortable no, and they get itchy... but at the same time I can hear – they’re just wonderful.”

Woman with hearing loss, South East England

Other technology and equipment

Equipment and assistive technology can be extremely helpful in minimising the impact of hearing loss by alerting people to sounds they wouldn’t otherwise hear, or by enabling them to hear more clearly. This can include amplified telephones and flashing doorbells, as well as loop systems. Most participants do not use any equipment other than their hearing aids, however it is clear that many participants could benefit from equipment. Not all participants were aware of what loop systems are, or how to put their hearing aids on the T setting. Of those using loop systems, most tended to use ones in public places rather than obtain ones for their home. There are no clear

lines of responsibility for who should provide equipment in the workplace.

According to our survey of audiology departments, one third (**33%**) provide information about other assistive listening devices, such as amplified telephones.

Additional support

Lipreading classes can be a good way of improving communication skills for people with hearing loss. They also provide a support network. Awareness of lipreading classes was low amongst participants and many believed their level of hearing loss was not great enough to need classes. Participants did not receive any other support, such as hearing therapy or general communication training (except for those with tinnitus).

Around half of departments surveyed do not refer to or provide information about voluntary services, organisations or charities. Positively, however, over three-quarters of departments said they do provide information about lipreading classes.

Impact of hearing loss

Even when users successfully navigate hearing services, issues remain. Hearing loss continues to have an impact and people continue to be confronted with negative attitudes to hearing loss.

Participants talked of withdrawing from social situations and feeling isolated due to problems communicating.

Hearing loss can also have a negative impact on experiences of employment. Some participants talked about needing to change their role, whilst others faced discrimination from colleagues.

“You can’t keep saying ‘Can you repeat that bit, I can’t hear you’. By then they’ve changed the subject. It can be exceedingly isolating, you feel like a wallflower with everything passing you by.”

Man with hearing loss, North West England

Personal attitudes to hearing loss

Most participants are initially in denial about their hearing loss. Getting it identified is only part of the process; they need to be supported and encouraged to ensure that they have accepted their hearing loss and are therefore willing to take steps to deal effectively with their hearing loss. There are clear advantages to telling other people about your hearing loss including raising awareness and improving perceptions of people with hearing loss.

“If people don’t know me well, they think I’m being rude.”

Woman with hearing loss, Scotland

Four key areas for improvement are evident from these findings. These are discussed in the next section.





Key improvements

The research shows that there are four key areas in hearing services that need to be improved to ensure that people with hearing loss are effectively supported and to minimise the impact that hearing loss has on their lives.

These areas are:

- removing the barriers to getting hearing loss identified
- improving access to information
- providing a personalised service
- providing additional hearing services.

Removing the barriers to getting hearing loss identified

Hearing loss has a significant impact on people's lives. It is therefore important to reduce the amount of time people take in getting their hearing loss identified and the time it takes to get support. It is widely accepted that people adapt to hearing aids better, the earlier they get them. It should therefore be an important part of public health strategy to encourage people to recognise and take action to deal with their hearing loss. This will improve outcomes for people with hearing loss. This includes increasing awareness of hearing loss and improving GP referral.

Improving access to information

Access to information is a key theme throughout the findings. Information is hugely important in ensuring people address their hearing loss, get the maximum benefit from their hearing aids, and are able to access other services and equipment designed to minimise the impact of hearing loss on their life. It is therefore vital that information is provided to people with hearing loss at the right time and tailored to the individual.

Participants generally needed to be proactive in order to get the best service and support with their hearing loss. Those who are most confident are able to access the most support. Information would help to reduce this inequality, by making everyone aware of the support that is available and where they can access it.

Providing a personalised service

People with hearing loss need to be recognised as individuals. Everyone has different information requirements, different hearing loss, different work and home circumstances. Hearing aids, equipment and support therefore need to be allocated on personal need. This includes providing information in a variety of formats and levels of detail, enabling people to return to the audiology department when they need to, offering a variety of appointment times and drop-in clinics for repairs and queries and having clinics in a variety of locations.

Providing additional hearing services

More support and rehabilitation must be made available to people with hearing loss. The research shows that hearing loss continues to impact on people's lives, despite having hearing aids fitted. Support must therefore be provided to help hearing aid wearers adjust to and effectively use their hearing aids. Support must also be provided to ensure that people with hearing loss are supported in their home and work lives, including through provision of equipment, lipreading lessons, communication skills and hearing therapy.



Recommendations

As discussed in the findings, the current service provided to people with hearing loss is mixed. Our recommendations are formed from the experiences of our participants as discussed in the main report. These recommendations reinforce current audiology standards. We therefore urge audiology departments to implement the best practice guidelines already available to them to ensure that a good, consistent service is provided to everyone with hearing loss in the UK.

Our recommendations support one or more of the key areas highlighted for improvement. We have targeted the recommendations at each of the key groups relating to hearing services including GPs, audiologists and audiology departments, and the government.

GPs should:

- receive deaf awareness training
- routinely ask older people about their hearing and refer them to audiology for assessment if they are having difficulty in daily life
- refer people with suspected hearing loss to audiology services promptly
- explain the benefits of taking action on hearing loss to people with a suspected loss
- maintain contact with their local audiology departments to update their awareness of technology, treatment pathways and referral protocols.

The private hearing aid sector should:

- ensure they are deaf and disability aware, and their premises are suitable for people with hearing loss, including minimising background noise in consultation rooms
- be transparent about the costs of their service and provide a breakdown of these
- develop best practice guidelines with the Health Professions Council and RNID.



Audiology departments and audiologists should:

- receive deaf and disability awareness training as well as customer service training
- encourage hearing aid wearers to return to the audiology department to ask questions and talk through any problems as and when they arise
- explain to patients what they can expect from hearing aids before they are fitted, give advice about how long it may take to adjust to hearing aids, and the importance of persevering with them
- consider alternative ways to provide further support to people with hearing loss, including through the use of voluntary services such as RNID's Hear to Help.¹ Audiology departments should also consider referring people to voluntary services at their first audiology appointment
- encourage partners, a family member or friend to attend appointments with the person with hearing loss
- where appropriate, ensure that hearing aids have a 'T' setting for loop listening. Hearing aid wearers should be offered the opportunity to test out their 'T' setting and to try out loop systems
- ensure their locations are accessible. This includes offering clinics in a variety of locations, ensuring good transport links and access to car parking. Free transport should be available to those who need it
- ensure that their premises are suitable for people with hearing loss, and that background noise is minimised in consultation rooms
- increase the choice of hearing aids available
- offer a wider range of rehabilitation and support options for people with hearing loss,



including, for example, communication training and hearing therapy

- raise awareness of what technology and equipment is available to help people with hearing loss and where this can be obtained
- provide the following services to people with hearing loss:
 - clear and comprehensive information on various issues and in a variety of formats. This includes the ways people can seek further help with their hearing aids and hearing loss
 - a follow-up appointment for all new hearing aid wearers. Telephone follow-up should only be used occasionally, and only with people whose hearing is good enough to use the telephone
 - ongoing reviews
 - a variety of ways (drop-in clinic, outreach clinic, appointment) and times for people to return.

¹ RNID's Hear to Help project trains volunteers, many of whom have a hearing loss themselves, to show others how to get the best performance from their NHS hearing aids. This includes helping with basic maintenance such as replacing tubing and batteries, as well as providing advice on equipment that can make life easier in the workplace and at home.



Local authorities/social service departments should:

- increase awareness about lipreading classes. For those who can't attend classes, lipreading DVDs and books should be available
- offer a wider range of rehabilitation and support options for people with hearing loss, including, for example, communication training or hearing therapy
- raise awareness of what technology and equipment is available to help people with hearing loss and where this can be obtained
- ensure equipment can be loaned or offered free of charge to people with hearing loss
- enable hearing aid wearers to try out equipment before they buy it
- signpost people with hearing loss to other organisations that can help.

Government² should:

- introduce a national hearing screening programme for older people. This should be linked to a public health campaign to increase awareness and encourage action to deal with hearing loss
- provide information about what to expect at each stage of the journey for a person with hearing loss
- ensure that up-to-date hearing aids are provided on the NHS and increase the choice of hearing aids available
- invest in alternative forms of rehabilitation and support such as communication training and hearing therapy
- provide funding to improve the availability and affordability of lipreading classes.

² Where we refer to government, this includes the UK government and the devolved governments of Scotland, Wales and Northern Ireland, as well as government departments such as the Department of Health.

RNID will:

- develop an ongoing relationship with GPs as commissioners and providers in order to raise awareness of hearing loss and improve the quality of services
- develop information on what level of service to expect from public, private and voluntary sector hearing services as well as provide an online service to allow the public to feed back about their experiences
- conduct and publish research into the experiences of people who lose their hearing whilst in employment.

Hearing services are vital in minimising the impact that hearing loss has on someone's life. Without it, people can become isolated and withdraw from society. Effective hearing services must therefore be provided. With an ageing society, the proportion of people in the population with hearing loss will increase. As the retirement and pension ages change, we will be working longer, resulting in more people in employment with hearing loss. The government, with audiology departments, therefore need to ensure that we continually improve our audiology and hearing services to ensure that people with hearing loss are effectively supported and the impact of hearing loss is minimised.

Introduction



This report sets out the findings from research looking at the experiences of people when addressing their hearing loss. One in seven of the adult UK population has hearing loss and we know that hearing loss can have a serious impact on quality of life (Weinstein and Ventry 1982; Thomas et al 1983). Hearing loss also impacts on relationships, with both the person with hearing loss and their partner feeling a sense of isolation and frustration (Echalier 2010).

It is therefore important that people are encouraged and supported to take action on their hearing loss in order to minimise the impact it has. The medical and social care profession refer to the support they provide as 'hearing rehabilitation'. The aim of rehabilitation is to reduce or eliminate the impact that hearing loss has on someone's life.

Currently in the UK the main method of support or rehabilitation offered through the NHS is the fitting of hearing aids. Hearing aids are an important step in dealing with hearing loss (Stark and Hickson 2004; Mulrow et al 1992). However, it has been found that hearing aids are often underused, or not used at all. In a study by Sorri et al (1984) over two fifths of respondents occasionally, seldom or never used

their hearing aid two years after being fitted with one. Gianopoulos et al (2002) found that only **43%** of hearing aid users were still using their hearing aids between eight and 16 years after initial fitting.

Other methods of rehabilitation are also available. For example, communication training such as lipreading lessons and communication tactics; counselling and/or therapy; and the provision of specialist equipment such as amplified telephones or loop systems.

A review of the literature indicates that support such as counselling and/or communication training for people with a hearing loss can have a positive impact on the hours of use of hearing aids as well as quality of life and self-perceived impact of the hearing loss.¹

There are best practice guidelines for audiologists with regards to rehabilitation. Scotland and Wales use the same quality standards whilst England has developed its own standards.² The standards are generally similar though. However, there is no research to show the extent of the support provided to hearing aid wearers since audiology services were modernised from 2000 onwards.³

¹ For example, Brooks 1979; Benyon et al 1997; Abrams et al 1992.

² Northern Ireland does not currently have any quality standards for audiology services.

³ Modernising Hearing Aid Services (MHAS) was the title given to the modernisation programme in England. Similar projects were undertaken in Scotland, Wales and Northern Ireland.

Similarly, we do not know if the focus on reducing waiting times⁴ has had a detrimental impact on the service provided to hearing aid wearers. Furthermore there is a general lack of qualitative research into rehabilitation and the personal impact it has on people with a hearing loss.

Echalier (2009) highlighted some issues with audiology services and the rehabilitation process. However, this research was undertaken with participants who obtained their hearing aids up to 10 years ago. With the Modernising Hearing Aid Services (MHAS)⁵ programme being undertaken during this time, it is important to speak with people whose first experience of using audiology services has been since these changes were implemented.

Most participants in Echalier's research were members of RNID and therefore are likely to have greater knowledge about the services available for people with hearing loss. Whilst we did interview some members for this research, the majority have had no previous contact with RNID.

Research objectives

We wanted to find out if a lack of hearing services and rehabilitation means that people are slower and/or are less likely to adapt to hearing aids and learn to use them effectively. We asked participants about the kind of support they received, and what kind of impact this has had on them. We also explored the support participants would like to receive and what factors influence how long it takes someone to get used to their hearing aid.

Research methodology

We interviewed 27 people who had acquired their hearing aids within the last five years. We asked them about their experiences of audiology services and what support they have received with their hearing loss.

We also asked NHS audiology departments throughout the UK what support they provide to people with a hearing loss using a brief questionnaire. This information was collated anonymously.

Report structure

The first part of the report focuses on the patient's journey to getting their hearing loss identified. What problems did they have prior to diagnosis and what prompted them to take action with their hearing loss? The report then examines the participants' experience with the health services, including GP, NHS audiology department or private hearing aid dispenser. Hearing aids are then discussed, including the benefits and problems. This is followed by a discussion of other forms of technology and equipment available to people with a hearing loss, such as loop systems, subtitles and amplified telephones. The report then looks at what other forms of support are utilised, before looking at the impact of the hearing loss on participants' lives.

⁴ In 2009, audiology was included in the 18-week referral to treatment waiting-time target. As a result of this, audiology waiting times, which in some parts of the country had been very high, came down to an acceptable level. This target was axed in 2010.

⁵ Or equivalent in Scotland, Wales and Northern Ireland.

Chapter 1: The journey to getting help with hearing loss



This chapter looks at the participants' journey to getting help with their hearing loss. The problems that participants experienced prior to getting help with their hearing loss are first examined, followed by a discussion about how the participants noticed they had a hearing loss and then a look at the reasons for initially getting help.

It is important to examine these experiences to see what more can be done to increase the number of people taking action with their hearing loss. As discussed in the introduction, hearing rehabilitation can help to minimise the impact of hearing loss on a person's life. It is therefore useful to examine the reasons why people take action with their hearing loss.

Problems experienced prior to getting help with hearing loss

Communication was the major issue for participants when they were describing the problems they had prior to getting help with their hearing loss. This included missing words, struggling to hear, not realising people had spoken, and struggling with certain frequencies or accents.

“I started to notice initially that if people have got any kind of accent – Irish, Scottish, whatever – I struggle.”

Woman with hearing loss, South East England

“You would say goodnight to me in the office going home, or speak to me, and I wouldn't hear you.”

Man with hearing loss, North West England

The communication problems were experienced in three main areas; at home, in work, and at social occasions. Many participants talked about experiencing problems at home, including problems using the telephone, and in particular the difficulties around needing the television volume louder than their family or neighbours would prefer.

“I knew because when my husband was watching TV on his own it was on 20 and when I was watching it was on 30.”

Woman with hearing loss, South East England

“The TV has to be quite high... and although I didn’t realise it at the time, it was affecting my wife and my neighbour. He used to say to his partner, ‘I see [participant’s name] hearing is playing up again!’... but they never ever complained about it.”

Man with hearing loss, South West England

Communication problems in social situations were also highlighted as a key issue for participants.

“If I was in the canteen at lunchtime that was the time it was difficult, so I would just read.”

Woman with hearing loss, South West England

“If I’m not looking at the person, if I’m in a room of people, certainly going to the theatre and sitting in the back row, I found I couldn’t hear. I missed certain words.”

Woman with hearing loss, London

For those participants employed when they first developed a hearing problem, communication at work was an important issue. Meetings in particular were difficult.

“When I was working I had a large number of staff and very often I would walk through the office and they’d say, ‘Good morning boss’. I would ignore them because I never heard them. One day I walked past and I heard somebody say, ‘Miserable old...’ When I responded they told me ‘We’ve been speaking to you all morning, boss, and you haven’t replied to us. Have we upset you or something?’”

Man with hearing loss, South West England

“It was getting to the point where I was avoiding going to meetings.”

Woman with hearing loss, South East England

Commentary

Unsurprisingly, communication was the major issue for people prior to getting help with their hearing loss. Communication problems were faced in three main areas, at home, in work and in social situations.

Early identification of hearing loss would in many cases reduce the time people struggle with their hearing loss. It would also help to ensure that people with hearing loss get access to hearing aids and other support and equipment earlier than is currently the case. Previous research has found that people adapt to hearing aids better, the earlier they obtain them (Brooks 1985; Brooks 1996).

For people in employment, problems communicating at work were most significant. This highlights the importance of deaf awareness for employers and employees as this could help to reduce the communication difficulties discussed by participants. A high proportion of older people have hearing loss, with 42% of people aged 50 and over having some form of hearing loss. Therefore the proportion of people in the workforce with hearing loss will increase as a result of our ageing population as well as changes to the retirement and pension ages.

Unrecognised hearing loss can therefore be seen to have a substantial impact on many participants’ lives. Rehabilitation needs to be considered a priority for people with hearing loss in order to reduce this impact.

Recommendations

- GPs should routinely ask older people about their hearing and refer them to audiology for assessment if they are having difficulty in daily life.
- Employers should provide deaf awareness training and information if a member of their staff has hearing loss.

Taking action on hearing loss

Respondents talked about realising they had a hearing loss in two main ways. For many it was their friends and/or family who pointed out that they were not hearing properly. This was often as a result of realising the TV volume was too high.

“I didn’t notice it but other people were telling me I was deaf because the telly was up loud.”

Man with hearing loss, East Midlands

“I kept saying to my wife – pardon, pardon – and she said ‘Are you going deaf?’ I said ‘I am not.’”

Man with hearing loss, North West England

“The son-in-law used to say ‘For goodness sake how many more times, I’ve just said that.’”

Woman with hearing loss, South West England

As discussed in Echaliér (2009) this raises an issue for people who live on their own and who have limited social networks. Their hearing loss may not be identified or the delay before their hearing loss is identified could be much greater.

For some participants, they had been aware of their hearing loss for several years, but it had deteriorated and was now having an impact on communication.

“I had it in the left side since birth. I really started noticing it when I was about 19, which is some good number of years ago.”

Man with hearing loss, North West England

“I knew I had a bit of a problem. When I was a little girl I had an accident and fractured my skull and the back of my ear so I’ve had loss of hearing for quite a while. It’s not a huge loss but it’s something I’ve learnt to grow up with.”

Woman with hearing loss, East Midlands

Previous research has found that some people have difficulty in accepting that they have a hearing loss (Brooks 1985; Brabbins and Hogg 1977). It is therefore important to look at what eventually prompts people to take action with their hearing loss. This information could then be used to encourage others to take action with their hearing loss. We therefore discussed with interviewees what finally prompted them to see their GP to discuss their hearing problem.

As found in previous research, families play a key role in encouraging participants to get help with their hearing loss (Echaliér 2010).

“So my family are basically saying to me, you need to go back because people are going to think you’re stupid because you’re not hearing things.”

Woman with hearing loss, East Midlands

“The worst bit was not being able to hear my granddaughter ...when she was chattering away at four or five years of age...especially on the telephone, I could not really understand what she was saying. So I knew I had to do something.”

Man with hearing loss, Wales

“It wasn’t until I began to feel that I was being a nuisance to my husband that I thought I have got to do something about this.”

Woman with hearing loss, South East England

For those having problems at work this appeared to be a strong motivating factor to take action with their hearing loss.

“I think it became worse. For my last five years of work, instead of being in an office I was working at [department store]. Most of the time, talking across the counter, people are facing you, it wasn’t too bad. But it just got so difficult so I thought this is it, I’ve got to go and get a hearing aid.”

Woman with hearing loss, South West England

For others it was a specific concern about their health that prompted them to see their GP.

“At first I thought it was wax, and there was pain so I went to my GP.”

Woman with hearing loss, North East England

Informal networks played a role in prompting some participants to go to see their GP.

“A GP happened to live opposite and I told him I was thinking of going to get a hearing aid because my hearing has deteriorated quite a lot recently. He said, ‘All you have to do is go to the GP and they will refer you to hospital. It’s a really simple system.’ He encouraged me in a way.”

Woman with hearing loss, South East England

Commentary

Some participants have had their hearing loss for a long period of time and it has gradually worsened. For others their friends or family have made them aware that they are missing hearing some conversations.

The key role that friends and family play highlights an issue for people who live on their own and for these people a screening service could be important in identifying their hearing loss.

Some participants with a long-term hearing loss may have benefited from getting support earlier. It is therefore important that people are aware of the signs of hearing loss so that they can take action to deal with it. This would help to ensure that the right support was given at the right time as well as maximising the benefit they could obtain from hearing aids. A national screening programme would help to facilitate quick identification and treatment for hearing loss. A public health campaign would need to support the screening programme and this would also help to raise general awareness about hearing loss.

For those in employment, work was a key area of motivation for people to take action with their hearing loss. It is where participants discussed having particular difficulties and, for some, was the reason why they decided to take action about their hearing loss. It can therefore be observed that hearing loss has a substantial impact on people in work. RNID will be undertaking further research into this impact.

Many people lose their hearing after they have retired. It is therefore important to examine the triggers to getting help for people who are not in work. For these participants it appears that friends and family play a key role in encouraging them to recognise and then take action about their hearing loss. This supports the findings in Echaliier (2010), which found that partners play an instrumental role in making people aware of their hearing loss.

Social networks are therefore key in both highlighting hearing loss and prompting people to deal with it. Therefore, as discussed above, it is important to consider people not in work and living alone, and/or without support networks. They will not have these triggers to encourage them to deal with their hearing loss and could therefore be at risk of further isolation. A screening programme would help to highlight hearing loss to this group of people, thereby reducing the disadvantage they otherwise may face.

Whilst social occasions were discussed as causing problems for people with hearing loss, this did not necessarily translate into action to deal with their loss. Instead, in Echalié (2010) we can see that people withdraw from those social situations they find most difficult.

Recommendations

- Government to introduce a national hearing screening programme for older people. This should be linked to a public health campaign to increase awareness and encourage action to deal with hearing loss.

Chapter 2: Experiences of health services



This chapter examines the participants' experiences of health services in relation to their hearing loss; from their initial visit to the GP, to their diagnosis and experience of audiology services. We know from the literature that people put off getting or wearing their hearing aids for many reasons. This includes expectations, attitude and problems with using hearing aids. Health services play an important role in helping people to deal with these problems so that they can get the most benefit from their hearing aids and thereby reduce the overall impact of their hearing loss.

Experience with the GP

Positively, most participants' GPs referred them on to NHS audiology departments either straight away, or after checking for alternative causes of hearing loss such as excess wax or ear infection.

“First off I had antibiotics and she looked and she thought there was some wax and referred me to the nurse... Things didn't get much better and so I went back again and she referred me to audiology.”

Woman with hearing loss, North East England

However, several people described negative experiences with their GP. Some participants' GPs were not willing to refer them to the audiology department when they went to see them about their difficulties hearing. Several participants described having to go to see a different GP in order to get access to a referral to the audiology department.

“If you go to him and say ‘I think I need a hearing aid’ he starts talking to you in a low voice. Then he listens to you and he’ll say, ‘Well, I heard every word you said. Did you hear everything I said?’ When I’d say I did he’d say ‘Well you don’t need a hearing aid because we conducted a conversation and you’re OK, you seem to be able to cope with it.’”

Man with hearing loss, East Midlands

“My GP gave me a long, long talk on how not to buy a private one because they were expensive. I came home and then my daughter started to complain. She would say ‘Mother, for goodness sake turn the telly down’ or she would tell me ‘I was walking home and could hear the telly walking along the road’. In the end I went back again. I think I put up with it for about eight months. I went back again and I got the same lecture.”

Woman with hearing loss, East Midlands

Two participants were referred to private audiologists, and their experiences are discussed in the next section. Some participants’ GPs warned them of long waiting times for NHS hearing aids and one GP suggested the participant visit a private hearing aid dispenser in order to get a hearing aid quicker.

“Three years ago I decided to do something about it. I went to see the GP, who said there was an awfully long waiting list and I would be far better off going down the private route. That’s when I find out that what I call ‘double-glazing salesmen’ are employed in the sector.”

Man with hearing loss, Wales

One participant talked of experiencing numerous problems related to her hearing loss such as problems with balance and co-ordination, but her GP did not offer her any help or support with this. As a result she was looking to join a new GP practice in the hope that she could get more support with these problems.

Commentary

It is encouraging that the majority of participants had a positive experience with their GP and were referred promptly to their audiology department. However, it is concerning that some participants were prevented or delayed in taking action with their hearing loss. It is important that people are encouraged to take action and it is not acceptable that the attitudes of some GPs prevent this. Some people will be permanently deterred from taking further action with their hearing loss if they have had a negative experience with their GP. They will continue to struggle with the impact of an unidentified hearing loss.

As discussed above, the earlier a person is fitted with hearing aids, the more likely they are to adjust to wearing them. It is therefore vital that GPs refer all people with hearing loss immediately.

We understand that long waiting times in the past may have encouraged GPs to suggest their patient visit a private hearing aid dispenser. However, with waiting times now reduced,⁶ we would advise that all people with hearing loss should be given the choice of a referral through the NHS. For some people, they may not have the money to visit a private hearing aid dispenser and so this may prevent them from taking further action with their hearing loss. However, we do recognise that referral to private audiologists can be helpful for some patients.

GPs need to understand the importance of referral and be alert to people presenting with hearing loss. Deaf awareness training could help with this as well as improve communication.

⁶ Waiting time statistics for England: In April 2010, 99.6% of those treated in that month had waited less than 18 weeks. In May it was 99.7% (with no individual Trusts falling below 95%). The average (median) waiting time in May was 4.9 weeks (Direct Access Audiology: Referral to Treatment Collection (May 2010) Department of Health).

GPs must also be aware of the steps to take when a patient with hearing loss presents to them. It is vital that this first step in the chain is improved to ensure that a consistent service and advice are provided. This will help to ensure that all people with hearing loss receive the support they need as early as possible. It would also be useful for GPs to be proactive in speaking to their patients about hearing loss if they think this might be an issue for them.

People with hearing loss should be empowered with the knowledge about what they can expect at each stage in the process. This would help them to feel more confident in asking for support, as well as complaining when necessary.

Recommendations

- GPs should receive deaf awareness training
- GPs should routinely ask older people about their hearing and refer them to audiology for assessment if they are having difficulty in daily life.
- GPs should refer people with suspected hearing loss to audiology services promptly.
- GPs should maintain contact with their local audiology departments to update their awareness of technology, treatment pathways and referral protocols.
- The government should provide information about what to expect at each stage of the journey for a person with hearing loss.

Initial experiences with NHS audiologist

All participants we spoke with have NHS hearing aids and all but two have been to see an NHS audiologist. The two who have not seen an NHS audiologist received their hearing aids from a private hearing aid dispenser contracted through the NHS to provide NHS hearing aids.⁷ Some areas in England initially contracted out audiology services out as a method of reducing waiting times to meet the government target. Now, whole audiology contracts are being given to private hearing aid dispensers.

Although NHS waiting times were initially a concern for some people, in general they were not an issue for most people.⁸ There has been a focus on reducing waiting times for audiology services and it is therefore reassuring to see that this is having some impact on the time that people have to wait for an initial audiology appointment.

Experiences with NHS audiologists varied considerably. Experiences between appointments also varied. Those who discussed having a bad experience in the NHS talked about the poor attitude of staff, the appointment feeling rushed and poor information and explanations given.

“The lad that tested me originally was very nice, but the one that actually gave me the hearing aid – I felt he was a bit dismissive.”

Woman with hearing loss, Scotland

Participants talked about the lack of time available in appointments to discuss issues and the lack of information provided.

“She put it in and said ‘How does that feel, fine? Well that’s alright then. Goodbye,’ and that was it.”

Man with hearing loss, Scotland

People with hearing loss are individuals, with different information needs. Some like to ask lots of questions and be fully informed of the process, whilst others may only want basic information. It is therefore important that the audiologist is able to establish this and to tailor the information they provide to the individual.

“I saw a different person at the fitting and I think it was fairly obvious that that person was more used to dealing with geriatrics, you know because I was dying to say to her, I understand exactly what you are saying, how you are saying it and I’ve got a couple of questions. So there was a little bit of conflict between that one person and myself.”

Man with hearing loss, Wales

⁷ Contracting to private companies has only happened in England. All NHS services in Wales, Northern Ireland and Scotland are provided in house, by the NHS.

⁸ Waiting times would have been a problem five years ago, when some participants were first referred to their audiology department. However, waiting times have now decreased.

Those people who had good experiences in the NHS talked of feeling listened to, having their questions answered, staff being friendly and thorough, receiving good, clear instructions and explanations, and not feeling rushed during the appointment.

“She was clear, she was telling me what she was doing all the time. I don’t know if it’s me or not but anything that is going on, I want to know all about it. What the machine was for and all things like that. I like to know what’s going on.”

Woman with hearing loss, South East England

“The head of audiology... He was the first one that listened to what I was saying... this young man... actually sat down and listened to my story. He was excellent... When I went back in on Saturday, I saw another young audiologist who was so painstaking... he allowed me to ask all the questions that I wanted and he listened to what I said. They were both excellent. I have no complaints. I don’t think I could have had better treatment.”

Man with hearing loss, South West England

There were also mixed reactions to the facilities in NHS departments. Some participants were impressed.

“I originally went on my private health insurance to get the audiogram... and they did not have a soundproofed room there and so I was really impressed by the facilities at [hospital] on the NHS.”

Woman with hearing loss, South East England

Others were not impressed by the facilities. Many audiology departments do not have air conditioning, and therefore fans are often used by audiologists to cool the consulting room. However, fans are noisy and are therefore not very appropriate to use when talking to a person with hearing loss.

“He had a fan on, so you could not test your volume or anything, which is ridiculous. When people are going in there with their hearing aids and everything, it should not be on. It’s one of those huge ones that make a terrible noise.”

Woman with hearing loss, South East England

What happens at the hospital lays the foundations for the whole experience and some people won’t return if they have a particularly bad experience. It is therefore important that this initial experience is good for everyone.

Commentary

Experiences are mixed for participants during their initial appointment and hearing aid fitting at the NHS audiology department. The experiences of the participants demonstrate the importance of enough time being available in the appointment for thorough explanations to be given and for patients to be able to ask questions.

Facilities are important to the patient, particularly the level of noise in the room when hearing tests are being performed or hearing aids are being fitted.

The attitude of audiology staff was a key issue. Training is therefore necessary to improve the consistency of the service provided and to ensure that all staff provide a minimum standard of service. Audiology staff should be providing a personalised service which caters to the needs of the individual. The audiology guidelines for England, Scotland and Wales state that all new staff who have contact with patients should be given deaf and disability awareness training, and suggests that refresher training be available where necessary. The guidelines also suggest that patient experiences are used to feed back into training. This would help to ensure that a good level of customer service is provided to people with hearing loss. We would therefore urge all audiology departments to ensure that their staff undertake both deaf awareness and customer service training.

We understand that with current budgetary restraints, it is not always possible for audiologists to spend sufficient time with some individuals. The audiology departments should therefore consider alternative ways to ensure that the service is provided, for example through a volunteer-led service such as RNID's Hear to Help⁹ service.

Recommendations

- All audiologists should receive deaf and disability awareness training as well as customer service training.
- Audiology departments and audiologists should encourage hearing aid wearers to return to the audiology department to ask questions and talk through any problems as and when they arise.
- Audiology departments should consider alternative ways to provide further support to people with hearing loss, including through the use of voluntary services such as RNID's Hear to Help service.
- Audiology departments and audiologists should consider the needs of the individual and tailor the information they provide to suit them. This includes considering the most appropriate level of detail of information to provide, the amount of information supplied and the format and timing.
- Audiology departments must ensure that their premises are suitable for people with hearing loss, and that background noise is minimised in consultation rooms.

The private sector

Several participants had experience of private hearing aid dispensers, whilst two participants had been to see an ENT consultant or audiologist based at a private hospital. No participants had bought hearing aids within the past five years. One participant ordered hearing aids but was unhappy with them and was successful in getting a refund. The remainder who had contact with the private sector only had their hearing tested. For various reasons they decided not to buy any hearing aids and instead went to the NHS for these. Amongst participants it therefore appears that they mainly use the private sector for an initial hearing test but do not go on to buy hearing aids.

Respondents discussed various reasons for choosing to go to see a private hearing aid dispenser or audiologist:

- long waiting times for NHS services
- recommendation from GP
- looking for a better quality or design of hearing aids (for private hearing aid dispensers)
- having private insurance through their workplace (for private audiologists).

Private audiologists

One respondent wanted to talk to someone quickly about her hearing loss and therefore decided to see a private audiologist.

“I was getting so depressed about it that I made a private appointment... And I paid for a hearing test there.”

Woman with hearing loss, North East England

⁹ RNID's Hear to Help project trains volunteers, many of whom have a hearing loss themselves, to show others how to get the best performance from their NHS hearing aids. This includes helping with basic maintenance such as replacing tubing and batteries, as well as providing advice on equipment that can make life easier in the workplace and at home.

Another participant visited a private audiologist and as a result of their discussions was much more willing to accept her hearing loss and to take action to deal with it.

The experiences of those attending a private hospital rather than a private hearing aid dispenser were positive. The participants found staff reassuring and were able to spend plenty of time talking through the issues in their appointment. They also experienced no pressure to purchase hearing aids.

Private hearing aid dispensers

Some of those who attended an appointment at a private hearing aid dispenser were disappointed with the service provided, including poor facilities for testing hearing and the negative attitude of staff.

“He was about 20 minutes late. Didn’t have a patient there, didn’t introduce himself to me, took me through into this little room. It was bouncing down with rain through the skylight. I could hear more of the rain bouncing down in the room than I could from his audiometer.”

Man with hearing loss, Wales

One participant ordered hearing aids, however when they went to collect them the dispenser tried to provide different hearing aids to the ones ordered.

Some people were put off visiting private hearing aid dispensers after learning about the bad experiences of other people. Participants also spoke of not trusting private hearing aid dispensers due to their desire to make a profit.

“I think the very first contact was the free hearing test... and they obviously wanted to sell hearing aids so I thought well you know there is an interest from their part.”

Woman with hearing loss, North West England

However, the majority of participants had no experience with private hearing aid dispensers,

although some had considered going to see one. They decided against it after finding out about the high cost, not only for the hearing aids but also the ongoing costs of repairs and batteries.

“I could have gone and got one privately but obviously I didn’t want to pay that money.”

Woman with hearing loss, London

“You can get so much nicer ones now, but they are so expensive. They are too much for me to buy.”

Woman with hearing loss, South East England

Private contractors for the NHS

As discussed above, private contractors have been used by some primary care trusts to increase the capacity of NHS services in order to reduce waiting times. In some areas, private contractors are also being awarded the contract to provide the whole audiology service.

Only two participants had been to see a private contractor for NHS hearing aids and they had opposite experiences. One participant found the whole experience extremely positive, with excellent facilities, and they received their hearing aids quickly. The other person had an awful experience with poor facilities for testing their hearing and staff showing little interest.

“You know I found them ever so helpful. I can’t fault them really.”

Man with hearing loss, South West England

“Maybe they could have treated me more as an understanding person rather than a dope to be talked at.”

Man with hearing loss, North West England

Commentary

Some participants used private hearing aid dispensers for the initial identification of their hearing loss. This may be due to a desire to get it identified quickly. Consultants or audiologists based in private hospitals were talked of positively. However, private contractors and private hearing aid dispensers got a more mixed reaction. Overall, participants were not aware of what to expect from private hearing aid dispensers. They might have more confidence in interacting with them if they have information about what to expect and what their rights are. RNID will develop information on what level of service to expect from public, private and voluntary sector hearing services as well as provide an online service to allow the public to feed back about their experiences

It can also be seen that the high cost of private hearing aids puts people off buying hearing aids. This is despite the view that private dispensers in general can offer a better design of hearing aids and a greater choice.

Recommendations

- Private hearing aid dispensers must ensure they are deaf and disability aware and ensure that their premises are suitable for people with hearing loss, including minimising background noise in consultation rooms.
- Private hearing aid dispensers must be transparent about the costs of their service and provide a breakdown of these.
- The private hearing aid sector, with the Health Professions Council and RNID, should develop best practice guidelines.

Follow-up and ongoing reviews

Several studies suggest that people need continuing support and training to get the most out of their hearing aids (Upfold et al 1990; Ward, Tudor and Gowers 1978; Gianopoulos et al 2002). It is therefore important to look at the support that participants received from the audiology departments after they were fitted with their hearing aids.

Follow-up

This section looks at participants' experiences of follow-up appointments. The term follow-up is used to describe the way that audiology departments check to see how well the person is adjusting to their hearing aid. Follow-up is generally undertaken within the first couple of months of the hearing aids being fitted and can be conducted in various ways depending upon the audiology department. This includes an appointment to see the new hearing aid wearer in person, or a telephone call, or through a questionnaire in the post.

Some participants reported receiving no formal follow-up from their audiology department after receiving their hearing aids. For these participants, it is their responsibility to contact the audiology department if they have any problems or questions.

“I suppose they are busy people, don't have a lot of time. They fit the hearing aid, that is it I suppose. They must just assume once you have got it, it is going to be alright.”

Woman with hearing loss, Scotland

“She fitted it and she computerised it and said ‘That's it’. I said ‘Is there any follow up?’ and she said ‘No, go away and get used to it, give it a chance.”

Woman with hearing loss, London

However, several participants spoke of the importance of having a formal follow-up appointment in ensuring that they get the best from their hearing aids.

“It didn’t seem to make a significant difference in the room and I would have quite liked to have talked to somebody about it, just to go back and say ‘Have I got it right?’ Also if your hearing deteriorates and they have programmed it to that hearing loss, do you need to have it upgraded?”

Woman with hearing loss, London

The following quote is from a participant who only realised with hindsight the benefit a follow-up appointment would have provided. This therefore suggests that there are many people who could benefit from a follow-up meeting but are not aware of it. Audiology services should therefore take the lead in providing follow-up. The effects of not having a follow up are clear.

“The first time I think I hadn’t really fully understood how to use them... I remember going to a social function with my husband and really, really struggling and coming away from that evening thinking, I can’t get used to them, I’m getting all the settings wrong. And this is the whole thing about follow-up and how you’re getting on with things. Perhaps at the time I should have gone back and said I wasn’t getting on with them at all well.”

Woman with hearing loss, East Midlands

Of those who did receive follow-up, some reported receiving a telephone call, whilst others talked of having a follow-up appointment at the audiology department.

“I had a phone call that was arranged when I first had my hearing aid fitted. So many weeks later, you agreed to be at home at a certain time and they would phone you and you’d just go through lots of questions with them. I suppose that’s instead of going back to them for an appointment.”

Woman with hearing loss, East Midlands

However, a telephone call may not be the ideal method of communication for someone with a hearing loss.

“There was a follow-up telephone call which is not the best form of communication for following up with somebody. I suppose it’s a good test if somebody can hear, isn’t it?”

Woman with hearing loss, East Midlands

As part of our survey of audiology departments, we asked if patients are given a follow-up appointment after the initial fitting of their hearing aids. As seen in Table 1 the majority of departments do have some kind of system to follow up patients. Just over half of audiology departments said they always offer a follow-up appointment at the audiology department and nearly two-fifths offer a follow-up appointment only sometimes.

One third of departments follow up with patients by telephone. However, we would urge caution in only using telephone follow-ups. As a minimum, we would suggest audiology departments ensure that any person who is not able to use the telephone is offered an appointment at the department. The audiologist can determine this at the fitting of the hearing aid. If a telephone follow-up is carried out, and the person is noticeably struggling to hear on the telephone, then a follow-up appointment must be sent automatically. An appointment must also be arranged for people who advise during the phone discussion that they are having problems with their hearing aids.

16% of audiology departments offer follow-up by post. Again, the department must have a mechanism in place to ensure that where hearing aid wearers indicate they are having problems, they must automatically be sent a follow-up appointment.

According to the audiology departments surveyed, the appointment, telephone call or letter is on average eight weeks after the initial fitting of hearing aids. A new hearing aid wearer needs to be given enough time to try the hearing aid out in different situations, in order to be aware of any difficulties. At the same time, the follow-up appointment must not allow too much time to pass since the hearing aid was fitted otherwise the person may give up on wearing the hearing aid if they have not been able to get used to it or gained any benefit from it.

Table 1: Departments offering a follow-up appointment after the initial fitting of hearing aids (respondents could select more than one option)

	Percentage
Yes, always	53
Yes, sometimes	39
No	4
Follow-up by telephone	33
Follow-up by post	16

Ad hoc return visits

Ad hoc return visits are when a person has a problem with their hearing aid or hearing and needs to return to their audiology department. This can be through an appointment or a drop-in clinic.

Currently, hearing aid wearers need to be proactive in dealing with any problems that arise with their hearing aids or hearing loss. For some participants this does not create any problems, and they are happy to go back again and again to ask questions. This can be down to their personality, but can also be due to having a positive first experience with the audiologist.

Some participants however were less confident about returning to their audiology department. So what are the factors that put people off from returning to their audiology department or dispenser if they have a question or problem?

• A previous bad experience

Some participants talked about the audiology team not having enough time to spend with patients.

“I got the definite impression at that time that they were so busy; that they’d done what they could for you and couldn’t really do any more so there was no point in coming back.”

Woman with hearing loss, London

“They always seem to be a bit pressurised maybe, I don’t feel you get a very sympathetic hearing.”

Man with hearing loss, North West England

Another participant talked about the poor behaviour of their audiologist which meant they never wanted to return.

“He was very off-hand... I wouldn’t go back to him anyway, I’ll wait until he leaves.”

Woman with hearing loss, South West England

The attitude and behaviour of other members of staff in the audiology department can also have an impact on the experience of people with a hearing loss. Several participants talked about the negative attitude of reception staff.

“When I saw the lady who fitted them she made me feel very comfortable. But it’s always the same isn’t it when you go and you get the receptionist – they’re never quite as understanding.”

Woman with hearing loss, South East England

One participant even bought her own batteries for her hearing aids in order to avoid having to deal with the receptionist.

“The lady behind the desk, she’s a bit formidable... I went and bought a whole set of these batteries hoping one of them would fit rather than going and asking for them... she’s quite offputting in her manner.”

Woman with hearing loss, East Midlands

- **A lack of confidence that their questions and worries are important**

Some participants did not think the problems they were experiencing with their hearing aids were significant enough to ask for help from the audiology department.

“... the thought of making an appointment and then somebody saying ‘There is nothing wrong with it you know, I don’t know what you’re worrying about...’”

Woman with hearing loss, London

- **Time/convenience**

Some participants suggested that they don’t have time to return to the audiology department.

“It is a question of time and convenience you know because we are still working so that limits what you can do.”

Woman with hearing loss, North West England

For most participants if they want to return to see their audiologist they must book an appointment, although some participants can drop in to their local audiology department clinic. Drop-in clinics however can be particularly time-consuming and this can put people off attending.

“They have basic office hours I think... 9 to 5... And you go. It’s like a cheese counter. You get a ticket and sit and read your paper and wait ‘til you get called... You have to expect to spend a couple of hours, so it messes up the day basically. Which is why I’m well overdue to go.”

Woman with hearing loss, North East England

- **Lack of information**

Hearing aid wearers need to be provided with clear and comprehensive information, including information about follow-up appointments and how to return to the audiology department if they experience any problems. This is not always done.

“I feel it’s getting worse and I don’t know what to do about that. That hasn’t been explained to me, whether I can go directly... to audiology... or if I have to go back through my GP.”

Woman with hearing loss, North East England

Obviously when some of these factors combine, they form an even stronger barrier for people taking action to deal with their hearing loss and associated issues. An ongoing review every few years would help to ensure that some of these barriers were removed.

Ongoing review

An ongoing review is when people with hearing loss are given an appointment to return to their audiology department, usually every two to three years. This appointment can be used to check how the person has adjusted to their hearing aids, if they are having any difficulties and to retest their hearing if necessary.

Some participants reported that their hearing is reviewed on an ongoing basis.

“They have called me [back] every year since then. Yeah, it usually comes up about November time, about this time of year and it goes through the hearing test again.”

Man with hearing loss, East Midlands

“I go regularly for follow-up appointments just to see how they are, to see if they need testing, do I need a more powerful one or a different mould in the left ear... How often do you go back? Every six months.”

Man with hearing loss, North West England

One participant, who obtained his NHS hearing aids through a private contractor, receives an appointment every two years.

“They call you forward for another hearing test every two years, just so they can update your hearing aids.”

Man with hearing loss, South West England

A scheduled appointment can be particularly useful for people who are not aware that they can return to discuss any problems they are experiencing, or may not be confident or comfortable in asking for an appointment at their audiology department. The appointment would encourage the person to discuss any problems they have had with their hearing aids and hearing loss more generally. For example, one participant had stopped wearing her hearing aids as she was not receiving any benefit from them. She was reluctant to return to the audiology department, but accepted that if they had given her an appointment she would have returned.

“Well if they had told me you have an appointment I probably would have gone.”

Woman with hearing loss, North West England

However, only a quarter of audiology departments surveyed have a procedure in place to automatically review the needs of their patients. Of these, the average review period was three years.

Table 2: Do you automatically review patients' needs?

	Percentage
Yes	25
No	75

In our survey of audiology departments, 94% allow patients to come back for reassessment, review and reprogramming direct to the clinic, without needing another referral from their GP. However, it is disappointing that some departments do not allow this. We know that some services require people to go back to their GP because of the way funding currently works in the NHS in England. This system risks putting people off from returning and resolving any problems they have with their hearing aids.

Table 3: Patients' ability to return direct to the clinic to see the audiologist for reassessment, review and reprogramming, without referral again by their GP

	Percentage
Yes	94
No	6

Commentary

Audiology guidelines in England, Scotland and Wales recommend that a follow-up appointment is offered to each patient after a hearing aid fitting and we urge all audiology departments to implement this. This would enable people to try out their hearing aids, discover any problems and then return to the audiology department for further advice, information or adjustment. This would ensure that the maximum benefit is gained from the hearing aids.

One research study found that often hearing aid wearers were satisfied with the instruction given to them but were not very skilled in handling their hearing aids (Sorri et al 1984). The implications are that individuals may not recognise when they require more instruction and/or may not be willing to ask for further help. Instead they become frustrated with the hearing aids and stop using them completely. We would therefore also recommend that all hearing aid wearers have an ongoing review scheduled every few years. This can also provide an opportunity for further information to be provided about other services that could be of use to an individual. Audiology guidelines recommend a review every three years.

Adjusting to hearing aids is a gradual process. Therefore it is unlikely that one appointment at the audiology department would be sufficient. The service provided by audiology departments should therefore reflect the fact that the adjustment is a gradual process.

As can be seen from the discussion earlier, participants were put off from returning to their audiology department for numerous reasons. Some had a bad experience with staff, others don't have the time to return, particularly if they are working. A lack of confidence to return and a lack of information all create barriers to people asking for help with their hearing aids or hearing loss. Some of the barriers can be solved through the audiology department offering ongoing reviews, ad hoc appointments and drop-in clinics, others however would need steps such as staff training in customer

service skills, offering appointments at convenient times and providing information about the ways a person can seek help. These would help to ensure that the maximum benefit is obtained from the hearing aids and thus the impact of their hearing loss is minimised.

Recommendations

- Audiology departments should provide a follow-up appointment for all new hearing aid wearers.
- Telephone follow-up should only be used occasionally and only with people whose hearing is good enough to use the telephone.
- Audiology departments should offer a variety of ways (drop-in clinic, outreach clinic, appointment) and times for people to return.
- Audiology departments should provide clear written and oral information about the ways people can seek further help with their hearing aids and hearing loss.
- Audiology departments should provide ongoing reviews at least every three years.

Information

Previous research highlights the importance of information being provided to hearing aid wearers in ensuring that they get maximum benefit from their hearing aids and minimise the impact of their hearing loss on their life.

A study by Smaldino and Smaldino (1988) found that a brief hearing aid orientation did not produce significant changes in how people perceive their hearing loss and therefore is not sufficient to maximise the benefit obtained from hearing aids. International comparisons indicate that higher hearing aid use in Denmark compared with the UK (amongst others) may be due to the post-treatment training programme in Denmark, where patients are instructed how to use their hearing aids under different conditions (Ewertson 1974). As Boothroyd (2007) discussed there is an important difference between 'instruction' and 'telling'. Hearing aid users need to learn how to operate and maintain the

hearing aid through instruction, rather than just being told how to do these things.

This section therefore looks at the content and format of the information provided to participants.

Information provided

The information provided by audiology departments varied enormously. Some participants were given clear and comprehensive information, whilst others didn't know how to clean their hearing aids, didn't know what a loop system is or what other equipment is available to help them in the home or at work (this is discussed in more detail in the equipment section).

Most participants did receive the manufacturer's booklet with their hearing aids. However, one participant said they were only given the booklet a year after first receiving their hearing aids. For many people, this booklet was not sufficient as the sole source of information. The following quote demonstrates the lack of information provided to some participants with regard to using their hearing aids.

“He didn't explain anything, not how to use it or anything else, just give me a little tiny book.”

Woman with hearing loss, South East England

Some were not given information about how to maintain their hearing aids such as cleaning methods, how to replace the tubing, or in some cases, some participants were not made aware of the need to regularly replace the tubing.

“I don't know if I should wash it – I'm frightened to put water on it. So I don't know, I wasn't told about that.”

Woman with hearing loss, North East England

Most participants were not given any information about other equipment that could be useful to them. The following quote is from a participant who guessed that she might be able to use the 'T' setting with her telephone after it was mentioned at church. She later spoke to the audiologist about this.

“I said ‘You didn't tell me about putting it on to telephone [t-switch]’, so she said ‘It depends on what your telephone is like’. I pointed out again that she didn't tell me and she said ‘Oh well we would've done if you'd have come back and complained’. I thought that was the most back to front thing I'd ever heard. She'd given me two books and I had searched backwards and forwards and there was nothing in either book that suggested that only certain telephones would work.”

Woman with hearing loss, North West England

Very few participants were given information about other services, although there were a few exceptions to this.

“Through the audiology, they invited me to see an occupational therapist, it was their suggestion.”

Man with hearing loss, North West England

Timely and effective information needs to be provided in order to ensure that people get the best use from their hearing aids and are able to lead an independent life as far as possible. There were some examples of excellent information being provided, including information about support groups, equipment and how to use hearing aids. This was given as both written and oral information. We want to ensure that everyone receives this high level of information and support.

“They were very good, they went through it quite thoroughly. They don’t leave you to walk out with it without knowing what to do with it. Obviously there’s not that many people who you can talk to that have got a hearing aid who can go through it all. But they tell you absolutely everything, how to keep it all clean and maintain it, absolutely everything, and they also say if there’s any problems just phone us back and someone will contact you so you’re not left on your own. If you’ve got any problems you can go back to them.”

Woman with hearing loss, East Midlands

“We both came away with a huge envelope with all the bits and bobs about how to clean them, who to ring, supply of batteries, where you can get your batteries from...”

Woman with hearing loss, East Midlands

We also asked audiology departments to tell us what information they provide to new hearing aid wearers. As can be seen in Table 4 on the following page, the vast majority provide training to all in how to put hearing aids in the ear, training in how to operate the controls and change the batteries, and provide an explanation of using the hearing aids in different situations and what to expect. However, it is concerning that a small minority do not provide what would seem to be the most basic service to all hearing aid wearers. One in three departments do not provide training to all in how to use the hearing aids with loop systems and other assistive listening devices. However, not all hearing aids will have a ‘T’ setting for loop listening and therefore audiology departments will only provide this information to those with a ‘T’ setting.

Written information is provided by less than half of all audiology departments. As discussed later, people can find it difficult to take in all the information when they first get their hearing aids. It is therefore vital that written information is also provided so that hearing aid wearers can look at it when they are at home.

One third of audiology departments provide information about other assistive listening devices, such as amplified telephones. Whilst we recognise that audiologists do not have a huge amount of time in appointments, we believe it is important that this information is provided, or at the very least, that signposting is given for where people can find this information themselves. For example, a leaflet could be provided with the contact details for both local and national organisations.

Over half of audiology departments surveyed state they provide information on other equipment when required, however not everyone is confident or able to make their needs or problems known and therefore these people will miss out on being provided with information.

Table 4: Support and services provided to hearing aid wearers
(respondents could select more than one option)

	To all (%)	Offered when required (%)	Only on request (%)	Referral to other agencies (%)	Written information provided (%)
Training in how to put the hearing aid in the ear	99	8	Less than 1	5	40
Training in how to operate the controls and change batteries	99	6	Less than 1	3	42
Explanation of use in different situations and what to expect	96	8	Less than 1	3	33
Training in how to use hearing aid with loop systems and other assistive listening devices	65	36	2	15	33
Training in cleaning and checking of aid	94	10	Less than 1	3	37
Training in replacing tubing/tips (when appropriate)	55	44	5	Less than 1	37
Replacing tubing/tips	67	36	Less than 1	Less than 1	35
Reprogramming hearing aid	53	34	6	Less than 1	8
Basic hearing tactics and communication training	71	26	4	6	29
Information about other assistive listening devices (e.g. amplified telephones)	36	56	5	18	33

Alternative sources of information

Where participants were not initially given all the information they needed, they used various methods to find it out. Some asked friends and/or family who also had hearing aids.

“I use my sister. We share knowledge about how she looks after my nephew’s hearing aids.”

Woman with hearing loss, East Midlands

The following participant’s partner already had hearing aids and so she was able to rely on them for information.

“I probably wasn’t paying attention to the cleaning bits because I thought well... she knows how to do it.”

Woman with hearing loss, East Midlands

Joined-up working

Several people were proactive when they had a problem and sought help with it. For some this was returning to the audiology department, or contacting their local deaf charity. One participant returned to see their audiologist as they were struggling at work with their hearing loss. They were told by the audiologist that they could do no more to help with their hearing; however they did provide contact details for organisations that might be able to provide support. This included a local deaf charity as well as the government employment fund Access to Work. Whilst this participant was given good advice to contact these organisations, she felt that she would have benefited from a more joined-up approach.

“You’re kind of referred to other people who then refer you onto other people and there’s no joining up.”

Woman with hearing loss, East Midlands

As can be seen in the table below, there is a general lack of joined-up working between services to support people with hearing loss. Three-quarters of audiology departments are able to formally refer patients to the social work sensory team, and around two-thirds can formally refer patients to a hearing therapist. However, these findings do not tell us whether departments make use of these referral systems.

Around half of audiology departments surveyed do not refer to or provide information about voluntary services, organisations or charities. We welcome however the fact that over three quarters of departments provide information about lipreading classes.

Over two-thirds of audiology departments have no formal referral or provide information about NHS mental health services. There are well-known links between hearing loss and mental health problems (Paddock, O’Neil, and Holwell 2008). Audiologists may not be qualified to refer people formally onto mental health services, however, we would expect audiology departments at the very minimum to

write to a person’s GP if they have concerns about their mental health.

Table 5: Percentage of audiology departments that formally refer people to other services or give them information on where to go for help (respondents could select more than one option).

	Formal referral (%)	Information	Neither (%)
Hearing specialist	64	28	29
Speech and language therapist	29	12	60
NHS mental health services	24	10	69
Social Work (sensory team)	74	47	17
Social Work (other team)	23	21	65
Volunteer services	25	41	51
Voluntary organisations/ charities	20	51	45
Specialist audiological services	49	15	49
Lipreading or speechreading classes	20	78	15
Listening training	24	28	54
Other	5	4	93

Processing information

The quality and quantity of information given was not the only issue for participants. As these quotes highlight, even if patients are verbally told the information by the audiologist, they may not be able to process everything they receive.

“I suppose at the time when you’re told, when you’re given the information and you’re a little bit in shock, you don’t start listening particularly well, do you? If you receive some news at a doctor’s it’s always useful to have somebody else who’s gone with you because then they can ask questions. Perhaps in retrospect I should have taken somebody.”

Woman with hearing loss, East Midlands

“I am sure they tried to do everything, I think it was just me forgetting. I think that the system that they had covered everything and they did give me a booklet to go with my hearing aid which I have got and I can refer to it and I am sure that it tells me in there how to clean it.”

Woman with hearing loss, South East England

It would therefore be helpful for a friend or family member to also attend the appointment. This would also enable them to help the hearing aid wearer with their hearing aids.

As shown in Table 6, in our survey of audiology departments two-thirds encourage the patient to bring a friend or family member. Echaliier (2010) found that people were not always aware they could bring someone with them to their appointment, although many thought this would be helpful. It is therefore important that audiology departments make it explicit to all patients that they are able to bring a friend or family member with them when they attend appointments.

Table 6: Audiology department that encourages patients to bring a friend or family member to appointments

	Percentage
Yes, always	66
Yes, sometimes	27
No	7

As discussed above, it can be difficult for some new hearing aid wearers to take in all the information given to them by their audiologist. It is therefore vital that audiology departments provide written information to patients as well as giving an oral explanation.

Formats Information

The Department of Health produced a booklet in conjunction with RNID titled ‘How to use your hearing aid.’ We asked participants whether they have been given a copy of this booklet or if they have seen it before. Only four of the participants have seen the booklet, and in general they were positive about it. Of those who had not received it, many remarked on how useful it would have been.

“It looks like it’s really, really good. No I didn’t even know I could sort the tubing out myself. Can I do that?”

Woman with hearing loss, East Midlands

“I think that would be very useful, anything that makes you feel that you can do something for yourself before you go and bother somebody else.”

Woman with hearing loss, London

However, it must be borne in mind that not everyone can readily understand written information.

“Did they give you any written information to take away with you?”

“There is a leaflet... I didn’t think it really helped a lot.”

“What kind of information did it have on it?”

“It told you... there is a button, you press it, goes peep, another goes peep-peep and I don’t know what that is for. Then there is a wee 1,2,3,4 button but I didn’t feel there was a lot of difference when I move that.”

Woman with hearing loss, Scotland

Even if people are given the information and they understand it, they may need to practise their skills in the presence of someone who can assist.

“I’ve read the booklet and I know that you can detach bits but I’m frightened because I rely on them so much I don’t want to damage them and then be without them, it would be horrendous.”

Woman with hearing loss, South East England

One participant has problems with his eyesight and so needs another person to read any written information to him. Information should therefore be provided in a variety of formats. It is important that people with hearing loss are provided with information and instructions through a combination of methods; in person, written information and through other media.

Audiology staff are the experts who should provide the information automatically, without expecting the person with hearing loss to have enough awareness to be able to ask questions.

“You’re dependent on them to tell you... you don’t know what to ask really.”

Man with hearing loss, Scotland

Some participants gave suggestions for what information or format of information they would like.

“... I think I would like reminders, when the tube needs doing. And possibly a defined appointment.”

Woman with hearing loss, North East England

Some participants thought an online video or a DVD would be helpful, to demonstrate how to use hearing aids.

This participant would like more time with the audiologist, in order to have more time to get instructions.

“I suppose they are busy people, don’t have a lot of time. They fit the hearing aid, that is it I suppose. They must just assume once you have got it, it is going to be alright.”

Woman with hearing loss, Scotland

This participant suggests a booklet of all the contact details of useful organisations would be helpful. This would save people time and effort in needing to search individually.

“If you had a booklet that you were given with all the different organisations... I used to work in disability services myself, physical disabilities, and I worked for a team and we had a very holistic approach to people and their lives. Not just their health needs, their work needs, everything and we’d also have a booklet... I mean I’m not incapable of doing it, I’m just saying it’s really, really time consuming.”

Woman with hearing loss, East Midlands

Commentary

An RNID Scotland report, 'Here to be heard' (2007) identified a lack of clear and comprehensive information available. This research highlights that information remains a key issue for people with hearing loss. This means they are unable to properly use or maintain their hearing aids, or are not aware of other equipment or support services which could be of benefit to them. Outcomes could be improved if clear and comprehensive information was provided. This would include oral information given by the audiologist during the appointment as well as written information provided to the hearing aid wearer to take away. Visual information could also be useful for some people, particularly with diagrams and pictures.

It is also worth reiterating that there is an important difference between instruction and telling (Boothroyd 2007). Hearing aid users need to learn how to operate and maintain their hearing aids through instruction, rather than just being told how to do these things.

It would also be useful if people were encouraged to bring a friend or family member to their appointment. This supports a recommendation in (Echalier 2010) which found partners attending appointments can help to generate shared understanding of hearing loss and its effects. Audiology guidelines also include this as a recommendation and we would therefore urge all audiology departments to incorporate this into their standard appointment letters.

Finally, a key issue to note is that audiology staff are the experts. New hearing aid wearers cannot be expected to know what questions to ask in order to elicit relevant and important information. The responsibility for providing information must therefore lie with the audiology department and the government rather than the individual.

Recommendations

- Audiology departments should provide clear and comprehensive information about hearing aids, including how to use and maintain the aids and a troubleshooting guide.
- Audiology departments should provide information in a variety of formats.
- Audiology departments should provide a list of useful organisations to contact such as voluntary organisations, support groups, social services and Access to Work.
- Audiologists and other healthcare professionals should encourage partners, a family member or friend to attend appointments with the person with hearing loss.
- Audiology departments should consider earlier intervention, for example referring people to voluntary services at their first audiology appointment.

Information provided should cover the following topics:

- Hearing aids – what to expect, how to use and maintain them, a troubleshooting guide, where to get further help, how long it may take to adjust to hearing aids and the benefits of wearing them.
- A list of useful organisations such as hearing loss charities and support groups.
- The various options for where people can get their batteries and repairs from, including postal repair services.
- Equipment – what is available and where it can be obtained.
- Employment – where to go for help and information.
- Everyone with a 'T' setting should be told both in person and in writing about how to operate the 'T' setting; and have loop systems explained to them.

Accessibility of services

The likelihood of hearing loss increases with age. Two-fifths of people aged 50 and over have some kind of hearing loss, increasing to over 70% of people aged 70 and over. The likelihood of other health problems also increases with age. In our 2009 annual survey of members, nearly half of respondents had a disability or long-term illness other than their hearing loss. It is therefore important that audiology services are designed so that they can be easily accessed by everyone.

We therefore asked participants about how easy it was for them to get to their local audiology department. We found that the location and accessibility of audiology services was an issue for some participants. Several people talked of problems with parking, which were particularly problematic for disabled people. One person said that even though they have a blue badge to park in a disabled space at the hospital, these are regularly all taken and so they have to park further away.

“Parking is awful. Although I’m registered disabled I have to walk. It seems a long way to get a parking space... It takes me 20 minutes to get there and then probably another half an hour to find a parking space... And to go there by bus... hour and a half.”

Man with hearing loss, South West England

For many of these people, public transport is not an option, due to the length of time it would take, the inconvenience or problems with accessibility.

For some participants the location of the services is very handy. However, for some the services are a considerable distance from their home. Disability was also an issue for some people when accessing their audiology services. One elderly person with arthritis was unable to walk to their clinic as it was situated at the top of a large hill.

“You couldn’t possibly walk... I tried it once and I think I had to stop four times to catch my breath. ...It’s a silly place to have a hearing place when

it’s the old people mainly I should imagine that go there... right at the top of the hill.”

Woman with hearing loss, East Midlands

Table 7 on the next page shows where repairs and batteries can be obtained in the audiology departments surveyed. The first column lists the possible locations where repairs and batteries can be obtained.

The second column shows the percentage of departments which offer repairs in each location. The third column shows the percentage of departments which offer batteries in each location. The final column shows the percentage of departments which provide neither repairs nor batteries in each of the locations.

Repairs are most commonly available at the hospital audiology department by appointment. However, over half of departments offer a drop-in clinic at the hospital or an outreach clinic by appointment for repairs. Very few departments offer repairs at local health centres. Two-thirds offer repairs by post, although most participants are not aware of this service.

Batteries are most commonly available from the hospital audiology clinic with no appointment needed and reassuringly around two-thirds of departments state that batteries can be obtained from the patient’s local health centre. The majority, 96%, say batteries are available by post. This would be particularly useful for people with mobility problems or those who live some distance from the audiology department; however none of the participants interviewed obtain their batteries by post, which implies that at least some of the participants are not aware of this service.

Some departments offer other options for getting batteries and repairs such as through social services, one-stop shops, housing offices, from volunteers and through home visits when required. It is important that hearing aid wearers are made aware of these options.

Table 7: Locations where hearing aid repairs and batteries are available (respondents could select more than one option)

	Repairs (%)	Batteries (%)	Neither (%)
Hospital audiology clinic by appointment	77	33	22
Hospital audiology drop-in clinic (no appt needed)	50	89	8
Audiology outreach clinic by appointment	60	25	40
Audiology outreach drop-in clinic (no appt needed)	30	67	33
Patient's local health centre/ GP	7	64	35
Post	66	96	3

Commentary

The location of audiology services is an issue for some participants. Audiology departments need to consider whether transport should be provided for some people. Departments should also consider having clinics in more convenient locations such as town centres or in local GP surgeries. Batteries and repairs should be available in a variety of locations in order to improve the accessibility of services and patient awareness of postal services should be increased.

Volunteer services such as RNID's Hear to Help can be used to increase the capacity and improve the accessibility of audiology services. For example, volunteer services are often able to offer home visits to those with mobility problems.

Recommendations

- Audiology departments should ensure their locations are accessible. This includes good transport links, access to car parking, and free transport available to those who need it, as well as offering clinics in a variety of locations.
- Audiology services should consider the use of volunteer services such as Hear to Help, which can provide services to people in their own home where necessary.
- Audiology departments should increase awareness of the options available for where people can get their batteries and repairs, including postal repair services.

Chapter 3: Hearing aids



This section looks specifically at the participants' experiences of their hearing aids, including their expectations of the benefit the hearing aids will provide, problems and difficulties with hearing aids and the actual benefit obtained from hearing aids. All participants had behind-the-ear hearing aids, with various ear inserts.¹⁰ One participant had previously tried an in-the-ear hearing aid.

Expectations

Previous research has shown the positive impact that realistic expectations can have on use (Meister et al 2008). It is therefore important that new hearing aid wearers have realistic expectations in order to maximise the benefit they obtain from their hearing aids. If people have high expectations as to what hearing aids can achieve, this can lead to disappointment when hearing aids do not restore perfect hearing, resulting in the user giving up on wearing their hearing aids (Watts and Pegg 1977; Kapteyn 1977; Brooks 1989). The following statement is made in relation to analogue hearing aids, and although digital hearing aids deliver improved sound quality, aids do not restore normal hearing (Boothroyd 2007).

“The instrument the hard of hearing person thought would restore his hearing, whilst it makes sounds much louder, does not necessarily make the sounds of speech clearer, and he is quite unprepared for this. Small wonder indeed that he experiences yet more frustration and ceases to use the instrument he thought would restore his hearing.” (Watts and Pegg, 1977 p103).

We therefore asked participants what they expected from their hearing aids. Expectations were mixed, with some people expecting more from hearing aids than they provided whilst others got what they expected. Those who had their expectations met were relatively realistic in what benefit the hearing aids would provide.

“I thought it would be quite good, I’ve got what I expected really, I didn’t think it would be perfect but it’s a help.”

Man with hearing loss, Scotland

¹⁰ This includes a full mould or open tip fitting.

Some people however have unrealistic expectations, believing aids to be comparable to natural hearing.

“You probably have an expectation that you’ll be able to hear as a normal hearing person would be able to hear.”

Woman with hearing loss, East Midlands

Others did not know what to expect from their hearing aids.

“You still don’t know what to expect until you actually get it fitted.”

Woman with hearing loss, East Midlands

It is important that people understand that hearing aids do not restore normal hearing. Hearing aid wearers’ expectations therefore need to be managed to reduce the risk of them becoming disheartened and possibly stop using the hearing aids altogether. All new hearing aid wearers should therefore be given information about what to expect from their hearing aids. Some participants were given this information by their audiologists.

“He did say you will probably feel uncomfortable. It’s obviously a new intrusion and you’re not used to having anything there. He also told me to break it in gently, to wear it for so many hours a day and get used to it slowly.”

Woman with hearing loss, East Midlands

“I was told by the audiologist they were very good, but sometimes may sound a little bit different, which is true, they did. But once you get used to it you find you can’t do without it.”

Man with hearing loss, North West England

We asked audiology departments if they explain what to expect from hearing aids. Positively, **96%** of audiology departments provide this information to everyone (see Table 4 above for further statistics). However, only one-third provide written information on this.

Commentary

Expectations were mixed amongst participants. As discussed above previous research has shown the positive impact that realistic expectations can have on use of hearing aids. It is therefore important that new hearing aid wearers have realistic expectations in order to maximise the benefit they obtain from their hearing aids.

The most effective way to achieve this is through information provided by the audiologist and audiology department. Information needs to be provided in person, when the patient is having their pre-fitting appointment, as well as written information to take away.

All audiologists need to give new hearing aid wearers information about what it is like to wear hearing aids, both positives and negatives, so that people have realistic expectations.

Recommendations

- Audiologists should explain to patients what they can expect from hearing aids before they are fitted.
- Audiology departments must ensure that hearing aid wearers are given advice about how long it may take to adjust to hearing aids, and the importance of persevering with them.

Difficulties and problems

Previous research has found that problems and difficulties with using hearing aids can prevent people from getting the full benefit. Many hearing aid users have some difficulty in handling and maintaining their aids resulting in a reduction or complete withdrawal of use (Brooks 1985; Brooks 1996; Brabbins and Hogg 1977; Oswal 1977; Upfold and Smither 1981; Sorri et al 1984; Ward, Tudor and Gowers 1978; Parving and Philip 1991). Whilst the design of hearing aids has improved since much of this research was undertaken, this project has highlighted that it is still an issue for many people today.

We specifically asked participants what difficulties or problems they have had, if any, with their hearing aids. All but one participant talked about having experienced some problems with their hearing aids. Problems ranged from the hearing aids being uncomfortable to wear, to the poor quality of sound, to difficulties with the design of the hearing aids.

• Comfort

One of the main problems discussed was about the comfort of hearing aids. Many participants described their ears as feeling itchy and sweaty when wearing hearing aids. This even developed into a skin condition for some people.

“It’s the most uncomfortable thing I have ever had to wear. My ear is itching now on this one, I am dying to take it out and give it a scratch.”

Man with hearing loss, Wales

“Often I get eczema or something like that from them as well.”

Woman with hearing loss, East Midlands

“I found I was having problems with the ears... seemed to make the ears sweat etc inside the ear. I left it off; I found it very discomforting to wear it.”

Man with hearing loss, West Midlands

However people will persevere with wearing hearing aids if they can perceive a benefit.

“They’re not very comfortable. The only way I can describe it to somebody is like... it’s just literally like you’ve got someone’s finger in your ears... So they’re not very comfortable no, and they get itchy. Your ear gets wet so that’s why... but at the same time I can hear – they’re just wonderful.”

Woman with hearing loss, South East England

Some participants talked of hearing aids being painful to wear.

“I’ve found it very, very painful to wear because it just irritated, ...so it took a while to get used to.”

Woman with hearing loss, London

“They make my ears all itchy and sometimes a sudden pain comes in them.”

Man with hearing loss, Scotland

For some people, although the hearing aids were uncomfortable initially, they gradually adjusted to them over time.

“The only hard thing I found getting used to was the actual part of the equipment that is in your ear, it’s like having a ring on your finger that is too tight and it’s really annoying, but that just lasts for so many days and it eases off.”

Woman with hearing loss, East Midlands

“Oh they are pretty good now. I have had trouble with this one, and after about three or four hours my ears started to ache, and I have had to pull it out, regardless of what’s going on I’ve had to pull it out.”

Man with hearing loss, South West England

For others, once the hearing aids were adjusted by the audiologist, the comfort improved.

“I became allergic to the other one and I was getting eczema in my ear, so they swapped it for this type that is non-allergenic.”

Woman with hearing loss, South West England

“They feel comfortable. One of the reasons was that the mould needed slightly amending to the ear... They are not going to get the hearing aid perfect when you go for the first fitting.”

Man with hearing loss, North West England

It can be tiring to wear hearing aids, as well as the need to concentrate on communication.

“People don’t realise how tiring it is. And... without it, it’s tiring, because you, um, you’re concentrating. I don’t do lipreading so to read people’s faces – you’re concentrating all the time.”

Woman with hearing loss, North East England

• Noise

Many participants talked about the problems of extraneous noise. As this quote highlights, hearing aids amplify all sound, with many people hearing things they haven’t heard in a long time.

“I’m afraid the world became a very, very noisy place, it was just as if somebody had blasted at me. Let me put it this way, when I went to the toilet it was like listening to Niagara Falls, it was unbelievable the sound... Suddenly I had a creak on my stairs that I didn’t know I’d got.”

Woman with hearing loss, East Midlands

Lots of people mentioned problems with general background noise. This is because hearing aids are not able to discriminate between, and filter out, background sound to the same extent that the ear can.

“I can hear you most of the time just now alright, but if I’m in company the background noise... is magnified as well as everything else... if someone is speaking you can’t hear them because of the background noise.”

Man with hearing loss, Scotland

Using hearing aids in a car can also create difficulties due to the background noise of the engine, traffic and wind noise.

“It does not do an awful lot of good in the car, simply because of the noise from the engine, or the wind noise, it amplifies all of those, so I turn the setting down a little bit and then of course when I can’t hear I turn it up again. It’s a bit of a battle.”

Man with hearing loss, Wales

Wearing hearing aids in windy conditions also created problems for some participants.

“If I am out in the wind, the wind gets me down and it’s surprising how much of a whistle you get from that, so you know in terms of design, I would be very, very pleased if the NHS decided that it would be worth experimenting.”

Man with hearing loss, Wales

- **Sound quality**

Poor or distorted sound quality of hearing aids were mentioned as a problem by several people.

“Sometimes I put it in and it’s all muzzy, as if you have got a terrible, terrible head cold.”

Woman with hearing loss, South East England

“It is like having your head in a bucket because they’ve got all the frequencies turned up as high as possible for me.”

Woman with hearing loss, East Midlands

Others talked about problems with whistling and feedback. The following quote is from a participant who was so embarrassed by their hearing aid whistling that they now no longer wear it.

“Sometimes my husband is here... he will say he can hear it. Or in the cinema, you are conscious people might be hearing this, so you tend not to use it.”

Woman with hearing loss, Scotland

Feedback on the telephone was mentioned as an issue by some participants, and several mentioned needing to take hearing aids out in order to have a conversation on the phone.

“Every time I picked up the phone there would be this whistling feedback all the time.”

Woman with hearing loss, East Midlands

Hearing aids amplify the user’s voice in a way which natural hearing does not. This can therefore be very distracting and hearing aid wearers may be hearing their own voice for the first time in a long time.

“And the most annoying thing about it is, you know when you put your finger in your ear, and you hear your voice in your head... I find that terrifically annoying.”

Woman with hearing loss, North East England

- **Directional sound**

Not knowing which direction sound originates from was discussed as a problem by some participants.

“The difficult thing is sense of direction – where a sound is coming from.”

Woman with hearing loss, North East England

- **Design**

Several people spoke about the unattractive or old-fashioned design of hearing aids.

“I said, good God, have you got anything more modern than this, because it’s very old.”

Woman with hearing loss, South East England

One participant thinks some people still think of hearing aids as the old body style.

“In the old days, hearing aids had this lead coming down. People are not aware everything is digital.”

Man with hearing loss, North West England

There were some differences of opinion over how noticeable the hearing aids are in the ear.

“I’m more aware of them with men with their short hair.”

Woman with hearing loss, North West England

“How do you feel about wearing one now?”

“It’s not bothered me too much. My wife said ‘They are very ageing looking and it’s a big thing in your ear. Why don’t you spend more money and get one of these tiny little things that go in your ear?’ I don’t think it’s worth it because I don’t think they are any better, I don’t think they improve people’s hearing. But visually it’s more acceptable to her.”

Man with hearing loss, East Midlands

Some respondents reported problems with putting hearing aids in their ear and/or keeping it in the ear. This is something that should be explained and demonstrated at the fitting of hearing aids.

“I somehow can’t even fit it in properly and it drops out. I am told that this is the equivalent of a hearing aid which is about £750 and if I lose it I won’t get another one or I will have to pay for it.”

Woman with hearing loss, North West England

This quote also highlights the issue that some people are reluctant to return to their audiology department for repairs as they fear they will be charged. There is therefore a fine balance to be made between making people aware of the need to look after their hearing aids and ensuring that

people will return to resolve any problems they have.

One participant has a paralysed hand and so needs another person to put in his hearing aids. He would like a hearing aid he could put in himself.

The size of the writing on the controls can pose difficulties for some people.

“The figures on the hearing aid ought to be as big as possible and as bold as is feasible within the confines of the size of the instrument.”

Man with hearing loss, North West England

Wearing hearing aids in combination with glasses caused problems.

“When you wear spectacles, that’s a bit tricky. You have to put it in before you put your spectacles on... I found once or twice that the thing was hanging off [laughter] hanging off my ear.”

Woman with hearing loss, London

“I... don’t know whether to put it under my glasses or over my glasses, I don’t feel it is really hooking on properly.”

Woman with hearing loss, Scotland

Commentary

The difficulties and problems associated with hearing aids were numerous. Some problems can be resolved with time and perseverance, with people getting used to how hearing aids feel in their ear and adjusting to the amplified sound provided by hearing aids. Hearing aid wearers therefore need to be made aware of this so that they will be more willing to persevere with wearing their aids.

Other problems can be solved by returning to the audiology department. People must therefore be made aware of when they can go back to the audiologist for help and advice, for example, when the mould needs adjusting. Other issues can be easily resolved by the hearing aid wearer and so troubleshooting guides should be provided at the fitting.

It is relatively common for full moulds to cause itching and sweating in the ear. Whilst in general this did not stop any of the participants from using their hearing aids at all, it did have an impact on the amount of time participants were willing to wear their hearing aids. The impact can be reduced with some modifications, for example by adding vents to the mould. This problem can also be resolved with the new design of hearing aid with an open fitting. The open fitting also resolves the problem with hearing aid wearers hearing their own voice.

The sound quality of hearing aids is also being improved with new technology and therefore some of the issues related to wind noise and background noise will be reduced for future hearing aids.

The problems participants experienced using the telephone indicates that not enough information is being provided either about the hearing aid and the 'T' setting, and/or about specialised telephones. The problem with feedback on the telephone can be resolved using a range of solutions.

Recommendations

- Audiology departments should provide hearing aid wearers with a troubleshooting guide for use with their hearing aid.
- Audiology departments should encourage hearing aid wearers to return to the audiology department, or to access a volunteer service, to ask questions and talk through any problems as and when they arise.
- Manufacturers to ensure that hearing aid technology is continually improved, with input from hearing aid wearers.
- The government to ensure that up-to-date hearing aids are provided on the NHS.

Benefits of hearing aids

Most participants talked of receiving benefit from wearing their hearing aids, whether all of the time, or only in particular situations or locations.

Some participants talked about the fantastic difference their hearing aids had made to their life. This participant describes the day she first received her hearing aids.

“I felt like the whole world had opened up to me again and it was one of the best days of my life.”

Woman with hearing loss, South East England

Hearing aids can even be seen to have a positive impact on the lives of family and friends.

Some participants described the pleasure of being able to hear things that they haven't heard in a long time.

“The thing I noticed was all the birds twittering in the trees. I could hear that – and the wife when she wanted a job done!”

Man with hearing loss, South East England

“The hearing loss, without a hearing aid, yes it does have an impact, but it doesn’t bother me. I go bird watching, certain bird sounds I can hear without my hearing aid, high pitch, something like that, no problems. If I have got my hearing aid in I can hear them all over the place. What a difference those wonderful sounds make. If I don’t have them in it is my loss, I can’t enjoy something as beautiful as those bird sounds.”

Man with hearing loss, North West England

For some the benefit of hearing aids comes from being able to watch the television at a lower volume.

“The level on the TV we’ve noticed we can put down now whereas it used to be up much higher.”

Participant’s wife, South East England

This participant finds her hearing aids useful when in an area with background noise.

“If I’m in a noisy restaurant I will click it onto the middle setting so that I’m not getting the background to the same extent and that can make a lot of difference, it can make it much clearer.”

Woman with hearing loss, North West England

For some participants, hearing aids have made a positive difference, but they still have some difficulties hearing.

“Occasionally with children, or if somebody, if I am not concentrating, somebody cracks a joke, I might miss the punchline, but nowhere near as much as I did, nowhere near.”

Man with hearing loss, North West England

“With my hearing aids it’s not back as it was but it is as near as I would hope to get it really. Because you can’t perfect what’s in your body and gone wrong can you? It’s like a clock, you can adjust it but you can’t get it perfect can you?”

Woman with hearing loss, South West England

However, for these participants, they do not think their hearing aids provide much benefit.

“I can never get this one loud enough. If people sit alongside me, and talk straight out past me, I couldn’t hear it.”

Man with hearing loss, South West England

“It did enhance it [hearing] for a while but I wasn’t sure that the advantage of that outweighed the disadvantage of it being uncomfortable and it did tend to whistle a bit and so I was a bit embarrassed about that.”

Woman with hearing loss, London

Interestingly, one participant talked of the main benefit of her hearing aids as being a signal to others that she has a hearing problem, rather than any improvement in her hearing.

“At least if you’ve got the hearing aid in that’s proof. If you don’t have it in and you go ‘pardon, say that again’ people get a bit irritated.”

Woman with hearing loss, North East England

One participant, however, would recommend hearing aids to everyone with a hearing loss.

“Absolutely, I would encourage all those that need a hearing aid, and are genuinely needing them, to go ahead and get them.”

Man with hearing loss, North West England

Commentary

Overall, most participants received benefit from their hearing aids. In general the hearing aids were useful for communication and watching the television. Hearing aids were also seen as a useful signal that someone has a hearing loss. However, several participants did not find their hearing aids useful, and for these people, a return appointment to talk to an audiologist would probably have been useful.

Audiology guidelines for England suggest that systems should be in place to support people who do not use their hearing aid. This includes dedicated channels for referrals to other agencies.

Recommendations

- Audiology departments should offer ongoing reviews to ensure that people are gaining the most benefit from their hearing aids.

Frequency of wearing hearing aids

Some participants talked of wearing their hearing aids all day, from morning to night.

“I always wear it now, I won’t go anywhere without it because you never know.”

Woman with hearing loss, South East England

“All the time. The only time that I don’t is if I’m going to the hairdresser’s just so that I don’t get them sopping wet. I remember to leave them out but other than that they’re always in, I put them in in the morning and take them out at night.”

Woman with hearing loss, North West England

It is recommended that people wear their hearing aids all day as this helps them to adjust to sound as heard through the hearing aids. If the user takes their hearing aids off on a regular basis, then the brain will be confused by the change in sound and thus it will take longer to adjust to the aids.

However, most participants wear their hearing aids for only part of the day. They remove their hearing aids for various reasons. For example, they do not need to wear them in certain situations or they would like a break from wearing their hearing aids due to them being uncomfortable.

“Well as I said, it used to be when I was at work. But I’ve just given up work. Hurrah [laugh]... so situations like this, obviously I had to wear it. And at the theatre and in concerts... places where they’ve got induction loops.”

Woman with hearing loss, North East England

“I really need to get this right because otherwise I’m really not going to hear. I’ve really persevered with them but that’s not to say that I wear them all the time. Because I did find when I was wearing them all the time that I was getting lots of ear infections in the outer ear. I tend to use them at work if I’m going into a meeting or if I’m going out somewhere where it’s noisy but I don’t have them in all day every single day. If I’m watching a film or something then I’ll put them in.”

Woman with hearing loss, East Midlands

Several participants talked of rarely using their hearing aids due to a combination of the aids not being comfortable, and not feeling like they are getting any benefit.

“I don’t feel it makes a big difference, and also it is very uncomfortable.”

Woman with hearing loss, Scotland

“To be honest, I don’t use it as much as I probably should. I don’t find it overly comfortable, so... I use it when I’m working or I go to meetings or when I’m with groups of people, but that’s not so often now.”

Man with hearing loss, South West England

There is often a fine balance between the disadvantages of wearing hearing aids and the disadvantages of not wearing them as demonstrated in the quote below.

‘It’s tiring. Yes it is. Really tiring. But it’s tiring not to wear them so it’s a different kind. I don’t know which is worse. What I feel, when I take her out [sigh] you don’t have all this clicking and clacking going on.’

Woman with hearing loss, North East England

Some participants talked of becoming increasingly reliant on their hearing aids due to their hearing loss getting worse, or anticipating that when their hearing gets worse they will need to wear their hearing aids more often.

“Not all day – well, sometimes I do all day, if I’m working with...machinery they are ...a disadvantage because I don’t necessarily want to hear the noise...but basically lately I’ve been wearing them more because I think my hearing is deteriorating.”

Man with hearing loss, North West England

However, some participants spoke about the benefits of persevering with wearing their hearing aids.

“I think I get more benefit out of it than other people do because they have this business of taking it off while you’re switching the TV on at certain times of the day. I have it on all the time and I think that I probably don’t have quite as many problems as they have.”

Man with hearing loss, East Midlands

“They do take a lot of time and money to provide them to people so you should give them a good shot. In the end you need to put a bit of perseverance into it... I think it’s marvellous, but some people can’t be bothered. It would improve their quality of life... It took me a couple of weeks I suppose. I had headaches for a little while with them but they did say that might happen because your brain is having to understand and deal with the noise.”

Woman with hearing loss, East Midlands

Commentary

The frequency and length of time people wear their hearing aids varies depending on the benefit they get from them and the comfort of the hearing aids. Therefore if more time and effort was spent on supporting the person to adjust to their hearing aid, ensuring it is comfortable and provides benefit, this could positively impact on the amount of time people are willing to wear their hearing aids.

Recommendations

- Audiology departments and the government should consider alternative ways to provide further support to people with hearing loss, including through the use of voluntary services such as RNID’s Hear to Help.
- Audiology departments should also consider earlier intervention, for example referring people to voluntary services at their first audiology appointment.
- Audiology departments must ensure that hearing aid wearers are given advice about how long it may take to adjust to hearing aids, and the importance of persevering with them.

Chapter 4: Other technology and equipment



This chapter looks at the kind of equipment and assistive technology, other than hearing aids, that people with hearing loss use, as well as looking at participants' requirements for equipment.

Technology can provide important support to people with hearing loss, for example through a listening device to aid communication, a loop system for watching the television, an amplified telephone or a smoke alarm with a flashing light. These can all help to play an important role in rehabilitation through reducing the impact of hearing loss on the individual's life. It is therefore important to look at what technology participants make use of in their homes and at work.

The chapter is divided into three sections: equipment at home, loop systems, and finally equipment in the workplace.

Equipment at home

As already discussed in the information section above, most participants were given little or no information about specialist equipment for use at home. However, there were some exceptions to this, with some participants referred to hearing therapists or occupational therapists, or told to contact external organisations.

“I mentioned at the hospital that I could not hear the television and they said there was a lady who worked there who could help. So she wrote to me. I had an appointment and she said ‘You can have a loop or buy a special phone.’ I tried one loop which did not work and then I tried another one, a nice little neat one.”

Woman with hearing loss, South West England

However, for the majority, they were either not aware of what equipment is available to help with their hearing loss, or they have had to be proactive in getting any equipment they have.

One participant found out by accident that she could use the T setting on her hearing aids whilst using the telephone.

“I came home and tried it on the telephone and found that apart from the radio one, which we can wander around the house with, it was heaps and heaps and heaps better.”

Woman with hearing loss, North West England

Whilst not everyone will have a hearing aid compatible telephone, it is important that people are aware that they exist and of the benefit they can provide. Several participants talked of the need to remove their hearing aids to talk on the telephone. Difficulties hearing on the telephone can be reduced through various options. Hearing aid wearers need to be provided with more information and possibly the opportunity to practise using a telephone with their hearing aid.

“If the phone rings now and I’ve got this in I have to take it out to use the phone, I can’t use the phone with that in.”

Woman with hearing loss, East Midlands

Some participants were able to get support from their local social services departments, including the loaning of equipment.

“They gave us a bigger phone. I just changed it yesterday because it wasn’t loud enough for me and there’s a booster. I haven’t heard it yet but the wife says it’s a lot louder now.”

Man with hearing loss, Scotland

This is particularly important for people who may not be able to afford to buy equipment for themselves.

“You have to buy everything yourself. If you can’t afford it, you have to go without.”

Woman with hearing loss, South East England

Audiologists can play a key role in providing information about equipment. However, the information needs to be clear and accurate.

“I didn’t know what he meant because he was so off hand. He said you can go down the [area of town] and get something for your phone but I didn’t know what he was talking about and my children don’t because they have never dealt with any of this.”

Woman with hearing loss, South West England

Some participants said they do not need any other equipment as their hearing loss is not too bad or view requiring equipment as a sign that your hearing loss is really bad.

“On a day to day basis my hearing loss isn’t... I mean some people’s hearing loss is debilitating. If you had to have a flashing light to be aware the front door bell is ringing that must be dire...”

Man with hearing loss, North West England

“I use that phone and I put it up to my unassisted ear and I manage OK.”

Man with hearing loss, East Midlands

People also learn to make adjustments to deal with their hearing loss, for example through turning up the volume of the telephone or relying on partners or family members.

“We just turn the telly up basically. We don’t have a doorbell. We’ve got five dogs so if anyone knocks at the door, even when something comes through the letterbox, there’s no way we wouldn’t know about it.”

Woman with hearing loss, East Midlands

“And how about the telephone? Do you have any problems?”

“I don’t have a problem with that. Because I can press that to my ear, I don’t have a problem. Hearing it sometimes I do. Even now, if I lie on my right side and the telephone goes off, I can’t hear it. I just can’t hear it and the wife’s here anyway, so she will. I can’t hear the alarm clock, but we get round it.”

Man with hearing loss, South West England

However, there was also a feeling with some of these participants that they were making do. Some participants could benefit from equipment.

“My wife will sit in the other room and watch the television in there and I might be watching in here and she’ll come out and say ‘That telly is loud’ because it’s interfering with what she is watching.”

Man with hearing loss, East Midlands

This participant has no specialist equipment; however it can be seen from this quote that she could benefit from having access to it.

“I can be walking around with my mobile phone in my hand and I don’t hear it ringing and I’ve got it up loud... I stay in a top floor flat, so it’s a buzzer entry and I don’t hear the buzzer. I sleep through all my alarm clocks. I’ve got three alarm clocks and my mobile and I just don’t hear them. I just sleep right through them completely and I think I wake up everybody else in the building, but they just don’t wake me up.”

Woman with hearing loss, Scotland

Subtitles are a way to aid television watching without the need to purchase extra equipment. However, only a few participants reported using subtitles, but they talked about subtitles positively.

“Even if I’m watching the telly, if I’ve got the sound up loud, again, it’s just a rumbling noise. I can’t make out what people are saying, so I’ve always got the subtitles on.”

Woman with hearing loss, Scotland

“I use subtitles on the television... it’s absolutely brilliant for films, you know, programmes that have been recorded.”

Woman with hearing loss, London

However, the participants did raise a few issues with using subtitles. For some participants, their family members do not like having subtitles on the television.

“I put text on TV now. At first my husband, it annoyed him.”

Woman with hearing loss, Scotland

Other participants talked of how it is tiring to read the subtitles.

“You feel as if you are sitting reading this all the time. Be nice just to relax, to listen the way you did before.”

Woman with hearing loss, Scotland

Some people have never thought about using subtitles on their televisions.

“I’ve never thought to, it has never occurred to me to do that. Isn’t that funny?”

Woman with hearing loss, East Midlands

Commentary

Most participants do not use any equipment however it is clear from the interviews that many participants could benefit from equipment. It is important that people with hearing loss are made aware of what equipment is available and where it can be obtained. It is also useful for people to be able to try out equipment so that they can decide what would be most useful to them. Under the quality guidelines for audiology services in England, equipment should be available for patients to try and written information provided about equipment. The guidelines also recommend that there is a lead member of staff who is responsible for keeping up-to-date about developments and disseminating information across the department.

Local authorities have a legal obligation to assess the needs of people with a disability for assistive technologies that can help an individual in their home. The equipment is generally loaned to the individual and can include smoke alarms, door bells or TV listening devices. All hearing aid wearers should be provided with information about equipment by their audiology department, including information about their local social services team.

For some people they may feel a stigma is attached to getting help from the social services, and so it is important that people with hearing loss are able to access equipment from a variety of locations.

Recommendations

- Audiology departments need to raise awareness of what technology and equipment is available to help people with hearing loss and where this can be obtained.
- Social services need to ensure that equipment can be loaned or offered free of charge to people with a hearing loss.
- Suppliers of equipment should enable hearing aid wearers to try out equipment before they buy it.

Loop systems

Induction loops and infrared systems help people with hearing loss to hear sounds more clearly when there are barriers such as a counter screen or the speaker is some distance away from the hearing aid wearer. Loop systems can be used in the home to assist with hearing the television, for example. They are also often available in public places such as banks, shops and places of worship.

Awareness

Awareness of loop systems was mixed amongst participants. Some people did not know about the ‘T’ setting for loop listening on their hearing aids, whilst others were regular users of loop systems.

“You know in Post Offices etc it says put your hearing aid to the T position? I don’t know what that means.”

Woman with hearing loss, Scotland

“I don’t think there is a T... I’ve never heard of what it is.”

Man with hearing loss, Scotland

It is important that people with hearing aids are given the opportunity to try out loop systems, so that they can learn how to use them.

“They did explain that but it didn’t register with me, you press the little button and it pips twice and then I don’t know what happens, I’ve never used it.”

Woman with hearing loss, East Midlands

It is also beneficial for people to be able to try loops out so that they can experience using them.

“When I did try the loop it was wonderful, it goes straight into your head and you can hear. It’s really nice.”

Woman with hearing loss, South West England

Participants who were aware used loops in church, at the theatre or cinema, in the bank and when using the telephone or watching TV.

“I use it in church and on the telephone and when I go to the bank.”

Woman with hearing loss, South East England

“I do put it on loop sometimes in church, but if I get any feedback at all then I will just click it onto the loop.”

Woman with hearing loss, North West England

Need

Of those who were aware what a loop system is, some thought their hearing loss not bad enough to warrant using a loop system.

“I don’t really need an induction loop, I mean I can hear quite well.”

Man with hearing loss, South West England

“I’ve never used it because I’ve not needed to.”

Man with hearing loss, East Midlands

However, there were occasions participants talked about when they would have benefited from using a loop system. This highlights the need to raise awareness of loop systems, both in the home and in public places.

“I don’t like it [television] too loud because it sometimes hurts my daughter.”

Woman with hearing loss, South East England .

“I’m learning Italian at college and I absolutely cannot hear when she puts the tape on, or the CD, I can’t make out any words at all.”

Woman with hearing loss, London

“It could be a lot worse obviously, I know people are quite profoundly deaf and it’s nothing as bad as that but it would be nice to be able to hear the TV.”

Man with hearing loss, Scotland

Benefit

Where loop systems were used, they were generally talked about positively.

“I think it’s absolutely wonderful... it’s just incredible.”

Woman with hearing loss, North East England

Participants found loop systems in theatres particularly beneficial.

“It’s so good I have to turn it down.”

Man with hearing loss, South West England

“I can sit in the back row and it’s absolutely brilliant.”

Woman with hearing loss, London

We also found that loop systems can be of benefit to the whole family and even further afield.

“That thing has been a godsend to me because he can turn it down so low now, the television, so I can’t hear it and he hears it.”

Participant’s wife, Scotland

“By considering other neighbours now I can have it down, can literally have no sound on, I can hear it very clearly. The sound comes directly through the hearing aid.”

Man with hearing loss, North West England

Problems

Some participants had experienced problems when using loop systems in public places. Loop systems need to be maintained and staff trained in their operation.

“Very often you find that they haven’t been switched on.”

Man with hearing loss, North West England

As can be seen from the quote below, it is also important that the loop systems are regularly checked. In this case, the soundtrack from a film on another screen was leaking through to the loop system.

“We went with some friends to watch Harry Potter and I switched on the loop system and... I didn’t know the soundtrack of Harry Potter was in French!”

Man with hearing loss, North West England

Other participants talked about problems with the sound quality or volume of loop systems.

“Yes I wired it up around the room myself and that was fine as far as it went. But if you want high quality in audio that is not the way to get it and I don’t use it any more with my hearing aids.”

Man with hearing loss, North West England

“I was advised to turn the volume down really low and then I could not hear the vicar taking the service and when they were singing the hymns the volume was too great.”

Man with hearing loss, Wales

Whilst loop systems in public places can be extremely helpful for people with hearing loss, they are not always available.

“I play the piano for a little church down the bottom there. They don’t see the necessity for putting a loop in at all.”

Man with hearing loss, South East England

“I found of course that most theatres here don’t have a loop system.”

Woman with hearing loss, London

There is also an issue with the cost of purchasing loop systems for the home.

“The loop is quite expensive, it’s about £100.”

Woman with hearing loss, London

One participant was recommended a neckloop for use with her mobile phone. However she was not given information about where to purchase this from.

“I went round God knows how many mobile phone shops asking them about it and nobody knew anything... you just think, I’m not going to bother. Whereas if the audiologist had suggested I look on the RNID site or phone up the RNID and ask it would have been made a lot easier than me going round every single mobile phone shop. They all look very blankly at you.”

Woman with hearing loss, East Midlands

Commentary

Not all participants were aware of what loop systems are, or how to put their hearing aids on the ‘T’ setting. Of those using loop systems, most tended to use ones in public places rather than in the home. This supports the findings from the 2009 annual survey of members where **85%** of respondents used loops in public places compared with only one-third using them at home.

Loops are beneficial to people with hearing loss, enabling them to hear more clearly, as well as benefiting other members of the family or even neighbours by enabling the television to be turned down. However, there are numerous problems with loop systems. To purchase one for home use can be prohibitively expensive and they can also be difficult to maintain. In public places, loops are often not installed, or where they are available, they are not maintained properly and staff are not trained in their operation. It is therefore important to raise awareness of loop systems to people with hearing loss, as well as to make service providers aware of their legal obligations.

Recommendations

- Where appropriate audiologists must ensure that hearing aids have a ‘T’ setting for loop listening.
- Everyone with a ‘T’ setting should be told in person and given information in writing how to operate the ‘T’ setting and it should be explained what a loop system is.
- Audiology departments should offer hearing aid wearers the opportunity to test out their ‘T’ setting and to try out loop systems.
- Audiology departments should provide information about loop systems, including where loops for home and work can be obtained and where to access loops in public places.
- Services should provide loop systems where appropriate and ensure that they are correctly maintained, tested and signposted. Staff must be trained in their use.

Work

Some participants talked of needing equipment at work. This will be discussed in further detail, in the chapter titled 'Impact of hearing loss'. The main issue for participants in work was that they were not sure of their rights in the workplace and were not aware of what support they could reasonably expect their employers to provide.

“I’m a magistrate and was absolutely appalled that there is no loop system in court. Absolutely appalled, because lots of people that I deal with do have hearing problems. This is something that I will address the next time I go back, because I believe there should be a loop system in a public building. Am I correct?”

Man with hearing loss, South West England

An induction loop would not be appropriate for a confidential area such as a court, however an infrared system could be installed to help people with hearing loss to hear better.

One participant received support from the government scheme Access to Work. This scheme can give disabled people and their employers advice and support with extra costs which may arise because of their disability. However, the participant found the application process to be extremely long-winded and complicated. She has received some basic equipment such as a telephone, however she was required to investigate loop systems herself.

“I thought, do you know what, I’m just going to give up [laughs] because I haven’t got the technical knowledge.”

Woman with hearing loss, East Midlands

Participants were provided with varying levels of equipment in their workplace to help with their hearing loss.

“We’ve got some portable loop systems... But you have to charge them up for a long, long period of time for them to be fully charged for you to be able to use them. And I kept plugging it in every day and again I just thought, this isn’t actually working for me, I might as well just stick with my hearing aids.”

Woman with hearing loss, East Midlands

“My T-Loud for my phone at work is probably about the best bit of equipment I’ve been given, and I don’t think they’re particularly expensive. To me it’s fantastic and it makes a really, really big difference.”

Woman with hearing loss, East Midlands

Commentary

There do not appear to be clear lines of responsibility for who should provide equipment in the workplace. Employers and employees are unclear about what equipment can and should be provided. Employers must therefore be made aware of their responsibilities to support staff with hearing loss, including through the provision of equipment. Employees must also be made aware of their rights to get help with their disability in the workplace.

Recommendations

- The government should increase awareness amongst employees and employers about the rights of people with hearing loss in the workplace.

Chapter 5: Additional support



This chapter examines what other forms of support are used by people with hearing loss and what forms of support would be useful. Communication training such as lipreading lessons and hearing tactics are useful in helping to minimise the impact of a person's hearing loss. They provide people with the tools to improve communication. How a person reacts to their hearing loss will also have an impact on their life, and therefore counselling and hearing therapy can be useful for some people.

Lipreading

Lipreading classes can be a good way of improving communication skills for people with hearing loss. They also benefit people through providing a support network. However, no participants were attending lipreading classes during the period of the research. One participant had previously been to lipreading classes but could no longer attend due to the class being held during working hours.

Some participants said they had considered attending lipreading classes, however most people were not even aware they existed. Participants in general did not consider themselves to be 'deaf enough' to need to go to classes. However, most said they would consider going to lipreading classes if their hearing got worse.

“I'd be interested if I thought it was necessary but I wouldn't try to pre-empt the situation where I'd think I must learn to lipread because I might in 10 years have to.”

Man with hearing loss, East Midlands

“I am not deaf, that is my mental state. I have a hearing problem but I am not deaf. Perhaps I don't want to admit to that fact if I went to lipreading.”

Man with hearing loss, Wales

Only one participant was interested in attending lipreading classes.

“I would love to learn properly how to lipread”

Woman with hearing loss, South East England

One participant suggested that a lipreading DVD would be useful so that they could practise at home.

Commentary

The Scottish Government’s BSL and Linguistic Access Working Group stated that lipreading classes are the ‘core business of health services as part of rehabilitation and should be funded as such’.¹¹ Mustapha (2010) found more than three-quarters of respondents in Scotland considered lipreading to be part of hearing rehabilitation.

Awareness of lipreading classes is low amongst these participants compared to those interviewed for Echaliér (2009). However, as discussed in the introduction, the majority of respondents to this research have had no previous contact with RNID and will therefore not have been exposed to information on RNID’s website or through the members’ magazine, *One in Seven*, about lipreading classes. It is therefore important that people with hearing loss are made aware of lipreading classes and the benefits they can bring. It should be made clear that people with all levels of hearing loss can benefit. The audiology guidelines in England suggest that audiology departments provide written information about lipreading classes. For example, RNID and ATLA (Association of Teachers of Lipreading to Adults) have produced a practical guide to lipreading called *Watch this Face*.

The RNID report, *Paying lip service* (2010) found some regions of England and Wales have very few lipreading classes available, or even none at all. The fees for some classes are also extremely high,

which can prevent some people from attending. The government needs to provide more funding to ensure that lipreading classes are available for all those who need them.

Previous research has found lipreading training via video was effective (Dodd, Plant and Gregory 1989). Students viewed the video in various locations, at home, in a class, or as supplementary teaching material. The location had no impact on the extent of the improvement. Lipreading training through DVD or online would therefore be helpful for people who are unable to attend lipreading lessons, or who would prefer to learn at home.

Recommendations

- Local authorities, health boards and providers to increase awareness about lipreading classes.
- For those people not able to attend lipreading classes, lipreading DVDs and books should be available.
- Government to provide funding to improve the availability of lipreading classes and to ensure they are affordable.

Other support

Participants did not receive any other forms of support, such as counselling, hearing therapy or more general communication training (except for those with tinnitus). This is surprising when the literature demonstrates the advantage of providing this support, both in terms of increasing the hours of use of hearing aids, as well as improving individuals’ perceptions of the impact of their hearing loss. For example, one study found follow-up counselling can help a significant number of occasional hearing aid users to become regular users, and decrease the number of non-users (Vuorialho 2006). The counselling also significantly increased the user’s handling skills.

¹¹ British Sign Language and Linguistic Access Working Group (2009). *The Long and Winding Road – A Roadmap to British Sign Language & Linguistic Access in Scotland*. Scottish Government. Available from: www.scotland.gov.uk/Resource/Doc/278136/0083565.pdf

Several studies by Brooks have demonstrated the efficacy of counselling in increasing the use of hearing aids (1981; 1985; 1989). For example, Brooks (1985) found **49%** of all subjects who received counselling use their aids for more than four hours per day compared with **37%** of the non counselled group.

We asked audiology departments if they provide basic hearing tactics and communication training. Less than three-quarters of departments surveyed provide this to all hearing aid wearers.¹²

Commentary

Overall, counselling and communication training appears to be effective in increasing hearing aid use and/or reducing self-perceived hearing handicap. Boothroyd (2007) suggests that the most appropriate approach to rehabilitation is through a holistic approach. People with hearing loss need to have access to a variety of instruction, counselling and communication training, as well as being fitted with hearing aids. The audiology guidelines for England, Scotland and Wales suggest that departments should provide details of support groups for people with hearing loss. We would urge all departments to implement this guidance.

Recommendations

- Audiology departments should provide a list of useful organisations to people with hearing loss such as voluntary organisations, support groups, social services and Access to Work.
- Audiology departments and social services should offer a wider range of rehabilitation and support options for people with hearing loss, including, for example, communication training or hearing therapy.
- Government should invest in alternative forms of rehabilitation and support such as communication training and hearing therapy.

¹² See Table 4 for full statistics.

Chapter 6: Impact of hearing loss



Despite all the participants being provided with hearing aids, the majority reported their hearing loss continuing to impact upon their life. It is therefore important to look at these impacts in order to shape future services and support.

Relationships, family and social situations

Echalier (2009) discussed the wider ramifications of hearing loss on family and social life. Hearing loss can lead to feelings of isolation and withdrawal from participating in activities. This research supports this finding, with hearing loss creating communication difficulties, particularly in group situations.

“Talking one to one isn’t so bad, but when you have got a group it is hard. I am in a writing group, so somebody is reading out what they have written and nine times out of 10 I don’t hear it.”

Woman with hearing loss, Scotland

These problems lead to feelings of isolation and exclusion.

“I’m not a bit embarrassed about it except for the situations where you can’t keep saying to somebody ‘Can you repeat that bit? Sorry I can’t hear you’ by which time they’ve changed the subject and are onto something else. It can be exceedingly isolating and you feel like a wallflower sitting on the edges and everything is bypassing you.”

Man with hearing loss, North West England

“Only on social occasions like birthday parties, Christmas parties – anywhere where there are a group of people like sitting around a restaurant table is when I feel it.”

Man with hearing loss, North West England

Feeling isolated can lead to people withdrawing from certain activities.

“I would avoid seeing friends who didn’t speak very loudly or wouldn’t.”

Woman with hearing loss, South East England

Some of these difficulties can be resolved by people being deaf aware. If they know someone has a hearing loss, they can take steps to ameliorate this.

“Are people generally quite good at involving you in a conversation in those situations?”

“No I don’t think so. I don’t think they do it deliberately. They probably don’t notice that one of them is missing out on the conversation and... the longer this goes on during an evening the more you feel that you can’t join in.”

Man with hearing loss, North West England

However some participants have the attitude that it is something you have to accept and get on with.

“With my hearing aids – it’s not back as it was but it is as near as I would hope to get it really.”

Woman with hearing loss, South West England

Commentary

Hearing loss can be seen to have a substantial impact on some of the participants’ lives, despite them having hearing aids. More support and advice therefore needs to be provided to people with hearing loss to ensure that the impact is minimised, and that people do not become isolated as a result. Providing hearing aids should therefore only be seen as one part of the process, rather than the end.

The general public needs to be more deaf aware and people with hearing loss can play a key role in this by being more forthcoming about their loss and raising awareness of the condition. A national hearing screening programme would also help to raise awareness of hearing loss.

Recommendations

- Audiology departments and social services should offer a wider range of rehabilitation and support options for people with hearing loss, including, for example, communication training and hearing therapy.

Work

People are working longer for a range of reasons and any increase to or removal of the default retirement age means that this trend is likely to continue. This will result in an increasing number of people in the workforce with hearing loss. It is important that hearing loss is identified and addressed to help people stay in work longer and to function as effectively as possible whilst at work. A high proportion of older people have hearing loss, with **40%** of people aged 50 and over having some kind of hearing loss.

Several participants talked about the negative impact that their hearing loss has had on their work. For some people they have had to change their role in order to adapt to their hearing loss. However, this would not necessarily be the case if they were supported and equipment provided.

“If there was a large group of people sitting in a circle at a meeting, then I would not go.”

Woman with hearing loss, South East England

The interviews also showed that some employers are not effectively supporting staff members who are deaf, for example through the provision of equipment or seating arrangements.

“I still find it difficult on the telephone at work sometimes because it’s a shared office.”

Woman with hearing loss, South East England

“I was at a board meeting and I just couldn’t hear. Although I’d said to my chairman, ‘I’ve got a problem, you’ll need to speak up’, they don’t.”

Man with hearing loss, South West England

There is a general lack of awareness about what support people can expect from their employers. For some their hearing loss has made them feel more vulnerable at work, as they do not feel able to fulfil the full range of tasks for their role.

“I felt quite vulnerable at work really. They’re appearing to be very supportive but you are in a position where you know all organisations are undergoing budget cuts and jobs are at risk.”

Woman with hearing loss, East Midlands

“I’ve seen a number of magistrates over the years retire because of deafness because you just can’t keep up and it can be so embarrassing, you know, if people don’t know.”

Man with hearing loss, South West England

Commentary

Echaliier (2009) found some were unwilling to admit to their employer that they had hearing loss, and where they did, some had suffered discrimination. It is therefore important to increase the deaf awareness of employers, to ensure that they are supporting their staff with hearing loss appropriately. This can partly be achieved through a national hearing screening programme and a public awareness campaign.

This research shows that people with hearing loss are not necessarily getting the support they need in their workplace and so employers and people with hearing loss need to be able to access information and support easily.

Employers must be aware of the need to support their disabled employees, make adjustments and look at alternative ways tasks can be undertaken – for example to enable a person who is not able to use the telephone to stay in their job or to provide loop systems in meetings.

The current trend for open plan and shared offices may create further problems for people with a hearing loss. As we know, background noise is a problem for people with hearing loss as well as for people who wear hearing aids.

Recommendations

- The government should increase awareness of the Access to Work scheme to support people with hearing loss in employment.
- Government should increase people with hearing loss’s awareness of their rights to support in employment.
- Audiology departments should raise awareness of what technology and equipment is available to help people with hearing loss and where this can be obtained.

Chapter 7: Personal attitudes to hearing loss



Some people may have difficulty accepting they have hearing loss (Brooks 1985; Brabbins and Hogg 1977). Brooks (1989) states “attitude is of importance in the acceptance and effective use of amplification. Consideration of the candidate’s feelings and perceptions should be accorded as much attention as the technical fitting of the hearing aid. Unless that individual has genuinely come to terms with his/her hearing loss the outcome is likely to be unsatisfactory” (p10).

It is therefore important to look at whether participants have accepted their hearing loss. This section is divided into participants’ acceptance of their hearing loss both prior and post diagnosis, followed by a section on how comfortable people feel telling others about their hearing loss.

Pre hearing assessment

Despite the warning signs there was generally no immediate reaction by participants to their hearing loss. Most participants described delaying in the beginning, before taking steps to deal with their

hearing loss. However, as can be seen in the following section on post diagnosis, this does not necessarily mean that participants had accepted their hearing loss.

This research supports previous findings that hearing loss is often thought of as a natural part of getting older and therefore people are reluctant to take any action to deal with it (Brooks 1996; Echalié 2009).

Some people delayed accepting their hearing loss by blaming the fact they couldn’t hear on other causes such as wax in the ear or people mumbling.

“The nurse said ‘Do you have a problem with your hearing?’ and I said ‘No it’s just that they need syringing’. She said I should have a word with the doctor. But I didn’t right away, but about a month after I thought I wonder if she’s right.”

Woman with hearing loss, South West England

“When I was working, I worked in the Post Office in front of the glass and I was having to ask my colleague what people said. It didn’t occur to me that it was me. I thought it was them.”

Woman with hearing loss, East Midlands

Interestingly, one participant’s hearing loss was initially masked by her partner’s hearing loss.

“When she got her hearing aid I said ‘I can turn the telly down now’, but we were turning it up instead. I thought that was a bit strange and I went to the doctor. He did a hearing test. So I booked in for that and that’s when they noticed that my hearing in that ear had deteriorated.”

Woman with hearing loss, East Midlands

Exceptionally, one participant was immediately accepting of her hearing loss and asked for help quickly, despite receiving assurances from her husband that she wasn’t losing her hearing. However, her positive attitude towards hearing loss is possibly in part due to a family member already wearing hearing aids, as well as having previous contact with a school for deaf children.

“I had discussed it with my husband and he kept saying ‘No, your hearing is fine’. Then in the local paper they had a list of waiting times for various specialities and I think the hearing aid at that time was six months. I thought if it’s going to be as long as that perhaps I ought to do something now, so I went to the GP.”

Woman with hearing loss, North West England

Commentary

Most people are initially in denial about their hearing loss. They may be blaming other causes for the reason why they miss what people are saying, or they may be in denial about hearing loss because of the connection with ageing. It is therefore important that general awareness about hearing loss is raised.

A national hearing screening programme would help to raise awareness of hearing loss amongst the general population. We also believe that GPs should play a greater role in encouraging people to recognise and take action with their hearing loss. This includes GPs being proactive and speaking to people about their hearing and providing information about hearing loss and hearing aids.

Recommendations

- GPs should routinely ask older people about their hearing and refer them to audiology for assessment if they are having difficulty in daily life.
- GPs should also explain the benefits of taking action on hearing loss to people with a suspected loss.

Post diagnosis

Even when participants were diagnosed with a hearing loss, this did not necessarily mean that they took action to deal with it.

“A while back, maybe three to four years back, an optician was giving hearing tests as well. My sister and I went in, I think he said she had lost 30% and I had lost 40%. Even then I didn’t do anything about it.”

Woman with hearing loss, Scotland

The reasons for delaying after diagnosis are varied. For some people it can be the result of a previous bad experience.

“One of the things that did put me off is... a doctor said ‘We can operate on it and I’d like to do it because it is something a bit more interesting’. It put me off because somebody did warn me, the only time to operate on it is when I’ve got total loss.”

Man with hearing loss, North West England

It can also be due to people not having accepted their hearing loss.

“Until you are ready to admit it nobody else can. They can keep on saying you’re going deaf, you’re going deaf, it doesn’t matter because you don’t want to admit that you are.”

Woman with hearing loss, South West England

This participant blamed problems with communication on her not making an effort, rather than on her hearing loss.

“If I really want to join in I can make the effort, you know. I’m lazy because I’m perfectly able to do that.”

Woman with hearing loss, London

Research has found that some people may feel embarrassed wearing hearing aids or not like the look of the aids (Brabbins and Hogg 1977). A few participants did speak about wanting to hide their hearing aids initially, but they gradually became more confident with them.

“I’ve grown my hair a bit longer to hide it a bit but I was very self conscious about going to work with them...”

“Did anyone say anything?”

“No. I said I’m running them in and made a joke of it, and they said they wouldn’t have known I had them in.”

Woman with hearing loss, East Midlands

“To really get used to it I would say a couple of months really because you have to realise that you are trying to hide them... which is ridiculous really because they are too big to hide aren’t they...”

“And do you still feel you want to hide them?”

“Oh not so much now, I don’t take that much notice of it, so long as I can hear.”

Woman with hearing loss, South West England

Several of the participants do not wear their hearing aids now. This is due to various reasons, including having had problems with them, and not feeling they get any benefit. However, some feel that their hearing loss is not too bad, and that they can manage without aids.

“I just didn’t feel the desperate need; if I didn’t hear at all obviously I would be there like a shot”.

Woman with hearing loss, North West England

Commentary

It can be seen therefore, that a person getting their hearing loss identified is only part of the process. They need to be supported and encouraged to ensure that they have accepted their hearing loss and are therefore willing to take the steps to deal with it effectively. It must also be recognised that people have different needs and that some will need more support than others in overcoming these barriers.

It is also important to note that people must first accept their hearing loss before they will take effective action to deal with it.

Recommendations

- Audiology departments and social services should offer a wider range of rehabilitation and support options for people with hearing loss, including, for example, communication training and hearing therapy.
- Government and audiology departments to increase the choice of hearing aids available.
- GPs should explain the benefits of taking action on hearing loss to people with suspected loss.

Telling others

Telling people about your hearing loss can be a sign that you have accepted the loss. It is also an important step in improving communication as well as raising awareness amongst friends, family, colleagues, and even strangers.

“If it’s proving a little problem I just say to people and then if they know, it’s so much easier. I haven’t got any qualms about it, I am not ashamed of it. I know it’s something that happens to you as you get older.”

Woman with hearing loss, South East England

Most participants talked of being comfortable telling people they have a hearing loss in order to aid communication. However, for some this had not always been the case, it was only as more time had passed that they felt comfortable telling people about their hearing loss.

“I always tell people if I’m sitting at a meal now with somebody on that side. I have to because otherwise it’s so rude you see, because they are trying to talk to me and I’m not listening. But I used to hate it when I was younger, hate it. I would suffer agonies of embarrassment rather than tell people.”

Woman with hearing loss, London

“It used to be that I didn’t want to [tell people], but now it doesn’t bother me so much.”

Woman with hearing loss, Scotland

People with hearing loss can sometimes be viewed as rude, since they can miss what someone has said to them and therefore do not reply. Being open about their hearing loss can improve people’s perceptions of them.

“A lot of people, if they don’t know me well, they think I’m being rude.”

Woman with hearing loss, Scotland

Some participants were however not comfortable with telling other people about their hearing loss. However, as the quote below demonstrates, this can be quite isolating behaviour.

“The telephone is still a problem and one of my best friends I haven’t spoken to for over a year on the phone because I know I can’t hear her ... I miss her because I don’t ring her. I finally plucked up the courage to tell her why I don’t ring her...”

Woman with hearing loss, South East England

Some participants talked of how other people should take responsibility too and act in a deaf aware manner.

“I find it too embarrassing to keep saying ‘Pardon, I can’t hear you’. Because I think they know so I shouldn’t have to.”

Woman with hearing loss, South East England

“There’s nothing worse than someone feeling like they’re different. If you can help them feel they’re not different then great, but not many people are like that.”

Woman with hearing loss, South East England

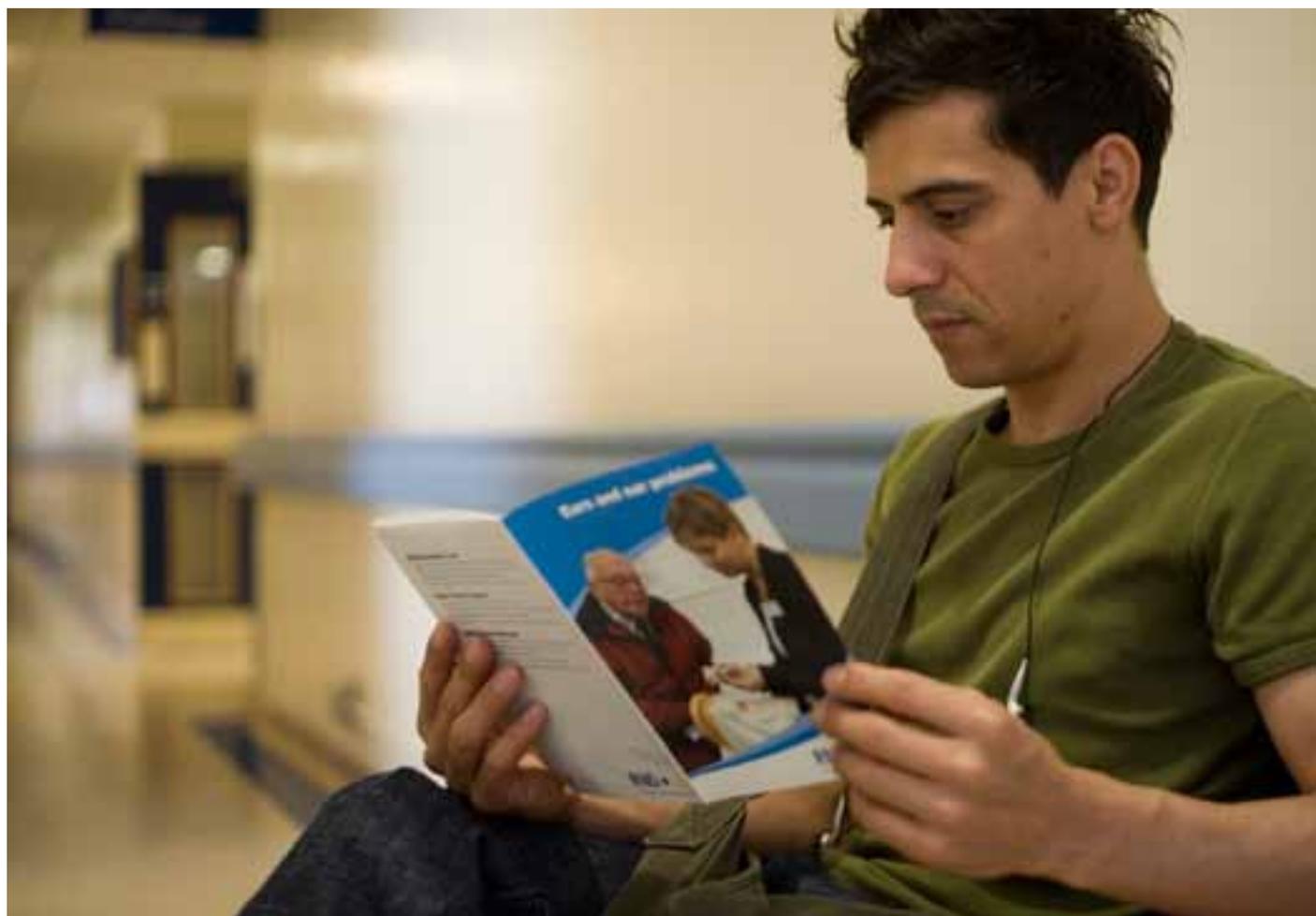
Commentary

The advantages of telling other people about your hearing loss can be seen, through raising awareness and improving the perception of yourself. However, some people need time to adjust before they feel comfortable with this. Improved general deaf awareness would help to make people feel more comfortable in talking about their hearing loss.

Recommendations

- Audiology departments should encourage people to be open about their hearing loss and explain the advantages of this.

Chapter 8: Conclusions and recommendations



In 1975 a Department for Health and Social Services (DHSS) report highlighted the issue that fitting hearing aids is not enough; people need further support to ensure that they get the best out of their hearing aids. As can be seen from this research, although NHS audiology has improved since 1975, ineffective use of hearing aids remains an issue and few other methods of support are available. The government and audiology departments therefore need to recognise that only providing people with hearing aids for rehabilitation will not eliminate the impact that hearing loss has on people's lives. They must be fully supported to get the best use out of their hearing aids, and it should be recognised that some people will need more help in adjusting to them than others. Other forms of support should also be available and people made aware of how to access them.

Hearing support available

The kinds of hearing support that the research participants have made use of include:

- hearing aids
- equipment (through social services and/or purchasing it themselves)
- support from other organisations such as deaf charities or Access to Work
- learning sign language (although this was seen as for fun rather than as a method of communication)
- tinnitus support group
- lipreading lessons
- tinnitus nurse.

Although this list appears extensive, the majority of participants only received hearing aids. Very few participants had accessed other services and support. This was due to a variety of reasons including participants not being aware of the support being available; having had a previous bad experience; participants not thinking they needed any support or not thinking their hearing loss was bad enough; and not wanting to be a nuisance. However, many of the participants could benefit from further support, whether it be extra help with adjusting to their hearing aids or help to gain the maximum benefit from their hearing aid. Many participants would also benefit from access to equipment to help either at home or in the workplace, as well as information about support groups or communication training.

Adjustment to hearing aids

The research identified numerous factors that affect how long it takes someone to adjust to their hearing aid. These include:

- the amount and detail of information provided
- whether they can return to their audiologist to ask questions
- if they are proactive and ask for help and information
- if they have support from friends and family
- if they recognise and accept their own hearing loss
- if they feel the hearing aid makes a positive difference
- if the hearing aid is comfortable to wear
- if they have other equipment to assist them (for example a telephone with a loop system).

More support and information therefore needs to be provided to ensure that people adjust to their hearing aids as quickly as possible.

Key improvements

The research shows that there are four key areas in hearing services that need to be improved to ensure that people with hearing loss are effectively supported and to minimise the impact that hearing loss has on their lives.

These areas are:

- removing the barriers to getting hearing loss identified
- improving access to information
- providing a personalised service
- providing additional hearing services.

Removing the barriers to getting hearing loss identified

Hearing loss has a significant impact on people's lives. It is therefore important to reduce the amount of time people take in getting their hearing loss identified and the time it takes to get support. It is widely accepted that people adapt to hearing aids better, the earlier they get them. It should therefore be an important part of public health strategy to encourage people to recognise and then take action to deal with their hearing loss. This will improve outcomes for people with hearing loss.

Improving access to information

Access to information is a key theme throughout the findings. Information is hugely important in ensuring people address their hearing loss, get the maximum benefit from their hearing aids and are able to access other services and equipment designed to minimise the impact of hearing loss on their life. It is therefore vital that information is provided to people with hearing loss at the right time and tailored to the individual.

Participants generally needed to be proactive in order to get the best service and support with their hearing loss. It is not acceptable that a two-tier service is in place, with those who are most confident able to access the most support. Information would help to reduce this inequality, by making everyone aware of the support that is available and where they can access it.

Providing a personalised service

People with hearing loss need to be recognised as individuals. Everyone has different information requirements, different hearing loss, different work and home circumstances. Hearing aids, equipment and support therefore need to be allocated on personal need. This includes providing information in a variety of formats and levels of detail, enabling people to return to the audiology department when they need to, offering a variety of appointment times and drop-in clinics for repairs and queries and having clinics in a variety of locations.

Providing additional hearing services

More support and rehabilitation must be made available to people with hearing loss. The research shows that hearing loss continues to impact on people's lives, despite having hearing aids fitted. Support must therefore be provided to help hearing aid wearers adjust to and effectively use their hearing aids. Support must also be provided to ensure that people with hearing loss are supported in their home and work lives, including through provision of equipment, lipreading lessons, communication skills and hearing therapy.

Recommendations

Our recommendations reinforce current audiology standards. We therefore urge audiology departments to implement the best practice guidelines already available to them to ensure that a good service is provided to everyone with hearing loss in the UK.

Our recommendations support one or more of the key areas highlighted for improvement. We have targeted the recommendations at each of the key groups relating to hearing services including GPs, audiologists and audiology departments, and the government.¹³

GPs should:

- receive deaf awareness training
- routinely ask older people about their hearing and refer them to audiology for assessment if they are having difficulty in daily life
- refer people with suspected hearing loss to audiology services promptly
- explain the benefits of taking action on hearing loss to people with a suspected loss
- maintain contact with their local audiology departments to update their awareness of technology, treatment pathways and referral protocols.

The private hearing aid sector should:

- ensure they are deaf and disability aware, and their premises are suitable for people with hearing loss, including minimising background noise in consultation rooms
- be transparent about the costs of their service and provide a breakdown of these
- develop best practice guidelines with the Health Professions Council and RNID.

¹³ Where we refer to government, this includes the UK government and the devolved governments of Scotland, Wales and Northern Ireland, as well as government departments such as the Department of Health.

Audiology departments and audiologists should:

- receive deaf and disability awareness training as well as customer service training
- encourage hearing aid wearers to return to the audiology department to ask questions and talk through any problems as and when they arise
- explain to patients what they can expect from hearing aids before they are fitted, give advice about how long it may take to adjust to hearing aids and the importance of persevering with them
- consider alternative ways to provide further support to people with hearing loss, including through the use of voluntary services such as RNID's Hear to Help. Audiology departments should also consider earlier intervention, for example referring people to voluntary services at their first audiology appointment
- encourage partners, a family member or friend to attend appointments with the person with hearing loss
- where appropriate, ensure that hearing aids have a 'T' setting for loop listening. Hearing aid wearers should be offered the opportunity to test out their 'T' setting and to try out loop systems
- ensure their locations are accessible. This includes offering clinics in a variety of locations, ensuring good transport links and access to car parking. Free transport should be available to those who need it
- ensure that their premises are suitable for people with hearing loss, and that background noise is minimised in consultation rooms
- increase the choice of hearing aids available
- offer a wider range of rehabilitation and support options for people with hearing loss including, for example, communication training and hearing therapy
- raise awareness of what technology and equipment is available to help people with hearing loss and where this can be obtained
- provide the following services to people with hearing loss:

- clear and comprehensive information on various issues in a variety of formats. This includes the ways people can seek further help with their hearing aids and hearing loss
- a follow-up appointment for all new hearing aid wearers. Telephone follow-up should only be used occasionally and only with people whose hearing is good enough to use the telephone
- ongoing reviews
- a variety of ways (drop-in clinic, outreach clinic, appointment) and times for people to return.

Local authorities/ social service departments should:

- increase awareness about lipreading classes. For those who can't attend lipreading classes, lipreading DVDs and books should be available
- offer a wider range of rehabilitation and support options for people with hearing loss, including for example, communication training or hearing therapy
- raise awareness of what technology and equipment is available to help people with hearing loss and where this can be obtained
- ensure that equipment can be loaned or offered free of charge to people with hearing loss
- enable hearing aid wearers to try out equipment before they buy it
- signpost people with hearing loss to other organisations that can help.

Government should:

- introduce a national hearing screening programme for older people. This should be linked to a public health campaign to increase awareness and encourage action to deal with hearing loss
- provide information about what to expect at each stage of the journey for a person with hearing loss
- ensure that up-to-date hearing aids are provided on the NHS and increase the choice of hearing aids available.
- invest in alternative forms of rehabilitation and support such as communication training and hearing therapy
- provide funding to improve the availability of lipreading classes and to ensure they are affordable.

RNID will:

- develop an ongoing relationship with GPs as commissioners and providers in order to raise awareness of hearing loss and improve the quality of services
- develop information on what level of service to expect from public, private and voluntary sector hearing services as well as provide an online service to allow the public to feed back about their experiences
- conduct and publish research into the experiences of people who lose their hearing whilst in employment.

Hearing rehabilitation services are vital in minimising the impact that hearing loss has on someone's life. Without it, people can become isolated and withdraw from society. Effective hearing services must therefore be provided. With an ageing society, the proportion of people in the population with hearing loss will increase. As the retirement and pension ages change, we will be working longer, resulting in more people in employment with hearing loss. The government, with audiology departments, therefore needs to ensure that we continually improve our audiology and hearing services to ensure that people with hearing loss are effectively supported and the impact of hearing loss is minimised.

Current audiology standards cover many of these issues already. We would therefore urge audiology departments to implement the best practice guidelines already available to them to ensure that a good service is provided to all people with hearing loss in the UK.

Bibliography

Boothroyd, A. (2007) 'Adult Aural Rehabilitation: What is it and does it work?', *Trends in Amplification*, vol 11, no. 3, 63-71

Brabbins, M. and Hogg, L. (1977) *What did you say? The use and misuse of hearing aids by the elderly*, Kensington, Chelsea and Westminster (South) Community Health Council

Brooks, D. (1981) 'Use of post-aural aids by National Health Service patients', *British Journal of Audiology*, 15, 79-86

Brooks, D.N. (1985) 'Factors relating to the under-use of postaural hearing aids', *British Journal of Audiology*, vol. 19, pp 211-217

Brooks, D.N. (1989) 'The effect of attitude on benefit obtained from hearing aids', *British Journal of Audiology*, vol. 23, pp 3-11

Brooks, D. (1996) 'The time course of adaptation to hearing aid use', *British Journal of Audiology*, 30, 55-62

Davis, A., Smith, P., Ferguson, M., Stephens, D. and Gianopoulos, I. (2007) 'Acceptability, benefit and costs of early screening for hearing disability: a study of potential screening tests and models,' *Health Technology Assessment 2007*, vol. II, no. 42

Department of Health (May 2010) *Direct Access Audiology: Referral to Treatment Collection*

Department of Health and Social Security (1975) *Report of a Sub-Committee to consider the rehabilitation of hearing-impaired adults*

Dodd, B., Plant, G. and Gregory, M. (1989) 'Teaching lipreading: the efficacy of lessons on video', *British Journal of Audiology*, 23, pp229-238

Echalier, M (2009) 'Hidden Crisis: Why millions keep quiet about hearing loss', RNID

Echalier, M (2010) 'In it together: The impact of hearing loss on personal relationships', RNID

Ewertson, H.W. (1974) 'The use of hearing aids (always, often rarely, never)', *Scandinavian Audiology*, 3, 173-176

Gianopoulos, I., Stephens, D. and Davis, A. (2002) 'Follow-up of people fitted with hearing aids after adult hearing screening: the need for support after fitting', *BMJ*, 325:471

Kapteyn, T.S. (1977) 'Satisfaction with fitted hearing aids. II. An investigation into the influence of psycho-social factors', *Scandinavian Audiology*, 6, 171-177

Meister, H., M. Walger, D. Brehmer, von Wedel, U., and von Wedel, H (2008) 'The relationship between pre-fitting expectations and willingness to use hearing aids', *International Journal of Audiology*, vol. 47, pp153-159

Mulrow, C., Tuley, M. and Aguilar, C. (1992) 'Sustained benefits of hearing aids', *Journal of Speech and Hearing Research*, 35, 1402-5

Mustapha, S. (2010) 'Read my lips: the case for lipreading classes in Scotland', RNID

Oswal, V.H. (1977) 'The National Health Service and social services link up for rehabilitation of hearing aid users', *British Journal of Audiology*, 11, 25-30

Paddock, M, B. O'Neil, and A. Holwell (2008) 'Actions speak louder than words', *BMJ*, 819 (10)

Parving, A. and B. Philip (1991) 'Use and benefit of hearing aids in the tenth decade – and beyond', *Audiology*, 30, 61-69

RNID (2009) *Annual survey*

RNID Scotland (2007) *Here to be Heard*

RNID (2010) *Paying lip service*

Scottish Government (2009) *Quality standards for adult hearing rehabilitation services*

181-188

Smaldino S.E. and Smaldino, J.J. (1988) 'The influence of aural rehabilitation and cognitive style disclosure on the perception of hearing handicap', *Journal of the Academy of Rehabilitative Audiology*, 21, 54-67

Sorri, M., Luotonen, M. and Laitakari, K. (1984) 'Use and non-use of hearing aids', *British Journal of Audiology*, 18, 169-172

Stark, P. and Hickson, L. (2004) 'Outcomes of hearing aid fitting for older people with hearing impairment and their significant others', *International journal of Audiology*, 43, 390-8

Thomas, P.D., Hunt, W.C., Garry, P.J., Hood, R.B., Goodwin, J.M. and Goodwin, J.S. (1983) 'Hearing acuity in a healthy elderly population: effects on emotional, cognitive and social status', *Journal of Gerontology*, 38, 321-5

Upfold, L.J. and Smither, M.F. (1981) 'Hearing aid fitting protocol', *British Journal of Audiology*, 15,

Vuorialho, A. (2006) 'Costs and Effectiveness of hearing aid rehabilitation in the elderly'

Ward, P.R., Tudor, C.A., Gowers, J.I., and Morgan, D.C. (1978) 'Evaluation of follow up services for elderly people prescribed hearing aids. Report of a pilot project', *British Journal of Audiology*, 12, 127-34

Watts, W.J. and Pegg, K.S. (1977) 'The rehabilitation of adults with acquired hearing loss', *British Journal of Audiology*, 11, 103-110

Weinstein, B.E. and Ventry, I.M. (1982) 'Hearing impairment and social isolation in the elderly', *Journal of Speech and Hearing Research*, 25, 593-9

Annex: Research methodology

The research consisted of two distinct parts. The first was a quantitative questionnaire sent to audiology departments. The second was qualitative interviews with hearing aid wearers.

Questionnaire

We sent a questionnaire to all audiology departments throughout the UK asking for information about what rehabilitation support they currently provide. This information was collated anonymously and analysed using SPSS, the statistical analysis programme. We received completed questionnaires from 107 audiology departments. We would like to thank those audiology departments who took the time to fill in the questionnaire. The findings from the questionnaire are used illustratively throughout the report.

Interviews

The main part of the research was qualitative, face to face interviews with hearing aid wearers. An interview guide set out the topics to cover during the interview. All interviewees agreed to the interview being recorded and these were then transcribed at a later date.

We interviewed people who received their first NHS hearing aid in the last five years. This was to ensure that their experiences were of audiology services post modernisation. However, we did speak to a few participants who have had their hearing aids for longer than five years. In these instances, only relevant information has been extracted for analysis.

The interviews were semi-structured to allow a free discussion about the participants' experiences of hearing loss. We asked respondents about the whole of their journey, from when they first noticed they had hearing loss to going to their GP and audiologist. We also discussed the impact their hearing loss has on their life now.

The interviews took place in either the participants' homes or in an RNID office. The interviews lasted between 30 minutes and 70 minutes each.

Twenty-six interviews took place between September and December 2009 involving 27 participants. The interviews were conducted by two members of the Social Research and Policy team. The breakdown of participants was as follows:

Sex

15 Women participants
12 Men participants

Approximate age

Over 60 – 19 participants
Under 60 – 8 participants

Working status

In work – 8 participants
Not in work – 19 participants

Location

4 South East England, 5 East Midlands, 1 West Midlands, 4 North West England, 1 London, 5 South West England, 1 North East England, 4 Scotland, 1 Northern Ireland, 1 Wales.

Research objectives

Hypothesis – a lack of rehabilitation support means that people are slower and/or less likely to adapt to hearing aids and learn to use them effectively.

- To find out if rehabilitation support is being provided to people with a hearing loss.
- What kinds of rehabilitative support do people make use of.
- To find out the personal impact of rehabilitation support on hearing aid wearers and what it means to them.
- What forms of support people who have a hearing loss would like to receive.
- What are the factors that influence how long it takes people to get used to their hearing aid.
- The benefits and drawbacks of each method of support.

We're RNID, the charity working to create a world where deafness or hearing loss do not limit or determine opportunity, and where people value their hearing.

There are a number of ways to support us. To find out more:

Go to

www.rnid.org.uk

Contact our Information Line

Telephone 0808 808 0123

Textphone 0808 808 9000

Or write to us

informationline@rnid.org.uk

19-23 Featherstone Street
London EC1Y 8SL

Fax 020 7296 8199



50% recycled
When you have finished with this leaflet please recycle it