



Hear me out

Audiology services in Scotland – services provided, patients' experience and needs

Florence Edmond
2011

Acknowledgements

This research was funded by the Audiology Services Advisory Group. Any opinions, statements, and recommendations expressed in this report are those of RNID Scotland and do not necessarily represent the views of either the Audiology Services Advisory Group or any part of the Scottish Government or its associates.

RNID Scotland thank all those who took part in the research including patients, audiologists, and other supporting organisations.



There are 758,000 people who are deaf or hard of hearing in Scotland. In 2009, the Scottish Government published the *Quality Standards for Adult Hearing Rehabilitation*¹, which define the services audiology departments offer to patients with suspected hearing loss. A year after publication of the Quality Standards, RNID Scotland carried out research to ascertain service users' needs and experiences and map out what services are currently available.

Patients' experience of audiology services

People's experience of losing their hearing varies, ranging from people who were born deaf or lost their hearing at a young age, to others who lost their hearing later on in life (deafened). People's experiences of waiting times vary from one NHS Board to the other. However, people's perception of waiting times also varies, so that what seems a long time to wait for an appointment for one patient is seen as acceptable by another.

The vast majority (70%) of service users only received an appointment letter and no other information before their first appointment with audiology. In particular, only 0.6% of service users had received information about communication

1. Scottish Government (2009). *Quality Standards for Adult Rehabilitation Services* available at www.scotland.gov.uk/Publications/2009/04/27115807/10

Executive summary

support services such as British Sign Language (BSL) interpreters and electronic notetakers.

During audiology appointments, 45% of respondents could not hear their name being called in the waiting room. Although some patients felt that staff were always polite and helpful, others commented on how audiology staff are not always deaf aware. Patients are given verbal information on how to use their hearing aids and information on where to get replacement batteries, but only a minority are given information on equipment/assistive devices or signposted to social services and other support organisations such as lipreading classes or voluntary organisations.

Following the fitting of their hearing aids, only 42% respondents said they had received a follow-up appointment. The onus is often on the patients themselves to initiate follow-up. Referrals to social work services and an explanation of what assistive devices they can supply is very rare, with only 5% of respondents being given information about social services and 10% being given information about other equipment and adaptations. Very few respondents said that they got referred to additional forms of support such as lipreading classes (6%), voluntary organisations (4%), hard of hearing support groups (3%), or BSL classes (0.9%). Yet many focus group participants, who often found out about these forms of support by word of mouth, commented on how useful they were.

What patients want

Patients would like to receive comprehensive training in how to use their hearing aids, including, for example, how to use the aids in different situations. Patients would like written information as well as practical demonstrations. They would also like to be given some explanation as to why they lost their hearing. Patients also found it important to be referred to social work services and to be given information about lipreading classes.

Nearly three-quarters of respondents said it was important to get information about coping strategies. Respondents said it had been an emotional shock to be told about their hearing loss and that they would like time to talk to someone about it.

Patients would like to have a regular re-assessment and review of their hearing aids. Over a third of respondents (39%) also said that they would like their family to receive further information, mostly through leaflets on communicating with and supporting someone with hearing loss.

Audiology departments

Only half of the heads of audiology in the 14 NHS Boards responded to our survey. Those who did highlighted that time and resources are very limited.

All audiology respondents said that staff had been trained in deaf awareness but admitted that audiology departments are not always physically accessible with only a minority of waiting rooms/consultation rooms fitted with induction loops. One NHS Board said that they equipped their staff with neck loops as new hospitals are fitted with induction loops but old hospitals are not.

Seventy percent of service users said they only received an appointment letter and no further information – but audiology respondents said they sent information on the hearing test and some said they sent information on communication support.

All audiology respondents said they trained patients in how to put the hearing aid in the ear. And although only a minority of service users said they had been given information on social services or assistive technologies, most audiology respondents said they give information leaflets about support services such as social work services. This may be because patients do not always take in the information given to them verbally.

Four of eight audiology departments said they offer a follow-up appointment and most audiology departments offer repairs and batteries through drop-in clinics and by post. In addition, a number of audiology departments distribute batteries through GP practices or the patients' local health centres.

Support provided by other organisations and other rehabilitation models

Providing a hearing aid is not always enough to ensure that it is used effectively. Focus group participants said they need additional support to take in all the information given over several sessions. People need emotional support from other people who are deaf or hard of hearing. Additional support services are also necessary because audiology staff do not always have the time to provide information that is targeted to the patient.

There is a range of initiatives in Scotland, from information provision to projects that provide maintenance of hearing aids and additional advice. However, there are geographical disparities with services not available throughout Scotland. In addition, people are not always signposted to additional rehabilitation services by audiology staff.

UK and international research projects have found that effective models of rehabilitation include: a combination of auditory training (for example, active listening) and visual training (such as lipreading); short courses that combine information on how to use hearing aids as well as coping strategies; the use of technologies (for example, a lipreading video); or 'counselling' (namely, information and advice on making personal adjustments). Research shows that the most effective approach to rehabilitation is through a 'holistic' approach, whereby people with a hearing loss receive a variety of training and advice as well as being fitted with hearing aids.

Section 2

Background

Key messages

- There are 758,000 people who are deaf or hard of hearing in Scotland. Of those, it is estimated that only about 160,000 people have a hearing aid whilst about 500,000 people in Scotland could benefit from hearing aids.
- The Scottish population is ageing. The number of people aged 75 and over is now projected to increase by 23% between 2008 and 2018, and by 84% between 2008 and 2033. As the most common reason for hearing loss is age-related, with more than half of people over 60 having some hearing loss, the number of people who are deaf or hard of hearing in Scotland is likely to increase in the future.
- The Scottish Government published the *Quality Standards for Adult Hearing Rehabilitation* in April 2009. This is a set of national standards for adult hearing rehabilitation services.
- A year after the publication of the Quality Standards, *Hear Me Out* aimed to map out what services are currently available, identify gaps in service provision and ascertain service users' needs and experiences.

There are 758,000 people who are deaf or hard of hearing in Scotland. There are about 160,000 people who have a hearing aid in Scotland², but about 500,000 people in Scotland could benefit from hearing aids – leaving about 340,000 who need them but do not yet have them.

In April 2009, the Scottish Government published the *Quality Standards for Adult Hearing Rehabilitation*³, which define the services audiology departments offer to patients with suspected hearing loss. A year after the publication of the Quality Standards, RNID Scotland was asked by the Scottish Government's Audiology Services Advisory Group to map out what services are currently available for people with suspected hearing loss and ascertain service users' experiences and needs. We used the Standards as the basis for our research. We assessed the demand for adult hearing rehabilitation services through a questionnaire sent to a wide range of service users, ran five focus groups throughout Scotland and carried out face-to-face interviews with people who had used audiology and other hearing rehabilitation support services. We mapped the supply of adult hearing rehabilitation services through a questionnaire to heads of audiology. To paint a picture of support services available to people who have lost their hearing, we carried out face-to-face interviews with several organisations including representatives of voluntary organisations and hard of hearing support groups. Altogether, 405 service users and 20 stakeholders took part in the study.

2. Estimate by RNID based on Medical Research Council (MRC) data on prevalence of deafness in the population and current population size and profile in Scotland.

3. Scottish Government (2009). *Quality Standards for Adult Rehabilitation Services* available at www.scotland.gov.uk/Publications/2009/04/27115807/10

2.1 Deafness and hearing loss



There are 758,000 people who are deaf or hard of hearing in Scotland. There are many reasons why some people are deaf or hard of hearing or lose their hearing. The most common reason is age-related deafness with more than half of people over the age of 60 with some hearing loss, whilst 72% of over 70 year-olds have some hearing loss. Other people may lose their hearing because of exposure to noise at work or because of long and repeated exposure to loud music. Deafness can be congenital and there are also some conditions such as damage to the eardrum or inflammation in the middle ear that cause deafness. There is a broad spectrum of levels of hearing loss ranging from people with mild deafness to people who are profoundly deaf.

Depending on their level of deafness, or on when they became deaf or hard of hearing, people use a range of methods to communicate. Between 5,000 and 6,000 people who are deaf in Scotland use BSL as their preferred or first language. Many rely on lipreading. Others use electronic notetakers or rely on equipment such as hearing aids. Some use a combination of all these.

Hearing aids make sounds louder and clearer. All hearing aids have a built-in microphone that picks up sound and converts it into an electrical

signal. The signal is processed electronically and amplified. Most modern hearing aids do this using digital technology. The resulting signals are then passed to a receiver, or earphone, in the hearing aid, where they are converted back into sounds for the person to hear, made louder and tailored to suit the person's hearing needs.

Analogue and digital hearing aids⁴ look very similar, but they process sound differently. Analogue aids amplify electronic signals, while digital aids use a tiny computer to process sound. This means it is possible to customise the aid very precisely to suit a person's hearing loss. Many digital aids can be programmed with different settings for different sound environments, for example, a quiet living room or a crowded restaurant. Some even switch settings automatically to suit the environment. Digital hearing aids are designed to reduce background noise, which makes listening in noisy places more comfortable. They are also less likely to 'whistle' or give feedback. Since the Audiology Services Modernisation project, which ran between 2003 and 2007, digital hearing aids are available as standard on the NHS.

Both analogue and digital hearing aids come in in-the-ear (ITE) and behind-the-ear (BTE) styles. Completely-in-the-canal (CIC) aids fit deep inside the ear canal so they are not visible from the outside. In-the-canal aids (ITCs) and ITEs sit just inside the ear canal and in the visible part of the ear. BTE aids are the most commonly used by people with hearing loss. They sit behind the ear and are linked to an earmould or ear tip in the ear canal. Earmoulds are made from an impression taken of the shape of the ear and come in different designs and materials. A traditional-style earmould for BTE aids has a piece of tubing connecting it to the actual aid.

4. Further information is available from RNID's website at www.rnid.org.uk/information_resources/need_hearing_aids/

5. Estimate by RNID, based on Medical Research Council (MRC) data on prevalence of deafness in the population and current population size and profile in Scotland.

Section 2

Background

There are about 160,000 people who have a hearing aid [s] in Scotland⁵ but about 500,000 people in Scotland could benefit from hearing aids – leaving about 340,000 who need them but do not yet have them.

2.2 Policy context

Scottish Government policies aim to ensure equal access to healthcare services in Scotland for all – including access to audiology services and adult hearing rehabilitation. RNID Scotland's report *Hear Me Out* aims to ascertain service users' experiences and needs and map out services.

2.2.1 Better Health, Better Care

The Scottish Government's Strategic Objectives, published in 2007, include Strategic Objective 2 to *"help people to sustain and improve their health, especially in disadvantaged communities, ensuring better, local and faster access to health care."*

The Scottish Government's strategy for a healthier Scotland, *Better Health, Better Care*⁶, outlined the actions the Government will take to improve health. The central themes are patient participation, improved healthcare access, and a focus on improving Scotland's public health and tackling health inequalities.

2.2.2 The Scottish population is ageing



The number of people aged 75 and over is now projected to increase by 23% between 2008 and 2018, and by 84% between 2008 and 2033⁷. In the same 25-year period, the number of people aged 60-74 is projected to increase by 33%. The size of increase will vary across local authorities, with larger increases generally expected in more rural areas.

The Scottish Government's long-term strategy for older people was published in March 2007. *All Our Futures: Planning for a Scotland with an Ageing Population*⁸ points out that *"older people form an increasing proportion of our population, and will play an increasingly important role in our prosperity and future."* The strategy gives the Scottish Government's vision of a Scotland where *"people enjoy more years of healthy life and are enabled to manage long term health conditions."*

6. Scottish Government (2007) *Better Health, Better Care: Action Plan*.

7. Projected Population of Scotland (2008-based), General Register Office for Scotland (<http://www.gro-scotland.gov.uk/statistics/publications-and-data/popproj/projected-population-of-scotland-2008-based/index.html>), October 2009

8. Scottish Government (2007). *All Our Futures: Planning for a Scotland with an Ageing Population* available from www.scotland.gov.uk/Resource/Doc/169342/0047172.pdf

2.2.3 Modernisation of Audiology Services

The Audiology Services Modernisation project aimed to invest in new Digital Signal Processing (DSP) hearing aid technology, new infrastructure, information systems and training. Nineteen million pounds of ring-fenced central funding was allocated to finance this between 2003 and 2007. Since the Audiology Services Modernisation project finished in 2007, NHS patients in Scotland now receive a hearing aid [s] with features that best overcome the consequences of their impairment (often a digital aid).

2.2.4 Audiology Services Advisory Group (ASAG)⁹

The Audiology Services Advisory Group was set up at the beginning of the Audiology Services Modernisation project in 2003. Its role is to provide a forum for discussion with representatives from all areas involved in audiology. This includes heads of audiology services, ENT consultants, representatives from voluntary organisations, from higher education or private hearing aids companies, hearing therapists and a representative from the MRC Hearing Institute¹⁰, and so on. In collaboration with a range of cross-border agencies, the British Academy of Audiology¹¹ and clinical experts from the NHS in England, Wales and Scotland, the Advisory Group produced *Quality Standards for Adult Hearing Rehabilitation*¹² and *Quality Standards for Paediatric Audiology Services*¹³. Both sets of Standards were published in April 2009.

2.2.5 Quality Standards for Adult Hearing Rehabilitation

The Quality Standards for Adult Hearing Rehabilitation is a set of national standards for what services for adults with hearing loss should look like. There are six standards that follow the service users' journey and three areas of infrastructure that are unique to audiology services.

Standards 1-6 describe the service user journey and care pathway:

1. Accessing the service
2. Information provision and communication with individual patients
3. Assessment
4. Developing an individual management plan
5. Delivering an individual management plan
6. Outcome (that is, the outcome and effectiveness of the Individual Management Plan are evaluated and recorded).

9. Further information about ASAG is available at <http://www.scotland.gov.uk/Topics/Health/health/audiology/advisorygroup>

10. The MRC Hearing Institute aims to provide a scientific underpinning and evidence base for the clinical effectiveness and cost-effectiveness of hearing healthcare services. Further information is available at <http://www.ihr.mrc.ac.uk/regional/scottish/>

11. The British Academy of Audiology is one of the organisations for professionals in hearing and balance in the UK. Further information is available from theloop.netplan.co.uk/~admin9/index.php?option=com_frontpage&Itemid=1

12. Scottish Government (2009) *Quality Standards for Adult Rehabilitation Services* available at www.scotland.gov.uk/Publications/2009/04/27115807/10

13. Scottish Government (2009). *Quality Standards for Paediatric Audiology Services* available at www.scotland.gov.uk/Resource/Doc/270506/0080556.pdf

Section 2

Background

The Standards define the services that should be offered by audiology departments to patients with suspected hearing loss. They include:

- Appropriate hearing testing and evaluation of the audiological needs of the service user
- Agreement with the service user on the best aiding device for their problems, and discussion about the likely effect of such devices on their ability to hear
- Fitting of aids to provide sufficient and appropriate amplification
- Training service users in the use and maintenance of their aid(s) and provision of rehabilitative support to ensure that they can use them effectively
- Providing information on other sources of help, support, equipment and assistive devices, or referral to organisations that can provide these as appropriate
- Ongoing repair and maintenance of hearing aids (including provision of batteries and replacement tubing).

The Quality Standards state:

*“Audiology departments supply services to manage disability associated with hearing impairment. This includes, in addition to hearing aid provision, support and counselling usually delivered within a team of professionals working in association with other agencies/voluntary sector organisations eg in some local teams this may involve care from Hearing Therapists and Language Therapists.”*¹⁴

14. Scottish Government (2009). Op. Cit. p 4.

15. Benyon GJ, Thornton FL, Poole C (1997). 'A randomized, controlled trial of the efficacy of a communication course for first time hearing aid users'. *British Journal of Audiology*, 31: 345-51.

16. Scottish Government (2009). Op. Cit. p 4.

2.3 Adult hearing rehabilitation

Adult hearing rehabilitation can be defined in a broad sense¹⁵ as including other forms of rehabilitation in conjunction with the fitting of a hearing aid. This can include, for example, communication training (such as lipreading or hearing tactics); the provision of assistive listening devices and equipment; hearing aid training; information and advice (for example, group-based information sessions or one-to-one information/advice sessions); education (for example, IT training so that people who are deaf or hard of hearing can use emails to communicate). The Quality Standards define adult hearing rehabilitation in a slightly narrower sense as including hearing testing; agreement with the service user on the best aiding device; fitting of aids; training of service users in the use and maintenance of their aids; provision of information on other sources of help; support and equipment/assistive devices; and ongoing repair and maintenance of hearing aids. The Standards state: *“The scope of this document does not include specialist hearing rehabilitation services but does cover the services provided for the majority of clinical activity.”*¹⁶

The Standards apply to NHS audiology but state: *“the hope is that their implementation will encourage and further develop collaborative working, both with fellow NHS professionals and external agencies.”* For the purpose of our research, we have used the Quality Standards definition of adult hearing rehabilitation as including:

- hearing testing
- fitting of aids
- training in the use and maintenance of aids
- repairs and maintenance of aids
- information on other sources of help
- information on equipment/assistive devices.

2.4 Research methodology



A year after the publication of the Quality Standards, RNID Scotland carried out research about audiology services in Scotland. This research aimed to map out what services for people with hearing loss are currently available and identify gaps in service provision and ascertain service users' needs and experiences.

The project aimed to engage with service users and audiologists, including hearing aid wearers, and had four key objectives:

1. To map out services currently available and identify gaps in service provision, including the role played by audiology staff and other supporting organisations such as voluntary organisations.
2. To ascertain service users' experiences of services.
3. To find out what services people would actually need, including people who have tinnitus.
4. To explore family/carers' experiences and actual needs.

To map out services currently available and identify gaps in service provision, we sent an in-depth questionnaire to heads of audiology in the 14 NHS Boards. We received eight responses.

A simple, easy-to-read questionnaire was sent and distributed to 1,012 RNID Scotland members and other respondents (for example, the questionnaire was distributed to some of Hearing Link's members). We received 350 responses – a 34% response rate.

We ran five focus groups. To reflect a spectrum of socio-economic and geographical areas, we ran the focus groups in different areas, including:

- Dumfries (26 August)
- Edinburgh (30 August)
- Glasgow (31 August)
- Inverness (2 September)
- Galashiels (6 September).

The focus groups were well attended, gathering people with a wide range of experiences, from people who had lost their hearing in childhood to people with age-related hearing loss. We asked participants to tell us about their recent experiences of audiology services and other rehabilitation services, such as those provided by voluntary organisations.

We also used in-depth semi-structured interviews to support our research as case studies.

We undertook desk research, covering past research, the Quality Standards, as well as other models and examples of adult hearing rehabilitation services that exist elsewhere.

As part of the research, we went beyond the remit of the Quality Standards to test out what services users need after being fitted with a hearing aid [s]. For this, we carried out face-to-face interviews

Section 2

Background

with employees from several organisations that support people who are deaf or hard of hearing. These included: Ayrshire Hearing Support, Deaf Action, Hearing Link, Lothian Deaf Counselling Service, National Deaf Children Society, Tayside Deaf Association and the West of Scotland Deaf Children Society.

Research started in July 2010 and was completed in September 2010.

2.4.1 Respondents' profiles

The majority of respondents (66%) said they were hard of hearing. Twenty-eight percent said they were deaf (although some people consider themselves both deaf and hard of hearing).

A vast majority (83%) have one or two hearing aids. A minority (1.4% or five respondents) have a cochlear implant¹⁷. Three respondents wear a bone anchored hearing aid (BAHA).

Respondents' hearing loss

Hearing loss	Proportion of respondents (%)
I am deaf	28
I am hard of hearing	66
I am deafened	5
I use BSL	1.4
I use Sign Supported English	1.1
I have a cochlear implant	1.4
I wear a hearing aid(s)	83
I wear a BAHA	0.9
I have no hearing loss	0.3
Other	6

Total number of respondents: 350

The majority of respondents had been fitted with their most recent hearing aid less than three years ago and had therefore recent experience of services and support provided by audiology and other organisations:

- 37% of respondents had been fitted with their most recent hearing aid within the past year
- 42% had been fitted with their most recent hearing aid between one and three years ago.

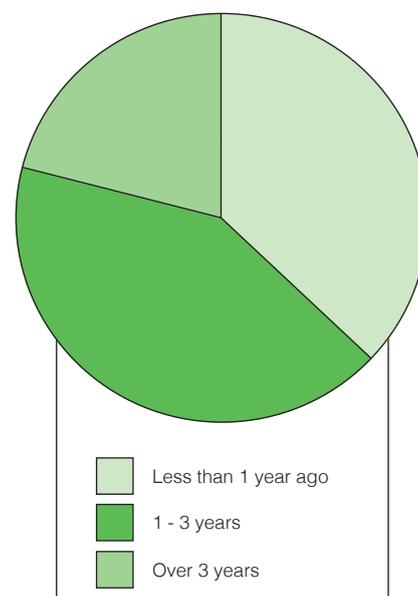
This means that respondents' views of audiology services and other hearing rehabilitation services are based on fairly recent appointments.

Fitted with most recent hearing aid

Time fitted with most recent hearing aid	Proportion of respondents (%)
Less than six months ago	19
Six months to one year	18
One to three years	42
More than three years	21

Total number of respondents: 350

The majority of respondents (69%) had received their hearing aid from the NHS, although 23% had experienced both the private sector and the NHS. As a result, a number of respondents and participants at focus groups were able to comment on the differences between the NHS and the private sector.



17. A cochlear implant is a small electronic device that gives a sensation of hearing to people who are profoundly deaf.

Patients' experience of audiology services – initial experience

Key messages

- 30% of respondents did nothing about their hearing loss for more than one year.
- Participants' experiences of waiting times vary from one NHS Board to another. However, people's perceptions of waiting times vary, so that what seems a long time to wait for an appointment to one patient is seen as acceptable to another.
- The vast majority (70%) of service users only received an appointment letter and no other information before their first appointment with audiology.
- Less than 1% of service users had received information about potential communication support such as BSL interpreters or electronic notetakers (notetakers provide a clear account of a meeting, using laptop computers and special software).

We asked respondents and focus group participants about what they did when they first discovered they had lost their hearing, their experience of waiting times and what audiology departments sent them before their first audiology appointment.

3.1 People's experiences of losing their hearing



People's experiences of losing their hearing ranged from people who have had some hearing loss since childhood or at a young age to people who had lost their hearing later in life (deafened). In most cases, people became aware of their hearing loss gradually, either because they experienced difficulties communicating with relatives or colleagues, or because they started to find it difficult to hear over the telephone:

"My hearing loss has been gradual in my 40s. I was playing music in church and could not hear people give me instructions."

"It was a gradual process. The first feeling was, 'I am not deaf, other people aren't speaking properly'. Gradually I realised I would have to talk to somebody about it."

This accords with previous research that showed that people tend to become aware of their hearing loss through interactions with their partners or other family member or because they are experiencing difficulties at work¹⁸.

18. For example, Echaliier M (2009). *Hidden crisis: why millions keep quiet about hearing loss*.

Section 3

Patients' experience of audiology services – initial experience

One service user recalls losing her hearing overnight. In her case, she felt that the response she got from her GP and her local audiology services was excellent: *“I woke up one morning and could not hear. It was not a gradual onset. I went to the GP that day and was referred to a consultant in two hours and had a hearing test by 1pm that afternoon.”*

Work and partners/family members were instrumental in making people seek help once they were aware of their hearing loss. Again, this corresponds to previous research carried out by RNID¹⁹:

“It started about 1997 when I was getting complaints from the family. I think that is pretty common.”

“My wife pointed out that she was struggling carrying out conversations with me and I had to do something about it.”

Service users tended to deny their hearing loss and although 39% of respondents said that they went to their GP within six months of noticing their hearing loss, 30% delayed action for more than one year.

“I started losing my hearing in about 2000 and I did nothing for a year because you think it is everyone else, it is not you. I eventually went privately and got one of the small ‘in ear’ hearing aids. That was fine for about two or three years and then one of them broke down and I thought, ‘I will go to the NHS and see what happens.’”

There are several reasons why people delay taking action with their hearing loss. For example, research found that GPs failed to refer 45% of people who reported hearing difficulties²⁰ onto audiology. Other factors include²¹:

- health problems or caring responsibilities
- previous experience with hearing professionals or an attempt to wear hearing aids that was unsuccessful
- losing hearing in one ear or being able to manage
- no self-perception as ‘someone with hearing loss or a hearing aid’
- denial of any sign of ageing such as hearing loss.

19. Echaliier M. *Op. Cit.*

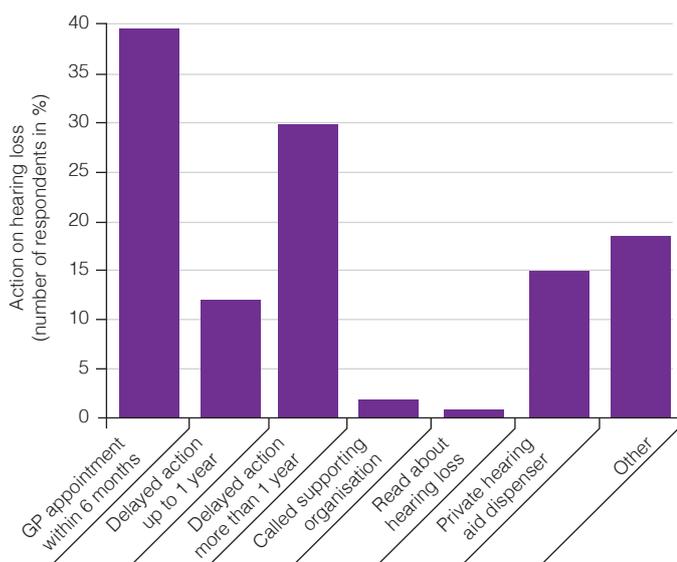
20. Davis A et al (2007). ‘Acceptability, benefit and costs of early screening for hearing disability: a study of potential screening tests and models’. *Health Technology Assessment*; vol. 11: no. 42.

21. Echaliier M. *Op. Cit.*

Action when losing hearing

Action	Proportion of respondents (%)
Within six months of noticing my hearing loss, I made an appointment with GP	39
I delayed taking action for up to one year	12
I delayed taking action for more than one year	30
I called RNID Scotland or another supporting organisation	1.7
I read about hearing loss	0.9
I contacted a private hearing aid dispenser	15
Other	18

Total number of respondents: 350



3.2 Waiting times

The Quality Standards state that: *“The maximum waiting time from referral to treatment of hearing should meet the national target regardless of the referral route and regardless of whether a patient is re-accessing the service or accessing it for the first time.”*²²

The national target is an 18-week waiting time (or less) from referral to treatment. In 2007, the First Minister announced that audiology would come under the 18-week waiting time by 2011. The 2009 *Referral to Treatment: Principles and Definitions*²³ guidelines on the 18-week target made significant reference to achieving waiting times for audiology.

In general, participants’ experience of waiting times varies from one NHS Board to another. One respondent said: *“The hardest part was waiting 67 weeks for first test appointment then gaps from testing, fitting, scan, etc, meant that I did not get both aids fitting well and working for two years total from first referral.”* Other respondents felt that waiting times were too long and, in some cases, participants decided to go to a private hearing aid dispenser because of work commitments. A participant explains: *“For my work I had to go private. If something went wrong I couldn’t wait for something like three months. Recently, I went back to the NHS. I paid but I needed to pay for my career. I needed to work, I needed to hear.”*

In other cases, though, participants felt that waiting times had improved over the years. Also, the perception of waiting times varies from one person to another. Whilst one participant recalled, *“I had a six-month waiting time for an appointment and I suppose it was OK”*, others felt that waiting for six months was a very long time.

22. Scottish Government (2009). *Op. Cit.* Standard 1a7.

23. Scottish Government (2009). *Referral to Treatment: Principles and Definitions.*

Section 3

Patients' experience of audiology services – initial experience

Some participants highlighted instances of a very short waiting time. For example, one participant said: *"[The hospital] wrote to me saying I would get an appointment within 12 weeks, but the next day I got a phone call saying there was a cancellation the next day so I went in for earmoulds and hearing test."*

3.3 Information and advice received before the first appointment with audiology



"No advice given at all. At any time."

"I didn't get any back up support at the time. I was very much on my own."

The Quality Standards²⁴ state that, before the appointment, service users and their significant other should receive written information about the assessment, the assessment procedures, types of assessment, possible interventions and clinicians.

Yet, before they went for the first appointment with audiology services, the vast majority of respondents to our questionnaire (69%) only received a standard letter asking them to come for the appointment and nothing else.

Whilst the Quality Standards state that *"[information sent prior to the appointment] will include a request to contact the department in advance of an appointment if an interpreter is required"*, less than 1% said that they had received information about potential communication support.

Similarly, only 7% of respondents received information about hearing aids, their benefits and limitations, and only 11% of respondents received any information about the hearing test itself. As one respondent explains: *"information should be given to first time hearing aid users regarding their concern of their first audiology appointments, not full-on, in-your-face counselling/information episodes."*

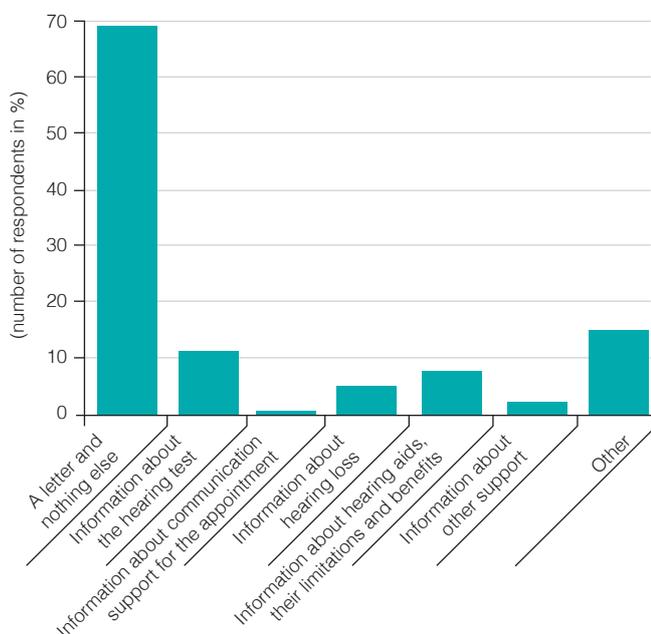
However, one participant did receive a pack of information along with the appointment letter. He explains: *"Prior to the appointment [my NHS board] sent out a package of data. I believe I had already self-diagnosed by using the RNID hearing test over the phone. They sent some documentation about different types of tinnitus/deafness. The one thing they didn't send was any, because I still play musical instruments, any ear plugs, etc. They did send a package of information with the letter."* We welcome this example of good practice and would like the appointment letter to include basic information about communication support services and how to book them, as well as what will happen during the hearing test.

24. Scottish Government (2009). Op. Cit: Standard 2a1. *"Written information about the service, assessment procedures, types of assessment, possible interventions and clinicians involved is provided by the Audiology service for all new and existing patients and their significant other(s) prior to attending the appointment. This will include a request to contact the department in advance of an appointment if an interpreter is required."*

Information before first appointment with audiology

Action	Proportion of respondents (%)
A letter and nothing else	69
Information about the hearing test	11
Information about communication support for the appointment	0.6
Information about hearing loss	5.4
Information about hearing aids, their limitations and benefits	7.1
Information about other support organisations	2.3
Other	15

Total number of respondents: 350



Recommendations

Appointment letters sent by audiology departments to patients before their initial appointment should include basic information about:

- the fact that patients can come to the appointment with a friend/family member
- communication support services that are available (for example, electronic notetakers who type the information on a laptop for the person who is deaf or hard of hearing to read on a screen) and how to book them
- what will happen during the initial appointment.

Section 4

Patients' experiences of audiology services – During audiology appointments

Key messages

- 45% of respondents said they could not hear their names being called in the waiting room.
- Although some patients felt that staff were always polite and helpful, other participants commented on how staff at audiology departments are not always deaf aware.
- Most patients are given verbal information on how to use their hearing aids and information on where to get replacement batteries. But only a minority are provided with information on equipment/assistive devices, social services and other support organisations, such as lipreading classes or voluntary organisations.
- Patients are given a lot of spoken information in one sitting and often forget a lot of it by the time they get home.

“The more information they give, the longer the appointment takes so they cut out all the peripheral information.”

“I got referred to [hospital], the consultant I saw was harassed and the service was diabolical. I was like a processed pea in the department with lots of people doing different things.”

“[The audiology department] is situated in a bright new building and the staff are pleasant, helpful and efficient.”

We asked respondents and focus group participants about their experiences of audiology services during appointments.

4.1 In the waiting room



A shocking 45% of respondents said that they could not hear their name being called in the waiting room at audiology departments, whilst an additional 15% said that an induction loop was not available or not working. Many respondents commented about staff calling out names in audiology departments:

“I do find it amusing that at a clinic for the deaf they are still ‘shouting out’ the names of people! Another extra form of communicating this would help many clinic users.”

Another respondent commented:

“I would really like to go to audiology and feel that they understand what it is like to have a hearing loss. Staff shout our names but I (and other people) can’t always see them unless you are aware that they might call on you from a particular direction, then it is difficult to hear who they are looking for – and my hearing loss is not as severe as many others’. Both my father and sister are profoundly deaf and I don’t think they would manage at my audiology clinic.”

These findings reinforce previous research carried out in 2009 by RNID Scotland²⁵, which showed that 50% of respondents could not hear their name being called in GP practices and 44% when attending a hospital as outpatients.

25. Edmond F (2010). *Are you listening? Access to health services for people who are deaf or hard of hearing in Scotland.*

We would like staff in audiology departments to use other means of communicating whose appointment is next. At the simplest level, we would like staff to approach the patient in person. More innovative ways of calling for the next patient have been used elsewhere. For example, in Newcastle²⁶ patients are given a mobile phone that vibrates when it is the patient's turn to go for their appointment. Some hospitals in England²⁷ issue a pager that vibrates to alert patients to the fact that they have been called.

4.2 Staff

The Quality Standards state that all frontline staff with direct patient contact should receive deaf awareness and communication training as part of their induction and that the training should be updated every three years³⁰.

Focus group participants' opinions of audiology staff attitudes varied from a positive one, where they found staff friendly and *"most helpful"*, to a very negative one, where patients felt they were seen as *"cog[s] in the service."* In several cases, participants found that staff were polite and they realised that staff were pushed for time. One participant said: *"audiology staff are always very helpful when you see them and are not to blame for any delays."*

However, a number of participants highlighted that staff in audiology departments are not always deaf aware. As noted above, 45% of respondents could not hear their name being called in the waiting room. Similarly, several participants highlighted that staff were not deaf aware once they got in the consultation room. For instance, staff do not always face the patient when they are talking to

Other systems that could be used include visual information systems²⁸ where names (or a number that was given to the patient on arrival) are displayed on a screen. For example, Chepstow Community Hospital²⁹ has adopted an electronic system for calling patients to the clinic whereby patients book in at a central reception desk where they are given a numbered ticket. Each call is made both audibly and visually on screen. Patients are given a number and an area that ensures confidentiality. The system can also be used to inform patients when a clinic is running late and advise about other services.



them, meaning that patients who rely on lipreading cannot lipread staff.

Repeatedly, participants told us how audiologists kept talking to them once they had taken off their hearing aids: *"They take my hearing aid out and talk to me, like they do with other people. I was sitting with my back to the desk and my hearing aids had been taken out for testing. They had been calling and everyone was looking at me, but I didn't realise they were calling for me."*

26. Related by a participant at the Dumfries focus group meeting 26/8/10.

27. Royal Berkshire NHS – further information is available at http://www.royalberkshire.nhs.uk/wards__departments/a/audiology/adult_audiology_rehab.aspx

28. Systems available include Jayex D300 patient call-in board (further information at www.jayex.com/news.html), Savience Call Out (further information at www.savience.com/keystone-callout.php), Envisage (further information at www.numed.co.uk/products/pdf/Envisage.pdf).

29. "Audio & visual patient call system", Gwent Healthcare NHS Trust, 26/10/04. Further information is available at www.wales.nhs.uk/news/2673

30. Scottish Government (2009). *Op. Cit.*: Standard 2a7.

Section 4

Patients' experiences of audiology services – During audiology appointments

Staff do not always read a patient's case notes before a follow-up appointment. For example, an audiologist asked a patient about testing the hearing in her left ear, when the hearing in this ear was already too low to benefit from a hearing aid.

In some cases, participants commented on the high staff turnover, which meant that they could not build up a relationship with staff and felt that there was a lack of continuity.

Case study – George

George³¹ started to lose his hearing twelve years ago. When he first went to his local hospital, staff were “*extremely good*”. He was fitted with one analogue hearing aid. He remembers that, “*Problems came later when I was given the second one [hearing aid] with no information on how my brain would take time to adjust.*”

Later, when he was fitted with digital hearing aids, he felt that staff were ‘rushed off their feet’. He comments on how they lack deaf awareness: “*I felt the staff had insufficient time to deal with the number of patients and it was difficult to get further appointments.*”

He also realised that staff spoke to his wife rather than having to face him and slow down: “*I said, ‘Wait a minute, I am the patient here.’ It is very frustrating. The most important thing is to come out with better hearing, but the communication leaves a lot to be desired.*”

He says that ideally he would like staff to be customer-orientated and would like to “*be treated like an individual and not stupid.*”

We would like all frontline staff as well as audiologists and audiology assistants to be trained in deaf awareness and for the training to be repeated regularly. Training should cover handling phone calls and communicating face-to-face. Deaf awareness is currently part of some audiology training. We welcome the example of Queen Margaret University's Diploma in Higher Education in Hearing Aid Audiology³², which includes topics such as counselling skills and psychosocial aspects of deafness and Deaf culture.

In addition, deaf awareness refresher courses should be offered so that staff are given the opportunity to keep up-to-date with good practice in communicating with patients who are deaf or hard of hearing.

Deaf awareness training

Deaf awareness training should cover:

- effective communication tips, for example, facing people who are deaf or hard of hearing so that they can lipread
- identifying accessibility issues that people who are deaf or hard of hearing face
- types of communication support available and how staff can book communication support services
- highlighting good and bad practice
- defining social and medical models of deafness.
- understanding The Equality Act 2010 (which replaced the DDA 1995).

31. Not his real name.

32. Further information is available at www.qmu.ac.uk/sls/Audiology/courses.htm

4.3 Information given to patients



“It’s a traumatic experience and people can’t absorb everything in one sitting.”

Sixty-nine percent of people received information on how to use hearing aids, but only 10% were told about equipment and adaptations.

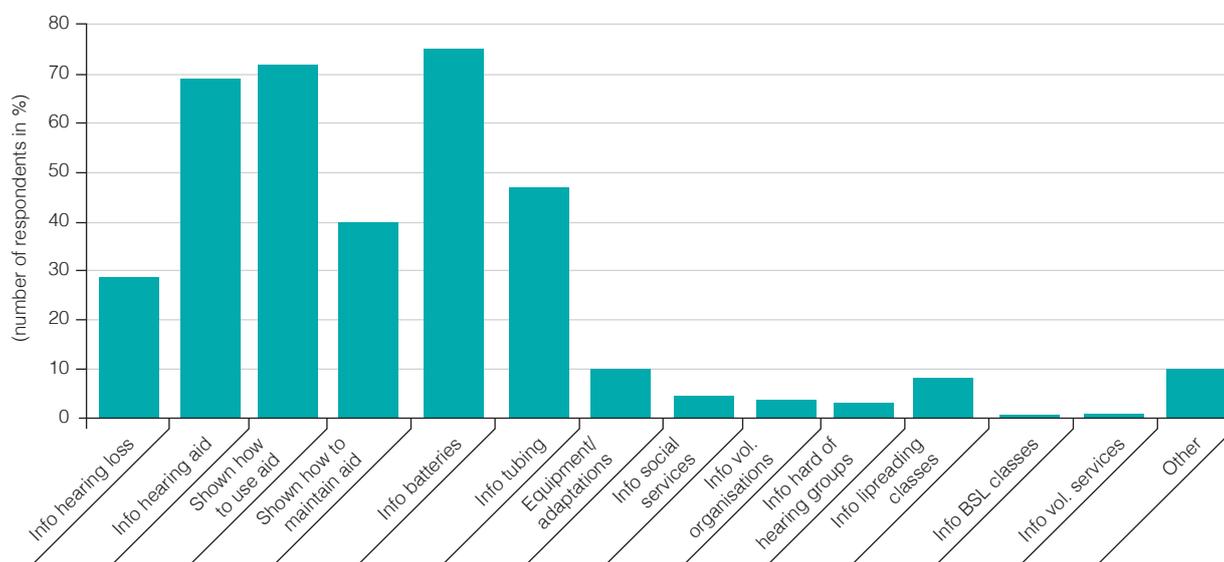
Information during first appointment with audiology

Action	Proportion of respondents (%)
Information about causes of hearing loss	29
Information on how to use hearing aid	69
Shown how to use hearing aid	72
Shown how to maintain hearing aid	40
Information about where to get replacement batteries	76
Information about where to get replacement tubing	47
Information about equipment/adaptations	10
Information about social services	5
Information about voluntary organisations	4
Information about hard of hearing support groups	3
Information about lipreading classes	7
Information about BSL classes	0.9
Information about volunteer support services	1
Other	10

Total number of respondents: 350

Section 4

Patients' experiences of audiology services – During audiology appointments



The Quality Standards state that: *“Timely and relevant information is provided to meet the needs of hearing impaired patients and their significant other(s), in formats that accommodate their communicative abilities³³”*.

The majority of respondents received information on how to use their hearing aids (69%) and they were shown how to use the hearing aid (72%). Equally, 75% were given information about where to get replacement batteries, yet less than half (47%) were given information about replacement tubing.

However, very little information is given on the limitations of hearing aids and very few people felt they were given time to discuss their expectations when being fitted with a hearing aid. As one respondent says: *“I still could not hear properly and it made things worse in some ways.”* Respondents described how it had been difficult to get ‘acclimatised’ to their hearing aids.

Few patients (29% of respondents) were given an explanation of what caused their hearing loss. One participant remembers, *“I got my hearing aids and then I was out of the door. But I wasn’t happy.”*

Only a few people were signposted to additional support services. Only:

- 5% were given information about social services
- 4% were given information about voluntary organisations
- 3% were given information about hard of hearing support groups
- 7% were given information about lipreading classes and 0.9% about BSL classes.

As a result, a lot of service users have to find out information about other forms of support themselves. Many got information through word of mouth or through knowing someone else who is deaf or hard of hearing. As one participant explained: *“You were told the basics when you went there and that was it. It was left up to yourself to do anything else.”* Another participant recalls: *“I knew where to go for assistance, I picked that information up from a friend.”* This raises an issue of equal access, as patients who are less educated are less likely to access information about support.

33. Scottish Government (2009). *Op. Cit.* Standard 2a.

Case study – Paul

Paul* first noticed a hearing problem about three years ago when he found it increasingly difficult to hear, in particular the TV. He went to see his GP after being advised to go by a speaker at a local retirement group meeting. The GP told him that he had a slight hearing loss and then referred him to audiology.

At his first appointment, he did not get any explanation of what hearing loss was, but he thought hearing aids would help him hear. During the fitting of his hearing aid, he was given very little information: *“she just put it in and said, ‘How does that feel?’ I said, ‘Fine’ and ‘Oh that will be fine’ then you know and that was about it.”* He was not told how to operate or clean his aid, or that he would have to re-tube it.

Although he finds the hearing aid comfortable enough to wear, he has not worn his hearing aid very often as he feels it has, over time, become somewhat *“useless”* and does not make a lot of difference to his hearing:

“certainly [it] did make a big difference when I first got it, but it didn’t seem to last very long.” As a result, he avoids answering the telephone as he finds it difficult to understand unfamiliar voices and accents.

Paul has not seen an audiologist since receiving his first hearing aid, but he is currently on a waiting list to see one. The waiting time is eight months. He knows that assistants can re-tube and replace his hearing aid when his is faulty, and that he can get his batteries from either the hospital or the GP at any time. He has a car and can reach the hospital in ten minutes and the GP is at the end of his road.

Despite his hearing loss, he is aware that he could have been more severely affected, but still misses things that others take for granted: *“It could be a lot worse, obviously. I know people [who] are quite profoundly deaf and it’s nothing as bad as that, but it would be nice to be able to hear the TV.”*

4.4 Training on maintenance of hearing aids

Whilst most respondents were given information on how to use their hearing aid (69%) and 75% were given information on where to get replacement batteries, only 40% were actually shown how to maintain their hearing aid. Focus group participants told us that it was a lot of information to take in at one sitting and that they had forgotten a lot of it when they got back home. As one focus group participant explains:

“You get very basic information from the audiology department and as they have told you to change things, etc, they have done their job as far as they are concerned. But you get bombarded with



information and you get home and think, ‘I have forgotten how it works.’”

Section 4

Patients' experiences of audiology services – During audiology appointments

One participant likened the experience to buying a mobile phone where, "You get a lot of information in the shop and by the time you get home, you've forgotten most of it."

As a result, over half the respondents (51%) said that they had found it difficult to use their hearing aid at first. Of this group, key difficulties included 'getting used to wearing it' (36%), putting the earmould in the ear (19%) and the hearing aid being 'uncomfortable to wear' (18%).

People who are fitted with a hearing aid for the first time should be given information in 'bite size' quantities, ideally through a series of one-to-one sessions backed up by some written information.

4.5 Private sector / NHS

The majority of respondents (69%) had received their hearing aid from the NHS. Yet a third (30%) had experienced the private sector at some point with 23% saying they had received hearing aids from both the NHS and the private sector, and 7% exclusively from the private sector.

When asked to compare services provided by private hearing aid dispensers, participants commented that private hearing aid dispensers tend to have more time to adjust hearing aids and that they were more "*customer orientated*". However, a number of participants said that the NHS had improved over the past few years and a third of respondents (33%) agreed that "*after my hearing loss was diagnosed, I felt well supported by audiology.*" Several participants agreed that minimal changes such as training NHS audiology staff or written information reinforcing verbal instructions would go a long way to improving services provided by the NHS.

Recommendations

- In waiting rooms, audiology services should use other means of communicating whose turn it is other than calling out patients' names. For example, they could lend patients mobile phones or pagers that vibrate or display patients' names on screens.
- Staff, including frontline staff, audiologists and audiologists' assistants should be trained in deaf awareness. This training should last at least half a day and be repeated regularly.
- The Scottish Government should work with audiologists to explore how to improve information provision to patients. This could be done through a generic information pack, to which audiologists could then add local information. This way, patients could refer to the written information after their appointment(s).

Patients' experience of audiology services – after audiology appointments

Key messages

- Only 42% respondents said they had received a follow-up appointment. Respondents said that they were not always aware that they could get help with the maintenance of their hearing aids.
- Some participants said the onus was on them to initiate a follow-up appointment and that they had to be assertive to obtain support.
- Referrals to social work services and an explanation of what assistive devices they can supply is very rare – only 5% of respondents were given information about social services and 10% were given information about other equipment and adaptations.
- Very few respondents said that they got referred to additional forms of support, such as lipreading classes (6%), voluntary organisations (4%), hard of hearing support groups (3%) or BSL classes (0.9%). Yet many participants commented on how useful these types of support were.
- Few patients had brought a friend/family member to the initial audiology appointment (26%). When they did, only 6% said their relative had received information about supporting them.
- A third of respondents said they had tinnitus, yet 84% of them did not receive information about coping strategies from audiology services.

We asked respondents and focus group participants about support they had received from audiology after being fitted with a hearing aid.

5.1 Follow-up appointments and maintenance



"I resent having to get batteries out from clinic/volunteers at clinic/post. Why not a chemist/GP like others with a regular 'prescription'? Also, no regular review – onus on patient to self-refer."

"For my personal experience, I found support with the audiology dept a bit poor and offhand. I was unaware that I could not just 'walk in', but had to go via GP. However, they saw me and updated my hearing aids. I was surprised to learn that they had destroyed all my audiology charts, as I had not been back for several years, maybe seven?"

The Quality Standards state that each patient should be given a follow-up appointment after the hearing aid fitting within a maximum time of 12 weeks.³⁴

Only 42% of respondents to our questionnaire said that they had received a follow-up appointment from their audiology department and a further 25% said that they had contacted audiology to make a follow-up appointment themselves.

34. Scottish Government (2009), *Op. Cit.*, Standard 5 c1.

Section 5

Patients' experience of audiology services – after audiology appointments

It is obvious that information about follow-up appointments and maintenance services provided by audiology departments is not given clearly or that patients may not take it in when they are first being fitted with a hearing aid. Only 21% of respondents said they got help with the maintenance of their hearing aids with a number of participants unaware that they could get maintenance services from their audiology department. As one participant said, *"I found out I had to make an appointment to change the tubing but only after three years!"*

Several participants commented on the fact that they had to initiate any follow-up: *"I think what I would like is follow-up. There isn't any follow-up, you have to go in and create it. I think I would like more time in audiology to talk about my problems, but I wonder if that is asking too much because the health service is always under pressure."* Another participant concluded: *"There is no follow-up help by them unless you call them and ask for it."* This raises issues of equal access, as patients who are more confident, or more 'pushy', are more likely to get follow-up than others.

5.2 Referrals to social work services



Referrals to social work services and an explanation of what services they can provide are very rare with only 5% of respondents being given information on this and 10% being given information about other equipment and adaptations.

People who are deaf or hard of hearing may need equipment and adaptations in their home, as well as care homes. Hearing aids are of benefit to many people who are deaf or hard of hearing, but there are many times when hearing aids are not enough or not always an appropriate solution. Equipment and adaptations range from basic equipment, such as amplified telephones or a flashing light on a doorbell, to more sophisticated products such as personal listeners for people who use hearing aids (a wireless listening device worn by the user which provides enhanced sound level and clarity).

These devices are essential to promoting independence and safety, enhancing quality of life and keeping people in their own homes. Yet only 10% of respondents were given any information about equipment and adaptations during their appointment with audiology. As one participant recalls: *"I never got signposted anywhere. The council department I knew just because my neighbour worked there. Audiology never mentioned it."*

Another focus group participant notes: *“I have been attending hearing aid clinics for 32 years and have yet to be told about local authority social services and the practical help they can offer with adaptations.”*

This finding corresponds to previous research carried out by RNID Scotland. We ran a consultation event on accessing equipment and adaptations³⁶ for our members and supporters, and they told us that:

- they were not given information about equipment or adaptations when diagnosed with a hearing loss
- it was a ‘postcode lottery’, with some people given a lot of information and others none, depending on which NHS Board they lived in
- they had to wait a long time before being put in touch with their social work services.

Many respondents said that they had to find out about equipment and adaptations and indeed any other forms of support themselves, on their own initiative. Eighteen percent of respondents got equipment or adaptation from their social service department and another 14% received equipment/adaptations from voluntary or private sector organisations. But in most cases they found out about it either through word of mouth or themselves. As one respondent summed up: *“[I] found other means of support but not through audiology.”*

As a result, some of the respondents felt that they had to fight to get what they were entitled to. A respondent who was born profoundly deaf says: *“Every step to make my hearing loss adaptations to life, communication and simple equipment and services has been a battle for me and my family/carers.”*

5.3 Referrals to other forms of support



Very few respondents said that audiology staff had referred them to other forms of support or services such as lipreading classes (6%), voluntary organisations (4%), hard of hearing support groups (3%) or BSL classes (0.9%).

Yet respondents also commented on how these forms of support are helpful: *“I saw an advertisement for the local lipreading class which I went along to which is fantastic. I got to know about all the aids you can have at home – doorbells and fire alarms, etc.”* Another participant said: *“My husband attends the lipreading group and this has been a great help in understanding the problems faced by deaf or hard of hearing people. He learns techniques that help us both.”* Support groups, including lipreading classes, are vital to providing emotional support and social inclusion, as well as information that people glean from other participants. As one respondent explains: *“I find the class is very useful for picking up information about all these contacts we have been mentioning. It also provides moral support. You can discuss your problems with people with the same problems.”*

For many participants, lipreading classes give the opportunity to find out about communication tactics and how to cope with hearing loss, and also to exchange information about equipment and adaptations that help them in their daily lives.

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

Section 5

Patients' experience of audiology services – after audiology appointments

An RNID Scotland report on lipreading based on a survey of our members³⁶ found that more than three-quarters of respondents considered lipreading classes to be part of rehabilitation following hearing loss. Apart from learning to lipread, for those who attended lipreading classes the reported benefits included:

- meeting other people with hearing loss (23%)
- finding out about equipment and adaptations that could help (23%)
- finding out about organisations for people who are deaf (20%)
- making new friends (15%).

Many respondents commented on the lack of 'joined up' working between audiology and other support services. Some respondents even commented on the lack of communication between different teams in the NHS, such as the balance clinic and audiology.

Respondents felt that they would like an information pack that includes written information about additional support services such as lipreading classes; BSL classes; hard of hearing support groups; deaf clubs; resource centres that demonstrate equipment and adaptations (if available) and local social work services. As one respondent explains: *"Early information on support groups would have been very helpful, rather than stumbling across this more than a year later, as well as lipreading classes. Audiologists do a great job but are far too busy to deal with this, but an information pack handed out when checking in at reception would be very helpful."*

5.4 Support given to family/carers

"If you have partners/family one must be at initial appointment so that they get correct information and then they will be able to give support and advice when required."

The Quality Standards state that *"significant others [should be] routinely encouraged, through formal invitation, to participate in clinical contacts (where consent has been provided). They are also encouraged to engage with the service through patient forums to facilitate planning, satisfaction auditing and information development, etc."*³⁷

Yet when we asked respondents whether a friend or family member came with them to the initial appointment that they had with audiology, 73% said 'no'. For those who came with their "significant other":

- only 6% got information about supporting them
- only 5% got information about hearing loss
- only 2% got information about support groups.

Respondents commented:

"No information was given at all. In fact, it was made pretty obvious that my companion was unwelcome."

The wife of a man who has become hard of hearing later on in life comments:

"I didn't get any support. Living with somebody who was hard of hearing, I had no support about how to communicate with [the] deaf, we now have our own way. Even speaking directly to him or being in the same room, you forget. Because it is hard sometimes, you feel isolated. There is no support for wife/family, etc. If you go to friends you have to ask can you put the TV off."

37. Scottish Government (2009). *Op. Cit: Standard 2a.11.*

5.5 Tinnitus

A third (33%) of respondents said they had tinnitus and an additional 18% said that they sometimes had tinnitus. Yet 84% of those with tinnitus did not receive any information about coping strategies from audiology services and only 2% attended a tinnitus clinic run by audiology. A third of those who did not attend a tinnitus clinic simply did not know that the clinics existed.



Case study – Martin³⁸

Martin recalls his experience of living with tinnitus: *“Following the sudden onset of severe tinnitus when I was 37, it took me four years to adjust to it. I had a complete breakdown and a spell in hospital because I was unable to cope.”* Martin decided that the only way to help himself was to start a Tinnitus Self-Help Group and started the Edinburgh and East of Scotland Group. Thanks to fundraising activities, the Tinnitus Self-Help Group were able to send two consultants and technicians to Portland, Oregon, USA, to find out how to set up a support unit. They invited academic experts from Nottingham, UK, to come to the group to talk to them.

Martin goes on: *“I am now 71 and still living with tinnitus, which has got worse with my hearing getting worse. Although there is a better understanding of tinnitus, there is still no cure or will be in my lifetime. The last department of audiology that I have attended was in [England]. They spent many hours with me, testing and explaining the fitting of new digital aids. I also received years of care from audiology in [a Scottish Hospital] from a doctor for whom nothing was too much trouble.”*

Recommendations

- Audiology departments should invite patients back for at least one follow-up appointment after the fitting of hearing aid(s) within a maximum of 12 weeks.
- The Scottish Government should work with audiologists to explore how to improve information provision to patients. This could be done through a generic information pack to which audiologists could then add locally. Generic information could include advice to relatives on communicating with someone who is deaf or hard of hearing, and advice to patients on coping with tinnitus. Local information could include lipreading classes, deaf/hard of hearing support groups and social work services.

38. Not his real name.

Section 6

Ideal adult hearing rehabilitation services

Key messages

- The majority of respondents find it very important to be trained in how to use their hearing aid. Training should be comprehensive and should cover: how to put the hearing aid in the ear; how to operate the controls; how to change the batteries; how to use the hearing aid in different situations; how to use the hearing aid with loop systems and other assistive listening devices; and how to clean and check the hearing aid.
- Patients would like the information to be given in 'bite size' quantities and would like to get written information as well as practical demonstrations.
- Most respondents find it very important to be given some explanation of why they have lost their hearing and half of respondents said they would like to be given coping strategies.
- A majority of respondents would like to be referred to social work services and to be given information about equipments and adaptations. Respondents also found it important to be given some information about lipreading classes.

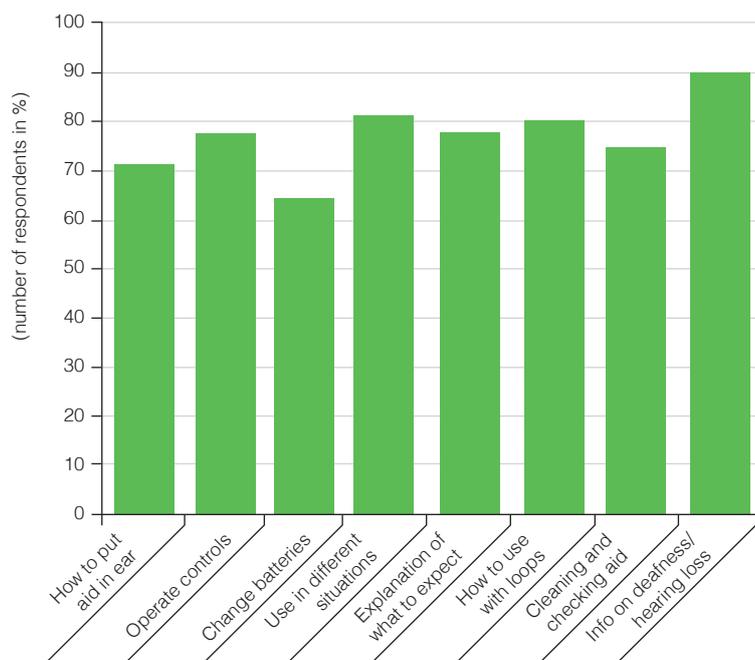
Having summed up patients' current experiences of adult hearing rehabilitation services, we asked people who had used them what is important to them and what would be an ideal service.

6.1 Use of hearing aid(s) and maintenance

Service	Proportion of people who said it was 'important' (%)
Training in how to put the hearing aid in the ear	71
Training in how to operate controls	77
Training in how to change the batteries	65
Explanation of use in different situations	81
Explanation of what to expect	78
Training in how to use hearing aid with loops	80
Training in cleaning/checking hearing aid	75
Information on deafness and hearing loss	90

Total number of respondents: 350

Importance of training



Total number of respondents: 350

Most respondents find it important to be shown how to use their hearing aid in detail. Whilst the majority of respondents (72%) are shown how to use their hearing aid just after fitting, they would like detailed information and training to be delivered on a regular basis, in 'bite size' quantities. Respondents would ideally like the information to be tailored to the needs of patients and some respondents commented that audiology staff need to be able to communicate the information clearly. As one participant said: *"Perhaps the main need is training for audiologists in teaching."*

Respondents would like the information to be written in an easy-to-read guide, as verbal instructions may not suffice: *"I would like to see a pack at the audiology with information/leaflets, etc. I had to make sure I had a pen and paper [during the audiology appointment] to write things down."* Respondents have also suggested that demonstrations of the written information would also be useful: *"access to demonstrations or equipment [would be ideal] because it is one thing looking at it in a book, but I think you need more than that."* Ideally, people would benefit most from verbal instruction accompanied by written information and visual demonstrations.

Only 28% received any information about deafness and hearing loss, yet this is important to 90% of respondents. One respondent recalls: *"Whilst audiology have helped with my hearing loss, they don't provide support/ explanations about my sudden hearing loss as an adult, which left me feeling very angry and isolated. It took a while to adjust and only through RNID did I find out possible reasons, two years later."* One participant would like *"more specific information at the beginning of why you have a hearing loss and what causes it" along with information about "all the types of hearing aids that are available and what is suitable for you and to have a trial of them."*

Sixty percent of respondents felt that training in how to use the hearing aid is very important. Respondents would like the training to be comprehensive and to cover how to put the hearing aid in the ear (60% found this very important); how to operate the controls (66%); how to change the batteries (54%); how to use the hearing aid in different situations (67%); how to use the hearing aid with loop systems and other assistive listening devices (62%); and how to clean and check the hearing aid (56%).

Section 6

Ideal adult hearing rehabilitation services

Several respondents also need information about ear care and problems that can be caused by wearing a hearing aid, such as wax build up, eczema and ear infections. People explained that they often could only wear their hearing aids for a limited amount of time each day because of these problems.

6.2 Emotional support



Nearly three-quarters of respondents said that it was important to get information about coping strategies. Yet participants at the focus groups said that they did not receive any emotional support, even though adjusting to hearing loss can be very isolating and several people referred to being “in shock.”

We live in a hearing world where being able to hear and speak to others is considered a normal part of human interaction. Being told that you have lost your hearing represents a huge emotional shock and can be very upsetting as one respondent remembers: *“The audiologists – some of them are quite unfeeling – they do it every day. I saw the head guy as I thought I just had tinnitus. The guy said that I did have tinnitus but, ‘It will not kill you – you have inoperable nerve damage and your deafness will worsen.’ It was not done in a nice way. I was only in my early 50s. It was shocking.”*

Respondents to our questionnaire said they would like time to talk to someone about their hearing loss. One respondent felt that *“the audiologist [was] very busy and more interested in changing the tube or getting you a new tube. You can’t really talk to them about your problems, it is just about your hearing aids.”* Another put it bluntly: *“There is no emotional support in the NHS.”*

A respondent summarises the emotional turmoil that can be associated with hearing loss and the lack of psychological/emotional support: *“I have been registered blind all my life, although I do have vision. I could not believe the lack of understanding, support, help or information that I got when first being given a hearing aid. My audiology dept gives no help or support and the lack of knowledge or equipment is astounding. Becoming deaf is a very frightening and isolating experience. Surely those that work in the field should empathise with that?”*

We would like audiology services to provide information to patients about peer to peer support and other counselling services. For example, the Hear to Help projects, based in Tayside, the Scottish Borders and Glasgow, are based on the principle of training community volunteers in maintaining and cleaning hearing aids. Many volunteers have some hearing loss themselves and can provide peer to peer advice. Another example of a peer to peer service is the befriending project run by Ayrshire Hearing Support, whereby volunteers visit people who are deaf or hard of hearing in their own homes, in nursing homes as well as sheltered accommodation. A focus group participant summarised: *“I would suggest there would be volunteers at every health centre who could help people at a specific time/day and it would need to be someone who knows about [hearing loss] and they could help people with new hearing aids and it could be done on a voluntary basis so it wouldn’t cost anything.”*

SISG Enterprises Limited – Ayrshire Hearing Support

Ayrshire Hearing Support was set up in the 1990s – the brainchild of the person who was then head of audiology and head of the sensory group at South Ayrshire Council. To start with, they ran classes for small groups of people with a hearing loss, covering issues such as how to cope with daily life, what environmental aids were available, and so on. The group ran deaf awareness sessions with bank staff, post office staff and others, and with funding from the Hewlett Packard Quality Healthcare Award, developed a video of self-help tips. The video included a variety of clips such as a lipreading exercise and followed a hard of hearing volunteer trying to order lunch at the hospital canteen. The group adopted charitable status in 1998 when a group of volunteers visited hearing aid wearers in a number of wards at Ayr Hospital to help them with their hearing aids. The idea grew from there and the group now offers:

- befriending visits – 56 volunteers now visit people who are deaf or hard of hearing in their own homes, in nursing homes and in sheltered accommodation. Initially, volunteers helped with the maintenance of hearing aids and this grew into a befriending service with funding from the Big Lottery Fund

- three drop-in centres (in Ayr, Cumnock and Girvan) with an additional outreach centre in Largs

- lipreading classes, which last either five days or a single evening. These classes cover much more than lipreading and provide information about a range of topics, such as how to book communication support services, how to use subtitles on television, as well as an opportunity for people to meet others who are deaf or hard of hearing

- digital hearing aid workshops to show people how to use their aids
- deaf awareness training
- signposting and advisory services
- complementary therapies for those with tinnitus
- 'Try before you buy' centre for BT phones
- SMS text and internet skills training – offering training in an alternative means of communication.

The service covers the whole of Ayrshire and, last year, volunteers did over 8,000 visits to 3,000 users. But with an estimated 50,000 people who are deaf or hard of hearing in Ayrshire, the demand for such a service is high. Dorothy McRobert is keen to foster the follow-up and the social support. She says: *“As hearing aids are now technically high-quality and expensive, a good follow-up is essential. Otherwise, expensive hearing aids will be left in the drawer.”*

Further information: tel 01292 286096, email www.sisgdorothy@aol.com, website www.sisg.co.uk

Further information about similar support groups is available from RNID Scotland: tel 0808 808 0123, SMS text 0808 808 9000, email informationline@rnid.org.uk

Section 6

Ideal adult hearing rehabilitation services

6.3 Referrals to external services



Type of referral	Proportion of people who said it was 'important' (%)
Referral to a hearing therapist	59
Referral to social work services	69
Referral to voluntary organisations	66
Referral to lipreading classes	76
Information about BSL classes	20*
Information about support groups	66

*Although 27% also said it was 'not at all important'.

Whilst only 5% of respondents received information about social work services during their first appointment, a referral to social work services is seen as important by 62% of respondents. People would like to get access to 'one stop shops' where they can get information about

social services, demonstrations of equipment, and access to lipreading classes and support groups, such as hard of hearing groups. The majority of respondents (70%) said that it was important that they got information about equipment/assistive devices.

Case study – Forth Valley Sensory Centre

RNID Scotland is a partner in the Forth Valley Sensory Centre, along with Falkirk Council, Stirling Council, Clackmannanshire Council, Forth Valley Health Board, RNIB Scotland and Guide Dogs for the Blind. It is a purpose-built centre where information, advice, diagnosis, treatment, follow-up, practical help, training, education and equipment are available and easy to access. In the review of social work services for older people in Forth Valley³⁹ published in 2008, the Forth Valley Sensory Centre was credited as providing high-quality services in an integrated approach with local authorities, including Falkirk Council, the Health Board and the voluntary sector.

RNID Scotland provides an information drop-in service every second Wednesday from 1-3pm, demonstrating equipment. Manned by a volunteer who is hard of hearing, the service aims to give practical advice to people with a hearing loss.

Forth Valley Sensory Centre, Redbrae Road, Camelon, Falkirk FK1 4DD: telephone/minicom 01324 590888, SMS text 0780 389 7928, email sensory@falkirk.gov.uk, website www.falkirkonline.net/specialistservices

Equally, whilst only 6% of respondents are given information about lipreading classes from their audiology department, 76% think it is important. Participants stressed that they would have liked a pack of written information giving details of lipreading classes, BSL classes, counselling and any local support groups.

6.4 Regular follow-ups

As mentioned earlier, only 42% of respondents said they had received a follow-up appointment from their audiology department. Service users would like to have a regular reassessment and review of their hearing aids at regular intervals. As one focus group participant explains:

"I feel there is a lack of follow-up, after the supply of an aid. Although using aids over 30 years, I have not once had any kind of test on how well it worked. Surprise surprise – most of the things stay in a drawer, unloved and unwanted. While a lot of us may be too old to learn new tricks, this is not true of ALL. I find an assertive attitude at the clinic is needed. It shouldn't be."

Participants felt that with an increasing older population, the audiology system in Scotland should be on a par with other screening and treatment programmes where *"patients are called back regularly for checking and review."*

We welcome the fact that some NHS Boards give a systematic 12-week follow-up appointment⁴⁰ and we would like other NHS Boards to adhere to this Quality Standard.

39. Social Work Inspection Agency (2008). *Multi-agency inspection: collaborative working across services for older people in Forth Valley* available at www.falkirk.gov.uk/services/social_work/community_care/older_people/swia_report.pdf

40. Based on our questionnaire to heads of audiology – see Section 6.

Section 6

Ideal adult hearing rehabilitation services

6.5 Support to families/carers



Currently, only 26% of patients had a friend or family member accompanying them when they went in for the first (fitting) appointment. For those who did have a friend or family member, only 6% received information about supporting them; 4% received information about hearing loss; and 2% received information about support groups.

Thirty-nine percent of respondents said that they would ideally like their family to receive further information and 12% would like their family member to get access to a support group. As one respondent explained: *“[I would like] information leaflets on how to speak clearly and support a deaf person, for example, don’t turn your face away, be sympathetic and patient.”*

In addition, service users would like their family to be trained in deaf awareness to *“grasp the limitation deafness imposes and how to help communication.”* Several people commented on the benefits of going to a lipreading class with their partner. As one lady explains: *“My husband attends the lipreading group and this has been a great help in understanding the problems faced by deaf or hard of hearing people. He learns techniques which help us both.”*

Recommendations

- Audiology staff should give patients some explanation of the reason(s) that they lost their hearing.
- The Scottish Government should work with audiologists to explore how to improve information provision to patients. This could be done through a generic information pack to which audiologists can then add local information. Local information could include information about local repair clinics as well as existing peer support/information services.
- NHS Boards should consider better ‘joined-up’ working in the community – for example, through developing ‘one stop shops’ where service users can access information about social services, demonstration of equipment and where support classes are run.

Section 7

Audiology departments

Key messages

- Just over half of the 14 heads of audiology departments in Scotland (8) responded to our survey.
- All respondents said that staff had been trained in deaf awareness.
- Audiology departments are not always accessible, with only a minority with induction loops fitted in waiting or consultation rooms.
- There are anomalies between service users' experiences and what audiologists told us. For example, 70% of service users said they only received an appointment letter and no further information. But heads of audiology said they sent information on the hearing test and some said they sent information on communication support.
- All audiology respondents said they trained patients in how to put the hearing aid in the ear. Most said they gave information leaflets about support services, such as social work services. However, service users said they did not get information about assistive devices or social services.
- Four of eight audiology departments said they offer a follow-up appointment and repairs/batteries are mostly available from drop-in clinics.

We sent a postal questionnaire to the heads of audiology departments in the 14 NHS Boards. This covered a wide range of areas and was based on the Quality Standards. We asked heads of audiology if they had an overall written pathway for adult hearing rehabilitation services; what information or training is sent or given both before and during the appointment when patients are fitted with a hearing aid; follow-up appointments and care; services patients are signposted to; support given to people with tinnitus; and staff deaf awareness training. Eight of the 14 heads of audiology responded, which is a good response rate.

7.1 Overall management

7.1.1 Rehabilitation service pathways

Five of eight heads of audiology said that they had an overall pathway for adult hearing rehabilitation services.

On the whole, several heads of audiology who responded to our questionnaire said that the key problem is a lack of time and resources. One respondent explained: *"The audiology services [...] are under significant pressure to reduce waiting times at present [...] It is hoped with additional resources more time and effort will be made to help improve and develop our present services."*

Section 7

Audiology departments

7.1.2 Staff deaf awareness

The Quality Standards stipulate that: *“all frontline staff with direct patient contact receive deaf awareness and communication training as part of their induction, which is then updated every 3 years. This training is approved by a relevant third party such as a voluntary sector organisation. The training will include deaf-blind awareness and also underline key areas of communication.”*⁴¹

Service users told us that staff are not always deaf aware, for example, talking to them once they had taken off their hearing aids or not facing them –

this means that patients who rely on lipreading cannot lipread staff. Yet all eight audiology departments that responded to our survey said that their staff received deaf awareness training. In four NHS Boards, deaf awareness training is part of the overall induction training and, in one case, deaf awareness training is part of overall disability awareness training. In most cases, deaf awareness training lasts half a day. Five NHS Boards repeat the deaf awareness training every three years, as stipulated in the Quality Standards.

7.1.3 Physical environment

The Quality Standards stipulate that *“the audiology centres provide ease of physical access to all areas where audiology is delivered.”*⁴² Yet only one NHS Board said that their services are fully DDA-compliant. Whilst five NHS Boards agreed that all areas are well-lit, only two said that they had induction loops in consultation rooms.

We understand that new hospitals are fitted with induction loops in both waiting rooms and consultation rooms. In one NHS Board, staff try to wear neck loops because induction loops are not available throughout the audiology service.



A majority of audiology respondents said that improved facilities would help them deliver better audiology rehabilitation services.

7.1.4 Individual Management Plan for patients

The Quality Standards state that an Individual Management Plan should be developed for each patient, initially based on information gathered at the assessment phase, determined in conjunction with the patient and updated on an ongoing basis⁴³. Encouragingly, six of eight audiology

respondents said that they had an Individual Management Plan for each patient. And one said that all patient activity was recorded in their journal, even though not always set out as an Individual Management Plan.

41. Scottish Government (2009). *Op. Cit:* Quality Standard 2a.7.

42. Scottish Government (2009). *Op. Cit:* Quality Standard 1a5.

43. Scottish Government (2009). *Op. Cit:* Standard 4.

7.2 Information sent to patients before their appointment

Seventy percent of service users who responded to our survey said that they only received an appointment letter and no other information. Only 11% said they had received information about the hearing test itself and less than one percent (0.6%) had received information about potential communication support services.

Table 7.1 shows that all audiology departments said that they send an appointment. Most of them (five of eight) also said that they had sent information about the hearing test and three of eight said they had sent information about potential communication support services.

Table 7.1 Information sent before the initial appointment

Information	To all	Sometimes	Only on request
Appointment letter	8		
Information about hearing test	5	1	1
Information about communication support	3		
Information about hearing loss	1		
Information about hearing aids, their limitations/benefits	2		2
Any additional support leaflets	1		2



Section 7

Audiology departments

7.3 Information and training given during the appointment

7.3.1 Information and training to patients

Service users told us that in most cases they are given information on how to use their hearing aids and information on where to get replacement batteries. But only a minority are given information on equipment/assistive devices, social services and other services, such as lipreading classes or voluntary organisations. This corresponds to some

extent with what audiology respondents told us. The table below shows that audiology staff always provide training in how to put the hearing aid in the ear and in how to operate the controls and change batteries. But few systematically provide information on assistive listening devices, for example.

Information/training	To all	Sometimes	Only on request
Training in how to put the hearing aid in the ear	8		
Training in how to operate the controls and change the batteries	8		
Explanation of use in different settings and what to expect	7		1
Training in how to use the hearing aid with loop systems	4	2	2
Training in cleaning and checking aid	7	1	
Training in replacing tubing/tips	4	2	2
Replacing tubing	2	4	2
Options for reprogramming hearing aid	5		1
Basic hearing tactics and communication training	4	4	
Information about other assistive listening devices	3	5	
Information leaflets for patients	5	2	1
Information/training on ear care and wax management	1	5	2

7.3.2 Information and training to family/friends

The Quality Standards state that “significant others” should be routinely encouraged, through formal invitation, to participate in clinical contacts (where consent has been provided)⁴⁴.

All audiology respondents said that they always encouraged patients to bring a friend or family member when they attend appointments. Similarly,

all audiology respondents said that they gave verbal information about hearing loss to the patients’ families and four said that they gave written information to the patients’ families. Yet when service users were asked the same question, only a minority said they had received information about supporting them and information about hearing loss.

44. Scottish Government (2009). *Op. Cit:* Standard 2a11.

7.3.3 Support for people with tinnitus

Seven of eight audiology services said that they provided specific support for people with tinnitus. Support for people with tinnitus falls into the following categories:

- A tinnitus clinic as part of audiology departments (5)
- Information leaflets (6)
- Signposting to support groups (3)
- One-to-one regular support (6)
- Other type of support (2) such as tinnitus rehabilitation group or referral to audiologists with expertise in tinnitus.

7.4 Information and signposting after the appointment

7.4.1 Follow-up appointments

The Quality Standards state that each patient should be given a follow-up appointment following hearing aid fitting within a maximum time of 12 weeks⁴⁵ and a review appointment is offered to all hearing aid patients every three years⁴⁶.

Five of eight audiology services said they always offer a follow-up appointment and two that they sometimes offer an appointment. Of those who said they offer a follow-up appointment, four offer an appointment within six to eight weeks and one offers an appointment within 12 weeks. One said that this is variable depending on each individual case.

7.4.2 Hearing aids maintenance



The table below summarises who provides batteries and who provides batteries and repairs. Most audiology services have a repair audiology drop-in clinic and most services provide repairs/batteries by post. GPs and patients' local health centres also provide batteries but do not provide repairs.

	Repairs provided	Batteries provided
Hospital audiology clinic by appointment	5	3
Hospital audiology drop-in clinic	6	7
Audiology outreach clinic by appointment	4	3
Audiology outreach drop-in clinic	1	3
Patients' local health centre/GP	0	7
By post	7	8

45. Scottish Government (2009). *Op. Cit:* Standard 5c1.

46. Scottish Government (2009). *Op. Cit:* Standard 5c2.

Section 7

Audiology departments

7.4.3 Signposting to other organisations

The Quality Standards state that written protocols/processes should be in place to support referral to social work, volunteer services, voluntary organisations, local NHS mental health services, specialist audiological and other health needs, such as speech and language therapy and falls prevention clinics⁴⁷.

The table below shows that audiology departments provide information to patients about a number of services such as lipreading classes (six of eight) and hard of hearing support groups (five of eight). Yet only a handful of service users said that audiology had signposted them to voluntary organisations (4% of respondents), hard of hearing support groups (3%) or lipreading classes (7%). This may be because patients do not take in all the information they are given in a short time span.

	Formal referral	Information provided
Hearing therapist	0	0
Speech and language therapist	2	3
Specialist audiological services(for example, cochlear implant, BAHA)	3	2
NHS mental health services	1	3
Social work (sensory team)	4	4
Social work (other team)	2	2
Volunteer services	5	4
Lipreading classes	0	5
BSL classes	0	3
Hard of hearing support groups	0	5

47. Scottish Government (2009). *Op. Cit:* Standard 8a2.

7.5 Conclusions

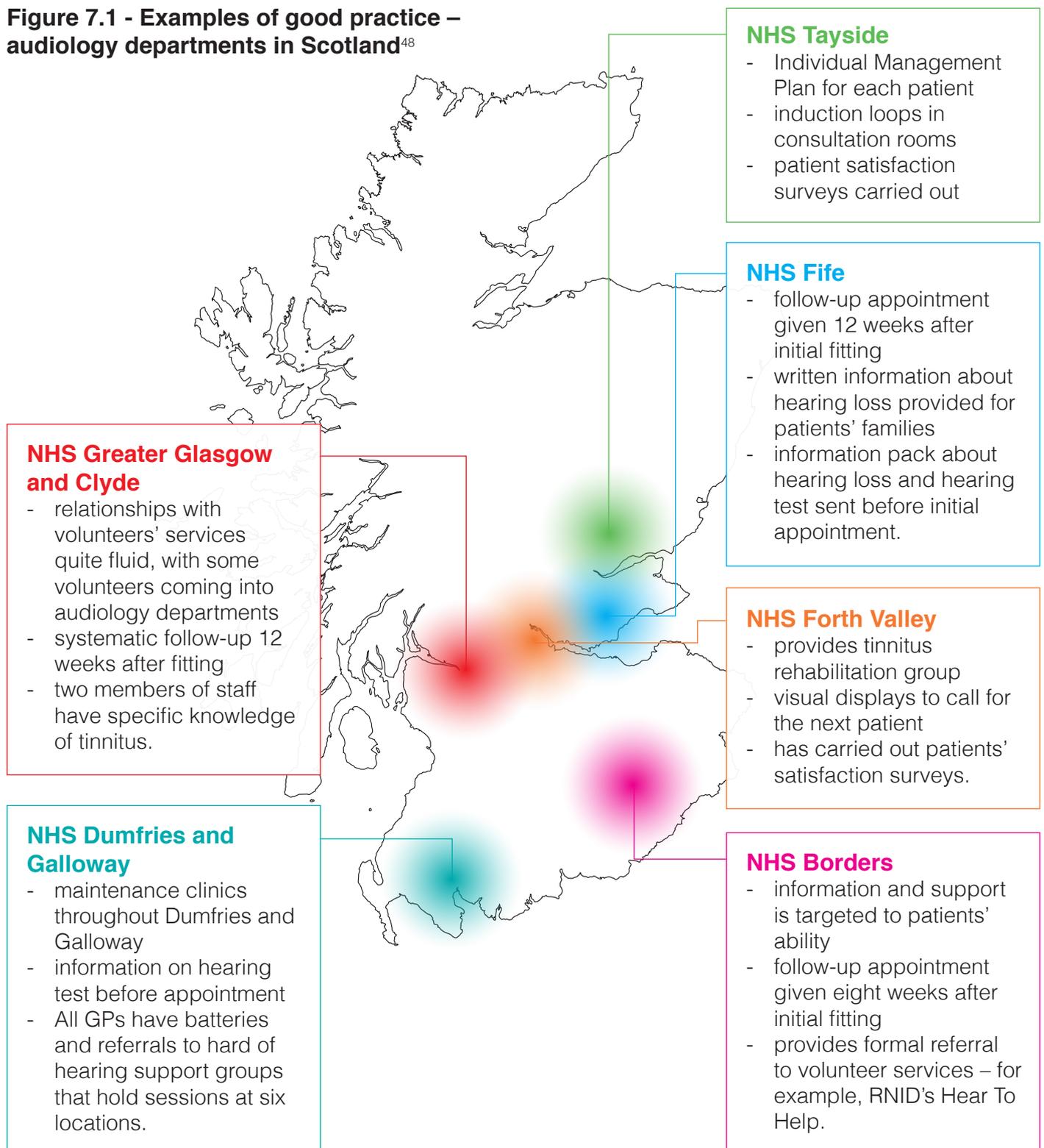
This research has attempted to look at the experiences of audiology services users against the Quality Standards of what they should receive. We also wanted to capture audiologists' experiences of providing services to ascertain how many of the Standards have been implemented, one year on from their publication.

We have found some examples of good practice in audiology services across Scotland (see Figure 7.1). This includes NHS Greater Glasgow and Clyde having staff with specific knowledge of tinnitus; NHS Forth Valley carrying out a patient satisfaction survey; and NHS Borders making formal referrals to voluntary organisations and support groups.

However, there are also clear anomalies between service users and service providers' experiences – for example, on how much information is given out with the appointment letter, during and post consultation. The Standards set a high bar for audiologists to work towards and we can see some progress in meeting the Standards.

Nevertheless, the gap we have found in our research is significant. Service users should be at the heart of the service and clearly more work needs to be done to make this a reality.

Figure 7.1 - Examples of good practice – audiology departments in Scotland⁴⁸



48. This map gives some examples of good practice by some of the NHS Boards from which we had responses to our questionnaires.

Section 7

Audiology departments

Recommendations

We welcome the instances of good practice such as the fact that most audiology staff are trained in deaf awareness.

However, we would like audiology departments to implement fully the Quality Standards for Adult Hearing Rehabilitation. In particular:

- ensuring that departments are accessible and in particular that there is an induction loop (either fixed or portable) available in waiting and consultation rooms
- each patient should have an Individual Management Plan
- information about the hearing test, about potential communication support services and about bringing a family member/friend/carer with them should be sent along with the appointment letter – and this information should be clear
- patients should be trained in all aspects of using their hearing aids – this should include written information as well as spoken advice, as people may not retain all the information
- patients' family members should be given information on how to communicate with their relative who is deaf or hard of hearing
- patients should receive a follow-up appointment within a maximum time of 12 weeks and a review appointment every three years
- patients should be given clear information on where/how to get their hearing aid maintained and where to get additional support. This should include local information on social work services, support groups and lipreading classes.



Support provided by other organisations and other rehabilitation models

Key messages

- Providing a hearing aid is not always enough to ensure that it is used. People need additional support to take in all the information given over several sessions. People also need emotional support from other people who are deaf or hard of hearing.
- Additional support services are necessary because audiology staff do not always have the time to provide information that is targeted to the patient.
- There is a range of initiatives in Scotland, from information provision to projects that provide maintenance of hearing aids and additional advice. However, these are not available throughout Scotland and people are not always given information about them by audiology staff.
- Research has shown that effective examples of rehabilitation programmes include, for example, short courses on how hearing aids work as well as coping strategies, use of technologies (for example, a lipreading video) as well as 'counselling' programmes (where counselling is defined as the provision of information as well as advice on making personal adjustments). A holistic approach whereby people have access to a variety of instruction, counselling and communication training, as well as being fitted with hearing aids, is most effective.

Giving someone a hearing aid is not always enough to ensure it is used properly and some people may require ongoing support after their hearing aids have been fitted. There are other forms of rehabilitation that can be used in conjunction with the hearing aid (or instead of it if the hearing loss is mild and the patient does not require an aid at this stage). Support that people with a hearing loss receive falls into a number of categories, ranging from provision of information through an enquiry helpline to lipreading classes and specialist support such as support to people with mental health problems. The table below summarises the different types of support that can be provided in addition to audiology services. We have mapped out services provided by other organisations in Scotland in a directory of supporting organisations (available in a separate publication).

8.1 Need for additional support services



Over half of service users (51%) had found it difficult to get used to their hearing aids at first. A third of respondents (35%) found it hard to get used to wearing a hearing aid, whilst 16% found it difficult to clean and maintain their hearing aids. Some focus group participants told us that they were *“never shown how to clean the earmould and tubing or told that it was necessary [to do so].”*

Section 8

Support provided by other organisations and other rehabilitation models

Some participants found it difficult to take in all the information in one appointment verbally and said that they would like support to be delivered over several sessions. For them, the explanation of how to use and maintain their hearing aid could be delivered by additional support services such as those provided by voluntary organisations. As one focus group participant explains:

“You get very basic information from the audiology department and as they have told you to change things, etc, they have done their job as far as they are concerned. But you get bombarded with information and you get home and think, ‘I have forgotten how it works.’ Support groups are therefore very important.”

Equally, participants told us that it had been a shock to be told that they had hearing loss and some would have liked other people who were deaf or hard of hearing to help them at the time. One focus group participant recalls: *“The people that were there – none of them were deaf. So it was all theory they would talk about. They couldn’t appreciate fully the problems you were facing. The problems you face at the beginning aren’t just about hearing, it’s the social, psychological aspect [...] It is very difficult to get information about how I deal with my deafness from people who are not deaf, but who think they know best.”*

During their first audiology appointment, only a handful of respondents said that audiology staff signposted them to voluntary organisations (4%), hard of hearing support groups (3%), lipreading classes (7%) or BSL classes (0.9%). Yet, when asked how important they thought these additional services were, 40% of respondents said it was important to be referred to voluntary organisations; 39% found it important to be referred to hard of hearing support groups; and 53% said it was important to get information about lipreading classes.

Additional support services are necessary principally because audiology staff do not always have the time to provide information that is targeted to the patient. Service users said that they, *“would have liked to know someone who could have spent more time with me explaining what was going on and give me information away to read in my own time.”*

Those who did access additional support commented on how useful it was. For example, one participant considers lipreading as *“an answer to a person who is deaf and will always be deaf.”* Service users told us that support groups had provided them with the information they needed as well as emotional support: *“Until you have a support group it is only then that you hear other people’s experiences. You should not need to have to go to a support group for that information as you should be given all the information by audiology.”*

8.2 Range of additional support services



The table at the end of this chapter summarises the types of additional support that are available in Scotland and gives a few examples of support services. There is a wide range of additional support services, from basic information provision to resource centres and lipreading classes. Focus group participants commented positively about some of the projects. For example:

“An Ayrshire Charity SISG now supplies a lipreading class and a fortnightly clinic in out of town to help with maintenance of hearing aids for people who cannot get to the hospital clinic. Elderly people need help with understanding their aids.”

“If you can get into Edinburgh, Deaf Action are fantastic. They have helped put in a loop system in my house, a vibrating fire alarm, they give me emotional support and help with finances.”

“I heard about Hearing Link through my lipreading class. They have been great.”

Case study – Hear to Help

Hear to Help offers basic hearing aid maintenance, such as replacing tubing and batteries. RNID Scotland has run a Hear to Help project in the Scottish Borders since 2007. Based on its success, it has expanded the project to the Greater Glasgow and Clyde and Tayside Health Board areas. Sessions are held at a number of locations and are run by trained volunteers, many of whom have a hearing loss themselves. Volunteers also make home visits to build the confidence of hearing aid wearers who have often become isolated due to their hearing loss. Further information on Hear to Help is available at www.rnid.org.uk/HearToHelp

“I am so glad I became a member of RNID. It's the only place that has given me clear information on topics I need help with. This has encouraged me to be more persistent and confident when speaking to medical staff.”

Although there are some examples of useful services, most people find out about services by chance, through word of mouth. As one service user recalls: *“I have been involved in different support groups so I know they exist but sometimes it has to be through word of mouth or leaflets or you read it yourself in books.”* We would like audiology services to provide written information about local support groups, including hard of hearing support groups, lipreading and BSL classes, as well as information about voluntary organisations and their local projects. We would also like audiology staff to mention support services to patients and their partners, family members or carers.

Section 8

Support provided by other organisations and other rehabilitation models

As well as a lack of information about additional support services, there are geographical disparities and whilst some areas of Scotland have a number of services, other areas have few support services available. As a result, several participants told us that support services are located too far for them to attend and that they would need home visits. Given that one in seven people in Scotland have a hearing loss, we believe more support services need to be available that meet their needs in the community.

Case study – Jim⁴⁹

Jim is an elderly man who lives in a nursing home. A year ago, he was becoming more and more withdrawn. When the Hear to Help volunteers went to visit the home they found that the nursing staff thought that hearing aid batteries lasted a year and had not changed Jim's battery, so his hearing aid had a flat battery. Once the volunteers had changed it, he was able to join in conversations with the other residents and activities that the home was putting on. Little by little, he regained his confidence and cheeriness.

8.3 Other rehabilitation services and support models

Numerous studies have been undertaken both in the UK and internationally, looking at the efficacy of various forms of rehabilitation programme. These studies are summarised in Appendix 4⁵⁰. The range of rehabilitation programmes includes:

- Communication training programmes: this can be divided into auditory training (for example, active listening/listening training) and visual training (for example, lipreading training, lipreading on video training)
- Provision of assistive listening devices and equipment
- Hearing aid training covering hearing aid maintenance and how to use hearing aids
- Counselling, such as adjustment counselling (including counselling at the patient's home)
- Counselling of significant others
- Pre-fitting visits and counselling
- Support courses/information sessions
- Group support sessions
- Peer support.

50. These studies are not directly comparable because they applied different methods and the programmes did not last the same length of time. However, these studies can be used to form an overall impression of the effectiveness of rehabilitation programmes for people with hearing loss.

8.3.1 Communication training

This can be divided into auditory training, which takes advantage of acoustic clues such as active listening/listening training, and visual training, which uses visual clues such as lip patterns or facial expressions.

Auditory training can help individuals make the most of their hearing aids because hearing aids distort sounds⁵¹. Research has shown that individual forms of training are not always the most effective way of improving communication. However, a combination of various forms of training is effective. For example, Watts and Peggs⁵² show that auditory training (which takes advantage of acoustic clues) combined with speechreading (which they define as looking at the lip, jaw, tongue and facial movements made in speech) is effective in improving communication.

8.3.2 Short courses

Research has found that short courses covering information about the ear, how hearing aids work, as well as other training such as coping strategies and lipreading, are an effective form of rehabilitation. For example, Smaldino and Smaldino⁵³ did a study where first-time users received a four-week aural rehabilitation programme consisting of information about the auditory system and how it works, and auditory training involving coping strategies and speechreading. The researchers found that participation in a short course was an *“effective tool in reducing first time hearing aid users’ perception of hearing handicap.”* The group receiving the short-term rehabilitation programme experienced a significant reduction in self-perceived hearing handicap than did the other groups.

51. Sweetow R and Henerson Sabes J (2006) in 'The need for and development of an adaptive listening and communication enhancement program', *J Am Acad Audiol*; 17: 538-58, show that *“the hearing aid user generally receives a partially degraded signal, either because of extrinsic sources such as noise interference or limited bandwidth, or from underlying intrinsic limitations such as imperfect audibility, cochlear distortion and impaired frequency and temporal resolution.”*

52. Watts WJ and Peggs KS (1977). 'The rehabilitation of adults with acquired hearing loss.' *British Journal of Audiology*; 11: 103-10.

53. Smaldino SE and Smaldino JJ (1988). 'The influence of aural rehabilitation and cognitive style disclosure on the perception of hearing handicap.' *J Acad Rehab Audiol*; 21: 54-67.

Section 8

Support provided by other organisations and other rehabilitation models

8.3.3 Use of technologies such as videos or IT based programmes

Several studies showed that lipreading training on video is effective. For example, Dodd, Plant and Gregory⁵⁴ gave a lipreading training video to a group of students. Students watched the video in various locations including at home, in a class or as supplementary teaching. The location had no impact on the extent of improvement, but the research showed that students with the poorest lipreading skills made the greatest improvements. Kramer et al⁵⁵ also found a home video education programme to be effective. The video included communication strategies and lipreading skills and was aimed at the hearing aid wearer as well as their partner. Ninety percent of the participants reported implementing the strategies in their daily life. Improved interaction with partner was also observed, as well as increased satisfaction.

Sweetow and Henderson Sabes⁵⁶ investigated a computer program that people with a hearing loss can use individually at home. The software program was designed to provide a variety of interactive and adaptive tasks that are divided into three categories:

1. 'better comprehension of degraded speech', for example, someone speaking very quickly or with background noise
2. 'enhancement of cognitive skills', for example, through auditory memory exercises
3. 'improvement of communication strategies', for example, 'assertive listening skills' or information about 'realistic expectations'.

Their study showed that those who followed the self-teaching program used their hearing aids more than those who did not.

8.3.4 Counselling programmes

Many research programmes looked at how counselling can have a positive impact on influencing people with a hearing loss to wear their hearing aid. Counselling is defined in a broad sense as the provision of information as well as advice on making personal adjustments. For example, Ward and Gowers⁵⁷ used training in hearing tactics, which they define as "*the actions which hearing impaired people can take, or can encourage other people to take, in order to facilitate communication.*" They stress the importance of giving people with a hearing loss information on the importance of visual clues and of letting other people know of one's hearing problems.

Several studies have demonstrated that counselling has been efficient in increasing the use of hearing aids. For example, Brooks⁵⁸ 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. Brooks⁵⁹ compared hearing aid use by patients who received their hearing aids in the conventional NHS manner, and those who also received counselling. The counselling included motivation to use the aid, benefits and problems, and how to overcome the difficulties. Those who received the counselling made significantly better use of their hearing aids and were considerably more adept at handling their aids.

54. Dodd B, Plant G, Gregory M (1989). 'Teaching lipreading: the efficacy of lessons on video.' *British Journal of Audiology*; 23: 229-38.

55. Kramer S, Allessie G, Dondorp A, Zekveld A, Kapteyn T (2005). 'A home education program for older adults with hearing impairment and their significant others: a randomised trial evaluating short and long term effects.' *Int J Audiol*, 44, 255-64.

56. Sweetow R and Henderson Sabes J (2006). 'The need for and development of an adaptive listening and communication enhancement (LACE) program'. *J Am Acad Audiol*; 17: 538-58. 57. Ward PR and Gowers JI (1981a). 'Teaching hearing aid skills to elderly people: Hearing tactics'. *British Journal of Audiology*; 11: 103-10.

58. Brooks DN (1985). 'Factors relating to the under-use of postaural hearing aids'. *British Journal of Audiology*; 19: 211-17.

59. Brooks D (1979). 'Counselling and its effect on hearing aid use', *Scandinavian Audiology*; 8: 101-107.

Some of the studies provided counselling in the patients' homes. For example, Vuorialho (2006) undertook a study with first-time hearing aid wearers receiving counselling at home, six months after receiving their hearing aid. The counselling resulted in a significant increase in hearing aid use and in the benefit obtained by wearing the hearing aids. Another study found patients who received counselling at home had a significantly lower level of non-effective use (27% versus 37%) than patients who had not been visited (Kapteyn et al, 1997).

Brooks and Johnson⁶⁰ suggest that a home pre-fitting visit should be included in counselling programmes. This can bring numerous advantages, including:

- establishing a personal relationship before fitting the hearing aid will ensure the patient is relaxed when they attend their appointment at the hospital
- an opportunity to discuss realistic expectations of what the hearing aid can achieve
- an individual's communication difficulties are assessed in their normal home environment
- an assessment can be made regarding the need for environmental aids
- the individual can be assessed and given advice on reducing their isolation as a result of hearing loss
- able to assess family relationships and provide counselling if necessary
- assess the ability of the patient to attend hospital.

This is supported by Meister et al⁶¹ who found that people are more likely to wear hearing aids if they believe that the aids will improve their quality of life, do not feel they are stigmatising, and are realistic about their level of hearing loss. A pre-fitting appointment would therefore appear appropriate to ensure that outcomes are maximised for hearing aid wearers.

8.3.4 Conclusion

Overall, research has shown that the most appropriate approach to rehabilitation is through a holistic approach⁶². 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.

Recommendations

- Audiology should provide patients with written information about local support services available.
- Audiology should take the lead in developing a holistic approach to rehabilitation, working in a joined-up way with statutory agencies, the voluntary sector and other rehabilitation services, such as lipreading classes and support groups.

60. Brooks D and Johnson DI (1981). 'Pre-issue assessment and counselling as a component of hearing aid provision', *British Journal of Audiology*; 15: 13-19.

61. Meister H, Walger M, Brehmer D, von Wedel U and von Wedel H (2008). 'The relationship between pre-fitting expectations and willingness to use hearing aids', *International Journal of Audiology*; 47: 153-59.

62. As shown by Boothroyd A (2007). 'Adult Aural Rehabilitation: What is it and does it work?' *Trends in Amplification*; 11(3): 63-71.

Section 8

Support provided by other organisations and other rehabilitation models

Type of support	What is provided
Information	Enquiries service through a phone helpline, emails or face-to-face contact
Drop-in sessions/centres/surgeries/clinics	Depending on the project, maintenance/cleaning of hearing aids; demonstration/trial of equipment; information on hearing loss; signposting.
Resource centres	Assistive devices are on display and can be tested by service users. Depending on the project, the centre might also have drop-in clinics staffed by volunteers.
Mobile bus clinic	A mobile bus to reach people who live in isolated areas.
Residential care home visits	Maintenance of hearing aids; hearing checks; checks of correct use of hearing aids for resident hearing aid users.
Home visits	1:1 home visits to hearing aid wearers who are homebound
Self-help groups/support groups	Support groups provided by hearing aid wearers (or with a hearing loss) to give advice and support to other people with a hearing loss
Email/internet/SMS text training	Training in IT skills or SMS texting to offer people with hearing loss alternative ways of communicating
Lipreading classes/listening/communication strategies	Classes in lipreading – sometimes provided for a limited period
BSL classes	Classes in BSL
Residential/short courses	Courses can cover a range of topics such as coping with hearing loss; communication strategies; confidence building; relaxation techniques
1:1 counselling	To help people who are deaf or hard of hearing cope with the emotional impact of hearing loss

63. See also Appendix 2: Directory of supporting organisations.

64. See also Appendix 3: Examples of projects in England and other international models.

Example(s) of projects in Scotland ⁶³	Examples of projects elsewhere ⁶⁴
RNID Scotland's information officer RNID Information Helpline Hearing Link's helpdesk	
RNID Scotland's Hear to Help project FVSC drop-in sessions	Hearing Help in Cambridgeshire and Essex Bridging the Gap in Cumbria Hi Kent! In Kent
Forth Valley Sensory Centre Gullane Street (Glasgow) Centre for Sensory Impaired People	Hearing Advisory Service in Hertfordshire
Action for Sight Loss in association with RNID Scotland (Hear to Help volunteers were involved) run a mobile bus in the Scottish Borders to give support to people with sensory impairment.	Listen Here! mobile bus clinic in Norfolk and Suffolk
	Croydon Hearing Resource Centre (www.croydonhearing.org.uk)
Ayrshire Hearing Support's befriending visits	DeafLincs in Lincolnshire
Dumfries and Galloway Hard of Hearing Group (www.dumfrieshardofhearing.110mb.com/index.html) with drop-ins in Thornhill, Wigtown, Annan and Kirkcudbright	
Deaf Action's IT training in Edinburgh	Hear Here in Merseyside
Information on local lipreading classes is available from the Scottish Course to Train Tutors of Lipreading (SCTTL)	
Signature courses	
Hearing Link's one-week residential training/short self-management training programme. Deaf Action's Including You project	
Lothian Deaf Counselling Service Deaf Action's Lothian Mental Health Service Breathing Space's video counselling	

Section 9

Conclusions and recommendations



There are 758,000 people who are deaf or hard of hearing in Scotland. The Scottish population is ageing and, as the most common reason for hearing loss is age-related, the number of people who are deaf or hard of hearing in Scotland is likely to increase in future. This means that there will be an increased demand on audiology services with additional pressures on resources and time.

The Scottish Government's *Quality Standards for Adult Hearing Rehabilitation*⁶⁵ define adult hearing rehabilitation in a narrow sense as the fitting of aids and ongoing maintenance of hearing aids. The Standards state that audiology services should provide patients with information on additional support services and equipment/assistive devices.

A year after the publication of the Quality Standards, RNID Scotland's *Hear Me Out* aimed to ascertain service users' experiences and map out services currently available. Our research found that patients want much more than being fitted with a hearing aid: they want audiology staff to be deaf aware; they want to be trained in using and maintaining hearing aids; and they want information about additional support services. They would ideally like written information to which they can refer and peer-to-peer advice on coping with the practical and emotional aspects of hearing loss.

Based on our findings, we would like the definition of adult hearing rehabilitation to be broadened to include a joined-up and holistic approach to services. Unless this happens, people who have been fitted with hearing aids simply will not use them.

65. Scottish Government (2009). *Op. Cit.*

Key recommendations

Audiology departments should send initial appointment letters that include basic information about the fact that patients can come to the appointment with a friend/family member; available communication support services and how to book them; and what will happen during the appointment.

Audiology should use other means of communicating in the waiting area whose turn it is other than calling out patients' names – for example, lending patients vibrating mobile phones or pagers, or displaying their names on a screen.

Audiology staff, including frontline staff, audiologists and audiologists' assistants, should be trained in deaf awareness. The training should last at least half a day and be repeated regularly.

Audiology staff should give patients some explanation of the reason they lost their hearing.

Audiology departments should invite patients back for at least one follow-up appointment after the fitting of hearing aid(s) within a maximum of 12 weeks and a review appointment every three years.

Audiology departments should aim to implement the *Quality Standards for Adult Hearing Rehabilitation* in full. In particular:

- ensuring that departments are accessible and that there is an induction loop (either fixed or portable) available in waiting and consultation rooms
- each patient should have an Individual Management Plan
- patients should be trained in all aspects of using their hearing aids – this should include written information as well as spoken advice as people may not retain all the information
- patients' family members should be given information on how to communicate with their relative who is deaf or hard of hearing
- patients should be given clear information on where/how to get their hearing aid maintained and where to get additional support.

The Scottish Government should work with audiologists to explore how to improve information provision to patients. This could be through a generic information pack to which audiologists can then add local information. Local information could include information about local repair clinics, as well as existing peer support/information services.

Audiology should take the lead in developing a holistic approach to rehabilitation, working in a joined-up way with statutory agencies, the voluntary sector and other rehabilitation services such as lipreading classes and support groups. For example, this could be done through the setting up of 'one stop shops' where service users can access information about social services, demonstration of equipment and where support classes are run.

Appendix 1 – References

Abrams, H.B., Hnath-Chisolm, T., Guerreiro, S.M. and Rittermanm, S.I. (1992) 'The effects of intervention strategy on self perception of hearing handicap' *Ear Hear*, 13, 371-377

Benyon, G.J., Thornton, F.L. and Poole, C. (1997) 'A randomized, controlled trial of the efficacy of a communication course for first time hearing aid users', *British Journal of Audiology*, vol. 31, pp345-351

Bode, D.L. and Oyer, H.J. (1970) 'Auditory training and speech discrimination', *Journal of Speech and hearing research*, 839-855

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

Brickley, G.J., Cleaver, V.C.G and Bailey, S. (1996) 'An evaluation of a group follow up scheme for new hearing aid users', *British Journal of Audiology*, 30, 307-312

Brooks, D. (1979) 'Counselling and its effect on hearing aid use', *Scandinavian Audiology*, 8, 101-107

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. and Johnson, D.I. (1981) 'Pre-issue assessment and counselling as a component of hearing aid provision', *British Journal of Audiology*, 15, 13-19

Chisolm, T., Abrams, H.B. & McArdle, R. (2004) 'Short and Long-term outcomes of adult audiological rehabilitation', *Ear and Hearing*, vol. 25, No 5, pp.464-477

Dodd, B., Plant, G. and Gregory, M. (1989) 'Teaching lipreading: the efficacy of lessons on video', *British Journal of Audiology*, 23, 229-238

Echalier, M (2009) *Hidden crisis: why millions keep quiet about hearing loss*

Edmond, F (2010) *Are you listening? Access to health services for people who are deaf or hard of hearing in Scotland.*

Hawkins, D. (2005) Effectiveness of counselling based adult group aural rehabilitation programs: a systematic review of the evidence', *J Am Acad Audiol*, 16, 485-9

Kapteyn, T., Wijkkel, D. and Hackenitz, E. (1997) 'The effects of involvement of the general practitioner and guidance of the hearing impaired on hearing aid use', *British Journal of Audiology*, 31, 399-407

Kramer, S., Allesie, G., Dondorp, A., Zekveld, A., and Kapteyn, T. (2005) 'A home education program for older adults with hearing impairment and their significant others: a randomised trial evaluating short and long term effects', *Int J Audiol*, 44, 255-64

Kricos, P.B. and Holmes, A.E. (1996) 'Efficacy of audiologic rehabilitation for older adults', *J Am Acad Audiol*, 7, 219-229

Kricos, P.B., Holmes, A.E. and Doyle, D. (1992) 'Efficacy of a communication training programme for hearing impaired elderly adults', *J Acad Rehab Audiol*, 25, 69-80

Matthews, L (2010) *Seen but not heard: Why patients with hearing loss are not receiving the support they need*

Meister, H., Walger, M., Brehmer, D., 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

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

RNID (2009) *The Facts about Hearing Aids*

RNID (2009) *Getting Hearing Aids: How to Use Them and What to Expect*

RNID Scotland (2006) *Here to be Heard: The information needs of hearing aid users in Scotland*

Scottish Government (2007) *Better Health, Better Care: Action Plan.*

Scottish Government (2007) *All Our Futures: Planning for a Scotland with an Ageing Population* available from www.scotland.gov.uk/Resource/Doc/169342/0047172.pdf

Scottish Government (2009) *Quality Standards for Adult Rehabilitation Services* available at www.scotland.gov.uk/Publications/2009/04/27115807/10

Scottish Government (2009) *Quality standards for Paediatric Audiology Services* available at www.scotland.gov.uk/Resource/Doc/270506/0080556.pdf

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

Social Work Inspection Agency (2008) *Multi-agency inspection: Collaborative working across services for older people in Forth Valley*

Sweetow, R. and Henderson Sabes, J. (2006) 'The need for and development of an adaptive listening and communication enhancement (LACE) program', *J Am Acad Audiol*, 17, 538-558

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

Ward, P.R. (1980) 'Treatment of elderly adults with impaired hearing: resources, outcome and efficiency', *Journal of Epidemiology and Community Health*, vol. 34, pp65-68

Ward, P.R., and Gowers, J.I. (1981a) 'Teaching hearing aid skills to elderly people: Hearing tactics', *British Journal of Audiology*, 15, 257-259

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

Appendix 2 – Directory of supporting organisations⁶⁶

Association of Teachers of Lipreading to Adults (ATLA)

Web www.lipreading.org.uk
Email atla@lipreading.org.uk

British Deaf Association Scotland

Address
1st Floor, Central Chambers, Suite 58, 93
Hope Street, Glasgow G2 6LD

Tel 0141 248 5554
Fax 0141 248 5565
Email bda@bda.org.uk
Web www.bda.org.uk

Deaf Action

Address
49 Albany Street, Edinburgh EH1 3QY

Tel 0131 556 3128
Text 0131 557 0419
Fax 0131 557 8283
SMS 07775 620757
Email admin@deafaction.org
Web www.deafaction.org

Deafblind Scotland

Address
21 Alexandra Avenue, Lenzie, Glasgow G66
5BG

Tel 0141 777 6111
Fax 0141 775 3311
Email info@deafblindscotland.org.uk
Web www.deafblindscotland.org.uk

Deaf Connections

Address
100 Norfolk Street, Glasgow G5 9EJ

Tel 0141 420 1759
Fax 0141 429 6860
Email enquiries@deafconnections.co.uk
Web www.deafconnections.co.uk

Hearing Link Scotland

Address
The Eric Liddell Centre, 15 Morningside Road,
Edinburgh EH10 4DP

Tel/Text 0131 447 9420
Web www.hearinglink.org

Lothian Deaf Counselling Service

Address
LifeSkills Health, 110-112 Cadzow Street,
Hamilton
ML3 6HP

Voice 0800 804 7462
Text 0800 804 7463
Voice/SMS 07872 604 642
Email teresa.brasier@lifeskillscentres.com
Web www.lothiandcs.org.uk

National Deaf Children's Society Scotland (NDCS)

Address
Second Floor, Empire House, 131 West Nile
Street
Glasgow G1 2RX

Tel 0141 354 7850
Text 0141 332 6133
Fax 0141 331 2780
Email ndcs.scotland@ndcs.org.uk
Web www.ndcs.org.uk

66. This directory is as comprehensive as possible, but we cannot guarantee that it is exhaustive.

RNID Scotland

Address

Empire House, 131 West Nile Street
Glasgow G1 2RX

Tel 0141 341 5330
Text 0141 342 5347
Fax 0141 354 0176
Email rnidscotland@rnid.org.uk
Web www.rnid.org.uk

Scottish Council on Deafness

Address

Central Chambers Suite 62, (1st Floor)
93 Hope Street, Glasgow G2 6LD

Tel 0141 248 2474
Text 0141 248 2477 and 1854
Fax 0141 248 2479
Email admin@scod.org.uk
Web www.scod.org.uk

Scottish Association of Sign Language Interpreters (SASLI)

Address

Baltic Chambers, Suite 404-408, 50 Wellington Street, Glasgow G2 6HJ

Tel 0141 248 8159
Fax 0141 221 1693
Email mail@sasli.co.uk

Sense Scotland

Address

43 Middlesex Street, Kinning Park, Glasgow
G41 1EE

Tel 0141 429 0294
Fax 0141 429 0295
Text 0141 418 7170
Email info@sensescotland.org.uk
Web www.sensescotland.org.uk

Signature

Address

TouchBase Community Suite
43 Middlesex Street
Glasgow
G41 1EE

Tel 0141 418 7191
Fax 0141 418 7192
Email Glasgow@signature.org.uk
Web www.signature.org.uk

Case study – Tayside Association for the Deaf, an organisation providing local support

Address

36 Roseangle, Dundee DD1 4LY

Tel 01382 221124
Fax 01382 200025
Text 01382 227052
Email mail@taysidedeaf.org.uk
Web www.taysidedeaf.org.uk

West Scotland Deaf Children's Society (WSDCS)

Address

281A Central Chambers, 93 Hope Street,
Glasgow
G2 6LD

Tel (voice/text) 0141 243 2953
Fax 0141 243 2203
Email wsdcs@btconnect.com
Web www.wsdcs.org.uk

Appendix 3 – Examples of support projects in England

Hear To Help – RNID

Geographical coverage: currently available in England, Scotland (Scottish Borders, Glasgow), Northern Ireland and Wales.

Services are provided free of charge and are available through local drop-in centres and home visits. Staff and volunteers provide support with:

- tubing, minor repairs, ear mould cleaning and battery replacement
- training on maintenance of hearing aids
- advice and support on making the most of the hearing aid
- information and signposting to other services
- introduction to other useful equipment.

Further information:
www.rnid.org.uk/service

Hearing Help

Geographical coverage: Cambridgeshire and Essex.

The projects are set up as registered charities and receive funding from a variety of sources such as local authorities, the Primary Care Trust (PCT) and grant-making trusts.

Services offered include:

- free batteries and hearing aid care and maintenance for NHS hearing aid wearers
- advice on hearing loss and the best use of hearing aids
- demonstrations of, and advice about, environmental equipment and how these can help to improve quality of life.

Drop-in sessions and home visiting services encourage new hearing aid wearers to 'persevere' with their hearing aids. 'Hearing Help Sessions' also offer the same services in residential homes, day centres, community health clinics and day hospitals.

Further information:
Essex: <http://beehive.thisisessex.co.uk/default.asp?WCi=SiteHome&ID=4442&PageID=22072>
Cambridgeshire: http://www.camtadcamb.org.uk/About_Us.html

Hearing Advisory Service

Geographical coverage: Hertfordshire.

Access to a demonstration room in which a wide range of equipment is demonstrated by volunteers. Hearing Support Service visiting 28 locations every month provides hearing aid maintenance and batteries together with advice. Resource Centres provide advice on hearing problems and are staffed by qualified volunteers.

Further information:
<http://www.hhas.org.uk/>

Listen Here! mobile bus clinic

Geographical coverage: Norfolk, Suffolk.

Norfolk Deaf Association Listen Here! mobile facility visits venues around Norfolk, offering support, advice and information to people with hearing loss and their families. This includes maintenance of hearing aids, signposting to other support services such as lipreading classes and information about free assistive equipment.

Norfolk Deaf Association also runs a befriending project whereby volunteers visit isolated Deaf and hard of hearing people in their own homes to offer support and companionship.

Further information: <http://www.norfolkdeaf.org.uk/nhss.html>

DEAFLincs model

Geographical coverage:
Lincolnshire.

DEAFLincs is a registered charity based in Lincoln. They run drop-in sessions twice a week and no appointment is necessary. Advice/support is available by professional staff and trained volunteers on any aspect of hearing loss. Home visits are also possible for those who live a distance away or unable to travel easily.

Further information:
<http://www.deaflincs.com/index.html>

Croydon Hearing Resource Centre model

Geographical coverage:
Croydon.

Provides private and NHS hearing aid wearers with services such as free batteries, free re-tubing (by appointment only), free advice and assessment on hearing equipment at home, free home visits for those who are housebound and free local surgeries all around the borough. In particular, they offer a 'Residential Care Home Package' which includes a check of hearing aids, re-tube and supply of batteries as well as a check of the correct use of hearing aids by the user and hearing checks for residents.

Further information: <http://www.croydonhearing.org.uk/>

Bridging the Gap

Geographical coverage:
Cumbria.

'Bridging the Gap' is a project run by Caritas Care, a charity in north-west England. The project aims to assist people with hearing difficulties to reduce their isolation by improving their communication skills, thereby enhancing confidence, raising self-esteem and enabling them to be more active. Advice, demonstration of equipment, lipreading, self-help groups, and regular clinics are provided.

Bridging the Gap project workers, supported by volunteers, are based in Carlisle, Warwick on Eden, Barrow-in-Furness and Preston. The project facilitates a home visiting service that offers information support and assistance in the use and maintenance of hearing aids and other equipment. But to enhance access to this service they run monthly out-reach clinics – 21 in the more remote parts of Cumbria.

Further information: <http://www.catholiccaringservices.co.uk/latestnews.htm#bridging>

Hear Here

Geographical coverage: Nugent Care, Merseyside.

Provides email/internet training: offers one-to-one basic training for hard of hearing people in how to browse the Internet and set up email accounts, etc.

Further information:
http://www.nugentcare.org/index.php/adult_services/view/the_hear_here_project/

Hi Kent

Geographical coverage: Kent.

(<http://www.hikent.org.uk/>)

Free lipreading classes provided at 19 sites across Kent. Demonstration of assistive equipment can be requested by appointment with one of the trained staff members. Free hearing aftercare is also available in clinics, which can be found throughout Kent. Clinics are run by volunteers and they can change batteries, re-tube and clean hearing aids free of charge.

Appendix 4 – UK/International studies of rehabilitation programmes

Reference	Study outline	Findings
Abrams et al (1992) USA	31 hearing impaired adults divided into three groups. First group received hearing aid and participated in a counselling-based aural rehabilitation programme. Second group received hearing aid only. Third group received neither. The Hearing Handicap Inventory for the Elderly was administered to all before evaluation and two months after receiving hearing aid.	Study found that those given a hearing aid, and those given a hearing aid and counselling, both showed a reduction of self-perceived hearing handicap. There was weak but significant evidence that participating in the counselling-based programme in addition to hearing aid use resulted in a greater reduction of self-perceived hearing handicap than hearing aid use alone.
Benyon et al (1997)	47 patients fitted with hearing aids for the first time, under the age of 80. All received hearing aid and then one follow-up appointment. Control group received nothing further. Treatment group had a four-week communication group. Hearing loss was mild to moderate. Questionnaire administered before and after to determine hearing handicap. Course included anatomy of ear, benefits and disadvantages of hearing aid, hearing aid maintenance, lipreading, coping strategies, hearing tactics.	Patients in both groups had a statistically significant reduction in reported handicap over 13-week period. 'This reduction in handicap for the control group indicates that rehabilitation in the form of hearing aid fitting and a follow-up appointment does significantly reduce hearing handicap.' Change for the treatment group was significantly larger than for the control group. 'These findings would suggest that first time hearing aid wearers would benefit from inclusion on a communication course.'
Bode and Oyer (1970) USA	32 adults with hearing loss participated in short-term auditory training programmes (involved listening tasks with varying degrees of background noise). Measured speech discrimination and self-perceived hearing handicap.	'Auditory training can bring about increase in speech discrimination by impaired listeners.' Older people gained most from auditory training
Brabbins and Hogg (1977) UK	Interviewed 41 people one year to 18 months after receiving behind-the-ear (BTE) hearing aid. Discussed problems and difficulties with the aid, why people had chosen to stop using the aid.	One in three hearing aids were not used. Suggests that counselling and instruction would be most beneficial and that encouragement is needed in the first week of use. Investigators also recommend that teaching be done at home, where the older hearing aid wearer will be more relaxed.

Reference	Study outline	Findings
Brickley, Cleaver and Bailey (1996) UK	<p>Questionnaires sent to 98 patients of an audiology department to assess self-rated performance and satisfaction with the hearing aid. Half attended group follow-up sessions and half attended individual follow-up sessions for new hearing aid wearers.</p> <p>Group sessions were one hour per week for eight people. Individual was the routine appointment for 15 minutes, which included instructions for using the hearing aid.</p> <p>Poor attendance rate for group session.</p>	<p>Those in the group follow-up sessions rated their performance as significantly better than those in individual follow-up. However, no difference for hours of use or satisfaction. Group attendees were generally more positive about their hearing aid, required fewer additional follow-up appointments and reported more benefit in various listening situations.</p> <p>Overall group follow-up is a cost-effective method of following up typical new hearing aid wearers. However, a group follow-up session may be a less attractive option than individual follow-up for some new hearing aid users.</p>
Brooks (1979) UK	<p>60 patients in study. Control group given hearing aid in conventional manner. Experimental group included in counselling scheme – motivating them to use aid, benefits to be obtained, problems that might occur, how to overcome difficulties.</p> <p>Measured handicap using Weighted index of Social Hearing Handicap (WISH) scale. Also, used digital measuring system to measure usage of hearing aids.</p>	<p>‘The findings suggested that subjects issued with hearing aids in the conventional NHS manner used their hearing aids even less than indicated by previous studies and achieved a low competence in handling. Significantly better use was made of their aids by subjects given a moderate amount of counselling. These patients were also considerably more adept in handling their aids and achieved a greater reduction in social hearing handicap than the non counselled patients.’</p>

Appendix 4 – UK/International studies of rehabilitation programmes

Reference	Study outline	Findings
Brooks (1996) UK	<p>Use of hearing aids by monitoring battery consumption over one year. Further investigation made 10 years after initial use.</p> <p>About one-third of the subjects made little or no use of the NHS BTE hearing aid over first year.</p>	<p>About one-third of patients made little or no use of the behind the ear hearing aid over the first year.</p> <p>Brooks suggests that counselling and support can help people come to terms with hearing loss and accept that a hearing aid can bring benefit and is not as stigmatising as feared. Therefore use increases.</p> <p>‘Candidates under, say, 55-60yrs of age may, with encouragement and counselling, increase their use of personal amplification and sustain that level of use into older age. Individuals obtaining their 1st HA when over 70yrs of age (or thereabouts) are less likely to adapt to personal amplification, perceiving the benefits as less than the drawbacks. HA candidates in the mid age range (55-70yrs) appear to accept amplification more readily than younger candidates and to adapt to use more readily than older candidates.’ (p. 61)</p>
Brooks (1985) UK	<p>Reviewed all adult patients (603) issued with a hearing aid at the hospital in 1980. Sent a questionnaire to find out daily average number of hours hearing aid used, general satisfaction rate, the performance of the aid in various situations, and how long it took them to become familiar with the aid. Received 412 questionnaires. Then interviewed 104 in own home to get more detailed answers of why they don’t use hearing aid.</p>	<p>Trend towards higher use with increasing hearing loss. ‘Of those with losses 40dB or less on the aided ear, only 14% used the aid more than 8 hours per day. Of those with losses of 41 to 59dB, 21% used the aid more than 8 hours per day and of those with losses of 60dB or over 39% used the aid more than 8 hours per day.’</p> <p>‘Counselling can significantly alter the outcome for a number of individuals. 49% of all subjects who received counselling use their aids more than 4 hours per day. For the non-counselled group the corresponding percentage of 37.’</p>

Reference	Study outline	Findings
Brooks (1989) UK	<p>Patients completed a questionnaire in advance of getting a hearing aid. Designed to measure if they have come to terms with their hearing loss, perceptions of stigma associated with hearing aids, support from relatives and the extent of withdrawal from social contacts. The relationship between these attitudes and the use of the hearing aid four months after being fitted were investigated.</p> <p>Study based on 200 people, fitted with hearing aid for the first time in 1984. One hundred in experimental group received pre- and post-fitting counselling. Other half were in the control group and received no counselling.</p> <p>Pre-fitting counselling included raising awareness of hearing loss and encouraging acceptance of hearing aids. Discussion of difficulties and perceptions, stigma.</p>	<p>Attitude is a significant determinant of hearing aid use.</p> <p>'Counselling of the family and associates may, in some instances, be as important as counselling of the hearing impaired person, and for this reason the significant other should be encouraged to attend the fitting and therapy sessions.'</p> <p>Further review found four years after fitting, the patients who received counselling were in average using their hearing aids 50% more than those who received only basic instruction.</p>
Brooks (1981) UK	<p>Investigated use of hearing aids through battery use. Two groups of 36. Both groups received a hearing aid. One group received pre- and post-fitting counselling. Control group received only the hearing aid.</p>	<p>Those receiving counselling used their hearing aids significantly more than those not receiving counselling.</p> <p>Found with experimental group younger people tend to make greater use of the hearing aid. Therefore younger people can make better use of counselling. No link found between hearing loss and hearing aid use, nor with living circumstances (although researcher suggests this may be due to weakness of measuring tool).</p>

Appendix 4 – UK/International studies of rehabilitation programmes

Reference	Study outline	Findings
Brooks and Johnson (1981) UK	<p>Volunteers provided counselling services before and after hearing aid fitting. Many of the volunteers were hearing aid wearers themselves. Pre-fitting interview partly for assessment – determining communication problems of individual and family, and partly for counselling purposes, including attitude modification and development of realistic expectations. Post-fitting volunteers visited hearing aid wearers in their own home.</p> <p>Volunteer counsellors received 12-15 hours training over a five-week period. Include the pathological and psychological aspects of hearing loss, the functions and limitation of hearing aids, and techniques of counselling.</p>	<p>Pre-fitting visit is important –</p> <ul style="list-style-type: none"> • Establish a personal relationship before fitting. Makes patient more relaxed. • Communication difficulties are assessed in normal home environment. • Assess need for environmental aids. • Assess and advise on isolation as a result of hearing loss. • Assess family relationships and counsel if necessary. • Ability of patient to attend hospital. • Discuss realistic expectations.
Chisolm et al (2004) USA	<p>106 veterans, with binaural digital hearing aids. Communication Profile for the Hearing Impaired (CPHI) administered to all before fitting. Half received only hearing aid. Others received hearing aids and were assigned to a four-week, two-hour group audiological rehabilitation programme. Programme included hearing process, communication strategies, listening in adverse conditions, managing the environment, telephone strategies, assistive technology, community resources. CPHI administered after programme, and again at six months and one year after hearing aid fitting to assess long-term benefits.</p>	<p>‘(1) Hearing aid use, with or without adjunctive counselling-oriented AR, results in significant and stable improvements in the self perception of communication performance. (2) inclusion of a counselling-oriented AR program, as an adjunct to hearing aid fitting, results in differential short term treatment benefits in terms of self perceived communication strategy usage and, possibly, personal adjustment to hearing loss...(4) these results may have practical clinical implications in terms of improving domains of self perceived hearing aid benefit through counselling-oriented AR programs during the 30 day period of time when patients are making the decision to keep or return their hearing aids.’</p>

Reference	Study outline	Findings
DiSarno (1997) USA	Series of four two-hour information sessions over four weeks; 267 people in total, 15-20 people in each class, aged 60 and over, and significant others. Included audiometric testing, explanation of types of hearing loss, hearing aid evaluation procedure and information about rehabilitation.	More than 50% became patients for hearing aid fitting, speechreading, therapy, etc. Only 2% return rate for hearing aid. Researchers suggest the low return rate is due to the programme 'having given these patients a thorough understanding of the potential benefits and limitations of amplification before they were fitted with hearing aids.'
Dodd, Plant and Gregory (1989) Australia	Lipreading lessons on video. Three-hour video with nine lipreading lessons. 45 subjects were tested for lipreading ability at the beginning and end of experiment. 19 subjects in control group, none of whom attended lipreading classes, and some were hearing. Second group had six hard of hearing, who attended the same lipreading class and studied the video at home. Third group had eight hard of hearing who studied video at home and didn't go to usual lipreading class. Fourth group, 12 hard of hearing used video in class instead of normal lessons.	Significant improvement in lipreading skills of students who studied the video compared with control group. Improvement did not differ depending on whether they studied the video at home, in a class or as a supplementary teaching material. Degree of improvement greatest for those with poorest lipreading skills.
Ewertson (1974) Denmark	Denmark developed a post hearing aid fitting hearing training programme in the 1950s. Ewertson undertook research amongst 1006 patients. Three to six months after patients received hearing aids, local hearing therapist must inform hearing centre on how often patient uses their hearing aid; always, often, rarely or never.	'52% use their aids in all waking hours, 38% use them daily according to need, 4% use them on special occasions, and 6% never use their hearing aid.' Ewertson concludes that 'the comparatively good results must be ascribed to the pedagogical training and after-care.'

Appendix 4 – UK/International studies of rehabilitation programmes

Reference	Study outline	Findings
Kapteyn et al (1997) Netherlands	Project aimed to increase the use of hearing aids. A structured referral form for GP to follow, including patient history, examination with tuning fork and whispered voice, and demonstration of hearing aid. Form sent on to ENT; 87 participants, of which 50% were visited once, at home by a trained volunteer. Volunteer gave further explanation of the hearing aid and some training in handling the aid. Questionnaire completed by patient before hearing aid fitting and after visit.	Better GP information increased use of hearing aid but not significantly. Patients who received counselling at home had a significantly lower level of non-effective use (27% versus 37%) than patients who had not been visited. Therefore hearing aid use is more likely if patient receives counselling as well as better information from the GP.
Kemker and Holmes (2004)	45 people in study. Used Glasgow Hearing Aid Benefit Profile (GAHBP) to measure hearing handicap. Three groups – control group, post fitting counselling group and pre-fitting counselling group.	<p>Results demonstrate advantage of both pre- and post-fitting hearing aid orientation sessions. Study demonstrated that counselling is helpful in expediting hearing aid benefit and satisfaction through the education of our clients and that this benefit and satisfaction is age-dependent as measured by the Glasgow Hearing Aid Benefit Profile (GAHBP).</p> <p>Patients less than 66 years of age in post fitting group were significantly more satisfied with their hearing aid than those in the control group. Therefore maybe different methods are needed for those 66 and over.</p> <p>‘Patients with greater initial disability, as identified by the GHABP, receive significant satisfaction from prefitting and or post fitting counselling as compared to patients receiving no counselling.’</p>

Reference	Study outline	Findings
Kramer et al (2005)	Study into effectiveness of a home education programme: 24 elderly hearing impaired people and 24 significant others. Includes communication strategies and speech reading. Control group only received hearing aid; training group got a hearing aid and the home education programme. Programme included a video sent to participant. When tape returned, another one was sent. Took five to 12 weeks to complete programme.	<p>90% reported they had learned from the programme and were implementing the communication strategies in their daily lives.</p> <p>Increased awareness of benefits of speechreading and improved interaction with the significant others were observed in the training group only. Improved quality of life and satisfaction in the training group.</p>
Kricos and Holmes (1996)	Study of 78 older adults with hearing loss. One-third received no training, one-third received analytic auditory training (structured syllable drill to improve recognition of individual consonants and vowels) and one-third received active listening training (coping strategies, good listening habits, nonverbal and situational cues, modifications of home to aid listening, and learning to ask for people to repeat). Effectiveness determined through measuring speech recognition, hearing handicap perception and psychosocial function. The treatment groups were seen individually for one hour, two times a week for four weeks. The analytic auditory training was based on Walden et al (1981) consonant training.	<p>Active listening was proven to be effective for improving recognition of speech in noise and psychosocial functioning. No difference in self-perceived handicap.</p> <p>Efficacy of analytic auditory training not demonstrated. Subjects did not significantly improve their ability to understand speech in a background of noise, nor in hearing handicap or psychosocial status.</p>

Appendix 4 – UK/International studies of rehabilitation programmes

Reference	Study outline	Findings
Kricos et al (1992)	<p>Study into efficacy of a communication training programme, 26 people in total. One group received a four-week communication programme involving attitude, assertiveness, repair strategies, anticipation strategies, relaxation strategies, and practice listening in background noise. Control group received no training.</p> <p>Assessment before and after training using Hearing Handicap Inventory (HHIE) to assess self-perceived handicap. Also administered a speech recognition test.</p>	<p>Significant reduction in self-perception of hearing handicap, and slight but significant improvement of speech recognition ability for all subjects. No difference between control group and experimental groups. 'It cannot be concluded that participation in a communication training programme had any influence on these changes.'</p>
Meister et al (2008) Germany	<p>100 adult first-time hearing aid candidates recruited from private hearing aid clinics. Completed a questionnaire around expectations and willingness to wear a hearing aid.</p>	<p>Three variables strongly influenced willingness to wear a hearing aid – expectations they will lead to an improvement of quality of life, stigmatisation (the negative perception of people wearing hearing aids), and self-rated hearing ability.</p> <p>It is important to foster positive expectations in people with a hearing loss in order to encourage their use of hearing aids and other products.</p>

Reference	Study outline	Findings
<p>Oswal (1977)</p> <p>UK</p>	<p>Joint rehabilitation programme between ENT dept and Social Services Department, with a Welfare Officer of the Deaf carrying out home visits giving further instruction in handling of hearing aids and supplying leaflets. Patients referred if live alone, have other disabilities, slow orientation and dexterity, unable to obtain batteries, etc.</p> <p>A feedback form was completed by the officer after every home visit.</p> <p>‘Further instruction in the handling of an aid was most beneficial in a relaxed home environment, at times, in the presence of friends, relatives or neighbours who could then continue helping these patients in the correct use of an aid.’</p>	<p>A significant number of patients had general difficulty in handling the aid, resulting in rejection of the aid. They also struggled with the sound, and they could not, or did not take care of their aids adequately. Many patients were isolated and lonely.</p> <p>Need to take following factors into account:</p> <p>Learning task – people learn at different rates.</p> <p>Listening task – people expect it to restore hearing, therefore get frustrated when it doesn’t.</p> <p>Listening environment – needs to be considered as this is where the aid will be most used.</p>
<p>Rubinstein and Boothroyd (1987)</p>	<p>20 adults with hearing loss were given three different speech recognition tests. They were tested on four occasions, at the beginning of the study, after one month of no treatment, after a month of intensive auditory training, and after a further month of no treatment. Half spent time on sentence perception and perceptual strategy (discussion of factors affecting communication, listening practice, listening strategy) and the other half did the same as well as consonant recognition activities. Training for both groups was eight one-hour private sessions over four weeks.</p> <p>Delayed training so that the subjects were their own control.</p>	<p>Formal auditory training resulted in a small but statistically significant improvement in speech recognition performance. The training method was not significant.</p>

Appendix 4 – UK/International studies of rehabilitation programmes

Reference	Study outline	Findings
Smaldino & Smaldino (1988)	40 adults fitted with a hearing aid for the first time. Hearing Performance Inventory used to assess hearing handicap both before and after the experiment. Control group received hearing aid and simple orientation on use of aid. Experimental group received a four-week aural rehabilitation programme and or information about individual cognitive style (how people learn) in addition to the orientation. The aural rehabilitation programme included information about the auditory system and how it works, auditory training, including coping strategies and speech reading.	<p>Those on aural rehabilitation programme had a significantly greater reduction in self-perceived hearing handicap than did the other in the groups. Simple disclosure of cognitive style did not significantly reduce perception of handicap – maybe because patients don't know how to apply this to their learning.</p> <p>'The results of this study indicate that participation in a relatively short aural rehabilitation programme can be an effective tool in reducing first time hearing aid users' perception of hearing handicap. Because the usual brief hearing aid orientation did not produce significant changes in perception of hearing handicap, we can conclude that an orientation by itself may not be enough if we wish to maximise the benefit that adult hearing individuals derive from their new hearing aid.'</p>
Sweetow and Henderson Sabes (2006)	Investigated the efficacy of a computer software program designed to provide a variety of training exercises such as listening and comprehension tasks and interactive communication strategies. Training was conducted for 30 minutes, five days a week for four weeks; 65 subjects, half received LACE (Listening and Communication Enhancement) following baseline testing and half were a control group for one month and then received LACE.	The results showed a significant improvement for the trained subjects on all but one outcome measure. These outcomes included listening span, speed of processing as well as a significant decrease in handicap as measured by the HHIE.

Reference	Study outline	Findings
Tomita et al (2001) USA	Used a subset from a larger study on aging, compared 227 people with a hearing impairment and 495 without. Two to three hour interview with older in person's home.	<p>People with a hearing impairment experienced more illnesses, particularly arthritis, heart and circulatory problems, poorer eyesight, higher levels of depression and more pain.</p> <p>Implications:</p> <ul style="list-style-type: none"> - need controls that can be operated with impaired fine motor coordination and diminished eyesight. - need to bring them back into social contact with hearing aids, to avoid depression. - lower using of hearing aids amongst minority groups compared with white groups. <p>Higher use of hearing devices by people who live alone – maybe because they don't have someone to assist them with using the telephone, hearing the doorbell, watching TV, etc.</p>

Appendix 4 – UK/International studies of rehabilitation programmes

Reference	Study outline	Findings
Vuorialho 2006 Finland	<p>98 first-time hearing aid wearers were counselled at home by an audiology assistant six months after hearing aid fitting. Counselled and instructed on how to use hearing aids, assessed their skills in handling the aids and checked the condition of the aids. Use of and benefit from were measured by means of an interview and HHIE-S and EQ-5D questionnaires. Results before and after counselling were compared. Patients interviewed at home.</p> <p>No control group. Was it just time that led to improvements rather than counselling?</p> <p>‘A choice has to be made between costs and quality: are we seeking small expenses or good use and benefits of hearing aids. There are differences in these policies in different countries. More labour is used in Finland than in some other countries. For example, in Great Britain 320, in Denmark 280 and in Finland 60 patients were fitted per audiology person in one year (Barton et al, 2003).’</p>	<p>Twelve months after hearing aid fitting, the users reported that they felt themselves more able to use the hearing aid and felt less need for counselling compared with the situation at six months. The greatest improvement in handling skills was achieved in cleaning the earmould and in hearing aid use on the telephone. The hearing aid wearers were also significantly better able to place the hearing aid in their ear after follow-up counselling.</p> <p>This investigation indicates that follow-up counselling can help a significant number of occasional hearing aid wearers become regular wearers, and decrease the number of non-wearers.</p> <p>This study also shows that follow-up counselling can also significantly increase the users’ handling skills.</p> <p>‘This study indicates that follow up counselling of first time hearing aid recipients can significantly increase the benefit of hearing aids. It increased hearing aid use and according to the interviews and the HRQOI measurements, it brought a clearly positive improvement in the life of hearing aid users.’</p>

Reference	Study outline	Findings
Vuorialho et al (2006) Finland	Overview of study by Vuorialho (2006) above.	<p>'The results show that hearing aid use and the consequent benefit can be significantly increased through counselling. The expense caused by follow up counselling at home is highly acceptable in addition to the cost of fitting a hearing aid.'</p> <p>'Our investigation showed that follow-up counselling helped a significant number of occasional hearing aid users to become regular users, and the number of non users also decreased.'</p>
Walden et al (1981) USA	<p>Study into consonant recognition training on speech recognition performance of hearing impaired adults. All 35 subjects participated in a general aural rehabilitation programme of about 50 hours of group therapy. This included hearing aid orientation, assertiveness training, speech conservation and adjustment counselling. One group of 10 also received seven hours of individual auditory consonant recognition training and another group received individual visual (lipreading) consonant training, whilst the last group received the general programme only. All the groups significantly improved but those receiving the consonant recognition training improved significantly more than those on the general programme.</p> <p>Audiovisual sentence recognition test, and tests of auditory and visual consonant recognition were administered before and after training. The extra training was generally in lieu of the group speechreading and auditory training received in the standard two-week programme.</p>	<p>All three groups significantly increased in their audiovisual sentence recognition performance. But the subjects of the individual consonant recognition training improved significantly more than subjects receiving only the standard two-week programme.</p> <p>Auditory speech recognition performance can be improved through training.</p>

Appendix 4 – UK/International studies of rehabilitation programmes

Reference	Study outline	Findings
Ward (1980) UK	<p>Paper discusses the effectiveness of different amounts of follow-up service to elderly people.</p> <p>Compares findings from other surveys to compare average hours of use with average hours of follow-up service received.</p>	<p>‘The evidence of the research reviewed above is that non-use can be reduced to about 5% (from 15%) if follow up is increased from one hour to two or more, although this should only be provided for those who need it. A universal follow up service for elderly people which concentrates on teaching basic mechanical skills would appear to be the most effective. Additional input should be concentrated on those who are not using their aids, or who have difficulty, by providing further training in these skills.’</p> <p>Findings indicate that patients achieve the largest part of an improvement in the use of their aids with an average of between half an hour and two hours of follow-up.</p> <p>‘Health authorities should give priority to providing a basic follow up service for elderly users of hearing aids. It is essential that the service should concentrate on handling and care of the aids and that it should be backed up by effective teaching of these skills from the time when the hearing aid is first fitted.’</p>

Reference	Study outline	Findings
Ward and Gowers (1981a) UK	Basic hearing tactics training to hearing aid users aged 65+. All were given hearing aids three months previously. The control group received no instruction; the second group were given a self-instruction package in hearing tactics (mainly pictorial); the third group were instructed by one of the researchers with the same material. Tactics included admitting they have a hearing difficulty, watching people's faces, where to position themselves in meetings, and effects of the environment on sound. Patients completed hearing tactics survey both before and after experiment. Thirteen people in control group and nine people in each experimental group.	<p>The group with hearing tactics training made significantly larger improvements in knowledge than the control group around hearing tactics in the short term. No significant difference between the self-taught and instructed groups.</p> <p>Positive that people can use self-instructional material.</p> <p>One half of the initial sample already had basic knowledge of hearing tactics (and so these did not participate in the experiment). Useful to target intervention.</p>
Ward and Gowers (1981b) UK	Follow-on study to Ward and Gowers (1981a) looking at the long-term effects of the hearing tactics training. This was undertaken six months after the aid had been fitted.	Patients who had received the training were significantly more likely to improve their HMS (Hearing Measurement Scale) score than those in the control group. Reported hours of use is a little higher among the experimental groups, but not significantly.
Watts and Pegg (1977) UK	Two randomly selected groups of students. First group received speech reading instruction, second group received speech reading and auditory training. Instruction over six months; 20 hours of speech reading and six hours of personalised auditory training; 49 students in total over two years.	Speech reading not enough for effective communication in many. Most effective when both methods are combined, which produced significantly more effective communication ability.

Appendix 4 – UK/International studies of rehabilitation programmes

Reference	Study outline	Findings
Ward, Tudor and Gowers (1978)	<p>Evaluated a pilot project. People aged 60 to 80. All fitted with a hearing aid. First group a course of two sessions of two hours each, given at two and four weeks after issue of aid. Second group four sessions of two hours given at fortnightly intervals. Third group is the control group only receiving hearing aid.</p> <p>Each group had six patients. Two replications of each treatment, therefore 34 patients in total. Sessions designed for older people. Measured effect of treatment through hours of use (through speaking to patient and no of batteries used) and change in hearing handicap (using Hearing Measurement Scale). Effects measured six months after treatment.</p> <p>Course included care of hearing aid and the limitations of hearing aid. The longer session included discussion of different hearing environments, information about lipreading classes and other services. Talked to relatives as well about expectations.</p> <p>Had poor attendance with the longer programme. Sessions were also too long, difficult to maintain activity for two hours.</p>	<p>Patients in control group did better than those in the treatment groups in terms of improvement in hearing handicap (HMS).</p> <p>No significant difference in hours of use between control and experimental groups.</p> <p>Groups not balanced in terms of sex, and men improved more in terms of HMS score than women. 'Hearing handicap, in reflecting the difficulties people have as a result of their hearing loss, may also mirror their motivation to use hearing aids.' The more severe the handicap, the greater the potential for improvement and the more they will wear the hearing aid.</p> <p>'The amount of practice and assistance needed to develop the mechanical skills necessary to manage a hearing aid was greater than anticipated. Sessions have insufficient repetition of handling and maintenance procedures to ensure that these were fully understood and adopted by the patients.' (p. 132)</p> <p>Suggest allow time to adjust to hearing aid before demonstrate other aids (for example, loops), as will be better able to understand how they could help.</p>

References

- Abrams, H.B., Hnath-chisolm, T., Guerreiro, S.M. and Rittermanm, S.I. (1992) 'The effects of intervention strategy on self perception of hearing handicap' *Ear Hear*, 13, 371-377
- Benyon, G.J., Thornton, F.L. and Poole, C. (1997) 'A randomized, controlled trial of the efficacy of a communication course for first time hearing aid users', *British Journal of Audiology*, vol. 31, pp345-351
- Bode, D.L. and Oyer, H.J. (1970) 'Auditory training and speech discrimination', *Journal of Speech and hearing research*, 839-855
- 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
- Brickley, G.J., Cleaver, V.C.G and Bailey, S. (1996) 'An evaluation of a group follow up scheme for new hearing aid users', *British Journal of Audiology*, 30, 307-312
- Brooks, D. (1979) 'Counselling and its effect on hearing aid use', *Scandinavian Audiology*, 8, 101-107
- 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
- Brooks, D. and Hallam, R. (1998) 'Attitudes to hearing difficulty and hearing aids and the outcome of audiological rehabilitation', *British Journal of Audiology*, 32, 217-226
- Brooks, D. and Johnson, D.I. (1981) 'Pre-issue assessment and counselling as a component of hearing aid provision', *British Journal of Audiology*, 15, 13-19
- Carstairs, V. (1973) 'Utilisation of hearing aids issued by the NHS', *British Journal of Audiology*, 7, 72-76
- Chisolm, T., Abrams, H.B. & McArdle, R. (2004) 'Short and Long-term outcomes of adult audiological rehabilitation', *Ear and Hearing*, vol. 25, No 5, pp.464-477
- Cohen-Mansfield, J. and Taylor, J. (2004) 'Hearing aid use in nursing homes. Part 2: Barriers to effective utilisation of hearing aids', *J Am Med Dir Assoc*, 5, 289-9
- Department of Health and Social Security (1975) Report of a Sub-Committee to consider the rehabilitation of hearing impaired adults
- Disarno, N. (1997) 'Informing the older consumer-a model', *Hear Journal*, 50, 49-52
- Dodd, B., Plant, G. and Gregory, M. (1989) 'Teaching lipreading: the efficacy of lessons on video', *British Journal of Audiology*, 23, 229-238
- 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
- Hawkins, D. (2005) Effectiveness of counselling based adult group aural rehabilitation programs: a systematic review of the evidence', *J Am Acad Audiol*, 16, 485-9
- Hickson, L. and Worrall, L. (1997) 'Hearing impairment, disability and handicap in older people', *Critical reviews in physical and rehabilitation medicine*, vol.9, pp219-243
- Kapteyn, T.S. (1977) Satisfaction with fitted hearing aids II. An investigation into the influence of psycho-social factors', *Scandinavian Audiology*, 6, 171-177
- Kapteyn, T., Wijkkel, D. and Hackenitz, E. (1997) 'The effects of involvement of the general practitioner and guidance of the hearing impaired on hearing aid use', *British Journal of Audiology*, 31, 399-407
- Kemker, B. and Holmes, A. (2004) 'Analysis of prefitting versus postfitting hearing aid orientation using the Glasgow Hearing Aid Benefit profile (GHABP)', *J Am Acad Audiol*, 15, 311-23
- Kramer, S., Alessie, G., Dondorp, A., Zekveld, A., and Kapteyn, T. (2005) 'A home education program for older adults with hearing impairment and their significant others: a randomised trial evaluating short and long term effects', *Int J Audiol*, 44, 255-64
- Kricos, P.B. and Holmes, A.E. (1996) 'Efficacy of audiologic rehabilitation for older adults', *J Am Acad Audiol*, 7, 219-229
- Kricos, P.B., Holmes, A.E. and Doyle, D. (1992) 'Efficacy of a communication training programme for hearing impaired elderly adults', *J Acad Rehab Audiol*, 25, 69-80
- Meister, H., Walger, M., Brehmer, D., 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. (1992b) 'Sustained benefits of hearing aids', *J Speech Hearing Res*, 35, 1402-5
- Oswal, V.H. (1977) 'The National Health Service and socla services link up for rehabilitation of hearing aid users', *British Journal of Audiology*, 11, 25-30
- Parving, A. and Philip, B. (1991) 'Use and benefit of hearing aids in the tenth decade – and beyond', *Audiology*, 30, 61-69
- Rubinstein, A. and Boothroyd, A. (1987) 'Effect of two approaches to auditory training on speech recognition by hearing impaired adults', *Journal Speech Hear Res*, 30, 153-160
- Smaldino S.E. and Smaldino, J.J (1988) 'The influence of aural rehabilitation and cognitive style disclosure on the perception of hearing handicap', *J Acad Rehab Audiol*, 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', *Int journal Audiology*, 43, 390-8

References

- Sweetow, R. and Henderson Sabes, J. (2006) 'The need for and development of an adaptive listening and communication enhancement (LACE) program', *J Am Acad Audiol*, 17, 538-558
- Sweetow, R. and Palmer, C. (2005) 'Efficacy of individual auditory training in adults: a systematic review of the evidence', *J Am Acad Audiol*, 16, 494-504
- Taubman, L., Palmer, C., Durrant, J. and Pratt, S. (1999) 'Accuracy of hearing aid use time as reported by experienced hearing aid wearers', *Ear Hear*, 20, 299-305
- Tomita, M., Mann, W. and Welch, T. (2001) 'Use of assistive devices to address hearing impairment by older persons with disabilities', *Int J Rehabil Res*, 24, 279-9
- Upfold, L.J. and Smither, M.F. (1981) 'Hearing aid fitting protocol', *British Journal of Audiology*, 15, 181-188
- Upfold, L.J., May, A.E. and Battaglia, J.A. (1990) 'Hearing aid manipulation skills in an elderly population: a comparison of ITE, BTE and ITC aids', *British Journal of Audiology*, 24, 311-318
- Vuorialho, A. (2006) Costs and Effectiveness of hearing aid rehabilitation in the elderly
- Vuorialho, A., Karinen, P. and Sorri, M. (2006) 'Counselling of hearing aid users is highly cost effective', *Eur Arch Otorhinolaryngol*, vol. 293, pp988-995
- Walden, B.E., Erdman, S.A., Montgomery, A.A. Schwartz, D.M. and Prosek, R.A. (1981) 'Some effects of training on speech recognition by hearing impaired adults', *J Speech Hear Res*, 24, 207-216
- Ward, P.R. (1980) 'Treatment of elderly adults with impaired hearing: resources, outcome and efficiency', *Journal of Epidemiology and Community Health*, vol. 34, pp65-68
- 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
- Ward, P.R., and Gowers, J.I. (1981a) 'Teaching hearing aid skills to elderly people: Hearing tactics', *British Journal of Audiology*, 15, 257-259
- Ward, P.R., and Gowers, J.I. (1981b) 'Hearing Tactics: the long term effects of instruction', *British Journal of Audiology*, 15, 261-262
- Watts, W.J. and Pegg, K.S. (1977) 'The rehabilitation of adults with acquired hearing loss', *British Journal of Audiology*, 11, 103-110
- World Health Organisation (WHO) (1980) International Classification of impairments, disabilities and handicaps
- World Health Organisation (WHO) (2001) International Classification of functioning, disability and health

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

rnidscotland@rnid.org.uk

Empire House
131 West Nile Street
Glasgow G1 2RX

Telephone **0141 341 5330**

Textphone **0141 341 5347**

Fax **0141 354 0176**



INVESTORS
IN PEOPLE

