Access to Primary Care and Accident & Emergency Services for Deaf People in the North West

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Summary

This study sought to identify and quantify the barriers experienced by Deaf people in the North West when accessing primary care and Accident & Emergency services, and identify means by which access can be improved. The study also sought to assess the extent to which Health providers in the region are aware of and are working towards meeting the requirements of the Disability Discrimination Act, 1995.

The study focused on five Health Authorities, with the exception of a region-wide survey of A&E units. Semi-structured interviews were conducted with a stratified sample of 98 Deaf people, 31 GP practice managers, and managers at 22 A&E units. Other aspects of the data collection included visual inspection of A&E units and collection of policy information. The interview with Deaf people incorporated a number of key questions for which comparative results for the general population in the North West were available from another study.

The study found that Deaf people have substantially poorer access to primary care and A&E services and experience difficulties at all stages of the health care process. Substantial proportions had difficulty making appointments; in waiting rooms, knowing when they had been called; understanding receptionists and health professionals; making themselves understood; obtaining all the information they required; and after a consultation understanding what they were supposed to do next, or the purpose or correct application of medication prescribed for them. Failure on the behalf of health professionals to attempt to communicate adequately was perceived to be widespread.

Problems were significantly worse for the 50% of Deaf people who were without communication support. More than half the sample expressed a preference to be supported by a British Sign Language (BSL) interpreter at consultations, yet interpreters were present at just 17% of GP and 7% of A&E consultations. On all questions where we had results for a comparative sample of the general population, Deaf patients, particularly those who attended alone, expressed considerably reduced levels of satisfaction. The cumulative effect of disadvantage at every stage of provision is reflected in the finding that 40% of the Deaf people had complained, or felt like complaining, about some aspect of the service received from their GP in the last twelve months. The comparative figure for the general population in the North West is just 11%. A similarly high proportion felt like making a formal complaint as a result of their experience at A&E.

Very few of the providers surveyed had implemented facilitating technologies such as Deaf Awareness Training for staff, BSL interpreters, textphones, or visual call systems. Very few had evaluated their services with regard to the requirements of the Disability Discrimination Act, and policy with respect to access for disabled people was almost non-existent.

The difficulties that Deaf patients experience could be greatly reduced by implementing a basic package of measures, consisting of a combined voice & text phone, a visual patient call system, Deaf Awareness Training, use of BSL interpreters when required, written instructions about medication and after-care, and double-length appointment slots. The total cost of implementing this package at all GP practices within an average-sized PCT is estimated to be around £66,000 in the first year, and £39,000 per annum after that. The estimated cost for A&E units varies between £4,088 in the first year and £2,588 per annum subsequently, for a small unit, and £9,000/£7,200 for a very large unit.

The report makes a number of recommendations for the NHS Executive, GP practices and Accident & Emergency units.

Glossary of terms

A&E   Accident and Emergency department

BDA   British Deaf Association

BSL   British Sign Language

CACDP   Council for the Advancement of Communication with Deaf People

DDA   Disability Discrimination Act

HoH   Hard of Hearing

NSP   National Survey of NHS Patients General Practice

PCT   Primary Care Trust

RNID   Royal National Institute for Deaf People

Chapter 1

Background

1.1 Introduction

It has been estimated that around 8.5 million people in the UK are deaf or hard of hearing, the majority being in the hard-of-hearing category. The Deaf community is a culturally distinct group with their own language. The capital letter "D" is used to spell "Deaf" when it relates to this community and the lower case "d" for "deaf" signifies a profound degree of hearing impairment. It is estimated that there are between 50,000 and 80,000 people in the Deaf community in the UK whose first language is British Sign Language (BSL). Hearings aids are either of no help or are of limited usefulness.

The majority of the Deaf community have little or no speech. To communicate with hearing people, Deaf people often call upon the assistance of professional sign language interpreters, family members or friends who can sign. For unassisted communication, they rely on the written word or their own ability to lip-read. However, Deaf people frequently have poorer than average literacy skills, and lip-reading only provides limited information for communication. The implication of having poor communication abilities is that members of this community will have difficulty accessing Health Services.

Another group with communication problems which affect their access to Health Services is the group who are hard-of hearing. The term "hard-of-hearing" (HoH) covers hearing losses of lesser degree and this group constitutes the larger number They have better speech and higher levels of literacy than the Deaf community. This group can utilize hearing aids and generally do not know sign language. Hearing aids, however, do not completely compensate for a hearing loss, particularly in the presence of background noise, and many HoH people rely upon visual clues and lip-reading in addition to their hearing.

Whereas both Deaf and HoH groups have communication problems, these are more marked in the Deaf population. Most medical practitioners have little exposure to the Deaf community and their previous training has not prepared them for communicating with Deaf patients. Only a minority have been able to attend Deaf Awareness courses and have ensured that these courses are available to their clinic staff. As a result, many clinicians are unaware of the devices available to assist communication with Deaf people eg. a textphone, and where this equipment is installed in clinics not all staff will have been trained to use it.

The sign language interpreter/lip-speaker service is an important means of facilitating access by Deaf people to services run by hearing people. However, numbers of professional interpreters/lip-speakers are relatively few for meeting the needs of the Deaf population. Issues such as funding for interpreter services, and providing availability on a 24-hour basis have yet to be resolved and vary in different parts of the country.

The Disability Discrimination Act, 1995, makes it unlawful to provide a lesser service purely on the grounds of disability. From October 1999 it also placed a duty on service providers to facilitate access for disabled people by providing auxiliary aids or targeted services. The Act has several important implications for providers in the context of Deaf patients.

This project was devised in view of the potential problems faced by the Deaf population in the North West Region when accessing health care and the need to identify and quantify them. It was also the intention to identify the steps that have been taken in the region to facilitate access for Deaf patients in the light of the Disability Discrimination Act.

1.2 The Disability Discrimination Act (1995)

An important aspect of the background to this study is the Disability Discrimination Act (DDA), which came into force in December 1996. Part of the rationale for the present study was the Act and what the implications might be for Deaf people and for health providers.

The DDA is the most significant piece of legislation for disabled people in modern times. One important feature of the Act is that it represents a fundamental shift away from the 'medical model' of disability, under which disability is viewed as resulting from individual people's impairments or illnesses, towards a more 'social model' which views disability as consequent on a failure of society to adequately provide for the full range of abilities and capacities amongst it's members. This model puts the onus on social organisations of all kinds, including health services, to change and adapt so that people with all forms of disability can access and interact with them with the minimum of inconvenience. The changes and adaptions required of organisations may take many forms. These might include staff attitudes and behaviour towards disabled people; organisational policies and practices; building design; the layout of offices and public areas; and the way in which information is presented. However, one criticism that has been levelled at the DDA is that it does not take the social model far enough, particularly insofar as individuals have to prove they have a disabling impairment to have rights under the Act (Memel, 2000).

The DDA is being phased in over a period of time. Since December 1996 it has been against the law to refuse a service, provide a lesser service, or provide a service on terms different to those for other people, purely on the grounds of disability. However, the more concrete duties are laid out in Section 21 of the Act, which came into force in October 1999. These require service providers to make 'reasonable adjustments' to practices, policies or procedures which make it difficult or impossible for disabled people to use their services. They will also need to provide auxiliary aids or alternative services to facilitate use of the service by disabled people. By 2004, service providers will also need to make physical alterations to their premises if the present arrangements prevent or make it difficult for disabled people to use the service.

The emphasis in the Act is on adjustments that are 'reasonable'. The Code of Practice relating to Rights of Access under the Act (DWP, 2000) provides a list (in passage 5.28) of auxiliary aids or services one or more of which, it says, "it might be reasonable to provide to ensure that services are accessible [to people with hearing disabilities]":

- written information (such as a leaflet or guide);
- a facility for taking and exchanging written notes;
- a verbatim speech-to-text transcription service;
- non-permanent induction loop systems;
- subtitles;
- videos with sign language interpretation;
- information displayed on a computer screen;
- accessible Websites;
- textphones, telephone amplifiers and inductive couplers;
- teletext displays;
- audio-visual telephones;
- audio-visual fire alarms (not involving physical alterations to premises);
- qualified sign language interpreters or lipspeakers.

The Code of Practice also emphasises that the type of auxiliary aid or service appropriate to ensure that services are accessible to people with impaired hearing will vary according to the importance, length, complexity or frequency of the communication involved. It gives an example of a small GP practice making surgery consultation more accessible to patients with hearing impairments by using a pencil and notepad to communicate, and says that this is likely to be a reasonable step to take, even though use of a sign interpreter would be even more effective, on the grounds that "the size of the service provider, the resources available to it and the cost of the auxiliary service are relevant factors." (passage 5.22). However, the severity of the case should also be taken into consideration. The same small practice, for example, may need to consider providing an interpreter when counselling about a life-threatening illness or explaining a decision as to whether a surgical procedure is necessary, as "this is likely to be a reasonable step for the practice to have to take in these circumstances" (passage 5.23). Similarly, a hospital consultant should consider using a sign interpreter in "some circumstances", such as when explaining the implications of major surgery to a Deaf patient (passage 5.22). The Code also acknowledges that a sign language interpreter may not be easily available, even if arrangements are attempted in advance, and in this situation it would be reasonable to consider an alternative method of communication: "For example, many (but not all) deaf people are able to lipread" (passage 5.24).

It is quite clear from the above that the way in which the DDA works out in practice will very much depend upon what comes to be widely regarded as a 'reasonable step' to take in each particular circumstance. A consensus on this is likely to only develop over time, and legal 'test cases' may need to be part of the process. Under the Act, disabled people, and their advocates, have the right to bring a claim of unlawful discrimination against a service provider who has failed to provide a reasonable auxiliary aid or service.

With reference to the Health Service, the NHS Executive has stated it's aim to "ensure that across the NHS steps are taken to meet the provisions of Section 21 of the Disability Discrimination Act in a planned, coherent and cost-effective way" (NHS Executive, 1998a). To this end the Executive has been developing a strategy and action programme to support changes to be phased in between 2000 and 2004 (Ibid). To date, the programme has resulted in the publication of two major documents that have been distributed to the Chief Executives of all Trusts and Health Authorities, and to individual GP practices as requested: 'Working in partnership to implement Section 21 of the Disability Discrimination Act 1995 across the health service' (Freeney et al, 1999); and 'Doubly Disabled: equality for disabled people in the new NHS: access to services' (NHS Executive, 1999a). In addition, a series of regional workshops for representatives from Trusts and HAs were held in October and November 1999; a tool called the Access Audit Checklist - to assist managers in auditing their built environment - was distributed (NHS Executive, 1998b); and a distance learning disability awareness training programme for Health Service staff has been established (NHS Executive, 2000).

The document 'Doubly Disabled: equality for disabled people in the new NHS: access to services' (NHS Executive, 1999a) spells out a number of initial steps that the NHS Executive recommends be taken by health authorities, Hospital Trusts, Community Trusts and Primary Care Trusts. These include appointing a disability services advisor, full-time if possible; evaluating services; consulting disabled users; and developing a local strategy to address such issues as staff training, information needs, service requirements, and progress monitoring. It is important to note, however, that none of the guidance or recommendations produced by the NHS Executive has been presented as being in any way obligatory.

1.3 The Deaf population

Most estimates of the numbers of Deaf people in Great Britain draw on data from the Medical Research Council's National Study of Hearing (NSH). The NSH involved a series of population based epidemiological studies in which a random sample of over 4,000 adults, stratified by gender and age had their hearing clinically tested (Davis, 1995). The NSH estimated that, in Great Britain in 1992, the adult population of 43 million contained approximately 8.6 million adults with a 'significant hearing impairment in both ears' (ibid, p1). Most of these were mild or moderate losses. About 900,000 were estimated to have a severe loss (average loss of >=65 db HL in the better ear), with a further 170,000 being profoundly deaf (>=95 db HL). However, a factor not often considered when NSH figures are quoted are the statistical confidence intervals associated with them: for the profoundly deaf group these are particularly wide, with the upper 95% confidence level being 260,000 profoundly deaf individuals (derived from table B5124-1 in Davis, 1995, p46).

The above figures refer only to adults. The RNID estimate there to be a further 23,000 to 25,000 children (aged 0-15 years) who are permanently deaf or hard of hearing, of whom 8,000 have severe or profound deafness (RNID, 1997).

The focus of the present study is on deaf people who use sign language as a principal means of communication. The most common form of sign language in Great Britain is British Sign Language (BSL), although another form, Sign Supported English (SSE), is also widely used. Many Deaf people understand both forms. Deaf sign language

users are principally people with severe or profound loss, but only a proportion of people in this group know and use sign. For example, over 80% of severe/profound losses are age-related losses in people over 60 years of age (RNID, 1997): it is unlikely that many people learn sign language at this later stage of life. Even amongst those who are pre-lingually deaf (born deaf or became deaf before acquiring language), not all develop sign language skills, especially those born to hearing parents or who receive an oral education.

The NSH did not assess use of sign language, and such estimates as there are may not be all that reliable. The BDA have produced an estimate of 70,000 people in Britain 'whose first or preferred language is BSL' (BDA, 2002); the RNID provide an estimate of around 50,000 (RNID, 1997). The basis for either estimate is unknown. The Department of Health document "Doubly Disabled-Equality for disabled people in the new NHS: Access to service" (NHS Executive, 1999a) suggests a slightly larger figure of 80,000 using BSL as their first or preferred language, but again without providing any rationale for the estimate.

While these numbers may at first sight appear relatively small, they do in fact represent around one in every 500 to 900 of the adult population, and despite not being recognised as an official national language it has been claimed that more people (Deaf and hearing) use BSL than speak Welsh or Gaelic (BDA, 2002).

1.4 Deaf people and health services

This section presents a summary of current knowledge about the accessibility of health services to Deaf people. Communication is central to the difficulties that Deaf people experience. However, misconceptions about communication with Deaf people are common, and therefore some discussion of this issue is included. We also present some brief descriptions of the main technologies available to assist Deaf people in overcoming the barriers to communication.

Much of the literature concerning Deaf people in relation to health services is "anecdotal' in nature. Many published papers are based on the personal experiences of the paper's authors in working with Deaf people and the opinions stated are not necessarily based on the results of planned investigations. Much of the 'hard evidence' comes from US studies, not all of which have included control groups, or applied statistical inference testing. The main evidence relating specifically to accessibility to services in the UK, comes from four studies: Dye et al (2000; 2001) conducted a series of interviews – one of which was about use of health care - with a quota sample of 236 Deaf BSL users from all parts of the UK; Huntington et al (1995) conducted a questionnaire survey of health service use by 134 Deaf and HoH women in Cheshire; Lomas (1998) interviewed 57 Deaf female BSL users living in the Manchester area about their experiences of using services; and the RNID (1999) conducted a postal survey of their membership (including a small number of questions about health service use), to which over 1,600 responded, while at the same time an independent agency was commissioned to survey a nationally representative sample of over 400 GPs.

A limitation of all four studies lies in the nature of the samples of Deaf people, all of which were heavily dominated by processes of either self-selection or opportunity

sampling. For example, Dye et al went to great lengths to produce a sampling frame representative of the general population in terms of area, age, gender, and other factors, but the selection of the individuals interviewed, provided they fitted the sampling frame, was principally opportunistic. Nevertheless, the evidence from these studies concerning the access of Deaf people to health care is consistent, giving additional validity to the claims made. Furthermore, when anecdotal reports are taken into account, the evidence is also repetitive over time suggesting that little has changed for many years.

How Deaf people communicate with health professionals

Speech
A considerable proportion of the Deaf population have little or no intelligible speech and have difficulty communicating in words with a doctor or other Health Service provider. In a national study of ordinary schools in England just 49% of profoundly deaf pupils were rated by teachers of the deaf as 'communicating very easily or quite easily' by speech; this compares to 94% of pupils with moderate hearing loss (Powers, 1996). In the absence of receptive - and in many cases expressive - aural language, Deaf people make use of a number of other modes of communication. These include sign language, lip reading, and the written word.

Sign Language
Sign language is an essential means of communication for Deaf people. Dye et al (2000; 2001), in one of the best designed UK studies of Deaf people to date, took a quota sample of 236 Deaf people from across the UK. 75% expressed a preference for using sign language to communicate whereas the remaining 25% preferred to use a combination of signing and speaking (Dye et al, 2001). However, very few people outside of the Deaf community are proficient in sign language. For this reason, Deaf people often rely on the services of a professional sign interpreter (see below) to assist them in communication with hearing people.

British Sign Language bears little resemblance to written or spoken English, even in grammatical structure. It is more appropriate to think of BSL as a different language altogether. One author has compared Deaf patients to foreign nationals: "Immigrants are not expected to read lips in English or to read a note written in English, nor is it assumed that they are mentally retarded if incapable of composing grammatically correct written questions in English. Yes these are the expectations and assumptions made by many health care workers regarding Deaf patients" (McEwen and Anton-Culver, 1988).

Lip-reading
Lip reading was included as one of the main methods of communication by 78 (58%) of 134 Deaf and HoH women from Cheshire studied by Huntington et al (1995).

It is not widely appreciated that lip reading is in many ways quite limited as a means of communication. Many words in the English language are difficult to distinguish from one another by mouth movement alone, leading to confusion and misunderstandings. Opinions differ regarding the amount of speech understood through lip reading but on average it is thought to be only 30-40% of the words used (Davenport, 1977; Ludders, 1987; MacKinney et al, 1995). Even under optimal conditions – rare in practice - the average is only 65% to 70% (Sanders, 1971). The

remainder is determined by extrapolating from the context and by guesswork (Sadler et al., 2001). The ability to lip read is further reduced in conditions such as low lighting, poor mouthing of the words, and when the speaker has a full beard.

<u>Use of the written word</u>
Communication between Deaf and hearing people is often based on use of the written word, and it has been observed that this is a means frequently used by Deaf people to communicate with health professionals (Ebert and Heckerling, 1995). However, the literacy level of those who became deaf prelingually is typically quite limited (Davenport, 1977; Barnett, 1999) and many leave school with a limited knowledge of the English language (Dye et al., 2000). Studies of the reading age of Deaf people in the UK are lacking, but the typical prelingually Deaf American adult reads English at fourth or fifth grade level (nine to ten years of age; Davenport, 1977; Tamasker, 2000)

Consequences of restricted communication with health professionals

Communication between the health professional and the patient is central to successful diagnosis, treatment, compliance and aftercare. If the patient is unable to fully convey the history of their condition, their symptoms, and other factors such as drug allergies to the practitioner, the ability of the latter to make a full diagnosis and prescribe appropriate treatment may be seriously impaired. Conversely, if communication from the practitioner to the patient is restricted, the patient may not understand the diagnosis or how to comply with the treatment. In the survey of 134 Deaf and HoH women in Cheshire by Huntington et al (1995), just 7% said they fully understand what their doctor says to them when they consult on their own, while 55% usually understood only some or none. A nationwide survey of 359 HoH people attending lip reading courses reported that 36% felt that hospital doctors made little or no special effort to communicate with them, and 25% felt the same about nurses (Hines, 2000). From a postal survey of over 1,600 of their members, the RNID (1999) reported that almost a quarter (23%) had left a doctor's appointment still unsure of what was wrong with them.

The restricted vocabulary of most Deaf people means that the Deaf patient often lacks a knowledge of medical vocabulary to name parts of the body, explain bodily functions and to identify diseases (DiPietro et al., 1981; Mohay and Kleinig, 1991). In an investigation of 22 Deaf subjects by McEwan and Anton-Culver (1988), fewer than 50% could correctly identify the meaning of gallbladder, stools, sober, anxiety, erection or nausea. Other common words reported to be unfamiliar to people whose first language is sign language include bowel, penicillin, smear, and fertility drug (Huntington et al, 1995). This restricted lexicon not only affects the ability to present a clear history but also the ability to understand any explanations given by the doctor. This is particularly a problem when medical jargon is used by the doctor or nurse (Huntington et al., 1995). The problems are exacerbated when the health professional does not appreciate the limitations of lip reading or the restricted literacy of many Deaf patients (Zazove and Doukas,1994).

Misunderstandings and communication failures can also arise as a result of the Deaf patient not wishing to admit that they do not understand (Zazove, 1997). Characteristically the Deaf person may nod in assent when asked if they understand an explanation even when they do not, as to do otherwise would be a source of embarrassment (DiPietro et al., 1981; Mohay and Kleinig, 1991). The doctor therefore

thinks that the patient has understood more than is actually the case. Unable to understand, Deaf patients may abandon further attempts to explain their problem (Sadler et al., 2001). They are also less likely to ask for additional information than are hearing patients (ibid).

Communication difficulties can be as frustrating for the health professional as they are for the Deaf patient. They may feel irritated by the Deaf person's inability provide a clear history, to follow instructions or to comprehend explanations. A questionnaire survey of 165 physicians about their Deaf and hearing patients showed that doctors felt significantly less comfortable with Deaf patients, and were more likely to say that such patients get frustrated easily (Ralston et al, 1996). The doctors believed that significantly fewer Deaf patients understood their diagnosis and the treatment recommended. They also believed that significantly fewer of their Deaf patients trusted them.

The consequences of inadequate communication go beyond the medical consultation itself. Deaf people may delay medical appointments or avoid going to see their doctor because of concerns over communication (Herring and Hock, 2000). From the postal survey of their members, the RNID reported that one in six said they avoided going to the doctor when ill because of communication problems (RNID, 1999). Avoidance and delays can lead to anxiety when a minor illness is believed to be a serious one (Herring and Hock, 2000).

Prescriptions can also present problems for Deaf patients (Lass et al., 1978). They may depend on being able to read a prescription in order to know what the doctor thought was wrong with them. Those with particularly poor literacy levels have been known to read prescriptions wrongly, taking the wrong dosage of the prescribed drug and jeopardising their health. Ludders (1987) reported that Deaf patients could only comprehend 59% of medical prescriptions. Zazove et al (1993) found that Deaf and HoH patients were more likely than hearing patients to worry that physicians might prescribe the wrong treatment because of communication problems.

Use of health services

In view of the difficulties of direct communication, it might be anticipated that Deaf people use health services less frequently than the rest of the population. In fact, however, the research evidence suggests the opposite. Ries (1982) found that Deaf people make more visits to their doctor than hearing people and spend more days spent in hospital. Dye et al (2001), from their study of 236 Deaf people from across the UK, reported that members of the sample were twice as likely to have visited their GP within the last 14 days as the hearing group described in the General Household Survey (Dye et al. 2001). The authors suggest that this may be in part due to the inability of Deaf people to access information and advice about illness by the means available to hearing people. Deaf people are likely, as a result, to be more anxious and consequently more likely to seek professional help.

The finding that Deaf individuals tend to utilise health services more frequently than the hearing population would appear to contradict reports that Deaf people avoid using doctors. This is an issue that is yet to be satisfactorily resolved.

Access to Health Information

As a result of limited literacy in written English and other communication barriers, Deaf people often have reduced knowledge of health matters compared to the hearing population. They tend to know little about basic first aid (Moray and Kleinig, 1990). There is a lack of knowledge about sexual activity and reproduction increasing the risks of an unwanted pregnancy, sexually transmitted diseases and sexual abuse (Miner 1984; Chacko et al, 1987; Van Biema, 1994). Deaf people have also been found to be less likely than hearing people to believe that smoking less, exercising regularly, weight control and regular physical examinations improve health (Tamaskar et al, 2000).

Much information is written but this is frequently inaccessible to those Deaf individuals who are limited in their ability to read English (Sadler et al., 2001). Pamphlets and even notices often use terminology which requires a level of literacy which many Deaf people have not obtained. Indirect access to health information is often obtained by hearing people through newspapers, magazines and television but again the ability of many Deaf people to access and assimilate this information is limited (Barnett, 1999;Tamaskar et al, 2000). An interview survey of 56 Deaf women in Manchester reported that the women found very little health information available in a format accessible to them, and instead relied on family, friends and even social workers (Lomas, 1998).

Communication support

For many Deaf people communication is facilitated by having a hearing person present to act as a conduit between them and the health professional. This person may be a family member or friend who can communicate with relative ease with the Deaf person, or a professionally qualified interpreter.

Family member/ Friend
Deaf people typically have established modes of communication with members of their own family. For example, lip-reading the person may be easy for them through long familiarity, or a family member may have learned sign language (either formally or informally) in order to communicate. In Dye et al's (2001) national survey 18% of those who had visited their GP in the previous two weeks had used a family member or friend as communication support, while in Huntington's survey in Cheshire (1995), 30% of the women interviewed stated that they usually visited their doctor with a family member of friend. The RNID from it's national postal survey of members reported a similar figure, 32%, had used family or friends to interpret for them at a GP or hospital appointment (RNID, 1999).

There can be drawbacks to relying on family or friends when it comes to medical consultations. For one thing the level of signing acquired may not be up to translation of medical terms. There are also issues of confidentiality, particularly where intimate subjects or serious conditions are involved. Again, relatives of Deaf patients may not be reliable as interpreters; they frequently fail to interpret word for word and even filter the information they pass on (Davenport, 1977). These problems are exacerbated even further when children are used as interpreters, as is sometimes the case (Kumar, 1997), and the experience can be emotionally traumatic for the child as well as demeaning for the Deaf adult concerned (Ludders, 1987).

<u>Professional Interpreter</u>
There are two types of interpreter for the Deaf in the UK. The first are professional sign language interpreters. The second are professional lip-speakers, who convey spoken communications through careful mouth movement. Lip-speakers are quite uncommon and hence the term 'interpreter' is normally taken to mean a sign language interpreter.

Studies relating to the effectiveness or otherwise of using interpreters for medical consultations are very scarce. However, one American study did compare a random sample of 90 Deaf people enrolled in a special programme to provide professional interpreter support for primary care consultations, with 85 other Deaf people not on the programme. Those in the programme were far more likely to be moderately or very satisfied with physician communication (92% vs 42%), and to have higher compliance with many preventative health measures, including Pap tests, mammography, rectal examinations, and counselling for substance abuse issues (MacKinney et al., 1995).

Research in the UK indicates that only a minority of GP consultations with Deaf people involve professional interpreters. In Dye et al's national study (2001) 19% of the Deaf people who had consulted in the previous two weeks had an interpreter present. Men were twice as likely as women to use an interpreter. Huntington et al. (1995) reported that 9% of their sample of women from Cheshire usually used an interpreter for GP and hospital visits.

One reason for the low level of interpreter use is that they can be hard to obtain at short notice. In July 2000 there were only 98 qualified interpreters and 197 trainee interpreters registered with the Council for the Advancement of Communication with Deaf People (the national awarding body; BDA, 2002). With only a small number of interpreters in the UK, demands on their time are very high. Lomas (1998) reported that many of the 56 Deaf women interviewed in Greater Manchester complained of a lack of interpreters and difficulty in booking them. One-third of the women in Huntington et al's Cheshire study (1995) said they would use an interpreter if one was available. Other barriers to interpreter use are that Deaf people often find them too expensive and that some are simply not aware of their existence (Kumar, 1997). In addition, not all Deaf people wish to use interpreters. Some feel able to communicate adequately by themselves; others do not trust sign language interpreters to maintain confidentiality (Naish and Clark, 1998); and some do not like the fact that doctors tend to speak directly to the interpreter rather than to themselves (Kumar, 1997).

Although a fair number of Deaf people make use of family, friends, or interpreters, the majority of medical consultations are conducted without any communication support. 59% of the people in Dye et al's study (2001) who consulted in the last two weeks did so alone, and a similar percentage, 57%, of the women surveyed by Huntington et al (1995) usually consulted on their own. However, what we do not know from these studies is the proportion for whom consulting alone was a preference, and the proportion who found it forced upon them by a lack of availability of family, friends or interpreters.

Deaf Awareness

'Deaf Awareness' refers to an understanding of the barriers to communication that Deaf and HoH people face, and using means to overcome these. One of the major complaints that Deaf people make about health service staff is a general lack of Deaf awareness (eg Huntington, 1995; Lomas, 1998). Simple but common errors include not facing the Deaf person when speaking; not mouthing words properly; standing with a bright light coming from behind; shouting; and failing to use plain and appropriate English. It is fair to say that a considerable percentage of the problems that Deaf people experience could be avoided if all health service staff were aware of such basic mistakes and avoided them.

A number of organisations offer courses in Deaf Awareness Training (DAT) for health professionals. As well as teaching the basics of direct communication with a Deaf person, such courses frequently include an introduction to Deaf culture and sign language, finger-spelling, lip reading, how to work with interpreters, communication equipment, the Disability Discrimination Act, and the psychosocial consequences of communication difficulties. Deaf Awareness is also taught as a component of courses in Disability Awareness Training. These are more general courses, designed to encompass all the major disability groups. Consequently the coverage they provide of issues related to deafness is considerably less than that provided by a dedicated Deaf Awareness course.

Other obstacles and aids to Communication

Deaf people often have difficulty making appointments to see their general practitioner. They often have to attend the surgery as they cannot ring to make an appointment. Otherwise, they are dependant upon a relative or friend to telephone for them (Rose, 1999).

A text telephone provides a means for Deaf people to contact their GP practice directly. While many Deaf people possess a textphone, few surgeries do. A survey of a large sample of GP practices, both geographically and demographically representative, revealed that just 4% had a textphone (RNID, 1999). Even where a surgery has a textphone, other research suggests a high chance that is not in operation (Lomas, 1998). Another method by which Deaf people can make direct contact is via the TextDirect (previously Typetalk) service operated by British Telecommunications. This is a relay service which enables textphone users and voice phone users to communicate with each other. In Dye et al's (2001) investigation 86% of the Deaf people surveyed had used this method of communication.

Another common problem area for Deaf people relates to the waiting room. Where patients are called by verbal announcement many Deaf people have difficulty knowing whether they have been called or not, which makes waiting a source of considerable anxiety. It is not uncommon for Deaf patients to miss their turn for this reason, and requests to reception staff to be informed personally are often not met (Lomas, 1998). 76% of the Women in the Cheshire study said they always or sometimes had a problem (Huntington et al, 1995). Many Deaf people would like GPs and hospitals to install visual patient call systems, such as an electronic name display or a number system (Huntington, 1995; Lomas, 1998).

Several aspects of the built environment have been identified that can hinder or enhance communication. Inadequate signposting can be a problem as Deaf people cannot easily ask others for directions; low lighting levels make lip reading more difficult; glass security screens at reception also hinder lip reading, as does light coming from behind the speaking person; and fire alarms that are solely audible provide no warning to Deaf people (eg Huntington et al., 1995; Lomas, 1998; RNID, 1992; Northern Health and Social Services Board, 1997; NHS Executive, 1999a).

Ethnic minorities

Deaf people from immigrant populations may have particular needs with regard to accessing Health Services that require special consideration. The available evidence suggests that Deaf people from minority ethnic groups are particularly disadvantaged in access to health services. Research by the RNID concluded that they often face a double isolation, caused by the communication barriers that all Deaf people experience, plus extra barriers due to differences of language, culture, religion, and conscious or unconscious racism (Sharma and Love, 1991; Badat and Whall-Roberts, 1994). Deaf clubs are often regarded as not welcoming (Ahmad et al., 1998). Sign languages – like aural languages – differ around the world, and so in some cases finding an appropriate interpreter can prove extremely difficult. Even where the Deaf person understands BSL, professional interpreters are often not aware of important cultural practices (Ahmad et al, 1998). The problems are greater for older Deaf people from ethnic minorities, particularly first generation immigrants who haven't acquired English and cannot read and understand health promotion literature, and know little of the range of services and benefits available to help them (Kumar, 1997).

Chapter 2

Methods

2.1 Introduction

The purpose of the study was to evaluate access for Deaf people to primary care and Accident & Emergency services in the North West Region. Primary care is an extremely important component of health care, both in itself and also because of the role of GPs as gatekeepers of access to other services. Use of A&E departments is recognised as a particularly problematic area for Deaf people because both access and communication has to be immediate. There were a number of strands to the research, designed to provide as full a picture as possible of access to primary care (specifically, GPs) and A&E in terms of the experiences of Deaf service users, their service needs, the provision currently made, policy and costs. The methodologies adopted for each aspect of the study are outlined later in this chapter.

Geographical basis of the study

The research was planned to focus on 5 of the 16 Health Authorities in the North West Health Region. One aspect of the study was the creation of a database of 'minimum details' on Deaf individuals, from which a random interview sample would be selected (see below). The extent to which the sample would be truly random would depend largely upon the completeness of the database: if certain subgroups, such as the young, those from ethnic minorities, or the more affluent members of the Deaf community, were inadequately captured then a random sample drawn from the database would be similarly biased. For this reason the scope of the database was restricted to 5 HAs, this being the maximum we estimated could be reasonably covered in depth given the resources and time scale of the project. Maximum coverage of 5 HAs is preferable to including more HAs at a lower level of coverage of each.

The specific HAs to be included were selected at the start of the project. The criteria for selection was that the HAs - as a group - should be broadly representative of the North West region as a whole. To this end we categorised each HA in the region as urban, rural or mixed, and selected a group of five HAs that included (roughly) a representative proportion of each type, while at the same time covering areas to the North, South, East, West and centre of the region. The five HAs selected were: North West Lancashire; Manchester; St Helen's and Knowsley; South Cheshire; and West Pennine. To identify the resident populations within each of these HAs we contacted the headquarters of each HA, and in some cases the Local Authority, to obtain lists of postcode areas within their boundaries.

These five HAs formed the focus of the study's investigation into primary care. All the Deaf people interviewed lived within one of these areas, and all the GP practices where a manager was interviewed (see below) were based within these areas. For the purposes of looking into A&E services and some aspects of policy however, we included the whole of the North West region wherever it was feasible (in terms of time and resources) to do so.

Project days at Manchester Deaf Club

Early in the fourth month of the study two 'project days' were held at Manchester Deaf Club: one day for Deaf people, and a second day for people who work with the Deaf in a professional capacity. There was a two-fold purpose to these meetings. The first was to raise awareness about the project in the region, partly to let the Deaf community know what we were about, and partly to encourage co-operation and participation in the study. The second purpose of the meetings was to create a means by which the research team could learn from the experiences of the Deaf community, and use this to inform the design of the research instrumentation and methods of data collection.

Project Day for Deaf people
This project day was held on 3rd April 2000. Around 70 members were at the Deaf Club to hear a presentation about the project. 16 people then took part in a group discussion. The group addressed two key questions:

(1) What do GPs and hospitals need to do to ensure Deaf people have good access?

(2) What questions should we ask Deaf people (about their experience of GPs and A&E) when we interview them?

Project Day for Professionals
15 people who work with the Deaf in a professional capacity attended the project day for professionals on 6th April 2000. The majority of the group were social workers, but in addition there were communication support workers, a manager of the RNID TypeTalk scheme, sign interpreters, teachers of the deaf, and the manager of the Deaf Club. Most of the professionals were profoundly deaf. After a short presentation about the project the group discussed three key questions:

(1) What sources should we approach in order to identify as many as possible of the Deaf people in the 5 project districts?

(2) What are the best ways of approaching Deaf people to gain their consent to be interviewed?

(3) What questions should we ask Deaf people (about their experience of GPs and A&E) when we interview them?

Both meetings proved extremely valuable in terms of informing the research.

2.2 Methodologies

To achieve the aims of the study, six main strands of research were planned: (1) semi-structured interviews with 100 Deaf adults across five Health authorities in the North West; (2) interviews with practice managers at 40 GP practices across the region; (3) interviews with A&E department managers at all 29 A&E units in the region; (4) visual assessments of facilities for Deaf people at each A&E unit; (5) a review of policy in the region on access to primary care and A&E units for Deaf people; (6)

estimation of the costs of facilitating access. Each strand, and the extent to which the target samples were achieved, is outlined below.

Interviews with Deaf people

An important aim of this study was to achieve a representative sample of Deaf people for interview. This was not an easy objective to attain, for the simple reason that Deaf people are not easily identified as a sub-group of the population. Consequently, considerable preliminary work had to be undertaken prior to selection of the sample.

We were concerned to achieve as representative a sample as possible out of awareness that otherwise the research may be at risk of particular sampling biases. Previous research with the Deaf community in the UK has predominantly been based on opportunity samples of Deaf people; that is, individuals chosen on the basis of availability rather than through random selection. Such opportunity samples usually draw heavily on members of Deaf clubs, as these provide the easiest means of access to Deaf individuals. The membership of these clubs, however, tends to be very much dominated by older age-groups (40 plus) and people in non-professional occupations. The members of a Deaf Club (like any other club) may also possess a shared 'culture' of views and opinions unrepresentative of the full range amongst Deaf people generally. In addition, Deaf people who are less socially active or who do not view themselves as members of the 'Deaf community' may be less likely to participate in clubs.

An alternative option for developing a sample would be to make use of social service registers of Deaf people. However, these have a bias in that they only include individuals in receipt of services (though some people register purely to receive advantages such as a free bus pass), and as such are under-representative of more affluent Deaf people. In addition, not all Local Authorities keep a register, and those that do exist are believed to include only a minority of all Deaf people within the catchment area (RNID, 1997).

The achieve the goal of minimising the potential for bias in this study, a two-stage sampling methodology was adopted. The aim of the first stage was to build up a database containing basic biographic details (initials, age, gender, postcode) on as many individual members of the Deaf community living within the five project areas as possible. In the second stage a random sample, stratified by age and gender, would be drawn from the records held on the database.

Building a database of Deaf adults

The goal of building a data-base covering as many as possible of the Deaf adults living in each HA was achieved by two means: (a) seeking information from organisations; (b) seeking out and contacting individual Deaf people directly.

<u>Organisations</u>
An initial list of the organisations in each district likely to hold records about Deaf people was drawn up. The list included: (a) Deaf clubs and social/sporting clubs specific to Deaf people; (b) Social Services departments; (c) Universities and colleges; (d) Community and Hospital Trust Audiology departments and Cochlear Implant teams; (e) other specialist health services for Deaf people; (f) the Disability

Employment Agency; (g) Greater Manchester Public Transport Executive (GMPTE) and Merseyside Public Transport Executive (MPTE; we were informed that these organisations keep lists of Deaf people, who are entitled to free bus passes); (h) regional branches of RNID and BDA. An appropriate individual in each organisation was identified and contact made. Contact in most cases was via an initial letter with telephone follow-up.

Each organisation was requested to complete a standard form providing basic identifying information about each individual Deaf person known to them. The information requested consisted of: forename; initial of surname; gender; date of birth or age; and postcode or town. Each organisation received a copy of the MREC ethical approval form and the letter of approval from the Association of Social Service Directors, but where there was reluctance to pass across all the requested details we accepted whatever the body was willing to provide (most provided the full set).

A list of the organisations that responded to our request for data about Deaf individuals is given in appendix 1.

Contacting individual Deaf people
The second means by which the data-base of Deaf people was built up was by direct (or in some cases indirect) contact with individual Deaf people. A one-page form was produced containing a brief explanation about the study and a tear-off reply slip for those willing to take part. The Deaf researcher distributed these at Deaf clubs and Deaf events (such as the annual Deaf rally at Blackpool), wherever possible encouraging people to complete them on the spot. A number of other individuals were also recruited to distribute these for us, including members of the Deaf community, sign interpreters, social workers and teachers of the deaf.

Further attempts were made to contact Deaf people directly via a variety of published media. British Deaf News carried an article for us in their August 2000 issue; articles were also posted on the BBC Read Hear Teletext pages in May 2000, and on one of the major internet sites for Deaf people, <http:/www.deafsign.com>. The RNID magazine "1 in 7" declined to publish an article, on the grounds that they have many similar requests for publications and do not want to show favouritism.

The information from the organisation lists and individual reply slips was put into a common dataset. Duplicates (ie the same individual identified by more than one source) were identified and eliminated. This was done on the basis of matching initials, gender, age and postcode/town, allowing for a suitable margin of error.

The process of building the database proved to be very slow, but in the ninth month of the study all the major sources of information were in for three of the districts, therefore the selection of the interview sample proceeded for these districts. The samples for the fourth and fifth districts (Manchester, and St Helen's and Knowsley) were taken at a later date, once the remaining major sources became available to us.

At the point in time when the samples were selected, the database contained details of nearly 1,000 Deaf individuals living in the 5 districts. Information that came in later continued to be added to the file.

Selection of a random interview sample

Table 1.1 shows that the five HAs ranged in terms of population size from 265,000 to 547,000 (ONS estimates for mid-1999, taken from the Compendium of Clinical and Health Indicators; NHS Executive, 1999b). Although the sample could have been selected proportional to the population in each HA, we had good anecdotal evidence that Manchester, NW Lancashire, and Liverpool (close to St Helen's) possessed atypically large Deaf communities, and on this basis we decided to ignore total population size and instead aim for an equal number of interviews (20) in each HA.

The numbers of people identified within each HA were as in table 1.2. For the purposes of sampling we stratified the population by gender and age. With respect to age we adopted four age-groups: 18 to 34; 35 to 49; 50 to 64; and 65 or over. This division reasonably represents different life stages (young adult, early middle-age, late middle-age, retired). Within the database, the %'s of people falling into each age group were similar enough to justify sampling equals numbers from each.

In the early stages of the study many people, including other researchers in the field, had warned us that for a number of reasons obtaining participation from Deaf people was likely to be difficult in many cases, particularly (in view of literacy levels) where the initial contact was by letter. To allow for a substantial non-response rate we selected an initial sample of 200, with the aim of achieving the target of 100 interviews from these (ie anticipating a 50% non-response rate). This strategy carries a risk that self-selection processes will affect the make-up of the final, achieved, sample. However, time constraints meant that if we had started with a sample of 100 we would have found it problematic to select a top-up sample at a later date should the response rate be low.

The initial sample of 200 was selected using stratified random sampling, to obtain 40 people from each district; 5 males and 5 females from each of the 4 age-groups. Members of the sample who had originally been approached personally and completed a reply slip were contacted directly for the purpose of arranging an interview. Those only known to us through information provided by an organisation were contacted via that organisation. In each case the appropriate organisation was asked to send a letter on our behalf. This letter explained more about the project and invited the individual, if they were willing to participate, to complete and return a reply slip so we could contact them directly and arrange an interview.

The response to the letters sent out on our behalf by organisations was poor; just 15% of the Deaf people completed and returned the reply sheet. The response to this form of contact being so low, it was decided that a second mailshot would not be an effective way to increase the sample. The response from those who had originally been approached by the Deaf researcher in person was much better.

In nine cases a selected individual turned out (in some cases at the time of interview) to be unsuitable for the sample: two people had passed away; the others had either moved out the area, were not profoundly deaf, or had a significant additional disability such as blindness or severe learning difficulties. These were the cases we found out about: it is likely that a number of those who never responded were also unsuitable. Ultimately, interviews were completed with a total of 41 individuals from the initial random sample of 200.

Another 57 interviews – resulting in a total of 98 – were achieved using a combination of replacement sampling and opportunity sampling. Replacement sampling involved the substitution of non-responders by individuals from the database of the same area, gender and age-group. This procedure was used up until the very last phase of data collection. At that point, there was still a short-fall of interviews in certain areas and in the oldest age-group. However, a lack of suitable replacements, and time, led us to adopt opportunity sampling – irrespective of area, gender or age - for the final ten or so interviews. The distribution of the achieved sample by district, age and gender appears in tables 1.3 and 1.4, where it can be seen that the largest shortfalls were in North West Lancashire and St Helen's & Knowsley (16 interviews achieved against a target of 20) and amongst people over 65 years of age (16 interviews achieved against a target of 25).

Given that one of the aims of the project was to achieve a representative sample of Deaf people, it is pertinent to ask whether the replacement of such a large proportion of the target sample with alternative choices has biased the overall sample in any way. This question is addressed in detail in chapter 4, section 4.8.

The interviews

Two interview schedules were developed for use with Deaf people. The 'main interview' collected basic background information about the interviewee and asked a range of both open and closed questions about experiences of using GP services (appendix 2). The 'A&E interview' was concerned with the last time (if ever) the interviewee had attended an A&E department. This schedule collected basic factual information about the visit and asked a number of open questions about the experience (appendix 3).

The main interview incorporated a number of questions taken from the 'National Survey of NHS Patients General Practice: 1998' (the NSP), a large-scale national survey of users of general practice, conducted in 1998 (Department of Health, 1998). The NSP targeted a random sample of 100,000 people (1,000 from each of the 100 Health Authorities in England) and obtained completed postal questionnaires from just over 61,000 of these. The purpose of incorporating questions from the NSP into our own study was to provide a means of comparing the experiences of Deaf people with those of a large representative sample of hearing people. Accordingly, we selected a range of questions felt to be most appropriate for this purpose. Results from the NSP have been published for both England as a whole and for each Government Office Region in England, one of which is the North West (on a sample of 8,000 people). For maximum comparability with our own survey therefore, all the NSP results quoted in this report are those for the North West region; however, it is worth stating that for the questions we used, none of the NSP results for the North West differed from the national results by more than three percentage points.

The interviews were trialed during the middle part of 2001 on 12 Deaf people in the Manchester and Stoke-on-Trent (the home town of the Deaf researcher) areas. Revisions were made after each interview, in order that revised questions could be tested out in subsequent interviews. The process of trialling was halted when it was felt that further revisions would not be necessary.

The main interview usually took between ninety minutes and two hours to complete. If the interviewee had attended an Accident and Emergency department at some time (and were able to sufficiently recall the details of their last visit to A&E), then the second schedule, the 'A&E interview', was also completed, with their consent. This interview usually took between 45 minutes and one hour.

Both interviews were undertaken in sign language; in most case BSL, but on some occasions - where the interviewee did not understand BSL - Sign-Supported English. The interviewer recorded each respondent's answers in pen on the interview form. In the case of open questions it was often necessary to summarise the response rather than record it verbatim. Video-recording of each interview was considered (audio recording, of course, did not apply), but rejected after discussions with members of Manchester's Deaf community, where the consensus was that many Deaf people would not agree to be interviewed if video-recording was suggested. Because we had other reasons to believe that co-operation might be difficult to obtain (see below) we did not want to increase the risk of non-co-operation even further.

The interviews were conducted between November 2000 and December 2001. They were undertaken by the Deaf researcher (profoundly deaf himself), mostly in the interviewee's own home but elsewhere if that was their preference. Prior to interview each participant was given both a verbal and written explanation of the project and required to complete a consent form.

Telephone interviews with GP Practice Managers

Practice managers at a stratified random sample of GP practices were interviewed by telephone during 2001. The sample of practices was selected from the General Medical Statistics database (which has details of all practices in Engand) held at NPCRDC. All practices in the 5 project districts were identified from the GMS database on the basis of postcode, and these were subdivided into 4 equal groups according to practice list size. Two practices of each size were then chosen at random from each district, giving a total sample of 40 practices.

Telephone interviews were successfully completed with 31 practices. The other 9 declined to be interviewed. The interview schedule (appendix 4) addressed such areas as: the number of Deaf patients on the practice list; technology in the practice to facilitate Deaf access (eg minicom, visual name display); access to interpreters; which staff (if any) had undertaken Deaf or disability awareness training; official policy on access for disabled people; awareness of the Disability Discrimination Act; future plans.

Telephone interviews with Accident & Emergency Department Managers

Telephone interviews were conducted with managers at 22 of the 29 A&E departments in the NW region during the first half of 2001. We were unable to arrange interviews with managers at the remaining 7 departments, despite repeated attempts. The interview (appendix 5) covered that same broad areas are the interviews with GP practice managers (above). At the close of the interview permission was sought for the Deaf researcher to visit the unit (see below).

Visits to Accident and Emergency Departments by a Deaf researcher

A checklist was drawn up of facilities that would benefit Deaf people when attending Accident & Emergency departments (appendix 6). The content of the checklist was based upon several sources: (a) recommendations made in official documents and published papers (eg Freeney et al, 1999; Lomas, 1998, Huntington et al, 1995; Northern Health and Social Services Board, 1997; Kumar, 1997; NHS Executive, 1998b); (b) the views of Deaf people who participated in the project day held at Manchester Deaf Club; (c) advice from the Deaf members of the project advisory group and the Deaf researcher. Certain important facilities that could not be checked for visually could not be included on the checklist, including whether reception or medical staff had been provided with Deaf or disability awareness training, or whether the unit had arrangements for obtaining an interpreter for a Deaf patient at short notice. In addition, the visit was of necessity restricted to those areas of each unit that were generally open to public access: that is, principally the reception and waiting areas, toilets and corridors; not the consulting or operating rooms.

Each A&E department was approached for prior permission for the Deaf researcher to visit the unit and make a visual inspection of the public areas of the unit. All 29 A&E departments in the North West health region were approached, and written permission to visit was obtained from 22 of these. Although units knew that a visit would take place they were not informed of the date or time that this would happen. The unit visits took place between October 2000 and February 2002.

Collection of policy information

Information was sought from GPs, Primary Care Trusts, and A&E service providers regarding written policy concerned with access to services for people with disabilities. We asked about disability in general, rather than deafness alone, as we anticipated that policy relevant to the latter would form part of a more general disability policy document. The term 'policy' was used to refer to statements of official duties or good practice guidelines, such as an organisational duty to provide training in disability awareness to new staff , or a staff duty to offer Deaf patients interpreter support. Expressions of general service goals or principles – such as "to provide an equitable service to all", or "minimise the handicap of disadvantage and disability" – on their own, were not classed as evidence of policy in this sense. Where a provider indicated that they possessed policy, a copy of the relevant documentation was requested. Our interest was specifically in written policy. For example, some providers followed working practices to benefit of Deaf patients - such as putting an external marker on the records of Deaf patients –which were not set down as official policy.

GP Practices
Practice policy with respect to disabled patients was explored in each interview with a practice manager (see above).

Primary Care Trusts
Primary Care Trusts (PCTs) can potentially set policy for all the GP practices within their group. In view of this, all PCTs in the North West region were contacted and information sought regarding policy relevant to disabled patients within their area of jurisdiction.

<u>Accident & Emergency departments</u>
Policy with respect to A&E departments might be set by the associated Hospital Trust or by the department itself (for example, in the form of staff guidelines). Issues of policy were explored with the managers of A&E departments as part the telephone interview (see above), and also with central management at each Trust.

In addition to the above sources, we approached each local authority in the North West region for a copy of their most recent Community Care Plan (CCP). Community Care Plans (CCPs) are intended to provide a statement about provision, policy and future planned development with respect to health and social services for vulnerable groups within each local authority. CCPs were collected during the first few months of the study, and again 18 months later to look for evidence of change. However, the requirement on local authorities to maintain the CCP had expired in the intervening period, and very few CCPs had altered or were still available. In addition, the CCPs proved to be extremely variable in quality and content, and not at all reliable as a source of information on policy. Consequently their use for this purpose was abandoned. However, some CCPs did contain details of projects and initiatives aimed at evaluating or improving health service provision for local Deaf people, and we have utilised this information in the report. CCPs were collected for a total of 13 local authorities.

Costs

Estimation of the costs of facilitating access for Deaf people is focused on the costs of implementing various technological aids (including 'soft' technologies such as staff training). We have not attempted to estimate the opportunity costs of the staff time consumed using these technologies (eg receptionist time spent booking interpreters), although we do provide an indication of how much time is involved (in most cases, quite minimal). To obtain component costs we consulted a range of supplier catalogues and obtained a minimum of three costings for each technology.

Chapter 3

Results: The Deaf population in the North West

3.1 Population Estimates and Study Identification Rates

The Office for National Statistics (ONS) produced national and regional total population estimates for mid-1998 (CCHI, 1999). These give a population of 45.7 million adults for Great Britain, of which 5.5 million live in the North West Government Office Region. Using these figures in conjunction with results from the National Study of Hearing (see section 1.3) would suggest that approximately 1.1 million adults in the NW region have a significant hearing loss, of which 138,000 are severe or profound losses. And on the basis of the BDA estimate of 70,000 BSL users nationally (BDA, 2002), around 8,500 of these would be resident in the NW.

With respect to the 5 Health Authorities on which this study has focused, the overall adult population in 1998 is estimated to be 1.9 million (based on figures published in CCHI, 1999), of which approximately 378,000 would be expected to have a significant hearing impairment, 48,000 to have a severe or profound loss, and 2,900 to be BSL users. However, these figures - particularly the last –must be treated with caution; for one thing they assume an even distribution of Deaf people across all areas of the country, which might not be correct.

The present study identified a total of 1,109 individual Deaf people whose residential postcodes indicated that they were living within the 5 target HAs. However, during the final stages of the study we discovered that the postcode lists for each HA we had been working from, omitted a number of postcodes for some areas. The NHS Postcode Directory provides fields that link postcodes to HAs. Using this, we determined that our lists omitted a small proportion of current residential postcodes for South Cheshire and St Helen's & Knowsley, and 56% of West Pennine postcodes. While these discrepancies in no way affect the main analyses of the study (since sampling was not done on the basis of area populations), they need to be taken into account in the calculation of the rate of identification of Deaf people relative to population.

Recalculated adult populations for each HA, based on the postcodes covered by the study, appear in table 3.1. This indicates a total population, in the five target areas, of just over 1.5 million. Of these, using the same method of estimation as before, about 2,300 would be expected to be Deaf BSL users. The 1,109 Deaf people identified by the project represents 48% of this total. The rate of identification of Deaf people relative to the total population of the five areas was 0.74 per 1,000 (table 3.1). However, in Manchester, North West Lancashire and West Pennine, we identified approximately one Deaf person for every 1,000 adults; whereas in South Cheshire the rate was only about one in every 3,500. The pattern of results does concur with the widely held view that there exist concentrations of Deaf people in Manchester and North West Lancashire. However, we did experience particular difficulties in obtaining information about Deaf people in South Cheshire, which will have depressed the rate of identification in this area.

3.2 The Deaf Population and Primary Care

When considering Deaf people in relation to primary care provision, one issue that arises concerns the number of Deaf patients a 'typical' GP practice can be expected to have on the patient register. To investigate this, we used the Department of Health General Medical Statistics database for 1999 to identify all practices located within the study's five Health Authorities. This revealed a total 468 practices, with a total of 1,330 GPs (full or part-time) between them. On the assumption of an even distribution of Deaf and hard of hearing patients in relation to practice list size, we have produced estimates of the expected numbers of Deaf patients in various categories for each different size of practice. The figures appear in table 3.2.

An immediate observation from table 3.2 is that estimated numbers of Deaf BSL users are small, ranging from between 2 and 3 at single-handed practices up to no more than 14 even at the largest practices. The average across all practices is 6 BSL users. In a later chapter it will be seen that these estimates are borne out by results from the telephone survey of GP practices (chapter 5). Expected numbers of patients with a severe/profound loss are many times higher, and even single-handed practices are estimated to have a sizable number of these. Numbers of patients with any level of significant loss are an order of magnitude higher again.

3.3 The Deaf Population and Accident and Emergency Services

Information on numbers of attendances at A&E departments is published as part of the Hospital Activity Statistics by the Department of Health (Department of Health, 2001). The total number of attendances to A&E departments in the North West Region during 2000-01 was 2.2 million (this includes follow-up attendances, which accounted for just 9% of the total). Using the same estimation procedures as before, approximately 3,400 of these attendances would have involved Deaf BSL users - assuming the accident and emergency rate is the same for this group as the rest of the population.

Excluding four small, atypical, services (eg the Cardiothoracic Centre at Liverpool NHS Trust) the A&E units in the NW ranged in terms of volume between 28,000 and 125,000 attendances during 2000-01; with 24 out of 31 units falling between 40,000 and 100,000 attendances. With this in view, table 3.3 presents estimated numbers of attendances for different categories of Deaf and hard of hearing people in relation to different sizes of A&E volume. It needs to be noted, however, that the estimates for people with any significant loss, and those for people with severe/profound loss, may well be considerable under-estimates: the great majority of people in these groups are elderly, and it is known that hospital episodes for accidents are considerably higher for the elderly population (Charlton and Murphy, 1997, p.168)

Chapter 4

Results: Deaf people's experiences of GP services

4.1 Introduction

A total of 98 interviews were conducted with Deaf adults resident in the study's five target areas. Some of the items on the interview schedule had been taken from the questionnaire used in the National Study of Patients (NSP), specifically for the purpose of being able to compare the study sample with a representative sample of hearing people from the North West (see section 2.2). The interpretation of such comparisons will be influenced by the degree to which the two samples are similar in important respects - such as age-structure and social class make-up – and therefore this issue is examined first.

4.2 Characteristics of the sample and comparison with the National Study of Patients

The interview sample consisted of 48 males (49%) and 50 females (51%). These proportions compare well with the sample of around 8,000 people living in the North West that completed the National Study of Patients (NSP) questionnaire (50% male, 50% female; see table 4.1).

Table 4.2 presents a breakdown of the sample by age, using the same age-groups as the NSP. Compared to the NSP, the sample of Deaf people was slightly more bunched towards the 'middle' age-groups, with fewer people under 35 years (26% compared to 31%) or over 64 (16% compared to 20%).

A division of the sample by social classification appears in table 4.3. Individuals have been categorised by occupation (or most recent occupation) on the basis of the government's Standard Occupational Classification 2000 (SOC2000) system. Where the interviewee had a working spouse or partner the 'higher' of the two classifications has been adopted. Table 4.4 presents the social classification collapsed from 9 down to just three categories. This shows that just under half the sample (48%) were in manual occupations; 30% were in managerial or professional occupations; and 22% were clerical or service industry staff, or students.

The NSP used an older system of social class categorisation - now superseded by SOC2000. Table 4.5 presents a comparison between data from the present study and the NSP; however, because considerable differences exist between the two classification systems the results provide only a very approximate comparison. (Note also that, for comparability with the NSP, this table differs from previous ones in that respondents are categorised on the basis of their own current or most recent occupation (ie taking no account of partners/spouses)). Table 4.5 suggests that people in the Deaf sample were slightly more likely to be in manual occupations (56% compared to 45%).

42% of the sample (41 people) were in full- or part-time paid work (this refers to interviewees themselves, not spouses/partners). This compares to 57% of the NSP sample (table 4.6). 20% were either unemployed or not working due to disability/ill-health (compared to 9%). 24% were retired (compared to 21%).

12% of the sample identified themselves as from non-white ethnic groups (table 4.7), a considerably higher proportion than did so in the NSP (4%). Certain ethnic minority groups are known to be at greater risk of congenital or acquired hearing impairment. A national survey of deaf pupils in 185 ordinary schools found that 22.4% of moderate, severe or profoundly deaf pupils had a non-white background, compared to 9% of all pupils (Powers, 1996). The ratio (2.5) is close to the result for this study.

In addition to the socio-demographic measures discussed above, interviewees were asked to rate their general health (table 4.8). A little more than one-third (35%) rated their health as 'excellent' or 'very good'; one-third (34%) rated it 'good'; and just under one-third (29%) thought it 'fair' or 'poor'. Compared to the NSP, it appears that more rated their health as 'excellent' (22% compared to 12%), but fewer as 'very good' (13% compared to 34%), with relatively small differences in the other categories. However, the relative values given to 'excellent' and 'very good' when these terms are expressed in BSL (as was done for the interview) may not be the same as when expressed in speech, and a more reliable result may come from combining the two categories: this would indicate that a smaller proportion of the Deaf sample thought themselves to be in the best of health: 35% compared to 46%.

4.3 General Interview Questions

Registration with a GP

All the people in the sample were currently registered with a GP. Ninety-five people were with a GP because the practice was close to their home and/or because this was their family GP. No-one had chosen their GP on the basis that they were known to be good with Deaf people. One person's GP had a Level 2 qualification in British Sign Language, but had not been chosen for this reason.

Changes of GP

Eight people had changed their GP at one time due to their deafness. Four people referred to communication problems with the GP, and three said it was because of the GP's attitude towards them. One person changed because their previous GP refused to allow them use of a sign interpreter at consultations.

A much higher number, 23 (23%), said they would like to change their current GP (table 4.9). For 16 people (70%) the main reason related to communication issues, and for another three (13%) it a perception that the GP had negative attitude towards them.

Contacting the practice via textphone

77 people (79%) had a textphone at home. Just eight of these indicated that their GP's practice possessed a textphone. Of these eight, however, six (75%) found it either 'quite difficult' or 'very difficult' to contact the practice by textphone. Four of these

mentioned that the practice textphone was either not always switched on or that staff didn't seem to know how to use it. Thus only two people in the total sample had reasonably easy textphone-to-textphone contact with their GP practice.

A Deaf person with a textphone can also contact their GP practice using TypeTalk (recently superceded by TextDirect), via which they can communicate with a practice staff member using a standard telephone. Just over one-third of the sample (34 people, or 35%) had used TypeTalk to arrange a GP appointment. However, TypeTalk is not without it's drawbacks, and nearly half of those who had tried (16 people, or 47%) had experienced difficulties, mainly problems accessing the operator or with the receptionist at the practice not understanding the system.

Communication support at consultations

A large majority of people, 63%, indicated that it was 'very important' for them to have someone present at consultations to help them communicate with the GP, and another 5% thought this 'fairly important' (table 4.10). The majority of the remainder, 20%, indicated that the importance of communication support depended upon the nature of the visit. Only 11% did not desire any support, about half of these stating that they did not need any, and the other half saying they preferred not to use support. One said they did not need support because their GP could sign, and three preferred not to use support because they did not trust sign interpreters.

Table 4.11 shows that just over half of the total sample, 54%, indicated a preference for communication support provided by a professional sign interpreter (or lip-speaker), while another 30% preferred to use a family member. Out of those who wanted support and had a preference, nearly two-thirds (64%) preferred a professional interpreter compared to 36% who preferred family or (in one case) a friend.

The major reason expressed for preferring a professional interpreter (given by 61% of people, on a free response question) was the greater quality or completeness of communication (table 4.12). In one case the respondent complained that when she used her family they 'took control' of the conversation, cutting her out, something that interpreters did not do. 44% (23 people) said they preferred interpreters because of confidentiality; that is, this kept personal health matters private from family or friends. Nine percent (5 people) only preferred interpreters because a family member was not available or (in one case) because the GP would not let their child interpret.

People who preferred to use a family member for support did so mainly because they found communication easiest this way (35%, table 4.12). Another 22% (5 people) mentioned confidentiality as a reason: these individuals were concerned that an interpreter might pass on personal information to others. In one instance the respondent worked alongside the interpreters in the same social services agency. A substantial proportion of those who preferred to use a family member said that this was because interpreters were difficult to obtain (22%), or that they had never attempted to use an interpreter (9%). A further three people (13%) were supported by family members who were themselves qualified sign interpreters.

Experience of using professional sign interpreters

52% of the sample (51 people) indicated that they had arranged, or tried to arrange, an interpreter for a GP visit in the past. Examination by age group (table 4.13) revealed that 69% of 50 to 64 years old people had done so, compared to 38% of the youngest age group, 18 to 34 years old. However, the difference was not statistically significant (p=0.142).

Attempts to arrange an interpreter also did not vary significantly by socio-economic group (table 4.14), with 52% of those in managerial or professional occupations having tried, compared to 60% of those in skilled or unskilled manual occupations, and 36% of the rest (p=0.198).

Of the 51 people with experience of arranging an interpreter, no less than 37 (73%) had experienced a problem doing this. In 35 instances (95% of people) there was a difficulty obtaining an interpreter for the given or desired appointment time (table 4.15). The majority of people (who had tried to arrange an interpreter) in all five districts reported problems, but there seemed to be a particular difficulty in Cheshire where all 12 people experienced problems. The heavy demands on the small number of practicing interpreters made this particularly true when the appointment was at short notice, say less that two weeks ahead. For example:

"Fully booked or have to wait a week or two weeks to get one. Get frustrated."

"Difficult to get an interpreter at short notice. I don't bother anymore."

The problems of finding an interpreter can sometimes lead to quite considerable delays, with potentially serious consequences:

"Waited two months before finally found an interpreter for a doctor visit."

In one case the Deaf person was told by the practice that it was a waste of the practice's money to book an interpreter just for a 5-minute consultation (most interpreters and agencies work to a minimum 2-hour booking fee). Some interpreters or interpreter agencies try to minimise inconvenience for the Deaf person by liasing directly with the practice to arrange a mutually convenient appointment time. This seems to work well in most cases, but one respondent experienced a problem with the agency forgetting to book the GP appointment.

Communication and GP visits

When asked if they would visit their GP more often if communication was easier, 76% (74 people) replied that they would (table 4.16). The implication of this is that communication barriers prevent the great majority of Deaf people from utilising services as often as they would wish. This was made more explicit in some of the comments made:

"I have refrained from visiting the doctor many times because no one to help me communicate with the doctor."

"I dislike to see doctor because of deafness problems. Doctor writes things down and I can't read his handwriting or understand the words. Puts me off."

It was also apparent that worries over communication caused some people to delay seeking help until their condition became serious:

"Because of communication problems I refuse to go to see the doctor unless I am very ill."

"Doctor can't communicate with the Deaf. Doctor always tells me off for waiting too long during illness before I visit him; but I tell him it's because of communication problems."

Patient call systems

The great majority, 74 people (75%), reported that patients at their practice were informed of their turn to see the GP by the receptionist or doctor calling out the patient's name (table 4.17). This is often problematic for Deaf people, particularly when they are alone. However some interviewees emphasised that the receptionist, knowing they were Deaf, would personally come and inform them when their name had been called. Visual systems are generally preferred, but were not very common in this sample: just 14% of practices operated a number system (whereby each patient received a number on arrival, which was displayed on their turn) and 8% provided an electronic display of the patient's name. The only other system in operation (at two practices) was 'rotation', where patients sit in order.

Making complaints

Interviewees were asked whether, over the last 12 months, they had felt like making a complaint about staff at the surgery (table 4.18). Nineteen (19%) reported that they had made such a complaint, and a further 21 (21%) said they had felt like complaining but hadn't actually made a formal complaint. These proportions are massively different to the results for hearing people, from the NSP, where just 1% had made a complaint and another 11% had felt like doing so.

Of the 40 Deaf people with a complaint, 55% (22% of the total sample) had a complaint against a GP, 43% (17% of the total sample) against a receptionist, and 8% (3%) against a nurse. In addition, 15% (6% of the sample) had a complaint about some other aspect of the practice, such as a lack of facilities for Deaf people.

Examination of the nature of the complaints indicated that ten of the 40 people had complaints that could not be directly attributed to their deafness (table 4.19); these were concerned with matters such as long waiting times and incorrect appointment times; problems that could affect anyone. Of the remaining 30 patients (31% of the total sample), 12 (30%) had complaints about inadequate communication from the GP or receptionist:

"Doctor. Couldn't understand his lips or handwriting, so left crying".

"Receptionist as she doesn't look at my face when talking. Speaks too fast and forgets to make appointments for me sometimes."

Another 10 complained about staff attitudes towards them or a combination of attitude and inadequate attempts to communicate:

> *"Doctor. Doesn't seem to be Deaf aware or bothered to assist due to deafness - too relaxed and uncaring approach."*

> *"Receptionist, because they wouldn't take TypeTalk calls."*

Five people had complaints related to medication. In most cases the patient believed they had been prescribed the wrong medication. Although such a concern is clearly not confined to Deaf patients, it does seem to be very prevalent amongst this population, and the potential for mis-communication resulting in inappropriate medication must be considerable. This theme is explored in more depth in a later section of the report.

> *"Previous doctor. Have tried to sue him as felt he was giving me wrong tablets and injections. Waiting for result of court case."*

> *"Wanted to complain about nurse; because she gave me tablets without explaining what it was."*

Perceptions about GPs and receptionists

The interview included a set of four items, drawn from the NSP, concerned with the interviewee's perception about various aspects of the way that their GP and reception staff at the practice relate to them. On all four items a considerably smaller proportion of people in the study sample held positive perceptions. 18% of the Deaf people felt that their current GP made them feel they were wasting his/her time 'all the time' or 'most of the time', compared to just 3% of people in the NSP sample; conversely, 48% of Deaf people 'never' or 'hardly ever' felt like this, compared to 78% of hearing people (table 4.20).

Similarly, while 85% of the NSP sample were of the opinion that their GP listened to them 'all' or 'most of the time', no matter how busy he/she was, a considerably smaller proportion (66%) of Deaf people were of this view (table 4.21). 93% of the NSP sample also felt that their GP treated them with courtesy and respect all or most times, whereas only 66% of the study sample felt this way; and while 26% of the Deaf interviewees were of the view that they received courtesy and respect just 'some of the time' or 'never/hardly ever', only 5% of those that could hear thought this way (table 4.22).

Perceptions about receptionists echoed the same pattern, with 75% of the NSP sample believing them to be as helpful as they would wish all or most times, compared to only 54% of the Deaf people interviewed (table 4.23).

4.4 Last visit to the GP

Reason for the last visit

For 93 people the last visit they made to their GP was concerned with themselves (table 4.24). Three others went about the health of a child less than five years old. Just one visit was concerned with the health of an older child, and one with the health of the interviewee's mother. Interviews with the 96 people who at their last visit had consulted about their own health or the health of a child under five concentrated on that particular visit. The other two individuals were interviewed with regard to the last time they had consulted their GP about their own health, as it was felt that visits about older children or other adults would be of a different character if the individual involved was hearing and was present.

To encourage participation in the project, care had been taken to explain to potential participants that the interview was not about their personal health, but rather about the service they had received. Consequently the interview did not include questions about the nature of any illness that people had consulted about. We did, however, determine in very general terms the purpose of the visits. These are summarised in table 4.25. 86 people (88%) had consulted about personal illness and three about illness in a child under 5. The remaining 9 visits were: three people had gone along to obtain a repeat prescription; three with the intention of obtaining a medical note for their employer or social services; two to receive a flu jab; and one for a holiday vaccination.

Interviewees were also asked if they considered the visit urgent or not (table 4.26). 23% said they thought it was. All of these were consultations about personal or child illness. A much higher percentage of patients in the NSP survey, 54%, reported that their last GP visit had been urgent. This would seem to indicate that the Deaf people surveyed were far more likely to consult for less serious conditions; although some note of caution is warranted given the different methods of data collection used in the two surveys.

For some of the subsequent analyses we have divided the study sample into three groups on the basis of the urgency of the visit: urgent personal or child illness (23 people); non-urgent personal or child illness (66); non-urgent other visits (9).

Making the appointment

96 appointments took place at the GP practice, with the remaining two being home visits (table 4.27). 79 practice-based appointments were booked in advance by the Deaf person, or by someone on their behalf. In 13 cases the patient attended an open-access surgery (ie no pre-booked appointment required). A very similar proportion of patients in the NSP attended open-access surgeries (14%). Four appointments did not require pre-booking either because they were by practice invitation or had been arranged at the end of a previous consultation.

38 appointments were booked by the Deaf people themselves (table 4.28). This represents nearly 50% of all the appointments that required pre-booking. Another 36 appointments were booked by a family member or friend. In four cases the sign interpreter or interpreter agency made the booking, and in three instances it was a social worker.

Of the 38 appointments booked by Deaf people themselves, in just three instances (8%, table 4.29) this was achieved via a textphone-to-textphone call (ie both the Deaf person and the surgery possessed textphones). In 14 cases (37%) the Deaf person contacted the surgery via TypeTalk, and in four cases they used either fax or letter. However, the most common method used to arrange an appointment was by visiting the practice in person (17 people, or 45%).

Table 4.30 presents information on how easy people found it to book an appointment, broken down by whether they booked it themselves, asked a family member/friend to book it, or had it booked by a social worker, interpreter or interpreter agency. A substantial proportion, 39%, of those that self-booked found it 'quite' or 'very' difficult. Surprisingly, however, a much larger percentage (64%) of those who used family/friends had difficulty. The difference in median level of difficulty between the two groups was highly significant (Mann-Whitney U-test, p=0.003). Examination of the reasons given by people for finding it easy or difficulty reveals the importance of being able to contact the practice from a distance: 14 out of 24 people (58%) who self-booked and found it easy stated that this was because they contacted the surgery via TypeTalk, textphone or fax; conversely, 15 out of 22 (68%) who used family/friend and reported difficulty said this was because they couldn't use Typetalk or weren't able to contact the practice via textphone or fax. For people in this sub-group, family/friends were only resorted to because they didn't have a facility to make the booking themselves.

Date of last visit (about own health)

Each interviewee was asked the date of their last GP visit, and also the date of the last visit *on their own behalf,* if this was different. Table 4.31 presents a frequency distribution of elapsed times (at interview) since the last personal health visit. Consultations about personal health were used for this analysis to maintain consistency with the NSP. 61% of the Deaf people had consulted within the last three months, compared to 47% of the NSP sample of hearing people. This finding concurs with other studies that have found higher consultation rates for deaf people (see section 1.4).

The elapsed times since last appointment have been used to estimate that on average the Deaf people visit their GP a little over 6 times per year. This compares to a rate of around 4 times per year for the general population (Yuen, 2001),

Companions at the appointment

Table 4.32 shows that the majority of people, 52, went alone to the appointment (this includes three who went with a child under five years). 26 had a hearing companion, all of whom were family members, and one other was accompanied by a son who could not only hear but was also a qualified sign interpreter. 16 other people had sign interpreters with them, one of whom also had their Deaf husband present. The remaining three people went along with a Deaf companion (all family members) only. For the purposes of analysis, the sample has been divided into three groups: 55 people who were either alone or with a Deaf companion only; 26 who were with a hearing companion; and 17 who had a qualified interpreter present. This last group includes

the woman whose son was an interpreter, and the woman who was accompanied by her Deaf husband as well as an interpreter.

Use of Professional Sign Interpreters or Lip-readers

17 people (17%) had a qualified sign interpreter with them for their appointment (table 4.33). No one had a professional lip-speaker. There was no apparent relationship between the urgency of the GP visit and the presence of an interpreter. Out of the 23 people who attended due to urgent personal or child ill-health, four (17%) had an interpreter. This compares to 12 out of 66 (18%) who visited about non-urgent ill-health, and one out of nine (11%) who went about other non-urgent matters.

The 81 people without interpreters were asked why they did not have an interpreter. The answers are summarised in table 4.34. 41% said it was because they preferred or could manage well enough either alone or with family members. 42% mentioned the difficulty of obtaining an interpreter to fit in with the appointment, either because interpreters are very busy or because there were none in their locality; while one other said they were just too busy themselves to book one. 16% said they had never considered using an interpreter or simply didn't know how to go about booking one, and two expressed concerns about who was responsible for paying. Five people (6%) didn't use interpreters because they didn't trust them to maintain the confidentiality of the appointment. one person was told by the GP practice that it was a waste of practice money to book an interpreter for a five minute appointment, and one other said that social services couldn't understand her desire for an interpreter and wouldn't provide one.

Of those who felt they could manage without a professional interpreter, one had a GP who was qualified at Level 2 BSL:

> *"Doctor can sign. That's brilliant. Can't ask for anything else."*

Others emphasised that they had gone with a family member who had good signing skills: one women went with her husband who had a Level 3 BSL qualification; and another women used her son who was a "very good signer – like as if he's qualified" (woman, St Helen's and Knowsley). This reflects the fact that many Deaf people have immediate family who have learnt at least some degree of sign language for communication. Those who said they could manage alone often expressed confidence in their ability to communicate with the GP on a one-to-one basis ("I communicate well with doctor. Can lip read well; write and read well" (woman, NW Lancashire)); while others said they managed alone for relatively trivial ailments but would seek to arrange an interpreter for more serious conditions.

Those who mentioned the difficulty of arranging an interpreter as a reason for not having one frequently explained that it was hard to organise an interpreter for anything earlier than two weeks ahead. Some had actually tried:

> *"Rang social worker, they couldn't do it, so rang RNID, they said to wait two weeks, so just went alone instead of waiting two weeks."*

More often however, previous experience meant that people didn't even try:

"Because knew that they wouldn't be available when I wanted one."

"Needed interpreter long ago. Was really upset that couldn't get one for doctor visit, so gave up trying to get one for doctor visits."

Some people didn't even have an interpreter in their locality:

"The nearest interpreter was 40 miles away."

In some instances a previous service had ceased to exist:

"Don't have a local interpreter living near me. Used to use a Social Worker for the Deaf, service now stopped by social services department."

16 of the 17 people who used an interpreter made the arrangement themselves; in the remaining case the arrangement was made on behalf of the person by RNID. Interviewees were in the main highly pleased with the performance of the interpreters. Table 4.35 shows that 14 interpreters were rated as being 'very good' and two as 'good'.

No-one in the youngest age-group, 18-34 years, had an interpreter, whereas 19% or more of people in each of the older age-groups used one (table 4.36). The difference is statistically significant (p=0.026). This result concurs with the finding (although not statistically significant ,see above) that a smaller percentage of younger people had attempted to book an interpreter.

It is of interest to observe that the percentage of people in manual occupations who had an interpreter was very similar to the percentage of those in managerial and professional occupations (19% compared to 24%; table x). Although only one person (5%) from the remaining occupational groups had an interpreter, the difference did not reach statistical significance (p=0.169).

At Reception

Communication with the receptionist was explored in detail in the interviews with 50 people who did not have anyone to assist them in communicating. Not all Deaf people have speech that is clear enough for others to understand, and just under half the sample, 46% (23 people) communicated using speech. Writing is an important alternative to speech for Deaf people, and 82% (41 people) used writing as part of their communication. For their part, 76% (38) of the receptionists communicated partly or mostly in writing. Sign is the first language of many Deaf people, but only three receptionists knew enough sign for the conversation to be conducted principally in this.

66% of the people alone at reception felt that the receptionist had tried their best to communicate (table 4.38). The reasons people gave for thinking that the receptionist did their best closely followed the precepts of Deaf Awareness: not speaking too fast, mouthing words clearly, using simple language, facing the Deaf person when

speaking, using writing when necessary, and so on. This is illustrated in the following quotations:

"Receptionist spoke slowly and wrote difficult words down."

"Receptionist came out of reception area to talk face to face with me."

"She was very patient this time! Took time to communicate. No rushing."

The majority of cases where the receptionist was thought to have not tried consisted of brief exchanges which frequently left the Deaf person dissatisfied:

"She didn't talk to me - only 'sit down."

"Only brief answers 'yes, yes, no etc'."

At times this seemed to be because the receptionist didn't know how to deal with the situation:

"Didn't appear to have met a Deaf person before and didn't know how to communicate with me."

Only in a few cases was the receptionist viewed as having a negative attitude:

"Receptionist hardly spoke much and called me 'deaf and dumb' to doctor."

"Receptionist attitude, is always in too much of a rush to communicate well."

"Receptionist didn't make any efforts, no smile or friendly gestures."

With regard to how much the Deaf people (those alone at reception) understood of what the receptionist tried to convey, 66% felt they understood 'everything' or 'most' (table 4.39), but 34% grasped only 'some' or 'very little'.

In the waiting room

A particular difficulty that many Deaf people have is to know when it is their turn to be seen. Table 4.40 compares those in the sample who were in the waiting area alone or with a Deaf companion, against those accompanied by a hearing companion or an interpreter (the two people who were visited at home by the GP have been excluded). 20% of the former group experienced some problems knowing when it was their turn compared to just 5% of the latter. The difference was significant on a Fisher's exact test (p=0.033). In nine of the total of 13 instances where there was a problem this was due to the person's name being called out and them not being aware or certain about this (table 4.41):

"Doctor kept forgetting I am Deaf and shouted my name many times - felt really embarrassed."

"Receptionist shouted name. I had to keep looking at her to try to lip read my name."

"Doctor calls peoples' names and it's always hard to lip read."

During the consultation

54 people had their consultation with the GP alone, three had a Deaf companion with them, 24 a hearing companion, and 17 a sign interpreter.

Those who were alone or with a Deaf companion reported shorter consultations than others: 42% said the consultation lasted under five minutes, compared to 29% of those with a hearing companion, and 12% of those with an interpreter (table 4.42). The median lengths of consultation were significantly different on a Kruskal-Wallis test (p=0.048). The pattern of consultation times was also quite different to that for patients in the NSP, where 26% reported spending less than five minutes with the GP. Comparison with the NSP group, reveals the interesting result that lone Deaf patients were more likely to spend less than five minutes with the GP (42% versus 26%), but also more likely to spend more than 10 minutes (38% versus 23%). This suggests that GPs fall into two groups: those who devote time and effort to communication, and those who try to get rid of Deaf patients as quickly as possible. Even so, the results show that a substantial proportion of lone Deaf patients get less time with their GP than would a hearing person, whereas those who attend with an interpreter typically get more time.

When asked if the time they'd spent with the GP had been the right amount of time, too little time or too much, 39% of those alone or with a Deaf companion said it had been too little, compared to 21% of those with a hearing companion and 18% of those with an interpreter (table 4.43). The difference between the first group and the other two groups combined was statistically significant (Fisher's exact test, p=0.049). Just 12% of the NSP sample had rated the time with the GP as too little. This figure is close to the result for Deaf people with interpreters (given the small sample size of the latter), but much smaller than the corresponding percentage for lone Deaf people.

Of the 54 people who saw the GP without any companion (Deaf, hearing, or interpreter), 48% used speech as part of their communication. A much higher proportion however, 78%, communicated in writing. 83% of the GPs responded in writing. One GP had a Level 2 qualification in BSL, and this consultation was conducted entirely in sign language.

The people with a hearing companion or interpreter were asked how much they relied on their companion to convey what the GP was saying (table 4.44). 63% of those with a hearing companion said they relied 'fully', and another 25% relied 'mostly' on their companion. Not surprisingly, 94% of those with an interpreter (16 out of 17) relied fully on the interpreter.

People who were alone at the consultation were asked how much of what the doctor had communicated had been clear to them. Table 4.45 shows that only just over half, 52%, felt that everything or most of the communication had been clear, while 32% thought some was clear and 16% had understood very little. Likewise, slightly more than half of this group (59%) thought that the GP had tried their best to communicate (table 4.46).

Those with a companion or interpreter were asked a similar question about how much of the communication had been passed on to them (table 4.47). While 16 of the 17 with an interpreter answered that everything or most had been passed on, the same was true for only 42% of those with a hearing companion. Even amongst the 15 people who said they had relied fully on their hearing companion only seven (47%) said they had received all or most of what the GP said.

There were no equivalent questions about communication in the NSP. However, a question about how well the GP explained the reasons for the actions he/she took does provide some degree of comparison: this found that 95% thought the GP explained in a way that was 'very easy' or 'fairly easy' to understand (table 4.48).

Table 4.49 summarises the responses to a question about whether people felt able to ask as many questions of the GP as they wanted. In total, just 56% of the sample had felt able to ask all the questions they would have liked. However, the presence of an interpreter made a big difference: 46% of those who were alone or with a Deaf companion said they had felt able, compared to58% of those accompanied by a hearing person, and 88% of those with an interpreter. The difference between groups was highly significant (p=0.008). The result for people with interpreters is close to the figure from the NSP for hearing people (89%).

Ten (18%) of the people who consulted alone or with a Deaf companion were of the opinion that the GP had not managed their case correctly (table 4.50). In contrast, only one of those who had a hearing companion with them, and none of the people with an interpreter, were of this opinion. On a likelihood ratio test (applied because of small cell sizes) the difference between the proportions was statistically significant (p=0.023). All three subgroups of Deaf people were far less likely to be confident that the GP's management of their case was correct than were hearing people in the NSP (63%, 63% and 76% respectively, compared to 92%).

Nearly one-third (31%) of all the Deaf people left the consultation feeling that they did not fully understand the GPs advice on what they should do next (table 4.51). The proportions were higher amongst those consulting alone/with a Deaf companion (37%) and those with a hearing companion (29%), than amongst the people with an interpreter present (12%), but the difference did not reach statistical significance (p=0.14).

Interviewees were also asked whether they thought that seeing the GP had given them a better understanding of what was wrong with them. The analysis of the responses is restricted to 89 people who consulted about personal or child ill-health (eg excluding people who attended for flu jabs or a holiday vaccination). In all, 37% (33 people) felt that they had not gained any greater understanding of their ill-health (table 4.52). Although the proportion was smaller amongst those with an interpreter (19%) than for either of the other two groups (43% and 37% respectively), the difference was not statistically significant (p=0.22).

4.5 Other visits to the GP

The interview contained sections relating to visits to the GP other than the last. Some of the questions in this section were concerned with comparing experiences of attending with and without communication support. Interviewees who had an

interpreter or hearing companion at their last visit were asked about times they had attended on their own. Those who did not have a professional interpreter at the last visit were asked about times they had attended accompanied by a professional sign interpreter.

Experiences of attending alone on previous GP visits

28 people who had a companion during their last visit, had previously made visits alone. 27 of these (96%) indicated that communication with the doctor and/or receptionist had been worse when they had been on their own (table 4.54); the one remaining person said it made no difference, because they had been using the same doctor since birth. The reasons given for communication being worse reflected a mixture of failings on behalf of both patient and doctor:

> *"Worse as couldn't understand doctor and just said 'yes, yes, yes' when doctor asked anything and I didn't even understand."*

> *"Worse when alone. Can't understand doctor's words or handwriting - nightmare! I miss everything and can't ask questions because I wouldn't understand the questions anyway."*

> *"Worse when on own. Hardly any communications at all with doctor when am alone. Dr just look at medical records and give prescription and say 'go'. Had got wrong tablets in the past."*

When asked of anything (other than communication) had been better when they had attended alone, two people (7%) replied that the consultation had been more confidential. The other 26 (93%) could not suggest anything that had been better.

A much larger number, 21 (75%), answered in the affirmative when asked if anything had been worse (table 4.56). The largest number of comments related to the psychological effect of being alone, in terms of having less self-confidence or feeling more anxious or embarrassed. 11 people (39%) made comments of this nature. Four people (18%) expressed concerns related to medication; either believing they had been prescribed the wrong form of medication, being worried (during the appointment) that they may receive the wrong medication, or being prescribed medication without any explanation. Other comments, made by smaller numbers, included shorter consultations, not being aware of being called, less explanation from the GP, and poorer staff attitudes.

Experiences of attending with an interpreter on previous GP visits

Of the 81 people who did not have the services of an interpreter during their last GP visit, 22 (27%) had used a professional interpreter on previous visits. 20 of these (91%) felt that communication had been better with the interpreter present (table 4.58). Only one person felt that it had been worse (this was in comparison with their daughter-in-law, who normally supported them): the interpreter was criticised for not made full translations.

> *"Absolutely better. Felt more confident and understood everything that was being said and asked questions. Would like interpreters at all times."*

"Better with interpreter as more information, better conversation, clearer information, more confident with professional interpreter with me."

16 people (73%) reported that other things had also been better with an interpreter present. 13 (59%) made comments about feeling more confident and relaxed when supported by an interpreter (table 4.59). This concurs with the earlier finding that being alone had a considerable negative psychological impact (see above). Four interviewees (18%) made comments to the effect that they got more from the consultation with the interpreter there:

"Dr talked more and explained things more clearly."

"Yes, more time spent with doctor when interpreter was there. Better consultation."

Where asked if the presence of an interpreter made any aspect of the visit worse, three (14%) expressed concern about the confidentiality of the consultation. 18 (82%) did not felt that anything was worse.

Other experiences during earlier visits

The focus of the interview, on the most recent GP visit, carried a risk that experiences important to the interviewee might not be picked up, if they were part of an earlier visit. Accordingly, the interview included a question about what else (other than already covered by the interview) "good or bad" had happened during any visit to the GP. 48 people (49%) had something positive or negative to report, between them providing a total of 59 comments, 20 of which were positive and 39 negative (table 4.61).

Half (10) of the positive comments were expressions of satisfaction with the way the GP related; in general rather than during a specific consultation:

"Previous doctor wasn't very nice. New one more friendly. When on home visits, sits on the floor, has a cup of tea and chats. Nice doctor."

Three interviewees described positive experiences of practice staff that could use sign language:

"Long ago, previous doctor could do sign language. That was brilliant. Could communicate fully with him."

"Yes. Nurse can sign. That's very good and very helpful."

Three others mentioned that GP visits were much better with an interpreter to help, and two had been pleasantly surprised when the practice had unexpectedly arranged an interpreter:

"The receptionist once booked interpreter for me. Not sure where they booked her or who paid for it. That was very nice. Why don't they do it more often?"

The largest category of negative comments related to disatisfaction with the GP's attitude. 20% of all interviewees made comments of this type:

> *"Two doctors in the surgery don't seem bothered to make extra efforts because of my deafness. They have wrong attitudes - don't communicate well and I'm not happy with them."*

> *"Once went to doctor with child. Dr was talking to child not me. Told doctor to talk to me not child as child is my responsibility. Dr was angry and moody."*

> *"Previous doctor asked 'Why bring an interpreter? You don't need one as it's private', and refused to let her in."*

Unhelpful attitudes were often accompanied by a failure to communicate. 8 people (8%) made a specific mention of communication difficulties:

> *"On one occasion, went to visit doctor. Couldn't communicate with doctor at all. So, walked out of doctor's room during consultation."*

> *"Once left doctors' office, was so frustrated and angry, went home and asked wife to ring doctor for me and explain [my medical] problems."*

Five people described bad experiences in connection with medication the GP prescribed for them. Issues to do with medication also arose several times in interviews about the last GP visit. This seems to be a particularly important topic for Deaf people, and accordingly is discussed in a separate section below.

4.6 Suggested improvements to services

Using a free response question interviewees were asked what, if anything, they thought their doctor's practice could do to make thing better for Deaf patients. A total of 356 different suggestions were made (table 4.62). The most popular, by far, was that GP's should learn to use sign language (suggested by 72% of interviewees), and the second most popular was that reception or other staff should learn the same (58%). While it is probably quite unrealistic to expect most GPs and practice staff to learn sign, these results do demonstrate just how strongly Deaf people desire direct one-to-one communication with their health providers.

A little more than half the sample (56%) would like to see a textphone in the practice and nearly as many (55%) suggested an electronic patient name display. The next most common proposal was that GPs and staff should be provided with Deaf Awareness Training (40%). A rather smaller, though still substantial, proportion (29%) recommended that the surgery have a system for obtaining sign interpreters, or at least a video-phone link to an interpreter. All other suggestions were make by relatively small numbers, though the next three, relating to fax machines (17%), text messaging (7%) and email (6%), all represent alternative to a textphone as a means of directly contacting the practice.

One observation that can be made about the suggestions put forward by the sample is that the top five (signing GPs, signing staff, textphones, visual name displays, DAT)

are all means of reducing obstacles to *direct* communication and reducing dependency on others. Provision of interpreters only appears in sixth place, and was proposed by a notably smaller proportion than the suggestions ranked above it.

4.7 Medication

A common theme to emerge from many of the interviews concerned the issue of medication. Although the interview schedule contained no specific question on this topic, the frequency with which medication was mentioned as part of a response to other questions, suggests that it has a central place in the concerns of Deaf people using health services. Comments about medication appeared in response to numerous interview questions, sometimes in connection with the last visit and sometimes in relation to visits prior to that, and so the information has been pooled across questions for the analysis presented here.

A total of 25 different people (26% of the sample) made at least one comment expressing concern over medication they had been prescribed or received. The comments have been categorised and will be discussed under four headings: inadequate information; incorrect medication; anxiety; and incorrect application (table 4.63).

Inadequate information

15 people made comments to the effect that they had received a drug prescription without being adequately informed as to what the purpose of the medication was, or if there could be any side effects. Frequently this was accompanied by very little attempt on the GPs part to communicate with the patient at all:

> *"Hardly any communication at all with doctor when [I attend] alone. Doctor just look at medical records and give prescription and say 'go'. Had got wrong tablets in the past."*

> *"Doctor didn't explain what tablet does or if any side effects?"*

> *"When [I attend] alone, receptionist or doctor doesn't say much. Once was given tablets without explanations. Took it and felt worse. Didn't bother go back to doctor with same symptoms."*

> *"[The doctor] said to rub cream, but what does cream do? Doctor didn't explain to me.'*

> *"This particular doctor seems to be in a hurry all the time. When I go for flu or other problems, doctor doesn't bother to check me up - just writes prescriptions, say 'ok, bye'. Refused to see him anymore."*

Incorrect medication

12 patients were of the opinion that they had been prescribed incorrect medication at some point in time. Incorrect medication may well indicate that the doctor had previously reached a false diagnosis – perhaps as a result of inadequate

communication - and began treating the patient for a condition they did not have. However, in some cases it wasn't clear whether the medication was actually wrong, or if this was just the patient's perception.

"Got tablets and felt very ill. Maybe because wrong tablet? Was vomiting. Didn't go back to doctor again because no interpreter - went to chemist with wife to buy something else."

"My English is not very good and signing isn't good and had previously had wrong tablets due to bad communication."

"Last doctor kept making mistakes with wrong tablets, so changed doctors."

In other cases, there were clearer indications that an incorrect prescription had indeed been made:

"Had wrong tablets, took them without knowing and was rushed to hospital. Was sick for 2 weeks…. Father rang doctor and complained. Now too scared to go alone."

"Asked questions, but doctor didn't reply. Just said to take paper to chemist…. Took tablets and felt worse…. Went to see sister who is a nurse and explained what happened with doctor. Sister thought tablet from doctor was wrong one. Have never been back to see doctor since."

"Have tried to sue him [the previous GP] as felt he was giving me wrong tablets and injections. Waiting for result of court case."

"When got home, wife saw tablets and said they were wrong ones and threw them away. She took me to chemist and bought something else."

Anxiety

3 other people, although giving no indication that they had ever actually received the wrong medication, expressed anxiety that poor communication might result in this happening:

"Even when I have to communicate with doctor through writing, I still get nervous that doctor doesn't understand me and she may give me wrong tablets."

"Very important [for me to have an interpreter] because could get wrong prescription if I don't communicate well with the doctor."

Incorrect application

In addition to the risk that poor communication may lead to a Deaf person receiving the wrong diagnosis and medication, there is a further risk that even when the diagnosis and medication are correct, a lack of communication may result in the patient applying the medication in the correct fashion. Two patients in the survey had

this experience, resulting in them consuming a medicine intended for external application only, with quite serious consequences:

> *"Once got medicine from doctor. Doctor didn't explain properly what it was for. Took liquid through the mouth rather than rubbing it on my back. Was very poorly. Thought it was prescribed for my chest. I went alone on this occasion."*

> *"Once doctor told me to put tablets in 4 cups of water. Didn't understand doctor. Drank liquid. Was supposed to dip hands in it for 2mins, but didn't understand and took 2 tablets and drank 4 cups of water. Was very ill and friend was shocked when read label and took me back to doctor."*

4.8 Comparison between randomly selected and replacement samples

41 of the 98 interviews were with members of the initial random selection from the database of profoundly deaf people. The other 57 interviews were undertaken with individuals that had been chosen to replace members of the initial sample – who we had been unable to contact - on the basis of same area, sex and age-group, plus a small number that were entirely opportunistic (see section 2.2 for more details). This 'replacement sample' is potentially a less representative group than those randomly selected. Therefore as a check for possible bias, this 'replacement sample' of 57 has been compared with the 'random sample' of 41 in terms of personal characteristics, characteristics of the last GP visit, and the outcomes from GP consultations.

Personal characteristics

Table 4.64 compares the random and replacement samples with respect to a number of personal characteristics (including views about communication, as well as demographics). For simplicity this table – as well as the others in this section – reports percentages but not raw counts. Statistical significance tests (comparing the two samples) have not been applied: these are inappropriate in the current context, where the issue is the size of any differences, not whether those differences reach statistical significance or not.

The two sub-samples are very similar with regard to gender balance (46% male compared to 51% male), but the replacement sample contains a much larger proportion of young people, and correspondingly fewer of age 50 or above. Most of the difference here was intentional: the replacements were selected partly on the basis of age (and gender), and more younger people were chosen to compensate for a lack of young people in the random sample.

Despite the difference in age profiles, the two sub-groups appear very similar on most other personal characteristics (socio-economic class, ethnic mix, views and preferences regarding communication with GPs). The one possible exception is the higher percentage of the replacement sample that were born deaf (58% compared to 44%). However, the proportions that became deaf after the first two years of life were fairly similar, suggesting that speech abilities did not differ greatly between the sub-groups. The fact that very similar percentages felt that it was 'very important' for them to have someone help in communication and had tried to arrange for interpreter support, also suggests an overall similarity with respect to communication ability.

Characteristics of the last GP visit

Very similar proportions of both sub-groups visited their GP (on the last occasion) to consult about a personal illness, and had booked the appointment themselves (table 4.65). Similar proportions also regarded the visit as urgent. Slightly more of the replacement sample went alone (63% compared to 51%) and slightly fewer had an interpreter present (14% versus 22%). These results may well be related to the younger age profile of the replacement sample, as there was a general tendency (across both samples combined) for younger people to visit alone and to not use interpreters (see section 4.4).

Outcomes of GP visits

The outcomes from the GP consultations fall into two groups. The first group consists of outcomes relating to the last GP visit: time spent with the GP; ability to ask questions of the GP; the patient's view of how the GP managed the case; and the information gained about the illness and after-care. On all the measures there was very little difference between the random and replacement samples (table 4.66).

The second group of outcomes consists of five items not specific to a single visit and mainly about the GP's general attitudes towards the patient (table 4.67). On two of these items there was a clear suggestion that substantially fewer people in the replacement sample were completely satisfied with the GP's attitude: 'does you doctor listen to you no matter how busy?' (39% versus 56% answered 'all the time'); and 'does your doctor treat you with courtesy and respect?' (44% versus 63%). Inspection of the responses broken down by age-group indicated that these results could not be explained by the younger age profile of the replacement sample.

Conclusion

With the exception of age (where a difference was intended) the random and replacement samples were similar with respect to all personal characteristics. The characteristics of the last GP visit were also very similar in almost all respects. Views about the outcomes of these visits also showed little difference, with the exception that more members of the replacement sample were not completely satisfied with their GP's attitude towards them. However, this is something of an isolated result.

Chapter 5

Results: Interviews with GP practice managers

5.1 Numbers of Deaf patients

Six out of the 31 practice managers that were interviewed couldn't provide any estimate of how many registered patients were profoundly deaf (table 5.1). Six stated that none of their patients were Deaf, while nine indicated that they had only one or two Deaf patients. No practice reported more than six Deaf patients. However, very few managers were confident that the number they gave was correct, with some explaining that their computer records system didn't include an identifier for profoundly deaf patients. Even so, the numbers reported by managers are fairly close – if a little lower – to the estimates presented previously in section 3.2 for various sizes of practice.

Two practices volunteered information about numbers of HoH patients. These were very much larger figures. One said they had 370 patients with hearing problems; the other said they had over 200. These figures are also in the same ballpark as the estimates presented in section 3.2.

5.2 Communication aids

None of the practices had a loop system (table 5.2). Only one had a textphone, but this was not always switched on and had no answerphone facility. One practice (a different practice) possessed a portable listening device.

Three practices (10%) were registered with the RNID TypeTalk scheme, thus providing a means for practice staff to contact Deaf patients by telephone. At two sites only reception staff had made use of TypeTalk.

The most common form of patient call system, used in 20 practices (59%) was a simple verbal announcement of the next patient's name, either by the receptionist or medical staff. Another four practices (12%) used a tannoy system – making it potentially even more difficult for a Deaf patient to keep track of what is happening. All these practices stated that staff would personally go and inform a Deaf patient of their turn. Some relied on familiarity with their patients in this respect:

> *"As a small practice we know which patients have a hearing problem and conduct them to the surgery."*

> *"Reception staff go to the Deaf patient. All are well known to the staff."*

Eight practices (24%) used a visual display system. At least five of these displayed the patient's name, whereas some just indicated which GP was free. There was some suggestion of a relationship between practice size and the presence of a visual call system: just two out of 15 (13%) practices below the median practice size (4,850

patients) had a visual system compared to 6 out of 16 (38%) of those at or above the median. Although the difference was not statistically significant (p=0.22, Fisher exact test), the sample was small.

Many Deaf patients find it more convenient to communicate via fax or email than to attempt to go through a telephone system. All 31 practices had a fax machine, and 25 (81%) indicated that this was available for patient use. 27 practices had an email address and 12 (39%) made this available to patients, while others had plans to do so. The interview did not probe into what services were available via fax or email (eg arranging appointments, repeat prescriptions, or information about test results), but with hindsight it would have been useful to have done so.

5.3 Access to BSL interpreters

Three practices (10%) claimed to have access to BSL interpreters (table 5.3), but when probed further two said they had never actually arranged an interpreter. The third said they could typically obtain an interpreter given about one week's notice. One other practice had a member of the reception staff who was qualified in BSL to Level 2 and acted as an interpreter for patients.

The single practice that had used interpreters stated that patients were informed they could have an interpreter by reception staff, and that the surgery covered the cost. This practice was not particularly large, with about 4,000 registered patients and two full-time GPs. Also, the practice reported having only one Deaf patient. Neither of the two other practices that claimed to have interpreter access could say how Deaf patients would know of this or who was responsible for the cost. One answered the question about how Deaf patients would be aware they could have an interpreter by replying that none had ever asked for one; thus putting the onus for awareness entirely on the patients.

Five practices (16%) said there was no alternative (at their practice) for Deaf patients who did not want a friend or relative to interpret for them and another 17 (55%) couldn't suggest an alternative. Only two practices said they would arrange for an interpreter, while a third would use the member of staff qualified in BSL.

Staff with some BSL skills were present at four (13%) of the sites. One was qualified to BSL Level 2 (see above) and said they hadn't experienced any problems when interpreting for Deaf patients. A second was qualified to Level 1, but only used sign at reception with the practices' (only) two profoundly deaf patients whom s/he knew well. A third had basic signing skills but was awaiting more advanced training. The fourth also had elementary skills that she had learnt as part of annual formal training in basic sign language provided to all practice staff; she commented that "patients seem to appreciate the skills we have". The practice manager expressed the opinion that because all staff received this basic training the practice had no need to use professional sign interpreters. The practices at which these staff worked were moderate to large in size (ranging from 5,000 to 12,000 patients).

5.4 Other provision for Deaf patients

The interview explored a number of further aspects of service provision of particular relevance to Deaf (and HoH) people (table 5.4). The RNID operates a membership scheme for GP practices which attempts to promote good practice and keeps practices abreast of relevant medical, technical and policy developments. None of the practices in the sample were aware of this scheme and none were members of it.

27 (87%) practices made a record of deafness in the patients' notes, and at the great majority of sites this was recorded on the computer file as well as in the paper notes. There is an advantage to having the fact of deafness marked on the front of the notes as well as inside, so that reception and medical staff are made aware immediately they receive the notes. The interview did not ask this as a specific question, but 10 sites volunteered the information that such was their normal practice.

As reported previously, the number of Deaf patients attending each practice tended to be very small. It may be, therefore, that the needs of Deaf patients would be best served if at each practice all were registered with the same GP: this might maximise the doctor's abilities at communication and understanding of health issues related to deafness. Three practices (10%; group practices only) indicated that all their Deaf patients were registered with one particular GP. However, this group included a practice that only had one registered Deaf patient. The other two practices had three and four Deaf patients respectively.

Communication with Deaf patients can be slow: where there is no interpreter present then much of the conversation may need to be in writing or repeated several times to ensure understanding; where there is an interpreter (or other companion) time needs to be allowed for translation. Just 5 practices (20%; practices with Deaf patients only) automatically allocated a different (longer) time for consultations with Deaf patients, typically an extra 5 minutes.

It was felt that to some degree the presence of an Audiology or ENT clinic at the practice site might both reflect and encourage GP awareness and interest in Deaf and HoH service needs. Such clinics were in operation at three of the 31 practices (10%).

Practice managers were also asked whether any of their GPs had a special interest in hearing problems or Deaf issues. 26 (84%) said "no" and the rest couldn't say.

5.5 Deaf Awareness Training (DAT)

Staff at 7 practices (27%) had attended (or were soon to attend) Deaf awareness training (table 5.5). However, at 5 of these only reception staff and (in one case) the practice manager had received DAT. Medical staff were involved in training at just two sites. Although not quite statistically significant (p=0.08, Fisher's exact test), there was a suggestion of a relationship between DAT and practice size: just one out of 15 practices (7%) under the median size had received DAT compared to 6 out of 16 (38%) equal to or above median size.

One of the above practices stated that they provide annual training in "basic sign language" to all staff. This was one of the largest practices in the sample, with over

13,000 registered patients. However, the practice manager estimated that no more than 5 were profoundly deaf. At one practice training was due to begin "very soon". One interesting aspect of this was that the Primary Care Group to which the practice belonged was reported to be funding the training.

Staff at four practices, two of which were different sites to those above, had also requested DAT. This brings the total of practices where DAT had been received or requested to 9 - 29% of all practices, and 44% of those equal to or above median size.

Only one practice manager indicated that staff had raised concerns regarding communication with Deaf patients. The manager also stated that it was these concerns that provided the driving force for DAT training. This was the site that had introduced annual training in basic sign for all staff. It seems likely that one practice out of 30 doesn't actually truly reflect the level of concern about communication, since a considerably higher number had implemented training.

5.6 Service evaluation

Two practices had evaluated their services with respect to Deaf patients, while two others were currently engaged in an evaluation (table 5.6). In three cases the evaluation had been prompted by the Disability Discrimination Act; in the fourth the practice was engaged in a general review of it's needs as it's premises were no longer adequate and it was planning a rebuild.

The outcomes of the two evaluations that had been completed appeared to be somewhat minimal. One practice had decided that one member of staff should learn BSL, but had no plans to improve it's facilities for Deaf patients in other ways (even though currently at a low level). The other practice already had a visual patient call system and good access to BSL interpreters (see above). The evaluation didn't result in any developments beyond those:

> "We had a disability assessment. The only thing to come out was no textphone, but we were not told to buy one."

5.7 Future plans re access for people with disabilities

Practice managers were asked about plans the practice might have for improving access for disabled groups. It was made clear that we were interested in plans relating not only to the Deaf but also to any other group. Six practices had specific plans being – or waiting to be -implemented; another three were in the process of formulating plans (table 5.7). A few practices without plans explained that they had addressed the issues in previous years.

Out of the 6 practices with specific plans, only one included a mention of the needs of Deaf patients:

> "Looking to have a loop system or a textphone installed."

Plans at the remaining 5 sites were almost entirely focused on patients with mobility problems:

> *"Stair lift being installed at present. Any signs to be printed in large type. We need a ramp, but it will need to be portable. Also need corridor widened for wheelchair access."*

> *"Increased consulting space and grab handles."*

> *"Lowering reception counter for wheelchair access."*

Deafness has been called the 'invisible disability' because it is not immediately visible to a casual observer. This may be part of the reason why the Deaf appear to have been forgotten when these plans were devised. Some of the comments from practices that had no current plans but had looked at access in the past gave a similar impression:

> *"No plans. New building so [disabled access] already addressed, apart from Deaf (no communication aids)."*

Chapter 6

Results: Deaf people's experiences of using Accident & Emergency departments

6.1 Introduction

A total of 42 of the 98 people interviewed had attended an A&E department and were able to recount their experience. Another 14 people indicated that they had been to A&E at some point in their lives, but the visit was too long ago for them to provide useful information about their experience. The make-up of the sample in terms of age and gender appears in table 6.1. 24 (57%) were female and 18 (43%) were male. 59% of the sample were aged 50 years or older. This is somewhat larger than the comparative figure of 36% for the 42 interviewees who had never attended A&E, but this is to be expected as older people are more frequent users of A&E services.

Each individual was interviewed about their last visit regarding an accident or emergency to themselves (excluding follow-up appointments). If there was no such visit then the interview focused on the last visit pertaining to a child (under 18 years), or failing that a spouse or partner. Table 6.2 indicates that 35 (83%) of the interviews related to a personal accident or emergency; five (12%) related to a child; and two (5%) to a spouse (Deaf, in both cases).

The 42 attendances were spread across 19 different A&E departments, only one of which was outside the North West region (Rotherham). The units at Chester hospital and Whiston hospital received the largest numbers of visits, five each, and because the numbers of visits to each unit were small it had not been possible to undertake analyses that compare between units. 28 (67%) of the visits involved injuries resulting from accidents and 14 (33%) involved medical emergencies.

6.2 Last visit to A&E

Getting to the A&E unit

16 (46%) of people who went to A&E about a personal accident or emergency travelled there by ambulance; 15 (43%) went along with a companion in a private car or taxi. In three cases (9%) the companion was also Deaf. Four people (11%) made their way to the unit entirely on their own (table 6.3).

None of the interviewees experienced any difficulty in finding the A&E department within the hospital complex (table 6.4). The majority (20; 48%) were simply taken directly there by the ambulance crew or taxi driver. Another 15 (36%) reported that they knew the place from having been there before, or were with a companion who knew it. All of the remaining 7 also found the unit without difficulty.

Communication support

Table 6.5 gives details of the kinds of companions each Deaf person had with them at A&E. For the purpose of this analysis we have excluded individuals who were also involved in the accident or emergency (eg friends in the same car crash), so as to

focus on those supporting the Deaf person. Just over one-third (15; 36%) had no support at all, although in three cases relatives arrived at a later time. 20 (48%) had a (hearing) adult relative or friend present, while one woman was accompanied by her 13 year old (hearing) daughter. Four people (10%) were supported by a Deaf adult, and just three (7%) had a professional BSL interpreter with them.

With regard to the patients with interpreters, none of these had been arranged by the A&E unit: in one case the patient had come directly from her GP, bringing the interpreter with her; in the other two cases the patient themself (or their family) made the arrangement. Patients were not asked directly, in the interview, if they had been offered an interpreter; but even so, only one commented that they had been (see below). In three cases, upon discovering that the patient was Deaf, the hospital called on a nurse with BSL skills to provide communication support. One nurse offered to obtain a professional interpreter if the patient preferred, but the patient was satisfied with the nurses signing abilities.

Taking into account the communication abilities of each different type of companion, we have coded the communication support available to each Deaf patient into four different categories (table 6.6): 21 patients (50%) had no signing support (alone or with a non-signing or Deaf companion); 15 (36%) had a signing and hearing relative/friend; three (7%) had a signing nurse; and three (7%) had a professional interpreter. For the purposes of some analyses we have further collapsed these categories into just two groups: no communication support (21 patients), versus communication support (21 patients).

Communication with A&E staff

The interviewees were asked a free response question about the quality of communication with the staff they saw in A&E. Table 6.7 presents the categorised responses, broken down by level of communication support. 57% of the patients who had no support made comments to the effect that the communication they received was inadequate. This compares to 29% of those with support. The difference between these proportions is of borderline statistical significance ($p=0.07$, Fisher's exact test).

Some of the communication difficulties where support was available occurred after the support left:

> *"Son was always with me for most of treatment. Then went home. All staff became quiet after son left - no more communication."*

> *"Was stressed sometimes - when interpreter had gone and hospital staff couldn't sign."*

In other cases the difficulties were due to a limitation in the signing skills of the support:

> *"Didn't get full information. Daughter [13 years old] can only sign simple words, so couldn't explain more difficult words, which I missed."*

For both groups, most of the negative experiences could be attributed to staff failing to use appropriate means of communication:

"Awful. Bad attitudes, bad communication. Spoke too fast and didn't speak looking at me or husband who is Deaf."

"Awful. Everything in writing and I missed a lot of what was written due to difficult English words. Same as at doctor's surgery, but worse because haven't seen these people before and not sure they have DAT."

"Wrote 'Deaf' to receptionist, but they kept shouting my name and I missed my turn. Doctor didn't explain that am required to stay overnight, so was angry to have to cancel plans at last minute."

In two cases where a Deaf parent had gone to A&E with a child who had been in an accident, staff attempted to communicate with the parent through the injured child:

"Crap - talk! Staff very busy and talking and looking at notes etc. Then told my daughter who was in pain "tell her..." [ie the Deaf parent] which annoyed me and I told doctor directly."

"Couldn't understand them. Doctor talked to injured son and son had to interpret for me what doctor was saying."

The three patients who had been provided with a signing nurse by the unit had no problems to speak of and all gave high praise to the arrangement:

"Yes - nurse could sign. That was brilliant"

"Very good. Nurse can sign and was with me most of the time for one week. Brilliant!"

"No problems - good signing from nurse interpreter - she asked if we needed a professional signer, we said 'no we are happy with your signing'"

Similarly, all three patients with a professional interpreter were entirely satisfied with the signing. What problems did exist came after the interpreter left (see above) or as a result of medical staff not offering sufficient information:

"None - after 3hrs of tests was asked to go home. Not a single reason given. Not happy with that."

In the waiting room

Some patients, who were emergencies, didn't experience any waits for treatment or were portered everywhere by hospital staff. The majority however did queue for a consultation or a test. 6 of the patients without communication support reported having a problem knowing when it was their turn to be seen (29% of this group), compared to one (5%) of those with support (table 6.8). The difference was not statistically significant (p=0.09, Fisher exact test). The one person with support who

experienced a problem was the woman who was accompanied by her 13 year old daughter.

The problems experienced were typically related to receptionists and medical staff forgetting that the patient was Deaf:

"Yes - waited up to an hour. Receptionist said she has been calling my name - she forgot that am Deaf."

"When got to reception, told receptionist am Deaf. She tried to shout at me, but wasn't any help, so wrote down 'am Deaf' again. She asked for name and address, but wouldn't write down what she is saying. Was asked to wait. Waited two and half hours, then went to reception to ask 'why so long?' and she said 'been shouting your name twice, no answer'. Was very angry!"

"Porter pushed me to x-ray waiting area. X-ray staff shouted my name and was hard for me to know when it was my turn."

Many people felt great anxiety in the situation, even if they didn't actually miss their turn:

"Wasn't happy that had to wait nearly 3hrs in reception not knowing what was happening. Felt angry and stressed. TV in receptionist didn't have subtitles and receptionist shouted at me and I can't hear."

"Yes. Dr and receptionist shouting names. Maybe waited too long because missed my turn? Wait about 4-5 hrs alone in reception. Was really so angry after ambulance staff dropped me for x-ray."

The presence of a hearing companion made the situation much easier and less stressful:

"No problems. Nurse with us all the time."

"No. My husband explained to me when it was my turn."

"No problems as mate was with me who can hear."

Getting around the hospital

Attendees at A&E frequently have to visit various different departments in the course of their visit, obvious ones being consulting rooms and the X-ray department. Just over half the sample, 23 people (56%) where portered everywhere by hospital staff and so had no difficulties in knowing where to go (table 6.9). In many other cases there were no difficulties because the patient received all their treatment in the one department. Only two people did report a problem. Both of these were without communication support.

"Wasn't easy to find where to go for treatment. Receptionist said for me to follow signs, but signs too high up the ceiling."

> *"Yes - didn't understand receptionist directions and she wouldn't write down what she was saying."*

The medical treatment received

28 (68%) of all patients indicated that they were satisfied with the medical treatment they had received at A&E (table 6.10). 8 (20%) were not satisfied, and a further five (12%) couldn't say one way or the other. Opinions didn't vary greatly between those with and without communication support.

The information provided

Only just over one-third of the patients (14; 34%) felt that they had received all the information they should have been given about their condition, treatment and aftercare (table 6.11). There was also a considerable, statistically significant (p<0.05, Fisher's exact test) difference between those with communication support (where 50% thought they'd received full information) and those without (19%). Two patients said that the information received was 'OK' but would have been fuller if an interpreter had been present. With these included, a total of 81% of patients without communication support – four out of every five – came away without all the information they felt they required.

Some of the comments from patients without communication support demonstrate their dissatisfaction and the distress caused:

> *"No. Dr didn't talk much to me. Didn't get full information. Went home still in pains, so next day, went to walk in clinic and was told it [foot] was broken and got treated there."*

> *"Missed all information. Would like to complain Didn't know what was happening at all."*

> *"Communication breakdown. They did so much with me without explaining what they were doing. I felt so left out until my daughter came to interpret for me."*

The comments provided by patients happy with the information received revealed a mixture of good staff practices and good communication support:

> *"Doctor explained to daughter and daughter explained to me. Doctor's writings were easy to understand."*

> *"Yes. Doctors explained everything through the interpreter that arrived just before the op. Doctor phoned RNID to book interpreter. That was good."*

> *"Yes. Nurse spoke well. Explained to me what would be done before they were done."*

All three patients who had been provided with a signing nurse expressed complete satisfaction with the information they had received. Two of the patients with professional interpreters were not entirely happy. In one case the medical staff had

done tests and sent the patient home without providing any information about what he should do next. In the other the interpreter had to leave partway through the treatment, leaving the patient floundering from then on:

> *"Could have better information - interpreter left and was lost on what was happening. Nurses did try to show me bit by bit, but I didn't fully understand what was happening."*

Follow-up appointments

17 patients were required to return to the A&E unit at a later date for a follow-up. In none of these cases did the unit offer to arrange an interpreter for the follow-up appointment. However, one did arrange an interpreter after the patient asked for one (table 6.13). Two patients booked interpreters for themselves (it is not known who paid for the interpreter's services), while a third was (at the time of interview) in the process of booking:

> *"Follow up appointment in two weeks time. Am trying to book an interpreter myself to ensure that I understand everything."*

Complaints

The interviewees were asked whether anything had happened at first visit or follow-up that they had felt like making a formal complaint about. The answers therefore indicate those aspects of the service that caused the greatest upset. 20 people (48%) said they had felt like making a formal complaint. The complaints have been categorised as being either directly related to the patients deafness (ie likely to have occurred because of the deafness), or not related. Two people expressed two complaints, one of each type, hence these have been counted as separate complaints. 36% of all the patients had a complaint that related to deafness (table 6.14), representing 68% of all complaints. Although there was a tendency for patients lacking communication support to have more deafness-related complaints, the difference was not significant (p>0.05, Fisher's exact test).

The deafness-related complaints have been coded into types in table 6.15. Half of the complaints (50%) were about the quality/completeness of communication from hospital staff:

> *"Poor doctor attitude, speech etc. Looking at notes while talking too fast. Doctor didn't make any efforts - bearing in mind our deafness. Doctor wore smart dress, but bad attitudes - disgraceful."*

> *"Wasn't happy that all communication was directed at husband and not me, the patient."*

> *"Would like to complain about the lack of information on what was the cause of pains and what to do next. Just told to go home. Not good."*

Issues of communication were also dominant for the three patients who felt the hospital should have provided an interpreter:

"Was angry as not a communicator in sight. Thought it was only a sprain, but was told it was broken - gave me low confidence and hard to trust hospital staff again."

"Yes. Didn't have anyone who could do BSL. So didn't know what was happening. Missed out on a lot of things - not fair."

Five patients - 12% of the whole sample – felt like complaining about the treatment they had received at reception. In four of the five cases the patient had informed reception that they were Deaf, but the receptionist forgot and still shouted their name rather than fetching them personally.

6.3 Experiences at previous visits

The focus of the interview, on the most recent visit to A&E, carried a risk that experiences important to the interviewee might not be picked up, if they were part of a different visit. Accordingly, the interview included a question about what else (other than already covered by the interview) "good or bad" had happened during any visit they had made to A&E. 19 people (45%) had something positive or negative to report, between them providing a total of 21 comments. Five comments were positive and 16 were negative (table 6.16). The positive comments mostly referred to occasions when hospital staff had taken time and made an effort to communicate properly:

"[On another occasion] Doctor and nurses were friendly and relaxed and wrote things down when my daughter wasn't there."

"On other visits, always reminded them am Deaf and hospital staff said 'oh sorry' - and repeated themselves and spoke slower. Very good."

"Once went to XXXX hospital. Was surprised that they brought in staff nurse who can sign very well and she stayed with me all week in hospital. Made me feel really good."

The negative comments have been sub-divided into three categories. 9 comments referred to personal communication issues, some relating to hospital staff and others to a lack of communication support:

"Went to XXXX hospital reception a while ago. Explained to receptionist about deafness, but receptionist still spoke very fast. Very awful. Felt doctor communication in hospital worst – I can't speak well or write well."

"Lack of interpreters during my visit was awful."

"Been to XXXX hospital. Was awful. No communication and felt alone and lonely."

"Felt it was awful experience for our son because his parents are Deaf and no communication support from hospital."

Two negative comments referred to a lack of facilities for either telephoning in, or telephoning out, from the hospital:

> *"Dad was in hospital recently. Mum wanted to ring me from hospital to let me know, but couldn't as hospital didn't have textphone."*

The final group of 5 comments were all concerned with the medical treatment provided, mostly a failure by medical staff to obtain or provide information:

> *"Once went to hospital when daughter injured her arm in a fall. Problems understanding hospital staff and didn't understand what tablets where being given to her. She couldn't sign as her arm was hurting."*

> *"On another occasion, a doctor gave prescription without investigating what was wrong. Mum took me to another A&E and I was admitted for 7 days."*

In one case the hospital tried to use an insufficiently qualified interpreter:

> *"Went to XXXX hospital before. They booked a Level 1 interpreter. I couldn't follow what was being said and had injections - didn't know why."*

Another case raises a very important question about communication support within the operating theatre:

> *"Also, XXXX hospital refused to let my interpreter go into the operation theatre with me. I rang two days before operation to let them know about interpreter. They refused to let me bring interpreter, but I already had one, so brought her along and hospital staff still refused to let her be with me. Am still complaining about it at the moment."*

6.4 Suggested improvements to service

Interviewees were asked (on a free response question) what, if anything, the unit could do to make their visits into a better experience. The 42 interviewees between them made a total of 138 suggestions. These have been categorised and appear in table 6.17. 24 people (57%) said they would like hospital doctors/nurses/other staff to learn to use BSL, and a further two suggested that staff should learn some basic signs. A similar number of people, 24 (57%), highlighted the need for interpreter support; and in fact no less than 16 of these suggested that A&E units should provide 24hr interpreter cover, either by using staff trained in BSL or through an on-call system involving professional interpreters. An equivalent number, 24 (57%), stated that the unit should possess a textphone, for use by Deaf patients wanting to telephone out from the unit as well as those telephoning in. Only slightly fewer, 20 (48%) suggested Deaf Awareness Training for the staff, and just over one-third (15; 36%) wished for an electronic name display system at reception. Other suggestions were put forward by smaller numbers: TV with subtitles (19%); flashing light fire alarm (14%); fax machine for patient use (7%); information in more accessible forms (7%).

Chapter 7

Results: Interviews with A&E managers, and visits to A&E departments

7.1 Telephone interviews with A&E managers

Telephone interviews were conducted with the managers at 22 Accident & Emergency departments in the North West region. Managers at another seven departments declined to be interviewed.

Numbers of Deaf patients

The managers had very little knowledge of how many Deaf patients had received treatment in the department over the previous year. Of the 22 managers that were interviewed, two thought it was 20 or less, but none of the rest could suggest a figure.

Communication aids

Three managers stated that their unit had a loop system (table 7.1). This concurred with the number found to have a loop when the Deaf researcher visited (see section 7.2). One other unit was due to have a loop installed as part of a re-build. Although a loop system does not help Deaf patients, it's presence does indicate that some attention has been given to the needs of those with hearing impairment.

Two units reported having a textphone. However, one acknowledged that the textphone was not switched on and staff did not use it. The other manager did not know if the textphone was always switched on, and when the Deaf researcher visited he in fact found that it was kept in a drawer at reception. Neither manager knew if the textphone had an answerphone facility.

No A&E department was registered with the RNID TypeTalk scheme.

Two units possessed a portable listening device. These are small amplifying devices which can be used by people with hearing impairment in conversational situations. Although of little use to most profoundly deaf people, for a department to have such a device is an indication that the needs of people with hearing problems have received some consideration.

None of the 22 departments had an electronic name display for calling patients (this was also the finding of the Deaf researcher when visiting). In all cases staff called out for the patient, with in two cases (at least) this being done via a public address system. When asked how a Deaf patient would know that it was their turn, all the managers indicated that a member of staff would personally approach the patient. In all cases the success of this method depends upon the patient having previously informed staff of their deafness and exactly where they will be sitting. In some cases it also

depended on some staff (eg the triage nurse or receptionist) passing the information on to other staff.

> *"Written on the patient's notes. Medical staff ask reception staff and then go to the Deaf person".*

> *"Triage nurses would inform other staff and indicate where the patient was sitting".*

> *"We rely on someone with the Deaf person. Or rely on the Deaf person alerting staff 'I am Deaf'".*

The managers were asked whether they thought the information leaflets within their unit were suitable for Deaf people, given that many had limited literacy skills. Twelve managers (55%) thought their leaflets were suitable.

> *"Suitable. No medical terms. Basic, brief and short."*

> *"Suitable. Planned with a wide range of people in mind."*

> *"Written in simple language. I would think they would be able to understand them."*

Of the remainder, five thought they probably weren't suitable and the other five couldn't say.

> *"Not very suitable. Although in simple language, had not realised profoundly Deaf people have difficulty reading language."*

> *"Don't know, need advice on this issue."*

Access to interpreters

15 managers said that their unit had a system in place for obtaining a sign language interpreter (table 7.2), although in one case the interpreter operated on a voluntary basis which – the manager admitted – was "very hit and miss". However, even excluding this unit, around two-thirds of the departments appear to be aware of, and have sought to address, the issue of interpreter support. When asked how quickly an interpreter could be made available some managers were quite vague, suggesting little experience of actually arranging interpreter support, but the majority gave enough detail to indicate familiarity with the process. Seven units reckoned they could obtain an interpreter quite quickly or within one or two hours, provided this was during the normal working day. Out of hours it usually took much longer. Two other units indicated that it could take several hours any time of day.

> *"Nine-to-five Monday to Friday very quickly. Out of hours very poor."*

> *"Monday to Friday half an hour. At weekends we have the home phone number of who's on call."*

> *"Hours. Also depends on whether one is available, they are not always."*

"One to two hours. If not English and need a signer for a different language can take a lot longer."

The managers were also asked who else might be used to interpret – other than professional sign language interpreters. 21 of the 22 units indicated that they sometimes used the child of a Deaf patient, though some were keen to qualify this by adding that it also depended upon the age of the child and if the parent was happy with this. The same 21 departments also at times used a friend or relative of the patient.

Six units (27%) made use of a staff member in the hospital with signing skills, while another two had used staff in the past, who had since left. One other unit had two staff members currently undergoing training in BSL. Most of the remainder said they would use staff if there were any that could sign. The six staff who acted as interpreters were all individually contacted. Two were children of Deaf parents and had learned to sign from an early age. One of these also had a BSL Level 2 qualification. Two others had also passed BSL Level 2, and the remaining two were at BSL Level 1. One of the latter stated that she only 'filled in' while waiting for a professional interpreter to arrive. None reported experiencing any particular difficulties when interpreting for patients. The only problem, mentioned by two, was the amount of time it took to discharge their duties in their own department and get to Accident and Emergency.

Eight managers (36%) answered positively when asked if they would book a BSL interpreter in advance if a return appointment was necessary. This may not reflect what happens in practice however, as this number included three managers who appeared to have little or no experience of arranging interpreters.

Deaf Awareness Training

As shown in table 7.3, three units (14%) had staff members who had undergone Deaf Awareness Training (DAT). In all three cases the DAT was part of training for a single staff member in BSL, and all three were interpreting for patients. Three other departments had also received training requests: in one case training was yet to happen because of other priorities, and in another funds were being sought not just for DAT but for BSL training as well. All the DAT that had been provided, or was planned, involved just individual members of staff: no unit had implemented group or department-wide training.

Service evaluation

Just three departments had evaluated their service with regard to the needs of Deaf patients. Two had done so because of awareness of the communication issues. The third had been prompted to undertake an assessment by the passing of the Disability Discrimination Act.

The outcomes of these evaluations appeared to be very variable. At one unit it had led to little more than the purchase of a textphone (which was not in use - see above): the manager of this unit didn't know if they had access to interpreters and there were no staff who could sign; no staff had received Deaf Awareness Training; and there were

no future plans to address issues of Deaf access. At another unit the assessment had identified a need for better access to interpreters, but there were no plans to provide staff training or improve access in other respects. The department that had acted as a result of the DDA had identified a need for staff training in BSL and Deaf Awareness. As a result, one staff member was attending college and had passed Level 1 BSL, and was going on to undertake Level 2.

None of these three units appeared to have addressed the issue of Deaf access in what may be called a comprehensive fashion. However, the Trust of which the last was a part currently had a working party looking at disability within the Trust generally.

Perceptions of barriers to access

21 of the 22 departmental managers thought that Deaf access to A&E could be improved, with the one remaining manager being unsure (table 7.4). Managers viewed a lack of resources as the single biggest barrier to service provision for Deaf patients (mentioned by 16 (73%) on a free response question). This was closely followed by a lack of staff awareness about the needs of Deaf people (13, or 59%). Other potential barriers, including other priorities, time, lack of training and facilities, were only mentioned occasionally.

In terms of improvements that could be made to the department, eight (36%) mentioned (on a free response question) training in Deaf Awareness, and a further two for staff to have more understanding of the problems faced by the Deaf – which implies a need for training. To some degree however the size of response may have been prompted by a previous set of questions about staff who had received or requested DAT. Four managers suggested that they needed more aids to communication, without being specific about what type of aids; two mentioned visual patient information/call displays; and one a textphone. Better access to interpreters was mentioned by only two managers. One manager indicated that his/her unit was due to be rebuilt, and the disability working party was looking at issues of access.

Future plans

When asked about future plans related to Deaf access only one unit knew of any. This was to look at access for disabled groups in general.

7.2 Visits to A&E Departments

The Deaf researcher made visits to 22 of the 29 Accident and Emergency departments in the North West health region. Another seven did not provide written permission for a visit. The researcher rated the public areas of each unit according to a checklist of items (see section 2.2), most of which could be assessed on the basis of a purely visual inspection, though where appropriate additional information was sought from reception staff. The researcher also noted down any additional observations he considered relevant.

Finding the A&E department and moving around within it

A number of items on the A&E checklist were concerned with finding the entrance to the department and the ease with which a person could find their way around inside. Difficulties of communication mean that many Deaf people, particularly those without speech, cannot easily obtain directions from a stranger. Hence clear directional signs and nameplates become especially important. The findings of the A&E visits with respect to this issue are summarised in table 7.5.

18 departments (82%) had an entranceway that was easy to identify from outside the building, leaving just four departments where the Deaf researcher had some difficulty knowing which was the correct way in. The checklist did not address the issue of finding the hospital itself, but in a few cases this was problematic in itself:

> *"No directions (by the roadside) at all to the hospital. I asked a police car and they escorted me to the hospital. Even then, the A&E signs were coloured green – so far, only hospital where the colour is not RED. It really confused me." (Deaf researcher)*

> *"A&E very well labelled from outside the hospital, but was confused which hospital I had to go to as there were two signs pointing opposite each other for hospitals! Drove to one first, then found it to be wrong one, then drove back to the correct one later! Could be better directions from main road showing which hospital is which." (Deaf researcher)*

Within the A&E departments themselves, the reception area was well signposted and easy to find in 18 cases (82%), but not obvious at all in the remaining four units. At one children's hospital it appeared to have never occurred to the planners that some parents might be Deaf:

> *"Very few instructions inside the hospital. Maybe because it is a children's hospital? What about instructions for the parents who could be Deaf or hard of hearing? I couldn't find the reception area and had to ask for directions. Even when I was in the reception area, I thought it was an office! No signs or anything to indicate it was a reception, except there were childrens' toys to play with." (Deaf researcher)*

The waiting area was also clearly defined at 17 departments. Some units had two or more separate waiting areas, with patients dependent upon asking at reception to know where they should sit.

At only five of the 22 departments (23%) were all the other main areas where patients might need to go (such as x-ray) clearly signposted. The following typifies some of the difficulties with signage:

> *"There are sign displays for various sections of the hospital on ceilings – many people in a hurry are unlikely to look up at the ceiling at times of emergencies to read the signs. There are some instructions/marking/directions on the walls, but it is not always clear what they mean." (Deaf researcher)*

Three departments had a system of colour-coded lines (to direct patients to other areas) on the floor. However, in two cases the system proved to be quite confusing:

> *"Partially colour-coded, but no clues as what the colours stand for. I was told that red was for an x-ray, so followed it and then it disappeared under a wheel chair! What was blue for? And it started just after the red disappeared!"* (Deaf researcher)

> *"Tried to follow one colour coded line on the floor. It led me to the side of a wall and when I approached the wall, the line disappeared! When next I saw the line, it was a different colour!"* (Deaf researcher)

Clear labelling of all the doors off the reception and waiting areas assists patients in finding their way around. Only seven units had all doors labelled, though all the remaining units did have some doors labelled.

Facilities for communication

Another set of items on the checklist were concerned with the provision made to facilitate communication with Deaf (and where they overlap, hard-of-hearing) people. The results with respect to these items appear in table 7.6.

The Sympathetic Hearing Scheme (SHS) is operated by the charity Hearing Concern. Organisations with staff who have undergone Deaf and hard-of-hearing communication and awareness training under the scheme (usually a half-day course) are entitled to display the SHS symbol. However, the symbol doesn't indicate what proportion or types of staff have had the training. five (23%) of the departments had the SHS symbol on display.

Three departments had a loop system (which assists hearing aid users to pick up spoken communication) installed at reception. All three also displayed a sign to indicate the presence of the loop system. Although loop systems do not help profoundly Deaf people (who find hearing aids of little benefit), the presence of a loop would indicate that the department had paid some attention to the needs of people with impaired hearing. One would hope that any site that displayed the sympathetic hearing symbol would have installed a loop system at reception, but this was clearly not the case.

Adequate lighting is important in communication for Deaf people, as bad lighting impairs the ability to lip-read and to read sign language. Although we have only assessed lighting subjectively (rating it as good, OK, or poor), the Deaf researcher relies heavily on lip-reading in everyday life and was therefore in a good position to make a judgement. The lighting levels at reception were rated as being "good" at just three units, but "OK" at another 14, while being "poor" at five (23%). Lighting within the waiting area was also rated "good" at three sites, but "poor" at a larger number, 10 (45%).

People attending A&E departments at times need to make essential telephone contact with someone - for example a relative – on the outside. A Deaf person may also need to telephone the A&E unit from outside. Deaf people cannot use standard telephones and require a different type of provision. The siting of a text-phone within the

department is the optimal solution. Some pay phones come complete with a pull-out keyboard, or a textphone can be made available at reception. None of the departments possessed a payphone with texting facility. Two (9%) had a textphone, but in one case this was kept in a drawer at reception when not in use, making it no use at all to a Deaf person trying to ring in, and at the other department the reception staff didn't know where the textphone was kept.

A substantial number of Deaf people keep a portable textphone with them that can be used in combination with standard BT payphones. However, the unit cannot be used effectively without a shelf or sturdy feature (eg table) next to the payphone to position it on (for typing purposes). None of the departments provided anything suitable. This was the researcher's comment about one of the sites visited:

> *"The telephone is located above a rubbish bin. The shape of the telephone is awful and a big problem for Deaf people who may have their own compact/mobile textphone for their use. The phone handset is square and would not fit into a compact textphone. The bin above the telephone is round, preventing patients from leaving things on top of it and further hampering the Deaf patient who may want to place a textphone on top of the rubbish bin. The telephone is located in a noisy location – which may cause noise interface for textphone/loop users." (Deaf researcher)*

None of the units possessed a visual patient call display system. In all units patients were called verbally, and in at least one sometimes over a tannoy system. Reception staff at a few departments said they had a special procedure for Deaf patients:

> *"If the patient is Deaf, this is specified on the patient's card/folder, and patient asked to sit in a specific location, so that they are easily identified by the receptionist or medical staff." (Deaf researcher)*

> *"The doctor comes round to shout patients names when it is their turn. The receptionist said she tells the doctor who is Deaf." (Deaf researcher)*

The drawback to a system such as the latter is that staff at reception sometimes go off duty without informing their replacement that a particular patient is Deaf.

The period when they are waiting to be called creates considerable anxiety for Deaf patients, more so than for hearing people. Deaf patients need to keep an eye continually on the receptionist and other staff (eg a nurse or doctor) who might call them, to try and lip-read the names that are called, or to see if they are being waved. The receptionist may also call them for reasons other than their consultation. Deaf patients at A&E have to keep such vigilance even while experiencing trauma from an accident or emergency. To minimise the difficulties, Deaf patients require a clear view of the receptionist (plus, ideally, and any other positions from which their name could be called). In only 6 (27%) of the 22 departments was it possible to lip-read the receptionist from the waiting area, and in 4 of these this was possible from certain seats only:

> *"Reception staff and patients cannot see each other. Deaf patients need to constantly look at reception staff to be aware of what is happening. This is not possible in this hospital's Accident and Emergency department…. Patients are*

sometimes called by a tannoy system. Sometimes, the nurse/consultant/doctor walks to the edge of the waiting area to shout out patient names…. When names are being called, the caller looks down at the paper/folder. This distorts their face and makes it difficult to lip read." (Deaf researcher)

"Sitting arrangement for patients very poor. Patients sit facing each other, or with their back turned to the receptionist." (Deaf researcher)

"Good waiting area plan, with all patients facing the receptionist. Unfortunately, patients can only see the receptionist's hair from a sitting position – they cannot see her face unless they stand up." (Deaf researcher)

At several units reception staff were seated behind glass security screens. These can create additional problems of communication for Deaf patients:

"It can be difficult to lip-read the receptionist due to the glass barrier which shows reflections at night – like a mirror." (Deaf researcher)

However, a few departments did have waiting areas suited to the needs of Deaf patients:

"Good sitting position for patients. The seats face the reception staff and it is easily to lip-read or see the receptionist wave to get the attention of a Deaf patient, etc." (Deaf researcher)

"Good reception sitting areas. Quite low and user-friendly. It is quite easy for Deaf people to feel comfortable and approach the receptionist if they have questions." (Deaf researcher)

Other facilities for the Deaf

Just one of the 22 departments had a flashing-light fire alarm system (table 7.7), to alert Deaf people to the need to evacuate in case of a fire. However, the system had only been installed in the corridors, rendering it ineffective for Deaf patients elsewhere in the building.

All departments had a television in the waiting area. Nine of the sets had a teletext facility, but in no instance were program subtitles (available via a teletext page) being displayed. When approached about this, reception staff typically did not know how to put the subtitles on, or even that they were available.

7.3 Vignettes of a few departments

Short vignettes are presented here for three of the A&E departments that were interviewed and visited. One is illustrative of a department that was particularly poor with respect to facilities for Deaf patients, the other two are somewhat 'mixed' in character: good in some respects, poor in others . There was no department that could reasonably be described as on the whole good in terms of the facilities provided for Deaf patients.

Hospital A (Poor)
The A&E entrance was easy to find, but the sign was confusing as it was not in the standard red letters used at most A&Es. There were not enough signs for reception and the waiting area was not clearly defined. Nor was it easy to find directions to other areas. In addition, only some of the doors were labelled and there was no colour-coded directional line system. The sympathetic hearing symbol was not on display, but there was a loop system at reception. There was no textphone - however, it might be possible to place a portable text-phone on top of the payphone. Lighting was poor (for the purposes of lip reading) at both the reception and waiting areas. The reception desk was protected by a highly-reflective glass security screen making it difficult to lip-read the receptionist even from close by, and no chance from the waiting area. When a patient was wanted a doctor or nurse would call out their name. The television set did not have a subtitles facility. There was no flashing-light fire alarm. The department had no system for obtaining BSL interpreters; no staff could sign and none had received DAT; nor had the unit assessed their services in relation to the needs of Deaf people.

Hospital B (Mixed)
Both the hospital and the A&E entrance were well signposted and easy to find. Inside, there were good directions to reception and the waiting area was clearly defined. All the doors were labelled, with clear easy-to-see signs at the top. However, directions to other areas were not always clear, and there were no colour-coded directional lines on the floor. There was no sympathetic hearing symbol and no loop system at reception. The unit possessed a textphone, but this was kept in a drawer and apparently not many staff knew about it or how it worked. The only place to balance a portable text-phone was on top a rubbish bin. The waiting area was well-designed, with the seats facing reception, making it easy for a Deaf patient to view the lips of the receptionist or see them wave. However, the benefits of the layout were somewhat marred by poor lighting levels. The television was capable of displaying subtitles but reception staff didn't know how to do this using the remote control. There was no flashing-light fire alarm system. The unit had access to BSL interpreters and also had a member of staff who was trained to Level 2 BSL. The unit had not evaluated it's services to Deaf people.

Hospital C (Mixed)
The A&E entrance was very easy to find; in fact the hospital itself was well signposted throughout the area. There were clear directions to reception at the door, but inside the waiting area was not clearly delineated. Only some of the doors were labelled, there was no colour-coded line system, and there was a lack of directions to other areas. However, a nurse said that staff members take patients to any other department they need to visit. The sympathetic hearing symbol was on display at the entrance door, but there was no loop system at reception for the benefit of the hard-of-hearing, nor did the unit have a textphone or a suitable place to balance a portable textphone. The lighting at reception and in the waiting area was good and patients are able to lip-read the receptionist from where they sit (though not from all seats). The receptionists said they make a note on the record of any patient who is Deaf. There was no flashing-light fire alarm and the television was not capable of displaying subtitles. The unit had access to BSL interpreters and claimed that during office hours an interpreter could be obtained very quickly, also that an interpreter would be booked in advance for follow-up appointments. Three staff members were able to finger-spell in BSL. The unit had not evaluated it's services to Deaf patients.

Chapter 8

Results: Policy and Service Initiatives

8.1 Policy

GP practices

The telephone interviews with GP practice managers (chapter 5) included a question about written policy with regard to access to the practice for people with a disability. Four practices out of 31 (13%) reported that they possessed such a policy. Two others stated that they were currently reviewing their policy, and one of these made a specific mention to the DDA as motivating the review. Two further practices said they were in the process of developing a policy. A total of 22 practices (71%) had no policy and no immediate plans to produce one.

The four practices that claimed to have a written policy all agreed to provide us with a copy of this. However, none did, despite follow-up telephone contacts one month after the initial request.

Primary Care Trusts

In Autumn 2001, all 15 Primary Care Trusts in the North West Region were approached for information regarding any written policy they may have produced with regard to access for people with disabilities. In three cases we were unable to make contact with a relevant person (someone with some responsibility or knowledge about policy) in the Trust. Of the remaining 12, 7 stated that they had no policy at present; one had just completed an audit in relation to the DDA and would be producing a policy in the light of this; three said they would come back to us with information but never did; and one asked us to provide an official request for information, to be approved by the Trust's Chief Executive - we supplied the request but received no reply.

In summary, most of the PCTs had not produced a written policy, and none of the rest – even if they had a policy – were either unable or unwilling to provide a copy of the documentation.

Accident & Emergency Departments

Telephone contact was made with all 29 NHS Hospital Trusts in the North West with an attached A&E unit to request information about policy pertaining to access to A&E departments for Deaf people. No Trust had any relevant policy, but two indicated that this was an area currently being looked at by a working party.

As part of their telephone interview (section 7.1), Accident & Emergency department managers were also asked about policy. This was partly in case any units had produced policy independently of their Trust, and partly to provide a check on the information obtained at the Trust level. 19 out of the 22 managers interviewed stated

that they had no written policy, while the remaining 3 did not know one way or the other.

8.2 Service Initiatives

In addition to formal policy, we gathered information with respect to relevant initiatives in health service provision by providers within the region. Such initiatives often represent a response to policy formulated at higher levels, such as government (eg the DDA) or the NHS Executive, or represent an attempt to operationalise the service principles or core values of the organisation itself. In addition, initiatives are often a preamble to the development of policy, for example where they involve audits or information gathering.

Information about service initiatives was not collected in a fully systematic way. We approached all Local Authorities in the North West for a copy of their most recent Community Care Plan (CCP), and obtained Plans for 13 Authorities. However, CCPs by no means provide a comprehensive review of service developments, and being for public consumption may present things in the best possible light. Some initiatives we found out about while reading other documentation, and some through personal contacts within the Deaf community and the Health Service. Consequently, the list below is by no means comprehensive and should be regarded as only representing examples of initiatives within the region. Furthermore, we have not attempted to follow-up initiatives that started some years ago, and therefore have no idea of how successful, or otherwise, they have been. Despite these caveats, however, these examples do demonstrate that a fair amount of activity has been going on at a number of localities in the North West region since the late 1990's aimed at improving services in ways that benefit Deaf people.

Bolton
The Bolton Community Care Plan for 1997-2000 describes a plan to "evaluate current service policies, procedures and practice to ensure adherence to the DDA 1995 in regard to access to services" (Bolton Social Services, 1997). A review is to be undertaken of access to GP surgery premises, and GPs are to be offered access surveys and resources to improve access for people with disability (although it is not clear from the plan if this covers sensory as well as physical disability).

Bury
One of the core principles of Bury and Rochdale HA is to provide "an equitable service" to all. Following a successful Health Action Zone bid, a design brief has been developed to improve the accessibility of properties in the public and private sector to people with physical and sensory disabilities. (Bury Metropolitan Borough Council, 2000).

North Merseyside
Since 1999 North Merseyside Community Health trust have been working to improve quality and access to their services by Deaf and HoH people. A training and development programme has been implemented to raise staff awareness of deafness and Deaf culture. Auxiliary aids such as induction loop systems and textphones have been installed at premises throughout the Trust. A free interpreting service has been

set up in collaboration with neighbouring Trusts. This project won an NHS Equality Award (Department of Health, 2000).

North and South Trafford PCTs
South Trafford PCT has established a DDA sub-committee working party. In 2002, both North and South Trafford PCTs implemented programmes to install induction loop systems and textphones in all GP surgeries. In addition, surgery staff are being provided with training in Deaf Awareness and use of the textphone. The PCTs are also making funding available to reimburse GP costs of providing interpreters to Deaf patients (Lambert, 2002).

Oldham
Oldham has a joint planning structure incorporating purchasers and providers of both health and social services. Service principles include: (1) purchasers and providers should take action to tackle any discrimination against disabled people; (2) disabled people should be equal partners in the planning and evaluation of services; (3) when providing services to a disabled person, staff should describe the choices available and ensure the person is able to select the option best for them; (4) information should be in accessible formats. Advisory groups form part of the joint planning structure, including a Physical and Sensory Disabilities group, comprised of providers, users and carers. One role the group has is to "identify gaps in service provision and advise on how these gaps can be filled". Members of the group have been advising hospital managers on changes to improve access at Royal Oldham Hospital (Oldham Social Services, 1998).

Sefton
The Sefton Community Care Plan 1999-2002 states that a survey of all health services has been undertaken to look at general access. Also an access booklet has been produced and distributed to all social service sites (Sefton Social Services, 1999).

Tameside
Tameside Metropolitan Council, in conjunction with West Pennine HA and Tameside and Glossop PCT, provide a free of charge BSL intepreter service. Interpreters can be booked by either the Deaf person or the health provider. For health appointments, an interpreter should be provided within 24 hours, and in an emergency, within 2 hours. There is also an emergency only Out of Hours Service. The reason why this service is free of charge is because the HA and PCT (amongst other organisation) have contributed financially to the service.

Warrington
Warrington Community Health Care (NHS) Trust has established a full time Disability Services Advisor post (NHS Executive, 1999a). The post holder is a senior manager with responsibility for the DDA. Duties include disseminating information to all Trust staff, facilitating specialist seminars and conferences on disability related topics, networking with other agencies, and delivering disability awareness training. As of January 1999 the Advisor had presented disability awareness training to more than 300 Trust staff. Within the present study, the A&E unit at Warrington Hospital was the only one to offer to obtain a professional interpreter for a Deaf patient.

<u>Wigan</u>
One of the aims of Wigan Borough Health Partnership (made up of representatives from each PCG) is to "minimise the handicap of disadvantage and disability". A research project was undertaken in 1998 into the needs and views of sensory disabled service users. An objective for 1999-2002 was to develop and implement an Action Plan on the basis of the research report. Another was to undertake a joint Health and Social review of services (Wigan Social Services, 1999)

<u>Wirral</u>
Wirral Community Care Plan for 1997-1998 states that Wirral HA has adopted a policy of "improving health by improving access to health services". The Plan also states that Wirral HA are developing an interpretation service to enable people with deafness to make better use of primary care services (Wirral Social Services, 1998).

Chapter 9

Results: Ways and costs of facilitating access

9.1 Problems and solutions

The principal problems that Deaf people experience when accessing health care can be divided into four main groups: (1) telecommunications; (2) difficulties when queuing; (3) communication with receptionists and medical staff; (4) written information. While other forms of difficulty certainly exist, the vast majority of the problems reported by people in our survey fall into these four categories. Solutions exist that can minimise the difficulties experienced in all four areas, and – as this chapter will show - most of these solutions are quite simple to implement and fairly inexpensive. Equipment costs vary depending upon the particular manufacturer, model, or supplier. The costs used in this section are therefore mid-range, based on information from supplier catalogues and other sources, and are exclusive of VAT.

Telecommunications

More than half of the Deaf people interviewed had difficulty making an appointment with their GP, in most cases because they were unable to personally contact the practice from a distance. Deaf people also have difficulty accessing other services - commonly available to hearing people - via telecommunication, such as repeat prescriptions and test results. Just over half the interviewees said they would like their GP to possess a textphone. None of the Accident & Emergency units possessed a means by which Deaf people could conveniently telephone either in to, or out of, the unit.

The traditional textphone is a separate piece of equipment to a voice phone and needs to be on a different line. In addition, being designed for use by Deaf people, textphones do not give an audible signal and have to be used in conjunction with a battery-operated 'telephone alerter' (or a standard voice telephone plugged into the same socket with a double adapter), to alert a hearing person when the phone is ringing. These inconveniences, along with infrequent use due to small numbers of Deaf patients, probably explains why so few GP practices have textphones, and why installed textphones tend to fall out of use. A more recent development is the combined voice & text phone, which provides both facilities and simply replaces a standard voice phone (note: this unit should not be confused with the far more limited text facilities available on mobile phones). A voice & text phone suffers none of the inconveniences of having two separate units, and because the user (eg a receptionist) uses the same equipment to deal with both types of call, infrequent use of the text facility is less of a problem. A voice & text phone, with a text answerphone facility, costs around £200. Running costs are the same as for a standard phone.

An entirely free service that providers should be aware of is the TextDirect system, operated by British Telecommunications. TextDirect replaced Typetalk in 2002. The advantages are that registration is not necessary and that the system is very simple to use. A TextDirect operator reads the text from the textphone user to the voice

telephone user and vice versa. A Deaf person making a text to voice call dials 18001 before entering the full phone number (code plus number); a hearing person making a voice to text call dials 18002.

Accident and Emergency departments are usually furnished with a public payphone. British Telecommunications (BT) have installed public text payphones at certain sites, such as airports and railway stations. It is possible to request BT to replace a standard payphone with a voice & text payphone, provided certain criteria are met, related to demand and necessity.

Queuing

One-fifth of the Deaf patients without communication support at their GP practice, and one-third of those at A&E, experienced a problem knowing when it was their turn to see a doctor. Even patients who did not miss their name being called, found the wait and the attendant fear that they had missed their turn a source of considerable anxiety. Over half the people interviewed suggested that their practice install a visual patient call system, while less than a quarter of the practices interviewed possessed such a system.

A simple way to minimise problems for Deaf people whilst queuing is to install a visual patient call system. These take two main forms. The first is an electronic board that displays each patient's name as their turn arrives, or each GP's name as they become free, or both. The second is a simple electronic number display, with each patient being assigned a number as they arrive, and being seen when their number is displayed. Both systems can be operated from a dedicated keyboard or via a personal computer. In terms of costs, although a number board is less expensive, a ticket dispenser and regular supply of tickets are also required, and so total costs do not differ greatly. Name displays are more versatile in what they can display, and possibly easier for some Deaf people to understand, therefore we cost only this type of system here.

A suitable system for GP waiting rooms would be a single-line 20 character display, with 5cm high characters. A person with normal vision would be able to read this from a distance of 25 metres. Using the keyboard or computer the receptionist is able to display standard or personalised messages in scrolling or static type. The typical cost for such a system is £500 (this includes the display, keyboard, computer software, fixing brackets and connecting cables). At some practices there may be additional installation costs, for example if there is no nearby power socket, or if the cables are to be run through a conduit.

The same system may be suitable for many Accident & Emergency unit waiting rooms, particularly if used in conjunction with a voice call whilst seats nearest to the display are reserved for patients with hearing impairment. In some A&E units the use of larger, 10cm, characters may be a better option. A 20 character single-line display board of this size typically costs around £1,100. A&E units are likely to incur installation costs, due to higher ceilings, greater distances to be spanned, etc, and depending on their layout, some units may require more than one display board.

Communication

The greatest source of problems for Deaf patients was inadequate communication with medical and reception staff. Two important means of minimising the barriers to successful communication are to provide staff with Deaf Awareness Training (DAT), and to provide BSL interpreter support to Deaf patients who require it. These are complementary rather than alternative ways of improving communication. For example, DAT courses usually include training in how to work most effectively with an interpreter.

Deaf Awareness Training
DAT can be delivered to staff either as a course in it's own right, or as a component of a more general disability training programme. A general programme is likely to be less effective at improving skills in communication with Deaf people, partly because the amount of time devoted to deafness will be less, but also because the trainer(s) may have no personal experience of being Deaf, or of any other disability. A dedicated DAT course is normally delivered by a Deaf or HoH trainer, and this provides participants with direct experience of the communication difficulties. In addition, a Deaf trainer will be supported by a BSL interpreter, which also gives participants valuable experience of working with an interpreter. The costings given here therefore, relate to Deaf Awareness Training.

A large number of different organisations offer DAT courses. Some, such as RNID, offer a range of different courses, each with a different emphasis (eg communication technology, Hard of Hearing people, basic sign language), and will tailor a course to the specific needs of a particular organisation. A basic half-day DAT course costs between £150 and £300 for 15 to 25 participants. One-day courses provide a more thorough grounding and range between £300 and £500. The Council for the Advancement of Communication with Deaf People (CACDP) offer a national Certificate in Deaf Awareness, on the basis of a 30 minute multiple-choice examination. Some one-day courses offer the opportunity for participants to take the examination at the end of the course, for an examination fee of £12 to £20.

BSL Interpreters
Health providers can book a professional sign interpreter or a lip-speaker either directly or through an agency. The cost varies depending upon the agency, the qualifications of the interpreter, and the assignment. There is a minimum booking time of 2 hours, with time charged hourly after that. A typical charge for an interpreter (within normal working hours) would be between £50 and £60 pounds for two hours, and £20 to £30 for each subsequent hour. The interpreter's mileage costs need to added in, costed at about £0.40 per mile.

Some providers have a service agreement with an agency, and some have grouped together to fund their own interpreter service. The costs to a particular provider of being part of such a scheme depend very much upon the annual amount of interpreter support required.

Another way of improving communication with Deaf patients is to train some members of staff in BSL. Training a staff member up to the level of the nationally recognised CACDP Level 2 BSL qualification will provide them with the skills to communicate with Deaf people in most situations outside of important medical

consultations (this is discussed in more depth in section 10.2). The CACDP Level 1 BSL qualification has to be achieved prior to Level 2. Stage 1 is a 60 hour course, usually taught in two-hour blocks or over a few days. Costs vary between £90 and £200. Entry to the examination is a further £33. BSL Level 2 is a 120 hour course (90 hours classroom based). Costs range between £150 and £500. Entry to the examination is £95.

An additional important communication measure is to allow extra time for consultations with Deaf patients. Each Deaf patient should be allocated a double-length appointment slot. In our survey, the patients with communication support at consultations tended to have considerably longer than normal consultations in any case. It was the lone patients that were disadvantaged, but if health professionals were using Deaf Awareness communication tactics they should also spend longer than normal with these patients. Extra time is also required to ensure that information about prescribed medication and after-care can be provided in written form (see below).

Written information

Communication barriers in face-to-face communication, plus the limited literacy of many Deaf people, makes the provision of appropriate written information particularly important to this group of patients. Written health information can be provided to patients in two main forms. The first is pre-printed health information leaflets about particular medical conditions, such as diabetes and asthma. The second is patient-specific information related to personal medication and after-care. It is particularly important that Deaf patients receive such patient-specific information in written form because of the likelihood that they will not have fully understood an aural explanation. The cost to a practice of providing this amounts to the one to three minutes it will take the GP, or nurse, to write down the information.

Health information leaflets need to be in a form appropriate to the literacy levels of Deaf patients. A search of the catalogues of the major Deaf organisations and health information publishers was undertaken, but failed to find a commercial source of pre-printed materials designed for this audience. We would not advocate that providers attempt to create their own. An alternative is to ensure that the generally available leaflets use plain English and avoid medical terminology, jargon, and abbreviations.

9.2 The cost of a basic package of measures to facilitate Deaf access

A basic package of measures that would serve to minimise the majority of problems of access for Deaf patients at most provider sites would consist of a combined voice-and-text phone, a visual patient call system, DAT for medical and reception staff, BSL interpreter support (where required), written information about medication and after-care, and double-length appointment slots. The analysis presented here is concerned only with the equipment and training costs associated with implementing this package of measures. For a full economic analysis other costs would need to be taken into account, including the opportunity costs of staff time, equipment depreciation, and the effect of improved access on demand.

The main opportunity costs of staff time are all fairly minimal. The time spent undertaking DAT amounts to a half-day or a day for each staff member; the 'average-sized' GP practice would book an interpreter just 18 times a year; and about the same number of appointments would involve medical staff spending a little more time with the patient than they do at present. Even the largest A&E unit would be unlikely to spend more than 30 hours a year, in total, on booking interpreters and providing additional medical staff time to Deaf patients. The potential effect of improved access on demand is not easy to estimate: a high proportion of the Deaf people surveyed indicated that they would use their GP more if communication was better, but conversely, improved communication at a first consultation could reduce the number of return appointments that Deaf patients make (eg for further information, or as a result of incorrect initial diagnosis or treatment). These factors to some degree will cancel each other out. There could also be considerable overall savings to the NHS if improved communication leading to better primary care reduces the need for referral and admittance to secondary services. The time that staff spend participating in DAT is assumed to be covered by the standard allocation of time for staff development. As with GP practices it is assumed that time spent booking interpreters and additional medical staff time with Deaf patients will be absorbed: even in the largest units neither is likely to consume more than 20 hours of working time in a year, an average of little more than 3 minutes per day.

GP practices

Table 9.1 presents the costs, for various sizes of GP practice, of implementing a basic package of measures for Deaf patients consisting of a combined voice-and-text phone, a visual patient call system, DAT for medical and reception staff, BSL interpreter support (where required), written instructions about medication and after-care, and double-length appointment slots for Deaf patients. In calculating the costs we have selected makes and suppliers that are reliable and represent good value for money. The costs make various assumptions, based upon the results of our survey, including the assumption that Deaf patients have an average of six GP appointments per year and that 50% of Deaf patients require BSL interpreters. DAT has been costed as a one-day course at the start, followed by annual half-day courses aimed at new staff and those wishing to 'top-up' their skills. Other assumptions are listed in the table.

Table 9.1 shows that 'start-up' costs (the voice & text phone, patient call system, and DAT) amount to £1,050 at each practice. When interpreter fees are added in, total costs over the first year vary from £1,478 for a practice with 2,000 patients (a typical single-handed practice), to £3,618 for a practice with 12,000 patients (a large health centre). Running costs for subsequent years are much lower, ranging from £578 to £2,718. Expressed as an additional cost to the practice per patient appointment (Deaf and non-Deaf) over a full year, this amounts to between 5.7 and 7.2 pence per appointment.

Table 9.2 presents the costs of implementing this basic Deaf access package across all GP practices within each of the five study Health Authorities. First year costs (which include equipment) range between £157,000 in St Helen's and Knowsley HA and £255,000 in South Cheshire HA. Running costs for subsequent years tend to be a little more than half the first year costs.

The Health Authorities were replaced in 2002 by a much reduced number of Strategic Health Authorities, and the key organisational unit for primary care became the Primary Care Trust. After the last round of PCT mergers, in April 2002, there was a total of 302 PCTs in England. Information on the precise make-up of each of these, in terms of practice numbers and sizes, is not yet available. For this reason we have been unable to estimate costs for the actual PCTs in the North West region. Instead, table 9.3 presents costs for a range of different sizes of hypothetical PCT (the average size, nationally, is 30 practices). The estimates are based on the distribution of practice sizes found in the study areas. In practice, two PCTs of the same size will have different costs depending upon practice sizes: a higher proportion of large practices results in a lower overall cost.

The table shows that to introduce the basic package across all practices in the average sized PCT (of 30 practices) would cost in the region of £66,000 for the first year, and £39,000 per annum after that.

Accident & Emergency departments

A similar analysis of costs with respect to different sizes of A&E unit appears in table 9.4. The cost of the visual patient call system is based on a board with larger, 10cm, characters, but two 5cm devices could be purchased for the same price. Most medical staff who work in A&E (or in services used by A&E, such as X-ray) are not exclusive to the unit (ie they also work in and for other hospital departments), but for simplicity the current analysis assumes that the DAT is undertaken for A&E related work only (and therefore the full cost can be assigned to A&E). DAT is costed as a one-day course for subsequent years (rather than a half-day, as was the case for GP practices), to allow for a high rate of change of staff in such units.

The table indicates that start-up costs for each unit are £1,800 to £2,100 (for larger units). Total costs in the first year vary between £4,088 for a small unit to £9,000 for a very large one. Running costs for subsequent years range from £2,588 to £7,200. Spread across all patients (Deaf and non-Deaf) seen in A&E over one year, this equates to an additional expenditure of between 6.0 and 6.5 pence per patient visit.

Chapter 10

Summary, conclusions and recommendations

10.1 Summary of main results

Deaf people's experiences of using GP services

Interviews were conducted with 98 Deaf adults (48 male, 50 female) resident in the study's five target Health Authorities. The sample was stratified by area, gender and age. Two-fifths of the sample (41 people) were obtained by random selection from a compiled database of Deaf adults living in the target areas; the other three-fifths (57 people) were principally matched replacements for randomly selected individuals that did not respond. The findings of the study were the same in all important respects for both the random and replacement sub-samples.

The interview schedule contained a number of items drawn from the National Survey of NHS Patients, General Practice 1998. This made it possible to compare the study's sample of Deaf people with a large representative sample of the general population in the North West on a number of key questions.

All the 98 Deaf people interviewed were registered with a GP. Eight people (8%) had changed GP at one time due to problems communicating with the GP or a perceived poor GP attitude towards their deafness. Nearly one in four (23%) would like to change their current GP for the same reasons.

Only two of the people interviewed (2%) could easily make a textphone - to - textphone call to their GP practice. Six other practices that possessed textphones did not always have these connected up or practice staff did not know how to use them.

Nearly two out of every three interviewees (63%) felt that it was very important for them to have someone help them communicate with their GP. Just 11% said they did not need, or preferred not to use, any assistance.

Just over half (54%) expressed a preference for communication support provided by a Professional Sign Interpreter, while around one-third (30%) preferred to use a family member.

About half (52%) had arranged, or tried to arrange, an interpreter for a GP visit, and 73% had experienced a problem doing this. In 95% of cases the difficulty lay in finding an interpreter who was available for the given appointment time.

61% of the sample had consulted their GP about their personal health within the last three months. This is a somewhat higher percentage than amongst the NSP sample of the general population in the North West (47%). The people in the sample were estimated to visit their GP on average around six times per year.

Even though the consultation rate for the sample was higher than for the general population, three out of every four (74%) said they would visit their GP more often if

communication was easier. Worries over communication led some people to delay until their condition became quite serious.

75% reported that their GP practice used a verbal announcement to inform waiting patients of their turn to be seen. Just over one-fifth of practices (22%) used a visual patient call system (an electronic display or number system).

Over the previous twelve months, one in five (19%) had made a complaint about staff or facilities at the practice and another one in five (21%) had felt like complaining but hadn't made a formal complaint. These proportions are very much larger than comparative figures for the general population, which show one in one-hundred making a complaint and about one in nine feeling like complaining. The majority of the complaints that Deaf people had were about poor communication or staff attitudes.

Compared to the sample of the general population in the North West, a smaller proportion of the Deaf people interviewed held positive perceptions about the way their GP related to them. Two-thirds (66%) felt that their GP treated them with courtesy and respect all or most if the time, compared to 93% of the general population; two-thirds (66%) were of the opinion that their GP listened to them all or most of the time, compared to 85%; and one out of every two (48%) said their GP never or hardly ever made them feel they were wasting his/her time, compared to nearly four out of every five (78%). Perceptions of reception staff were also generally less positive, with 54% saying receptionists were as helpful as they would wish at all or most times, compared to 75% of the general population.

With regard to the last visit to the GP, in those cases (the great majority) where an appointment was required, about half (47%) were arranged by the Deaf person themselves, and the remainder by someone else, usually a family member. Amongst those who made their own appointment, nearly half (45%) did so by visiting the practice in person, while most of the remainder (45%) booked by telephone (either using TypeTalk or via a textphone in the practice).

Two in every five (39%) who self-booked found this either quite difficult or very difficult, whereas a significantly higher percentage, 64%, of those who used family or friends reported difficulty (p<0.01). The majority of this latter group were people who didn't have a facility to contact the surgery themselves from a distance, so had to resort to depending on family/friends. In contrast most of those who self-booked said it was easy because they made direct contact from a distance using TypeTalk, textphone or fax.

Just over half the sample (53%) were alone on their last visit to their GP, while another 3% took along a spouse who was also Deaf. A little more than a quarter (27%) were accompanied by a family member who could hear. The remaining 17% had a Professional Sign Interpreter. The urgency, or otherwise, of the reason for the visit made no appreciable difference to the presence of an interpreter.

A few had tried to arrange an interpreter but had not been able to get one in time for the appointment. Many more, however, had not tried because on previous occasions they had been unable to obtain one. 13% of the sample had never considered using an interpreter or didn't know how to go about booking one.

One in four (26%) of the Deaf people alone at reception felt that the receptionist had not done his/her best to communicate, and about one-third (34%) understood only 'some' or 'very little' of what the receptionist tried to convey. In most cases much of the communication was conducted in writing. Just three receptionists knew enough sign language for the exchange to be conducted principally in sign.

One in five (20%) of those alone or with a Deaf companion experienced problems knowing when it was their turn to see the GP, mainly as a result of not being aware (or being uncertain) that their name had been called out. Significantly fewer (5%) of those with a hearing companion or interpreter had a problem (p<0.05).

People who saw the GP alone (or with a Deaf companion) reported significantly shorter consultation times than either those with a hearing companion or with an interpreter (42% of those alone said the consultation lasted less than five minutes, compared to 29% and 12% respectively; p<0.05). As a group, the lone Deaf patients also had notably shorter consultations than most of the general population sample (26%).

Lone Deaf patients were also more likely to feel that the time they had with the GP was not sufficient, with 39% saying it was 'too little' compared to 21% of those with a hearing companion and 18% of those with an interpreter (p<0.05). Just 12% of the general population sample felt the same way.

One-third (32%) of those who saw the GP alone thought that he/she had not tried their best to communicate, and nearly half (46%) understood only 'some' or 'very little' of what the GP attempted to communicate. Only one in five (19%) felt they understood everything. As with the receptionists, much of the communication was in writing, but one GP had a qualification in BSL and the consultation was carried out in sign language.

The people with communication support were asked how much of what the GP said they thought their companion had passed on to them. 16 of the 17 with an interpreter (94%) felt that everything or most had been passed on, but the same was true for only 42% of those with a hearing companion. Likewise, all but two of 22 other people who had used an interpreter in the past, felt that communication was better with an interpreter present.

Only just over half the sample, 56%, felt able to ask the GP all the questions they wanted. Amongst those with an interpreter the figure was 88% - very similar to the figure for the general population (89%), and significantly greater (p<0.01) than the results for those alone (46%) or with a hearing companion (58%).

Around two-thirds of the Deaf people (65%) were confident that the GP had managed their case correctly. The presence of a hearing companion or interpreter did not make much difference to the result. The level of confidence was much greater amongst people in the general population sample (92%).

Nearly one-third (31%) of all the Deaf people left the consultation feeling that they did not fully understand the GP's advice on what they should do next. The proportion was highest amongst those consulting alone (37%) and lowest amongst those with an interpreter (12%), but not significantly so (p>0.05).

Nearly two in every five (37%) felt that the consultation had not given them any greater understanding of what was wrong with them. The proportion was lowest amongst those with an interpreter (19%), but not significantly so (p>0.05).

One out of every four (26%) expressed a concern related to prescribed medication. In most of these cases patients had, at some time, been given a prescription but little or no information about the purpose of the drug or possible side-effects, or believed they had been prescribed incorrect medication. One woman had taken her GP to court over the medication she'd been receiving. Two people had been seriously ill after consuming an external medicine, owing to misunderstood instructions from a GP.

In response to an open question about what their GP's practice could do to make things better for Deaf patients, 72% of people suggested that the GP should learn sign language, and 58% said that receptionists or other staff should learn sign. Other popular suggestions were a textphone in the practice (56%), a visual patient call system (55%), Deaf Awareness Training for GPs and staff (40%), provision of sign interpreters (29%), and alternative means of contacting the practice (fax 17%, text messaging 7%, email 6%).

Interviews with GP practice managers

Telephone interviews were conducted with the managers at a stratified random sample of 31 GP practices based in the study's five Health Authorities.

The number of Deaf patients at each practice was low. No practice reported more than six Deaf patients, and some had none. Numbers of hard-of-hearing patients were very much larger.

Only one practice possessed a textphone, but this was not always switched on and had no answerphone facility. All practices possessed a fax machine, with 81% making this available for patient use.

Three practices (10%) were registered to use the RNID TypeTalk system, but none of the managers were aware of the RNID GP Membership scheme.

No practice had a loop system, but one possessed a portable listening device.

About a quarter of the practices (24%) used a visual patient call system, in most cases displaying the name of the next patient to be seen. Most other practices used a verbal announcement, and stated that staff would personally approach a Deaf patient to inform them of their turn.

87% of practices made a record of deafness in the patient's notes.

Five of the practices with Deaf patients (20%) automatically allocated a longer time to consultations with Deaf patients, typically an extra five minutes.

Although three practices (10%) claimed to have access to BSL interpreters, only one had actually arranged interpreter support for a patient. Reception staff informed patients they could have an interpreter and the practice covered the cost. Neither of

the other two practices claiming to have access to interpreters informed patients about this or could say who was responsible for paying.

Staff with (some) BSL skills were present at four sites (13%), but at three the level of training was below a BSL Level 2 qualification, although at one of these the staff member was awaiting more advanced training.

Staff at seven practices (27%) had undergone Deaf Awareness Training, but medical staff participated in the training at only two of these. Staff at two other sites had requested DAT. One practice had introduced annual training in basic sign for all staff. This was one of the largest practices in the survey.

Two practices (6%) had undertaken an evaluation of their services with respect to Deaf patients. As a result one practice had decided to train a member of staff in BSL, but was making no other changes; the other already had access to BSL interpreters and a visual patient call system, and the evaluation did not result in any further developments. Two other practices were currently engaged in an evaluation.

Six practices (19%) had specific plans for improving access for disabled groups, but only one of these included any mention of the needs of Deaf (or HoH) patients.

Deaf People's experiences of A&E departments

Interviews were conducted with 42 people (24 female and 18 male) who had at some time attended an A&E department. The 42 attendances were spread across 21 different A&E units, all but one located in the North West. Two-thirds (67%) of the visits involved accidental injuries and one-third (33%) medical emergencies. 83% related to personal accidents or emergencies, 12% related to a child, and 5% to a (Deaf) spouse.

Nearly half (46%) were taken to A&E by ambulance, while most of the rest (43%) went with a companion by car or taxi. Only four (11%) made their way to the unit entirely on their own. No one experienced any difficulty finding the entrance to the A&E unit within the hospital complex: the majority were taken directly there by the ambulance crew or taxi driver; most of the rest (or their companion) were already familiar with the place.

During the visit, half the sample (50%) were without any signing support (alone, or with a non-signing or Deaf companion). The other 50% had some form of signing support: just over one-third (36%) were with a hearing friend/relative who could sign; 7% had a professional interpreter; and 7% had a signing nurse assigned to them for the duration of the visit. None of the professional interpreters were arranged by the A&E unit.

57% of the people who had no signing support found communication with staff to be inadequate in many respects. In two cases Deaf parents were attending with an injured child and staff attempted communication with the parents through the child. A smaller proportion (29%) of those with signing support thought communication to be inadequate; the difference is of borderline statistical significance (p=0.07). The six patients who had an interpreter or signing nurse were all entirely satisfied with the quality of the signing.

Of those who had to queue for a consultation or a test, one-third (34%) had a problem knowing when it was their turn to be seen. All but one of these was without signing support; the other was with a 13 year old child. Many more people felt considerable anxiety in this situation, even if they didn't actually miss their turn.

Most people (56%) were portered around by hospital staff and so had no difficulties finding different departments. Many others received all their treatment in the one department. Just two people (5%) reported a problem finding their way around. Both were without support.

One in five (20%) of the patients were not satisfied with the medical treatment they received for their condition. Satisfaction was unrelated to the presence of signing support.

Two out of every three (66%) felt they had not been given all the information they should regarding their condition, treatment and aftercare. The presence of signing support made a significant difference here: four out of every five (81%) of those without support came away without full information, compared to half (50%) of those with support (p=0.05). All the patients with a signing nurse expressed complete satisfaction with the information provided. Two of those with interpreters did not: in one case medical staff had not explained aftercare; in the other the interpreter had to leave partway through treatment.

17 patients were required to return to A&E at a later date for follow-up. In no case did the unit offer to arrange an interpreter for the follow-up appointment, although one did after the patient requested it.

Nearly half the sample (48%) felt like making a formal complaint after their visit. Two-thirds of the complaints could be directly related to the person's deafness: the majority of these (50%) concerned the quality or completeness of communication from staff; others concerned bad experiences at reception (31%); and the lack of interpreter support (19%).

In response to an open question about what, if anything, the A&E unit could do to make things better for Deaf patients, 57% of the sample suggested that medical and other staff should learn BSL. An equal number (57%) wanted units to provide interpreter support, preferably 24-hour on-call cover. 57%, again, wanted units to have a textphone, for Deaf patients wishing to telephone out, as well as those telephoning in. Other popular ideas were Deaf Awareness Training for staff (48%) and visual patient call systems (36%)

Interviews with managers of A&E departments

The managers of 22 A&E departments in the North West region were interviewed by telephone.

Two units (9%) possessed a textphone, but neither was in operation: in one case the textphone was not switched on and staff did not know how to use it; in the other it was kept in drawer at reception.

No department was registered with the RNID TypeTalk scheme.

Three units had a loop system at reception, and one other was having a loop installed as part of a rebuild. Two units possessed a portable listening device.

None of the departments had a visual patient call system. All relied on patients responding to a verbal call, which in at least two cases was via a public address system. All the managers indicated that Deaf patients would be personally approached when it was their turn to be seen.

Only just over half the managers (55%) were confident that the information leaflets available in their unit were suitable for Deaf people.

Two out of every three managers (68%) indicated that their unit had a system in place for obtaining BSL interpreters, although some of these did not appear to have much actual experience of arranging sign interpreters. Seven managers (32%) reckoned they could obtain an interpreter within a few hours during the normal working day. Out of hours it was normally much longer. Eight managers (36%) stated that they would book a BSL interpreter in advance if a return appointment were necessary.

Six departments (27%) made use of a hospital staff member with signing skills to interpret for Deaf patients. One other department was currently training two staff in BSL. At least four of the staff had trained while employed by the hospital. Most other departments said they would use signing staff as interpreters if they had them. Three of the staff were qualified to BSL Level 2, while one other was working towards Level 2.

Apart from the staff who had trained in BSL, three other departments had received requests from staff for DAT training. In one case funds were being sought not just for DAT but for a staff member to learn BSL.

Just three units (14%) had evaluated the service they provided with regard to the needs of Deaf patients. The outcomes of the evaluations were very variable but all only addressed the problems of access in a very limited way. Only one other unit had any immediate plans to undertake an evaluation - with respect to disabled groups generally, not just hearing impairment.

21 of the 22 departmental managers (95%) felt that Deaf access to their unit could be improved (with one unsure). The biggest barriers to improving services for Deaf patients were thought to be a lack of resources (mentioned by 73%, on a free response question) and lack of staff awareness about the needs of Deaf people (59%). In terms of improvements that could be made, training in Deaf Awareness was most frequently mentioned (45%). Only two managers suggested better access to sign language interpreters.

Visual inspections of A&E departments

A Deaf researcher made visits to 22 A&E departments in the North West. The researcher rated the public areas of each unit according to a checklist of items relevant to Deaf access. Because Deaf people do not find it easy to obtain directions from strangers, a number of the items were concerned with signage.

18 departments (82%) had an entranceway that was easy to identify from outside, although in a few cases the hospital itself was not that easy to find.

Within the department, the reception area was well signposted and easy to find in 18 cases (82%). The main waiting area was also clearly defined in 17 units (77%). However, only five departments (23%) had clear and unambiguous signposting to all the other principal areas patients might need to visit (such as X-ray), and in two out of three cases colour-coded directional lines on the floor hindered more than they helped. Just seven units (32%) had labels on all doors leading off from the reception and waiting areas.

Five departments (23%) had the Sympathetic Hearing Symbol on display, which lets patients know that some of the staff have attended DAT, and three (14%) had a loop system at reception.

The lighting at reception was rated as poor at nearly a quarter of the units (23%), meaning that lip-reading the receptionist could be difficult. Nearly half the units (45%) were rated as having poor illumination in the waiting area.

Two departments (9%) possessed a textphone, but in one case this was kept in a drawer when not in use, and in the other the reception staff didn't know where it was kept or how to use it. None of the departments had a payphone with a text messaging facility and none provided a shelf or other suitable place to position a portable keyboard for connection to the payphone.

No unit had a visual patient call system. At all sites staff relied mainly on patients hearing their names being called out. At only six units (27%) was it possible to lip-read the receptionist from the waiting area, and at four of these this was possible from certain seats only. At several sites lip reading was made even more difficult by the presence of a glass barrier at the reception desk. Reception staff at a few departments claimed to have a special procedure for identifying and informing Deaf patients of their turn.

Only one department possessed a flashing light fire alarm system, and this was restricted to the corridors.

All departments had a television set in the waiting area but none were displaying programme subtitles. When approached, reception staff typically did not know how to turn the subtitles on, or even that this was possible.

Policy

Six GP practices (19%) indicated that they possessed, or were in the process of developing, a policy on access for disabled people, but none provided the study with a copy of their policy, despite agreeing to do so. At a higher level, out of twelve PCTs in the North West region that were contacted, seven stated that they had no policy, four gave no clear answer, and one was currently developing policy.

None of the A&E managers were aware of any policy pertaining to their units. A relevant individual at each Hospital Trust with an A&E unit was also contacted, but at this level also we found no concrete examples of policy on access.

Three GP practices (10%) and one A&E unit (5%) had been motivated to evaluate their services in the light of national policy, in the form of the DDA. One PCT was also undertaking an audit for the same reason.

The costs of facilitating access

The widespread problems experienced by Deaf people when using services could be greatly diminished if GPs and Accident & Emergency units were to implement a basic package of measures to facilitate access for Deaf patients, consisting of a voice & text phone, a visual patient call system, Deaf Awareness Training for reception and medical staff, use of BSL interpreters, written instructions about medication and after-care, and double-length appointment slots. The cost of introducing such a package at all GP practices within an average-sized PCT of 30 practices, is estimated to be around £66,000 in the first year, and £39,000 per annum after that. The latter figure equates to an increase in GP costs of around 6.5 pence per patient appointment (Deaf and non-Deaf).

The estimated cost of implementing a similar package at A&E units varies between £4,088 in the first year and £2,588 per annum subsequently for a small unit, and £9,000/£7,200 for a very large unit. Spread across all patients (Deaf and non-Deaf) seen in A&E over one year, this equates to an additional expenditure of between 6.0 and 6.5 pence per patient visit.

10.2 Discussion and recommendations

This study has found that the provision made at GP practices and A&E departments in the North West for Deaf patients is extremely patchy. Only a small minority of GP practices had introduced any measures to facilitate access for Deaf people, and where measures had been introduced they represented very partial attempts to improve access. Whereas around a quarter of the practices possessed visual patient call systems, and 20% allocated longer consultation times for Deaf patients, only one practice provided and paid for interpreter support, only one had a textphone, and just two possessed medical staff trained in Deaf Awareness. Where practices had plans to improve access for people with disabilities, the needs of Deaf patients tended to be overlooked.

Part of the reason for the low level of provision is presumably the fact that most practices have only a very small number of Deaf patients, in almost all cases no more than six, and sometimes none. Hence for most practices, Deaf patients are not a particularly visible sub-group of their clientele. A GP may be aware that he or she is not communicating well with a Deaf patient, and is providing them with a substandard consultation, but from the GP's perspective this may represent just one consultation out of every 1,000 and therefore finding a resolution to the difficulties isn't one of the GP's priorities. As far as the Deaf patient is concerned, however, every time they visit the GP the experience is disappointing and frustrating.

Provision at A&E units, while also very limited, is different in some respects. Unit managers were more aware of the importance of BSL interpreters, and a fair number claimed to have a system in place for obtaining interpreters. Around one-quarter of the units made use of staff, mainly nurses, with BSL signing skills as interpreters for Deaf patients, and a few others had staff in training or awaiting training. However, despite these positive aspects, other facilities for Deaf people were almost non-existent: no unit possessed a visual patient call system; none had a functioning textphone; and training in DAT didn't extend beyond the occasional individual staff member. Only three units had evaluated the service they provided to Deaf people, and the outcomes of the evaluations were quite variable and addressed issues of access in very limited ways.

The experiences of Deaf patients bear out the general picture of GP practices and A&E units being inadequately geared up to meet their needs. If anything, the interviews with Deaf people suggest an even bleaker picture. For example, despite the claim from most A&E managers that their units had systems in place for obtaining interpreters, none of the Deaf people who had attended A&E had been provided with one, and none were offered one for a follow-up appointment. Similarly, GP practice and A&E managers alike reported that Deaf patients would be approached personally when it was their turn to be seen, yet a substantial proportion of lone patients in both settings were not approached but only called by name.

Deaf patients can, and do, experience problems at all stages of the health care process. In our survey, substantial proportions had difficulty making appointments; in waiting rooms, knowing when they had been called; understanding receptionists and health professionals; making themselves understood; obtaining all the information they required; and after a consultation understanding what they were supposed to do next, or the purpose or correct application of medication prescribed for them. About half the sample went to their GP, or to A&E, alone or with a Deaf spouse, and people in this group were much more likely to experience problems than people accompanied by a hearing relative or friend, or a professional BSL interpreter. On all the questions where we had results for a comparative sample of the general population, lone Deaf patients (and those with hearing companions to a lesser extent), expressed considerably reduced levels of satisfaction with the service they received. The cumulative effect of disadvantage at every stage of provision is perhaps best reflected in the finding that fully 40% of the Deaf people we interviewed had complained, or felt like complaining, about some aspect of the service received from their GP in the last twelve months. The comparative figure for the general population in the North West is just 11%. A similarly high proportion of Deaf people, 48%, felt like making a formal complaint as a result of their experience at A&E.

Measures that can be taken to facilitate access for Deaf people are discussed below. The NHS Executive have published two previous major reports in connection with the DDA that set out a number of key recommendations for improving access to health services for all disabled groups: 'Working in partnership to implement Section 21 of the Disability Discrimination Act 1995 across the health service' (Freeney et al, 1999); and 'Doubly Disabled: equality for disabled people in the new NHS: access to services' (NHS Executive, 1999a). Some suggestions about what constitutes 'good' or 'reasonable' practice also appear in the Code of Practice on the DDA (DWP, 2000). Practical issues to do with the built environment are addressed in detail in the publication 'Access to Health Service Premises: Audit Checklist (NHS Executive,

1998b). It is not our intention to repeat all the recommendations from the above documents. Rather, we focus on recommendations that emerge from the findings of our own particular study. This study has looked in considerable detail at all important aspects of the current situation regarding access for Deaf patients to GPs and Accident & Emergency departments, and is able to make detailed recommendations in relation to this specific client group based upon hard evidence from the study. Most of the recommendations concur with those contained in the documents alluded to above, and in some cases expand on these. We also present additional recommendations that do not appear in those documents. In one or two instances we disagree with statements from those documents: these instances are pointed out and our reasons for disagreeing explained. Some issues which are not addressed in the discussion here, but on which relevant recommendations can be found in the aforementioned documents include: patient records; appointment letters; signage; loop systems; visible fire alarms; and stationary.

Communication support

Slightly more than half the sample expressed a preference to have a Professional Sign Interpreter provide communication support at GP consultations. The Code of Practice on the DDA suggests that (using the terminology of the Act) a 'reasonable adjustment' GPs can make when undertaking consultations with Deaf patients is to use pen and paper for communication, except perhaps where a life-threatening illness or a decision about surgery is involved (see section 1.2). In the present study 83% of consultations with lone patients involved pen and paper communication, and the outcome was that nearly half of these patients understood only some of what the GP tried to convey, less than half felt able to ask all the questions they wanted, and two in five left the consultation not fully understanding what they were supposed to do next. On all these items patients with interpreters fared very much better. Lone Deaf patients also reported shorter consultations and were more likely to feel that they had not had sufficient time with the GP. From these results it is clear that for a large number of Deaf patients who consult alone, reliance on pen and paper communication is not a 'reasonable' means of overcoming the communication barriers. Part of the reason for this may be the limited literacy of many Deaf people, particularly with regard to many common health-related terms; and part may be down to the legibility of both the patient's and the GP's handwriting, plus a tendency for GPs to resort to medical jargon and abbreviations.

Worryingly, the Code of Practice also suggests that in the absence of an interpreter, "many" Deaf people will be able to cope by lip reading (see section 1.2). This suggestion suggests a lack of understanding of the limitations of lip reading (see section 1.4).

The guidance produced by the NHS Executive with regard to use of interpreters, as set out in 'Doubly Disabled' (NHS Executive, 1999a) is stronger than that in the Code of Practice, and closer to the recommendation made by the present study (see below). The NHS Executive states that "Where the deaf person uses British Sign Language, check if they require a BSL interpreter for meetings, interviews or consultations. Qualified BSL [or SSE] interpreters should be used in *any* situations where complex and/or technical information needs to be communicated, *such as in formal consultation with medical staff*" (our italics; Ibid, p32). The Executive's guidance also states that it is the Trust's responsibility to arrange the interpreter, that staff with only

a basic knowledge of BSL should not be used, and that "hospitals and health centres should maintain an up-to-date list of accredited interpreters they can call upon" (Ibid, p33).

While providing an interpreter to every Deaf patient who feels they need one is a highly laudable aim, the shortage of interpreter availability, especially at short notice, is likely to mean that in practice such a goal is unachievable. In our study, many patients were without interpreters for this very reason. Obtaining interpreters becomes even more difficult where the patient has a preference for a male or female interpreter. For some types of consultation it is quite understandable that a patient should have such a preference, and the NHS Executive's guidance is that health providers should establish the patient's preference beforehand (Ibid, p65).

An alternative means of providing communication support would be to train one or more members of staff to a suitable standard in BSL. However, as a solution for GP appointments this is unlikely to be practical except for the largest practices. Apart from the time and expense, to train a staff member in BSL and maintain their skills requires two things: (1) to have a staff member who is interested, with an aptitude for learning the language; (2) to have Deaf patients visiting the practice sufficiently frequently that the staff member's BSL skills do not deteriorate over time. In addition, while a staff member, trained to BSL level 2 say, might communicate reasonably well in non-technical situations, some organisations are firmly opposed to the use of anyone other that a fully certified interpreter for medical consultations (eg ADSUP, 1996).

An alternative may be to seek a solution at the PCT level. The average population of a PCT is 130,000, which suggests something like 150 Deaf patients making a total of around 900 GP consultations per year, plus an unknown number of visits to other primary care professionals. This may represent sufficient workload to justify the PCT either arranging a contract with an agency for 24-hour interpreter cover, or employing one or two interpreters directly. Given that there are many more PCTs in the country than there are fully qualified interpreters at present, the preferred solution might be for a PCT to train some of it's own staff up to interpreter level, else improved interpreter cover in primary care will be at the expense of less interpreter availability for Deaf people engaged in other activities.

The DDA makes it clear that it is the provider who is responsible for paying for any 'auxiliary aids', such as interpreter support. However, in the context of primary care, it is not at all clear whether the responsibility for paying lies with the individual GP practice, or with the PCT of which the practice is a member. Within the North West region, we know of one PCT that meets the cost on behalf of it's GP members, and another that require practices themselves to pay (although it is not known if interpreter support is subsumed under a component of the annual allocation of funds that all GPs receive from the PCT). It is quite probable, given the findings of our survey of practices, that very few GPs or PCTs have given much thought to this matter. Nevertheless, if we wish to improve access then there will need to be greater use of interpreters, and PCTs and GPs will need to establish responsibilities and mechanisms for payment.

The position regarding use of interpreters within A&E services is rather different. About two-thirds of the A&E units surveyed claimed to have a system in place for

obtaining professional interpreters at fairly short notice. However, we weren't in a position to test these claims out, and none of the patients surveyed had been provided with a professional interpreter by any A&E unit. About a quarter of the units, however, had access to nurses within the hospital that were trained in BSL, and three patients who had been assigned a signing nurse had been impressed with their abilities. In contrast, more than half the patients with no communication support at A&E thought that communication from staff was inadequate, and four out of every five felt they had not been given all the information they required.

To have trained nurses within the hospital (not necessarily from within the A&E unit itself) has a number of potential advantages. A signing nurse may be able to attend at shorter notice than an interpreter from an agency, and there may be less of a risk that they will have to leave before the end of treatment (as happened with one interpreter in the study). They will be more familiar with the hospital and it's procedures, and more familiar with medical terminology and practices. Where a patient is admitted to hospital from A&E, the nurse may be able to continue providing support (in the study, a signing nurse supported an admitted patient for the following week), and when not required in A&E (which will be most of the time) the signing nurse can be supporting Deaf in-patients and out-patients. Other advantages are that the presence of nurses with BSL skills can help make other hospital staff more Deaf-aware; and that training nurses in BSL helps to alleviate the general national shortage of available communication support for Deaf people.

To ensure 24-hour cover, every day of the year, a number of nurses would require training in BSL, perhaps a minimum of four. This would be the ideal, but even in the largest hospitals there may not be sufficient demand for BSL support to justify training four nurses. A more viable alternative may be to operate a combination of one, or maybe two, signing nurses and a contract with an interpreter agency. At least one A&E unit in the North West has this kind of set-up, with Deaf patients being offered a choice between a signing nurse and a professional interpreter.

An important concern regarding the use of BSL-trained nurses, is that the level of training received should be adequate for the kinds of situations in which the nurse is required to act as go-between. A nurse who has attained BSL Level 2 should be able to communicate with Deaf patients in most non-technical and non-complex situations. As mentioned previously, it is highly contentious to anyone other that a fully certified interpreter to interpret during patient consultations (or where aftercare is being explained). In practice, however, in an emergency situation the alternative to using a nurse may be no interpretation at all, or a long delay before an interpreter can arrive. An important consideration is that nurses interpret purely within a medical context where their training and nursing experience becomes a considerable additional asset.

Communication barriers can be as frustrating for medical staff as they can for patients, and when mis-communication results in serious consequences to a patient, this can also have devastating effects – both psychologically and professionally - on the health professional involved. The provision of interpreters therefore ought to be viewed as being as much for the benefit of staff as it is for patients. Furthermore, with the coming of the DDA, provider organisations and individual doctors need to be increasingly aware of the risks of litigation should they fail to take all reasonable steps to provide a service that meets the patient's needs. For these reasons as well, GPs and

consultants may justifiably feel that they require communication support for consultations with Deaf patients.

One concern that providers must have, particularly smaller GP practices, is the cost of providing interpreter support. For example, one Deaf person we interviewed was refused an interpreter by her GP on the grounds that the expense was too great for just a five-minute consultation. Professional interpreters cannot be booked for less than a two-hour slot, with the typical charge being from £50 upwards. This expense, however, should be seen in the context of several other cost factors that can apply when an interpreter is not provided, if this results in an inadequate consultation: (1) the patient may need to re-attend earlier for further consultation; (2) if the patient's health needs are not addressed appropriately or at an early stage, the health service could incur very substantial subsequent treatment and management costs; (3) the patient might sue the provider successfully under the DDA; (4) society in general will incur economic costs if the patient cannot work due to untreated illness. When these factors are taken into consideration, the provision of interpreter support may well prove to be a cost-effective solution for the NHS, and certainly for society in general.

One further issue that deserves mention in the context of communication support concerns the desire of Deaf people to be able to communicate directly with health professionals, rather than through a third person. When asked what steps their GP could take to improve access, a large majorities wished for the GP and other practice staff to learn BSL. Although this probably represents an unrealistic hope, it does demonstrate the widespread desire for direct communication. The provision of interpreters for GP visits actually came some way down the Deaf people's 'wish list', below several other measures that would facilitate direct communication: textphones; visual patient call systems; and Deaf Awareness Training. The reasons for preferring direct communication are fairly obvious: not wishing to inconvenience others; not wanting to wait on someone's availability; wanting consultations to be confidential; and wishing to be independent. In recent years there have been a few attempts to create electronic signing systems, by which text or voice is converted to animated signs on a computer screen. The development of a reliable and usable 'virtual interpreter' is probably still some years off, but is clearly a technology that the health services should pay attention to when and if it arrives.

Recommendations for GP practices

*GPs should be aware that the use of pen and paper or relying on patients to lip read **does not** provide adequate communicate with most Deaf patients. All GP practices should know how to obtain appropriately qualified BSL interpreters, and when booking appointments offer to arrange an interpreter for any Deaf patient whose preferred method of communication is sign. Deaf patients should be asked if they have a preference for a male or female interpreter, and be informed in advance of the appointment who the interpreter will be. Practices with a suitable number of Deaf patients may wish to consider training a member of the nursing or medical staff in BSL.*

Practices should establish an arrangement with their PCT regarding a suitable mechanism for paying for interpreter support. PCTs themselves might wish to consider employing interpreter staff directly, or training some of their existing staff in British Sign Language.

In order to allow adequate time for communication, Deaf patients should be allocated longer than usual appointment slots. This applies to all Deaf patients, irrespective of whether they attend with communication support or not.

Recommendation for A&E departments

All Accident & Emergency Departments should establish mechanisms for obtaining a BSL interpreter for any Deaf patient whose preferred means of communication is sign. Deaf patients should be offered an interpreter, they should not have to first request one. Patients should be asked if they have a preference for a male or female interpreter. Interpreters should be offered for follow-up appointments as well as initial visits. Consultants, as well as the Deaf patient, should be given the option of requesting that an interpreter be present at a consultation. Hospital Trusts should consider training at least two nurses up to a minimum of BSL Level 2.

Textphones

To have the ability to contact their GP practice from home, without requiring assistance from another person, would be an important benefit for many Deaf people. More than half of the people interviewed had difficulty making an appointment, in most cases because they were unable to directly contact their practice from distance. Just over half the patients mentioned a textphone as one thing they would like their GP to possess (note: a textphone should not be confused with the more limited text facilities available on mobile phones). Only two of the people interviewed could easily make a textphone - to - textphone call to their GP practice. The other practices that possessed textphones typically did not always have these connected up or staff didn't know how to use them.

One of the difficulties of traditional textphones is that to be permanently available they have to be on a dedicated line. Lack of a dedicated line was a reason why so many of the practice textphones were unavailable when Deaf patients tried to ring in. The recent development of a combined voice & text phone – which simply replaces a standard telephone - eliminates this problem. Many Deaf patients would also benefit from being able to do basic tasks, such as arranging appointments, obtaining test results, and obtaining repeat prescriptions, by fax, email or text messaging over a mobile phone. Reception staff also need to be familiar with use of the British Telecommunications TextDirect system for telephone communication between Deaf and hearing people.

The majority of patients felt that A&E departments should possess textphones. However, none of the 22 units visited under the study had a functioning textphone; neither did any of the payphones in these units have a facility for sending or receiving text messages. In no case was there even a shelf or suitable surface near the payphone to balance a portable textphone, for use in conjunction with the payphone. This has to be regarded as an unacceptable state of affairs. It is particularly essential that Deaf people (as it is with those who can hear) who find themselves in A&E as a result of an accident or medical emergency, or Deaf parents attending with a child, have some means of contacting family or friends outside. It is not appropriate to expect a Deaf person to relay messages via a hearing person, using a standard phone, in this

situation: the message may involve intimate or serious matters, or even the death of a loved one.

Recommendation for GP practices

Practices with Deaf patients should consider installing a textphone, or replacing a standard telephone with a combined voice & text phone. To be fully effective this should possess a text answerphone facility. It is advised that reception staff receive training in operation of the textphone. All practices should provide means by which Deaf patients can contact the practice directly to make appointments, if not by textphone, then by fax, email or mobile phone text messaging.

Recommendation for A&E departments

All A&E departments must possess a functioning textphone facility, particularly for Deaf patients and visitors wishing to telephone out from the department, and preferably also for Deaf people wishing to telephone in. This might take the form of a stand-alone textphone on a dedicated line, a combined voice & text phone, or a payphone with texting capability. It is advised that reception staff receive training in operation of the textphone. The textphone needs to clearly visible, not hidden away until asked for.

Visual Patient Call Displays

The GP practice managers that were interviewed were generally confident that reception staff would take special steps to ensure that Deaf patients were personally informed of their turn to see the GP. The experience of Deaf patients, however, did not concur with this: considering the last GP visit only, one-fifth of those attending alone experienced difficulty, nearly all because their name was called and they could not hear it. Presumably many other Deaf patients had similar experiences on visits prior to their last. Over half the people interviewed suggested that their practice install a visual patient call system: currently, 22% of practices possessed such a system. One reason why visual call systems were more widespread than other technologies that benefit the Deaf, such as textphones, is probably because they are also a benefit to the many - possibly hundreds - of hard of hearing patients as well.

Nearly one in every three Deaf patients without communication support at A&E had a problem when it came to their turn to see a doctor, in every case because their name was called and they were not aware of it. Even patients who did not in the event miss their name, found the wait and the attendant fear that they had missed their turn, a source of considerable anxiety. Many, if not all, patients had previously informed staff that they were Deaf, but this fact had either got forgotten or was not passed on. This was also despite a claim, from all the A&E managers, that their unit had a procedure for ensuring Deaf patients were identified and informed in person. The problems and anxiety were exacerbated where the layout of the reception and waiting areas did not provide the patient with a view of the receptionist from their seat, which was the case at three out of every four departments. At many sites, poor lighting at reception and waiting areas compounded the problems further by making lip-reading more difficult. None of the units we visited possessed a visual patient call system, and some even used a Personal Address system, which from the point of view of a Deaf person is particularly unhelpful.

The document 'Working in partnership to implement Section 21 of the Disability Discrimination Act 1995 across the National Health Service' (Freeney et al, 1999) suggests that GP practices can "avoid the need to invest in an audio visual paging system for deaf patients if all reception staff were trained to approach and inform deaf patients as their appointment becomes due" (page 39). As the previous discussion shows, the finding of the present study is that, in practice, relying on reception staff in this way is unsuccessful in a substantial proportion of cases, and that a visual system is far more preferable.

A visual call system would clearly benefit Deaf patients at A&E considerably. It would also benefit the many hundreds more patients who are hard-of-hearing. However, the feasibility of implementing a visual system may depend upon how the A&E unit organises patient reception: for example, the use of triage nurses and multiple waiting areas could make a visual system impractical.

Recommendation

All providers should consider the feasibility of implementing a visual patient call system. They should also seek to ensure that a reasonable proportion of seats in the waiting area allow a clear view of the receptionist or of any other person who may call for patients. Lighting at reception and waiting areas needs to be at a sufficient level to allow patients to lip-read.

One other aspect of reception areas that emerged in this study, and has received comment from other researchers, concerns the use of glass security screens at reception desks. Reflections on the glass, notices, grills, and so on, obstruct the view of the receptionists face and act as impediments to lip reading. The glass also muffles the receptionist's voice, causing difficulties for all people with hearing impediments, and where there are speaker systems these often produce distorted sound.

Recommendation

Wherever possible glass security screens should not be used at reception. If they are used, they need to be made of non-reflective glass and be free of notices, grills or other features that obscure the view of the receptionist's face and mouth.

Deaf Awareness

A high proportion of the communication difficulties experienced by the people we interviewed came about when staff failed to allow for the person's deafness, or tried to allow but did so inappropriately. Typical behaviours that damaged communication included: not facing the Deaf person when speaking; not mouthing words clearly; speaking too quickly, or overcompensating and speaking too slowly; shouting; illegible handwriting or refusing to write things down; and use of medical jargon, either written or spoken. The problems are further compounded when staff are unaware that many Deaf people, out of embarrassment, pretend to comprehend when they do not, and assume that the patient understands if they do not indicate otherwise. Invariably, where the Deaf people reported good communication the staff involved had taken time and effort to make themselves understood.

Failure to even attempt to communicate adequately is widespread. One third of those who saw their GP alone thought the GP did less than his or her best to communicate. A much higher proportion of lone patients also had short consultations, and were more dissatisfied with these, than were Deaf people who attended with hearing companions or interpreters. The consultations were also on average shorter and less satisfactory than those received by hearing people, yet to relay the same amount and quality of information to a Deaf person as to someone who can hear requires considerably more time. At A&E also, over half the sample felt that communication from staff was inadequate. To the best of our knowledge, Disability/Deaf Awareness does not form part of the normal undergraduate curriculum for medical students.

The import of these findings becomes even more considerable when viewed in relation to the reported 87% of GPs who feel they communicate effectively with their Deaf and HoH patients (RNID, 1999). This latter figure is based upon a very large nationally representative sample of GPs, surveyed by an independent (of RNID) agency, and can therefore be taken as reliable. It points to a considerable mismatch of perception between GPs and their Deaf patients. One implication is that a considerable proportion of GPs may be under the misconception that they are already communicating effectively and have no need to undergo training in Deaf Awareness.

The provision of Deaf Awareness Training (or the more general Disability Awareness Training, provided a substantial element of Deaf Awareness is included) to all staff that have direct contact with patients could do much to eliminate or minimise communication problems. This recommendation appears in the Code of Practice on the DDA (DWP 2000; passage 10.3). 'Working in partnership to implement Section 21 of the Disability Discrimination Act 1995 across the National Health Service' (Freeney et al, 1999) not only classes disability training as an 'essential recommendation', but regards it as also essential that all specialist medical staff providing services to people with sensory disabilities "must receive additional, in depth, impairment specific training" (page 36). However, at the time of our survey very few staff at either a GP practice or an A&E unit had undergone DAT, and the involvement of medical staff in training was at a particularly low level.

One of the great benefits to an organisation of investing in DAT is that the precepts apply to communication with all patients with hearing impairment, not only those who are Deaf. It seems logical also that many of the principles of DAT would benefit communication with patients whose first language is not English. Consequently DAT training could add value to a considerable proportion of all patient consultations, perhaps up to ten or twenty percent of the total.

Recommendation for GP practices and A&E departments

All staff in direct contact with patients should receive training in communication with Deaf patients. This may be provided in the context of general training in Disability Awareness, although specific Deaf Awareness training would be preferable. It is particularly important that medical staff receive such training. Disability/Deaf Awareness Training should form part of the induction programme for new staff.

Written information

Given the limitations inherent in verbal communication with Deaf patients, including the considerable risk that a Deaf patient will give the impression that they have understood instructions when they have not, it becomes particularly important that Deaf patients receive appropriate and accessible written information.

Many Deaf people have a quite restricted vocabulary of English words (just as most hearing people have an extremely limited vocabulary of signs), and this fact needs to be taken into account when providing written information. Information needs to be phrased in ordinary language, avoiding medical terminology, jargon and abbreviations as much as possible. Free guidance on how to present medical information in plain English is available on the website of the Plain English Campaign (http://www.plainenglish.co.uk/). This applies to the kind of pre-printed information sheet about common conditions, basic self-help, support groups and so on, available from most health providers, but is even more important with respect to individualised instructions to a Deaf patient about aftercare and the use of prescribed drugs. In our survey, one-third of all Deaf patients left their GP not fully understanding what they were expected to do next, and two out of every three left A&E feeling they had not received all the information they needed. There were also many cases of patients being prescribed drugs with little or no accompanying information about the purpose of the drug or possible side effects.

Failure to provide clear information where medication is involved can have serious, even life-threatening, consequences. Two patients in the survey had fallen seriously ill after mis-understanding instructions and consuming an external medicine. Many Deaf people do not understand instructions from their GP at the time they receive a prescription, but study any written instructions later, or rely on a hearing relative or friend to explain them. This is why it is so important that all essential information is provided in writing, particularly where a powerful drug is concerned. Such information includes: the purpose of the drug; potential side effects; contraindications (eg pregnancy, allergies); dosage, method of application, and whether repeat prescriptions are required. Even though the GP may have attempted to cover all these issues during the consultation, there will always be considerable doubt as to how much the patient understood at the time.

Recommendation

Health (and other) information sheets need to be phrased using simple, plain English, avoiding the use of medical terminology, jargon, and abbreviations. Pictures should be included in the design where they help convey the information.

All Deaf patients should be provided with essential information about aftercare and the purpose and use of any prescribed medication in writing before they leave the premises. Plain English should be used, avoiding the use of medical terminology, jargon, and abbreviations.

Service evaluations

Only a few of the GP practices or A&E units had evaluated their services in relation to access for Deaf people. A matter of concern regarding the evaluations that had been

conducted, was just how little positive change had resulted from them. None of the evaluations appeared to have addressed issues of access for Deaf people in what might be called a comprehensive manner. We do not know the details of the evaluations, but we do know that in some cases, and maybe all, they encompassed all disability groups, not only Deaf people. It may be that the needs of Deaf patients are not sufficiently headlined when part of a general evaluation. Such certainly seemed to be true in the case of sites with specific plans to improve disabled access; almost all the plans concentrated on those with mobility and visual difficulties, and made no mention of Deaf patients.

Recommendation

Where an evaluation of access for people with disabilities is being undertaken, it is important that the needs of Deaf patients are not overlooked. Evaluations need to examine access in a comprehensive fashion, addressing all important aspects, including communication support, Deaf Awareness, telecommunication needs, patient call systems, patient records, information leaflets, signage, lighting, and waiting room and reception area design.

Policy

The DDA in effect provides a national policy on access for people with disabilities, and enshrines this in Law. However, very little of the DDA has yet found expression in policy statements from Health Authorities, Hospital Trusts, Primary Care Trusts, or individual GP practices. Just three of the GP practices and one of the A&E units that were surveyed had been motivated to evaluate their services to Deaf/disabled patients as a result of awareness of the DDA. One reason for the fairly limited impact of the Act to date, however, may be that the Section 21 duties – the more concrete requirements of the Act – only came into force in October 1999, and so it is still very much 'early days'.

It might be thought that the existence of the DDA makes it unnecessary to formulate policy about access for disabled people at the local organisational level, since all organisations have a duty to comply with the Act. The DDA, however, only makes fairly general policy statements. These need to be interpreted at local levels in a manner appropriate to each particular organisation, so that they find expression in the policies, practices and procedures of that organisation. For example, the Act states that there is a duty to provide auxiliary aids to facilitate access. Hospital Trusts, PCTs, or even individual GP practices, will need to decide what forms of auxiliary aid are to be provided and under which circumstances: it may not be feasible for a GP practice to engage a BSL interpreter for every consultation with a Deaf patient, but policy guidelines would help a GP determine, in any given situation, whether an interpreter should be offered.

Policy needs to be set with respect to both organisational duties and staff duties. Organisational duties might include, for example, policy on Deaf/Disability Awareness Training for staff (such as a statement that all new staff in direct contact with patients should receive training within their first six months); responsibilities for arranging and paying for interpreters; the provision of aids such as textphones, visual call systems, and visible fire alarms.

Staff duties relate to the specific practices and procedures to be adopted by staff with respect to individual Deaf (and other disabled) patients. Examples include a requirement that an external marker be put on each Deaf patient's notes; that Deaf patients be given double-length consultation slots; and that all Deaf patients who prefer to communicate in sign should be offered a BSL interpreter. Policy of this form is essentially a list of guidelines for staff so they understand the actions they should to be taking. Staff who deal directly with patients frequently do not know what to do for the best when faced with a Deaf person, and unless provided with clear guidance this state of affairs is likely to continue. In addition, while a number of providers have adopted practices such as those listed above, if they are not part of a codified system their use is likely to be variable and partial.

This study has shown that it would be fairly inexpensive for providers to implement a basic set of measures to facilitate access for Deaf patients, consisting of a combined voice & text phone, a visual patient call system, DAT for staff, use of BSL interpreters, written information about medication and after-care, and double-length appointment slots. PCTs could use this list as the basis for developing organisational policy on Deaf access, to be implemented at all GP practices within the Trust. Similarly, Hospital trusts could use it as a basis for an A&E access policy.

Recommendation

PCTs, GPs, and Hospital Trusts should develop policies with respect to access to their services for Deaf people. Such policies need to be in line with the Disability Discrimination Act, and may form part of a broader set of policy statements on access for people with disabilities. It is particularly important that the policy includes specific guidance to frontline staff about the practices and procedures to adopt with respect to Deaf (and other disabled) patients.

PCTs, GPs, and Hospital Trusts may like to consider basing their policy on providing a basic package of facilitating technologies and practices for Deaf patients, consisting of a combined voice & text phone, a visual patient call system, DAT for staff, BSL interpreter support where required, written instructions about medication and after-care, and double-length appointment slots.

Encouraging change

Progress in improving access for Deaf people has been very slow. The widespread difficulties reported by the people we interviewed are the same ones that were being reported in the literature 30 years ago. Only a few of the providers we surveyed, whether GP practices or A&E units, had implemented facilitating technologies such as DAT, BSL interpreters, BSL training for staff, textphones, visual call systems and so on. Where there did exist plans to improve access, the needs of Deaf people tended to be overlooked.

It is to be hoped that the DDA will provide some impetus for change. However, those providers that had undertaken evaluations of access had made very few changes to benefit Deaf patients. The USA has had anti-discriminatory legislation in place to promote equal access since the Rehabilitation Act of 1973, later superseded by the 'Americans with Disabilities' Act (ADA) of 1990. In terms of the rights it enforces for people with disabilities, the ADA is a stronger piece of legislation than the

Disability Discrimination Act,. For example, the ADA requires that where a hospital provides a telephone for public use, an appropriate telecommunications device for use by Deaf people must also be provided; and all new buildings used by the public must have visible as well as audible alarm systems. Although the ADA does not require that qualified interpreters are provided for all consultations, the examples given in the Technical Assistance Manual for the Act (US Department of Justice, 1993) imply that for the majority of consultations health providers should offer to provide interpreters (paragraph III-4.3200). A survey of 73 hospital physicians in Illinois found that nearly two-thirds agreed that initial communication with a Deaf patient who signs ought to involve an interpreter (Ebert and Heckerling, 1995), and at least 19 legal actions have been pursued in the United States, under both the Rehabilitation Act and the ADA, against health organisations for failing to provide interpreters or telecommunication aids (Office for Civil Rights, 2002). However, despite the long history and strength of legislation in the USA, a number of surveys have found that only relatively low percentages - 13% to 20% - of Deaf people have interpreter support during consultations, either at hospital, family physician offices, or chiropractic clinics (Ebert and Heckerling, 1995; Rose, 1999; Mackinney et al, 1995; Zazove et al, 1993). The implication from the American experience would appear to be, therefore, that legislation alone does not produce major change.

What is needed in the UK in addition to the DDA, therefore, are means of encouraging health providers to make necessary improvements. The work that the NHS Executive has been doing to develop a strategy to support implementation of Section 21 of the DDA across the NHS (see section 1.2) represents a vital aspect of this process. It is important, however, that the Executive establish mechanisms for monitoring and encouraging compliance with their strategy at the Hospital Trust and PCT level. For example, in a Health Service Circular of September 1998 the Executive advised all NHS Trusts and primary care providers to designate a person (or persons) as disability services adviser and begin raising staff awareness of the DDA (NHS Executive, 1998a). However, our surveys of provider units, conducted in 2001, found that awareness of the DDA, at that time, was still very limited.

Recommendation

The NHS Executive needs to continue to actively support and encourage implementation of Section 21 of the Disability Discrimination Act across the whole of the health service. It is also important that the Executive closely monitor the progress that is being made at the level of individual Hospital Trusts and PCTs, and provide additional support and encouragement where needed.

One other avenue for encouraging change deserves consideration: Deaf representation within provider organisations. The Code of Practice on the DDA states that as a matter of 'good practice', service providers should seek the views of disabled service users (DWP, 2002; passage 10.10), and the NHS Executive's report on the implementation of Section 21 across the NHS (Freeney et al, 1999) makes an 'essential' recommendation that in order for Primary Care Groups and Trusts to comply with the requirements of the Act "Consultation with disabled service users at a local level…. needs to be built in as a standard element of service monitoring, evaluation and review" (paragraph 3.2.2).

In response to these directives, a number of provider organisations have established user advisory groups that include users with disabilities. Such groups can provide a mechanism by which the Deaf community may be able to make providers aware of the needs of Deaf people and possibly influence service developments. Within the North West, we know of one Hospital Trust that operates a system of this type, part of the advisory group's role being to identify gaps in service provision for disabled people and suggest how these can be filled (see section 8.2). The effectiveness of arrangements such as this is still something of an unknown, but will probably be related to the degree to which the views of the advisory group find representation at all levels of the Trust's service planning and decision-making structure.

Without representation at the highest levels, such groups may turn into little more than 'talking shops'. To ensure the involvement of Deaf people in advisory groups of this kind, providers may need to be pro-active in seeking out and encouraging participation. They will also need to ensure that Deaf people are provided with professional BSL interpreter support at advisory group meetings.

Some providers consult disabled users by means of surveying a sample of such users for their views. Unless considerable care is taken in the method of data collection, the views of Deaf patients will be considerably under-represented in such surveys. Deaf patients will be unable to participate in face-to-face interviews in waiting rooms, for example, unless someone is present who can interpret. Mailed-out questionnaires, or questionnaires left in waiting areas for patients to complete, will fail to get a response from the many Deaf people with limited literacy skills. A further big disadvantage of relying solely on the survey method, is the lack of any mechanism by which disabled people can determine whether their views are, in fact, being taken into account in terms of service developments.

Recommendation

PCTs and Hospital Trusts should establish mechanisms for consulting Deaf users of services on their views of existing services and ways in which these can be improved. Consultation needs to be on a regular basis, not just a one-off, and be built in as a standard element of service evaluation and development. The consultation process needs to ensure that views of Deaf users find representation at all levels of decision-making related to service development. Consultation that relies solely on patient surveys is not recommended.

10.3 Summary of recommendations

Recommendation for the NHS Executive

The NHS Executive needs to continue to actively support and encourage implementation of Section 21 of the Disability Discrimination Act across the whole of the health service. It is also important that the Executive closely monitor the progress that is being made at the level of individual Hospital Trusts and PCTs, and provide additional support and encouragement where needed.

Recommendations for GP practices

*GPs should be aware that the use of pen and paper or relying on patients to lip read **does not** provide adequate communicate with most Deaf patients. All GP practices should know how to obtain appropriately qualified BSL interpreters, and when booking appointments offer to arrange an interpreter for any Deaf patient whose preferred method of communication is sign. Deaf patients should be asked if they have a preference for a male or female interpreter, and be informed in advance of the appointment who the interpreter will be. Practices with a suitable number of Deaf patients may wish to consider training a member of the nursing or medical staff in BSL.*

Practices should establish an arrangement with their PCT regarding a suitable mechanism for paying for interpreter support. PCTs themselves might wish to consider employing interpreter staff directly, or training some of their existing staff in British Sign Language.

In order to allow adequate time for communication, Deaf patients should be allocated longer than usual appointment slots. This applies to all Deaf patients, irrespective of whether they attend with communication support or not.

Practices with Deaf patients should consider installing a textphone, or replacing a standard telephone with a combined voice & text phone. To be fully effective this should possess a text answerphone facility. It is advised that staff receive training in operation of the textphone. All practices should provide means by which Deaf patients can contact the practice directly to make appointments, if not by textphone, then by fax, email or mobile phone text messaging.

All practices should consider the feasibility of implementing a visual patient call system. They should also seek to ensure that a reasonable proportion of seats in the waiting area allow a clear view of the receptionist or of any other person who may call for patients. Lighting at reception and waiting areas needs to be at a sufficient level to allow patients to lip-read.

Wherever possible glass security screens should not be used at reception. If they are used, they need to be made of non-reflective glass and be free of notices, grills or other features that obscure the view of the receptionist's face and mouth.

All staff in direct contact with patients should receive training in communication with Deaf patients. This may be provided in the context of general training in Disability Awareness, although specific Deaf Awareness training would be preferable. It is particularly important that medical staff receive such training. Disability/Deaf Awareness Training should form part of the induction programme for new staff.

Health (and other) information sheets need to be phrased using simple, plain English, avoiding the use of medical terminology, jargon, and abbreviations. Pictures should be included in the design where they help convey the information.

All Deaf patients should be provided with essential information about aftercare and the purpose and use of any prescribed medication in writing before they leave the

premises. Plain English should be used, avoiding the use of medical terminology, jargon, and abbreviations.

Where an evaluation of access for people with disabilities is being undertaken, it is important that the needs of Deaf patients are not overlooked. Evaluations need to examine access in a comprehensive fashion, addressing all important aspects, including communication support, Deaf Awareness, telecommunication needs, patient call systems, patient records, information leaflets, signage, lighting, and waiting room and reception area design.

PCTs and GPs should develop policies with respect to access to their services for Deaf people. Such policies need to be in line with the Disability Discrimination Act, and may form part of a broader set of policy statements on access for people with disabilities. It is particularly important that the policy includes specific guidance to frontline staff about the practices and procedures to adopt with respect to Deaf (and other disabled) patients.

PCTs and GPs may like to consider basing their policy on the provision of a basic package of facilitating technologies and practices for Deaf patients, consisting of a combined voice & text phone, a visual patient call system, DAT for staff, BSL interpreter support where required, written instructions about medication and after-care, and double-length appointment slots.

PCTs should establish mechanisms for consulting Deaf users of services on their views of existing services and ways in which these can be improved. Consultation needs to be on a regular basis, not just a one-off, and be built in as a standard element of service evaluation and development. The consultation process needs to ensure that views of Deaf users find representation at all levels of decision-making related to service development. Consultation that relies solely on patient surveys is not recommended.

Recommendations for A&E departments

All Accident & Emergency Departments should establish mechanisms for obtaining a BSL interpreter for any Deaf patient whose preferred means of communication is sign. Deaf patients should be offered an interpreter, they should not have to first request one. Patients should be asked if they have a preference for a male or female interpreter. Interpreters should be offered for follow-up appointments as well as initial visits. Consultants, as well as the Deaf patient, should be given the option of requesting that an interpreter be present at a consultation. Hospital Trusts should consider training at least two nurses up to a minimum of BSL Level 2.

All A&E departments must possess a functioning textphone facility, particularly for Deaf patients and visitors wishing to telephone out from the department, and preferably also for Deaf people wishing to telephone in. This might take the form of a stand-alone textphone on a dedicated line, a combined voice & text phone, or a payphone with texting capability. The textphone needs to clearly visible, not hidden away until asked for.

All A&E departments should consider the feasibility of implementing a visual patient call system. They should also seek to ensure that a reasonable proportion of seats in

the waiting area allow a clear view of the receptionist or of any other person who may call for patients. Lighting at reception and waiting areas needs to be at a sufficient level to allow patients to lip-read.

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Hospital Trusts should develop policies with respect to access to their services for Deaf people. Such policies need to be in line with the Disability Discrimination Act, and may form part of a broader set of policy statements on access for people with disabilities. It is particularly important that the policy includes specific guidance to frontline staff about the practices and procedures to adopt with respect to Deaf (and other disabled) patients.

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Tables

Table 2.1: Adult populations (age 15 years or over) of each of the 5 Health Authorities		
Health Authority	Adult population	%
Manchester	332,000	17
NW Lancashire	383,000	20
St. Helen's and Knowsley	265,000	14
South Cheshire	547,000	29
West Pennine	375,000	20
Total	1,902,000	100

Table 2.2: Numbers of Deaf adults identified by the project	
Health Authority	Number of Deaf people identified
Manchester	324
NW Lancashire	379
St. Helen's and Knowsley	105
South Cheshire	115
West Pennine	186
Total	1109

Table 2.3: Numbers of Deaf adults interviewed by HA		
Health Authority	Number of Deaf people interviewed	%
Manchester	23	24
NW Lancashire	16	16
St. Helen's and Knowsley	16	16
South Cheshire	24	25
West Pennine	19	19
Total	98	100

Table 2.4: Interview sample, by gender and age-group						
	Male		Female		Total	
Age group	n	%	n	%	n	%
18 to 34	13	27	13	26	26	26
35 to 49	11	23	16	32	27	28
50 to 64	15	31	14	28	29	30
65 to 76	9	19	7	14	16	16
Total	48	100	50	100	98	100

Table 3.1: Rates of identification of Deaf adults			
Health Authority	Population covered by study[a]	Number of Deaf people identified	Deaf people per 1,000 adult population
Manchester	332,000	324	.98
NW Lancashire	383,000	379	.99
St. Helen's and Knowsley	220,000	105	.48
South Cheshire	405,000	115	.28
West Pennine	166,000	186	1.12
Total	1,506,000	1109	.74
[a] Estimated adult population in postcode areas included in study			

Table 3.2: Estimated numbers of Deaf and HoH patients by size of GP practice					
Number of GPs	Number (%) of practices	Average number of patients on register	Estimated number with significant hearing loss	Estimated number with severe/profound loss	Estimated number of BSL users
1	138 (30%)	2187	335	42	2.6
2	104 (22%)	3837	588	74	4.5
3	81 (17%)	5421	830	104	6.4
4	56 (12%)	7317	1121	140	8.6
5	48 (10%)	8894	1363	171	10.5
6 or more	41 (9%)	12025	1842	231	14.2
Overall average:		5277	808	101	6.2

Table 3.3: Estimated numbers of Deaf and HoH patients by size of A&E department			
Number of attendances per annum	Estimated number of attendees with significant hearing loss	Estimated number of attendees with severe/profound loss	Estimated number of BSL users
40,000	7,960	1000	61
60,000	11,900	1,500	92
80,000	15,900	2,000	122
100,000	19,900	2,500	153
120,000	23,900	3,000	184

Table 4.1: Interview sample by gender			
	n	%	% from NSP
Male	48	**49**	**50**
Female	50	**51**	**50**
Total	98	**100**	**100**

Table 4.2: Interview sample by age-group (as used in the NSP)			
Age-group	n	%	% from NSP
18 to 24	11	**11**	**11**
25 to 34	15	**15**	**20**
35 to 44	18	**18**	**18**
45 to 54	20	**20**	**18**
55 to 64	18	**18**	**13**
65 to 74	14	**14**	**11**
75 or over	2	**2**	**9**
Total	98	**98**	**100**

Table 4.3: Social classification		
	n	%
Managers and senior officials	6	**6**
Professionals	20	**20**
Associated professional and technical occupations	3	**3**
Administrative and secretarial	4	**4**
Skilled trades	26	**27**
Personal services	7	**7**
Sales and customer services	1	**1**
Machine operatives	8	**8**
Elementary occupations	12	**12**
Students	10	**10**
Never worked	1	**1**
Total	98	**99**

Table 4.4: Recombined social classification		
	n	%
Managerial and professional	29	**30**
Manual	47	**48**
Clerical, services, and students	22	**22**
Total	98	**100**

Table 4.5: Comparison of social classifications from Deaf Access study and NSP				
	n	%	% from NSP	
Managerial and professional	24	**25**	**31**	(Social class I and II)
Manual	55	**56**	**45**	(Social Class III M, IV and V)
Clerical, services, and students	19	**19**	**25**	(Social class III NM)
Total	98	**100**	**100**	
Note: Counts and %'s are based on the social classification of each respondant's present or most recent occupation				

Table 4.6: Which of the following best describes your current situation?	n	%	% from NSP
In paid work (including self-employed)	41	42	57
Unemployed	10	10	4
Retired	23	24	21
Unable to work because of long-term disability or ill health	10	10	5
Looking after family or home	3	3	8
In full-time/part-time education or training	11	11	4
Total	98	100	100

Table 4.7: Ethnic identification	n	%	% from NSP
White	86	88	96
Black - Caribbean	2	2	0
Black - African	1	1	0
Indian	4	4	1
Pakistani	4	4	1
Bangladeshi	1	1	0
Chinese	0	0	0
Other	0	0	1
Total	98	100	99

Table 4.8: In general, would you say your health is…	n	%	% from NSP
Excellent	22	22	12
Very good	13	13	34
Good	34	35	31
Fair	21	21	17
Poor	8	8	6
Total	*98*	*99*	*100*

Table 4.9: Reasons given for wanting a change of doctor (based on 23 saying they would like to change')	n
Dr not deaf aware	4
Problems communicating	8
Dr cannot sign	4
Dr always in a rush	2
Want a better doctor	2
Dr's negative attitude	3
Wrong gender	1
Want to but can't - only GP nearby	1
Total	23

Table 4.10: How important is it for you to have someone present to help you communicate when you talk with your doctor?		
	n	%
Very important	62	**63.3**
Fairly important	5	**5.1**
I do not need anyone to help	6	**6.1**
I prefer not to have anyone help	5	**5.1**
Depends on reason for visit	20	**20.4**
Total	98	**100.0**

Table 4.11: Who do you prefer to be present to help you communicate with your doctor?		
	n	%
Professional sign interpreter or lip-speaker	53	**54**
Family member	29	**30**
Friend	1	**1**
Depends on reason for visit	4	**4**
Prefer to have no-one	5	**5**
Do not need anyone	6	**6**
Total	98	**100**

Table 4.12: Reasons given for preferring an interpreter or a family member for communication support		
Reasons given for preferring an interpreter (based on 52 people who gave a reason)		
	n	% (of people)
Quality or completeness of communication/ personal control over communication	31	**60**
Confidentiality	23	**44**
No family members available	4	**7**
GP refused entry to family member (child)	1	**2**
Reasons given for preferring a family member (based on 23 people who gave a reason)		
	n	% (of people)
Ease of communication	8	**35**
Family member is an interpreter	3	**13**
Confidentiality	5	**22**
Difficulty getting interpreters	5	**22**
Never used an interpreter	2	**9**
Don't like interpreters	1	**4**

Table 4.13: Arranged or tried to arrange a professional sign interpreter for a GP visit, by age group										
	Age group								Total	
	18 to 34		35 to 49		50 to 64		65 to 76			
	n	%	n	%	n	%	n	%	n	%
Yes	10	**38**	13	**48**	20	**69**	8	**50**	51	**52**
No	16	**62**	14	**52**	9	**31**	8	**50**	47	**48**
Total	26	**100**	27	**100**	2	**100**	16	**100**	98	**100**
Chi-square=5.4, df=3, p=0.142										

Table 4.14: Arranged or tried to arrange a professional sign interpreter for a GP visit, by socio-economic group

| | Social group | | | | | | Total | |
| | Managerial and professional | | Manual | | Clerical, service, and students | | | |
	n	%	n	%	n	%	n	%
Yes	15	**52**	8	**36**	28	**60**	51	**52**
No	14	**48**	14	**64**	19	**40**	47	**48**
Total	29	**100**	22	**100**	47	**100**	98	**100**
Chi-square=3.2, df=3, p=0.198								

Table 4.15: Problems encountered when arranging an interpreter (based on 37 people who reported a problem).

	n	% (of people)
Couldn't arrange an interpreter for the appointment time	35	**95**
Difficulty contacting the interpreter	2	**5**
Surgery said it was a waste of money to book interpreter for 5 minute consultation	1	**3**
Interpreter didn't arrive	1	**3**
Interpreter agency forgot to book GP appointment	1	**3**

Table 4.16: Would you visit your doctor more often if communication was easier?

	n	%
Yes	74	**76**
No	3	**3**
No communication problems	21	**21**
Total	98	**100**

Table 4.17: How do patients know it is their turn to see the doctor?

	n	%
Receptionist/GP calls patient's name	74	**75**
Number system	14	**14**
Electronic name display	8	**8**
Other	2	**2**
Total	98	**99**

Table 4.18: In the past 12 months, have you felt like making a complaint about a GP, nurse, receptionist, or other member of staff at your GP surgery?

	n	%	% from NSP
Yes, and I have made a complaint	19	**19**	1
Yes, but I did not make a complaint	21	**21**	11
No	58	**59**	88
Total	98	**99**	100

Table 4.19: Reasons for making a complaint		
	n	%
Reason unrelated to deafness	10	**25**
Quality of communication	12	**30**
Problems with medication	5	**13**
Staff attitude	6	**15**
Facilities for deaf	3	**7**
Communication plus attitude	4	**10**
Total	40	**100**

Table 4.20: Does your current doctor make you feel you are wasting his/her time?			
	n	%	% from NSP
All the time	10	**10**	**1**
Most of the time	8	**8**	**2**
Some of the time	22	**22**	**12**
Never/hardly ever	47	**48**	**78**
Can't say	11	**11**	**6**
Total	98	**100**	**100**

Table 4.21: Does your current doctor listen to you no matter how busy he/she is?			
	n	%	% from NSP
All the time	45	**46**	**62**
Most of the time	20	**20**	**23**
Some of the time	24	**24**	**9**
Never/hardly ever	6	**6**	**1**
Can't say	3	**3**	**5**
Total	98	**100**	**100**

Table 4.22: Does your current doctor treat you with courtesy and respect?			
	n	**%**	% from NSP
All the time	51	**52**	**79**
Most of the time	14	**14**	**14**
Some of the time	19	**19**	**4**
Never/hardly ever	7	**7**	**1**
Can't say	7	**7**	**2**
Total	98	**99**	**100**

Table 4.23: Are the receptionists as helpful as you think they should be?			
	n	**%**	**% from NSP**
All the time	37	**38**	**43**
Most of the time	16	**16**	**32**
Some of the time	37	**38**	**18**
Never/hardly ever	6	**6**	**5**
Can't say	2	**2**	**2**
Total	98	**100**	**100**

Table 4.24: Focus of last visit to the GP		
	n	%
Own health	93	**95**
Health of a child 5 or less	3	**3**
Health of a child over 5	1	**1**
Health of someone else	1	**1**
Total	98	**100**

Table 4.25: Reason for visiting GP		
	n	%
Personal health matter	86	**88**
Child's health matter	3	**3**
Medical/sick note	3	**3**
Repeat prescription	3	**3**
Flu jab	2	**2**
Holiday jab	1	**1**
Total	98	**100**

Table 4.26: Was the visit for something you thought urgent, or not?			
	n	%	% from NSP
Yes, I thought it urgent	23	**23**	**54**
No, I did not think it urgent	75	**77**	**46**
Total	98	**100**	**100**

Table 4.27: Place and form of appointment		
	n	%
At surgery - booked by patient in advance	79	**81**
At surgery - open-access clinic	13	**13**
At surgery - GP invitation at specified time	2	**2**
At surgery - arranged at last consultation	2	**2**
Home visit	2	**2**
Total	98	**100**

Table 4.28: Who arranged the appointment?		
	n	%
Booked by self	38	**39**
Booked by family member	35	**36**
Booked by interpreter/interpreter agency	4	**4**
Booked by social worker	3	**3**
Booked by friend	1	**1**
Open-access surgery	13	**13**
Invitation/arranged last visit	4	**4**
Total	98	**100**

Table 4.29: How did you arrange the appointment? (self-booked appointments only)	n	%
By textphone (surgery has a textphone)	3	8
By TypeTalk	14	37
By going to the surgery	17	45
Letter	1	3
Fax	3	8
Total	38	101

Table 4.30: How easy or difficult did you find it to arrange an appointment?	Booked by deaf person themselves		Booked by a family member/friend		Booked by social worker/interpreter	
	n	%	n	%	n	%
Very easy	14	37	6	17	2	29
Quite easy	9	24	6	17	3	43
Quite difficult	13	34	10	28	1	14
Very difficult	2	5	13	36	1	14
Don't know	-	-	1	3	-	-
Total	38	100	36	101	7	100

Table 4.31: Elapsed time since last visit to GP surgery to see a doctor on own behalf	n	%	% from NSP
Within last month	36	37	27
1 to <3 months ago	25	26	20
3 to <6 months ago	10	10	16
6 to <9 months ago	8	8	9
9 to <12 months ago	7	7	8
12 months or longer	12	12	19
Total	98	100	99

Table 4.32: Companions at the appointment	n	%
Alone	52	53
Deaf companion	3	3
Hearing companion	26	27
Professional Interpreter	15	15
Family member who is also a professional interpreter	1	1
Deaf companion and interpreter	1	1
Total	98	100

Table 4.33: Use of interpreter by nature of visit	Own or child Illness, urgent		Own or child illness, non-urgent		other non-urgent		Total	
	n	%	n	%	n	%	n	%
Sign interpreter	4	17	12	18	1	11	17	17
No sign interpreter	19	83	54	82	8	89	81	83
Total	23	100	66	100	9	100	98	100

Table 4.34: Why was there no professional interpreter / lip-speaker? (based on 81 who did not have an interpreter)	n of people	% of people
Prefer/can cope alone; prefer or can cope with family	33	**41**
Hard/impossible to get interpreter in time for appointment	34	**42**
Don't know how to book/haven't considered it	13	**16**
Lack of confidentiality/don't trust interpreters	5	**6**
Told one wasn't needed	2	**2**
Concerned about payment	2	**2**

Table 4.35: How good was the interpreter / lip speaker?	n	%
Very good	14	**82**
Good	2	**12**
OK	1	**6**
Poor	0	**0**
Very poor	0	**0**
Total	17	**100**

Table 4.36: Had a professional sign interpreter for last GP visit, by age group										
	Age group								Total	
	18 to 34		35 to 49		50 to 64		65 to 76			
	n	%	n	%	n	%	n	%	n	%
Yes	0	**0**	5	**19**	9	**31**	3	**19**	17	**17**
No	26	**100**	22	**82**	20	**69**	13	**81**	81	**83**
Total	26	**100**	27	**101**	29	**100**	16	**100**	98	**100**
Chi-square=9.3, df=3, p=0.026										

Table 4.37: Had a professional sign interpreter for last GP visit, by socio-economic group								
	Social group						Total	
	Managerial and professional		Manual		Clerical, service, and students			
	n	%	n	%	n	%	n	%
Yes	7	**24**	9	**19**	1	**5**	17	**17**
No	22	**76**	38	**81**	21	**95**	81	**83**
Total	29	**100**	47	**100**	22	**100**	98	**100**
Chi-square=3.6, df=3, p=0.169								

Table 4.38: Do you think the receptionist tried their best to communicate with you? (Based on 50 people alone at reception only)	n	%
Yes	33	**66**
No	13	**26**
Don't know	4	**8**
Total	50	**100**

Table 4.39: How much of what the receptionist said did you understand?		
	n	%
Everything	18	**35**
Most	16	**31**
Some	10	**22**
Very little	6	**12**
Total	50	**100**

Table 4.40: Did you have any problems knowing when it was your turn to see the doctor?						
	Alone/deaf companion		Hearing companion/interpreter		Total	
	n	%	n	%	n	%
Yes	11	**20**	2	**5**	13	**14**
No	43	**80**	40	**95**	83	**86**
Total	54	**100**	42	**100**	96	**100**
Fisher exact test, p=0.033						

Table 4.41: Did you have any problems knowing when it was your turn to see the doctor?	Number of interviewees	% of interviewees
Name was called and couldn't hear it	9	**9**
Receptionist forgot I was deaf	1	**1**
Embarrassed by behaviour of the receptionist towards me	1	**1**
Couldn't understand the number system	1	**1**
Was unclear that receptionist was waving to me	1	**1**
Any problem (total of the above)	13	**13**

Table 4.42: How much time did you spend with the doctor?									% from NSP
	Alone/deaf companion		Hearing companion		Interpreter		Total		
	n	%	n	%	n	%	n	%	
Less than 5 mins	24	**42**	7	**29**	2	**12**	33	**34**	26
5 to 9 mins	11	**19**	4	**17**	4	**23**	19	**19**	51
10 to 19 mins	19	**33**	9	**38**	9	**53**	37	**38**	21
20 to 29 mins	3	**5**	4	**17**	1	**6**	8	**8**	2
30 to 39 mins	0	**0**	0	**0**	1	**6**	1	**1**	0
Total	57	**99**	24	**101**	17	**100**	98	**100**	100
Kruskal Wallis test: Chi-square=6.2, df=2, p=0.046 *									

Table 4.43: Was this the right amount of time (with the doctor) or too much or too little?									% from NSP
	Alone/deaf companion		Hearing companion		Interpreter		Total		
	n	%	n	%	n	%	n	%	
Right amount of time	35	**61**	18	**75**	14	**82**	67	**68**	87
Too little time	22	**39**	5	**21**	3	**18**	30	**31**	12
Too much time	0	**0**	1	**4**	0	**0**	1	**1**	0
Total	57	**100**	24	**100**	17	**100**	98	**100**	100
Chi-square=4.1, df=2, p=0.126 Alone/deaf companion vs hearing companion/interpreter: Fisher's exact test p=0.049									

Table 4.44: Who did you rely on to tell what the doctor said?				
	Hearing companion		Interpreter	
	n	%	n	%
Relied fully on companion/interpreter	15	**63**	16	**94**
Relied mostly on companion/interpreter	6	**25**	1	**6**
Understood mostly for myself	3	**12**	-	**-**
Understood fully for myself	-	**-**	-	**-**
Total	24	**100**	17	**100**

Table 4.45: How clearly did you understand the doctor? (those alone only)		
	n	%
Everything	10	**19**
Most	19	**35**
Some	16	**30**
Very little	9	**16**
Total	54	**100**

Table 4.46: Do you think the doctor tried his/her best to communicate with you? (those alone only)		
	n	%
Yes	32	**59**
No	17	**32**
Don't know	5	**9**
Total	54	**100**

Table 4.47: How much of what the DR said did the interpreter/companion pass on to you? (those with interpreters/companions only)				
	Hearing companion		Interpreter	
	n	%	n	%
Everything	5	**21**	14	**82**
Most	5	**21**	2	**12**
Some	12	**50**	1	**6**
Very little	1	**4**	0	**0**
Don't know	1	**4**	0	**0**
Total	24	**100**	17	**100**

Table 4.48: Did the doctor explain the reasons for [the action he/she took] in a way that you found easy or difficult to understand? (Question asked in NSP)	
	% from NSP
Very easy to understand	**69**
Fairly easy to understand	**25**
Fairly difficult to understand	**2**
Very difficult to understand	**0**
Reasons were not explained at all	**3**

Table 4.49: Did you feel able to ask as many questions as you wanted?									
	Alone/deaf companion		Hearing companion		Interpreter		Total		% from NSP
	n	%	n	%	n	%	n	%	
Yes	26	**46**	14	**58**	15	**88**	55	**56**	**89**
No	31	**54**	10	**42**	2	**12**	43	**44**	**11**
Total	57	**100**	24	**100**	17	**100**	98	**100**	**100**
Chi=9.7, df=2, p=0.008 **									

Table 4.50: Do you feel that the doctor did the right things to deal with your case?									
	Alone/deaf companion		Hearing companion		Interpreter		Total		% from NSP[a]
	n	%	n	%	n	%	n	%	
Yes	36	**63**	15	**63**	13	**76**	64	**65**	**92**
No	10	**18**	1	**4**	0	**0**	11	**11**	**4**
Can't say	11	**19**	8	**33**	4	**24**	23	**24**	**4**
Total	57	**100**	24	**100**	17	**100**	98	**100**	**100**

[a] The question in the NSP was 'Do you feel that the doctor took appropriate action to deal with the reason(s) for your visit?' 12% responded 'There was no need to take any action'; in the table above these have been included in the 'yes' category.

Table 4.51: Did you feel that you fully understood the doctors advice on what you should do next?								
	Alone/deaf companion		Hearing companion		Interpreter		Total	
	n	%	n	%	n	%	n	%
Yes	36	**63**	17	**71**	15	**88**	68	**69**
No	21	**37**	7	**29**	2	**12**	30	**31**
Total	57	**100**	24	**100**	17	**100**	98	**100**
Chi=3.9, df=2, p=0.14								

Table 4.52: Did you feel that the meeting with the doctor gave you better understanding of your illness?								
	Alone/deaf companion		Hearing companion		Interpreter		Total	
	n	%	n	%	n	%	n	%
Yes	28	**57**	15	**63**	13	**81**	56	**63**
No	21	**43**	9	**37**	3	**19**	33	**37**
Total	49	**100**	24	**100**	16	**100**	89	**100**

Note: 9 people consulting for things other than 'illness' have been excluded (eg those attending for repeat prescriptions or holiday/flu jabs)
Chi=3.0, d=2, p=0.22

Table 4.53: Been to your current doctor on your own before? (based on 41 with a hearing companion/interpreter at last visit)		
	n	%
Yes	28	**68**
No	13	**32**
Total	41	**100**

Table 4.54: Was communication with the receptionist and doctor better or worse when you were on your own?

	n	%
Worse	27	**96**
No difference	1	**4**
Total	28	**100**

Table 4.55: Was anything (else) better when you went on your own?

	Number of interviewees	% of interviewees
Nothing	26	**93**
Consultation more confidential	2	**7**
Total	28	**100**

Table 4.56: Was anything (else) worse when you went on your own?

	Number of interviewees	% of interviewees
Less self-confidence/more anxious/more embarrassed	11	**39**
Nothing	7	**25**
Everything	3	**11**
Less explanation from Dr	3	**11**
Knowing when turn to see Dr	3	**11**
Less time with Dr	3	**11**
Doctor/receptionist's attitude	2	**7**
Given wrong medication	2	**7**
Given medication with no explanation	1	**4**
Worried may receive wrong medication	1	**4**
More forgetful	1	**4**
Consultation takes too long	1	**4**

Table 4.57: Been to your current doctor with a professional interpreter or lip-speaker before? (Excluding 17 who had an interpreter at the last visit)

	n	%
Yes	22	**27**
No	59	**73**
Total	81	**100**

Table 4.58: Was communication with the receptionist and doctor better or worse with a sign interpreter/lip-speaker?

	n	%
Better	20	**91**
Depends on purpose of visit	1	**5**
Worse (compared to daughter-in-law)	1	**5**
Total	22	**101**

Table 4.59: Was anything (else) better with a sign interpreter / lip-speaker?	Number of interviewees	% of interviewees
More confident/relaxed	13	**59**
Nothing	6	**27**
Dr explained more/better consultation	4	**18**
Knowing when turn to see Dr	2	**9**
More time with doctor	1	**5**
Dr's attitude better	1	**5**
Everything	1	**5**

Table 4.60: Was anything (else) worse with a sign interpreter / lip-speaker?	Number of interviewees	% of interviewees
Nothing	18	**82**
Confidentiality	3	**14**
Interpreter not very good	1	**5**

Table 4.61: What else good or bad can you tell me about any other visits you have made to your doctor's surgery?	Number of interviewees	% of interviewees
Positive comments		
Pleased with GP's attitude	10	**10**
Pleased staff could sign	3	**3**
Better experience with interpreter present	3	**3**
Pleased surgery arranged interpreter	2	**2**
Good experience at reception	1	**1**
Negative comments		
Unhappy with Dr's attitude	20	**20**
Poor communication with GP	8	**8**
Bad experience at reception	6	**6**
Bad experience with medication	5	**5**
Bad experience with interpreter	1	**1**

Table 4.62: What, if anything, do you think your doctor's surgery could do to make things better for deaf patients?	Number of interviewees	% of interviewees
GP to learn BSL	71	**72**
Receptionist /other staff to learn BSL	57	**58**
Textphone in the surgery	55	**56**
Electronic name display	54	**55**
Staff to have deaf awareness training	40	**41**
Surgery to have system for arranging sign interpreters/access to interpreters via videophone	28	**29**
Allow patients to make appointments via fax	17	**17**
Surgery to have mobile phone for text messaging	7	**7**
Allow patients to make appointments via email	6	**6**
TV with subtitles	4	**4**
Doctor to provide more explanation	4	**4**
Medical records of Deaf patient to be marked 'Deaf'	3	**3**
Doctor to personally fetch Deaf patients from the waiting room	2	**2**
Flashing light fire alarm	2	**2**
Longer consultations for Deaf patients	2	**2**
More accessible information	2	**2**
Other (one mention only)	2	**2**

Table 4.63: Comments expressing bad experiences/concern in relation to medication	Number of interviewees	% of interviewees
Inadequate information provided	15	**15**
Believe medication to be incorrect	12	**12**
Anxious that may receive incorrect medication	3	**3**
Incorrect application of medication	2	**2**

Table 4.64: Personal characteristics of the random and replacement samples		Random sample	Replacement sample
Gender	Male	46%	51%
	Female	54%	49%
Age	18 to 34	12%	37%
	35 to 49	24%	30%
	50 to 64	44%	19%
	65 plus	20%	14%
Socio-economic classification	Managerial and professional	29%	30%
	Manual	49%	47%
	Clerical, service industries, and students	22%	23%
Ethnicity	White	90%	86%
	Non-white	10%	14%
Age became deaf	Born deaf	44%	58%
	Became deaf by age two	32%	23%
	Became deaf after age two	24%	19%
How important is it for you to have someone to help you communicate with your GP?	Very important	66%	61%
	Fairly important	7%	4%
	Do not need anyone/prefer not to have help	7%	14%
	Depends on reason for visit	20%	21%
Who do you prefer to help you communicate with your GP?	Professional interpreter	56%	53%
	Family/friend	32%	30%
	Depends on reason for visit	5%	4%
	Do not need anyone/prefer not to have help	7%	14%
Would you visit your GP more often if communication was easier?	Yes	78%	74%
	No	5%	2%
	No communication problems	17%	25%
Have you arranged or tried to arrange an interpreter for a GP visit?	Yes	54%	51%
	No	46%	49%

Table 4.65: Characteristics of the last GP visit		Random sample	Replacement sample
Reason for last visit to the GP	Personal illness	88%	88%
	Child's health matter	2%	4%
	Other	10%	9%
Who arranged the appointment?	Booked by self	37%	40%
	Booked by other	42%	46%
	Open-access surgery	17%	11%
	Invitation/arranged last visit	5%	4%
Did you regard the visit as urgent or not?	Yes, I thought it urgent	20%	26%
	No, I did not think it urgent	80%	74%
Companions at the last GP consultation	Alone/deaf companion	51%	63%
	Hearing companion	27%	23%
	Interpreter	22%	14%

Table 4.66: Outcomes of the last GP visit		Random sample	Replacement sample
Was the time you had with the doctor the right amount of time?	Right amount of time	68%	68%
	Not enough time	32%	30%
	Too much time	0%	2%
Did you feel able to ask as many questions as you wanted?	Yes	59%	54%
	No	42%	46%
Do you feel the GP did the right things to deal with your case?	Yes	68%	63%
	No	10%	12%
	Can't say	22%	25%
Do you feel the visit gave you a better understanding of what was wrong with you?	Yes	71%	60%
	No	29%	40%
Did you feel that you fully understood the doctor's advice on what to do next?	Yes	66%	72%
	No	34%	28%

Table 4.67: Perceptions of GP and receptionist attitudes		Random sample	Replacement sample
		Random sample	Replacement sample
Does your doctor make you feel you are wasting his/her time?	All of the time	7%	12%
	Most of the time	10%	7%
	Some of the time	22%	23%
	Never/hardly ever	46%	49%
	Can't say	15%	9%
Does your doctor listen to you no matter how busy	All of the time	56%	39%
	Most of the time	15%	25%
	Some of the time	20%	28%
	Never/hardly ever	2%	9%
	Can't say	7%	0%
Does your doctor treat you with courtesy and respect	All of the time	63%	44%
	Most of the time	10%	18%
	Some of the time	20%	19%
	Never/hardly ever	2%	11%
	Can't say	5%	9%
Are the receptionists as helpful as you think they should be?	All of the time	42%	35%
	Most of the time	20%	14%
	Some of the time	29%	44%
	Never/hardly ever	5%	7%
	Can't say	5%	0%
In the last 12 months have you felt like complaining?	Yes, and have made a complaint	20%	19%
	Yes, but did not make a complaint	20%	23%
	No	61%	58%

Table 5.1: Numbers of profoundly deaf patients registered with each practice	Number of practices	% of practices
None	6	**19**
1 to 2	9	**29**
6 or less	10	**32**
Don't know	6	**19**
Total	31	**99**

Table 5.2: Communication aids available at GP practices		n	%
Does the practice have a loop system?	Yes	0	**0**
	No	31	**100**
Does the practice have a textphone?	Yes	1	**3**
	No	30	**97**
Is the textphone always switched on and ready for use?	Yes	0	**0**
	No	1	**100**
Does the textphone have an answerphone facility?	Yes	0	**0**
	No	1	**100**
Does the practice have a portable listening device?	Yes	1	**3**
	No	30	**97**
Is the practice registered with TypeTalk?	Yes	3	**10**
	No	28	**90**
What type of patient call system does the practice have? [a][b]	Verbal announcement	20	**59**
	Tannoy	4	**12**
	Visual display	8	**24**
	Number system	1	**3**
Does the practice have a fax machine?	Yes, and available to patients	25	**81**
	Yes, but not available to patients	6	**19**
	No	0	**0**
Does the practice have an email address?	Yes, and available to patients	12	**39**
	Yes, but not available to patients	15	**48**
	No	4	**13**

[a] Categorised from an open-ended question
[b] Sums to more than 31 because at one health centre each practice uses a different system

Table 5.3: Access to sign interpreters			
		n	%
Does the practice have access to BSL interpreters?	Yes	3	**10**
	BSL qualified staff member	1	**3**
	No	27	**87**
How soon can an interpreter be made available? [a]	Within one week	1	**3**
	Very quickly – staff member	1	**3**
	Have never tried	2	**6**
	Not applicable	27	**87**
How are deaf patients made aware that they can have an interpreter? [a]	Reception informs them	1	**3**
	No one has ever asked for one	1	**3**
	Don't know	1	**3**
	Not applicable	28	**90**
Who is responsible for booking the interpreter?	Reception staff/surgery	2	**6**
	Don't know	1	**3**
	Not applicable	28	**90**
Who is responsible for covering the cost of an interpreter?	The surgery	1	**33**
	Don't know	2	**67**
	Not applicable	28	**90**
Is there an alternative if a deaf patient doesn't want a friend/relative to interpret for them? [a]	Would arrange interpreter	2	**6**
	Member of staff that signs	1	**3**
	No alternative	5	**16**
	Don't know	17	**55**
	No deaf patients	6	**19**
Do any of the practice staff communicate with deaf patients by sign language?	Yes	4	**13**
	No	27	**87**
Sign language skill level of staff [a]	Basic skills	2	**6**
	BSL Level 1	1	**3**
	BSL Level 2	1	**3**
	Not applicable	27	**87**
[a] Categorised from an open-ended question			

Table 5.4: Other provision for deaf patients		n	%
Are you aware that the RNID have a GP membership scheme?	Yes	0	**0**
	No	31	**100**
Do you record whether a patient is deaf on their notes?	Yes	27	**87**
	No	4	**13**
Are all deaf patients registered with one particular GP? [a]	Yes	3	**15**
	No	9	**45**
	Don't know	8	**40**
Does the length of appointment given to deaf patients differ from other patients? [b]	Yes	5	**20**
	No	20	**80**
Does the practice have an audiology or ENT clinic?	Yes	3	**10**
	No	28	**90**
Do any of the GPs have a special interest in hearing problems or deaf issues?	Yes	0	**0**
	No	26	**84**
	Don't know	5	**16**
[a] Group practices and practices with profoundly deaf patients only [b] Practices with profoundly deaf patients only			

Table 5.5: Deaf Awareness Training		n	%
Categories of staff that have attended Deaf Awareness Training [a]	Reception staff only	4	**13**
	Reception and practice manager	1	**3**
	Reception and some medical staff	1	**3**
	All staff (currently being arranged)	1	**3**
	None	24	**77**
Have any (other) staff requested Deaf Awareness Training?	Yes	4	**13**
	No	27	**87**
Have any staff raised concerns over communication with deaf patients?	Yes	1	**3**
	No	30	**97**
[a] Categorised from an open-ended question			

Table 5.6: service evaluation			
		n	%
Has the practice evaluated the service it provides for deaf patients?	Yes	2	**10**
	Currently under review	2	**3**
	No	21	**68**
	No – no deaf patients	6	**19**
What prompted you to look at your service provision? [a]	DDA	3	**10**
	Part of a general review	1	**3**
	Not applicable	27	**87**
[a] Categorised from an open-ended question			

Table 5.7: Future plans			
		n	%
Are there any plans for addressing disabled access within the practice?	Yes – specific plans	6	**20**
	Yes – planning in process	3	**10**
	No	22	**71**
Do the specific plans take deaf people into account? [a]	Yes	1	**3**
	No	5	**16**
	Not applicable	25	**81**
[a] Categorised from an open-ended question			

Table 6.1: Gender and age breakdown of the A&E sample						
	Male		Female		Total	
	n	%	n	%	n	%
18 to 24 years	3	**17**	6	**25**	9	**21**
35 to 49 years	5	**28**	5	**21**	10	**24**
50 to 64 years	8	**44**	12	**50**	20	**48**
65 and over	2	**11**	1	**4**	3	**7**
Total	18	**100**	24	**100**	42	**100**

Table 6.2: Reasons for the A&E visits		
	n	%
Accident or emergency to self	35	**83**
Accident or emergency to a child	5	**12**
Accident or emergency to spouse[a]	2	**5**
Total	42	**100**
[a] in both cases the spouse was also Deaf		

Table 6.3: Mode of travel to the A&E unit; cases of personal accidents and emergencies only		
	n	%
Travelled by ambulance	16	**46**
Went with hearing companion	12	**34**
Went with deaf companion	3	**9**
Went alone	4	**11**
Total	35	**100**

Table 6.4: When you arrived at the hospital, how easy was it to find the A&E department?		
	n	%
Easy – taken there by ambulance staff/taxi driver	20	**48**
Easy – been before/companion knew the place	15	**36**
Easy – well signposted	4	**10**
Easy – reason not given	3	**7**
Total	42	**101**

Table 6.5: Companions with the Deaf patient at A&E		
	n	%
Hearing adult relative/friend	19	**45**
None (patient was alone)	15	**36**
Deaf adult relative/friend	4	**10**
Professional BSL interpreter	2	**5**
Hearing adult and interpreter	1	**2**
Child (<18 years)	1	**2**
Total	42	**100**

Table 6.6: Signing support		
	n	%
No signing support	21	**50**
Companion who can sign and hear	15	**36**
Signing hospital nurse	3	**7**
Professional BSL interpreter	3	**7**
Total	42	**100**

Table 6.7: What was communication like with the staff you saw in A&E?						
	No communication support		Communication support		Total	
	n	%	n	%	n	%
Poor/inadequate communication	12	**57**	6	**29**	18	**43**
Good/adequate communication	9	**43**	15	**71**	24	**57**
Total	21	**100**	21	**100**	42	**100**
Fisher's exact test (two-tailed), p=0.073						

Table 6.8: Did you have any problems knowing when it was your turn to be seen, or who to see?						
	No communication support		Communication support		Total	
	n	%	n	%	n	%
No problems	15	**71**	19	**95**	34	**83**
Problems	6	**29**	1	**5**	7	**17**
Total	21	**100**	20	**100**	41[a]	**100**
[a] one patient didn't know (her husband was the injured patient)						
Fisher's exact test (two-tailed), p=0.093						

Table 6.9: During the visit, did you have any problem finding your way around the hospital? For example, if you had to go to another department for an x-ray or test?						
	No communication support		Communication support		Total	
	n	%	n	%	n	%
No problems	9	**42**	7	**35**	16	**39**
Problems	2	**11**	0	**0**	2	**5**
Taken around by hospital staff	10	**47**	13	**65**	23	**56**
Total	21	**100**	20	**100**	41[a]	**100**
[a] one patient didn't know (her husband was the injured patient)						

Table 6.10: What did you think of the medical treatment you were given for your condition?						
	No communication support		Communication support		Total	
	n	%	n	%	n	%
Satisfied/happy	15	**71**	13	**65**	28	**68**
Not satisfied/unhappy	5	**24**	3	**15**	8	**20**
Can't say/uncertain	1	**5**	4	**20**	5	**12**
Total	21	**100**	20	**100**	41[a]	**100**
[a] one patient didn't know (her husband was the injured patient)						

Table 6.11: Do you think you were given all the information you should have been given?						
	No communication support		Communication support		Total	
	n	%	n	%	n	%
Yes	4	**19**	10	**50**	14	**34**
OK, but could have been better	2	**10**	0	**0**	2	**5**
No	15	**71**	10	**50**	25	**61**
Total	21	**100**	20	**100**	41[a]	**100**

[a] one patient didn't know (her husband was the injured patient)
Fisher's exact test, p=0.052

Table 6.12: Did you have a follow-up appointment at a later date at A&E?		
	n	%
Yes	17	**41**
No	24	**57**
Can't remember (too long ago)	1	**2**
Total	42	**100**

Table 6.13: Did the hospital arrange or offer to arrange a sign interpreter for the follow-up appointment?		
	n	%
Yes, after I requested one	1	**6**
No, but I arranged one myself	3	**18**
No	12	**71**
I preferred to go alone	1	**6**
Total	17	**101**

Table 6.14: Did anything happen during the first or any follow-up visit that you felt like making a formal complaint about?						
	No communication support		Communication support		Total	
	n	%	n	%	n	%
Yes – related to deafness	9	**43**	6	**29**	15	**36**
Yes – not related to deafness	3	**14**	4	**19**	7	**17**
No/can't remember	10	**48**	12	**57**	22	**52**
Total patients	22	**100**	22	**100**	44	**100**

Note: two patients are counted twice; they had complaints both related and unrelated to deafness.

Table 6.15: Breakdown of deafness-related complaints		
	n	%
Quality/completeness of communication from staff	8	**50**
Treatment at reception	5	**31**
Hospital did not provide interpreter support	3	**19**
Total	16	**100**

Note: one patient is counted twice; they had two different types of complaint.

Table 6.16: What else good or bad can you tell me about that or any other visit you have made to an A&E department?		
	n	%
Positive comments	5	24
Negative comments – personal communication	9	43
Negative comments – telephone contact	2	10
Negative comments – medical treatment	5	24
Total	21	101

Table 6.17: Can you think of anything the hospital could have done to make your visits to A&E a better experience for you?	Number of interviewees	% of interviewees
Dr/nurse/staff to learn BSL	24	57
24hr interpreter cover/provide interpreter support/videolink to interpreters	24	57
Textphone in unit	24	57
Deaf Awareness Training for staff	20	48
Electronic name display	15	36
TV with subtitles	8	19
Flashing light fire alarm	6	14
Fax machine	3	7
More accessible information	3	7
Staff to know basic signs	2	5
Other (1 mention only)	9	21

Table 7.1: Communication aids available at A&E departments		n	%
Does the department have a loop system?	Yes	3	**14**
	No	19	**86**
Does the department have a textphone?	Yes	2	**9**
	No	20	**91**
Is the textphone always switched on and ready for use?	No	1	**50**
	Don't know	1	**50**
Does the textphone have an answerphone facility?	Don't know	2	**100**
Does the department have a TypeTalk number?	No	21	**95**
	Don't know	1	**5**
Does the department have a portable listening device?	Yes	2	**9**
	No	19	**86**
	Don't know	1	**5**
What type of patient call system do you have? [a]	Verbal announcement	22	**100**
	Electronic name display	0	**0**
In your opinion how suitable are your information leaflets for deaf people?	Extremely suitable	1	**5**
	Suitable	11	**50**
	Not suitable	5	**23**
	Don't know	5	**23**
[a] Categorised from an open-ended question			

Table 7.2: Access to interpreters			
		n	%
Does the department have access to BSL interpreters?	Yes	14	**64**
	Yes, voluntary	1	**5**
	No	5	**23**
	Don't know	2	**9**
How soon can an interpreter be made available? [a]	Quickly/within 2 hours (in office hours)	7	**47**
	Could take hours	2	**13**
	Unknown/not sure/variable	6	**40**
Are children ever used as interpreters for deaf parents?	Yes	21	**95**
	No	1	**5**
Are relatives or friends ever used as interpreters?	Yes	21	**95**
	No	1	**5**
Use of staff as interpreters [a]	Used staff in the past (no longer with Trust)	2	**9**
	Currently use staff	6	**27**
	Staff not used	14	**64**
Qualifications of staff used as interpreters	BSL Level 1	2	**33**
	BSL Level 2	2	**33**
	Child of deaf parents	1	**17**
	Child of deaf parents and BSL Level 2	1	**17**
If a return appointment is necessary would a BSL interpreter be booked in advance?	Yes	8	**36**
	No	13	**59**
	Don't know	1	**5**
[a] Categorised from an open-ended question			

Table 7.3: Deaf Awareness Training			
		n	%
Have any staff attended deaf awareness training?	Yes	3	**14**
	No	18	**82**
	Don't know	1	**5**
Have any (other) staff requested deaf awareness training?	Yes	3	**14**
	No	19	**86**

Table 7.4: Barriers to access		n	% (of respondents)
Do you think deaf access to the department could be improved?	Yes	21	**95**
	Don't know	1	**5**
What barriers are there to service provision for deaf patients within the Trust? [a]	Insufficient resources	16	**73**
	Not enough staff awareness of needs of deaf patients	13	**59**
	Lack of staff training	3	**14**
	Low on list of priorities	2	**9**
	Not enough time	2	**9**
	Other	4	**18**
What improvements could be made within the department to improve deaf access? [a]	Staff training in deaf awareness	8	**36**
	More communication aids	4	**18**
	Increase staff understanding of problems faced by deaf people	2	**9**
	Better access to interpreters	2	**9**
	Visual patient information/call display	2	**9**
	Other	4	**18**
[a] Categorised from an open-ended question; more than one response could be given.			

Table 7.5: Finding and moving around within A&E departments			
		n	%
Is the Hospital A&E entrance easily identified from outside?	Yes	18	**82**
	No	4	**18**
Are there clear directions to the reception area?	Yes	18	**82**
	No	4	**18**
Is the waiting area clearly defined?	Yes	17	**77**
	No	5	**23**
Are there clear directions to different areas?	Yes	5	**23**
	No	17	**77**
Is there a colour coded direction system on the floor?	Yes	3	**14**
	No	19	**86**
Are all the doors labelled?	Yes	7	**32**
	No	0	**0**
	Some	15	**68**

Table 7.6: Facilities for communication at A&E departments		n	%
Is the Sympathetic Hearing Scheme symbol displayed on the entrance door or near reception?	Yes	5	**23**
	No	17	**77**
Does the reception area have 'loop' system?	Yes	3	**14**
	No	19	**86**
Is there a symbol indicating a loop system?	Yes	3	**14**
	No	19	**86**
How good is the lighting at the reception desk?	Good	3	**14**
	OK	14	**63**
	Poor	5	**23**
How good is the lighting at the waiting area?	Good	3	**14**
	OK	9	**41**
	Poor	10	**45**
Is there a textphone text phone for patient use?	Yes	2	**9**
	No	20	**91**
Is there a shelf or table for portable text phones?	Yes	0	**0**
	No	22	**100**
Is there a visible text display system of patient names?	Yes	0	**0**
	No	22	**100**
Can sitting patients lip-read the receptionist from their chair?	Yes – from all seats	2	**9**
	Yes – from some seats	4	**18**
	No	16	**73**

Table 7.7: Other facilities at A&E departments		n	%
Is there a flashing light fire alarm system?	Yes	0	**0**
	Partially	1	**5**
	No	21	**95**
Is there a television set in the waiting area?	Yes	22	**100**
	No	0	**0**
Does the television have a Teletext facility?	Yes	9	**41**
	No	13	**59**
Were the Teletext subtitles switched on?	Yes	0	**0**
	No	9	**41**
	N/A	13	**59**

Table 9.1: Costs of implementing a basic 'access package' in GP practices						
	Practice list size					
	2000	4000	6000	8000	10000	12000
Estimated mean number of Deaf patients (rounded to one decimal place)	2.4	4.8	7.1	9.5	11.9	14.3
Costs (£s) for first year, including start-up (ie training and equipment) costs						
Combined voice and text phone	200	200	200	200	200	200
Visual patient call system[1]	550	550	550	550	550	550
1-day DAT course for up to 20 staff[2]	300	300	300	300	300	300
Hire of BSL Interpreters[3]	428	856	1284	1712	2140	2568
Total for first year	**1478**	**1906**	**2334**	**2762**	**3190**	**3618**
Subsequent years (at 2002 prices)						
Half-day DAT course for up to 20 staff [4]	150	150	150	150	150	150
Hire of BSL Interpreters[3]	428	856	1284	1712	2140	2568
Total for subsequent years	**578**	**1006**	**1434**	**1862**	**2290**	**2718**

[1] Single-line display of twenty 5cm high characters; includes £50 installation costs
[2] Cost of 1-day Sympathetic Hearing Scheme course
[3] Assumes average cost of £60 per appointment
[4] Cost of half-day Sympathetic Hearing Scheme course

Table 9.2: Costs of implementing a basic 'access package' in all practices by Health Authority			
Health Authority	Number of practices	First year costs (£s)	Subsequent annual costs (£s)
Manchester	114	227,000	124,000
NW Lancashire	89	189,000	109,000
South Cheshire	97	255,000	167,000
St Helen's and Knowsley	76	157,000	88,000
West Pennine	92	197,000	114,000
Total	468	1,025,000	602,000

Table 9.3: Estimated costs of implementing a basic access package by size of PCT		
Size of PCT (number of practices)	First year costs (£s)	Subsequent annual costs (£s)
10	22,000	13,000
20	44,000	26,000
30	66,000	39,000
40	88,000	52,000
50	109,000	64,000
60	131,000	77,000

Table 9.4: Costs of providing basic access facilities at Accident & Emergency units					
	A&E annual volume of patients				
	40,000	60,000	80,000	100,000	120,000
Estimated number of attendances by Deaf patients (rounded to one decimal place)	61	92	122	153	184
Costs (£s) for first year, including start-up (ie training and equipment) costs					
Combined voice and text phone	200	200	200	200	200
Visual patient call system[1]	1300	1300	1300	1300	1300
1-day DAT course for up to 20 staff [2] (two 1-day courses for larger A&Es)	300	300	600	600	600
Hire of BSL Interpreters [3]	2288	3450	4575	5738	6900
Total for first year	**4088**	**5250**	**5675**	**7838**	**9000**
Subsequent years (at 2002 prices)					
One-day DAT course for up to 20 staff[2]	300	300	300	300	300
Hire of BSL Interpreters [3]	2288	3450	4575	5738	6900
Total for subsequent years	**2588**	**3750**	**4875**	**6038**	**7200**

[1] Single-line display of twenty 10cm high characters; includes £200 installation costs
[2] Cost of 1-day Sympathetic Hearing Scheme course
[3] Assumes average cost of £60 per appointment