

# **Issues in Health Care Access for Deaf people**

**A preliminary review**

**based on recent research work at CDS and Deaf Studies Trust**

**2000 - 2005**

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*A starting point based on Dye & Kyle (2000) and Kyle et al (2005)*

Public services, by definition, serve the people – all of the people. Public services are created from the needs of the people, are administered by the people and are assessed by the people.

The problems start when the resources created by the people do not match the aspirations of all of the people and when there is inherent diversity in society. If there were only Deaf people in society, then there would be no problem of access to service. That is, Deafness itself, is not a barrier to participation, to information or to interaction. The problems arise because Deaf people are in the minority, with a different language and experience.

### **Deaf people in Europe**

It is commonly believed (eg Pullen & Jones, 1987) that Deaf people underachieve in relation to their cognitive ability and need better service and support. However, Kyle and Allsop (1997) in a study of 17 countries in Europe reported that Deaf people saw the issue in terms of the right to their language for all transactions in daily life while, in contrast, hearing people saw sign language as an option, which was subject to needs assessment, financial analysis and targeted provision.

In comparative terms, the UK was relatively well off in statutory provision. Deaf people believed full-time interpreters existed (87%) but in emergencies, Deaf people were sceptical of having access through an interpreter - at hospital (22% said yes - low compared to other countries), if there was a car crash (9% yes - very low). Deaf people in the UK did not have confidence that they would be able to access public (or any services) through interpreters.

### **Deaf People in the UK**

In Deaf People in the Community (DPIC), a national examination of Deaf lifestyle, (Deaf Studies Trust, 1997-2002), a representative sample of 240 Deaf people from all over the UK, including Scotland, was interviewed seven times, in BSL. In terms of demography, the study produced a great deal of relevance to the description of the Deaf community.

## ***Deaf and Health Services***

Data from the DPIC study (2000) which relate to health were striking. Compared to hearing people, Deaf people were much more likely to visit the GP (even though they disliked the experience); they were much more likely to be given prescriptions than hearing people; Deaf women had problems in alcohol use and younger Deaf people were more likely to smoke than their hearing peers.

Although 34% said they used text relay services to make an appointment, 23% asked a friend and 21% went themselves to the health centre, just to make the appointment. Ninety-one percent said that there was no one who could sign at the Health Centre.

Deaf people prepared in advance with 46% making notes before their visit to the GP. Interestingly, 39% tried to speak first and then gesture eg point to the pain. Around 44% asked for pen and paper and 43% spoke first and then wrote down. Some 21% used a sign language interpreter but 29% used family or friend to mediate and 44% tried to lip-read the doctor. When asked why Deaf people went to the doctor more than hearing people, 61% said it was because they did not understand the first time and had to go back to check.

There are serious causes for concern about the use of health services by Deaf people.

### **Direct contact with Emergencies and Hospitals**

Of the topic areas covered in the interviews in Kyle et al (2005) , this is probably the most predictable and the most disturbing. In certain situations, Deaf people have no option but to try to communicate directly. At the point of greatest need in emergency situations, Deaf people's well being is greatly at risk and often for the sake of most trivial of alterations which minimal Deaf awareness training would provide. Deaf people frequently languish in waiting areas not knowing that their names have been called.

*It happened to me at the A&E. I waited for a long time, unaware that my name was called out 3 times. After a while I saw the staff change their shift. I went up and asked what happened and they said they called my name three times. I had told them I was Deaf. They need more Deaf awareness training, to change their attitude and staff should be able to sign. A8*

*I went to hospital, told them my name and that I was Deaf. I showed them where I was sitting, so there was no need to shout but they should come up to me or “wake” me when it was time to see the doctor. But after waiting, I saw someone call my name with exaggerated mouth pattern. I was embarrassed ... I told them ... but they simply ignored what I had said. A26*

Deaf people consider this failure as a matter of ‘attitude’. Hearing people are seen not to care, to be resistant to change in their routine and sometimes, just ignorant of the needs of Deaf people even when these have been pointed out. It is a matter of considerable frustration. This frustration can turn into very bad experiences.

*It happened with my (hearing) wife who was diagnosed with breast cancer. It was confusing as the doctor explained to her about it in front of me. I was lost for information. My wife was upset and she was crying while trying to explain to me. The doctor was not aware of Deaf needs. On the next visit, I called for an interpreter so that my wife did not have to try to explain to me what the doctor said. A14*

*One time after a chest operation, I was transferred from Edinburgh hospital. I was left in the waiting room overnight as the bed wasn’t ready. I was in so much pain and they gave me no medication. I was cold and really suffering. The next day, the nurse found me and said “you are up early”. I explained that I hadn’t been given a bed. The medical team were shocked and I demanded to be sent home to recover. E79*

This is an area of great concern where communication barriers and lack of simple procedures were reported to be seriously affecting Deaf people’s well being. In terms of waiting, Deaf people see the problem as lack of a visual display system and simple lack of Deaf awareness – one would think these would be simple matters to rectify. In the case of the communication issues, they see the problem in terms of lack of emergency interpreters.

### **Dealing with Doctors**

In all surveys of Deaf people, contact with the local GP and with medical services is one of the most problematic areas. Deaf people feel their personal well-being is at risk and view the communication transaction with some apprehension. However, some Deaf people reported success with the doctor.

*My GP is fine and understandable as he is my family doctor for more than 30 years. He is Deaf aware and uses gesture. No problem. A27*

*My doctor can use fingerspelling. It helps better to communicate. She has really good Deaf Awareness. I am not very good at English. She wrote only simple words. Most doctors do not do that! A23*

However, these responses were very much in the minority; usually there were complaints of lack of communication and problems of attitude. Deaf people as usual partially solved the problem by taking a relative or friend but in this situation, there are major questions about privacy and independence.

*Always brought a friend with me. He knows a lot of information about me. B38*

*My aunt always goes with me to the GP. I am not happy as it affects my privacy and also can affect her if anything is seriously wrong and she tells the family. A1*

It is difficult to make this feeling clear to hearing readers. In a hearing society, particularly in the UK, personal privacy is closely guarded. It is true that people have close friends with whom personal problems can be discussed but people expect these confidences to be respected. In any case, they have the choice to make the information available to the other person. In contrast, Deaf people receive second hand information from other people. The doctor speaks and a friend or relative passes on the information which is deemed relevant to the extent of their communication abilities – which is often not at the level of fluency in BSL. The hearing person makes the choice about which information to share with the Deaf person – about that Deaf person's well-being. When the intermediary is a family member, there is a serious dilemma about which other people might be informed. The Deaf person has no control over this – “He knows a lot of information about me” – and there is a suspicion that the person “tells the family”. This creates great insecurity.

At the same time, the involvement of a family member may cause severe problems for that person.

*Writing notes does not help. I am never happy with doctors. Last year I went to hospital, my daughter helped me as interpreter. It was impossible to find a interpreter. It was a very bad experience. My doctor told me I may have cancer but it really frightened my daughter because we are in the same family it was not right. I do not have any privacy. C54*

Where Deaf people reject the intermediary, they go to the doctor on their own. In this case, they have to rely on the doctor's preparedness to make adjustments in communication. In Stornoway in this study, where there are simply no alternatives, Deaf people reported being unhappy about their poor communicative contact with doctors.

*I am used to going on my own – all my life. .... Doctor would write down just one word like ‘operation’ or ‘hospital’. I would show or point to my body where the problem is. If there is a problem with the children, my husband goes. I wouldn’t want an interpreter as it is my privacy. The doctor should sign to communicate with me. S2*

*I had a terrible pain here. He (doctor) told me there was nothing wrong. I went back again. Same reply. Six months later I went to see a different doctor, who took an x-ray and told me I had kidney stones. So I had treatment in the hospital. There should be a nurse to interpret for Deaf people – not the family. S3*

This problem was possibly even more acute in Shetland where there are no services at all.

*I have a work colleague, who is head cook, who I taught to sign, She helps me phone the doctor and sometimes she comes with me. Sometimes I go on my own. It is difficult to communicate with the doctor - I have to lip-read or write down. I only get a brief response. I had a smear test and waited for the result by letter – there was none. That was three years ago. Also I had a urine test and I am still waiting for the result. I told them I was Deaf and unable to use the phone, so I gave them the number to fax me with the result - no response. It is so hard being Deaf with little support. L2*

*It is so hard – there is no one to help with communication. It is so difficult to explain to the doctor what I want to say. It is difficult to do it by writing..... Social worker never helps in Shetland. There is a Deaf club but the social worker never comes to meet us Deaf people to see if we need anything or any help – nothing at all. L4*

In health settings, Deaf people lose control of their own bodies and their own well-being. The problems that can be caused by these circumstances are enormous.

However, as before, it is the Deaf person who ends up feeling bad about the lack of information or explanation.

*..frustrated waiting in the waiting room. I often have to wait a long time as they seem to forget about me. I complained to the doctor about the lack of display system and the doctor said they had no money. Sometimes after leaving the doctor, I feel depressed and angry because I don’t understand the doctor. I feel the doctor should write down all the information or have an interpreter. A25*

It is quite clear that Deaf people are outsiders in health settings. It is very difficult to establish ownership of their own health information. Adjustment is seldom by the health professional and the net result is to reduce the Deaf person’s self esteem. Such problems also have serious repercussions.

*The doctor explained but I did not understand. He wrote notes but I didn’t understand his handwriting and jargon. I tried to explain about my baby son. I knew there was something wrong with him but he just gave me some medicine and never*

*explained what I should do with the medicine. It really stressed me. A few weeks later, my son was really ill. The other doctor was shocked about his serious illness. I am still very angry with this. B41*

In contact with health services Deaf people continuously use the terms frustration and loss of privacy. Deaf people often blame themselves for the problems with the doctor – yet the root of this must be the service provision as *every* Deaf person can recount a bad experience with health staff in hospitals or in a doctor's surgery. From the lack of the simplest notions of Deaf awareness (inability to tell the Deaf person it is his or her turn, other than by shouting) to the most serious insensitivity in refusing to write down or take the time to explain properly, Deaf people's experience of health care is very poor indeed.

## **Further Issues – DPIC Study 2000**

### **Visiting the Doctor**

Whenever a hearing person feels ill, he or she can make an appointment to see the General Practitioner (GP). A phone call is normally followed by an appointment within a week or two, resulting in a 5-10 minute consultation with the doctor. As a result, the patient may receive advice, a prescription for medicine, or referral to a specialist or consultant.

For Deaf people, however, the process may not be as straightforward. Initially there is the problem of making the appointment - if the Health Centre has a minicom, staff may not be well trained in how to use it. There may also be problems with the consultation itself. One can safely predict that few GPs have signing skills adequate for a medical consultation, and the scarcity of professional sign language interpreters may mean that the Deaf person has to rely upon a family member or friend for communication support. Given potential difficulties with communication, there is the worry that the GP may be more likely to issue a prescription, as reassurance and health advice are impeded by communication difficulties.

### **Attending Sessions with GP**

The DPIC sample (240 people) was asked how often they had visited their GP in the

two weeks prior to interview. Overall, 29% of the sample had visited their GP within this time period. Women (31%) were marginally more likely than men (27%) to have made a visit, with those aged 65 years or older were the most likely to have gone to the doctor, for both genders. For men and women of all age groups, the Deaf sample were approximately twice as likely to have visited their GP as the hearing sample interviewed in the General Household Survey (1996). This goes against what we might have predicted as Deaf people commonly say that they dislike these consultations. However, it seems that the incidence of feeling unwell is greater and sufficient to overcome any hesitation in going to see the doctor.

The reported incidence of GP visits in the two weeks prior to interview, along with the frequency of such visits, was used to estimate the average number of GP consultations within the year. The results, by gender and age group, are reported in tables. Age trends are similar for the hearing and Deaf samples. The number of GP visits made by women does not vary greatly with age, but for older men there are more visits. The projected number of visits within a year is two to three times higher for the Deaf sample compared to hearing people.

Although the Deaf and hearing samples are equally likely to have visited a GP surgery (88% and 87% respectively), Deaf people are far less likely to have received a home visit from their GP (2% compared to 8% of the hearing sample from the GHS). This is an interesting finding but it is hard to explain. Deaf people may find it easier to “turn up” at the surgery, while hearing people may more easily call for help by telephone. Typically some diagnosis can be done on the telephone and this may lead to a home visit.

It seems that despite potential difficulties in making appointments and communicating with their GP, Deaf people are much more likely to have appointments than are hearing people. There are several possible reasons for this. Communication problems may result in Deaf people feeling "I still don't know what's wrong with me", and making repeat appointments. The same problems with communication may mean that diagnosis was less clear, the doctor may not have been able to understand the symptoms as reported, and the problem was never resolved. Or it may be possible that Deaf people are more likely to suffer from medical complaints than the majority hearing population. The first two explanations seem more likely, although further



studies are required to establish the precise reasons for the larger number of GP visits by Deaf people.

### ***Satisfaction with GP***

Those who had consulted a GP in the 14 days prior to interview were asked if they were happy with their GP and the communication during the appointment. Levels of satisfaction within the population were generally high, with 88% of men and 80% of women expressing satisfaction with their GP. Satisfaction was lowest for younger respondents (16-44 years old), although still high at 80% for young Deaf men and 72% for young Deaf women. The reported levels of satisfaction are higher than expected, although comparison figures for the hearing population were not available at the time of publication (these figures may in fact be low compared to hearing norms). The measure of satisfaction used in this study was not detailed, consisting of only one question. Clearly satisfaction with one's GP may depend upon a host of factors, including communication, doctor's manner, speed with which the problem was resolved and the quality of advice and reassurance given. These different areas must be separated out if we are to have a valid and reliable measure of Deaf people's satisfaction with their GP. In addition, it is possible that Deaf people's expectations are lower than those of hearing people given what they may see as a natural barrier in communication.

### ***Prescriptions***

Those who had visited a GP within the two-week reference period were asked whether their GP had issued a prescription. Men were more likely to receive prescriptions than women; older people were more likely to receive prescriptions than younger people; and Deaf people are more likely to be given a prescription by their GP than are their hearing peers.

This finding supports the hypothesis mentioned earlier, where it was anticipated that communication problems would lead to a greater reliance upon prescriptions and less upon the provision of advice and reassurance.

### ***Communication Support***

The same group of respondents was asked whether they utilised communication support (ie interpreters or signing or text systems) during their GP consultation. Only 36% of respondents reported doing so. For those who did use some form of communication support, men were more likely to use a professional sign language interpreter (24%; 11% for women), and women were more likely to use a friend (17%; 8% for men).

These points need to be emphasised – at least 60% of men and nearly 50% of women went to the doctor in the last two week without support for communication. The DPIC sample was selected because of their language choice – BSL – which is not shared by the doctor. The implications for diagnosis and treatment are enormous and indicate that there could be serious problems to be dealt with here.

Given the scarcity of professional sign language interpreters, particularly those qualified to a level suitable for medical consultations, these results are not surprising, at least in one respect – although we have no sense that Deaf people tried to find an interpreter and were unsuccessful. It is much more likely that interpreters simply cannot be provided for short consultations. One might also argue that Deaf people are reluctant to use an interpreter as the consultation may be of a personal and/or embarrassing nature. This is more likely to be the case for women, which may explain the marginally more frequent use of a friend for communication support.

### **Attending Hospital**

The DPIC population was also asked how often they had received outpatient treatment in the last 3 months. Except for those aged 65-74 years, Deaf respondents were more likely than their hearing peers to receive outpatient treatment in the last year. – ie the same trend as for visits to the doctor. However, the sample size was very small here for the DPIC sample as the age group was limited to 65- 74 years.

For day-patient treatment, Deaf respondents of all ages were much more likely to have been into hospital than were hearing people. There is an increase in day-patient treatment with increasing age (as for the hearing population), but the treatment rates are three to four times higher than for hearing people.

If Deaf people have limited access to health information or to information about how the health service works, they may be more likely to go directly to the hospital. They may also be more likely to build up problems which mean more serious treatment at hospital.

Overall, the figures for Deaf respondents receiving inpatient treatment are the same as those reported for the hearing population. There is a gender difference however. Young Deaf men appear more likely to receive inpatient treatment than hearing men, although the reverse is true for Deaf and hearing women. This is also reflected in the average number of nights spent in hospital. The problem here is that there are very few cases in these figures for Deaf people.

### **Satisfaction with Hospital Consultant**

All respondents who reported receiving day-patient or inpatient treatment within the 12 months prior to interview were asked whether they were satisfied with their communication with the consultant. Overall, 66% were satisfied although this figure was higher for men (71%) than for women (59%). These satisfaction rates are lower than those for GP consultations, although again comparison figures are not available. In reality, we are dealing with small numbers of cases and these figures should not be taken as too firm. Also we should remember that the concept of “consultant” may not be so readily understood by Deaf respondents.

### **Summary**

Anecdotal evidence suggests that Deaf people do not like visiting their GP, and try to avoid it as much as possible. However, results from this study suggest that Deaf people are *more likely to visit* their GP for a consultation, *and more likely* to receive day-patient treatment in hospital than are the population as a whole. The study also suggests that satisfaction rates are high. However, other data suggests that the picture is not as rosy as would first seem to be the case. Over half of the Deaf people go to the doctor without professional support for communication. They are more likely to receive a prescription than their hearing peers. Taken together this is weak support for the view that communication between GPs and their Deaf patients may be poor. The satisfaction measure used (which has given apparently high ratings) may not have been specific enough to identify certain areas where satisfaction was low (such

as communication), and may reflect lower expectations of services held by Deaf people.