

Deaf Health

Analysis of the current health and access to health care of Deaf people in the UK

Part 2: Interviews and Workshops – What Deaf people say

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1. Summary

As well as determining the pattern of Deaf people's health and their attitudes to the health process, we also needed to know about Deaf people's experiences in health care and their own internal constructions about the nature of health. In this second part of the investigation of Deaf health, 45 Deaf people who had taken part in health assessments were interviewed. At the same, we set up workshops in 5 locations to feedback to participants and also to elicit their own responses to the health information. These two elements form separate sections in this report with the joint implications are drawn out in the final chapter.

The 45 interviewees were chosen from the original sample of 298 people as individuals who would have considerable experience of contact with the Health Service and who were showing a range of symptoms and diagnoses which placed them in categories of interest in public health.

Each person was interviewed individually in their chosen location close to their home. The interviewer was Deaf and used BSL.

Qualitative analysis in BSL on the recordings of the semi-structured interviews was carried out. Categories of response were established and themes were extracted in discussion on the data in BSL. Only in the final stage was this report prepared in order to protect the BSL integrity of the data and the analysis. These in depth accounts were then compared with Deaf people's experiences after their health assessment.

The analysis established particular themes in regard to experience and the presence of interpreters, the provision of information, the issue of control of the health transaction and of one's own health, the presence of "depression" as a result of the marginalisation of the Deaf person.

As a major overarching theme, we consider that Deaf people experience a dissociation of their own health transaction in the community and even their own health, from an inner person and identity. This separation arises from the need to preserve their own inner well being when external information is inaccessible and when efforts to deal with it are ignored by the community and the health professionals.

Recommendations which might address these issues are considered but we conclude that an adjustment of the Health Service itself may be needed if we are seriously to improve Deaf Health.

2. Prologue

It is perhaps unusual to set out a prologue in a technical/academic research report of this nature although it is common in individual work where qualitative and reflective methods are used. However, such was the journey of the researchers involved that it is necessary and important for some of these feeling and reactions to be set out. The context that they provide is vital to the understanding of what follows in the report. It may also help to contextualise the responses of the research team to what Deaf people said and then in turn, help the reader to understand how these responses are to be presented to the outside world. If the text here seems abrupt, direct or even frustrated, it is because the experience of meeting with and interviewing and discussing the ‘health mysteries’ of Deaf members of the community, has pressured the researchers into expressing exactly what is being said by Deaf people. We use the word ‘mystery’ here because much of what has been relayed to us in interviews reflects the confusion and mystification which Deaf people feel about the health processes.

The message is simple: it is not enough to look for headline figures, key soundbites or even expressions of surprise, shock, outrage; it will not be enough to find solutions involving the transfer of responsibility to intermediaries (such as interpreters); it will not be enough to try to “educate the Deaf” in order that they are more aware of their rights to health care. The problems which have been discovered by this research go much deeper and have been present for a much longer time than has been imagined.

At this moment, in 2013, Deaf people are generally disillusioned, marginalised, socially isolated and ignored. Their response has been largely to absent themselves from any discussions. This is tied up with the general feeling that nothing that is talked about is going to make a difference. Deaf people face the pressures ... no, actually the way it is expressed is that the first lesson the new Deaf baby learns is “oppression” and then the second is “how to survive as oppressed”. The common sign when we get to the heart of health care experiences is translatable as “grin and bear it”. So far, among Deaf people any “trust” in the health care system has not been rewarded by improvements which are visible. Deaf people remain of the view that medicine views their problem as hearing *loss* and it is the eradication of that hearing loss which is of the highest priority – not the health care of the Deaf community (which in any case would not be a problem if there were no hearing loss in the first place).

The small elements of individual progress where one professional communicates or demonstrates awareness of Deaf issues, are insufficient to encourage all Deaf people to come forward to express their views. This was clear in the number of people whom we identified as being of interest to this part of the research, who were unwilling to come to be interviewed on exactly those interesting experiences. Nevertheless, those who did come forward provide considerable insight into the way in which Deaf people manage their health.

At the same time, the Deaf researchers in the team have had their own health journeys during the period of the project. The discussions with many Deaf people and the explanation of those experiences have led them to reflect on their own contact with health professionals. This has produced a sense of frustration at current circumstances in their own lives and also anger when realising the injustice of previous interactions with the health service whether on their own or on behalf of other people.

Many of the issues which are described in the analysis in the following sections are experiences shared also by the Deaf researchers and almost certainly by the Deaf members of the research advisory group for the project. In conducting the research and in making comparisons with hearing people (the general population) it has become clear how far from equality of access to health care that Deaf people really are. This is difficult to accept for the researchers since it has led to widespread low expectations of communication when interacting with health care professionals. In BSL it is simply the “grin and bear it” sign or as one interviewee said:

“...the attitude (of those out there) is awful, but you just have to accept it It’s part of life”

Consequently, there has been no protest movement nor any significant uprising. In terms of assessing and responding to needs, the health managers can point out that they are not receiving complaints and in fact, are probably unaware of when Deaf people are in contact with doctors, nurses, health centres, hospitals and other health care provision. Nothing changes. Deaf people appear to be apathetic and detached from the responsibility for their own health. Deaf people are seen as ‘disabled’ and ineffective.

This report should provide an alternative view and one which we wish to see taken forward in terms of action.

3. Introduction

There is a considerable amount already in the literature concerning the problems that Deaf people face in health care. Most recently, Ringham (2012) in a survey for Action on Hearing Loss and SignHealth (2008) in a re-analysis of the GP patient Survey data (http://www.signhealth.org.uk/documents/Why_report.pdf) have claimed extensive problems for Deaf people in engaging with the health services.

The SignHealth report being mainly an examination of the GP patient survey in 2008, considers that Deaf people are marginalised by the health care delivery system. They refer to the RNID report in 2004, *A Simple Cure*, as the baseline study indicating lack of access for Deaf people. For example, 19% of Deaf people are said to have missed appointments due to communication difficulties and 35% were unclear on their condition for the same reason (SignHealth, 2008, p. 8). The studies mentioned claim that over £20m would be saved in missed appointments if communication problems were removed.

Reynolds (2007) in interviews with Deaf people identifies outcomes of this access problem in illness and increased use of the health service.

None of these reports seem to have made an impact on the health care delivery and the comments and experiences of Deaf people seem to be repeated each time there is a research study.

Interestingly, Reynolds (2007, p140) constructed a scale of responses in regard to health experience and included the notion of “responsibility” for health. She maintains that many Deaf people have no internal sense of responsibility for health—it appears to be something external governed by the hearing people who provide care.

The majority of the London informants (75%) felt that the National Health Service was responsible for their health. This indicates a lack of confidence in their ability to look after themselves where their health is concerned. These feelings of dependency and disempowerment can be attributed to various factors such as poor education, communication problems and a reliance on others, for example, family, teachers and social workers. This dependency culture and a desire to be nurtured apply to the London sample whereas it is a different story for Bristol. Again the presence of a strong Deaf community may play a part in that deaf people in the area take more responsibility for their own health and use the community as a support network

It seems likely given these research studies that Deaf people’s relationship with the health care system is an atypical one and one which is costly to the services and to the individual.

However, from a Deaf perspective, health is a concept of the hearing community; it is always tackled outside of the Deaf community. The question of whether Deaf people

could feel in control of their own health or indeed if they could understand their own health symptoms and outcomes, was a central aim of the study which follows.

4. Issues in health interactions

4.1. Other minority groups

It is perhaps trivial to indicate that the delivery of health care in an appropriate way to minority or marginalised groups, is complex and by and large, has not been solved to the satisfaction of those in those minority groups. In a large survey of 55 practices in London, and using the General Practice Assessment Survey (with scales on access to care, technical aspects of care, communication, interpersonal care, trust, doctor's knowledge of the patient, nursing care, services provided by receptionists, and continuity of care, Campbell et al (2001) found that:

Differences in scores between ethnic groups were evident for eight of the 13 scales examined. White respondents consistently reported more favourable scores in each of the domains examined than those from other ethnic groups. Respondents from black ethnic groups tended to give intermediate responses while those from the Indian, Pakistani, or Bangladeshi communities tended to report lowest scores. In particular, substantial differences existed between ethnic groups in relation to the reported performance of reception staff, the perceived accessibility of care, and the trust between doctor and patient. Campbell et al (2001) p 93

The greatest differences were in performance of receptionists, accessibility of care and trust between patient and doctor. As we will see these are also major issues for Deaf people. Among Deaf people, a great deal was also made of the provision and involvement of interpreters and this forms a major part of the initial stages of the analysis.

4.2. Interpreting

Although in the interviewing, we wished to focus more on Deaf people's health, we found that Deaf people wanted to talk about communication and a major component in that was the presence or absence of an interpreter in health care settings.

Chilton (1996) argues that effective communication in medical settings can be achieved only through the use of a qualified sign language interpreter. The failure of health care providers to provide qualified interpreters is disturbing, when there is a critical need for accurate, immediate and effective communication in medical settings. Many studies have indicated that a lack of sign language interpreters, and the resulting communication problems that occur in medical settings, has had a negative impact on the health of the deaf population as a whole. Without the benefit of interpreters, deaf patients often find communication in medical settings frustrating, difficult and even frightening. Cited by Reynolds (2007) p 49

This view was reinforced by the statement of one of her informants in a discussion:

At hospitals I have used interpreters twice, because doctors there cannot be bothered to make an effort to talk to me. The second hospital visit I made I brought an interpreter and it made a big difference. My interpreter was demanding. I think the doctor was a

bit stunned. I did not say a lot myself but thought it was great! Now my doctor is making progress quicker. I realised before that I had wasted a lot of time so having an interpreter there is really useful. Now if I go to the hospital I will always book an interpreter. It is worth it and useful. (Jo, 27 years)

This offers a glimpse of the interpreter in an advocacy role which is often not expected nor even desired (Jimenez, 2005). Reynolds (2007) goes on to consider the dependency which interpreters create for the Deaf person and proposes that this may not always be helpful.

4.3. Family and Support

Despite professional resistance to the practice, it is still quite common for Deaf people to be accompanied by others when they attend for consultation. Many will take a family member. Many will still be “taken” by their parents. Reynolds (2007) quotes one of these cases:

I go with my mother (laughs). If I am in my home area, then yes I will go with my mother; my father cannot come because he is working during the day. I have to put up with it because of my deafness. Every time we go, the doctor always talks to my mother. I am the one who is ill, not my mother! If I am by myself I will ask the doctor to write down what they are saying on a piece of paper. It is OK but if I had an interpreter then that interpreter would make sure that I understood everything. (Ian, 24 years) - page 90

Deaf couples will often attend together, especially if one partner is more able to speak than the other.

4.4. Interpreter relations and perceptions

Jimenez (2005) characterises the doctor-patient relationship as complex.

It comprises, for instance, individuals in non-equal positions; it is often non-voluntary; it usually concerns issues of personal suffering and sometimes life and death; and it is this intrinsically emotionally charged. In addition, the parties must come to some consensus on the nature of treatment. Linguistic incompatibility of course only exacerbates these difficulties and the loss of control over communication can have grave implications if informed consent is desired. (p1)

In this situation, the intermediary (interpreter or other) has considerable power and control of the transaction often passes from the interactants to the intermediary. Jimenez (2005) indicates that health professionals appear to prefer the medically trained bilingual hospital employee as sharing the same institutional knowledge and is sensitive to the pressure to process the patient quickly. Davidson (2000) suggests that the

“... language intermediary is ultimately co-opted into the objective of the clinician. ... the medial interpreters as much more than a conduit for words, ... the third party actually serves as a co-diagnostician of sorts.... This perception is invisible to others and as a result absolves the interpreter from any (medical) responsibility ...” Jimenez, 2005, p3

Deaf people are sensitive to these pressures and often cite interpreter attitude as a problem. This is to some extent a result of the perceived unfair relationship of two hearing people in control and the Deaf patient as only the recipient.

In extended care settings, however, there is scope for the development of a different relationship. Labun (1995) proposed the concept of “shared brokering” as a way of describing the three way relationship ... with the interpreter at the centre. This was built on Campinha-Bacote’s (1998) proposed model of cultural competence in health care, whereby the interactants develop cultural awareness, cultural knowledge and skill, in order to meet the needs of the patient. This notion implies that the

The nurse is able to understand the emic or insider client worldview and well as the etic or outsider perspective of the client within the wider community and health care system. (Labun 1999, p215).

Shared brokering is how the nurse-interpreter relationship develops in order to meet the “mutual goals of care for the client”. The nurses in her study cared for Vietnamese clients. They perceived the interpreter as part of the team and seemed able to allow the interpreter to act as a cultural mediator and not strictly speaking as a simultaneous interpreter. It is also important to note that these community interpreters were of the same ethnic group as the client. It is clear that the nurse was able to ask questions of the interpreter and determine cultural norms by learning from the interpreter. That type of relationship would seem to be unlikely if the health professional was a doctor, where contact was fleeting or intermittent and the perceived status of the interpreter was lower than that of the practitioner. Trip-Reimer & Brink (1985) indicated three strategies for successful cultural brokering:

(a) taking power from the clinician and giving it to the client; (b) providing sufficient time for the negotiation process to occur and (c) treating the cultural assessment as a process of learning and gathering of cumulative data ... Labun, 2001, p 20.

It is clear from the descriptions offered that interpreters were at times advocates but at all times (when successful) were demonstrably bi-cultural. The likelihood of sign language interpreters being accepted in this role by both parties (when they are hearing and (usually) later learners of sign language) is slim.

Elderkin-Thompson, Silver and Waitzkin (2001) examined the situation where bilingual nurses were used as interpreters – something which may occur in hospitals in regard to Deaf people. They found that around half of consultations had serious miscommunication problems affecting the clinician’s understanding or the concerns which the patient had. They identified four contexts in which these errors were to be found:

“1) physicians resisted reconceptualising the problem when contradictory information was presented; (2) nurses provided information congruent with clinical expectations but not congruent with patients’ comments; (3) nurses slanted the interpretation, reflecting unfavourably on patients and undermining patients’ credibility, and (4) patients explained the symptoms using a cultural metaphor that was not compatible

with Western clinical nosology.” Elderkin-Thompson, Silver and Waitzkin (2001) p 1343

These findings are not unexpected as Ebden et al (1988) found that between 23 and 52 percent of doctor’s questions were either misinterpreted or not interpreted at all by non-trained, ad-hoc staff interpreters.

Interestingly, Elderkin et al (2001) mention the distinction between proximate-consecutive interpreting as often used by untrained bilinguals or inexperienced interpreters and simultaneous interpreting which is ‘proven’ to be more effective. Sign language interpreters would be expected to be working simultaneously, but there is also some value in a consecutive approach in order to try understand better the whole statement of the Deaf person.

These issues in consultations where a third party is involved form an important context for the research analysis which follows.

5. The Participants and the Interview

The questions used in the interview are shown in the Appendix.

In the first part of the interview, some personal details were noted and the analysis of these is reported here. Health assessment data from the Bupa assessments is also included to provide the overall description of the group of 45 interviewees.

This sub-group have been chosen for their degree of contact with the health service and for the combinations of illness/symptoms that they have. They are likely to be experiencing more problems although they are also much greater users of the service and are in a better position to offer a view of their own health and of their passage through the health service.

There were 17 males and 28 females. Twenty were in the age range 45-64 years. This probably reflects the choice of “interesting cases” – being those with a longer history of contact with health services and also with more likelihood of illness. But is it also a result of the pattern of non-participation (older and younger people were less enthusiastic about coming back to talk to the researcher).

The distribution of interviews were: 12 from London, 8 from Nottingham, 5 from Manchester, 5 from Glasgow, 14 from Bristol and 1 from Cardiff. Five interviewees were from the BME group.

Average BMI for the males was 29.8 and for females was 32.2 (compared to 28.1 and 29.3 respectively for the whole of the Deaf sample). Twenty-one of this group were in the moderate–severe obesity group. Eleven (9 women) had elevated cholesterol - this is 24% (compared to 32% in the sample as a whole). Twenty-one of the interviewees had mild to moderate/severe hypertension (47% as compared to 37% of the Deaf sample as whole).

Twenty-six were married. Thirty-eight considered themselves “Deaf” and 2 said they were “hard of hearing”. All said they preferred signing as their means of communication with four saying “signing and speaking”.

Twenty-seven said they were deaf from birth, and a further 7 by the age of three years. Two had become deaf after the age of 6 years.

Twelve always wore a hearing aid and 19 never wore one. One had a cochlear implant. One said that she could hear someone talking in a normal voice, even without the hearing aid – although only one said they could hear someone shouting from across the room. The likelihood is that the first question was asked as – “if you are wearing a hearing aid...”

Five had at least one parent Deaf.

Sixteen said they were working.

Twenty said they learned to sign before the age of five years. (This is similar to the national and international data we have on this. It confirms a very worrying situation that half of Deaf people had limited functional language until after the usual age for learning languages). Four said they learned to sign after they left school.

Thirty-six said they always understood other Deaf people *signing to them*, but 6 of those said they did not always understand other Deaf people *signing to each other*. This suggests a general insecurity in language use. When asked if they always understood the (sign language) interpreter, only 11 of the thirty-six said they did. Twenty-six out of 40 said they only sometimes understood the interpreter. This is not purely an outcome of learning sign language late, as 14 out of 20 who had learned by the age of five, did not always understand the interpreter.

Seventeen (out of 40) said they read a newspaper every day, Twenty-three said they read a magazine every month. Ten said they read a book at least once a week.

Twenty-one said they would use a computer to find out information, “with confidence”. When finding a difficult medical or health word, 12 would look it up on the Internet and 9 would ask a friend or family member.

In the last 12 months, 5 had visited the GP 16 or more times, 5 had gone 10-15 times and 9 had gone 5-9 times. Over 40% had been to see a GP more than five times in the year. Six had been to a hospital more than five times. Sixteen had never gone to hospital.

Twenty-two had booked an interpreter for a visit to the doctor. Twenty-six had booked an interpreter for a hospital appointment. Attempts to use interpreters is more widespread than might have been predicted.

Fourteen said they thought their health was “about the same” as it was a year ago, while 11 said it had got worse. In general terms, people said they were very well (1) quite well (4) and “well enough” (26). Nine thought they were not very well “inside” (ie mentally). Twenty-nine thought Deaf people have more mental health problems than hearing people.

Thirty-five (out of 37) said that the health service for Deaf people was not good or was poor. Three out of 37 said that in the last 12 months, they felt that they had personally had a good service /support from the health service. Twenty-four said it was “poor” and 10 were unsure.

5.1. Analysis Method

All interviews were video recorded (with consent from the participant). Taking each of the starter questions in turn, notes were made on the response of each participant to that question, to determine commonalities in the data. Having gone through that process, the common themes which were emerging across the answers were noted and then used for a further iteration, searching for the meaning of those themes. At that

point the core researchers met a number of times and in several discussions conducted wholly in BSL attempted to establish the overarching meanings in what the Deaf participants were reporting. These themes and meanings are what have now been used to structure the report. Although this is now presented as text, the meaning and implications were expressed in BSL. The themes are presented in order of increasing complexity in the next section.

6. Major themes from interviews

6.1. Different groups

The purpose of the interviews was not to go over general problems of access to health care (which is already well documented) but to determine Deaf people's own construction of "health". In examining 47 interviews, three distinct reactions and groupings were noted:

1. those people who appeared to accept that no part of the process was in their control – almost as if their own health was not something which included them. This response meant that other people took control and the Deaf person simply participated.

Interviewer asked: "*are you happy with the doctor*"

She said: <face-expression – dismay/negative> "No, not for me or the children. It's just ... he's a man (doctor). Just gives out writes down hands out prescriptions."

Interviewer: *do you complain?*

"No, it's just like talking to the wall.<negative expression throughout>" Woman in her thirties

In her case, she tried hard to arrange an interpreter and an appointment with the same doctor but still felt, there was no control over the consultation.

2. A second response was one of anger and the reaction was to withdraw from this unsatisfactory situations. In this case, the person refused to go to the doctor as he/she was upset by previous situations and simply tried to shut it out.

After complaining a great deal about the poor service and particularly, the hospital and interpreters who let her down, this woman over 65 years, said:

It was about an injection. Doctor said you must have an injection. 'hang on a minute...' he said 'you have to have an injection'. I said 'Wait. WHY? It is my right to know why you want to give me an injection. (I want an) explanation. That was the worst experience. I walked out. I am not having that anymore. I know I upset her but ...

3. A third response was frustration and anger but in this 'group' there were (still ongoing) attempts to challenge the health system. This in turn caused more frustration and anger due to the inaccessibility of the system. This tended to be more aligned with those Deaf people in semi-professional and professional roles. One person whom we would assign to this group, was engaged in advocacy work on behalf of other Deaf people, and so knew his way around he system but still seemed insecure in understanding his own health problems. Another had been a researcher and had spent a great deal of time talking to Deaf people in different countries.

There were rather more people in the first group than in the others.

What they talked about was then organised into themes.

6.2. Interpreting

Despite us trying to form a view about self-perception of health, Deaf people talked continuously about interpreting in regard to their experiences in health care. It is perhaps not surprising that the communication issue seems at first to swamp all else in the contact with health care.

The interpreter's standard was basic. I got stressed. There were lots of misunderstandings. Female 37 years old

Generally speaking there was both a positive and negative aspect on the topic. Some always arranged for an interpreter; others did not want to use them at all.

Interpreters are good IF.... those Deaf people know how to use them in the doctor's. Most do not. Male in 50s

Sometimes OK, but I would say 10 times the interpreter let me down. Female 37 years old

Doctors, nurses are fine but the interpreting situation is not good. <later> I don't use interpreters. I am sick of them changing all the time – different interpreters (male in 50s)

I walked out – I had no confidence in the interpreter Female 73 years old

Although there is a baseline demand for the provision of interpreters in consultations, at the same time, Deaf people report a considerable range of bad experiences when the interpreter was unqualified or untrained in the medical field.

6.2.1. *System (how to?), Procedures (who owns?), Qualifications (what level?)*

There were several concerns under this heading:

System

The first issue was how does a patient/doctor go about the booking of an interpreter? Who is the gatekeeper for the provision of such a service? Some Deaf people try to control the process in an organised fashion.

“When I am unwell or for a check up, I contact the interpreters and the doctor at the same time to find out when they are free and then match up the times” female in 30s

However, it is seldom the case that a Deaf person pays directly for an interpreter, even though this might be considered a reasonable expenditure under the disabled living allowance heading. It is then, typically the receptionist in a health centre or an administrator who makes the arrangement. The expectation is then that the health care provision meets the cost.

Where the health professionals arranged the interpreting there could be system errors eg interpreters not turning up – as told to the Deaf patient (but were they booked in the first place?). Interpreters tend to report last minute attempts to arrange interpreting and then explanations by the provider to the Deaf patient that it was not possible to arrange or that the interpreter had not turned up.

A 62-year-old woman explained her experience:

“Normally the receptionist should book interpreters. There was a month when there was a problem. I arrived and was told that there was no interpreter so I cancelled the appointment. The receptionist told me that I ‘cannot cancel’ the appointment. I asked if the GP was here now but she said the GP would not arrive until 10. But the appointment was for 8:50. So I refused to see the GP. I argued with her that the GP is supposed to arrange the interpreter. I said it is the responsibility of the receptionist to book the interpreter. The receptionist was new and the manager was on holiday. So I arranged a new appointment, but again no interpreter was booked. This happened four times. Finally on the 5th occasion there was an interpreter.”

The situation is not uncommon according to our interviewees but it is rare for the Deaf person to challenge in this way.

Procedures

The difficulty is then about who “owns” the interpreter? We will tackle this in more detail under the higher level theme of *control*, but the interpreter is usually seen as ‘belonging to’ the Deaf person. The logic for the health professional is simple: “I treat patients directly by having them speak to me; this patient cannot speak to me directly; an interpreter speaks for the Deaf person and therefore is an attachment to the Deaf person.”

This greatly alters the dynamics of the situation.

Qualifications

There were many reported cases of interpreters being supplied who were inappropriate– ie they were not qualified, they had little preparation and no health-specific training. Deaf participants had to struggle with this.

Difficult ... as I have to fight to get a better interpreter. Luckily my friend helped me to get a professional interpreter as it is important to have a professional interpreter to enable me to communicate with the professional doctor. If not I believe my health would deteriorate. There is important information between the three of us. Female 37 years old

I am disappointed with interpreters. I have been let down so many times..... Once I got a person coming who was Level 1, I knew them. No thank you. Hospital is too ... too important. Female 73 years old

This could be due to the use of agencies and the existence of national or even local contracting, where there was simply no capacity in the agency. There is a protocol now in place, where the interpreters are meant to show their registration cards when they arrive for an appointment. It was reported that this seldom happened. There were more cases of dissatisfaction in this respect in the London area.

6.2.2. GP awareness, interpreter performance, GP adjustment

Deaf interviewees generally reported that GPs and health professionals were usually unaware of how to work with interpreters but more significantly would abdicate responsibility for communication to the interpreter. The expectation was that the interpreter would handle the whole communication transaction.

In some cases, doctors were said to insist on having an interpreter present. On the one hand, this seems reasonable as it could then be considered that the interaction would flow more smoothly; on the other hand, sensitivity to the Deaf person's lack of understanding of the interpreter's signing was almost totally lacking. In one case, the interpreter signed "radiology" as the sign "RADIO" and in another case, the interpreter was using ASL signs for a local Deaf person. These aspects could not be picked up by the doctor, due to lack of awareness of the extent of communication mismatch. One 37-year-old woman described an experience of having poor interpreting:

One time, I had enough and so I stopped the consultation and asked for a new date with a different interpreter. I explained that I needed a professional interpreter. The doctor agreed. So I found one. Then the new appointment with the professional interpreter was good. The doctor recognised the difference and agreed to use the same interpreter. But sometimes the interpreter did not turn up. The nurse asked me why I felt low. I told her that is difficult to communicate with the doctor and nurse. It is hard to have to wait a week for an appointment – it is useless. The service is bad and I feel they do not care.”

The concern here is in the loss of trust in the health care system due to the uncertainties in the supply of interpreters.

6.2.3. Interpreter attitude/power, communication

There were several aspects to this topic. Despite dissatisfaction, there were almost no instances where the Deaf interviewee objected to the interpreter who attended and only two examples where the Deaf person abandoned the consultation because he or she could not understand the interpreter sufficiently. This lack of action by the Deaf person was explained as “I was ill – I needed to have health care- it was not possible to delay further.”

One factor specific to the Deaf community was the booking of interpreters who were also work colleagues or who frequently interpreted for the Deaf person in other situations. They were deemed inappropriate as they would then hold information

which would affect their working relation in future situations. In one instance, during the Bupa health checks, the Deaf attendee flatly refused to have any contact with one of the interpreters who had been booked. Fortunately there was another interpreter in the session. However, the interpreter seemed to be oblivious to the rejection by the Deaf person and tried to intervene in order “to do the job”.

In another situation, the Deaf person realised that the interpreter who was known to the family, would now learn more than the son and daughter of the Deaf person. Since the Deaf person felt this consultation and any resulting health issues were private, this created a dilemma. In the end, the Deaf person felt impelled to tell the family in order to ensure that they knew at least as much as this third person – the interpreter.

It is understood in the interpreting literature, that the interpreter is not simply a conduit for one spoken message transferred into a signed message. The interpreter is a participant in the transaction. This is not well understood by the other participants and allowances for this do not seem to be made.

The whole arrangement works against equality of treatment. It is usual practice for the interpreter to attend the appointment a little in advance in order to prepare with the Deaf patient. While in some respects one can sympathise with this practice, it usually becomes a question and answer session with the Deaf person about why the Deaf person is there, what the medical condition is and so on. This was considered intrusive by some of the Deaf people and in cases where the Deaf person was feeling unwell, it could be an unwelcome nuisance.

The interpreter then entered the consultation *with* the Deaf person, reinforcing the notion that this was an “interpreter for the Deaf.” One view was that the interpreter should enter the transaction separately and not accompanying. However, the rationale of the arrangement relates to some language insecurity on the part of both the interpreter and the Deaf person. The alliance of interpreter and Deaf person both emphasises the support/advocacy role and attempts to ensure signing compatibility.

Physical layout was also a challenge as usually interpreters are advised to sit behind the doctor and face the Deaf patient (standard also for job interviews), thus reinforcing the direct doctor-patient relation and allowing the Deaf person to attend visually to the interpreter and to the doctor. However, consultation rooms may not have sufficient space or it may not be appropriate to use this layout eg when the patient has to lie down. In one case the interpreter had to change position as she would have been able to overlook the computer screen which the doctor used – which might show confidential information.

All of this places the interpreter in a position of considerable power, given that the doctor is unlikely to know any sign language and the Deaf person, because of visually attending to the interpreter, is unable to monitor the spoken message.

At the same time, despite the doctor's perception of the provision being the "interpreter for the Deaf", the Deaf patients indicated that their view was that they saw it as two hearing people against one Deaf – two for hearing culture versus one for Deaf culture. There was no indication that the concept of shared brokering might apply. The interpreter was not usually considered as 'belonging' to the Deaf person, by the Deaf patient, except on a superficial level as facilitator.

6.3. Related issues/experiences

These are other common experiences which people discussed but which are consistent with the generally poor experiences that Deaf people have in contact with the health care system.

6.3.1. *Interacting with the receptionist*

None of the interviewees expressed satisfaction with the receptionists at health centres; hospital receptionists were worse.

There are always problems with a new receptionist. Female aged 53 years

They always "forgot" to book the interpreter Female 36 years

The issue was of simple understanding – lack of Deaf awareness.

The only problem is in the waiting area. They called out my name and I wasn't able to hear it. I saw people were looking at me. I turned around and asked for the name. I realised it was my name being called out. I felt stupid and embarrassed. They should provide a ticket/number.... Female age 62 years

I went to see a GP at a walk-in clinic. I asked for pen and paper and explain the problem. Then the receptionist put my name on the system. So I waited until my name appeared on the screen. I waited and waited. I saw people coming and going. In the end I went back to the desk but the woman I spoke to had gone (which often happens), so I wrote down and explained that I had been waiting for more than an hour. She checked and then apologised that my name was not on the system. It seemed that the previous receptionist had not put my name on. Female aged 53 years

Basic communication skills were not in place and Deaf people approached the reception desk with very low expectations of interaction. This was stress-producing.

These comments and findings are hardly new. The surprise is that nothing has altered since Deaf people first pointed out these problems. The issue may be whether Deaf people made their complaints known through any formal system.

6.3.2. *Comparing dentists and opticians*

Interesting comparisons emerged with a number of interviewees indicating that they had good experiences at the dentist (where there was some suggestion that these were

not English native speakers ... and might be more aware of non-English speaking clients).

Brilliant! The dentist was from overseas. He communicates in gesture Female 53 years old

However, there were also some difficulties.

Bad experience, I won't go back Male 22 years old

In comparison, experiences at opticians were considered to be poor. Rather predictably the usual eye-test involved changing lighting and lenses and removing glasses. Without clear vision, Deaf clients could not receive whatever messages were being relayed. A re-think on procedures for those who rely on sight was needed.

One High Street chain of opticians was mentioned favourably as being prepared to engage an interpreter, while another specialist chain was considered to be resistant to the use of interpreters.

It is also the case that Deaf people have considerable fear of losing their sight. The possibility or diagnosis of cataracts, for example, was approached with dread.

6.3.3. *Presence of family members*

There were many circumstances where family or friends were taken along to a consultation. This was often motivated by the confidentiality–privacy distinction (section 3.5 below). Where the Deaf person needed to have a private conversation, a family member would be taken along. There are inevitably difficulties about this according to whether that accompanying person was of the same generation (brother/sister) or the previous generation (parent, aunt/uncle) or the next generation (son/daughter). While maintaining the view that there were no other options (because of emergency), there was still awareness of the risks that family members would learn about their health to an extent which they did not wish to happen. It would also be the case that family members may be upset either by the treatment received or by the content of the messages which, they were supposed to interpret.

Lack of awareness of the situation of the family member appears to be commonplace. A recent episode (November 2013) of *Holby City* provoked considerable reaction from the Deaf community (<http://www.bbc.co.uk/news/blogs-ouch-25125714>) :

See Hear presenter Memnos Costi recently appeared in an episode of BBC One medical drama *Holby City*, with his nine-year-old daughter Kachina. Reflecting their real life situation, they played a deaf dad and his hearing daughter. Kachina's character had to act as sign language interpreter for her father in a complex medical setting. The episode got some of the highest viewing figures in the series but received a mixed reaction from the deaf community. Some criticised the programme for seemingly portraying the use of children as interpreters as normal or commonplace. In **an open letter to the BBC**, the Gloucester Deaf Association (GDA) wrote:

"It has taken 20 to 30 years for people working with the deaf community to have medical authorities understand how critical it is for a fully qualified BSL interpreter, who will have taken years to train in their profession, to be the one that acts as a communication conduit in these situations".
The letter also said that interpreters are better able to stay neutral in potentially emotional situations than family members.
Others praised the episode for the realistic depiction of something they say still happens.
Matt Dixon, a child of deaf adults, had to interpret for his terminally ill father in a medical setting in 2009. Dixon endorsed the Holby City storyline in online deaf community magazine **Limping Chicken** saying, "Sadly, that is reality and I applaud them for running with such a story."

One interviewee reported that in her case, her father who was a doctor, intervened and telephoned the GP on her behalf. He conducted the health negotiations and interpretation of results without her presence and then advised on outcomes. There is a general view among interviewees that such intervention by hearing family members is common and not at all ideal.

This is a complex area but one of which health professionals might become more aware.

6.3.4. Palliative care

There was some mention of palliative care situations where it was considered that staff would be chosen more selectively as being able to adapt to the needs of the patient in this serious circumstance. However it was also said that the treatment/ interaction with Deaf relatives was not as well thought out. The issue concerns whether the support is for the patient or the family (who might have Deaf members). It was unclear whether the palliative care team had resources to deal with the Deaf family.

It was also pointed out that interpreters may begin to change role in these situations where they become counsellor and supporter and then close friend, given the extreme emotional content of the transactions. We do not believe that at this time interpreter training provides the necessary preparation for such situations. This can be a major issue as Deaf participants expressed a clear desire that the same interpreter should be used throughout. It was even described as the interpreter beginning to be a friend as the process unfolded.

6.4. Hospital, Ambulance and paramedics

Emergency situations where ambulances or paramedics had to be called were considered among the worst of circumstances where there was no communication. However, the greatest overall concern was when the Deaf person had to stay in hospital.

"When the interpreter goes, how do I communicate with doctor, nurse and so on. This is especially a problem as I get drowsy or emotionally unstable due to say, anaesthetic. It is vital to have someone there to help with communication and to support me."
Woman 37 years old.

The largest amount of criticism of health care situations was of admission to hospital and continuing presence in hospital. It was seen as an enormous problem for the Deaf person in communicating with staff. This universal (and very obvious) problem of Deaf people in hospital implies the need for a more extensive training programme and communication resources on demand for health professionals.

6.5. The doctor

Judgements of satisfaction with the doctor related to communication. This can be separated from the success of the transaction as a whole. As suggested in the Prologue, the expectations of Deaf people are very low in regard to interaction with the doctor and as a result, they feel content if there seems to be some level of awareness.

One man said with satisfaction, the doctor “always had time” for him – an aspect which would be a simple requirement for hearing people. He followed this up by indicating that this was a transaction carried out by writing down (which would take longer).

This contrasts with the more common view that the writing down was minimal communication as in the person who reported that she had significant concerns:

“In attempt to improve the dynamic and elicit further information I produced a paper and pen and requested that the GP write down what he had been attempting to tell me. After giving me a long, exasperated look he summed up the entire conversation with writing down two words, 'fatty liver'. He then looked at me and said he did not think this was a problem. Needless to say I left the surgery feeling extremely confused and uncertain as to my situation and what to do next.” Woman in her 50s

It was clear that writing down, gave some degree of personal, direct contact with the doctor, but since many of those interviewed, do not read well, it is something of a false comfort.

One woman said she had tried six GPs to try to find one where the communication was satisfactory and had still not been successful.

Another professional Deaf woman indicated that she did not think the hearing experience with the doctor was the same as the Deaf one.

“I remember I went to the doctor (a while ago) because of back pain. The doctor talked about a possible operation on my back. He explained to me “I don’t understand why Deaf live alone in the centre of London. They should all go to church.” I was really angry. I told my other doctor. He said he’s always like that..... just go to church.” Woman aged 64 years.

It may not be so unusual to have eccentric doctors but from a Deaf perspective it tends to confirm that lack of sensitivity to their situation.

Another participant compared the experience at Bupa which she thought was very positive with her visits to the GP.

When I went for assessment I received a copy of the results, which was good as the doctor would not give me that even if it was my own health information that should be my right! When I received the letter, I thought to go to find out how healthy I am ... because with the GP, he kept saying 'normal' etc – different words each time. With Bupa, 'one-go' (one-off) assessment. When the nurse explained all the tests, mentioned smoking, but I only do 1 or 2 a day. But when she explained to me about being 'fat' I was shocked. The GP had never said anything to me. So I have to do something about it. Female aged 62 years.

There is (as there is for many hearing people) great difficulty in challenging the medical opinion or any aspect of the transaction. However, this seems to be related to a fear of being “rejected” by that doctor. We will consider this further under the topics of control and power.

We should point out that almost all positive experiences reported by Deaf people were with doctors with whom they had built up a relationship over many years.

6.6. Information

There is a relatively low-level and recurring theme that Deaf people do not have access to information. When much of the direct communication is provided in spoken language, then there is no doubt that there is considerable deprivation. The same is true of information provided in text form – letters, maternity folders, posters, leaflets, websites.

What is more complex and represents a higher level theme, is the ownership and responsibility for information. Deaf people may be provided with information (in effect, the health professional believes that the information has been provided); however, not only is that information inaccessible, the Deaf person is unable to question the lack of information because there is no baseline knowledge upon which questions can be formulated. Educators sometimes refer to gaps in knowledge (due to a large degree to the difficulty of incidental learning) but here this is more profound as the knowledge required is about self. Deaf people feel unable to question or to admit to not knowing or not understanding.

Provision of BSL video while sometimes requested is of limited value. The medium is inappropriate, being similar to providing information to hearing people on an audio cassette. The value of text is its flexibility; the possibility to scan and to select – something which is much more difficult in video as there is not adequate search mechanism and scanning can be difficult. Providing BSL video does not solve the problem. Considerably more work is required in order to determine which information media and which delivery mechanism is needed to have maximum impact.

6.7. Responsibility

One of the key themes which we were interested in was the notion of responsibility for health. It seems likely in marginalised groups that there are difficulties in taking responsibility for their own health. This can often be dealt with by giving responsibility for health care to the minority group itself. This would mean that individuals, groups, families would take the lead in providing appropriate care to those who were ill and also that there would be health professionals from that community.

This aspect has not been open to Deaf people. There are no members of the Deaf community who have trained as doctors and relatively few who have nurse status. There are professionals who have grown up in a Deaf family and who may themselves be able to sign, but their upbringing may not have encouraged them to become representatives of the Deaf community.

6.8. Control

This refers to the engagement with health professionals in situations where personal control is a factor. Typically control is at a low level in one to one situations with the doctor. Deaf interviewees often felt they had no real involvement in the health decisions made about them. In all three categories of people which we described in the beginning of this chapter, we find Deaf people on the periphery of their own health care.

There are two different aspects to the control of health care. The first is in relation to routine GP consultation and the second concerns hospitalisation.

Deaf people resent their loss of control of the settings where they choose to consult the doctor. Findings from the quantitative component of the research imply a lack of trust in doctors and a lack of belief in the system as a whole. Yet Deaf people return again and again to the doctor. Our interpretation is that this is as much to try to regain control of the situation as it is to clarify what the doctor had said on the previous occasion.

While hearing people will consult (and at that point defer to the doctor), they may also seek to question by looking for a second opinion and will be able to differentiate between different opinions given. When given a diagnosis, they may be re-assured and when given a treatment will exercise their own right to follow and to monitor that treatment. The provision of a name for an illness or difficulty, acts as a key to further information and may in itself be comforting. However, that name has no value to Deaf people who do not use English. The process which has been multi-layered for hearing people, simply becomes one-dimensional for the Deaf person since they have no access to the “keys” supplied by the English-based diagnosis. At no point does the process come within the Deaf person’s control. Choice exercised in regard to stopping taking medicine or changing lifestyle may not be based on knowledge but

rather on feeling and incomplete discussion *with other Deaf people*. In essence the sense is of a mysterious fog surrounding the illness/difficulty with no means to clarify and resolve.

Perceived status of the health professional also seems to make the loss of power accepted. For Deaf people, that power may simply be out of reach.

The second situation is when in hospital; this can refer to admission or to longer term care. For almost all people (hearing and Deaf), admission to hospital means a loss of personal control. The role of an ill person is to accept the treatment. Most people accept this role and it can be very hard to countermand the views of the doctor in that situation; it is very hard to discharge oneself, for example. Deaf people in the same way are likely to accept the role of patient and defer. However, the *loss of control* now passes to the doctor, since there is no means for him/her to carry out the usual health negotiation in speech. We see nurses, having been told that the person is Deaf, approaching and greeting, “how are you today Mrs Jones” etc, as if the patient was hearing. The loss of control has then transferred to the health care side and the only strategies for dealing with the patient become de-personalised and separate since interaction is limited by inability to use sign language. The experience on the Deaf side is well known – Deaf people greatly dislike being in hospital because of these circumstances. What has not yet been considered is how the loss of control by the doctor affects diagnosis and treatment.

These are complex areas where new training and new awareness will be needed.

6.9. Confidential, Private and Personal

A very significant aspect to health care in the views of deaf people is the distinction between confidential, private and personal. Each has a different sign and each has a very different meaning and implication for a Deaf person.

When a medical consultation or diagnosis is confidential it refers to the fact that this should not be broadcast to other people. Given the nature of the Deaf community, others should not know that this person has this problem. By and large interpreters can be used in this situation as it is recognised that they have a “vow of confidentiality” even though they will personally come to share that knowledge with the Deaf client.

However in many circumstances, a Deaf person may feel that a transaction is private. Not only should this not be shared with the community, there should be no knowledge that a health matter is being investigated – no one should know that the person has gone to the doctor. In this case, only a close *friend* could accompany the person (or the person would attend alone). Paradoxically of course, the flow of communication may be lessened but this is a judgement to be made by the Deaf person and is a matter over which he/she can exercise control. Matters which begin as private may become

only confidential if there is repetition of the consultation or if the visits become routine. In which case it becomes acceptable to involve an interpreter.

Matters which are personal are matters where no intermediary is desired. These are aspects which should be known only to the person and may be considered to impact on their own identity and personal well-being. One Deaf person described a situation where there was an interpreter present but during the session, the doctor wanted to ask a personal question and negotiated with the Deaf person about the appropriateness of the presence of the interpreter. As a result the interpreter left the room temporarily and the doctor addressed the Deaf person in text of a very personal nature. The interpreter later returned. The Deaf person was surprised and ultimately pleased about the sensitivity on the part of the doctor. This may be a positive strategy but is dependent on the Deaf person's confidence and capability for text communication.

However, it also highlights the problem of a Deaf person seeking an interpreter for a confidential matter but finding that the discussion progresses through confidential to private and then even into the personal. At this point the Deaf person may feel invaded, dismayed and powerless.

6.10. Depression

Although the quantitative data is not sufficient to process this, the interviews indicate that this is a major issue among Deaf people in dealing with the world and as an adjunct to health. In this case it is not doctor–diagnosed but rather is Deaf-defined. What society terms and offers as depression is:

Depression is severe, typically prolonged, feelings of despondency and dejection.

That is melancholy, misery, sadness, unhappiness, sorrow, woe, gloom, gloominess, dejection, downheartedness, despondency, dispiritedness, low spirits, heavy-heartedness, moroseness, discouragement, despair, desolation, dolefulness, moodiness, pessimism, hopelessness

It is the very last of these terms which is closest to the situation of the Deaf interviewees, who are almost all described as being depressed by the Deaf researchers. The researchers annotated the interviews with terms such as anxiety, hidden or suppressed (depression), anger, worried, trying to cope, as well as clinical depression. One 65 year old man related this to the awful attitude of people – he said simply,

“You just have to accept it, it is part of life.”

Although there is a higher rate of self-report of depression in the quantitative data, the extent of Deaf-defined depression in the interviewees seems even higher.

Much of this can be predicted from the points which have been discussed in previous sections. Deaf people are seen as *the* problem – they need interpreters – they cannot communicate – they are the people at odds with normalcy in society and in the

provision of healthcare. One adviser to the project suggested that this was the first lesson learned by all Deaf people, that they were not normal and would be provided for but not enabled. Literally, the sign used for this is OPPRESSION but it implies an acquired state, created by the outside world. As Deaf people come in contact with service provision and particularly in the area of health, this oppression is internalised and becomes a helplessness in the face of ill-health.

6.11. Separation of identity from health transactions

Perhaps the highest level of insight gained from the interviews is the notion of separation of personal and public self. The former is the protected Deaf identity and cultural home which manages Deaf experience and retains a positive self-belief. From this stems communication and a community membership. However, in daily life and everyday, this would be challenged by hearing society, if it were not protected.

All of health provision takes place in the hearing community. All discussions about the individual's illness, treatment or prognosis, is carried out in a hearing context and the decisions are made by hearing professionals. None of the consideration of personal health occurs in a Deaf context. One interviewee described going back to the Deaf club with an interpreter but feeling greater compatibility with even the Deaf cleaner, than with the hearing interpreter.

When we talk to Deaf people about their health experiences we have the sense that it is somehow separate from them as persons. The negotiation with doctors, the problems of understanding, the inability to reach the shared knowledge of the health care, is displaced from the person. While this is possible in terms of everyday transactions going to the shops, having meetings with hearing people, when it impacts on the person's own physical wellbeing, it can be much more serious. We detect a reluctance to engage with own health, as being a set of transactions rooted in the hearing society. While illness and problems are real, they are somehow separate and are not resolvable by the individual. Diagnosis, treatment, care all take place in that other society and cannot be resolved by bringing to bear the personal resources of that person. The existence of ill-health remains remote from the person and to date, has not led to widespread protest by Deaf people about their marginalisation in the health care system.

There is a good deal more to say about these last themes and we will return to them in the final chapter.

7. Narratives

There are five selected narratives presented here; although it is true that nearly all of the interviews have provided interesting and illuminative cases and could have been included. However, these chosen five can illustrate slightly different aspects of the experiences. In the nature of these open interviews, the participants tended to change topic and direction at various times and the narratives may have some deviations and regressions, which we have tried to smooth out. It is also true that the accounts have been presented in sign language and there are many instances where there is no simple translation into English of what the person signs. All of the cases illustrate the detachment of Deaf people from the knowledge about illness, from the process and from the ownership of the problem.

<Our comments are inside these brackets>.

7.1. The value of communication

“I went to the GP, she saved my life – she can sign”

Naomi is 63 years old and was ill with bowel cancer 2-3 yrs previously (later on she refers to it as 8 years ago). She explained that she had been to see a range of people (unspecified) – then it all went quiet (she signs literally, “where is everyone?”). She tried herself to get information but nothing was available (again it is not clear where she was looking for the information and how she was asking the questions but the likelihood is that she had no direct means of access). She was going round in circles with minimal information. So she went to her GP and she can sign – and she saved her life. There was no satisfaction anywhere else. There had been tests over an 8-year period and she considered that they were all clear, “touch wood”. She then described one of her experiences – although it is not clear if this was most recent or at the time of first diagnosis:

Naomi was told she had low blood pressure and that she did not have enough iron. She went for a scan. There was no interpreter. They said she did not need an interpreter but she was very nervous as it was dark – as was her husband whom she had taken along with her. Naomi was re-assured by a nurse whom she had taught to sign. The interpreter arrived 15 minutes late. The husband was still nervous. The interpreter then had to leave early because she had another appointment.

<Comment: the narrative appears muddled and inconsequential, indicating a lack of clarity in the signer as to what was going on. She was unclear about exactly what was

or is wrong and consequently, her reference point was anyone who could sign during the process. She seemed also unclear about what the interpreter was doing and how to “use” the interpreting service.>

7.2. Terrible Attitude – serious consequences

Dan is 42 years old has a mild physical coordination problem. He was interviewed with his friend Doris who had accompanied him on his journey through the healthcare system. This story unfolded over several years. He was feeling unwell. So he went to the doctor.

The first doctor he saw was Asian and he explained what was wrong

“But she ignored me (was not listening, not attending to his reported symptoms). I feel the doctor was putting me down – like ‘a cover up’. I went to her several times but the consultation was so short that each time I had a question, she told me to book another appointment.”

Then Dan began to take his friend, Doris with him; he “wanted proof”. *The attitude was terrible.* (Doris confirmed and elaborated). Doris said the doctor thought it was mental (psychological) ... in his head. But he was only depressed – “weak and tired”. Doris had seen him change over many years. She confirmed: “he is worn out”. The doctor indicated that nothing was wrong with him and dismissed him.

The interviewer asked whether they had an interpreter. Doris said no – what was the point given that the consultations were very short – “it made no difference.” Each time they had to arrange new appointments but always they were very short.

Each time was different as there were different doctors. “How come?” he asked. When they did manage to have an interpreter the situation was a little better. But then they had unqualified interpreters – “cheek!” They asked if the interpreter had a card (ie the identification and membership of the professional association). The interpreter had “messed up and had left his/her card at home. It happened three times – a man, a woman and a woman”

The interviewer asked : how did you feel about this. Dan said, after thinking about it for a few moments: (literally) depressed (but with an outward focus as in fed up with them) <the sign used is hard to translate>

Having decided his problems were psychological, he was referred to a specialist unit for mental health for Deaf people. He was upset by this. Dan told them he was only depressed by all of what had happened. He had been put on medication but it made little difference. Meanwhile Dan was becoming more ill...

He had been going to hospital (presumably for tests) and interpreters never turned up ... again and again. The doctor said he had to carry on without the interpreters as otherwise he would lose his appointments. On another occasion, Doris's son booked an interpreter but he did not turn up. Doris said, "but the doctor continued to try to ask loads of questions (leading up to an operation) ... but without the interpreter. He said the interpreter will turn up but it was just lies."

On another occasion the doctor wanted to postpone because there was no interpreter and Doris had to ask her son (who is an interpreter) to come along.

But there were just more delays and eventually Dan got ill and collapsed.

Dan had not been well and she told him to come over to her house. He had black urine. And he collapsed. So she took a photo (because how else would she be able to explain to helpers). She texted her son and got him to call an ambulance. When the ambulance arrived she showed a photo to them. That possibly saved Dan's life. They took him to hospital where he stayed for five weeks.

Doris and her son kept trying to get the hospital to provide an interpreter while Dan was in hospital. But no interpreters ever appeared. They were probably never booked.

While in hospital Doris noticed his leg was swollen and told the nurse; they gave him an injection. At that point, finally there seemed to be a diagnosis. They said something about "red cell".

The interviewer asked "How did you communicate in hospital". Dan said "it was impossible – there was no communication."

Eventually an interpreter did come for a consultation with the specialist which was to explain what was wrong. The specialist was shocked that he had not noticed the problem before and it had reached this crisis point. Dan told him he had been telling the doctor he was ill for three years.

The situation had been serious – he was told he had lost four and half pints of blood through his bowel and in urine. The specialist asked why it had taken so long to come to this point. But Dan had told the doctor again and again. He "was ignored."

The interviewer asked if he went back to the same doctor. Dan said "I don't bother."

The interviewer asked, "why not change doctor?" Dan said, "I don't know what to do about that"

In hospital they had tested and found a rare blood condition. Doris explained "the problem was linked to family history but his mother was dead. He had thought he would be in hospital for 2 days – ended up being there for 5 weeks. They had kept him in to try to find out what was wrong."

The interviewer asked “How did you feel about all this?”

Dan replied “I just switched off ...”

“You have medication?”

“ Yes, for red cell.”

“How long do you need to take it?”

“SHRUG... no idea. No explanation.”

Doris said “he is more tired now ... keeps falling asleep. Could be linked to thyroid – why don’t they check? But nothing.”

“You could the change doctor?”

“Can’t. NHS says no because I am in a particular zone. There is a polyclinic. It is a very Asian area. You only get 10 minutes and then sorry, you have to make a new appointment.”

Doris said. “He needs help but he won’t go back to the doctor.”

He lost his job because he was ill. He is still worried about his health but does not know what is wrong.

<This is an extensive narrative on the mysteriousness of the health care system from the perspective of a Deaf person. In this case, it had serious consequences which could have been fatal.>

7.3. Injection Required

Yvonne is a 70 year old woman, who is assertive and would be considered a member of the third group (section 5.1).

“It was to do with the injection. The doctor said I must have an injection. Hang on... what for? The doctor said, ‘because I said so. You have to ...’ But why? It is my right to know why I need an injection? He never explained. That was the worst experience. I walked out. I am not going to have that any more. I know I upset him but it was not good enough for me. I never saw him again.”

<This is an assertive older lady, who was quite clear about her need to retain control and so was dissatisfied with decisions being take from her.>

7.4. Baby Blues

Daisy is now 51 years old and has had no work for 12 years. Her experiences are linked to childbirth and post-natal depression over that period.

Daisy explained that she had had post natal depression after her first child. She was OK at first but after a few months it hit her. They called it the 'baby blues'. But it got worse and worse. Her family is split up so they live far away and she has a small family anyway.

<She then explained about her experiences with the doctor but the time sequence of this is not absolutely clear.>

Anyway, she was hit with this depression but she tried to pull herself together and go to the doctor.

After some time, she decided to have a second child (it might be much be easier). But this time it was worse.

She had to communicate by writing down. The suddenly the doctor was gone and it was a different doctor. She explained to her that she was not well. She found out later that the doctor she had been seeing until then, had hanged himself because of abuse allegations. This really shocked her.

The new doctor was a woman so there should be a connection but the doctor just tried to give her tablets which she didn't want. It was just in and out – there was no time in the consultation. Communication was writing down or lip-reading. It seemed like these were typically closed questions which Daisy was to answer yes/no, but this questioning was causing her a lot of stress. <The signs here are not easily translatable as the questions were putting her on edge and building up stress and tension.> She was also reading the doctor's body language and it was really negative. The doctor had no patience with her and really wanted to get rid of her. She was not answering Daisy's questions – just platitudes. Daisy never realised that there could be an interpreter there. She was worried who would pay and pay for the time. She had never really thought about interpreter, she was just in the Deaf world all the time.

In the end through talking to a friend with a baby, she realised she could use an interpreter. She went back to the doctor. Again it was unpleasant, Daisy could tell she was not pleased with her. But there was an offer of interpreter but presented in an aggressive way towards Daisy – 'You, you (pointing) can get an interpreter.' Daisy did not know how but there was a list offered. She did not know anything about them.

However, she did have an interpreter the next time. Now there was more interaction. With the questions Daisy began to explain and she broke down, using lots of tissues, worried about the queue building up in the waiting room. The doctor was being more sympathetic and said to continue the next day.

The doctor now wanted to increase the dosage in the tablets. They negotiated about this as Daisy did not want stronger tablets and not over a long time. The doctor pleaded with her to take the tablets and not to put them away, to try them for a few months and then to see. She was also to see a physiotherapist. So she tried the tablets, sceptically.

Daisy found that there was a gradual change.

“I had been sleeping 24 hours with the curtains closed, not cooking/eating being sick. It was a horrible time. Now with taking the tablets, my life changed. That was just last year or so. My son is now 8 years old. Eight years wasted/lost.”

<There is a good deal in this, in that lack of awareness, unfortunate experiences with the doctor make things worse and she was unable until very late to find support from an intermediary, at which point a relationship could develop with the doctor and the problem was gradually resolved.>

7.5. Who is the interpreter for?

Vera aged 70 years.

The problem arose as Vera's husband got cancer. When they went to the hospital, they asked for an interpreter but the hospital said: 'it's the husband who is the patient and he is hearing. We only provide for the patient.' But she was upset – she said “I am the wife, how can I get the information – we are married. But there was a big argument. And it was impossible to get through to them.”

The interviewer asked if there was a policy. But the policy was for the service to be provided to the patient only.

So there was no way through. When the consultant came, her husband started to interpret for her. The consultant objected saying that it was a personal one to one interaction. But it then the penny dropped that the wife would not be able to follow. So he agreed that there would be an interpreter for the next appointment.

When the interpreter came for the next appointment, it became clear the consulting room was too small and they had some difficulty in placing the interpreter. There was some negotiation on this as the consultant had never used an interpreter before. From then on, there was an interpreter each time.

On the day of the operation, Vera was able to wait with her husband and then he went off for the operation. It was very early about half past six in the morning. She was left then with the interpreter, and she was very upset because it was cancer. The interpreter suggested a coffee. Vera was quite tearful. The interpreter asked her if she was going home, but she did not have the car. The interpreter offered to take her

home but she decided to go to the Deaf club. Of course it was not usually open at that time in the morning, but there was a Deaf cleaner there. And that was a much better connection than the interpreter, who was hearing. The stress immediately was gone and she relaxed. That was the power of being with another Deaf person.

But of course, she was now cut off from information. How were they to get in touch with her? Well she managed to get someone from the Deaf club to phone and she was able to visit. It was all puzzling as there was no interpreter. So Vera asked the ward sister to book an interpreter for the next day but she just said 'yeah, yeah' and there was no interpreter.

She continued to visit but he wasn't getting any better. In fact, he was getting much worse. Communication with the ward sister was not producing any information. His Deaf daughter visited and was concerned. But it was her hearing son who came and was appalled by his condition; and immediately talked to the nurse and then insisted on calling the doctor immediately.

Vera was completely bemused as she had no information on what to expect. She was just desperately worried as were the family.

Vera explained, "A doctor did come. The family asked what's going on? Is he well? The doctor said "he's alright". Just "ALL RIGHT" (pointing to her lips to emphasise she was lip-reading him). He explained absolutely nothing. He just said, "alright". What was that all about? My husband looked awful, but all the doctor could say was "all right". I was frightened he was dying and all he could tell us was "alright."

<There are two significant issues here – the difficult situation of the Deaf partner when there is a serious illness (we are back to the problem of "who is the interpreter for?") and the lack of information when care is needed or when next of kin would usually be briefed.>

These narratives are often not expressed in a linear fashion but involve a great deal derived from visual perception of the situation. At times, the signs express the direct physical arrangement and the emotions of the people involved; at other times, they simply illustrate the puzzlement of the Deaf participants. There is evidence of assertiveness but an underlying thread of being unable to change other people and of being marginalised at every step on the journey.

8. After the Health Checks – Deaf awareness and action

8.1. The rationale

Following an initial analysis of the health data of the Deaf participants, concern was expressed among the medical advisers to the project.

In normal circumstances, we would provide feedback and advice after the end of the project. However, we considered the risks to health, sufficiently great as to require action immediately and this to be carried out in parallel with the completion phase of the project. Deaf people's health was significantly worse than expected; the extent of explanation about health outcomes and the action taken by Deaf individuals when serious health risks are identified, was insufficient as a response to the serious health problems being identified. In 25% of those assessed, there were serious health problems being identified. The potential for serious impact on health was great.

We decided to bring forward actions to disseminate findings but also to implement a programme of Q&A at an individual level for those who had taken part.

8.2. The emerging problem

One of the significant points in the ethical approval feedback process was that there should be no direct relation of the research data analysis with the GPs of the Deaf participants. In effect, we were disallowed from supplying information directly to the GP. The rationale for this was that Deaf people should have control of their own health planning and outcomes.

We set out to deal with this by significantly increasing the onsite support to the Deaf people who attended for health checks. At each centre we supplied two Deaf advisers who would act as advocates and representatives of the project in regard to the procedures and two sign language interpreters who would work with the Bupa advisers and the Deaf person, in order to ensure that the health checks ran smoothly and that the feedback from Bupa advisers was presented in sign language. The intention also was that that this would support the Deaf person in asking questions and clarifying the nature of any problems detected.

Although this arrangement has worked well as a supportive procedure at the time, there is now increasing evidence that Deaf participants were unable to use the opportunity at the end of the session to ask meaningful questions and that the recommendations to seek further help were not being implemented.

There are several reasons

- The information provided is in the form of an explanation of a routine series of tests, rather than as a personal discussion of health. This is no different from the way in which this might be presented to hearing people; however, they have a great many other resources to call upon in quickly processing that information and relating it to their own circumstances
- The supplied information is in text and on forms with a formality which is the norm for Bupa's work with hearing people. Much of this text is not understood by the Deaf people
- The information supplied provides graphic illustrations in the form of 'traffic lights'. People typically receive information which is a mixture of green, red and amber. Interpretation of which aspects are particularly significant is presented in text – again difficult for access.
- The capacity to query the information is limited by the circumstances: it comes at the end of a journey to an unfamiliar centre, a health check, contact with an unknown interpreter and potentially, a rushed end-point as the next person's assessment has to take place shortly after. Deaf people cannot look at the provided health assessment information and at the interpreter at the same time.
- In cases of concern, the usual advice is to "go to your GP". However, this was the starting point of the research: Deaf people have serious problems in going to the GP because of communication difficulties.
- Where we have been able to monitor this end process of Deaf people going back to the GP, Deaf people report that the GP did not respond to this 'external' report, laid it aside, suggested that there was no need for concern and continued in the same way as usual.

The net result is that we were discovering and attempting to inform Deaf people of the state of their health but the process was still not fulfilling our duty of care to these participants.

As a result we set up local workshops to feedback results and to discuss with the participants.

8.3. The Workshops

There had always been a plan to provide end-point reporting and feedback but this now needed to be brought forward.

The procedure was to

- a. invite all participants to a presentation and workshop to explain the results of the research

- b. present the results in sign language by the main Deaf researchers in the project
- c. provide each participant with a short signed explanation on DVD with guidance on how they might more effectively interact with the Health Service; the DVD to be produced by the project team (in the end this had to be produced after the workshops as decision to hold back publication of the results was made in order that a considered campaign could be mounted in 2014)
- d. Offer individual consultations (10-15 minutes with a health professional – usually a Bupa adviser). Deaf people were encouraged to bring their personal health check report for private discussion.
- e. Set up a forum during the meeting (open to all) which allowed general issues to be aired in regard to health and to health outcomes.
- f. Provide an online forum for disseminating and commenting on the work – this was also held over in order not to undercut the impact of the coordinated campaign in 2014.

The workshops took place in Glasgow, Manchester, Nottingham, Bristol and London (twice). An event planned for Birmingham was cancelled as there was insufficient response from participants.

8.4. The programme

The workshops were delivered in July and September 2013.

The programme typically consisted of:

- i. welcome and presentation of initial headline findings of the Deaf health assessments
- ii. questions and answers
- iii. individual consultations (overlapping with item ii)
- iv. group forum – provision of handouts/dvd

This programme was repeated at 2pm, 4.30 pm and 6.30pm.

All the participants who had taken part in the Bupa health assessments were contacted by email, fax or by text message. The take-up response was disappointingly low. There are number of explanations for this:

- The “short” notice of the Deaf health workshops – although we had felt that the priority of health might have meant Deaf people were likely to make adjustment
- The unsuitability of the given dates for those who were unavailable including those who were away on holiday

- For those with poor literacy levels, the lack of understanding of the purpose of holding the Deaf health workshop.
- General lack of awareness – in fact one of the main findings of the research so far – that Deaf people did not engage fully in their own health

However, for those who did attend, the feedback was that they found the event to be informative and useful. One venue had to be cancelled (at Birmingham) and a number of timed slots were also cancelled as they were not viable in terms of numbers of respondents. Table 5.1 shows how many people attended each event – in total, 63 people.

Table 5.1: Deaf Health Workshops

<i>Venue</i>	<i>No of participants contacted</i>	<i>no of participants who have attended</i>	<i>Response rate %</i>
Glasgow	37 people	2.00pm 8 people; 6.30pm 3 people	30
Manchester	39 people	2.00pm 5 people; 6.30pm 5 people	26
Bristol	68 people	2.00pm 5 people; 4.00pm 4 people; 6.30pm 6 people	22
London	102 people	2.00pm 6 people; 4.00pm 6 people; 6.30pm 8 people	20
Nottingham	41 people	6.30pm 7 people	17

Following the presentation and in parallel with the individual consultations with a health adviser questions were put to the discussion groups in BSL:

- Was the feedback information useful?
- How did it make you feel?
- Did you discuss your Bupa results with others?
- Has this made you change your lifestyle in any way?
- What changes will you make in future?

8.5. Analysis of responses

This was meant to be an informal discussion group and no video was recorded. Notes were made during and after the session by one of the Deaf researchers.

8.5.1. General reactions to the workshop presentations

Despite the low turnout (20% of all those who had attended for a health assessment), all who attended said that they found the information (with regard to the overall health findings) “very useful and informative” and said that it has helped them to have more awareness of their own specific health needs. However, they stated that the terminology that was used with them was too complex. Some examples:

- Some struggled with ‘statistical’ concepts eg one in four or 25%. It was necessary to explain that they were one of 303 people who had taken part in the study and the example was used to show that two people in a group of eight may have this health condition.
- Some did not understand the concept of *risk* of developing an illness or disease eg the *risk of becoming diabetic*. They were unable to manage the word ‘*risk*’ in relation to likely illness. They wanted to know that you are either ill or not.

Participants said that they rarely discuss health matters among themselves within the Deaf community. Many said that had not shared their Bupa health results, except with their spouses/partners. This confirms the concern (stated earlier) that deaf people may not understand the significance of health results (this confirms the data from the interviews with Deaf participants described earlier in this report).

Some participants reported changes to their lifestyles as a result of the health checks (described in section 7.6). For others, changes are neither easy nor straightforward as also seen in Section 7.6.

In one location, Deaf participants were more able to articulate their needs, probably as a result of an ongoing health campaign in that area. In that area they have a representative/advocate who is employed by the NHS. His role is to facilitate improved communication between Deaf people and the NHS. This person is a fluent signer and also has extensive knowledge of how the NHS operates. Deaf people are able to contact this person to ask for guidance and advice when necessary and he is able to report back directly to NHS in drawing the attention to meeting specific needs.

8.6. What Participants said

Given that this was not a formal data collection scenario, we chose to offer individual stories and perceptions and to provide a commentary on the main points in that theme at the end of each section.

8.6.1. Acting on the advice given

Peter, a 35 year old man who reported that his Bupa health check had identified high blood pressure of ‘197 over something’, because of which he was advised to see his G.P. He acted on this advice and his G.P. made an immediate hospital referral for him

where further tests were carried out. He was told that if he was to experience any pain in his neck that he should return to hospital immediately. Approximately 2 weeks later he did indeed experience neck pain and wondered whether he should go to the hospital or not. He stated that it was only because the hospital staff had been so insistent that he made the decision to go. On arrival, he was immediately admitted for emergency treatment and informed he must come to hospital immediately if he experienced any pain in his neck. About two weeks later he thought he felt a pain starting and wondered if he should go to hospital, he remembered how insistent the hospital staff had been and decided he should go in. He was treated and later told that if he had not gone in when he did he could have had a massive heart attack which he may not have survived. He was very grateful that he acted on the information given during the project.

Helen, a diabetic sat through the workshop quietly, as her husband did the most of the talking. The workshop emphasised that Deaf people themselves had to take responsibility for their own health. On the following day, one of the facilitators received a text to say that this person with her husband had made an appointment to see the doctor the following morning as she has not been feeling right for some time. It turned out that her cholesterol level was high. The doctor was then able to arrange for her to be monitored.

Grace was very grateful that she went to Bupa health check because she was told to see her GP after being told that she was on the borderline of being diabetic. The doctor carried out some further tests and told her that she needed to lose some weight. She was also given medication. She has managed to lose three stones by watching her weight and doing some exercises. On a return visit, the doctor was really pleased with her as she no longer needed to take her medication and is no longer heading for diabetes. She felt that if she has not gone for a project health check that it would have been most likely that she would have become diabetic.

Jack and Jill had lost seven stones in weight between them. Jill had already started to lose weight as she was considered very overweight. By having the project health check she was motivated to lose more weight. She is now a slim size 10 and is very healthy conscious. Since the visit to Bupa her husband has also joined with her; Jack was overweight and had high BMI. Since then Jack has lost two stones in weight. They regularly go for a long walk with their dog. She has also begun to help a number of her deaf friends with dieting. She believes that none of the commercial diet “foods” are of any value as they have high salt and sugar content.

Jack and Jill have changed their eating habits. Jill would like to see a support group for those who wanted to stay fit and healthy and suggested that the project should have different people coming to talk about their experiences as this would help deaf people to become more aware.

8.6.2. Comments

If Peter had not been given specific instruction to act as he did, it is quite possible that we would be reporting a different outcome. It is interesting to note even though he was given his blood pressure measurements he had not understood enough to realise the serious health implication. This implies that other Deaf people may not have sufficient understanding of their health results and are unable to judge whether further actions are needed. By taking the Bupa health assessment when they did, they were rewarded with the possible improved health outcomes. The critical learning point for

the project was that it was the Deaf-led and sign language supported health assessments which made the difference.

8.6.3. Peer Support Groups

Tracey presented as quite obese. She explained that when watching television programmes about obesity, or when it came up in conversation, she would dismiss it as not really being relevant to her, even though she was aware of the risk of further health problems. However, at the workshop, faced with Deaf peers explaining the problem, she felt that it was very obvious that she could no longer continue with her previous state of denial. The information was being presented in her first language and that brought home to her that she would need to do something about losing weight (and to sort out her other weight related health problems). She said she has been trying to lose weight for years but had not succeeded. Part of the problem had been the lack of communication support available at self-help groups (e.g. weight watchers). Consequently she would like to see a support group available for deaf people so that they can help each other to stay motivated.

Natalie said that she wanted to take up running and had asked her deaf friends if they would join her. She couldn't find any deaf friends who were interested and was disappointed by this. One of her hearing friends has asked her if she wanted to join in with a group who ran regularly. She was unsure at first but decided to give it a try as this friend had been learning to sign. They now regularly run together, but she would still like to have deaf friends to run with.

Gail explained that one of her workmates, Jo, had recently been diagnosed with breast cancer and wanted to know if the project could put her in contact with a Deaf person who had gone through this treatment; as Jo would like the opportunity to talk through her options with someone who had had this experience. Jo wanted to have access to a support/peer group to share experiences and if necessary, to have important aspects explained to them.

Katy looked very fit for her age. She said she regularly went to the gym to keep fit and she felt it would be good to have other deaf people there. She thought the leisure centre should have special deaf sessions say, one hour a week on a trial basis to see if enough Deaf people would be interested in attending, making this part social gathering as well.

8.6.4. Further comments

These participants were looking for ways forward (to take responsibility for their fitness and well-being) and making suggestions on the promotion of health for the community. They talked about the benefits that they could gain if there were a peer group of Deaf people to share their experiences and to support each other. To try to join a mainstream group is a problem as no one will bear the cost of providing an interpreter; even so, it would be mostly “learning from hearing people’s perspectives” which although useful to some extent, would not share deaf life. Jo’s request for a deaf peer/self-help group for cancer treatment would be important in other crises eg being taken ill and requiring emergency treatment at the hospital. The importance here is that by group action or pressure, stress-creating situations such as needing to

phone ahead and managing the intercom upon arrival, can be anticipated by the patient and solutions found by the staff.

Again the primary aspiration is for Deaf-led peer groups with similar health issues.

8.6.5. *Being Open and Sharing their Experiences:*

Norman being diabetic raised some money to put on diabetes information evening for deaf people and had worked hard to get the people to come. He had arranged for a person to come from the Diabetes organisation but only two people deaf people turned up. Later, after the talk, he went downstairs and saw other people whom he knew were diabetic and he asked them why they didn't come to the talk. They were furious that he was talking to them in front of other people as they didn't want the others to know they were diabetic.

Norman went on to explain how important it is that others should be aware of who is diabetic as it had been a problem for him. He was away in London for a meeting. It had finished late and the participants wanted to have a quick drink *before* going out to eat. It was too long a fast for him; he lost consciousness. The landlord was about to ring for an ambulance. Luckily his friends knew that it was because he had not eaten. When he came around he was pleased that his friends knew what to do and felt that it was important that deaf people should not be so secretive about their medical condition.

Molly was disappointed when Deaf Women's Health Group had folded as she found that group to be useful especially when she had to undergo a hysterectomy. She had been very worried but after talking to others who had been through the operation, it helped her to decide to go ahead. She would like to see this group start up again so that other deaf people can get to benefit from this support group too.

Lisa has a history of depression and that it has been difficult for her to obtain the appropriate support. She also said that she would like other Deaf people to be more aware so that they could give better support to those with depression. She felt that there is a stigma attached to the problem and that it would be good to have a support group for deaf people so that they can "feel safe" within a small supportive group.

Victor came up to talk about the health problems that he had, since starting to look after his mother. He was very overweight. However, since that time he had lost 7 stones and was feeling much better. During that time he had been diagnosed as very depressed and had had four heart attacks. Being depressed had not helped as he was eating all the wrong food; since that time, he has been much more careful about what he eats. He said that being at the Deaf club and being with his friends had helped him to deal with his depression and he now felt much better. He now knows that if he feels low he can turn to his Deaf friends for support; they have been good to him over the years and he is very grateful to them. Now his friends can sense when things are not right for him.

8.6.6. *Additional comments*

It is important to learn from Victor that what has helped him is consistent with the others talking about the need to be open and honest about feelings. It would seem that even for those who suffer from depression that there is double isolation where Deaf people are concerned. This highlights the need not only to educate the Deaf

community about health matters but also to recognise some of early symptoms of illness, such as depression so that they can support each other better. More Deaf-led groups might go some way to dealing the problem.

8.6.7. Taking on the responsibility for their health care:

Pam claimed that there are 129 deaf organisations in the UK and that it would be good if they would all take on the responsibility of doing their share with regards to deaf health. Pam would also like to see the Deaf health promotion start when children are at school so that they already have the information on how to look after themselves so that they can learn to take on the responsibility.

Felicity has become a Deaf advocate in which she had to help many deaf people to learn to become more assertive of their needs. She also mentioned that it was important for Deaf people to be aware of their rights especially when receiving health care. She feels that there should be more training provided for those wishing to become Deaf health advocates.

Michael is a member of an active Health campaign group within the Deaf community. He talked about how they have managed to secure 24 hours access to interpreting services within the Health services. He has also requested that the Bupa health assessor should come to their group to give a talk about looking after their health better.

Steve is a member of an ethnic group, who regularly sees young deaf people. He was concerned about the lack of understanding about their sexual activities and the risk of acquiring STD. He said that many of them are frightened and do not attend their health clinic so he is always urging them to do this as he feels that they are not aware that if they have the disease nor that this can be passed on if not using condoms.

8.6.8. More comments

Pam has raised a valid point that the majority of the Deaf community were brought up in hearing homes where communication may be limited. Pam suggested that we need to think about positive health promotion much earlier in school in order that children can learn how to take on the responsibility as they become older.

8.7. Taken as a whole

Eighty percent of Deaf participants (by not attending the feedback sessions) demonstrated the problem we highlighted in the interviews: there is a dissociation between personal health, the process of health care and in this instance, the feedback and potential strategy issues which might be taken forward. It seemed that they considered there was little point in re-visiting their health issues and did not see any benefits to be gained from working to change the system.

The remaining 20% had stories to tell and were engaged in the management of their own health ... to the extent that that was possible. In doing so, they were able to share their insights into processes and actions which would improve health and engage with others in the Deaf community. The strong message is not one of outrage

at the poor state of Deaf health but the simple development plan for Deaf-led joint action to support the Deaf community itself.

9. Discussion and Conclusions

9.1. What does it mean?

We can see that Deaf people's contact with hearing health professionals does not always lead to effective treatment and it is often the case that Deaf people's health issues are not well treated. Reynolds (2007, p100) offered some insight into this situation:

It is clear from the comments made by both of the focus groups that deaf people settle into a routine, which avoids the stress of contact with hearing people. When the surrounding community is not easily accessible, people retreat into structures, which they are familiar with.
All contact with hearing people in a medical setting is potentially stressful and can have an impact on their health and well-being. If they lack the confidence to pursue appointments due to these communication barriers, then what is important is that there are systems in place available to provide the necessary information and guidance.

Deaf people do not believe that such systems are available or accessible.

9.2. Workshops and matters arising

The workshops demonstrated that Deaf people benefited from the discussion as an opportunity to discuss the kind of difficulties that they may have had to encounter in their lives. They confirmed the struggles they have with the Health Service.

- When asked about which changes they could achieve themselves as part of the Deaf community, there was a sense of apathy and a general feeling that they could not hope to achieve anything by themselves. This may be due to past experiences and a history of oppression that Deaf people face that they have become more tolerant or accepting.
- Many felt that change is the responsibility of others, despite reminders that this would take years to achieve. This could be as a result of traditionally paternalistic attitudes towards deaf people or that they have acquired a sense of learned-helplessness from being with other people.
- They commented that they found the discussion group helpful and would like them to be held regularly. However when asked if they would take on the personal responsibility for running such course, the participants expressed some reluctance despite the researchers reminding them that there would be no further funding from the project.
- There is a lack of role models in positions of authority especially in the health industry that Deaf people can turn to or learn from.

The workshops and the plan to deal with the problems in health which were discovered through the Bupa health assessments, failed in its ambitious goal. Too few Deaf people attended, too few brought their own health assessments with them, too few used the opportunity to ask meaningful questions during the one to one sessions with the health adviser. The relationship between the health assessment, the project and personal health priorities was not established strongly enough. Yet the realisation of this and the message of the few people whose lives had changed and for whom the message of ill-health had promoted some action, was instructive. The problems are deep and are likely to be changed only slowly. The clear signal is that intervention needs to be deaf-led and needs to grow from Deaf needs rather than public health needs with the expectation that these two routes would collide in the near future.

9.3. Understanding what Deaf people say

The interviews created an opportunity to discover not only Deaf experiences but their reactions to and interpretation of their contacts with health professionals.

At a superficial level, the primary issue is communication and the explanations centre around the provision of interpreters and the availability of health practitioners who can sign. We consider it would be misleading to take this at face value and to try to build solutions around this point.

At a secondary level, the difficulties relate to culturally inappropriate interactions. In this case, the Deaf person's perception of the world and their construction of the interaction comes into play. The fact that all interpreters are hearing creates an adversarial view of health care provision for the Deaf person. When it comes down to it, they are all hearing and really, they do not understand the Deaf situation – they do not walk in Deaf shoes.

However, it is at a more fundamental level that we consider the problems lie. Deaf people have almost from birth, been isolated from explanations about health. Families have difficulty in communicating, schools are unlikely to have an accessible programme of health awareness which will impact the person. This latter is becoming more problematic as almost all Deaf children are in mainstream schools. Deaf children young people and adults have to find and maintain their own personal identity; and their own psychological well-being is dependent on being able to protect and preserve that inner self. All transactions in health and illness take place in the hearing community – there is no Deaf health service. These transactions are then subject to all the usual stresses and puzzlement of contact with hearing people. However, more significantly, these are not optional. If you dislike one shop you can simply not ever go there again. If you are ill, you *do* need to go to the hearing doctor. All the reports confirm that this interaction is unsatisfactory and Deaf people do not trust the doctor (in the way that hearing people do). The net result is that the health message delivered by the service is a hearing one and may not be perceived as deaf-relevant.

The solutions are bound to be complex.

9.4. Recommendations?

It is relatively easy to set this set of problems in the area of inclusion. The perception might be that the Health Service is universal and the best means to manage public health. We believe that groups in the margins of society perceive this value and therefore wish to take part and to benefit from it. The problem is then how to provide access.

This thinking would lead us to ‘solutions’.

- During the Bupa Health assessments, some Deaf people had their first experience of using interpreters. Questions were asked to how they could request interpreter support in the future for health appointments. A more-available interpreting service would be an advantage.
- We might configure the problem in terms of reaching out to the community, even involving community self-advocacy. In one area at least, the notion of Deaf Health Advocates/Ambassadors has been offered. The individuals involved are selected to be knowledgeable about the existing Health Service and can act as bridges between community and the ongoing Health Service. Sign Health have already started with this model in the employment of two Deaf Health Champions in Liverpool and in Manchester. However, the model remains the same one of assimilating Deaf problems in the existing service.
- The alternative is to reach out from the hearing service by training paramedics as sign language, Deaf community experts. This model has been used in some police forces where PLODs, (Police Liaison Officer for the Deaf) have been specially recruited and trained in signing skills to act as mediators and points of contact. This appears to have had varying degrees of success with the service in the Avon area having been disbanded after a few years of work.
- Health education is another route. However, this has proved to be of limited success with hearing minority groups and has changed considerably towards a focus more on health promotion. A natural port of call is the provision of signed materials in fixed format (DVD) or in interactive format on the Internet. So far initiatives of this sort have been limited and perhaps as a result have had limited impact and are not in the perception of Deaf people.
- The last resort is to give the Deaf community ‘a good shake’ and try to make them more responsible for their own health – to make them more aware. It is relatively easy to say, deaf people should talk to each other more about health, they should make more complaints, they should build more relations with health care providers and take a stronger leadership role in the specifying the type of intervention required.

Given the Bupa health assessments, Deaf views on their contacts with GPs and their more extended narratives in interview, we are sceptical of the success if these ideas are implemented. None of the recommendations above require any significant change in the Health Service itself.

Changes needed would go right to the heart of the medical discourse on hearing loss (as opposed to health understanding of Deaf community and culture). If Deaf people are given a marginal position from birth, they are medically disabled. The professional view is that they start on the outside and somehow have to be brought back into contact.

Changes which would make a difference would be the presence of a Deaf Health Service, where there was no inclusion necessary. Services would be sympathetic to Deaf needs because they were responding to Deaf needs on their own terms. Given the geographical distribution of Deaf people and the low incidence of Deafness, the economics of a specialist community service might be challenging. Yet if we are seeing Deaf people going to the doctor repeatedly or avoiding the GP long enough for serious medical conditions to develop, the net consequent cost may be just as high for the existing service.

For change to occur, there needs to be a re-appraisal of the concept of Deafness along the lines of the newer concept of Deafhood ... which offers a value to Deaf people in their own right and does not see them simply as marginalised groups who need communication help. The change has to be partly the responsibility of the existing Health Service – not the creation of intermediaries.

The disadvantage that Deaf people experience in access to health care and the consequent ill-health which this project has established are very deep and longstanding within the systems we operate as a society. An adjustment of society's view on Deafness is likely to be needed if we are serious about improving Deaf health.

10. References

- Reynolds S (2007) *Deaf People's Understanding of Health and Health Care Systems*, Bristol: MPhil Dissertation, University of Bristol
- Campbell JL, Ramsay, J and Green J (2001) Age, gender, socioeconomic, and ethnic differences in patients' assessments of primary health care *Quality in Health Care* 2001;**10**:90–95

- Davidson B (2000) The interpreter as institutional gatekeeper: the social-linguistic role of interpreters in Spanish-English medical discourse, *J Sociolinguistics*, 4, 379-405
- Ebden P, Carey OJ, Bhatt A and Harrison B (1998) The bilingual consultation, *The Lancet*, I (8581), 347
- Elderkin-Thompson V, Silver RC and Waitzkin H (2001) When nurses double as interpreters, *Social Science and Medicine*, 52, 1343-1358
- Jimenez X (2005) The Patient-Interpreter-Physician Triangle: Issue of power, transparency and self regulation, *Revista Romana de Bioetica*, vol2 no 3, 1-7
- Trip-Reimer T and Brink PJ (1985) Cultural Brokereeage, in Buloechek GM, McCloskey JC and Aydelotte MK (eds) *Nursing Interventions: Treatment for Nursing Disagnosis*. Philadelphia: Saunders pp 352-364

11. Appendix Interview schedule for personal data

Deaf Health Project PERSONAL DATA RECORD (store page 1 separately from the other details)

Location of interview:

Interviewer:

Date of Interview:

Purpose of interview explained? Yes

Consent form signed? Yes

Participant Record Number: _____

PERSONAL

1. Full Name: _____

2. Address Details:

Address 1: _____

3. Post Code: _____

4. Contact Details:

Minicom or Text Number: _____

Fax Number: _____

E-mail Address: _____

5. Date of Birth: _____ Day _____ Month _____ Year

6. Gender: Male: Female:

7. Your marital status is:

Married: Single: Divorced: Separated: Widowed:

8. Which ethnic group do you belong to:

White: Black: Asian: Other: _____

Participant Record Number: _____

ABOUT YOU

9. Do you call yourself:

Deaf: Hearing Impaired: Hard of Hearing: Partially Hearing:

10. What is your preferred method of communication? (Please tick one only!)

Sign Language: Spoken Language: Signing and Speaking:
 Gestures: Writing: Other: _____

11. When did you become Deaf?

At birth: 0 – 3 years: 3 – 6 years: 6 years or older:

12. Do you wear a hearing aid

Always sometimes never

13. Do you use a cochlear implant

Always sometimes never

14. Without wearing a hearing aid or cochlear implant, can you hear at all, a person talking in a normal voice two feet away from you?

Yes No

15. Without wearing a hearing aid, can you hear at all a person shouting on the other side of the room?

Yes No

ABOUT YOUR FAMILY

16. Tell us about your family:

Members	How many?	Deaf or Hearing?
Mother		Deaf <input type="checkbox"/> Hearing <input type="checkbox"/>
Father		Deaf <input type="checkbox"/> Hearing <input type="checkbox"/>
Brother (s)		Deaf _____ Hearing _____
Sister (s)		Deaf _____ Hearing _____
Husband/ wife/ partner		Deaf <input type="checkbox"/> Hearing <input type="checkbox"/>
Your children		Deaf _____ Hearing _____

YOUR JOB AND QUALIFICATIONS

17. Are you:

Employed: Unemployed: Retired:

Student: At home: Other:

18. What is your main job title?

19. What does your job involve?

20. How many hours per week do you usually work? _____

21. How old were you when you left school? _____ years

22. When you were at school, what qualifications did you get? (List the three best)

<i>Subject</i>	<i>A-Level</i>	<i>GCSE</i>	<i>O-Level</i>	<i>CSE</i>	<i>Other</i>	<i>Year Achieved</i>

23. After you left school, did you achieve any qualifications? (list the three best)

<i>Subject</i>	<i>A-Level/ GCSE/ O-level/ Certificate/ Diploma/ Degree</i>

SIGN LANGUAGE

24. At what age do you think you learned signing?

Younger than 5 years Between 5 and 10 years

Over 10 years but before you left school After you left school

25. Where did you learn sign language?

At school From your parents/family On a course
 From other deaf people outside of school
 From other deaf people inside school Other: _____

26. Do you always understand other deaf people who are signing to you?

yes sometimes no

27. Do you understand other deaf people when they are signing to each other?

yes sometimes no

28. Do you always understand the interpreter?

yes sometimes no

WHERE YOU LIVE

29. Is your house in the:

City Centre Suburbs Village Countryside

30. How many people live with you? (apart from yourself)

[If family members – indicate what relationship you have e.g. mother, father, partner, etc. If not family member, is it flatmate, boarder, landlord, etc?]

Type of relation	Are they ...?		They communicate with you in:				
	Deaf	Hearing	Sign	Gestures	Sign & Speech	Writing	Speech

INFORMATION

31. For information do you read:

	<i>Every day</i>	<i>At least once a week</i>	<i>Once a month</i>	<i>Rarely</i>	<i>Never</i>
<i>Newspapers</i>					
<i>Deaf News</i>					
<i>Magazines</i>					
<i>Books</i>					

32. Do you use a computer to obtain information?

Yes with confidence yes but I am not confident rarely or never

33. Do you use the Internet to find out about staying healthy?

Every day At least once a week At least once a month Rarely or never

34. If you find a difficult medical or health word, do you

look it up on the Internet

ask a friend or family member

look it up in a book

don't bother

GOING TO THE DOCTOR

35. Thinking about the last 12 months, how often did you go to:

	16 or more times	10-15 times	5-9 times	Less than 5 times	Never
a) GP Surgery or Health Centre					
b) NHS hospital					
c) Private hospital					

36. Thinking about the last year, did you make repeat visits to the doctor for the same problem?

yes no

37. When you made a repeat visit why was this?

the doctor asked you to come back

you did not get enough information the first time

the information the first time was not clear

the medicine was not correct

the problem got worse

you needed more medicine

other reason _____

38. **Have you booked/used sign language interpreters for the following people/ places?**

a) Visiting doctor

b) Hospital appointment

c) Health workshops or health information days

d) Health appointments for your child or relation

YOUR HEALTH

39. **Compared to one year ago, how would you rate your health in general now?**

Much better now than one year ago Better now than one year ago

About the same Worse now than one year ago

Much worse than one year ago

40. **What exercise do you take?**

41. **How often do you do exercise?**

42. **Do you think you are well, physically:**

Very well *Quite well* *Well enough* *Not very well*

43. **Do you feel you are well “inside”:**

Very well *Quite well* *Well enough* *Not very well*

44. **Do you think that deaf people have more mental health problems than hearing people?**

Yes *No* *Do not know*

45. **If you had a question about health, would you use a help-line (e.g. NHS Direct)?**

Yes

Yes but only with video relay service

yes with text relay service (TypeTalk)

No

Do not know

46. **If you were feeling depressed who would be the first person you would tell about the problem? (tick one only)**

Family *Close friend* *Doctor* *Social worker*

Professional in Mental Health *Help-line* *Interpreter* *No one*

47. **Who would you prefer to have help from? (tick one only)**

Deaf person *Hearing person* *Both* *Do not know*

48. Why would you want them to help?

IN GENERAL

49. Do you feel that the health service for Deaf people is

Very good good OK not good poor

50. In the last 12 months, do you feel personally, that you had a

a good service/support from the health service?

a poor service/support from the health service

Not sure

Thank you

there is now a second part where we can talk about your experiences in more detail

Deaf Health Project PART 2: Open Questions

This section to be used by the Interviewer only

Encourage the person to talk openly and freely about the experiences.

Use only one question in each section – use the probing questions only if the interviewee does not give much information from the first.

Explain the purpose of the questions informally – for example,

“ we want to find out about your experiences of using health services and receiving information. We want to know what happened and how you managed to get around the problems if there were any. We especially need to know about how you communicated and if you understood. Also tell us about your experiences in using BSL either with hearing friends or family or interpreters.”

Explain that the session will be video recorded but will be used only to allow analysis of what has been said. It will be viewed only by the immediate research team at the University of Bristol and will not be shown elsewhere. Any quotes from what people tell us, will be disguised so that the person cannot be identified.

After the warm up, you can vary the order of the questions according to what the people say and you can add new examples if it makes it easier for them to describe their experiences. However, you should mark the order you used for the questions, in the margin.

Warm Up questions

(a) Can you remember any situations where you went somewhere and were surprised to find the person at doctor or hospital could communicate with you on signing or fingerspelling? Tell us what happened.

(b) Are there any other situations where you went and you found that the people at the desk or in the service, could not understand you and you had to give up in frustration? What did you feel at the time and then afterwards, did you do anything to complain? Did you ever go back to that place?

Contacting Health Services

Thinking about the last year, how do you usually contact your doctor or health centre if you or your family have health issues?

Has this process been smooth or have there been some problems?

Do they book an interpreter for you?

Do you find them helpful?

Reception

When you arrive at the reception desk in your health centre, are you able to understand and be understood by the receptionist?

Do you feel this is a smooth process or are there some stresses?

How do you usually communicate with the receptionist?

Do you think this situation could be improved – how?

Waiting areas for service

Can you tell us about good experiences or bad experiences you have had when in the waiting room?

How do you know when it is your turn to go to see the doctor or nurse?

Have there been embarrassing experiences in waiting your turn?

Going to hospital

Can you tell us about the last time you went to the hospital for yourself or with a family member or friend?

Did you feel you had a good service?

What were the problems? Which aspects were good?

Waiting at Hospital

At the Emergency & Accident Department in the hospital or at a clinic in hospital, you usually have to wait your turn...

Can you tell us about your experiences in the waiting room in the hospital.

How recently was this?

How would you improve facilities for the deaf people in the waiting rooms?

Going to the Dentist

Can you tell us about your experiences of going to the dentist

Is it possible to improve this service for Deaf people?

CURRENT MEDICAL ISSUES

(this section will be the most extensive in discussing current health)

Discovering the problem

You have mentioned in your medical assessment replies that you have had xxx health problem, can you tell me about how this was discovered and how you are being treated?

How were you told about this?

How did you feel at the time?

What were they able to do for you?

Preventing the Problem

Was it possible for you to know about the problem earlier?

Could the tests be carried out earlier?

How would it help if you had known earlier?

What would be good for Deaf people so that they know more about this problem?

<allow the person to talk in detail about the current health problem and how they feel about it>

Your Medical Assessment

As part of the project, you recently attended a BUPA centre and went through a number of medical tests.

What information did you receive about yourself?

How was the information given to you?

Did you receive adequate feedback on the results of the tests?

From Your Medical Assessment

When you attended, you were given the results of your tests and this was explained. Did you discover some new information about your health?

What did you feel about this?

Did you learn new information about your health?

Do you feel this medical assessment helped you?

Do you now have more clear information (is it still confusing?).

Going to the GP afterwards

Did you go to see your doctor as a result of this?

What did your GP say to you about the tests and results?

Mobile Text messaging

Most deaf people have mobile phones and can text each other

If doctors were to start using the text system for contact, do you think this would be beneficial to deaf people.

Would it be helpful to use texts with hospital or clinics?

What other things would you like to see in future with texting/SMS?

Internet

Nearly every house has access to the Internet...

What kind of information do you look for on the Internet?

What sort of medical advice have you looked for on the Internet?

Fixed media: newsletters, leaflets, video

Now Deaf organisations made information videos with signing...

Have you seen any signed videos? Were they any good? What have you learned from these videos?

Have you looked at leaflets about health? Were these helpful?

Have you seen information about health in magazines? Was this helpful?

What is the best way to give health information to Deaf people?

(To the Interviewer) remember to say Thank you

Don't forget to ask the person to sign the payment form. Make sure you have completed all questions