

Deafblind Worlds

Final Report on a project funded by the Big Lottery

RG/1/010095274

Prepared by Deaf Studies Trust and Sense

October 2012

Prepared by Jim Kyle and Susannah Barnett

Jim.kyle@bris.a.cuk

Susannah.barnett@sense.org.uk



Supported by

The National Lottery[®]

through the Big Lottery Fund



Acknowledgements

The project would not have been successful without the work of a number of people.

Staff at Sense - Liz Woodall who was the Project Administrator at Sense and Alison Bennett at Sense who supported and line managed the research work at Sense.

Anne Stygall at the Deaf Studies Trust who provided the firm base at Deaf Studies Trust

Debbie Harvey who was administrator and supporter to the project work.

Raychel Hills who worked with Andrea Tafurrelli.

And all the Deaf and Deafblind people who travelled to various centres and took part in the interviews and workshops.

Special thanks to our Steering Group of:

Dr Katia Herbst, Fiona Hall-Jones, Charlie Tyrell, and Linda Day.

And finally Professor Alys Young of the University of Manchester who not only attended the Steering Groups but also acted as a special adviser to the researchers in the final reporting stage.

Initially the administrator of the project, Lucy Dunbar became the researcher charged with encoding and providing the initial analysis of the data. She contributed text to the final report which was finally compiled by Jim Kyle and Susannah Barnett.

Thanks to all

Deaf Studies Trust,
Vassall Centre, Gill Avenue, Bristol BS16 2QQ

Table of Contents

Acknowledgements	2
Brief Summary	6
Chapter 1: Introduction	9
1.1 Who are the Deafblind people?	9
1.2 Experiences	10
1.3 Deaf People.....	11
1.4 Blind People	11
1.5 Research on the Deafblind Experience	12
1.6 Deaf and Deafblind people	13
Chapter 2: The Study	15
2.1 The workplan	15
2.2 Schedule	17
2.3 Description of participants	17
2.3.1 Deaf	17
2.3.2 Deafblind.....	17
2.4 The method used for analysis	18
2.4.1 First Level Codes – Deaf Data.....	18
2.4.2 First Level Codes – Deafblind Data.....	19
Chapter 3: Deaf People’s views on contact	21
3.1 Access	21
3.2 Barriers.....	23
3.3 Lack of awareness	24
3.4 Communication.....	25
3.5 Summary of Contact	27
Chapter 4: Deaf views on Community	28
4.1 Deaf Identity.....	28
4.2 Deaf Community.....	28
4.3 Happiness.....	31
4.4 Dreams	32
4.5 Summary of Community.....	33
Chapter 5 Dealing with others	34
5.1 Deaf People on Deafblind	34
5.1.1 Time	34
5.1.2: Trust and Familiarity	34
5.1.3: Awareness.....	35
5.1.4: Benefits of contact with Deafblind people	35
5.1.5: Complexity of the nature of Deafblindness and its definitions.....	35
5.2 Isolation.....	36
5.3 Independence	37
5.4 Reliance on others	38
Chapter 6: Personal Circumstances of Deafblind People	40
6.1 Independence	40
6.1.2 Independence and Self Fulfilment	41
6.1.3 Independence in an Environment	41
6.1.4 Independence – being the ability to make a choice.....	41
6.1.5 Perceptions of Independence	42
6.2 Isolation.....	42

6.2.1 Isolation – Research Limitations.....	42
6.2.2 Isolation and Environmental Experiences	42
6.2.3 Social Isolation	43
6.2.4 Choosing to be ‘isolated’.....	43
6.2.5 Effects of Isolation as seen in ‘Others’	43
6.3 Awareness of Physical Environment	44
6.3.1 Use of the Senses	44
6.3.2 Vision.....	44
6.3.3 Touch.....	44
6.3.4 Hearing	45
6.3.5 Other Senses.....	45
6.3.6 Combination of Senses.....	46
6.3.7 Interpretation of Information.....	46
6.3.8 Augmented Lighting.....	46
6.3.9 Obstacles at home.....	46
6.3.10 Other Strategies used to gain Environmental Information	48
6.3.11 Information Provided by Others.....	48
6.3.12 Information gained through Technology	48
6.3.13 Summary	49
6.4 Imagination	49
6.4.1 Imagination and cognitive maps	49
6.4.2 Using the imagination and cognitive maps	49
6.4.3 Imagination and Memory	50
6.4.4 Summary	50
Chapter 7 Feelings and Hopes.....	51
7.1 Emotions.....	51
7.1.1 Reflections on state of Mind	51
7.1.2 Factors which Trigger a Change in Emotion	51
7.1.3 Material Factors.....	51
7.1.4 Social Factors	52
7.1.5 Employment.....	53
7.1.6 Personal Factors.....	53
7.2 Feelings of Confidence and Control (DB7).....	53
7.2.1 Confidence and Self-Assuredness	53
7.2.2 Confidence and Familiarity.....	54
7.2.3 Confidence and Gaining New Skills	54
7.2.4 Confidence and Communication.....	54
7.2.5 Confidence and Contact.....	54
7.2.6 Confidence and Support From Others	55
7.2.7 Confidence and Control.....	55
7.3 Feelings of Insecurity	56
7.3.1 Unknown Environments.....	56
7.3.2 Other Things Happening in the Environment	57
7.3.3 Perception of Self within the Environment	57
7.3.4 Vulnerability.....	57
7.3.5 Aloneness.....	58
7.3.6 Control	58
7.3.7 Concerns and Worry.....	58
7.3.8 Communication / Meeting New People.....	58
7.3.9 Insecurity in relation to Future Events	59
7.3.10 Summary	59

7.4 Future Plans/ Dreams	60
7.4.1 How Deafblind People Reflect on the Future.....	60
7.4.3 Hopes and Plans for the Future	60
7.4.4 Person Centred Aims.....	60
7.4.5 Hopes requiring others to intervene.....	61
7.4.6 Being Deafblind in the Future.....	62
7.4.7 Issues Identified which prevented Hopes and Plans being achievable.....	62
7.4.8 Summary.....	63
Chapter 8: Other people	64
8.1 Contact with Deafblind People	64
8.1.1 Opportunities for meeting other Deafblind people.....	64
8.1.2 Starting Conversations	64
8.1.3 Issues in meeting with other Deafblind people	64
8.1.4 Summary.....	65
8.2 Contact with Deaf People	65
8.2.1. Positive Contact with Deaf People	66
8.2.2. Issues Preventing Contact with Deaf People.....	66
8.2.3 Perceptions of Deaf people’s Understanding of Deafblindness	67
8.2.4 Summary.....	68
8.3 Awareness of others	68
8.3.1 Awareness of Others through Direct Contact.....	68
8.4 Information provided by guides	68
8.5 Communication choices affects awareness of others	69
8.6 The ‘Deafblind friendliness’ of the environment	70
8.7 Control	71
8.8 Interpretation of contact	71
8.8.1 Summary.....	72
8.9 Involvement of Others	72
8.9.1 Relationships with Family Member, Friends and Other non-Professionals.....	72
8.9.1.2 Family and friends as ‘interpreter’	74
8.9.1.3 Family as Guide	74
8.9.1.4 Help with child care.....	74
8.9.2 Friends/ Neighbours	75
8.9.2.1 Friends as Guides.....	75
8.9.3 Involvement of Professionals	75
8.9.4 Use of Interpreters and Guides	76
8.9.5 Changing Guides	79
8.9.6 More than one guide.....	79
8.9.7 Guide implications.....	79
Chapter 9: Reflections	80
Chapter 10: Conclusions and final points	85
10.1 Benefits of the project	85
10.3 The nature of the Researchers	85
10.4 The Partners in the Research	86
Reference list	87
Appendix 1:	89
Appendix 2	93

Brief Summary

To date, there has been no clear description of the experiences of Deafblind¹ people. Deafblind Words was set up to meet with Deafblind people to talk about their lives and experiences. The aims were to

- a) examine the experience of being Deafblind
- b) determine if this was similar to Deaf people's experience
- c) discover if Deaf and Deafblind people could work together

In Deafblind Worlds, we adopted the perspective of the Deafblind person. The researchers were Deafblind. Their analysis shaped the questions and the methodology. Deafblind people were in the Steering group. Deaf blind people were re-visited and in groups, discussed the findings. The project was carried out wholly in British Sign Language (BSL) or the Deafblind variants, such as hands-on signing or with the use of Deafblind manual alphabet. We interviewed 21 Deafblind people and 38 Deaf people. They lived in Scotland, England and Wales. They were aged from 21 to 66 years with a range in gender, employment and marital status. Researchers made visits to each person individually to explain the project. Individual interviews then followed.

The Results: Deafblind People

There were fifteen females and six males. Forty-one percent were aged 21 to 35 years. Around 85% had a hearing loss since before the age of five years. Forty-one percent had acquired a sight problem by the age of ten years. Around 90% could not hear at close quarters; however, over a third were able to see at a distance of a metre in front. Most (77%) used BSL by preference but rather less were married or living with a partner (only 27%) compared to the usual for Deaf people of (over 50%).

Deafblind people feel independent in different ways from the usual way that carers and service providers think about it. Independence is more about the decision-making of whether to request assistance than the actual assistance. Deafblind people think about these choices in terms of their own challenges, not in comparison to what society thinks of as normal.

Most people think Deafblind people are isolated but Deafblind people considered that the key variable was the extent to which they could control the environment and control their interactions.

The reports of the experience of a Deafblind person in a group were unexpected. Deafblind people may be unaware of who is in the group and what they are doing. We found that Deafblind people attending Deafblind meetings often had no idea how many other Deafblind people were there. We found, sometimes, that Deafblind people were communicating through a guide/interpreter to another guide /interpreter to a second Deafblind person ... instead of directly.

¹ Throughout, we use the term Deaf (capital D) to refer to sign language users who are members of the Deaf community. Deaf implies a cultural affiliation. Deafblind (capital D) is used to refer to people who communicate primarily in sign language mode (either by BSL, or hands-on signing or by the use of a manual alphabet or by a personal manual system).

Our results show that Deafblind people may find it hard to think about the future but much easier to think about what is happening now. Deafblind people may worry about losing their eyesight in the future.

We found that some Deafblind people have never met another Deafblind person while some Deafblind people only have friends who are also Deafblind. Most Deafblind people do not have experience of communicating in a group.

We discovered that many people continued their involvement with the Deaf Community but other people said they did not go to the Deaf club. This was because they felt 'it was boring, Deaf people ignored them and Deaf people did not know how to communicate'.

The Deaf community was not seen as a friendly environment by many people.

Deafblind people can lose confidence and feel insecure as a result of loss of control of the situation.

We found that employing guides is the means for Deafblind people to go out of their home. This can mean that they feel independent. Other people said they HAD to use a guide and HAD to accept this, but this meant that guides were not seen as a positive part of Deafblind person's life and ... in any case, booking of professional services is done through organisations. Deafblind people feel restricted by this as they cannot have a guide when they want. Sometimes the guide they were expecting was changed at the last minute. Sometimes it meant they could not stay out as long as they wanted.

The provision of guides may be seen as 'solving a problem' of providing a way Deafblind people can get out of their homes with someone who can facilitate communication – the Deafblind person is therefore seen by service providers as becoming more 'independent'. Yet through this process, Deafblind people become more dependent on organisations and the Deafblind person's control of his/her own life has been reduced.

Deaf people's responses

A total of 38 Deaf participants were interviewed. Of these, 36 transcripts were used in our analysis. There were 20 men and 55% were married or living with a partner. Seventy-six percent were white – a low figure which was partly due to trying to find more people in ethnic groups. The average age was 42 years. Almost all (95%) could not hear speech. Over 80% said that they preferred to sign and to be signed to. Only 45% were in work. In the Deafblind group only 18% were working. Most of the group claimed to be in contact with other Deaf people and with the Deaf community at least weekly.

Deaf people said they did not know how to communicate with Deafblind people. It was as if Deafblind people were "foreigners. Deaf people valued ease of communication and said Deafblind people were slower and different. Deaf participants thought Deafblind people were 'hard work', requiring patience, and forcing on them a responsibility that they were reluctant to accept. Although we believed that Deaf people and Deafblind people were similar we now think that it would be difficult to bring them together.

Conclusions

Although there is much in common in Deaf and Deafblind experience, there is a gap in the perception of the two groups with respect to each other. Deaf people at present see Deafblind people as different and time consuming.

Deafblind people do not form groups. While somewhat simplistic, it is however, intensely significant. Many of the Deafblind people we met, had never been able to discuss their experiences with another Deafblind person. Even those who attended meetings where there were other Deafblind people were seldom able to carry out direct conversations with other Deafblind people.

The limitations which are inadvertently created by the provision of guides ensures that Deafblind people have hitherto been unable to form social groups. There are significant obstacles to conducting Deafblind-only meetings such as how to overcome the limitation of pair-wise interaction, that is Deafblind people can only talk to one person at a time.

Relationship with the guide has turned out to be a major issue and one which will require further more detailed study. Deafblind people rely on guides but wish to have more control over when, where, how and with whom the associate.

There were many superficial contradictions in the results but most can be resolved when we listen to the experiences and aspirations of Deafblind people.

Chapter 1: Introduction

1.1 Who are the Deafblind people?

Persons are regarded as Deafblind if they have a degree of combined visual and auditory impairment resulting in problems of communication, information and mobility (Deafblind Services Liaison Group 1993). The exact nature, cause and level of sensory loss varies among people; however the feature common to individuals who are Deafblind is that they have some significant deprivation in the use of the *distance* senses (McInnes 1999). In the UK, it was in the past estimated that there were over 23,000 Deafblind people (Deafblind Services Liaison Group, 1993). The majority of people who are Deafblind are elderly, estimated at 14,000 Deafblind people (Sense, 2002).

These figures have been radically revised in the Sense commissioned report by Emerson and Robertson (2010).

We estimate that in 2010 approximately 132,000 people in the UK have more severe impairments of both hearing and vision (66,000 women and 65,000 men; equivalent to 212 people per 100,000 of the general population) and that approximately 356,000 people in the UK have impairments of both hearing and vision (193,000 women and 163,000 men; 572 per 100,000). Nearly three quarters of all people with more severe impairments of both hearing and vision are aged 70 or over. (Page 3)

The report is based on analysis of existing data sources and does not give a clear indication of extent of hearing loss or visual impairment. It makes it difficult to determine the numbers in the population categories which we have to examine. However, it does point to a likely increase in the overall group as the population as whole is becoming older.

The population includes

1. People with congenital Deafblindness (ie those who are born or become Deafblind before they could learn to speak). For individuals born Deafblind, awareness of the world around is often limited to touch and . Communication difficulties may affect progress in education and may reduce interaction with other people. Some individuals will have complex additional physical and/or learning disabilities.
2. People born with a hearing loss who later acquire a sight disability. They include
 - a) those who are hard of hearing and choose to use English to communicate and are more likely to interact with members of hearing society, and
 - b) culturally Deaf people, users of sign language, who are members of the Deaf community.
3. People born blind, who develop a hearing loss later in life.
4. People who acquire both hearing loss and sight problems later in life.

This study deals predominately with groups 1 and 2b, whose communication choice is sign language, possibly adapted to include gestural and physical means of communication. As a crude

estimate, this group may be 5,000 in the UK – in the age range 18 years to 65 years. However, there is not a good base of statistics for this group. We predicted that this group were most similar in outlook and experience to Deaf people. They may also be the most challenging for service providers.

Those in groups 2a, 3 & 4, are culturally hearing, and their communication choice is likely to have been English speech.

In this report when we use the term *Deafblind*, we are referring to groups 1 and 2b.

1.2 Experiences

Although it seems obvious in all areas of research, that a first step should be to understand the perspective of those with whom you are working, there has been very little attempt to understand the world which a Deafblind person inhabits.

Although some elements of the Deafblind person's understanding can be learned through autobiographical work written by Deafblind people e.g Smithdas, 1958, and Stiefel, 1991, the case of Helen Keller remains possibly the only detailed account which allows us to understand the way in which a Deafblind person experiences the world around. A more recent study by Schneider (2006) mentions the concept of 'experiencing interactional powerlessness'. The remainder of the literature appears to focus on children, on assessment techniques and on service provision.

From the few studies, we can project a world view which relies on touch and taste and imagination but into which we have not been prepared to venture further. Of course, the situation is complicated by the major individual differences within the group. However, there seems little doubt that service providers could benefit greatly from a better understanding of the views and perceptions of Deafblind people.

As indicated, research into Deafblindness in adults often focuses on aspects of incidence and costs to service (although the work of Moller, 2008, described below offers more analysis of the interface between Deafblind experience and services).

There are 53 studies listed in the Laurence Report (for the period between 1983 and 2000). All follow the trend of trying to identify within the UK community, those with a dual sensory problem in order then, to carry out a needs assessment and provide a set of recommendations. The vast majority of studies have been carried out by, or in conjunction with, social services departments or Local Authorities and usually by people who do not themselves have direct experience of dual sensory problems. Often such studies are limited to determining incidence, establishing definitions and are governed by finance-led concerns on policy and provision.

Other studies focus on understanding causes of Deafblindness e.g specific implications of Deafblindness such as the effect Deafblindness has on communication e.g. Woodford, 1987, Reed & Floyd 1998, Naish 1999, or the effects Deafblindness may have on the family unit e.g Singh & Guest 1991.

In the USA, Macdonald (1994) and Spear (1994) explore Deafblind Culture within their own country and offer some insights into the lives of Deafblind people. Kilsby and Cook (CAUSE, 2003) undertook a comparative survey of how people with Usher Syndrome in 6 different European Countries (including the UK) maintain their independence. Although on the surface

this survey sets out to study lifestyle, the report limits itself to focusing on factors of communication, mobility, access to information and the impact that Usher Syndrome has on these elements. It tends to focus on services and the obstacles a person faces but does not go beyond this to look at lifestyle experiences and perceptions of those people.

As far as can be determined there has been no study of the personal experiences of those who are Deafblind within the UK, other than Barnett (2002) which is discussed below. The experiential studies which have been carried out tend to concentrate on Deaf people (e.g Ladd, 2003, Padden 1980) or on blind people (Higgins & Ballard 1999, Tobin 1998).

1.3 Deaf People

We have established that Deaf people form a dynamic community based on use of sign language – a language which can be traced back at least 400 years. Deaf people are said to establish their primary ties at school and develop their community affiliation through social contact in Deaf clubs and other meeting places. As Deaf schools have reduced in number, the early socialisation has changed and technological means for interaction have appeared – textphone, texting on mobile phones and even videophones. Deaf clubs have seen reducing attendance while young people seek more appropriate youth culture venues for meeting. However, no matter the location, the same transactions occur where Deaf people can meet others and share experiences, often having travelled long distances, and where the human basic need for interaction can be experienced.

At the same time, we can see that the opportunity for community interaction forms only a small part of daily life, the major part of which is lived among hearing people – where interaction is limited. It used to be said or thought that Deaf people became community members only when they were in direct contact with each other (Kyle and Allsop, 1982) but the texting facility on mobile phones has brought an immediacy of distant contact which acts to allow people to feel in contact without seeing the other person.

We should not use the word “isolated” to mean physical distance, since Deaf people see and experience other people, everyday. The personal fulfilment of Deaf people comes not from being physically close to others, but from being in meaningful dialogue with others. This is important within the context of this project since by comparison with, but unlike Deaf people, we consider that Deafblind people seldom have the opportunity for this meaningful dialogue. This point is crucial to our understanding.

1.4 Blind People

In the case of blind people, the saying that they have an isolation from things not from people, is a useful starting point. The experiences of blind people have been much more extensively documented. Blind people are more closely integrated into the hearing community, are more visible to hearing people and have experiences to which hearing people believe they can relate. Since they are united with hearing people, usually through a shared common spoken language, there is greater access to the experiences of sighted people and obviously greater dialogue. In this way, blind people differ from both Deaf and Deafblind people for whom such a dialogue does not exist.

Research into the Deaf experience and blind experience offers some useful comparisons. However Deafblindness is not simply a combination of being Deaf and blind but is a unique condition which has its own experience.

1.5 Research on the Deafblind Experience

Barnett (2002) for the first time and from the perspective of someone who is Deafblind, collected data on experience, through interviews and email contact with nine people with acquired Deafblindness.

The study found no established community or specific culture among Deafblind people. However Barnett (2002) found that Deafblind people do have a unique experience involving a number of different factors and which appear to be common among individual Deafblind people - such as ways of perceiving and making sense of the world through touch and imagination.

Deafblind people use touch in a number of ways: for receiving information about their environment, for communication and also as a feature of general behaviour. Although the study is limited in size, there are implications from the data which contribute to understanding the lifestyles of Deafblind people:

- The ideal Deafblind environment is reported to be where the sense of touch is most stimulated. Different textured surfaces, areas of floor covering which allow vibrations to be felt and objects which are easily recognisable through a standard shape are consistently reported in regard to mobility.
- Touch is seen to be vital in communication not only as manual communication but also in non-linguistic communication e.g. in detecting personality and emotion of the conversation partner. Deafblind people, when introduced to individual people physically, claim to be able to determine personality and mood.
- The use of imagination² is an essential part of the Deafblind experience. Deafblind people use information obtained through the senses and from past experience to make sense of their environment and to provide a context into which they place themselves. Imagination is the process which drives this and is a crucial process to give meaning to the experience (and to prevent Deafblind people from living in a void). The practical implications of this include the need to have internal creative descriptions of their surroundings. Communication aides can provide environmental detail such as locations of furniture, the size of the room, the weather, or sources of sound.

As well as the importance of touch and imagination, Barnett (2002) also described the Deafblind experience as being in the present tense, i.e. without knowledge of the sequence of events. Deafblind people are not always aware of an event until it happens and contact is made in some way. Events are often not predicted, but seem to occur in isolation. Once the event has passed or contact had been broken, the Deafblind person is again left not knowing what happens next. This appeared to be a common element of the Deafblind experience.

² Imagination is taken to mean the active process of internal construction of the world – the representation which is built up jointly from sensory information, even when it is limited, from past experience and from internal creations – i.e. by imagining what it might be like.

Further to this, Barnett (2002) proposed the idea of the Deafblind person as an island - both the physical isolation which many Deafblind people experience and the social isolation resulting from limited contact with other people. However the reports of the Deafblind participants highlighted the importance of the times when Deafblind people come together and communication is achieved – even when the content of the communication is relatively minor, positive feelings of well-being arose. These factors are significant because these become the fundamental conditions for community development – shared experience and interaction

On the basis of the research we can support the view that the lack of sight and hearing produces a void in stimulation and information content. This removes the basis of social interaction and creates an island, in which imagination has to sustain the personal well-being of that individual.

While hearing-sighted individuals may claim to have had experience of isolation, they can seldom know the continued lack of contact which is the daily life of the Deafblind person. Empathy with such individuals is very difficult.

The Deafblind experience is the result of a unique condition of impairment to both vision and hearing. Whilst hearing-sighted people cannot share this experience, it is believed there are some elements of shared understanding between Deafblind and Deaf people.

1.6 Deaf and Deafblind people

Although the lack of hearing from an early age can be said to produce a reduction in stimulation, discoveries about Deaf people's language and culture suggest that Deaf people are able to circumvent the limitations. What Deaf people have developed for themselves (often in direct opposition to the pressures of society and even of families) is a fully functioning linguistic minority with an active community life, inter-marriage and cultural expression. The Deaf Community is built on a visual and spatial representation of the world around them, whilst the shared language, community life and mobility of its members create the possibility to communicate and share this world experience. The variation in Deaf people's experiences in childhood and adult life in all of these aspects, leads one to view the Deaf community as a rich and varied society which tolerates diversity in its communication and patterns of exchange.

However, there are no formal care structures or support systems within the Deaf community to deal with other Deaf people who are at risk – e.g. elderly people. There is awareness of the need to support Deaf children in hearing families and there is considerable progress in counselling for those with adjustment problems and notably for Deaf women's health. As yet, these applications are incompletely developed or arise wholly as an adjunct to a hearing-led service. To date, like Deafblind people, Deaf people have been considered mostly as recipients of service rather than providers of service. The Deaf community is not empowered to support others.

In our initial group 2b, there are many Deaf community members, who later became Deafblind. However their position in the Deaf community is weakened as their sight declines and they are often to be found only in the margins of society, and then as elderly people, may disappear off the radar altogether. In terms of group 1, those with congenital Deafblindness may use visual/spatial communication methods and use behaviour patterns based on gesture and touch. Given the potential shared primary cultural experiences and possible similarities of language use and behaviour patterns, there is an argument for exploring the relationship of Deaf and Deafblind people.

Although there are some examples of Deaf people in communication and contact with Deafblind people, (e.g Deaf people taking some of the CACDP Deafblind Qualifications, including the 30 or so Deaf staff members who currently work supporting Deafblind people in services at Sense) there has been no attempt to date, to try to understand the community relations and the shared experiences which could support a more coherent interaction, particularly within the context of service provision.

Put very simply, the closeness of Deaf and Deafblind experience means that Deaf people may be better at reaching Deafblind people in communication and in empathy.

Chapter 2: The Study

2.1 The workplan

There were two phases/aims to the project:

- To explore the Deafblind experience (particularly in comparison with that of Deaf people);
- To test a framework for interaction and support by Deaf people for Deafblind people.

All interviews have been carried out by peers – i.e. Deafblind researchers for Deafblind participants and Deaf researchers for Deaf people. A range of communication approaches have been taken with the Deafblind participants – BSL, manual alphabet and hands-on signing; interviews with Deaf people were conducted in BSL.

Phase 1: (12 months³) There were four components:

- Individual interviews (months 6 -18)
- Group meetings (months 14 to 20) for Deafblind people;
- Interviews with Deaf people (months 6-12); and
- Survey of Deaf organisations and independent initiatives in this area (months 4 to 6).

The core group were 20 Deafblind individuals (chosen from a larger group of potential interviewees) aged between 21 years and 65 years (7 aged 21-35 years; 7 aged 36-50 years; and 6 aged 51-65 years), representing a range of people of employment age, gender, location; it included also BSL signers, those using the Deafblind manual alphabet and those using hands-on signing. It has proved more difficult to find older Deafblind people. Participants were chosen to represent the UK but also in groups, with a target of at least 4 individuals within relatively close geographical proximity. The participants are almost exclusively those who have acquired blindness after being Deaf.

These first interviews collected data to build up characteristics of the 'Deafblind experience'. The interviews dealt with aspects of communication, behaviour, touch, imagination, social interaction and lifestyle as well as specific experiences of meetings, and opportunities for social contact through other means eg e-mail. Contacts with Deaf people, the Deaf community and relation to the Deaf experience were also examined.

The interviews also explored the service and support concepts as perceived by Deafblind people. These were specialist service provision e.g. services provided by social services, other agencies, interpreters, guides. We were unable to establish the presence/effectiveness of the range of service provision based in the Deaf community – our survey indicated that none existed – Deafblind people were perceived as separate by Deaf clubs.

³ The time scales for the project are lengthened from the norm, because of the complexity of arranging a Deafblind researcher to travel to various locations in order to meet with other Deafblind people. Also, we should not minimise the additional communication issues of working with this group – for every stage of the research.

In the second phase of the study, opportunities were set up where Deafblind people could interact with each other. This activity is complex requiring communicators and facilitators but we believed this could be of great benefit as it would allow Deafblind people to try out ideas with each other. In this case, the groups were focused on themes which have emerged from the interviews in regard to Deafblind world views as well as aspirations for contact and service.

The third component allowed Deaf people to express their views on the same topics as those of the Deafblind participants i.e. to allow for comparison between experiences. Concepts of service, responsibility, community membership were explored. Current perceived extent of interaction between the two communities was also examined.

Thirty-eight Deaf people were interviewed in the same geographical areas as the Deafblind participants as it had been intended to create matched pairs in regard to gender, age. (This proved to be impossible in the end). They were advised from the outset that the aim was to work with Deafblind people and there would be some commitment to take part in the second phase of contact with Deafblind people.

The analysis used qualitative methods to establish themes emerging from interviews and group sessions. The software program N6 (now NVivo) was used to organise the English transcript of the BSL interviews (prepared by Deaf researchers) and to offer an analysis base. In certain sections, quantitative methods were used to summarise the gathered numeric data and preferences (indicated on scales).

As the fourth component, a survey of local authority social services and other agency support (interpreters, guides) was carried out. The aim was to investigate current types and range of provision – specifically to establish which groups of people e.g hearing-sighted, Deaf, blind - are currently involved in service provision, and also to establish the provision that is made for Deafblind people to meet and to interact as a group. This was a traditional survey with postal questionnaires, followed up by telephone/textphone and with statistical data analysis of the responses. The survey indicated no coherent provision nor indeed any real commitment to providing for/ supporting Deafblind people.

Phase 2: (months 18 to 30), the project was set up to bring together Deaf and Deafblind people, firstly in workshops in a range of locations and then in one to one contact (based on pairing of those interviewed), to monitor interaction and to elicit reports on this experience.

As a precursor to this interaction, both groups had feedback on the results from the first phase. Deaf community members were also provided with general background data on those who are Deafblind (they had a Deaf Blind Awareness mini-course). The workshops were driven by the themes which had emerged and the interaction was facilitated by Deaf and Deafblind researchers.

This phase was designed to test the proposal for Deaf-Deafblind interaction and to consider how this may support a new service model. The data collection could not be wholly specified in advance as it had to arise in the expressed wishes of the participants. Proposing a detailed model of Deaf service, based on existing experiences in care and support to Deafblind people, would have defeated the object of the research and removed the component of empowerment and choice which is so vital to the research and development in the project.

(Note: the Deaf-Deafblind sessions could not be arranged as part of the data collection and occurred only in the final dissemination workshops.)

It is true there are training implications, financial aspects, and locational feasibility issues, but the bringing together of Deafblind people firstly and then the interaction with Deaf people is considered a major achievement of the project. The fundamental point was to provide the platform for Deafblind people to communicate their needs in this respect and then to bring them into contact with Deaf people because they may be closer to them in terms of experience.

Separate group meetings of Deaf people and of Deafblind people were achieved and some Deaf-Deafblind sessions were arranged as part of the final dissemination phase. The latter proved extremely difficult to coordinate as Deaf people showed little enthusiasm and there were enormous complications in trying to arrange the guides for the Deaf blind people's attendance. The issues arising from these attempts to create the groups are set out in the Deafblind field notes chapter.

2.2 Schedule

The project was arranged in a set of work packages with a series of tasks to reflect the pattern of work described above. This was used as the primary management tool.

2.3 Description of participants

The interviews were held in Cardiff, London, Bristol, Birmingham, Glasgow, Peterborough and Preston (Deafblind only).

2.3.1 Deaf

A total of 38 Deaf participants were interviewed. Of these, 36 transcripts were used in our analysis – ie those who had complete data.

There were 20 men and 55% were married or living with a partner. Almost all (36) of the group claimed to have a hearing loss before the age of five years (73% from birth). Seventy-six percent were white – a lower percentage than the national which was partly due to ensuring that we included more people in ethnic groups. The average age was 42 years with an even split into three age groups 21-35 years, 36 – 50 years and 50 year plus. Almost all (95%) said that they could not hear speech but only 38% claimed that they had learned BSL before the age of five years. This figure is a little different from the national figures (around 50%) described in Kyle and Allsop (1998). The fact of learning BSL late has a major impact on a range of linguistic aspects of language use and is likely to have an impact on interpersonal communication. However, because Deaf children are born in hearing families, typically more than half (in Europe) do not learn sign language until they arrive at school (Kyle and Allsop, 1998).

Over 80% said that they preferred to sign and to be signed to, while the remainder suggested that a mixture including writing down was acceptable.

In terms of employment, 45% claimed to be in work while the remaining 55% included students and housewives and 5% who said they were retired. This contrasts markedly with the Deafblind group where only 18% were working.

2.3.2 Deafblind

There were seven males and fifteen females. Forty-one percent were aged 21 to 35 years. Around 85% of the group had a hearing loss since before the age of five years. Forty-one

percent had acquired a sight problem by the age of ten years. Around 90% could not hear at close quarters; however, over a third were able to see at a distance of a metre in front of them. Therefore we are not dealing with a group who have no access through sight at all. Most (77%) said they used visual BSL by preference but rather less were married or living with a partner (only 27%) compared to what would be considered usual for Deaf people of over 50%. Very few were working, with the largest group (41%) declaring themselves unemployed.

2.4 The method used for analysis

Following translation/transcription as previously described, all interviews were read several times in order to identify recurring themes. These themes were concepts, descriptions, recurring words/phrases, feelings/emotions, issues of context, behaviours, general expressions of appraisal. From an initial long list, a short list of 12 major themes was established. The themes do not necessarily summarise or apply to all aspects of the data collected but only to those elements that are pertinent to the original research questions. The themes were discussed within the research team to establish agreement.

We used the QSR N6 sort and retrieve qualitative software program. The themes were made into first level codes to be applied to relevant sections of data. This coding enables the data to be reorganised from individual narratives (organised by participant) into thematic groups of data that cut across all participants. In this way it was possible to

- (i) identify the extent to which the theme is of significance across all participants, including the identification of divergence i.e. patterns of difference are as important as patterns of similarity;
- (ii) to describe in detail what constitutes the theme including its conceptual elaboration;
- (iii) to identify key examples of the theme area. The organisation of the data in this way also enables the tracking of the influence of particular characteristics on kinds of response (e.g. gender, communication preferences).

2.4.1 First Level Codes – Deaf Data

The following provides a list of the codes used to organise the data and their basic definition as they were applied to Deaf participants. They are not a summary of results, but rather a statement of the intended meaning and boundaries of the codes that have been applied to the data.

- D1 Access
Access to information or services, perhaps through sign language, interpreters, lip-reading, subtitles or support from others.
- D2 Barriers
Deafness itself, negative perceptions or lack of awareness of others, lack of linguistic access, lack of confidence or insecurity.
- D3 Community
Contact with others, Deaf community rules and customs, feelings, attitudes, duties.

- D4 Dreams
Hopes, aims, ambitions for the future.
- D5 Lack of awareness
experiences of others' lack of awareness, feelings about and impacts of lack of awareness.
- D6 Isolation
Isolation from people, information and services – experiences of isolation, feelings about isolation, impacts of isolation.
- D7 Attitude towards Deafblind
Experiences of contact with Deafblind people, perceptions of Deafblind people and their lives, attitudes towards them and their involvement with the Deaf community
- D8 Communication
Preferences of communication methods, experiences of communicating with others, impacts of easy or difficult communication, strategies employed in communicating
- D9 Deaf Identity
Expressions of Deaf identity, perceptions of Deaf identity, impacts of Deaf identity.
- D10 Happiness
Expressions of happiness and unhappiness, what makes Deaf happy and unhappy.
- D11 Independence
Feelings of/about independence, expressions/perceptions of independence.
- D12 Reliance on others
Examples of needing support from others, examples of others relying on participants for support, attitudes towards relying on others.

2.4.2 First Level Codes – Deafblind Data

- DB1 Independence
Feelings of independence/ skills used to gain independence/ times when can be independent
- DB2 Isolation
Feelings of isolation/ skills used/ times when isolated
- DB3 Hopes/ Plans/ for the future

Plans/ aims/ dreams/ things want to achieve. Fears for future.
- DB4 Contact with Deafblind
Opportunities for meeting/ communication/ feelings towards other Deafblind people/ conversations / establishing understanding.
- DB5 Contact with Deaf people
Opportunities for meeting Deaf people/ communication/ feelings towards Deaf/ perceptions of how Deaf people view Deafblind people

- DB6 Emotions
Types of emotions and their reasons/ influences
- DB7 Feelings of confidence, control
Situations when this occurs and the reasons
- DB8 Feelings of insecurity, loss of control
Situations when this occurs and the reasons
- DB9 Awareness of others
Ways in which Deafblind people are aware of others and the level of importance attached to knowing
- DB10 Awareness of environment
Skills used to make sense of environment
- DB11 Imagination
Ways in which the imagination is used
- DB12 Use of others
Use of Guides/ interpreters/ Family members / feelings towards the involvement of others

The transcripts were examined repeatedly for content relevant to each topic and then the relevant “quotations” were collated using N6 and then analysed.

Chapter 3: Deaf People's views on contact

The analysis below (in the next three chapters) examines the transcribed interviews in relation to each of the main themes in turn. These reflect the issues which were uppermost in Deaf people's minds when they were being interviewed.

3.1 Access

Thirty-four of the Deaf respondents reported experiencing barriers to access across a broad range of areas, primarily in terms of linguistic access. From their perspective, these experiences indicated the necessity of sign language interpreters, subtitles and communicating directly with others who could sign and also dissatisfaction with the convenience, affordability and suitability of such support structures. These issues have been widely reported in other studies relating to Deaf people (eg Kyle et al, 2005) and to a great extent, are the expected findings.

Twelve of the participants, ranging from age 26 to 60 years, who described difficulties with access reported experiencing frustration, stress and insecurity as a result of lack of access. Although these feelings were mainly responses to particular situations described by the participants, they appeared to exemplify a recurring rather than a one-off experience. For example:

"It's really hard, I have to keep moving seat. I have to listen if they call my name, because the doctor's surgery has no BSL. I rely on people, asking them is it my name? I told them I am Deaf...I always keep my eye on everything, watching what they say...It can be stressful, I am quite fed up with that....I keep my eye on what is going on and someone lets me know. Importantly, I let the reception know that I am Deaf. It can be a bit stressful." (PP36)

"I would like improved access to things as I use public transport a lot, like the bus and the trains and they have loudspeakers that I cannot hear. I feel frustrated as I miss out on information." (14)⁴

The problems of public service locations, particularly in health centres and hospitals is a common topic of complaint for Deaf people. It usually represents the use a technology which disadvantages those people who do not hear. Participants also reported barriers to gaining employment and equal access to services and information.

"Angry! Example. Last Friday I wanted to watch a special programme, called 'CSI'...I was all ready to watch then the announcement came up saying 'sorry no subtitles' I was so angry. It is not fair. When the hearing can have an advantage to watch 'CSI' and not Deaf." (3)

This disadvantage in comparison to hearing people produces a strong sense of indignation at being excluded from an anticipated leisure activity. These are seen as everyday occurrences and part of the Deaf experience when marginalised.

Where linguistic access was unsatisfactory, most participants reported employing alternative strategies to gain understanding. Most commonly cited was the use of lipreading and writing as a means of communication where signing was not possible. This was seen to be an acceptable

⁴ We have numbered the participants in the study and these are used to anonymise the quotations but yet to allow the attribution of the statements to particular individuals.

alternative where the communication took place in close contact with one other person, was brief and did not require understanding of what was perceived to be detailed or complex information. Here a respondent describes how he felt about using lipreading and written English for communication:

"It's really difficult to communicate like that. Not so much at the doctor's, I can read their writing okay. But maybe at a tribunal, I would have to have an interpreter there or at the hospital." (10)

Around one third of participants reported accessing more incidental and environmental information visually, such as observing body language, non-verbal signals and taking cues from the behaviour of others. In many cases, this was seen to be less satisfactory as it did not allow the participants to relax, requiring more effort to deduce their surroundings from sometimes ambiguous indicators.

"I have to rely on people moving on the platform and this means I have to find a member of staff and ask them for help." (14)

One participant, however, responded positively to gaining understanding by using these alternative perceptual means:

"I watch closely and carefully so I am able to follow and I use my imagination as to what is going on! It makes me creative, compared to subtitles as they tell me what is going on and I'm not keen!" (22)

Here, the interaction between the participant's imagination and the information available is viewed as an enjoyable process, where he or she may impose their own interpretation of events without the challenge of deciphering written English.

There was also a factor of the familiarity which the participants associated with key individuals. Interactions with others who have knowledge of these respondents' histories, contexts and needs appeared in some cases to create increased trust and confidence. Access is not only an issue of practicalities such as the physical environment and language but also that it has a psycho-social component. The following quotes indicate that predictable continuity is a factor that can mitigate against stress and make for positive outcomes:

"I am happy at the doctors as the doctor knows me...While this doctor knows that I am Deaf and always waves at me. I'm more confident and happy." (7)

"Yes, reception know that I'm deaf. They will tell me when it is my turn...It is easy. My doctor understands what I say." (33)

"If it is for general services, like the doctor's, then I use my priest as he knows my background. I feel if I use an interpreter I would feel I had to repeat myself, but with my priest he knows my background" (22)

The routine created by repeated contact with the same person leads to a trust being developed, even when the communication itself is incomplete.

Access is a crucial issue in the minds of Deaf people.

3.2 Barriers

Twenty-five Deaf participants discussed barriers, primarily in the general areas of communication, accessing information, socialising and leisure activities, employment and education. Of course, there were often overlaps and participants commonly faced barriers that were interwoven and compounding. The way that the majority of participants described the barriers they faced, showed that they perceived them to be external – as the result of an unsuitable environment. However, a small number did report feeling that the barrier was as a result of their own weakness.

For example, two participants felt that they were limited by their own English language skills:

“the problem is communicating, I don't have very good English...I feel ashamed if someone starts talking to me and I can't understand and tell them I am Deaf, I'm frightened of what they would say.” (17)

“The teachers write on the blackboard with their backs to me, and they talk at the same time. I did not understand them. I didn't know speech. I'm not very good at English.” (20)

These participants appear to have internalised a sense of responsibility for the barriers they face. It is interesting to note that the first of these respondents has neither English nor BSL as a first language, having moved to the UK as an adult. The second respondent appears to have experienced an oral education, typical for someone of their age, between fifty-one to sixty-five years old. Another participant, also in this age group and discussing their experience of oral education, perceived the barrier to be deafness itself:

“I do not have any qualifications. I kept failing because of my deafness – I wasn't allowed to sign so I was only allowed to speak. I was repeatedly taught how to speak my 'T's and I became fed up. We signed when we went out to play and got told off by the teacher who then told us to speak.” (23)

The remaining twenty-two respondents who described facing barriers, perceived these to be external. Communication problems caused by the paucity of sign language users and interpreters was most commonly cited, followed by the negative attitudes of others, then the inaccessibility of written English. The following example is characteristic of the isolation experienced as a result of being excluded from group communication:

“I want to paint...so I went to evening classes at college but the communication was a big problem. Before I used to go to art classes but I wasn't satisfied because I would paint and the teacher would come up, look at my painting and say 'very nice', then walk off. There was no discussion. I realised with art, you need criticism, praise and to share your feelings about the painting. I was just painting myself, everyone said it's good but that didn't mean anything to me. You couldn't share your interest with others. I thought of self-tuition, again I felt lonely.” (18)

Here, we could say that the barrier arises through the participant being in the minority because he has a different language from that of the larger, surrounding group. This was a theme which arose repeatedly throughout participants' discussions about barriers, indicating that the obstructions were perceived to be a result of their difference, which was then viewed as deviance from the norm. Six of the participants actually referred to this inequality between themselves and the hearing majority as being a barrier, for example:

“One situation I faced at university is being the one Deaf [person] and [it was] always [a] problem being the last or beneath hearing” (4)

The same participant discussed the converse situation of Deafness being the norm and therefore feeling no barriers:

“...because I come from a Deaf family and I feel natural. No label/ any barrier against me or my family. We are positive and nothing around can affect me, we equal...” (4)

As with Access, the topic of barriers looms large in the thinking of Deaf people – most of the time, the barrier is perceived as external to the Deaf person.

3.3 Lack of awareness

One of the most frequent complaints of Deaf people is that hearing people are not aware of them nor of their needs and perspective on the world. This is usually expressed with the sign for ATTITUDE, implying that there is some conscious aspect to the rejection of Deaf needs. Hearing people are often classed as having good or bad attitude.

The usual comments are that hearing people seem to reject or ignore Deaf people in daily life because of a lack of knowledge of how Deaf people approach their work and social activities. Many of the contributions under this theme were examples of when hearing people had not been ‘deaf aware’.

One of the classic situations is when going to the doctor who is perceived to have a bad attitude.

That happened to me a lot, I hate that. I arrived at the doctors, go to reception let them know I'm here, I told them I am Deaf, wrote down my name. I was told to go and wait there (points). I hate the arrangement. Chairs all around the room and have same poles (columns) blocking my view. I cannot see. A man came, shouted something, somebody got up and went. Sometimes the doctor is lazy and just opens the door, shouts out and somebody goes in. I can't see the doctor, so when it's like that. I just wait and wait. The doctor shouted and looked, I then have to walk and check he looking at me using face expressions “your turn?” Doctor shows attitude – no patience, by using face expression. Should like come and check if it's me, ask me, easy way. (6)

One person also bracketed the deaf awareness need inside the barrier of the communication difficulty itself. Hearing people not only do not have awareness, there is no way to get through to them because of the language difference.

I feel I can't explain fully because I don't have the right signs and don't know who the right person is to do it. That's a problem. But I explained my English is a visual language and also I reminded them that I am Deaf Some have good attitude and are aware, my personal tutor is aware and has been very supportive all the time since, that's great. But one upstairs, responsible for making papers seemed not to understand and needed to change and needed to be aware. Like I asked for a camcorder ... to be filmed as it's easy; writing is hard and the person can't understand this, that Deaf people find it impossible to write. From her I feel that barrier, a different attitude, she needs Deaf Awareness, that's all. (4)

The description implies a double discrimination – one because of the ‘disability’ and the second because of the lack of communication of the difference. In both of these long statements, the sub-text is the frustration of having always to try to explain to people. At times, the respondents

consider the hearing people to be stupid and lazy; sometimes they express their own inability to overcome that barrier. Accordingly, the responsibility for becoming Deaf aware should rest with the hearing people according to the Deaf respondents and this is justifiable because of the lack of success Deaf people (on their own) have had to date.

In some cases, with waiting rooms, Deaf people report some success in eliciting an appropriate behaviour but often this is at the expense of identifying themselves as different. We can see that an obvious temptation would be just to avoid predictable situations where lack of Deaf awareness would lead to frustration and stress. We suspect that this is a normal adjustment for Deaf people as they become older. It would be an expected strategy for managing stress.

3.4 Communication

It is a reasonable supposition that Deaf people are concerned with and talk about their language a great deal. In nearly every discussion, the topic of sign language as communication comes up. Often, this is in the context of hearing people having to learn; sometimes it can be seen that other Deaf people do not communicate well and at other times, it is about discovering sign language later in life – ie after school. Deaf people need sign language in order to be a community. Anyone entering the community has to be able to learn to sign.

These features come out clearly in the interviews and reflect the nature of the primary barrier which might be faced by Deafblind people. An inability to sign BSL could be thought to be an indifference to the community and might not provoke an adaptive response from Deaf members of the community.

Yet there are stories of adaptation by Deaf people in interaction with hearing people – eg using pen and paper. Those Deaf people who can speak may well try to carry on a conversation through speech and lip-reading.

Oh we 'talk' and write. Am good at lipreading, I try to pick it up then if I don't understand, I write. (6)

Yes comfortable with hearing but use writing, it takes longer and doesn't feel right, writing. Preferred to use signing, if interpreter there, I use it, they can translate. (6)

Sometimes, the Deaf person will knowingly try to cope with hearing people and see this as an important statement of independence.

Well I went as I had a problem with my hearing aid. I went there and tried to use writing but the woman there knows that I am Deaf and used speech slowly. So I explained about problem with the tube in the hearing aid. They took it and gave it back fixed. No problem there, no need for social worker, no need at all. I rather go myself. I always go myself - more private as more confidential. (7)

The problems in communication however, are usually more prominent and even within the family there are serious issues.

When I go to see my family, see my mother – she can't sign. That was the old philosophy, that you shouldn't sign. When I go to see her, I try to talk but she doesn't understand what I say. She asks other people 'what's she saying? What's she saying?' and I get really annoyed with her. It's difficult because the way I was brought up, I could never tell her anything. (10)

This final sentence of “I could never tell her anything” is a very common statement on their own hearing family within the Deaf community and carries the reality of lack of communication and the real disappointment of impoverished relations.

This is not necessarily helped when the hearing person is learning to sign. Deaf people will not always tolerate the problems of expression of those hearing learners.

The person tries to sign, they say I'm learning Sign Language, I usually walk off, I don't bother, it's not comfortable talking with them, I usually say hang on I need to go over there and I go off. (11)

Although this seems like a negative response, it is understandable in the context of identity and community life. It is also consistent with the Deaf view that it is other people who are responsible for making the main adjustments (even in the process of learning to sign itself). Where the relationship starts with a perceived positive attitude to Deaf people there can be a different response.

First I'd say hello, if there's a connection there we'd start being friends then if they are interested to learn sign language I'd teach them. If they're not interested I'd leave them and smile politely. It's important that the connection is there, if there's no connection then I'd leave them. (16)

The evaluation of communication is then bound up in perceived purpose of the individual and the assessment of good attitude.

Sometimes the family context has one person who is able to sign – or at least is able to sign a little. Deaf people talk about switching attention to that person and this person might even be a child. The Deaf person will then talk to and talk about this person. Sometimes this will be only a person who uses gestures.

One factor mentioned on several occasions is the reduced opportunity for signing which occurs because of living among hearing people.

I didn't sign on Saturday but I signed lots on Friday from about seven o'clock to twelve o'clock then nothing on Saturday as I was mostly on my own then I finally signed on Sunday- it was like I was itching to sign! (13)

This aspect is hard for hearing people to comprehend when their spoken language is ever present in one form or another. However, Deaf people have many fewer opportunities to use their language. This may tend to make attitudes stronger in regard to the protection of the language.

There are some people who feel they can communicate well with hearing people yet, at times, cannot and have to use other means. Here the communication discussion is dissociated from identity and culture and is expressed only insofar as it is a vehicle for information.

I have a good communication with hearing people those who do not use BSL. I always write or lipread with them. I am really used to hearing people through working with them. I usually lipread or write. I would like to teach them BSL but nobody is interested? Because they told me that I have a good voice also I speak very well and I can hear too. But sometime they cannot understand me I have to write to them. (2)

Here the somewhat tortuous argument illustrates that the basic issue in this case is of the transmission of information – hearing people feel that whatever is happening is satisfactory and they do not see the need to embrace the language as a part of the Deaf person's culture.

Inevitably there is a great deal more to say about communication and in particular Deaf people's perception of the centrality of sign language. The community solidarity on this issue seems somewhat weakened by Deaf members who seem content to believe that all is well and that communication is possible with hearing people through mixtures of gesture, speech and lipreading (and even writing down). This tends to be presented as an aspiration for others (ie I can communicate OK with hearing people, so other people should try as well). Yet the reality is that this level of communication relates to the simple transactions about and transmission of, information, often in specified contexts. The nature of language as a part of identity and culture as prioritised by the community is not a feature of this type of interaction. Deaf people can claim on the one hand that they are able to adjust to hearing people and on the other that their language is central to their well-being. The creation of this duality is an outcome of what Ladd (2003) identifies as colonisation – hearing society has implanted the justification for spoken language as the natural means of communication.

3.5 Summary of Contact

Not surprisingly, Deaf people view contact with others as a critical aspect of their existence. However the question of access is not measured only in language competence terms, but may be related to purpose of the interaction and the confidence Deaf people have in themselves and the trust they have in those with whom they interact. Barriers to development are viewed often in terms of language. Requests for access may be as much a cultural request for parity as they are requests for specific elements of information.

-

Chapter 4: Deaf views on Community

In this section we consider where Deaf people position themselves and how significant their membership of community really is.

4.1 Deaf Identity

This theme is a well established one in the literature on the Deaf community. It centres on the need to relate to others with similar experience and then to internalise that membership of that particular group. Deaf identity is expressed in the simple question “are you deaf?” when people meet and is taken to mean a cultural affiliation. In these interviews people often talked about identification – with either Deaf people or with hearing people. More than we might have predicted claimed that they could move between both Deaf and hearing groups.

I think it is a mixture of both. I feel it is both worlds. I am in the deaf world and the hearing world. I am happy in both. I couldn't be in just one world. It is impossible to choose one world as to me it is a mix of both the deaf and hearing world. It is both and that gives me happiness. (27)

Others described the journey from the hearing to the deaf community through the acquisition of sign language.

I grew up oral with my hearing family. Then aged sixteen I went to a Deaf Club and saw sign language. I felt great learning that and used it ever since up to now. (1)

The relation to signing of this identification is expressed in this statement from a participant in a rather convoluted way.

My number one is signing, but when I sign to you and you understand what I am saying also you sign to me I understand what you are saying, we have a bond we do understand each other and we know what we talk about in that situation. (38)

The bond referred to is the identity and from these interviews the most salient feature is the ability to communicate directly in sign language.

4.2 Deaf Community

It is generally recognised that the Deaf community is a key to Deaf life. It is particularly significant since most (at least 95%) Deaf people are not born into the Deaf community – but are rather born to hearing parents who have no knowledge of and no involvement in the lives of other Deaf people. In order to express community feelings and to join the Community, Deaf people have both to make a choice and to overcome obstacles of hearing expectations, educational directive and often distance, transport and even inertia. Being involved in the community requires positive choice and action.

Deaf community consists of the interactions of Deaf people and for most of the time, people describe their communications and meeting with others as the community itself. That is they rarely think of it in terms of services or provision by the hearing community. The Deaf community is the network of contact and interactions not the physical structure. It is not tied to a specific location and while attendance at Deaf clubs declines, the ‘community’ is simply re-defining its interactions. In this respect, it represents the backdrop for what Ladd (2003)

describes as Deafhood – an ever changing pattern of interaction and contact with each other and with the hearing community.

At the same time, the location (the Deaf club wherein the heritage lies, dating back in many cases to the 19th century) has a significant place in community history and tradition. Forty years ago all community life was centred in the Deaf club which existed in each town. Although Deaf events and inter-club activity still continue, there is now a broader range of activities which Deaf people engage in together. A particular distinction is emerging between the Deaf clubs (in the past, the home of the community) and the meetings and interactions which take place outside of the clubs.

I was in Deaf club for so long... for (many) years....but now I start to go less in Deaf Community. I try to meet them in the pubs. Am still in the Deaf Community but not in clubs, not important so less. (2)

There is a generally observed decline in Deaf club attendance throughout the UK and possibly in most developed countries. Often people describe the community involvement in terms of routines – this is more common among older people who still attend while younger people are more likely to be found in pubs. The generation gap can be significant.

Usually, every Monday morning I go to the Deaf Club. We all meet up and chat, catch up. On Tuesdays I go to another club, in the afternoons from 12 until 4, I go for chats and meet friends. On Thursday, I go to the same Deaf Club all day. I never go to the Deaf Club on Saturdays, it's full of young people. On Wednesdays it's OAP day, my age group. I go and talk to them. (18)

Three-quarters of the participants discussed the concept of community, principally in terms of their views and experiences of the Deaf Community. The majority of participants viewed their relationship with the Deaf Community positively, most commonly reporting ease of communication as the benefit of contact with other Deaf people. It was indicated that communicating in sign, and also as part of a group, led to self-confidence and a sense of bonding with others.

"Because it's easier to communicate, I am more confident, I can't communicate with hearing people, I am not confident enough. We share news, it's exciting, I enjoy it." (17)

"When I'm signing to you and you understand what I'm saying and you are signing to me and I understand what you are saying, we have a bond. We understand each other and we know what to talk about in that situation." (38)

There appeared to be a perception of automatic connection with others who shared the same experiences and language, resulting in the elimination of isolation otherwise experienced.

Some people had been divorced from the Deaf community for some time. Here is one respondent's quite beautiful description of becoming part of the Deaf Community:

"before, yes, I was isolated. Because when I was living in _____,....I was not integrated into the Deaf Community at that time...I bumped into a Deaf friend I know, she encouraged me to come into the Deaf community. Like, you know a river that has many fishes. One is Deaf and Deaf Communities surrounding at the sides. You need someone to cast in and hook that Deaf fish and put it in Deaf community – welcome to the Deaf Community." (2)

This analogy illustrates not only the transition from being alone and different to being accepted and belonging, but also that established members of the Deaf Community ought to feel a responsibility to nurture the uninitiated. It is important to note that this role is assumed by both those known to the novices and also by strangers, as is exemplified here:

“...grew up oral. When I was twenty, I was in town talking with a crowd of deaf girls, I was talking and pointing at the air, not signing, no, but like gestures. A Deaf man tapped me on the shoulder and asked me if I was Deaf. I was not sure as I didn't understand his signing, so he pointed at his ear. 'Deaf?' I said yes, he beckoned to me to look at his watch...we agreed to meet next Tuesday at the same place. I was puzzled, not sure, when I got home I told my mother. So my mother came with me and we found ourselves at the Deaf club, so we went in. That was the first time I saw Deaf people, Deaf signing that way, when I was twenty.” (3)

Encouraging and mentoring behaviour was not seen as being restricted to the introduction process. Nine of the twenty-eight participants who discussed the topic of community reported either receiving or providing support, indicating a strong sense of ongoing collective responsibility. Again, the support described was not restricted to that shared between close friends but was also extended to the wider Deaf Community, in particular deaf children and the elderly.

“I am a mentor and I don't mind how severe the child's behaviour is as I believe the deaf child should be with a deaf adult, not a hearing adult as this makes the behaviour worse.” (25)

When comparing Deaf participants reports on meeting a Deaf stranger with those on meeting a hearing stranger, most participants indicated that they would be more welcoming towards a Deaf stranger. This attitude again appeared to be rooted in the understanding of shared language and experiences

“I'm not reluctant to meet hearing people, we just don't have anything in common. They're hearing – I'm Deaf – there's no common ground. We're different. If they're an interpreter or have a Deaf family then we do have a common ground. If they've never met a Deaf person before then what do we have in common? We're Deaf, we've suffered, we support each other etc.” (32)

This strength of community does not seem to extend to inclusion of Deafblind people as we will see later in the report, The community definition is closely bound by a particular experience. There can be dilemmas for the Deaf person in regard to community. This uncertainty and balancing of the positive and negatives is apparent in this respondent:

... yes, two things. In Deaf community, there is lots of back stabbing and there lots of aggressiveness – I got fed up/don't bother and get out (get away). While in the hearing community, me unhappy due to language barrier like trying to understand but make me feel embarrassed and humiliated myself. Sometime I wish hearing 'listen' as I say 'No I am happy with myself'. Sometime both communities make an effort for me and can open their mind (2)

In this case, the limitations and negativity in the Deaf community are recognised but the lack of understanding and communication is apparent in the hearing community. However, at the heart of it is a sense of not being accepted by either community.

Deaf people meet because they have their experiences in common. This distinguishes them from other groups in hearing society – where clubs are formed for a single activity eg tennis club, yoga club. The Deaf community is a multi-purpose social and cultural community which does not rely on a location to exist and to function. It is a network of direct interaction through the lifetime of its members.

4.3 Happiness

Typically people respond to questions about happiness and what constitutes happiness for them by reporting their present state. Typically this is presented positively.

As for me being Deaf, I have an identity, and am happy for what I am. I feel I have achieved my aims and my dreams and also there are one, two or three things I'd like to achieve, so I try to plan, save and do that. I am happy because I have a home, I have a shelter, food in the fridge, have a partner, have a car, have friends, I'm happy. (3)

The material and social achievements are similar to those we would have reported by hearing people. One implication of this common expression of being happy is that the Deaf community are satisfied and despite the claims for recognition through political activism, their own personal mental state is positively adjusted.

Often the question on happiness is related back to communication. A particularly good example of this is:

For myself, If I gave birth to a hearing baby I would worry about communication problems. But I gave birth to three Deaf children and that makes me very happy, we can all sign to each other. Maybe I've got an attitude problem, I don't know but I'm happy. If they were hearing they'd be left out on their own, we'd all be signing away forgetting there's one hearing, I'd worry about that. My son's partner is hearing – I was boiling inside because she's hearing, I thought - how can she mix with Deaf people. But her mother and father are Deaf and she's a really good signer, like a Deaf person. A lot of people think she's Deaf, when we say no she's hearing they're shocked. It's true she signs fantastically but I don't know what will happen in the future. Some days I feel hearing people are in control like my hearing family, they won't speak to me now... (12)

This viewpoint links the issues of communication within the family to the happiness of the members and offers an insight into Deaf feelings about non-sign users. Many respondents reflected this view saying they were happier with Deaf people than with hearing people.

I am happy with deaf people and being in the deaf world. Signing to them and going out - it is relaxing. The hearing world is different because I am often left out when they are speaking, it is different. (24)

This highlights the lack of stress in talking to Deaf people as compared to the difficulties of talking to hearing people. This was often most obvious in relations with members of the family – parents and siblings.

Another respondent offered a philosophical perspective on the significance of Deaf people's existence.

If there are no Deaf people in the world, it would mean there would be no signing and that would be boring. It's better to have Deaf people there that can sign different language from hearing people who talk. That's what makes me happy. (8)

The expression of satisfaction in being different is an important feature of the presentation of Deafhood.

A more obvious form of comparative happiness, mentioned several times by Deaf people was the fact that they did not hear intrusive noises – could concentrate better in studying, at work and so on. The sense that this gave them an advantage over the hearing community was considered within the evaluation of personal happiness.

The notion that the Deaf community is repressed and consequently quite depressed, can be rejected. Deaf people have established their own interaction and network and within the known framework they can be happy. Contact with hearing people tends to be stressful and is often seen as a source of unhappiness.

4.4 Dreams

In certain respects, we would be surprised to find that Deaf people had different aspirations to those of other people in society. Living as they do as a community within the hearing community and with some access to the material and consumer models which apply to hearing people, we would expect Deaf people to aspire to developments in their own personal quality of life. This would include such aspects as better housing, more financial security, travel and so on.

This indeed was the case for the vast majority. People wished for personal achievements eg climbing mountains, skiing, or personal travel or family health,

I'd like a good future. I want to be happy at home, good children, good health – I want to see the children brought up well. I don't want them to get involved with drugs or arrested by the police and put in jail. (10)

Two other themes specific to Deaf people emerged: education and signing. Often Deaf people see education of children as the key and there are many who wish to be involved.

well I like to build up something for hearing mother and father with Deaf babies, train them. (1)

I want to teach Deaf children, I always want to help Deaf Children. It was my dream since I was eight years old. (8)

The other significant theme centres on the acceptance and use of sign language by everyone.

A world full of BSL users! (12)

I wish all the shops had Deaf people that signed! (17)

sign well and have a bigger club and to have Deaf doctors too that can sign, not now but in the future. Like say in 2010 here have a Deaf Doctor. My own Deaf Doctor here. (7)

This is a recurrent theme in research when Deaf people are asked about their relation to the community at large. It is linked to a very strong sense that Deaf identity *is* language and to ignore

that (which is common) is to deny Deaf people not just their communication but their very identity. Not surprisingly, they wish to be accepted as sign language users.

Very few had no aspirations but it was not uncommon for people to say they were content with life at present.

To be honest, I don't think of the future as I think it makes things worse. I always think of what is happening now or what's happening next week? But I am happy with my life now, but my future will change as I might change my job? Maybe, I don't know but I am happy now. I have no intention to change myself as I am happy! (13)

Deaf aspirations can be seen as those of a community on the margins of society – wishing for many of the material and personal gains which society offers. It implies that Deaf people have an awareness of the possibilities for personal growth and achievement. However, two aspects which separate Deaf people are seen to be goals – education of Deaf children and use of sign language by all people.

4.5 Summary of Community

It is clear that identity is a crucial component of community involvement. Equally there is recognition that the person has to opt in and sometimes must be helped to reach the Deaf community. With declining attendance at the Deaf club, community has come to mean a network and not necessarily a place. While Deaf community life tends to be organised on a different plane to the service provision, the concept of happiness is defined on those premises – ie that sign language interaction and routine and contact with other Deaf people is possible. People then appear to consider themselves to be happy. Their dreams and aspirations are not dissimilar to those of hearing people except insofar as they apply to the positive internal impact to be gained by improving the Deaf community or supporting Deaf children.

Chapter 5 Dealing with others

5.1 Deaf People on Deafblind

The findings discussed so far have explored what the Deaf participants thought of their own lives and experiences. These findings will now be used to understand and interpret the Deaf participants discussions about Deafblind people.

Perhaps the primary theme which runs through is that Deafblind people are different.

I think they have a different understanding, different, not the same, just different. We communicate by signing, but deaf- blind people are different with their sense of touch and the manual alphabet. We can talk to a group of people, but deaf- blind people cannot do this - they have to talk to one person only and in turn. Deaf people can see everything, know what I mean? Deaf- blind people can only talk to one person at a time and it is always the same. (2)

It is this difference which comes up again and again.

5.1.1 Time

Deaf participants stated that for their chosen communication in sign language, speed and convenience were significant factors. For example, they were reluctant to use the textphone for communication with hearing people as it took too long to convey messages. Those who stated that their preferred method of communication was BSL also described its benefits in terms of quickness and ease. Some participants found it unacceptable to wait a number of weeks for an interpreter booking in order to have a medical appointment – preferring just to try to deal directly with hearing people in speech and by writing down.

Perhaps one of the reasons behind the reluctance of the Deaf participants to welcome Deafblind people into their community is the perception that the ease of communication is affected by the pace of communication when this has to be rendered in hands-on or in a limited visual field. It seems to take a lot longer to communicate with Deafblind people.

5.1.2: Trust and Familiarity

Some Deaf participants welcomed others when they knew their backgrounds or had been in contact with them for a long time. These kinds of relationships were seen by some as facilitating access through trust and familiarity and were positively viewed.

Not surprisingly then, Deaf participants would be more likely to support and include a Deafblind person with whom they already had established contact over time, or with whom they had had a friendship relation than they would with a new Deafblind person whom they did not know.

In contrast, the data indicates that many Deaf people would instantly welcome a Deaf stranger, indeed they would actively seek to meet new Deaf people, e.g. by travelling to different areas of the UK or abroad or professing an interest in learning new languages and cultures. It seems that some Deaf participants might perceive other Deaf people as automatically trustworthy and immediately familiar, whereas this connection does not appear to exist with Deafblind people.

5.1.3: Awareness

Some Deaf participants expected the hearing community to be aware of Deaf needs and capabilities and for the hearing community to take responsibility for ensuring its members were informed. This requirement on the hearing community of awareness of Deaf needs was often discussed in terms of Deaf rights and the lack of such awareness was perceived to be discrimination.

On the other hand it seemed to be a common perception amongst participants that it was the responsibility of Deafblind people or other authorities associated with Deafblind people to ensure that Deaf people had awareness of Deafblind needs.

Some Deaf may be aware of Deafblind but for me I know nothing as I have no awareness training nor meet, oh, meet a few but I don't know how to communicate so I backed off. I have no awareness to be honest. (2)

Deaf participants expressed an expectation that they would be provided with the means to increase their awareness so that they might adjust their behaviour or increase their understanding. In other words, it seems like a double standard was in operation.

5.1.4: Benefits of contact with Deafblind people

Deaf participants described the benefits of contact with other Deaf people in terms of identity and community life; the importance of BSL use and so on (Chapter 4). At the same time, there was an indication from some respondents that participation in the Deaf community involves commitment and obligation to other known and unknown Deaf people, especially Deaf children. This may indicate that the Deaf participants were willing to accept perceived responsibilities in return for perceived benefits.

By contrast, the data indicates that some Deaf participants perceived interaction with Deafblind people as being hard work, requiring patience, as time consuming and constituting a responsibility that they were reluctant to accept. There appeared to be no assumed obligation and responsibility to Deafblind others in the same way as towards other Deaf people.

We can't really empathise with them as we are different. Deaf people can get on with life and we have sight while deaf-blind people cannot. They have three senses left while deaf people have only lost one of their five senses. So I can't really empathise with them (14)

They do not regard them as being Deaf like themselves, and therefore they lie outside the circle of obligation. Some Deaf people mentioned the lack of contact and criticised other members of the community for the lack of engagement.

5.1.5: Complexity of the nature of Deafblindness and its definitions

There may be an issue with the questions used in the interview schedule or the nature of the delivery of the project explanation that we should bear in mind when considering the participants' perceptions of Deafblind people. For the purposes of this study, our definition of 'Deafblind' was restricted to those individuals who did not have spoken language as their first language – i.e. signing Deaf people who had experienced sight loss either completely or to a significant degree, or those born with a significant combined sight and hearing loss who relied on

tactile communication, possibly sign-based. Information about causes of Deafblindness was not collected within the project as it was not seen as relevant to this discussion. The key criteria was that participants were primarily sign language users.

However it is impossible to tell from the interview transcripts how effectively the definition of 'Deafblindness' was transmitted to the Deaf participants for the simple reason that this was done in pre-interview contact which was not video-recorded.

There is an indication that participants were aware of the distinction between those with Usher (a cause of Deafblindness arising in adult life and affecting sight) and others with Deafblindness (who use other forms of communication). It does appear that participants held the stereotype that 'Deafblind' people had a hearing loss, had sight problems and might use speech as a form of communication. Those who may have been sign language users and had partial sight were not necessarily identified as 'Deafblind.'

Given the unexpected negative response to Deafblind people, it is tempting to project the view that interviewees simply constructed an extreme view of Deafblindness. However, a fairer diagnosis is to consider that responses indicate an ambiguity in the Deaf community in regard to people with sight problems.

The most obvious reason for this would be the dread which is often expressed by Deaf people about the potential loss of sight.

Each don't understand each other, both ways. But if, my friend become Blind, maybe I give him support, try to encourage him, more involved. Because I know if myself become blind, I tell you to be honest, I would kill myself. I can't see myself how to be fit in... (2)

This extreme view is not unusual among the Deaf respondents.

5.2 Isolation

This concept is relatively simple to apply.

If I was in a room full of hearing people, yes I would feel lonely, as they would chat amongst each other. If they do come up to me and I have to chat, that makes me happy but when they chat amongst each other, I feel left out. If full of Deaf in the room, then I won't feel lonely, as all just sign away (1)

Deaf people view loneliness and isolation not in terms of lack of people presence but in terms of lack of meaningful interaction. This would be a meaningful insight if it could then be introspectively applied to the situation of Deafblind people in attendance in a group of Deaf people. However, this view was not expressed.

In a statement (used elsewhere in the report) a Deaf participant expressed the isolation from the community of Deaf people.

I became isolated for about three – four years. I bumped into a Deaf friend I know, she encouraged me to come in the Deaf Community. (2)

This implies that the isolation is not somehow a feature of the person's character (nor in regard to daily life around the hearing community) and can be temporary in terms of remoteness from peers. Isolation occurred when not in communication with other Deaf people.

When I am not communicating with Deaf people. When I was at school, the only one Deaf in a mainstream school, I felt alone. Same as when I was at college. If I'm with Deaf people communicating, then I am happy. (8)

However, some people also experienced what can be termed 'classic' isolation.

I just sit at home staring at the walls. I don't go out a lot. Some of my friends go out to the pub and get drunk – lots are couples – but I'm single, so it's a bit boring (10)

and its effects

I need people to talk to. It keeps my brain working. If I'm ignored or on my own at home too much, it makes me depressed. I need to keep my spirits up by talking to other people. (10)

It appears that Deaf people do consider isolation in terms of communication and not physical presence and are well aware of the consequences of finding themselves apart from peers. However, this was not developed as a topic for Deafblind experience and even in later group interviews, there was no sense of understanding that Deafblind people might experience these same feelings in a group of Deaf people at a club or event.

5.3 Independence

There are apparently contradictory issues in regard to independence on both the personal level and on a community level. On a personal level almost all respondents reject the notion of dependence. "I am able to do everything for myself" is a common response but at the same time people will accept disability benefits and service provision. The community is proud to be self contained with its own cultural expression yet at the same time will argue that it is marginalised and excluded. Reaching the heart of these contradictions is not easy and these interviews were probably not extensive enough on this topic to provide a full explanation.

The starting point was typically expression of personal independence.

I passed my driving test recently and I jumped for joy! I am independent and I don't like relying on my mother, asking her to take me food shopping! I am finally independent and I can now drive so it means that people can finally rely on me too! (13)

At the same time, this independence can be expressed in separateness and space for oneself.

I was by myself for most of the day, but I like my own space and independence sometimes and I dislike being with someone all the time. (13)

Sometimes, the independence can be seen as determination to succeed

I have to cope more in the hearing world as I struggle with my language support but I have got it, as I am determined. Before, my mother and father thought that because I am deaf I wouldn't be able to do things, but I proved them wrong. I wanted to show them and also for myself too. That is what I am proud of. (13)

When there is a suggestion that there could be dependence there is a sense of outrage.

What do you mean help? I'm independent, I help out, it's positive. I help the children, I drop them places I go shopping by myself if communication is difficult I would write it down to explain, like if an item is £2 or £3 but they charged me £4, I will explain, they say sorry and refund the difference. (1)

The sense here is of self determination versus dependence which is not altered by the use of external resources. People judge their independence by the extent to which they feel they can control their lives not by the resources they call upon from society.

In another case, the need to be assertive helped to locate problems outside of the person and to place responsibility on others.

I am an advocate for three years, I have to support Deaf people - never thought about myself. This job makes me more confident and assertive. Like if people tell me and I don't understand, I tell them it's their problem not mine. So with more confidence, I accept who I am, more myself. (30)

The interaction with people can then be seen as at least two-way but even at times, can be the responsibility of others to solve. This has become much more of a community view – that resources and Deaf awareness are the responsibility of others and not directly of the Deaf community itself. Deaf people do not view the Deaf community as having physical or financial resources (unlike other ethnic minorities, there are no agencies created from within the Deaf community to support other Deaf people or to promote language for example).

What we might conclude from this brief analysis is that in the end, Deaf people wish to be in control of the use of external services but never to accept them as 'help'.

I need them, the Interpreters, when chatting with hearing people. Like at work or at an Interview. I need them. But when without them I'm fine. I can cope, life goes on, I can cope on my own, in the world on my own, I can cope on my own, bills sort out fine, carry on, going out, on myself, I am fine. When talking with hearing people, I don't understand, then I need the interpreter, that's all. (3)

Interpreters required as part of the interaction, are not considered irreplaceable and Deaf people believe that they can cope.

5.4 Reliance on others

One of the crucial aspects of Deafblind life is the impact that a dual sensory loss might have on mobility and self care. The usual understanding is that Deafblind people have to rely on others. From what we know of Deaf people, and their responses in regard to the theme of independence, we can predict that Deaf people will reject the notion of needing other people to conduct their daily lives.

People typically assert their independence as predicted but there are also areas of reliance on others.

... she reads them for me (my daughter) if they're not important, they get thrown out. Sometimes she replies to them for me, by writing back or phoning on my behalf, for example – maybe it's from the DLA. She'll read it and help me because I wouldn't understand it. (10)

Some of the older respondents are more likely to need relatives.

Yes, I'd panic (if my wife was not around). If she wasn't here I'd ask other Deaf people what to do, who I need to contact, how do I contact them, then I'd go (to sort it out). (18)

Deaf people acknowledge that they help one another.

Well, both as I feel independent and support, both. Old people text me and ask me to get them a taxi, and I do so using the minicom. They do not have a minicom, only a phone, so I help them out, no problem by using typetalk. (23)

We can see that there is a layer of reliance which is not seen as having an impact on independence, but yet it is not something which is under control.

The specific area of problem is predictably text information and mail. In this case, Deaf people do rely on others. In some cases, they say they will just ignore text information which comes through the letterbox, in order to maintain their own independence.

Older people in the sample may themselves have or may have partners with physical difficulties and this results in the need for home care or other health services.

The other area in which others have to be relied upon is in case of emergency, car breakdown or similar, where typically hearing members of the family have to be used in order to obtain help.

These examples of need in regard to others are never expressed in terms of giving up independence. Typically Deaf people report being in control – ie positively asking someone to do something, rather than *needing* to be helped. In this way, the apparent obstacles to life can be reconfigured as manageable and as a demonstration of independence rather than as reliance on external help.

Chapter 6: Personal Circumstances of Deafblind People

We now move from the views of Deaf people to the transcripts of the interviews with Deafblind people. It is important to remind ourselves that these interviews were conducted by a Deafblind researcher, because we aimed for peer acceptance during the sessions. However, Deafblind respondents may not always be able to verify that another person is also Deafblind. Interviews with the Deafblind person where the sight was significantly impaired constituted a very unfamiliar situation for most of them. The interviews proceeded slowly and in some cases had to be spread over two sessions. These interviews were also emotionally draining for the researchers.

In the case of respondents whose sight problems were mainly in the limitations of the visual field, the interviews could proceed with BSL once the limitations of the visual field were made explicit. At the present time, all the interviewees are treated as one group but it may in future be possible to separate out the transcripts of those with no sight. The primary analysis of this data has been carried out by the principal Deafblind researcher (Barnett). In reference quotes, the link is usually to page numbers in the transcript rather than to the line numbers.

6.1 Independence

Deafblind people are often thought NOT to be independent. This gives us an image of Deafblind people being unable to do much for themselves, of being constantly reliant on others and of an inability to take control of their own lives. The participants were questioned on their perceptions of their own independence. The majority said they felt they *were* independent. However, this common self-perception of independence masks a variety of understandings of the concept of independence in this group.

6.1.1 Independence in Personal Care/ Daily Life.

'Independence' may be interpreted as the ability to manage a lifestyle without support.

mostly I am independent – I do everything myself (65)

Being able to manage personal care is usually understood to reflect a person's feeling of independence. Most of the Deafblind participants reported the ability to wash/ bath themselves (65). One participant stated that she needed additional help from her husband to get in and out of the bath because of a problem with her leg (76). The participant further explained that she was waiting for social services to provide a more accessible bath, so that she would be able to get in and out herself (and therefore achieve independence). The need for assistance from her husband arose because of her physical limitations rather than her Deafblindness. The participant also described how a guide would help her to understand the controls in an unfamiliar bathroom, such as in a hotel. But once she had been given this information she could continue the task alone - again achieving independence.

Some Deafblind people achieved some daily tasks for themselves whilst other family members took on other tasks such as preparing meals (54). It is not clear if this is simply a part of the division of tasks within a family unit or a particular result of the person's Deafblindness. However one participant explained that her husband did all the cooking as she did not feel safe in the kitchen (76).

6.1.2 Independence and Self Fulfilment

Independence was also shown to be understood in reference to how self-contained an individual felt.

Sometimes I like to be on my own, other times I like company. I can't talk to the wall. I need to talk to people. I have an independent mind but I like talking to people. (65)

Although she recognised the benefits of being with others, independence meant being able to exist and be content with her own company. The participant felt she had the strength of an 'independent mind' i.e. she did not need others to be able to live. Independence was therefore being perceived as the opposite to dependence/ reliance. Contact with others was for the purposes of company rather than to 'help' the Deafblind person in any way.

6.1.3 Independence in an Environment

'Independence' was also understood by participants to mean the ability to negotiate different environments. Deafblind people reported feeling independent in their own homes, as they knew where everything was (76). However outside of the home, Deafblind people's experiences varied. Some people felt confident in going out alone. (64) (78). Others felt confident in going out alone only in their locality or to places they knew.

Locally, I'm independent but if I go further I depend on other people (65)

If the environment was unfamiliar the individual required support. (90)

Similarly, if a person was going to a new environment for the first time, they required support. But once they 'knew the way' they felt confident and independent to go alone (52). (These issues are explored in more detail within the section on 'Confidence'.)

Independence relating to the ability to negotiate an environment may be a state which the Deafblind person achieves over time.

I would not go out on my own as before when I was younger as I always lost my way, It's better now with people together (56)

This participant was reluctant to go on her own in the past, but felt the situation was better now there were other people to accompany her.

6.1.4 Independence – being the ability to make a choice

Another aspect of 'independence' recognised by the participants in this study is the ability to go out when and where a person wants to. This is described as

Being on my own, feeling free, and I can do what I want to do, go out when I want to (68).

Independence means being able to act spontaneously, 'feeling free' to go out when it pleased as opposed to being forced to stay in because the person cannot go out alone. A person might choose to stay in. The important point is that he/she has the choice.

The 'feeling free' mentioned in this example may also refer to not needing a guide to go out, or to the sense of not being tied to anyone. In this context it may also refer to a state of contentment when alone. There is no one else to please and the person can do as he/she chooses.

6.1.5 Perceptions of Independence

Other people often think that Deafblind people who must use a guide are not independent i.e. they cannot negotiate locations alone. However one Deafblind person explained how he perceived the use of guides

If I want to go out. I just book guides. I can go where I want. It's simple. Yes, I am independent (54).

This participant gained his independence through the use of guides. It is as if the booking of guides is seen in a similar way that others might book a taxi. The guide was functional i.e. to take the respondent from A to B. The man still felt he was independent.

6.2 Isolation

The traditional view suggests that Deafblind people are isolated (as well as lacking independence). Deafblind people are seen as being alone, stuck in their own homes and having limited contact with other people and especially with other groups. This is commonly thought to be caused by communication barriers which Deafblind people face, and is also a result of mobility issues – the Deafblind person being unable to travel out alone and is consequently stuck in their own home. The resultant impact is lack of information about what is happening in the world which may produce further withdrawal

The interview aimed to explore the extent to which these issues applied to our sample group.

6.2.1 Isolation – Research Limitations

The traditional view of 'isolation' – i.e. that Deafblind people are stuck in their own homes was not supported in the case of this group. However our results are likely to be more 'positive' on this topic as those we interviewed, by their agreement to become involved in the project, demonstrated they were more confident and were on the whole, people who were *already in contact* with organisations and services for Deafblind people or those who have friends who were also Deafblind. Even the two people in the sample group who had never met another Deafblind person before - one had a Deaf wife, and the other a Deaf partner. Isolation from communication particularly, was therefore not likely to be an issue.

We were also able to ask participants about *their* perceptions of isolation

6.2.2 Isolation and Environmental Experiences

Earlier in this report it has been suggested that there is a link between a Deafblind person's confidence and being in a known environment and also a link between familiarity and environment. Sometimes Deafblind people find themselves in environments where such feelings cannot easily be re-produced. The resulting effects lead to the Deafblind person feeling isolated.

Sometimes if I am away at a hotel, I have to plan to travel through the day as I can't see at night. When night-time comes, I have to stay up in my room as I can't go out and I feel isolated (66)

Deafblind people plan their day around their normality – i.e. knowing their own abilities and planning the day to match their needs. During the day while it was light, Deafblindness was not seen as disabling. However a different set of factors prevailed once darkness had set in and the use of reduced vision, on which they relied, was no longer possible.

6.2.3 Social Isolation

As has been pointed out for Deaf people it is also possible to feel isolated even if there are many people around.

Isolated.....(participant thinking) it depends on the situation.... Maybe if I am in a group and everyone is talking. Sometimes I miss what is happening and I feel left out and can be isolated. (66)

This can apply to hearing people also; however, it is likely that for Deafblind people, this feeling is always present.

6.2.4 Choosing to be 'isolated'

Being apart from others was not necessarily seen as a bad experience. Just as with hearing people, time on one's own might be less stressful.

I like company sometimes I like to do things alone (90)

I feel peaceful...I feel peace and I am happy (78)

Choosing to be alone may be a reflection of an individual's own character or preferences at that time.

I have my pets, animals my rats. I have three. Also I have televisions and computer, all the things to do at home. I am not bored. Also at home, my garden, so I can go out gardening, I have everything. (6)

This example links to earlier examples of Deafblind people being 'self contained.' The Deafblind person had plenty of things to do or was occupied. Being on one's own was therefore not considered to be isolating.

The common perception that Deafblind people would feel isolated within their own homes was therefore not supported from the participants' perspectives.

6.2.5 Effects of Isolation as seen in 'Others'

Even if participants said they did not feel isolated themselves, they were often able to describe how isolation affected other people.

For other Deafblind people who live alone, it can be a problem because there is no stimulation for their brain, their thoughts become stagnant. That's what it could be for me if I was not married, my brain would become stagnant not be stimulated, brain would be empty (76).

Another participant linked isolation with not being able to see.

If you are totally blind you will feel isolated but its different for me, I can see ok, I feel positive about going out but if you are totally Deafblind maybe you will. (90)

Sight problems create lack of mobility and then lack of contact – this is what is seen as isolating for other Deafblind people. In this, we may be seeing some displacement of experience to other people.

6.3 Awareness of Physical Environment

We asked:

- How Deafblind people make use of different senses to perceive their environment
- How Deafblind people interpret this information, particularly how information perceived may bring positive or negative understanding of the environment
- Which other strategies they used to gain environmental information

6.3.1 Use of the Senses

The participants in the project had different levels of vision and hearing loss. Although the understanding of the environment was often affected by how much sight/hearing people had, varying environmental conditions often had a major impact on the level of sight which they could use.

6.3.2 Vision

The majority of the Deafblind people involved in the project had some residual sight. However, situations were identified where use of vision was not possible.

I can't see clearly if it is dark, I can possibly see shadows in the pub, but I can't see if it's a man or woman (86)

"I do not like to go out in very bright sun as see white. When I wear sunglasses I can see alright, but my friend always put his hand on my shoulder to walk until my eyes see better but in the shop dark again can not see well. (63)

As conditions reduce the possibilities for vision, there may be an increase in the use of touch.

I had some tests on my retina. They said I had a little change from last year. I think that is right, just a small change. It's a little worse. But I feel, now I walk around and touch things. I feel where I am going. (62)

"if it's hard to see because it is dark, then I might touch things to find out where they are" (74)

6.3.3 Touch

Touch is a sense traditionally associated with blind or Deafblind people. Touch can be used in different ways e.g. in hands-on communication or to explore and move around objects in the environment or to make contact with other people.

"I am not sure where I am. It's hard to balance. I use my hands to touch things and find where things are. When I am with a person I can feel them at my side" (62)

Although hearing-sighted people might equally use touch to feel their way when there is no light at all, Deafblind people are probably more aware of how they use touch or vibration and how such use is then interpreted. Another example

"Yes, we are in the same bed so I can feel if he is there." (76)

"Yes. I use touch to feel the music, if I'm sitting in a chair I can feel the vibrations of the music playing and I'm happy as I feel the beat of the rhythm of the music" (76)

Touch sensitivity can be both 'active' and 'passive.' A Deafblind person might actively reach out to explore the environment to feel what is around using the hands while kinaesthetic awareness may detect that someone is by close by – somehow even without direct touch. To some extent, this may be equated to peripheral vision in sighted people.

It will be obvious that use of the hands makes environmental sensitivity 'immediate'. For some Deafblind people, their awareness of what is happening in their environment is based solely on what they themselves can touch with their hands – their 'reach'. For them, sensitivity to the environment is very focused and individual. It relies on what is actively collected from this reach and what is remembered of that touch related to experiences when they had some sight.

Even though, some people are likely to stress the use of their remaining sight, touch is acknowledged as significant.

"Yes you're right- it's important because for example, my old flat was dark, I would arrive at the door and try to find the keyhole was. So yes its important, everything for example if I am looking at my clothes and I cant see, I feel them, I know which piece of clothing to choose" (68)

The way in which Deafblind people respond to touch-contact from others is examined in a later section.

6.3.4 Hearing

Since extent of hearing loss varied within the group, some respondents were able to use sound cues.

"I was born profoundly Deaf, but I have a cochlear implant. I had this ten years ago, so I am used to the cochlear implant. I wear this all the time. I can hear sounds; it makes me aware of what is happening around me." (67)

"I can hear noise, music, voices sometimes. Its difficult if there is a lot of noise from different directions I get confused." (64)

Sound cues might be helpful or confusing. Most of the participants did not indicate any value in hearing.

6.3.5 Other Senses

One participant mentioned an awareness of warmth.

"If I'm in a park its beautiful and I'm sitting relaxing I feel the sun on my face" (86)

It would be usual for a hearing-sighted person to report this feeling; however, for the Deafblind person the feeling of warmth on the face is possibly the *only* source of input for this person and that the whole construction of meaning has to be built on this perception.

6.3.6 Combination of Senses

Responses indicated, not surprisingly, that people used as much as they could sense, in order to construct meaning in their environment.

"So when I am on my own I do listen for sound and noises. Sometimes I can hear the PA or doors opening and shutting. Maybe the doors on the carriage are slamming shut. I just look around at normal things. I'm not really bothered, I just look around ... people are there. ... maybe at what station it is so I know where to get off." (64)

Much depends on residual sight to support these strategies.

6.3.7 Interpretation of Information

The reported use of sensory information is significant for everyone; however, for a Deafblind person it is the extent to which the available information can be related to previous experiences in order to understand that situation.

6.3.8 Augmented Lighting

Deafblind people may add lighting in some circumstances.

"When I am in bed its dark. I can't see, I use lights I have three. I have a light in the bathroom and two in my bedroom" (52)

"Sometimes we go to the pub, but it gets dark and dim, so I asked the manager if he could turn the light on and told him about my eye problem. The man had a good heart and turned the light brighter for me" (57)

Colouring the walls also has an impact on how people feel.

"I had a dark kitchen but now it's changed to a bright colour and also I know things like where is light, which is easy for me, same as my bedroom before dark now changed lighter for me. I feel a lot better." (56)

Other participants reported making changes to their home environments.

6.3.9 Obstacles at home

There may also be problems in the home.

"When my son is not there, I have to hold my hands on the handlebar. There is a light so that helps me see but sometimes there is no light, so I would have to move my hands across the bar to help me walk up the step. I have told the housing association about the steps and I have fallen over the steps - that I need to be re-housed." (57)

She continues

"I explained that I wanted to move to a house or flat and I told her that I have fallen over the steps in the dark especially in the winter, sometimes my son ran over the busy road and didn't wear his hearing aids and the car hit him. It's not a safe road, busy road" (57)

These are fundamental concerns of a Deafblind person related to mobility and danger. Service provision may not be sufficient to prevent withdrawal by the Deafblind person.

Fear of "danger" is something other Deafblind people also mentioned especially when touch was insufficient to re-assure.

"If I get up I might bump into things or fall over, it's not safe. It is better to stay sat where I am, because I don't know what is around. I reach out and feel to my left and nobody is there and then I reach out and feel to my right there is nobody there. So I am on my own. I reach out behind me and there is nothing there. This is quite frightening and there is nothing there. I might shout the name of my guide, the guide comes and I am relieved." (76)

This is perhaps, the ultimate environmental fear – where touch is either inoperable or is indicating non-presence of objects or other people. The fear arises from not being able to touch or make contact with anything around. Without physical contact, confidence in the wider environment drops to zero. Knowledge of that location can only be developed through physical reach. Without this, it becomes virtually impossible to be aware, or take control. Fear of this situation of lack of control commonly leaves the Deafblind person feeling vulnerable.

This fear is *never* relieved without the return of the communicator guide who may reduce the stress. However, this increases reliance on the guide to counteract fear of danger.

"If there is a fire or anything happens, I don't know, I'm just left sitting there. Nobody helps me. I feel frustrated and stressed and panicky. That's why I have a guide with me all the time so I feel safe." (76)

These scenarios set the role of the guide as the relief of stress.

A third Deafblind participant expressed similar sentiments:

"If I was on my own I would panic; I can't hear, I can't see and if I walk I would bump into many people. I would panic, so it's best if I am with somebody. I would feel comfortable and confident" (79)

Moving from one environment to another can also be threatening.

"My friend orders the drinks, I follow. I need time to adjust; it's bright outside, but inside dark – I feel disorientated." (86)

Similarly

"It's dark, I'm on my own and I don't like it. I can't see. I don't know what is there, if I can see it's fine, if it's black all around I can't cope" (68)

Another Deafblind participant described the tactics used within busy environments which might otherwise be threatening.

"I worry about bumping into other people. Sometimes I may decide to use an old newspaper and roll this up and hold it out in front of me as I walk, this is easy and works." (66)

One Deafblind person also gave an example of how some environments are not designed in a way which meets her needs.

“The glass door is not clear, would walk through but bump into it as I can’t see. There is the same problem in town, there is a glass automated slide door” (78)

The same person goes on to explain what she does in this situation:

“I would avoid it and find a door I can open myself” (78):

Avoidance is a common strategy. It is relatively easy to completely de-skill and disable a cognitively able person by choosing the wrong environment.

6.3.10 Other Strategies used to gain Environmental Information

Deafblind people may also use information provided through other people e.g. interpreters/ guides/ others. As yet, there is not a huge impact of technologies to support Deafblind people.

6.3.11 Information Provided by Others

Information about an environment may also be provided by other people. One participant explained:

“It’s different for everybody. Some people are happy, some are frightened, some are sad, some are not very happy because of their communicator guide. The reason they are not happy with the communicator guide is because they don’t explain fully what they can see around them; the environment.” (76)

Receiving environmental information is of central importance and this affects satisfaction with the guide.

“If it’s a new place, I’ll have someone with me. Well, it depends where I am. If the place is where I can sit down for a bit and the person explains the environment. I will then be able to handle fine and the person leaves. If it’s dark no. If it is daylight and interesting, I’d like to sit and wait – maybe walk around a bit while the person leaves for 5 minutes. If I have to wait for a long time, I’d rather not. Really it depends on the situation such as in the middle of the tube or dark places – I grab hold of the person, not letting him leave me alone.” (91)

In any new environment, reliance on the guide (or relatives) is likely to be increased.

6.3.12 Information gained through Technology

Deafblind people may gain awareness about what is happening in their environment through the use of low level technical aids.

“If my husband is there he can hear the knocking or the doorbell. If I’m on my own I have a pager like on Wednesday. I have a pager I can feel the vibration” (76)

“Yes I have everything; I have a fire alarm, for the phone, door bell. They will all flash”

Such technology is mostly unintelligent and not adaptable to the specific needs of the person. Service providers need to consider the Deafblind person's use of devices (rather than what such devices *might* be able to do).

6.3.13 Summary

There is a belief that Deafblind people only have a partial picture of their environment. However, Deafblind people actively interact with their environment as far as they can in order to create a subjective model. This individual model has to be understood by those who wish to support Deafblind people.

6.4 Imagination

As we have indicated in previous work Deafblind people use imagination as a dynamic tool for interpreting the environment and the interactions with other people.

6.4.1 Imagination and cognitive maps

Deafblind people build images in their mind to try to understand an environment.

"I imagine in my mind what its like and what's there....Imagine, its like I'm in the pub, I'm on my own and its dark, people are sitting around gossiping, hearing or deaf I don't know, I'm just sitting there on my own." (86)

Using the imagination in this way helps Deafblind people to place themselves within a context. Further to this the imagination is also used to help orient oneself within an environment and know what is around. A cognitive map is created. One participant explained

"I know where everything is. Everything has its place and I can recognise things easily. In the kitchen I know the kettle is there, and the pans are there, I know where everything is" (62)

Part of the skill in building such cognitive maps is being familiar with the organised part of the environment. This may be achieved by creating the environment oneself.

"I choose colours which suit my eyes, so I can see certain colours and recognise it easily. If its full white its too much. Its disorientating I can't see things. But a little colour added here and there makes it better and easy to see" (62)

Familiarity and preferences are vital. While most people organise their home space to their own liking, Deafblind people need this to be internalised.

6.4.2 Using the imagination and cognitive maps

Images created within the imagination are the stage on which interaction can take place.

"The guide might tell me there is coffee and tea there and where it is....the guide puts it down and tells me where, I have to leave it in the same place, if it is moved I have to slowly reach out and find it again when I bring it back to where it was" (76)

The Deafblind person uses her imagination to store the location of her coffee cup. This 'image' is then used when she wants to return to her cup, i.e. she remembers 'in her mind' where this is. The imagination used in this way creates a map based on touch and space perception.

Other participants reported using similar skills to complete everyday tasks e.g. being able to shop and know where to find things on the shelves through the use of memory and knowing where things were. (54)

One participant mentally added up the cost of items as he proceeded round the shop, so that he would know the right amount of money to give (54). In this way the Deafblind person feels in control as he is able to complete the task alone.

6.4.3 Imagination and Memory

All of the participants in the project had at least some level of vision at some point in their lives. An image of a known location from past experience may be projected onto a similar but newly experienced location.

"we walking to the car. The door is opened and she (the guide) puts my hand on the roof and the inside of the car and I find the seat. I know where the seat is. ...the door is far away so I have to lean over to shut it, then we are ready." (76)

The participant had a clear map of 'knowing' where the car seat was, and of the distance needed to lean over to shut the door. This was part of the image in her mind, built on past experiences. It did not have to be exactly that model of car, her past experience gave her the information to use.

Deafblind people may have an image in their minds of train stations and know there are trains/ platforms/ ticket offices located there. It is as if a prototypical projection is used to aid navigation.

"I don't know what the room is like, but I know we are going to the same place as we go quite regularly, so I know we have to go up to the top in the lift." (76)

By projecting previous experience on to the imagined, the Deafblind person creates a means to understand the navigation needed.

6.4.4 Summary

Not surprisingly, we find that prior experience is used to create the model of space required to support a Deafblind person's mobility. This appears to be a dynamic process and one with which guides and services could engage, in order to support the Deafblind person's independence.

Chapter 7 Feelings and Hopes

7.1 Emotions

Participants were asked to reflect on events which triggered a particular emotion or a change in emotion.

7.1.1 Reflections on state of Mind

As with Deaf people who were interviewed, Deafblind people stated positive feelings of present happiness.

"I have no time to be fed up, I am always happy." (56)

"I feel happy to wake up, every morning I wake up earlier and earlier. I am happy" (52)

The participant continues in response to question 'Do you always feel happy? Do you ever feel miserable?'

"Never, I am a happy person." (52)

"No, I'm very happy with my life, I enjoy life...I want more of life. That is a good thing. Yes I want more. If I didn't I would be a depressed person." (76)

It would be unlikely for interviewees to say they were miserable as most people have to function in the conditions they face. With a little more prompting, there was more reflection.

"It's hard; it's a very broad question. Anything. Different things make me happy, but it's a hard question. I'm not saying I'm miserable all the time, just different things make me happy" (65)

"I'm happy really; I just carry on with things. I would like my eyes to be better but I just carry on with it." (67)

Participants often found it hard to identify (or to disclose) factors which caused happiness or sadness. This may be an indication that Deafblind people are not used to reflecting on their own experiences – there is a lack of opportunity to talk to others in this way. However, the general response to the question was that Deafblind people claimed to be happy.

7.1.2 Factors which Trigger a Change in Emotion

Participants identified a number of factors which led to changes in how they felt. These can be grouped as:

- *Material factors*
- *Social factors*
- *Employment*
- *Personal factors*

7.1.3 Material Factors

Like Deaf people involvement in hobbies and activities is a source of happiness.

"I'm happy when I do photography; I watch football and play with the dog." (52)

"like sewing, card making, I want to be busy" (74)

Participation in external activities is reduced if guide provision is not available. A Deafblind person's happiness may be restricted by lack of appropriate personnel.

7.1.4 Social Factors

Extent of interaction, particularly in a family group, affected emotions:

"What things make me happy? Number 1, I have a wonderful wife. She's a good carer for me; she has respect, patience and puts up with me. I know some wives can be worse so I have a good wife and I have two good sons and a lovely home. That what makes me happy" (79)

"I would say I would be happy by telling myself I have a lovely family and a wonderful husband. My children, regardless if there were Deaf or hearing are important. A strong family unit, At the moment the family relationship is good. Some days – No! Would I say I am fully happy? No I would say 80% happy. It's not at easy job being a mother. There are times I just want to switch off. But I would say more than 80%, I am happy" (91)

Contact with others, friends and family who live further away was also mentioned:

"when I meet my boyfriend I am happy. I am happy all the time, I am happy to go shopping, or meeting friends, I am happy all the time" (69)

"I am happy when I meet my sister and we have a good chat, yes I am happy to see my family and my niece going to friends for coffee it's the company" (76)

Equally, lack of contact produces an effect.

"I am depressed if friends can't come" (73)

While it is to be expected that interaction with others is a key determiner of happiness (for all people), Deafblind people's experience is affected by failure of service provision to support their external mobility. The importance of guide provision was explained:

"Like last Friday I was going to Deaf club with Pete. He never phoned me. I was sad because I really wanted to go to Deaf club. I was sad because he never phoned me, nothing..... I was frustrated, I really wanted to go and meet-----" (52)

"If I am told there is no guide and I have to stay at home and I get bored with the same four walls, that makes me feel sad." (76)

When let down in this way, Deafblind people are left with no control over the situation and consequently, their mood is altered. A more positive statement about the relation with a guide seems to be based on communication ability.

"my guide, my best friend who is called Melanie, she can sign to level 2 before, she is hearing but can sign and I am happy" (52).

Not surprisingly, quality of interaction and consequent 'attitude' is significant.

"I like meeting with friends, particularly if they have a good attitude that makes me happy" (66).

Relationships are driven by the communication and attitude factors.

7.1.5 Employment

Unemployment was a factor mentioned more than once:

"My old job made me redundant, it was a difficult situation but that makes me sad" (66)

"sometimes I am happy and sometimes, I'm depressed. But really I am bored by not having a job and really that is quite depressing." (73)

Employment was seen as a positive experience and is sought after by Deafblind people.

7.1.6 Personal Factors

Some Deafblind people mentioned issues relating to their eyesight as affecting their happiness.

"I feel sad and depressed about my eyes. I remember in the past I used to be able to see well. I could drive, and I was at university and I passed a lot of exams. It feels like a waste now and that makes me feel sad." (69)

There is a sense of loss in this case.

7.2 Feelings of Confidence and Control (DB7)

The data from the interviews revealed a complex picture of differing experiences which could affect how confident a Deafblind person felt.

Confidence is not an immediate state of mind. It is a state which has to be achieved. The data revealed different ways in which Deafblind people developed feelings of confidence. These can be examined:

- Confidence and Self-Assuredness
- Confidence and Familiarity
- Confidence and Gaining of New Skills
- Confidence and Communication
- Confidence and Contact
- Confidence and Support from Others

7.2.1 Confidence and Self-Assuredness

Confidence can result if a person feels totally happy with their life and situation in which they find themselves. One Deafblind person expressed such feelings

"When I wake up, I feel quite confident and happy. I think about my plans for the day" (64)

"Well, if my friend goes off and I am left on my own, really I am happy and confident. I'm not really nervous. I can see what is happening so I am not really nervous." (64)

For him, his ability to see (at least something) plays a part in this confidence.

7.2.2 Confidence and Familiarity

Another way in which Deafblind people feel confident is when they are in a familiar place or when undertaking a familiar task.

One participant mentioned feeling confident if she had to travel (67). Another participant identified feeling confident when he was able to get out with his dog in **the park (1G, P.14, 903-908)**. Some participants were able to identify particular situations in which they felt confident. A common response was personal confidence when in the participants own home (52) (64).

Another person said

"Yes I am confident, I can achieve. It's nice. I like relaxing in the house by myself. I'm not lacking in confidence and I am not bored, also I can cope" (54)

This Deafblind person clearly links a sense of achievement with confidence.

7.2.3 Confidence and Gaining New Skills

One participant referred to being able to attend college as a specific way his confidence was being built up (52). A second person explained

"Now I am okay, before it was bad, I didn't want to go out, no social life but now I stand up for myself, try to learn, and not to feel sorry for myself. Now I go to college to learn English, go to Deaf club etc." (1G, P.5, 876-879)

The gaining of new skills is further way confidence can be achieved.

7.2.4 Confidence and Communication

Being able to communicate with others is another way identified as generating feelings of confidence (65) Particularly being able to communicate through sign language (52) **(1G, P.52, 662-663)**. When other people are prepared to adapt their communication, this has an effect.

"When other people have learned hands-on and they come and talk to me, it makes me confident, happy in myself. It's good, nice, fantastic. I taught them hands-on and they come and talk to me" (54).

The Deafblind person is empowered by being able to pass on his skills while the willingness of others to learn reinforces the Deafblind person's confidence and self-worth.

7.2.5 Confidence and Contact

In addition to the importance of communication, one participant referred to the importance of contact with the Deaf community in general.

"What makes me feel good? Having connection with Deaf people. They are like me, Deaf like me. So we all have the same wavelength, including my husband. My friends and I gossip, without them I would feel

lonely...maybe, starved, needing news from them ... it's Deaf culture to know what is going on in Deaf community and having a good rapport with Deaf people, intermingling and socialising". (54)

This was our starting point in the research work, but most of the participants felt there was a gap between themselves and the Deaf community. However, contact with another was a priority:

"I need to communicate to another person to express my frustrations, to get it out, if I feel listened to my confidence comes back" (65).

This pushes us towards the notion of isolation when contact is lost.

7.2.6 Confidence and Support From Others

Some participants mentioned needing other people around to be able to feel confident.

"If I was on my own I would panic, I can't hear, I can't see and if I walk I would bump into many people. I would panic, so it's best if I am with somebody. I would feel confident" ?????

The presence of guides was particularly mentioned (52) (73)

Friends of the Deafblind person may also have an influence on the Deafblind person's confidence. One participant explained:

"The first time I went to Deaf Usher weekend in Leicester, I felt so stiff because I have never met people before (presume means DEAFBLIND people). Deaf people encouraged me to go and tell me that I should go, enjoy myself and get more information about DEAFBLIND. I travelled myself to Leicester and was nervous as I have never met these people before. Then the meeting started, I went in and saw you (the interviewer). I was happy and shocked to see you there. You talked a bit and I picked up information" (57)

This example shows some of the reasons Deafblind lack confidence, but also describes how Deaf friends were able to encourage the person and therefore give confidence. It also again refers to the need and benefit of meeting others with similar experiences.

7.2.7 Confidence and Control

The data also gives examples of how Deafblind people feel confident when they are able to take control. In a situation when booking a guide, a Deafblind person describes:

"That's why I think it (the guide) would be better if it was someone I know well, a friend, I can ask them if they agree they could work for me and that way I have control. It's a balance" (62)

The Deafblind person feels happier and more confident when she is able to take the lead on who is used as a guide.

Another Deafblind person gives an example of how confidence may be lost initially, but this is restored once the person takes control of the situation.

"For example, yesterday I was at a party and some people ignored me. I explained I have Usher but they ignored me, so my confidence went down. But I have to remember that person has the problem not me. I just

have to ignore it. Some people accept and it's fine, I will teach them and they become confident. I help them, other people have problem with attitude" (86)

After taking control, the Deafblind person feels able to install confidence in others.

"I'm fine. I always arrive at the reception ... and I would say excuse me I am Deaf, please tap me and let me know when the Doctor is ready. The lady said fine. Then I would wait until I was tapped and they told me that the doctor is ready for me". (57)

"Well the Doctor is aware of Deaf/ Deafblind people, they don't come over and tell me, tap me. There's a screen up above with a name that comes up. With (participant's name) and the door number I have to go to, so I get up and go, the screen is quite big so I can see" (69).

Because the environment was accessible the Deafblind person was able to feel in control of what was happening.

7.3 Feelings of Insecurity

An earlier section of the report examined situations in which Deafblind people expressed feelings of security and confidence. This section considers examples of situations in which Deafblind people feel less secure.

The data revealed Deafblind people expressed feelings of insecurity in different ways. Feelings of insecurity can be a very personal response resulting from feelings of anxiety or fear. Insecurity may also result from situations in which a person feels vulnerable as a result of perceived danger. A third possibility is insecurity resulting from situations in which control is lost.

7.3.1 Unknown Environments

In unfamiliar settings, problems may arise:

"I remember a time that happened before. I am a strong independent person. I wanted to go to a new area, I was a little uncertain, and would have preferred to go with someone but something happened and they had to go. But I was trying to be confident and I thought I could do it. If I went to the wrong place, I might be sitting there and thinking this is a different environment, I would realise I was wrong and try to call my friend back. In that situation I will panic. (69)

Deafblind people there may be reluctant to go to unknown places. For some people this may prevent the individual going out at all. The participant below reflects on experience of others.

"some Deafblind people like to go out but it depends on the person, Some people are frightened. " (76)

Another participant described being in an environment in which access was difficult.

"Its dark, I'm on my own and I don't like it, I cant see, I don't know what's there, If I can see its fine, if its black all around I cant cope" (68)

Disorientation in darkened surroundings is something which sighted people can understand but it is likely that such feelings and insecurity are heightened for Deafblind people.

Deafblind people may use strategies to gain information about the environment.

"If I get up I might bump into things and fall over, it is not safe. It is better to stay sat where I am because I don't know what is around. I reach out and feel to my left and nobody is there and then I reach out and feel to my right and nobody is there. So I am on my own. Then I will reach out with my left foot and there is nothing there. I reach behind me and there is nothing there. That's quite frightening I feel insecure. I might scream for help or I shout the name of my guide." (76)

This difficult situation confirms that it is this 'near' information which is of most use to a Deafblind person i.e. physically being able to reach out and touch, and gain information about the environment. The 'distant' information is provided by a guide.

7.3.2 Other Things Happening in the Environment

The actions of others can affect the well being of the Deafblind person.

"I don't mind if people gently tap my arm, but if they come roughly bumping into my arm, I think this is rude. That frightens me, I don't know what is going on or what happened. I panic and ask my guide what happened. The guide tells me the person who bumped into me said sorry, I say ok, and I'm relieved and calm down." (76)

"if I am sitting down I might look around and check nothing around me and then a person bumps into me suddenly, I am shocked. I think it's a strange woman. I am frightened. I am relieved when someone comes back again." (1H, P.1020-1023)

Unexpected collisions can create feelings of fright and panic. The Deafblind person is unable to predict the possibility of this happening i.e. they do not see the person approaching and therefore are not prepared for this intrusion upon their 'space'. The event of collision is unexpected and then also unexplained as the Deaf blind person does not hear or see the apology, nor the person moving away.

7.3.3 Perception of Self within the Environment

There may be some uncertainty about how other people perceive the Deafblind person.

"I stay sitting and wait. I never move.....I am a little unsure...I worry about myself and other people looking at me" (52)

"maybe people looking at me and think why is she on her own maybe they don't see me at all. O don't know I just don't feel comfortable I just prefer to be with a guide." (90)

The sensation of being watched is understandable and is probably a concern of blind people. It may be a factor in feeling vulnerable.

7.3.4 Vulnerability

Insecurity is a strong sensation for some.

"If I don't know who is coming and someone comes into my home that I am frightened and I worry "who is it?" as they may be a burglar or a thief. That's the problem when I am alone. In this situation I lock the doors." (76)

This may tend to give credence to the stereotype of Deafblind uncertainty.

7.3.5 Aloneness

The vulnerability and insecurity is also linked to being alone.

“well because it would be strange being by myself. There would be no one to talk to; I would not be able to access the phone, or use e mail..” (76)

“If I lived alone I would get quite down and depressed and I would worry.” (76)

“when I am in a waiting room, I’m nervous because I am on my own” (64)

These issues are almost certainly the driver for control. The more control, the less likely insecurity, vulnerability and aloneness will affect the individual.

7.3.6 Control

Loss of control produces these feelings of insecurity.

“Do I feel I have control? No I don’t feel I have control because I have to look up to know what is going on. I find this quite stressful. Its not only the doctor. I remember one time I went to the hospital for an appointment there and I had to keep looking at the number on a screen. I couldn’t read my book, I was there for 40. 50 minutes maybe more one hour and I had to keep my eyes in the screen constantly.” (66)

“So I am waiting and worrying and not in control about what is happening, The interpreter has to keep asking people or has to tell someone to let us know what it is my turn” (76)

Trying to monitor the visual display or continuing to ask the guide, makes the Deafblind person feel more dependent. This is heightened when the environment is not supportive.

7.3.7 Concerns and Worry

Taking all these negative issues together, the Deafblind person can become a worrier.

“I feel I would like a different life, but at the same time I’m happy. I mean I don’t like to be miserable or stressed. I don’t like it when things are difficult. I worry about that. I don’t like the pressure of things of everyday life. I might worry about my money, health and different things about the shopping, If I can find a job and different things. That can be quite stressful to think about.” (64)

Balancing the positive to support happiness, with the uncertainty which produces worry, may be difficult.

7.3.8 Communication / Meeting New People

Some Deafblind people will only meet people alone within their own home.

“Its easy to meet people I know at my home when I know who is coming, if I was outside I wouldn’t meet a new person unless I have my guide” (76)

Unfamiliar surroundings combined with unfamiliar people, seems to be something to be avoided. Poor communication makes the meeting of new people more of a problem.

"If I meet a hearing person, so they come up and say hi, I maybe try and lip read them but I don't understand. My confidence goes down, they can't sign" (52)

"I wouldn't meet people alone, I would be with a guide but if I was alone and a strange person came up I would feel apprehensive and uncomfortable about meeting a strange person and wouldn't know how to talk to them. But I would talk to a stranger if my guide was with me and they showed the person how to use block on my hand." (76)

Reliance on the guide provides a defensive front for the Deafblind person without which there is considerable apprehension.

"I panic and gesture for them to communicate via my hand. I also put my hands over my ears and eyes to indicate that I am Deafblind. So if the person uses their voice to talk to me I panic as I wouldn't know what they were saying, so I hope there would be help around. If my communicator guide stays with me; they would explain that I was deaf and blind so I would not need to panic." (76)

Lack of response in this situation may provoke a negative reaction from the other person.

"if people talk to me they will think that I am ignoring them but I don't know what they are saying, I cant see. Then they might tap me suddenly/ aggressively on the shoulder to move me out the way. They don't realise that I am Deafblind." (90)

The lack of understanding by others creates the insecurity and stress.

7.3.9 Insecurity in relation to Future Events

Some concerns may be projected on to events which have not yet taken place.

"In my own home, yes I think I feel confident but at the same time I worry about things. For example, what would happen if there was a fire or if the water burst. At the moment there's a problem with the roof gutter and water leaks through. I need to phone a person to come and have a look and tell me how much it will cost to repair. Because my mother has been ill, that has been put on one side. So in some things I feel confident but at the same time I am aware of things that might happen like my mother might move the furniture and bumps into it and there's an accident. Because I did not see it and I did not know it was there. So all the time for 24 hours a day I feel confident but at the same time I am aware of things which might happen" (64)

"If I go out, that's different I feel more nervous. I feel confident yes but at the same time I am always looking around looking for what might happen. I am worried about having an accident; bump into things or tripping up a step. There is more risk. So yes I feel confident to go out but at the same time I feel quite stressed because of the risk" (64)

A great deal can be explained by the need to have some control and that appears to draw upon the knowledge of the surroundings and the people who inhabit the space.

7.3.10 Summary

What we see most clearly here are the negative aspects of Deafblind experience. Insecurity, vulnerability, aloneness are major stressors. Service providers often choose these as justification for intervention and allocation of the guide to protect. From a Deafblind person's point of view, it seems more significant that the importance is to be able to control the situation.

7.4 Future Plans/ Dreams

We asked about the future. This proved to be a difficult area. A number of themes emerged:

- Hopes and plans for the future
- Being Deafblind in the future
- Issues identified which limited future plans

7.4.1 How Deafblind People Reflect on the Future

Deafblind people dealt with the issue of 'the future' in a number of ways. Some participants could identify plans and hopes they had for the future. Other people expressed contentment with life – they were happy to continue with life as it was.

I am happy... it's improving...its improving (his life) because I am going to college and its building up my confidence, (52)

"I feel better and happy with the future. The future is good. I go out everyday. Work is done and I bump into people and chat. I chat everyday which is good. Work can be stressful but I'm done with it now. I feel better with the change in my life" (58)

Other participants expressed similar sentiments. (90), (52).

These responses seem to cling to the present, as the expectation for the future. One response appeared not to have thought about the future at all, (57) or to have only a limited time span eg one year ahead. We can speculate that this relates to the uncertainty we identified earlier.

Another possibility is that Deafblind people are used to being recipients of service. The options which are given to Deafblind people are limited by what is available ie the choices made by others, possibly without consultation with Deafblind people. Deafblind people's own thoughts about what might happen in the future are therefore constrained by what they are offered.

A further reason is that Deafblind people may have through life experience, developed a 'learned helplessness.' Deafblind people have not been encouraged to hope or dream or plan and consequently thinking about the future is not something they have been asked to do before.

7.4.3 Hopes and Plans for the Future

Some participants identified specific plans or hopes they had for the future. Often the aims were related to personal achievement.

7.4.4 Person Centred Aims

Participants identified a variety of aims which related to personal achievement and also to changes they would like to make to their own circumstances. People mentioned Photography (52), Woodwork (74) and Computing (69). Other aims included a desire for a new job or change in job; e.g. getting involved in filmmaking (52), becoming a manager or teacher (83), (68). Getting involved in a particular activity, bingo (78) diving (68) or sport in general were mentioned (79). Visiting a specific attraction such as visiting art galleries (91) or the cinema or pub (73) are further options.

Deafblind participants also expressed the desire to increase their social circle and meet new people (58), (57).

Changes in living circumstances were also identified. Some participants stated they wanted a new house, often a bigger house, (67). Some had some very clear ideas related to their homes.

In the future I want a house so I can do freelance work. Set up my own business for clients. I have plenty of ideas. (67)

"I want to move to a bigger house, I like this to be in a good location near to shops and near to friends and family. At the moment they are too far away" (66)

"Why is it important to be near? Why have a difficult life? I want things to be easy. I want to be near shops so the access is good. I need food everyday so I don't want to walk a long way carrying heavy bags. I also don't like it taking a long time to travel anywhere. I would like somewhere where it's easy to get home, near the tube, I would like a swimming pool!" (66)

One person expressed a desire to live on her own (73). Plans for travelling (64) (66) (78) or holidays were given as thoughts for the future (74) (83).

These do not seem to be different to the responses we would have from the general population.

Learning skills such as learning Deafblind Manual or Braille were identified. (79)

Another response was more extroverted.

"I want more of life that's a good thing, yes I want more, if I didn't I would be a depressed person... (participant continued) "its difficult to explain, yes I would like more but if somebody tells me its finished, I think 'oh' its over and feel disappointed" (76)

"I want new and exciting things to happen in my life. Like I might want to go for a meal, or meet with my friends. I enjoy doing this. I also like it when I go travelling as an examiner or I look forward to meeting people again" (76)

In this case, it was her own personality which was driving her thoughts for the future.

7.4.5 Hopes requiring others to intervene

One participant reflected on what she could do to encourage other Deafblind people to achieve.

"In the future I would like to achieve.... I want to tell other Deafblind people to stop being frightened, be positive and carry on. When you are blind things don't really change because of things like for example computers can be through Braille or you can use scanners and there are other things, I would like to teach them that they can achieve in the future." (69)

Participants also hoped for changes in society. One example is a desire that everyone should know sign (67) or should be able to call upon interpreters (76). Another person mentioned the provision of a communicator guide.

"In the future I want to go out, I want a communicator guide to be with me when I go out. To meet friends to go out, to do what I need." (64)

These hopes for better conditions for Deafblind services was not uncommon but there were often issues which might prevent this, even if a person's own situation was to improve.

7.4.6 Being Deafblind in the Future

A number of responses specifically focused on how participants perceived themselves in relation to their own Deafblindness. The desire for improvement to eyesight or a cure to be found was particularly evident.

"In the future I hope to see clearly, that's what I hope for. At the moment I have tunnel vision, I hope in the future I will have full vision." (54)

"it would be good in future if my eyesight was better, but also if my balance was normal, but that's it." (67)

"I would like a more secure job and know I can get the right services and equipment. Everyday things Deafblind people want. I would like to have normal vision, but at the same time I accept I have Ushers. So I try to change the negative into the positive. Really I learn different things everyday. So when things get worse I know how I can improve things, how to overcome problems" (64)

"I am happy with life and improve but if my eyes problem also I always worry about my eyes, What will happen in the future I pray that my eyes will carry on the same but I don't know what will happen in the future I have to be brave for myself." (63)

"My sight has been the same for a long time, I have to put up with it, I use hands-on.... I have to put up with the problems of watching T.V. and with the light, and I have to use a guide dog. Its like a person who is ill, you have to put up with it. I want full sight; I'm waiting for it to happen. Hopefully one day in the future a doctor will find a cure and have full sight again, I don't know." (54)

"I have got used to my life for a long time, so I don't want to change it, only need brand new eyes" (65)

There appears to be a fine balance between an acceptance of the current state so that day to day life can go on, yet there is still room for hoping that the situation may change and vision might be improved.

7.4.7 Issues Identified which prevented Hopes and Plans being achievable

There were also obstacles to achievement.

"I wanted to go swimming, the one near the University because I have not been there for ages, But my sister won't go because she is embarrassed for her body. I cannot go I need someone to come with me..... last year or two years ago I went jogging but I am not very good at breathing and also I am frightened of being murdered. There is a park behind my house with big field, I am frightened someone would come up behind me and I wouldn't hear them and they would murder me. I rather have someone with me for company" (57)

Personal security is of some concern, if the person was to be alone. Needing to rely on other people and the issue of safety appears in the responses.

"I wish I could go on holiday abroad but my friend let me down, I was very disappointed and my son too. I told my parents that I want to go on holiday with my son to Spain but my father said no because July and August is a very busy time of year and get overcrowded. My father said it was not safe for me but I need a break from home. I wish I could go on holiday so I have to go somewhere in Britain"

Not being able to drive was also an obstacle to doing what a person wished to achieve (91).

The loss of vision can also have a direct impact on what individuals might want to do.

"I can't play bingo because of my eyes. Also I really love table tennis. But my eyes are the problem, with table tennis the ball is a problem. There are some other things, I love knitting and sewing and drawing but my eyes are a problem" (62)

"I would love to work but I am not allowed to. My doctor told me I can't work, and I can't go on flights when on holiday" (79)

Another reason hopes and plans may not be achievable is pressure on an individual's time.

..like more time to myself, for example like you said to go swimming or to the gym, But I never feel I have the time to organise it other things just happen and I go running all over the place. Those are the things I would like to do if I had the time but I'm too busy" (64)

Although some Deafblind people were upset when asked about the future (since they saw it negatively or they saw it as out of their control), there were still a majority who had plans and would attempt to overcome the obstacles.

7.4 8 Summary

Deafblind people like everyone else think about the future. There are many who have plans to change their lives or to take on new skills. However, the scope for planning is limited by the level of *appropriate* service provision. It was also clear that for some Deafblind people the future was "the present" and the idea that there could be growth and development was hard to imagine. This was distressing for some of those interviewed. We suspect that the lack of someone to talk to about hopes and dreams and about the practicalities makes this a much more difficult area for the Deafblind person.

Chapter 8: Other people

8.1 Contact with Deafblind People

We have already considered some aspects of isolation from society as a whole. Now we turn to opportunities and experiences for Deafblind people when contact is made with other Deafblind people.

8.1.1 Opportunities for meeting other Deafblind people

Deafblind Groups Groups such as Usher UK, which met 4 times a year was mentioned by some as an occasion when they met other Deafblind people (65). Another person mentioned a group which met in his locality but has since stopped meeting (52). Meeting Deafblind people at the pub occasionally was mentioned, as happening 3 or 4 times a year (66). One participant said she was not involved in any groups for Deafblind people but did go out with Deafblind friends (90). Apart from her family, her Deafblind friends appeared to be her main social group.

There are some instances of families with Deafblindness. In one interview a Deafblind woman described how she was out with her guide and met her Deafblind sister in a shop (also out with a guide) (76). The significance of guides in this situation is examined later.

8.1.2 Starting Conversations

Meeting and starting a conversation with another person requires certain customs to be observed eg gaining attention, shaking hands and so on. For Deafblind people there are added complexities for example, of even knowing whether a person is there in the same space and also of determining a mutually appropriate communication method, once a physical contact is made. Participants were questioned about how they began conversations when meeting another Deafblind person and we explore the responses in the following sections.

8.1.3 Issues in meeting with other Deafblind people

Deafblind people who are BSL users may not necessarily be experienced at using hands-on signing with other Deafblind people. However in order even to begin, the two Deafblind people have to meet.

It is likely that guides will *bring* Deafblind people to meetings. Interpreters may then be used to facilitate communication and inadvertently become the mediators between Deafblind people. In such situations, Deafblind people may not know that another Deafblind person is the originator of the message or even when it is known, the Deafblind person may not be able to locate the other, in the room.

This means that Deafblind people may not experience communication with each other, directly – even when they are together.

It can also mean that at a meeting of Deafblind people there can be more interpreters and guides (who are often hearing-sighted) than Deafblind people (90). As a result, the communication may be initiated and mediated by hearing-sighted people and Deafblind may not have the opportunity to connect directly.

This is very different from Deaf people' experience where they share the same issues of mediated communication i.e. through an interpreter, but not usually without the power to initiate communication in the first place.

Another issue is that Deafblind people are not used to communicating as a group. One participant explained that there had been a group of Deafblind people that used to meet regularly in his locality but this closed down. He explained that he found the group to be boring (54).

Deafblind people have not traditionally been encouraged to socialise as a group in the same way that Deaf people have. This may be partly because Deafblind people often live in isolation from one another; travelling outside of the home is difficult; and even communication preferences may be different. Deafblind people may not have the opportunity to develop the conventions to interact as a group.

In our group meetings, Deafblind people were given tasks to encourage direct sharing with each other and to encourage group interaction. However once the formal part of the meeting ended and we had a break for drinks or lunch – it was noticeable that the interpreters/ guides immediately resumed their role in assisting and communicating with the Deafblind person. All further spontaneous communication between Deafblind participants was curtailed. The interpreters/ guides just assumed a role that they were used to, and the Deafblind people accepted this as the norm.

During the interviews some participants reported difficulties which arose when meeting a Deafblind person who used a different communication method from BSL. One participant remarked she did 'not want to bother' (62). In such situations, a communicator guide or interpreter may be used to facilitate communication.

As one might expect compatible communication is necessary but there seems to be no conventionalised approach and even among Deafblind people there may be resistance to compromising around BSL or Deafblind Manual or hands-on.

This strikes at the heart of our project aims since the expectation would be that users would naturally share or at least negotiate a shared communication.

8.1.4 Summary

We are faced with a largely unexpected situation which impacts the very nature of human communication. The fact that people are Deafblind means that others intervene to meet perceived communication needs but in doing so may isolate the person from the peer group which is so important to social development.

8.2 Contact with Deaf People

The Deafblind people who took part in the project were all BSL users, (or used an adaptation of BSL such as hands-on signing). Some Deafblind people maintained contact with Deaf people and the Deaf Community. These were usually those with the greatest residual sight. For other Deafblind people contact proved to be more difficult.

8.2.1. Positive Contact with Deaf People

Deaf gatherings at pubs, rallies, weddings were cited as places where Deafblind people meet with Deaf people (66) (52) (74). Deafblind people see this communication compatibility as the priority:

“Deaf, alright, hearing there are problems with communication.” (65)

“easy communication, we can relax and have a laugh, you can relax” (66)

“because I can communicate in sign. I feel confident” (52)

Another interviewee also made the connection between the importance of shared language and personal well-being:

“I meet lots of people, its good for me.... when other people have learnt hands-on and they come and talk to me, it makes me confident, happy in myself. It's good, nice, fantastic, I taught them hands-on and they come and talk to me” (54)

Deafblind people may have to ask Deaf people to alter their signing styles

“I say hi, I am Deafblind please don't sign quickly, please sign slow. I am blind half so I need them to communicate where I can see. They say they understand and sign slowly.” (52)

As long as an adjustment can be made, Deaf blind people can interact.

8.2.2. Issues Preventing Contact with Deaf People

Other participants reported not attending Deaf club. Reasons for this included “it's boring” (90, P. 65). Interviewees also reported occasions when relationships with Deaf people proved to be problematic.

“If other Deafblind people are there...Deaf just ignore. Deaf may say hello, but that's it then they go off. They are not included, its not the same.” (meaning Deafblind people are not included) (90)

There are a number of reasons which prevent Deaf people involving/ interacting with Deafblind people. It may require an additional adjustment. However, it also seems that there is lack of understanding of the communication choices of Deafblind people.

“they panic, they think I cant do Deafblind manual so its better if another person goes and talks to Deafblind. (90)

“Deaf people don't seem to ask Deafblind people to go out. Deafblind are happy if someone asks them if they want to go out.....Deaf people never ask Deafblind 'come on lets go' its mostly hearing people who ask, like their mother, their sister, their friends will ask” (77)

There appears to be a psychological barrier here. Deaf people are unused to taking the lead and tend to avoid responsibility of this sort. Deaf people may be put off by the presence of (“bodyguard”) guides (possibly hearing). Deaf people may think because the Deafblind person is with a guide, they are ‘OK’.

However, a stronger interpretation is that Deafblind people are being viewed as 'disabled'. This seems likely.

8.2.3 Perceptions of Deaf people's Understanding of Deafblindness

Deafblind interviewees were questioned on whether they thought Deaf people understood what it was like to be Deafblind. There were a number of significant responses.

"Not really. They are aware I have Ushers, but they don't understand the issues, this can become a problem for friendships – they treat me like something that is not right. I'm shocked. They don't understand. It's a lack of awareness" (66)

"Deaf get into a group signing and having good Deaf chat. The Deafblind person is left out of this and is alone. I think this is Deaf attitude. Its not good." (90)

"They say they understand but they don't fully understand the experience. Because they don't have the experience themselves..... for example at the pub in a group, I'm the only Deafblind person there, the other people are Deaf. They are all signing to each other they forgot about me. I try to stop them but they say it does not matter." (65)

Deaf people are seen to have only a superficial awareness of Deafblindness. At times they are considered to be pre-occupied with the visual impairment, rather than understanding the need for social interaction. Whenever adjustment is requested (to include the Deafblind person) it is seen as a chore and one which is not welcomed. One can argue that this repeats the circumstance of hearing people not adjusting to Deaf individuals.

The 'Deaf attitude' described in the example above. (90) is further explained

"they come over talking and feeling around, but they are just like 'pests'. Like touching all around and saying 'you alright' in a patronising way, its like at the football. I cant be bothered."

"another time I was on a table full of people.... The next table was empty, we said to someone that they could sit there that's fine. But no they went off, it was a waste. They didn't want to be near Deafblind. I felt really angry with them. It's that attitude again. It's not good" (90)

A number of references were made in the interviews to the desire that Deaf people *should* be able to communicate with Deafblind people, particularly using hands-on

"I think Deaf should...they know...because it's the same, signing and hands-on...its natural. I never learnt how to do hands-on, I just did it. They might need to ask someone and check they can see, but this is simple. But other Deaf panic and withdraw. They might be unsure about Deafblind manual, they might be embarrassed if not very good English. But they could learn, simple short fingerspelling. But BSL is simple. Deaf already know this. But Deaf feel embarrassed" (90)

"At first they are shocked that I am Deafblind and are a bit nervous at first about my communication. Then I teach them and they can improve their hands-on. They says thanks and they improve."?????

This nervousness and lack of understanding seems to create the barrier.

8.2.4 Summary

Our simplistic assumption that Deaf and Deafblind would have some common experience that they would be able merge and communicate is not supported. Deafblind people see a barrier between themselves and Deaf people.

8.3 Awareness of others

Literature focussing on how Deafblind people become aware of other people within their environment often places the focus on the person's ability to use residual hearing and sight to gain information. They may rely on guides, who describe the people in the room and what they are doing. There may be other sources of information.

- Awareness of others through direct contact.
- The way in which information is provided by guides, enables Deafblind people to become aware of others.
- The 'Deafblind friendliness' of the environment i.e. how familiar are the other people with Deafblindness.
- Control i.e. how far a Deafblind person is able to self determine access to information about others present.
- Interpretation of contact – how Deafblind make assumptions resulting from direct contact with others.

8.3.1 Awareness of Others through Direct Contact

Other people notify the Deafblind person of their presence by touching them.

"People touching my shoulder to say hi at the pub." (58)

This is seen by Deafblind people as an acceptable way of getting attention. Contact between the Deafblind person and three other Deafblind people is also mentioned in the example below.

"I met three people and we used hands on. That was good. Some people used manual but it was quite difficult, I asked the interpreter to come and do hands on (54).

The Deafblind person is describing meeting people at a Deafblind rally. The question he had been asked was "How many people were at the event?" The person responded 'I met three'. This may have been a misunderstanding of the question, or it may be a reflection of the fact that he only had a tactile direct conversation with three people. Therefore this may mean that he has not realised many more people are in fact present beyond the three, but he has no means of knowing this without direct contact. It might also mean that for the Deafblind person the 'reality' of his environment, the elements which are important to building up a 'mind map' are only the people he physically meets.

8.4 Information provided by guides

Information about the environment and who is in that environment may be provided by others.

"My wife tells me who's there, what's there and guides me" (79)

Similarly

"I wouldn't meet someone alone, I would be with a guide, but if I was alone and a strange person came up I would feel apprehensive and uncomfortable about meeting a strange person and wouldn't know how to talk to them. But I would talk to a stranger if my guide was with me and they showed the person how to use block on my hand" (76)

The guides or family members 'create' the environment for the Deafblind person. They have control of how many people are in the environment and what information is given. Presumably the Deafblind person can also verify some of this information as they try to interact with the others who have been described..

8.5 Communication choices affects awareness of others.

The preferred communication of the Deafblind person may affect the way in which they become aware of and are able to interact with others.

One participant explained

"Then I went to the pub and stood at the bar and I had a drink. Someone came up and tapped my shoulder. It was Jim so I said hello. We talked through hands-on. His wife is Julie and she is deaf. Jim is hearing." (54)

Jim was able to use hands-on signing so could communicate with the Deafblind person. It is likely that others were in the pub who did not know hands-on signing and therefore the Deafblind person did not have direct contact and may not have known they were there. If others use different communication methods – contact and interaction may not be as easy.

"If I meet a hearing person, so they come up and say hi, I maybe try and lip read them but I don't understand. My confidence goes down, they can't sign." (52)

This creates an interesting problem: often hearing-sighted people will try to engage with a Deaf or Deafblind person, assuming that that person has some skills in lip-reading or some residual hearing. The Deafblind person has the task of trying to appear grateful and of understanding (when the strain of trying to understand is great and the extent of understanding is limited).

Deafblind people may exhibit flexible communication signals to cope with this situation. This tends to encourage the hearing-sighted person who may believe the Deafblind person is understanding everything when this is not the case. The conversation seems likely to founder. The Deafblind person has the decision to make as to whether minimal communication is better than no contact at all.

A participant explained how he communicated with a hearing person who did not understand sign language.

"They might try and use gestures, so they use a little sign, like miming 'car' or 'drink' they might try and write something down" (52)

There is no simple answer here.

8.6 The 'Deafblind friendliness' of the environment

Deafblind people becoming aware of others may be dependent often on how aware the hearing-sighted people are.

On the other hand, Deafblind people encounter others by accident and this may not be positive. A participant explained.

"hearing people bump into me a lot when I go shopping, why don't they say sorry. It's cheeky and rude. It's not very nice" (76).

It is not clear how they should "say" sorry if the person does not hear and they are unaware of Deafblindness. The same participant went on to explain

"If they talk to me they will think that I am ignoring them but I don't know what they are saying, I can't see. Then they might tap me suddenly in the shoulder to move me out the way. They don't realise I am Deafblind" (76).

The Deafblind person is made aware of others near, by being tapped. The people around him have not realised he is Deafblind. The Deafblind person has interpreted the events, from the tapping. The suddenness of it, leads him to think something is not right. Being pushed out of the way, leads to the deduction that the hearing-sighted people probably thought they were being ignored.

Another Deafblind person had a similar experience.

"I am looking at the chest freezer, again a person might ram me with the trolley. Maybe my mum or the guide has gone off somewhere else when this happens..... and then it's too late. People don't think. They don't recognise I am Deafblind because I don't have a stick. They just look at me and think I am normal. It's hard." (90)

The demands of hearing-sighted mobility collides with the Deafblind personal space. This constitutes an unfriendly environment.

Additionally, there is mention of the 'uniform' or flag which could signal the Deafblind personal space. In this case, a Deafblind cane is mentioned. A guide dog might be another signal. Even these signals may not be enough to avoid the invasion of personal space. A red and white cane may not be understood by members of the public.

The example is also interesting as the person describes other people presuming she is 'normal.' Normality in this case means hearing-sighted. This is a problem in that it is a tacit assumption of deviance and places the Deafblind person on the defensive.

Sometimes others in an environment respond to Deafblind people in a positive way.

"there is one doctor who comes out to get my attention by tapping me, others know me but assume that someone else will help me which is hopeless. It's really nice when the doctor comes out, it feels very respectful" (90).

The doctor makes the adjustment. Difference is respected and acknowledged.

8.7 Control

Guides have responsibility for interpreting the environment accurately. This did not happen in the example below:

"I don't realise that there are some people trying to get past me and they are talking but I don't hear. The guide doesn't hear – she is dreaming. Then there will be a sharp tap on my shoulder and they will be talking at me, then the guide will come over and say she is Deafblind. The people make face/ grumble and walk off, Really the guide has missed it, it's the guide's fault. But for me it's not very nice because I get roughly tapped on shoulder or sometimes people push me out of the way roughly (90).

There are many layers to this. On the surface, there is the reported problem that the guide has not done her job by protecting the Deafblind person. However, the intervention to say that "the person is Deafblind" after the fact of contact appears as an excuse and invites sympathy without offering any positive support such as, "I can interpret for you, if you let me know what the issue is". The additional layer is the effect on the hearing-sighted person which is a mixture of guilt, surprise, upset and anger. We might imagine that Deafblind people may need a uniform to avoid this situation.

It is also significant that even within a 'Deafblind friendly' environment, it is still within the power of others to make the decision to make contact or not. From the data from Deaf people the avoidance of contact is common among people who feel they do not want to become involved with 'high maintenance' Deafblind people.

8.8 Interpretation of contact

Deafblind people interpret the intent of the person from the way they are touched.

"I remember when I was in hospital, the nurse kept tapping my left to get me to look at her. I didn't like that. It depends how a person taps you. If it's softly and done in a nice way then this is fine. If it's too aggressive, that this is too much of a shock. I feel this is too abusive and I don't like that. Sometimes if people are frustrated they can take the frustration out on a Deafblind person and tap them too hard. This is not right" (66).

Deafblind people can interpret the way people touch them to mean different things. Another participant echoes these sentiments.

"Yes it's like if a person uses their voice normally this is like a gentle touch. If they touch you forceful it's like being shouted at. Yes, there are different ways. If they touch you hard it means they are angry" (86).

One issue that became apparent from the data is the need for Deafblind people to understand why they have been touched. A participant explained

"I am not happy but I have to know why they grabbed me. Sometimes I might accept this if there is something dangerous there. See I have to wait to know why they have grabbed me ... but if it is nothing and they just grabbed me then I want to know why. I think its wrong and I will explain that." (64)

Touching is a very blunt communication tool. It indicates contact and within a limited scale, the urgency or significance of the contact. However, it provides no explanation and usually does not indicate who has initiated the touch.

Understanding why a person has been touched enables the Deafblind person to gain an understanding of what is happening around them. It may also give the Deafblind person a sense of control.

8.8.1 Summary

Deafblind people are typically reliant on hearing-sighted people to describe who is there and what is happening in any location. However the Deafblind person's space which is of great significance may be easily invaded by unaware hearing-sighted people. This can take the form of unintended or intended touch and is often not understandable to the Deafblind person. A more effective means of informing hearing-sighted people and guides as to how to manage such a circumstance is needed.

8.9 Involvement of Others

The research revealed different groups of people who have involvement within Deafblind people's everyday lives. This includes family, friends and professionals such as interpreters and guides. It also includes the role of organisations, which provide a service to Deafblind people. The data collected in this section is rich and could be examined in a number of ways. However for the purposes here, the data will be examined by looking at examples of how others are involved and particularly the meaning behind the relationships, which exist. This includes:

- Relationships within the family unit.
- Relationships with friends and other non-professionals.
- Relationships with professionals such as guides and interpreters.

8.9.1 Relationships with Family Member, Friends and Other non-Professionals

We will deal with the relations with non-professionals first.

8.9.1.1 Practical Assistance

One of the issues in interpreting the data is understanding which factors may be part of a Deafblind person's unique experience, i.e. is a result of the person's Deafblindness and would not apply to other groups, and which part of a person experience might be a result of other factors which could equally apply to other groups. This issue is evident when considering the type of assistance members of the family take in a Deafblind person's life.

Deafblind people reported family members undertaking a variety of tasks.

Some Deafblind people reported family members driving them to various locations. This includes to college (52), to the local sports centre (58), to a sign language class (58). It is assumed that Deafblind people do not drive and therefore need others to take them.

"I walked over to my parents house. Good time sun bathing. I lay down for about 4 hours. My parents would cook dinner. I think I had chicken – large. It was delicious! After dinner my father gave me a lift back to the flat." (58)

One of the issues in receiving lifts from other people is that this has to be done at a time that suits the driver.

"I would read first then pass to my parents. My father would read and take me out to different events when they are free. My parents are great and lovely. The letter would be from Jane. It gets posted once a month about different deaf events in many different places. It can be interesting." ?????

Deafblind people therefore do not have control in deciding where/ when they go out.

Family members give practical assistance in other ways. Reading letters was mentioned by several participants. Letters are often received which are either inaccessible in terms of print size, or arrive in print when Braille is the individual's preference. There may also be difficulties with English.

"If it's a typed letter I can read it myself. If its handwritten I get someone else to read it." (65)

"I don't understand it at all, I give it to my mum to read." (52)

"if I have my glasses and I use magnifier, but if I don't understand it I ask my mother." (90)

"I will have a problem e.g. English words make me confused also I get mad and I get desperate on my own for a long time. I have some good deaf friends always me help me also good family friends who are hearing always think of me they always visit me here to check if I am alright and need any help" (63)

"My God daughter or my pal Edward, his daughter who helps me with problems and helps me sort it out. When I had a letter I ask a hearing person to phone because I do not understand what it means in the letter.so I have to fax to my God daughter to telephone them." (63)

In these examples other people, family members or friends were involved in reading letters sent to the Deafblind person. The Deafblind person may ignore the task of reading or rely on another person to read the text. This has a number of implications. The Deafblind person loses privacy and control over their lives – which may not be desirable even with good friends or family.

Family members sometimes also took on the role of making phone calls for the Deafblind person.

"my mother phones the doctor and books the appointment and I go if I have a cough" (52)

"I don't contact social worker about housing association, only my mother who sorts housing association out, speaks to them, or speaks to the lady in the office. About one month ago I was a bit angry because I have been waiting for a long time, so I told my mother to telephone the office to tell them to come to my flat." (52)

Calls made by other people could be problematic.

"I ask hearing people to phone for me, I wait too long... without telling me until finish, talking on the phone then tell me say Thursday 12pm no extra information. They tell me short but on the phone a long time." (52)

This common experience of another negotiating on your behalf, leads to frustration for the Deafblind person. The hearing-sighted person controls the exchange.

Taken together these points suggest that the Deafblind person has little choice. The Deafblind experience may have to include an acceptance of loss of autonomy.

8.9.1.2 Family and friends as 'interpreter'

Family members acted as gatekeepers but not always as interpreters.

"sometimes my father comes with me, he wants to make sure he knows what is happening, wants to know if my eyes are getting worse or the same. Sometimes my father would talk to the doctor then afterward he would explain to me." (57)

It is likely that some Deafblind people are not aware of the importance of employing an independent interpreter, rather than having a family member perform such a role, badly. The whole tone of this remark by the Deafblind person seems wrong, the parent appears manipulative and the interaction is inappropriate.

Other Deafblind people similarly report family members acting as 'interpreters' for them.

"I would sign to my father and he would talk to the doctor. He communicates in sign and speaking." (58)

"I never have a guide with me only my mother, my mother is very good but my mother talks more than me, it is like being a little girl.... if something happens urgent and the doctor has to come to my house. They panic and the doctor is very nervous ... they will be trying to write it down but they will probably ask me where my mum is. My mother is not there, so they are nervous and want my mum to be there." (90)

The Deafblind person is here seen as dependent – almost child-like.

Less problematic, informal interpreting by family members may improve cohesion.

"when I'm signing my sister translates for my brother in law, he can only sign basic if he wants more deep conversation he speaks to my sister then she signs to me what he said. I rely on my sister for interpreting" (83)

It seems as if the hearing family takes on the role of interpreter for the best of motives, but may succeed in making the Deafblind person more dependent.

8.9.1.3 Family as Guide

Family members may act as guides.

"R my husband guided me to Green Cross station by underground from Bankford station" (62).

"no I don't have a guide, Not at present, maybe later. I never ask for one. I seem to manage well. Sometimes, I'll ask my husband to go with me. If I have difficulties in the future maybe I will ask for one." (62)

This would appear to be a practical and usual situation.

8.9.1.4 Help with child care

Family members may also help with child care.

"my step father drives to the hearing schools and picks them up, if it was raining. If it's a nice day they can walk round but if it rains they get picked up. My mother and father do not work and they live around the corner from my house." (90)

This would seem to be a usual grandparent task.

8.9.2 Friends/ Neighbours

In a similar way to family involvement; friends and also neighbours are reported to take a role in some Deafblind people's lives.

8.9.2.1 Friends as Guides

Friends may act as guides.

"sometimes I might go with my mother or friends who I know I can trust." (64)

"with a new place – yes I would ask a friend. If it's a new place I'm not sure about, or London I would ask a friend but if I know well its fine" (68)

"yes sometimes if I can't see I would use a guide. But I rely on friends to come with me." (64)

There may also be simple friendship activities.

"yes when I got up and get ready for my friend to pick me up. We went for a drive to town at Kent also had a lovely time then after went for a meal. Then walk around the park and the shops, sometime have a drink at the pub also take me over my family house and have a cup of tea and talking stay about one hour.... After drive back home in the evening as it is my time also they ask me to come back to their house again. I really enjoyed myself." (63)

"Yes sometimes I feel bored, I fax my friend to come over, other time I received fax from other friend to go out with him around and see other deaf friend, and we see them and then drive back to my house. It makes me more jolly if I stay home everyday I get bored." (63)

The line between employing a guide for a particular activity and the invitation to a friend to accompany, may be a very fine line indeed. Companionship with someone who understands you may be more significant than the 'professionalism' of a guide. It could also be difficult to have a guide at certain times.

"I think it would be better if it was someone I know well as a friend, I can ask them if they agree they could work for me and that way I have control. It's a balance." ????

The issue of control comes in here in a strange context, blurring friendship and employment.

Good neighbours may be called to help.

"If I have a problem, I always go to my neighbour to help me, she is Scottish woman..... she help me with my phone, or if my husband is ill or anything she always go shopping for me." (56)

It seems natural that people in need call upon friends and even neighbours.

8.9.3 Involvement of Professionals

Deafblind participants reported using a variety of paid professionals. The roles named by participants included that of 'interpreter', 'guide', 'communicator-guide', (and 'guide-

communicator' the term used in Scotland,) 'support worker', 'communication support worker' and 'notetakers'. However, different individuals used different terms to refer to someone in an identical role. The term 'interpreter' may be used to describe someone interprets messages from others but is also used by other participants to refer to a person who also guided and was essentially a communicator-guide. Likewise the term support worker was used to describe someone who was essentially a communicator-guide. Some caution should therefore be applied when thinking about the exact roles referred to in some of the examples below. For simplicity in the analysis, the terms 'interpreter' and 'guide' will be used.

8.9.4 Use of Interpreters and Guides

Deafblind participants mentioned using interpreters in a college setting (52,73). The use of a notetaker was also mentioned (67).

Interpreters are also used for appointments such as with the social worker (76) or with the doctor. (56), (62) (63) (69) (79). For some, the decision to use an interpreter may depend on the complexity of the appointment:

"yes I use interpreter for Doctor and hospital. if easy symptom I don't need an interpreter, Doctor and I write each other." (83)

Traditionally 'interpreters' are thought to have a role in more formal situations, such as medical appointments. 'Communicator-guides' then take on the less formal role of guiding and interpreting in social situations. Sometimes the role is blurred.

"social services came to ask me questions, they asked me a lot of questions more and more over the last four months. That's why I am not sure. But it would be good to have interpreter with guiding skills. Then I could relax. If I have appointments then they could come, but the problem is they don't do social things. That's different. They focus on work things." (52)

"sometimes they (the interpreter) meet me there, sometimes they come and pick me up, it's the same for the doctor they ask the interpreter to come and pick me up so they guide me as well as interpret." (62)

"in the future I want to go out. I want a communicator guide to be with me to go out. To meet friends and go out, to do what I need." (62) "

Interpreters working with Deaf people do not usually pick up clients and take them to the appointment. However, when working with Deafblind people, this may be a necessity unless a separate guide can also be booked. As this would double the cost of a service, some funding bodies will not cover this. Interpreters therefore are asked to take on the additional role of picking up the clients and driving them to the appointments.

This may give the interpreter additional information about the client which would not normally be received if working with a Deaf person, e.g. where the person lives, and even the state of their house. Deafblind people could not maintain the same level of personal privacy in this case.

The engagements for guides may vary.

"Tina and Chaz are my guides.... On Friday at 10 am she will come and we go shopping and to the gym" (54)

“about 6 pm I wanted to go to the Gym for a swim but my husband suggested I went to bingo. I said it was too expensive but my husband gave me £20. My guide arrived and I told them I had changed my mind I did not want to go for a swim anymore we were going to bingo, the guide laughed, and said it was ok. We arrived and it started.” (90)

“I was with my guide, she was working with me, we went for something to eat and I ate it quickly and then wanted a cake. I had a look at them and I picked one and the guide picked one as well but a different one. So we enjoyed eating those and it felt better. We went for a walk round the shop and brought a zip up top I wanted a new jumper. Then we went back home about 3 pm” (90)

The guide enters into a personal interaction with the Deafblind person which will require a significant extent of trust.

“I was waiting for a guide, it was a different guide, she arrived about half past 9. We were just chatting and catching up on what had happened and laughing. I notice that the guide has an engagement ring so I wished her congratulations. That was last Friday. She was telling me how wonderful it was. So we were just talking about that.” (90)

“we just had a look around, and we were teasing each other and having a laugh. I like it, it makes me happy...we sat down and had a drink and a laugh ” (74)

Guides who can also communicate in sign language provide Deafblind people with contact with the outside world. Therefore it is important that they do pass on news about what has happened. Within this and the course of a conversation, other personal events may be discussed.

“I don't think about anything. I want a guide with me to talk. So I don't think about anything really.” (74)

The guide is seen as a person to talk to, as a route to break social isolation.

Because of the nature of Deafblindness, guides do have to take on an intimate role in that they have to allow the Deafblind person to physically hold them. If communication is hands-on, this also adds an element of intimacy. Deafblind people also have to be able to trust the guide with their own safety which again suggests a level of personal confidence. This is a complex area where control seems to be set aside in favour of a physical closeness. We have not really explored this aspect but it offers an intriguing aspect to be drawn out in the final discussion.

A guide may be the only communication partner for the Deafblind person during long periods – maybe a week or more. The guide then offers a release from aloneness; hence the need for social interchange.

It is not self-evident that guides themselves have a clear understanding of their role with Deafblind people and boundaries within the relationship. Training to become a communicator-guide is narrowly focused. In recent years, the only communicator-guide qualification available took between 3 and 5 days to achieve. The training focused on practical skills such as Deafblind manual and guiding skills. Issues such as boundaries of role are barely touched upon but rather expected to be developed ‘on the job.’

A further point is that Deafblind people themselves do not receive training in how to use communicator-guides. Their only direction comes from guides themselves.

Guides may have a role in decision-making about the activities.

"I ironed my shirt, then had a shower. At half past nine my guide starts work she arrived and we decide what we are going to do, if we are going to go shopping or if we are going to head office to help with cleaning and things" (74)

The presence of a guide may also influence how Deafblind people respond to other people around them. One participant reported.

"I met my sister when shopping with Helen (guide). I was at the checkout I then go out and we talk while Helen is waiting. We carried on talking using hands-on, we took it in turns, and then realised Helen was still there. So we finished." (76)

The influence which the presence of a guide has on this process is obvious as the Deafblind person and guide travel as a pair. It is rare that a Deafblind person goes out in order to meet another person – the guide is the companion. The presence of a guide may not encourage the Deafblind person to seek direct interaction with others. For Deafblind people going out 'socially' often means going out with a professional guide. Even in a group or at a meeting, it is often the case that almost all communication passes through the guide.

There are some circumstances where the guide 'delivers' the Deafblind person to other people – friends or relations – and in this case, the guide may withdraw until a designated time. This may be within the control of the Deafblind person, but it may be time limited if the guide is booked only for a certain period and has to return the Deafblind person to home.

We believe that relationship with the guide is an area for further detailed study.

A point which becomes apparent here is that service providers arrange a guide for a single purpose such as enabling the person to go shopping. Needs are defined in terms of these practicalities and seldom in terms of the emotional or psychological needs for interaction or community engagement.

A guide may be constrained by their contract or by 'lone worker' policies which require that the employee specifies exactly where they are:

"it is not far to the bowling. My guide came with me but I was worried about the weather because it was raining. I thought they might change the venue to somewhere indoors; the guide phoned the office to check. But they said it would carry on we would just have to put coats on. ... we arrived but nothing seemed to be happening. . . we went to have a look for someone and another guide came up and said we had to go into town. . . . We talked amongst ourselves and decided it was too far, it was better just to go for a coffee. My guide phoned the office to tell them what we were doing." (90)

The presence of a professional with a Deafblind person may also be seen as a barrier by others. Other people who see the Deafblind person in town for example, may make a decision not to approach the person, as they are perceived to be 'OK' as there is a guide to help. The presence of a guide with a Deafblind person may also be perceived to be a 'work' relationship; other people therefore do not interrupt. The provision of a guide, rather than giving the Deafblind person independence, can in fact become a barrier. This idea needs further research since for the Deafblind person, there is always a suspicion that other people are out there but are not coming into interaction.

8.9.5 Changing Guides

A source of frustration may be changes in personnel. Such changes may occur without consultation.

“when my guide is changed, it makes me frustrated, but I have to be patient. I accept when the guide is ill, But when they are just changed all the time its frustrating.” (74).

“it varies, when timetables are changed and people come at the wrong time its very confusing and that’s frustrating.” (74)

8.9.6 More than one guide

It seems that there can be complications when guides are together.

“one (of the Deafblind group) can see well at a distance, the other can see near. So I have to sign in the middle as sometimes one person misses what is happening, so I sign it to her. It’s hard trying to communicate with both people. The guides are just there talking to each other when they really should be helping communication and telling the person what was said. The guide should be watching what is being said and the relaying it to the Deafblind person. But the guides have withdrawm. They should think.” (90)

This is an interesting example because it is an example of Deafblind people communicating together as a group. However, it seems it may be less than perfect arrangement and there remains an expectation that guides will help out.

8.9.7 Guide implications

Sending a guide is often seen by service providers as ‘solving the problem’ of Deafblind people. Providing Deafblind people with someone who can communicate and the means to access the environment is seen as a sufficient ‘resolution’ to the Deafblind issue. However the evidence suggests that to some extent one set of problems is being replaced by another. Deafblind people are not given full control of their guides or by their guides – they may not have a choice of who becomes their guide or when there are guides available; the presence of guides also limits relationships being built with other people. These issues, the relationships between Deafblind people and their guides, and the meanings behind the roles adopted is an area which needs further research.

Chapter 9: Reflections

In this project, we have tried to find out the views of Deafblind people themselves and to compare those views with the views held by Deaf people. The rationale for this comparison was that Deaf people and Deafblind people share the same early experiences. Both were Deaf from an early age and in both cases we expect them to have learned sign language at an early age. The majority of Deafblind people whom we saw had a declining sight problem which affected them to a greater or lesser extent in mobility and also in their communication. Nevertheless the communication was to a large extent, very similar to the communication of Deaf people. The degree to which an adjustment had to be made in communicating with Deafblind people varied enormously. In some cases our researchers could communicate directly in sign language; in other cases, the language used involved a form of hands-on signing or the use of the Deafblind alphabet or spelling out on the hand. In a small number of cases the Deafblind person preferred to have information and to respond through an interpreter.

Our proposal was that Deafblind people could be supported much more appropriately by Deaf people. However this proposal proved to be inoperable in the end. It seems quite clear that the views of Deaf people about their own situation and also about the situation of Deafblind people meant that they felt that they did not have a great deal in common with Deafblind people. This view was supported by the comments we heard from Deafblind people who felt that the Deaf club environment in particular, was not suited to Deafblind people and that Deaf people did not understand or respect the experience of the Deafblind person.

The net result of this finding was that the latter stages of the project, where we had planned to provide support to pairs of Deaf and Deafblind people could not take place as we were still negotiating the understandings about Deafblindness with the two groups.

We will return to this particular theme later in this chapter but first we must look at the analysis that was carried out and some of the implications that we can draw from that.

First of all, reflecting upon comments by Deaf people, we can confirm their preoccupation with the concept of access; this concept is applied to all supposed sources of information and is generally expressed as a lack of access and the dissatisfaction with the state of affairs in regard to support to Deaf people who wish to have such access. In spoken language situations most Deaf people resort to trying to lip-read the hearing person or even requesting that information should be written down. Writing down, of course, is not the answer since many Deaf people cannot read effectively.

Related to the concept of access is the similar notion of barriers. These barriers exist when there is an environment which is unfriendly to Deaf people. This is often expressed as being a presentation of information in English in formal structures which make it hard for a Deaf person to follow. The barrier itself may be a barrier which hearing people have not recognised, as it arises through lack of awareness according to the views of Deaf people. This lack of awareness can also be expressed through the notion of lack of communication; that is, hearing people are

not aware that they must adapt the form of communication in order that Deaf people can take part in conversation.

Deaf people often consider that their access to all aspects of society is affected by the attitudes and by the lack of communication in sign language. Sign language itself is an essential and significant factor in the development of identity amongst Deaf people and is central to their own self image.

Deaf identity is well established in the literature and is often seen in terms of a journey from the hearing world into the Deaf world. In this respect Deaf people see the vital component of community membership and the statement of identity as being the capacity to use sign language. To that extent people who are Deafblind may well make the journey from the Deaf world into another, more marginalised world. It seems obvious that the Deaf community is under stress – a stress created by the changes in schools and the general trend towards mainstreaming. As a result, it may well be the case that the definition of Deaf community membership and of Deaf identity is becoming narrower.

When we asked about issues of future planning and happiness, by and large, Deaf people gave responses consistent with society and culture in Britain. Aspirations tend to be for material and personal development. For those people with a central position in the Deaf community it seemed that aspirations for the promotion of Deaf identity were also very strong.

When it came to a discussion about the situation of Deafblind people, it seems quite clear that Deaf community members see Deafblind people as being somehow alien. Where those Deafblind people had an established role in the Deaf community or had grown up and attended school with Deaf people there was greater likelihood that the Deaf people would indicate a greater degree of understanding. However there was an unusual, but perhaps not unexpected, contradiction in position in regard to Deafblind people. Deaf people, on the one hand, believe that the hearing world should adjust and cooperate with the difference that is the Deaf identity. However, on the other hand, those same Deaf people believed that Deafblind people should somehow be more able to fit into the Deaf community and professed a lack of awareness (of Deafblindness) displaced as if that lack was due to not being trained or not being instructed in the ways of Deafblind people. There was no sense of responsibility or need for the Deaf community to adjust to the needs of Deafblind people. We found that Deaf people often considered Deafblind people as being hard work, as requiring patience and as being time-consuming. They were seen as creating a responsibility which Deaf people were, on the whole, reluctant to accept.

Deaf people recognise the sense of isolation which came from being surrounded by hearing people but this was not somehow transferred to the Deafblind person who might find himself alone inside the Deaf community.

In the area of dependence, we find many strong themes which can be related to difficulties in dealing with communication from hearing people. Notable amongst these is the difficulty that surrounds managing literacy and dealing with correspondence from hearing people or from hearing agencies.

Taken together, these features summarised above, confirm what we know of the Deaf community seeking a single identity based on sign language and interaction with other Deaf

people. What we did not find was any real concern or acceptance of responsibility for the integration of people who might be on the margins – such as Deafblind people.

On the basis of the responses from Deafblind people we find the strongest term coming through is that of 'control'. To the extent that control can be exercised, Deafblind people feel independent. Especially at home in surroundings which are familiar, Deafblind people feel that they function like any other person; they feel comfortable and unstressed in those situations. We can define independence in that sense, as being the capacity to make choices and to follow through on those choices. Therefore, when people may be physically isolated or may have problems in meeting and interacting with other people, it is the extent to which they can exercise choice that determines the extent to which they feel comfortable.

Much of our analysis seems to become somewhat contradictory. On the one hand, Deafblind people explain and identify circumstances which others would call isolated and alone but where Deafblind people do not present themselves in that way. Ability to exercise control is the expression of their own independence.

Not surprisingly, Deafblind people use all of their residual senses in order to construct meaning in the environment and in the interactions that take place. For those who have had declining sight, experience of the environment is determined by the link to knowledge of that environment as it was when they had sight. Much of current experience then involves a projection onto information accumulated prior to losing sight. We might liken this to the creation of cognitive maps. Using a form of retrospective mapping, Deafblind people are able to take partial images that are generated from current experience and relate them to larger images available in the past or as experienced in a different circumstance. This in turn, is linked to imagination i.e. the active construction of knowledge on the basis of partial information.

In terms of issues such as emotion we find Deafblind people rather similar to the rest of the population - most people consider themselves to be happy. Confidence came from familiarity, often applied to the physical environment. Insecurity arose in unknown environments or where the layout had been changed. In situations of change, insecurity becomes a real problem and we begin to enter the domain of vulnerability. We find this terminology of insecurity, aloneness and vulnerability seems to give credence to the stereotype of Deafblind people as being uncertain and dependent. As we have said already, this appears to create a contradiction in our view of Deafblind people – dependent *and* independent. Deafblind people may have difficulties in meeting other people and may have anxiety surrounding those sorts of encounters.

As with Deaf people aspirations for the future tend to follow similar lines to the community as a whole. At the same time however many of the Deafblind people found it difficult to project into the future given that they had a realistic view of their own ability to control the future and the limitations of service provision.

One of the areas which was unexpected, and turns out to be significant, is contact with other Deafblind people. Interestingly Deafblind people tend not to meet other Deafblind people. The Deafblind person in the room may simply be unable to detect the presence of another Deafblind person. Where that presence of the other Deafblind person is pointed out, it is likely to have been explained by a guide and since both Deafblind people may have guides, those guides may act as intermediaries between the two Deafblind people. When we tried to bring Deafblind people into contact with other Deafblind people, we found in many circumstances, that they were unable to conduct a conversation which involved explaining about their own personal circumstances. It

would appear that contact with other Deafblind people has tended to occur in the context of specific meetings, conferences and so on and relatively rarely in the context of personal explanations of social activity.

We find contradictions in beliefs about contact with Deaf people. On the one hand Deafblind people see the Deaf community as a natural home for their interactions. At the same time, others find it to be an unfriendly environment; they find it a cause of stress in regard to being ignored, avoided and simply left out of events. It was certainly the case that Deafblind people felt that Deaf people did not understand the needs of Deafblind people. Touch was particularly significant in this regard and it was often felt that even Deaf people were not aware of the best way in which to attempt to gain attention and to begin communication. Because touch is such an important aspect of Deafblind people's exploration of the environment and of other people, it implies that Deafblind people need the understanding and contact with others in order to create a sense of the environment beyond the point at which they can touch.

We found issues with the involvement with family members. In some cases, this could be entirely supportive and enabling but on the other hand, it could be stifling and difficult. Parents, in particular, may well treat the Deafblind adults as if they were still dependent.

In the discussion with Deafblind people, one aspect which came to our attention as being of great significance, was the relationship with the guide. Most of the time a guide is provided by an agency. That agency makes a formal and/or informal assessment of the apparent needs of the Deafblind person and gives an appropriate level of service through the provision of a guide. In some circumstances, the guide may be replaced by an interpreter; in other circumstances the guide becomes the interpreter. Deafblind people may need guides in order to leave the home and to carry out simple personal and social activities. However, these activities have to be arranged around the availability of the guide and cannot simply be spontaneous. Deafblind people become attached to the guide often on a personal level. In fact it is vital that the guide earns a level of trust which allows the guide access to information about that individual. Deafblind people are clear on the value of having a guide and an interpreter; they also note the constraints and difficulties which arise from having to rely upon the guide, provided usually by an external agency. We believe there is much to be gained from a more detailed study of the relationship between guides and the Deafblind people with whom they work.

If we try to summarise the considerable amount of qualitative data which we have collected, we can see why society holds the stereotype of Deafblind people as isolated and dependent. It fits with the model of service delivery. However on the basis of the statements by Deafblind people themselves this external isolation does not mean that the Deafblind person sees himself/herself as dependent. The Deafblind person develops a range of strategies in order to make sense of the world in which they live and to be able to plan for and ultimately to try to control the interactions with other people in the world beyond the home. When a desired level of control can be exercised, then Deafblind people can function effectively and will make a significant contribution to the community. However, we have some way to go before we can enable this control and have some way to go in incorporating Deafblind views into the service models that society operates.

We now know that the solution for effective interaction for Deafblind people, is not to be found directly in the Deaf community. Deaf people expect the hearing community to adapt and adjust to them (the minority) but on the other hand do not see the minority group of Deafblind people

as being their responsibility even though this group of Deafblind people have grown up in the Deaf community.

There is more to be gained from analysis of this data set but there is also a need for further study of the contradictions we have highlighted. The conduct of research on Deafblind people by Deafblind researchers is costly but it provides much deeper insights and offers much greater benefits to the community of Deafblind people than a simple analysis of service provision which has been the norm in the past. We will seek wherever possible to build on these findings and to disseminate the conclusions.

Chapter 10: Conclusions and final points

Deafblind Worlds was an investigation into an unexplored area.

We consider that a major development has been that the study placed the Deafblind person firmly at the centre of attention, and provided an opportunity for Deafblind people to reflect upon their own life experience in a way which may support the better definition of services to meet their chosen lifestyle. It provides an understanding of Deafblind people's own views as a way to drive the service.

We did not find that the Deaf community had empathy with Deafblind people, suggesting that the Deaf community's own status as recipients of support, seems to preclude them from achieving the confidence needed in order to support others.

The project's data collection has been inevitably more expensive per unit than that of typical studies of minority groups. We could have denied this cost, used intermediaries and secondary sources, but we would have lost the opportunity to learn directly what Deafblind and Deaf people think. We do not consider such an approach is appropriate and it will not serve the function of bringing Deafblind people particularly, directly into the consultations on their own aspirations.

Deafblind Worlds focused on the groups for whom the relevance of signed, gestural and spatial communication is established

10.1 Benefits of the project

The benefits of project can be identified in a number of different ways.

As a contribution to research theory, the results offer insight into the world of touch, hearing and sight as it impacts on community and culture. The project aims to create an understanding of Deafblindness in a way which has not been achieved before.

As a social project, it provides an opportunity primarily for Deafblind people as an 'excluded' group to share their perceptions, views and understandings of their world. Understanding how Deafblind people think and perceive is important because it has an impact on how lifestyle options and service provision could be designed to optimize the lives of Deafblind people. This creates an opportunity to 'include' Deafblind people in society in a way which suits them.

The project also offers practical implications in service provision by providing the feedback from Deafblind people which can make such provision more sensitive to needs.

10.3 The nature of the Researchers

The project was organised, planned, managed and carried out by Deaf and Deafblind staff. There was an advisory group made up of Sense and DST staff or Trustees, together with an independent researcher and representative of the British Deaf Association.

10.4 The Partners in the Research

The **Deaf Studies Trust** was set up in 1984 as a research charity in the field of Deafness. It has conducted a range of projects in all areas from infants through to deaf community and elderly people. It has managed and participated in social and technological research projects.

Sense has worked with and for Deafblind people for nearly 50 years. Over recent years Sense has conducted a range of small scale and large scale research and practice developments e.g. successes of direct practice interventions and research into aspects of the social, medical and employment experiences of people who are Deafblind. Sense has considerable experience in the practical arrangements necessary to enable Deafblind people to take part in research directly.

Reference list

- Barnett, S, 2002 *Deafblind Culture* Masters Thesis: University of Bristol
- Deafblind Services Liaison Group (1993) *Coming Together - Proceedings of a Seminar Concerning the Formation of a United Kingdom Coalition of Deafblindness (nov 26th 27th, 1993)* Birmingham: Sense
- Higgins, N & Ballard, K. (1999) Reflections on the Meaning of Blindness in the Life experiences of Four New Zealanders (Parts 1 & 2) *British Journal of Visual Impairment* 17(1), p.36-40
- Kilsby M & Cook L (2003) *Maintaining Independence. A report for the CAUSE project*, (Internal Sense Publication)
- Ladd, P. (1988) *The Modern Deaf Community in D Miles British Sign Language: A Beginners Guide*. London: BBC Worldwide Publishing
- Laurence Report Summaries of Reports on Dual Sensory Impairment 1983 – 2000, London: DoH
www.doh.gov.uk/scg/laurence.report.htm
- MacDonald, R J, (1994) Deaf-blindness: An Emerging Culture? In Ertling, C.J, Johnson R.C, Smith D.L, Snider B.D (eds) *The Deaf Way – Perspectives from the International Conference of Deaf Culture*. (Gallaudet University Press)
- McInnes, J M. (Ed.) (1999) *A Guide to Planning and Support for Individuals Who are Deafblind* Toronto: University of Toronto Press.
- Naish, L, (1999) *Communication Project* (Internal Sense publication)
- Paddon, C. (1980 originally but reprinted) *The Deaf Community and the Culture of Deaf People*, in Gregory, S & Sheldon, G. 1997 *Constructing Deafness* Milton Keynes: Open University Press
- Reed S & Floyd J, (1998) *Communication through Touch. An 18 month Research Project from 1996*, (Internal Sense publication)
- Robertson J, E, and Emerson E. (2010) *Estimating the Number of People with Co-Occurring Vision and Hearing Impairments in the UK*, Lancaster: Centre for Disability Research. Available at: http://www.sense.org.uk/what_is_deafblindness/urgency
- Singh, R & Guest M, (1991) *Parents Answer Back – A survey of parents and Children (including adult children)* (Internal Sense publication)
- Smithdas, R, (1958) *Life through my fingertips* London: Elek Press
- Spear, K C. (1994) Is there “Deafblind Culture?” in *Nat-Cent News*. 25(1), 12 - 20
- Stiefel, D H. (1991) *The Madness of Usher's: Coping with Vision and Hearing Loss (Usher Syndrome Type II)*, Corpus Christi, TX: The Business of Living Publications
- Tobin, M. J. (1998) Is Blindness a Handicap? *British Journal of Special Education* Vol. 25, Nos. 3, 107-113
- Woodford, D, (1987) *Survey of Sign Language Reception and Modification for Deaf people who are Losing their Sight* (Internal Sense publication)

1. Appendix 1: DB interview schedules

2. Appendix 2: Deaf interview schedules

Appendix 1:

Main Interviews Phase 1 – Deafblind Participants

1. Personal reference number _____
2. Date of Birth _____
3. At what age did you leave school? _____
4. What qualifications did you achieve at school?

5. At what age, did you first learn BSL? _____
6. At what age did you first learn Deaf blind manual alphabet? _____
7. At what age did you learn other systems for communication?
hands-on _____
Braille _____
Other _____
8. How many people live with you in your home?
Hearing Sighted spouse/partner
Deaf Sighted spouse/partner
Deaf Blind spouse/partner
Hearing Sighted Children or others numbers
Deaf Sighted children or others numbers
Deaf Blind others numbers
9. At this moment, what is your preferred method for communication and why?

10. How would you describe your sight at the moment?

11. How would you describe your hearing at the moment?

12. Is your sight getting better or worse at present?
better the same worse
13. Is your hearing getting better or worse at present?
better the same worse

Life situation

These questions are more open for you to tell us about your experiences.

14. Can you tell me what you did yesterday, from the time you got up until you went to bed in the evening? (if yesterday was not typical (eg had a hospital visit or person was ill – go back in time to find a “typical day”)

(Q 14 should deal with a day at work if the person is working)

15. During the day, how much time were you talking to someone else? Minutes hours

16. During the day, how much of the time would you say **you** used the following to talk to someone else:

- Deaf Blind alphabet.....%
- BSL signing%
- Gestures %
- Speech%
- writing down or other way%

Not used these as did not meet anyone

17. During the day, which methods did people use to communicate with you?

14. Can you tell me what you did on a full day last weekend – Saturday or Sunday, from the time you got up until you went to bed in the evening?

18. During the day, how much time were you talking to someone else? Minutes hours

19. During the day, how much of the time would you say **you** used the following to talk to someone else:

- Deaf Blind alphabet.....%
- BSL signing%
- Gestures %
- Speech%
- writing down or other way%

Not used these as did not meet anyone

20. During the day, which methods did people use to communicate with you?

21. Here are a list of services which may operate in your area. Which of these have you used in the last month?

22. Thinking about the two days, you described would you say that you are independent or do you feel you have to rely on other people?

23. Do you feel happy with this lifestyle? How would you like to improve it? What things would you like to do which you cannot at the moment?

24. Which media are you able to use?

Televisiondirectly only with special aids

Television subtitles ...

Radio

Newspapers

Books

Braille/Moon books

The Internet/email

Letters which are posted to you

25. Are you involved in any clubs or associations for Deaf Blind people?

26. How often do you attend/take part

every week

every month

only occasionally

27. Are there activities which you would like to do but you cannot at the present?

Questions for contacts with Deaf Community

28. How often are you in contact with Deaf people?

every week

every month

only occasionally

29. what benefits are there for you to be in contact with Deaf people?

30. Do you think that Deaf people can understand what it is like to be Deaf-Blind?

Characteristics of Deafblind experience

These are much more open questions to try to understand your experience.

Typical questions (these will need to be piloted):

How would you describe your feelings when you wake up in the morning?

What would be the first things you become aware of when you wake up?

What makes you happy? Are there things which make you happy which are different from hearing people or different from Deaf people?

What events or circumstances make you unhappy? Are these events different from those for hearing people or from Deaf people?

Do you feel isolated?

What would be your ideal method of meeting other people e.g. in person or via technology?

Typical scenarios (to be piloted)

If a new hearing person is introduced to you, what do you do and how does the person react?

If a Deaf person is introduced to you, what do you do and how does the person react?

If a Deafblind person is introduced to you, what do you do and how does the person react?

When in a new place, without a guide or interpreter or hearing friend, there are times when you are left on your own for a few moments, what do you think about and how do you judge your surroundings?

Touch is a very important part of communication. What are your feelings when someone touches you? Are there different sorts of touch? What effects do they have?

Sometimes you have to build up an impression of where you are or who you are with, or when you are in new circumstance – how do you do this? How can you use your imagination?

You are in a situation such as sitting in a doctor's waiting room, waiting to be called – do you feel you have control of events happening around you?

When you are at home on your own, what do you think about?

What ambitions do you have – what would you like to do in your life?

Appendix 2

Main Interviews Phase 1 – Deaf Participants

1. Personal reference number _____
2. Date of Birth _____
3. At what age did you leave school? _____
4. What qualifications did you achieve at school?

5. At what age, did you first learn BSL? _____
6. How many people live with you in your home?
Hearing spouse/partner
Deaf spouse/partner
Deaf spouse/partner
Hearing Children or others numbers
Deaf children or others numbers
7. At this moment, what is your preferred method for communication and why?

Life situation

These questions are more open for you to tell us about your experiences.

8. Can you tell me what you did yesterday, from the time you got up until you went to bed in the evening? (if yesterday was not typical (eg had a hospital visit or person was ill – go back in time to find a “typical day”)

(Q 14 should deal with a day at work if the person is working)

9. During the day, how much time were you talking to someone else? Minutes hours
10. During the day, how much of the time would you say **you** used the following to talk to someone else:
BSL signing%
Gestures %
Speech%
writing down or other way%

Not used these as did not meet anyone

11. During the day, which methods did people use to communicate with you?

12. Can you tell me what you did on a full day last weekend – Saturday or Sunday, from the time you got up until you went to bed in the evening?

13. During the day, how much time were you talking to someone else? Minutes
hours

14. During the day, how much of the time would you say **you** used the following to talk to someone else:

BSL signing%
Gestures %
Speech%
writing down or other way%

Not used these as did not meet anyone

15. During the day, which methods did people use to communicate with you?

16. Here are a list of services which may operate in your area. Which of these have you used in the last month?

17. Thinking about the two days, you described would you say that you are independent or do you feel you have to rely on other people?

18. Do you feel happy with this lifestyle? How would you like to improve it? What things would you like to do which you cannot at the moment?

19. Which media are you able to use?

Televisiondirectly only with special aids

Television subtitles ...

Radio

Newspapers

Books

The Internet/email

Letters which are posted to you

20. Are you involved in any clubs or associations for Deaf people?

21. How often do you attend/take part

every week

every month

only occasionally

22. Are there activities which you would like to do but you cannot at the present?

24. How often are you in contact with other Deaf people?

every week

every month

only occasionally

25. What benefits are there for you to be in contact with Deaf people?

Characteristics of Deaf experience

These are much more open questions to try to understand your experience.

Typical questions (these will need to be piloted):

How would you describe your feelings when you wake up in the morning?

What would be the first things you become aware of when you wake up?

What makes you happy? Are there things which make you happy which are different from hearing people or different from other Deaf people?

What events or circumstances make you unhappy? Are these events different from those for hearing people or from other Deaf people?

Do you feel isolated?

Typical scenarios (to be piloted)

If a new hearing person is introduced to you, what do you do and how does the person react?

If another Deaf person is introduced to you, what do you do and how does the person react?

Touch is a very important part of communication. What are your feelings when someone touches you? Are there different sorts of touch? What effects do they have?

Sometimes you have to build up an impression of where you are or who you are with, or when you are in new circumstance – how do you do this? How can you use your imagination?

You are in a situation such as sitting in a doctor’s waiting room, waiting to be called – do you feel you have control of events happening around you?

When you are at home on your own, what do you think about?

What ambitions do you have – what would you like to do in your life?

Contact with Deaf Blind people

26. How often do you have contact with Deaf blind people?

- every week
- every month
- only occasionally

27. Do you know any communication methods for Deaf Blind people

- Deaf blind manual alphabet
- hands-on signing
- Braille
- Other

28. Do you think that Deaf people can understand what it is like to be Deaf-Blind?

29. If we compare Deaf people and hearing people – do you think that they have different understanding of what it is like to be Deaf Blind?

30. Do you think that Deaf blind people should be involved in the Deaf community?

31. Do you think that Deaf Blind people want to be part of the Deaf community?

Thank you

Deaf Blind Worlds

Participant Details and Consent Form

Date of Meeting: _____

Interviewer: _____

Participant Record Number: _____

PERSONAL DETAILS:

1. **Date of Birth:** Day:____ Month:____ Year:_____

2. **Title:** Mr: Mrs: Ms: Other:

3. **Male** **Female**

4. **Full Name:** _____

5. **Address Details:** (use large print Braille)

6. **Contact Details:**

Minicom Number: _____

Fax Number: _____

E-mail Address: _____

SMS/text number: _____

Consent Form

(sign this before the interview)

I confirm that:

- The study has been explained to me in English and BSL
- I understand that I will take part in several interviews
- I understand that the project will continue until 2006
- I am happy to take part in the study

- I understand that I can withdraw at any time
- I will not be identified in the results collected from this study

Signed: _____

Name: _____

Date: _____

Deaf Blind Worlds

Personal Data

7. **Participant Record Number:** _____(office use)
8. **Date of Birth** _____
9. **What's your preferred communication method for you to talk to other people?**
- (a) BSL
- (b) BSL Hands-On Signing
- (c) BSL Visual Frame
- (d) Deafblind Manual
- (e) Spoken English
- (f) Mixture speaking & signing
- (g) other _____
10. **What's your preferred communication method for other people to talk to you?**
- (a) BSL (b) BSL Hands-On Signing
- (c) BSL Visual Frame (d) Deafblind Manual
- (e) Spoken English & Lip Reading
- (f) Speech To Text (g) Speech to Braille
- (h) mixture of _____
11. **At what age did you become Deaf?**
____ years ____ months old
12. **At what age did you become Blind?**
____ years ____ months old
13. **If another person asks you, how would you describe yourself**

(prompt Deaf, Blind etc)
14. **Without wearing a hearing aid, can you hear a person talking two feet away (arms length) from you?**
- a) Yes
- b) No

15. Without glasses, can you read the newspaper headlines if you hold the paper at arms length?

- (a) Yes
- (b) No

16. Which school(s) did you go to?

17. Do you have a job at the moment?

- a) Employed
- b) Self-employed
- c) Unemployed
- d) Retired
- e) Student
- f) Housewife/husband
- g) Out of work due to illness
- h) Other (specify)_____

18. What is your main job title?

19. In this job, explain what your work is?

20. How many hours do you work in your MAIN job? _____ hours a week

21. Your Marital status:

- a) Married – or living with partner
- b) Married and separated from husband/wife
- c) Single, (that is never married)
- d) Divorced
- e) Widowed

22. What is your ethnic background?

- a) White Black Caribbean
- b) Black African Black other
- c) Indian Pakistani
- d) Bangladeshi Chinese
- e) Other (specify) _____

16. Interviews will be carried out in British Sign Language, would you like a ...

- (a) BSL interpreters
- (b) Hands-On Interpreter
- (c) Deafblind Manual interpreter
- (d) Other _____

17. Will you need a guide to attend a meeting?

- (a) Yes
- (b) No

15. Please tell me your best time(s) to be interviewed? And where?

- 1) _____
- 2) _____

16. What is the best way to contact you?

- (a) Email
- (b) Minicom

(c) Letter- Large Print

(d) Letter - Braille

(e) SMS/Text message

(f) Fax

(g) Other

Please sign the declaration below:

I understand that the data (answers to the above questions) will be kept on computer for the purposes of research analysis, only, within the “Deafblind Worlds” project. All such information will be held strictly confidentially. No details, which will allow a third party to identify me, will be revealed outside of the project team. If I decide to withdraw at any point during the project, I understand that my records will be removed from the computer and will not be used in the project analysis.

Your signature: _____

Date: _____

Deaf Blind Worlds – questionnaire for Deaf

Personal Data

23. **Participant Record Number:** _____(office use)

24. **Date of Birth** _____

25. **What's your preferred communication method for you to talk to other people?**

- (a) BSL
- (b) Spoken English
- (c) Mixture speaking & signing
- (g) other _____

26. **What's your preferred communication method for other people to talk to you?**

- (a) BSL
- (b) Spoken English & Lip Reading
- (c) write down
- (d) mixture of _____

27. **At what age did you become Deaf?**

____ years ____ months old

28. **Without wearing a hearing aid, can you hear a person talking two feet away (arms length) from you?**

- c) Yes
- d) No

29. **Which school(s) did you go to?**

30. **Do you have a job at the moment?**

- i) Employed
- j) Self-employed
- k) Unemployed
- l) Retired
- m) Student
- n) Housewife/husband
- o) Out of work due to illness

p) Other (specify) _____

31. What is your main job title?

32. In this job, explain what your work is?

33. How many hours do you work in your MAIN job? _____ hours a week

34. Your Marital status:

f) Married – or living with partner

g) Married and separated from husband/wife

h) Single, (that is never married)

i) Divorced

j) Widowed

35. What is your ethnic background?

f) White Black Caribbean

g) Black African Black other

h) Indian Pakistani

i) Bangladeshi Chinese

j) Other (specify) _____

15. Please tell me your best time(s) to be interviewed? And where?

3) _____

4) _____

16. What is the best way to contact you?

(a) Email

(b) Minicom

(c) SMS/Text message

(d) Fax

(e) Ordinary mail

Please sign the declaration below:

I understand that the data (answers to the above questions) will be kept on computer for the purposes of research analysis, only, within the “Deafblind Worlds” project. All such information will be held strictly confidentially. No details, which will allow a third party

to identify me, will be revealed outside of the project team. If I decide to withdraw at any point during the project, I understand that my records will be removed from the computer and will not be used in the project analysis.

Your signature: _____

Date: _____