

# **Deaf People's Understanding of Health and Health Care Systems**

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A dissertation submitted to the University of Bristol in accordance with the  
requirements for the degree of Master of Philosophy

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## **MEMORANDUM**

**I certify that this dissertation is my own independent work and has not been presented previously for any other degree.**

Signed:

Date:

## **ACKNOWLEDGEMENTS**

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## **ABSTRACT**

A growing emphasis upon equal health care access has been evident in governmental documentation. Deaf people have a right to access health care and health information in the same way as the general population.

There has been a growth in demand for improved service access along with an emphasis upon improving individual's lifestyles. However, little is actually known about deaf people's health needs, related community initiatives in the Deaf community and effective strategies for reaching this community.

The aim was to look at the various factors influencing deaf people's health, their access to health care systems through their experiences, and the effectiveness of intervention work. In addition, exploration was made of the issues from the perspectives of deaf people and their lay views. Recommendations are made towards appropriate intervention work for the improvement of the deaf individual's health.

The approach undertaken included a range of qualitative interviews with deaf individuals. These were carried out in the form of focus groups, and one-to-one semi-structured interviews with Deaf community members and health professionals.

The findings illustrate that deaf people are disadvantaged when trying to access health services, and generally have low self-esteem along with poor circumstances, leading to poor social economic status. Acknowledgement is also made of the medical profession and funding bodies to recognise the communication needs of deaf people and to gain respect for the cultural diversity of the Deaf community.

The results from this research will provide invaluable information for health professionals and the Deaf community. The value of this approach will provide clearer quality standards and a working model towards improving deaf people's current health status.

## CONTENTS

<b>CHAPTER 1 ESTABLISHING THE TARGET GROUP UNDER STUDY .....</b>	<b>1</b>
1.1 INTRODUCTION.....	1
1.2 DEAF COMMUNITY – NUMBERS AND DEFINITIONS .....	2
1.3 HOW THE DEAF COMMUNITY IS PERCEIVED .....	5
<i>1.3.1 The Medical Model .....</i>	<i>6</i>
<i>1.3.2 The Social Model.....</i>	<i>8</i>
<i>1.3.3 The Culturo-linguistic Model.....</i>	<i>9</i>
<i>1.3.3.1 Language and cultural affiliation .....</i>	<i>12</i>
1.4 COLLECTIVISM AND INDIVIDUALISM .....	14
1.5 EXTERNAL FACTORS THAT AFFECT THE DEAF COMMUNITY .....	15
<i>1.5.1 Deaf community and governmental relationships .....</i>	<i>16</i>
<i>1.5.1.1 Funding and its implications .....</i>	<i>18</i>
<i>1.5.2 Deaf community employment.....</i>	<i>19</i>
<i>1.5.3 Limited enculturation through parents .....</i>	<i>21</i>
<i>1.5.3.1 Diagnosis .....</i>	<i>21</i>
<i>1.5.3.2 Oralism and the Deaf community .....</i>	<i>23</i>
<i>1.5.4 Deaf education.....</i>	<i>24</i>
<i>1.5.4.1 Resistance of belief in existence of the Deaf community</i> <i>and its language.....</i>	<i>27</i>
<i>1.5.5 Further negative interventions.....</i>	<i>27</i>
1.6 SUMMARY .....	30

<b>CHAPTER 2 HEALTH ISSUES AND HEALTH CARE SYSTEMS .....</b>	<b>32</b>
2.1 INTRODUCTION.....	32
2.2 HEALTH PROMOTION .....	33
2.2.1 <i>Health and well-being</i> .....	34
2.2.2 <i>Mental health</i> .....	36
2.3 COMMUNITY GROUP’S ROLE IN HEALTH PROMOTION .....	37
2.3.1 <i>Empowerment</i> .....	38
2.3.2 <i>Evaluating a community health programme</i> .....	40
2.4 HEALTH INEQUALITIES .....	41
2.5 INDICATORS OF DEAF HEALTH .....	42
2.6 STRUCTURAL BARRIERS TO HEALTH.....	43
2.6.1 <i>Planning of Health Authorities training</i> .....	43
2.6.2 <i>Deaf people’s health status</i> .....	45
2.6.3 <i>Deaf people’s status as health professionals</i> .....	47
2.6.4 <i>Demographic limitations</i> .....	48
2.6.5 <i>The interpreter effect</i> .....	49
2.6.6 <i>Mode of communications in health care settings</i> .....	51
2.6.7 <i>Specialist equipment</i> .....	51
2.6.8 <i>Misinformation</i> .....	53
2.7 CULTURAL BARRIERS .....	53
2.7.1 <i>Access to Health Information</i> .....	53
2.7.2 <i>Principle of autonomy/informed choice</i> .....	55

2.7.3	<i>Attitudes of health professionals</i> .....	56
2.7.4	<i>Cultural viewpoint</i> .....	57
2.7.5	<i>Communication barriers</i> .....	57
2.8	COMMUNITY HEALTH PROJECTS.....	60
2.9	ETHNIC MINORITIES .....	61
2.9.1	<i>Double discrimination</i> .....	61
2.10	SUMMARY .....	62
 <b>CHAPTER 3 METHODOLOGY</b> .....		<b>64</b>
3.1	RESEARCH QUESTIONS.....	64
3.2	RESEARCH METHODOLOGIES.....	65
3.3	WHICH APPROACH? .....	66
3.3.1	<i>Quantitative research</i> .....	66
3.3.1.1	<i>Snowball sampling</i> .....	67
3.3.2	<i>Qualitative research</i> .....	68
3.4	FOCUS GROUP TECHNIQUES .....	71
3.5	SEMI-STRUCTURED OPEN-ENDED INTERVIEWING .....	72
3.6	FACTORS AFFECTING METHODOLOGIES AND CHOICES .....	73
3.6.1	<i>Written surveys</i> .....	73
3.6.2	<i>Ethics</i> .....	74
3.6.3	<i>Difficulties with sampling procedures for Deaf populations</i> .....	75
3.6.4	<i>Developing a cultural and linguistic approach to data collection</i> .....	75

3.6.5 <i>Insider researcher issues</i> .....	76
3.6.6 <i>Cross cultural conflict</i> .....	77
3.7 THEORETICAL BACKGROUND TO THE RESEARCH DESIGN OF STUDIES .....	80
3.7.1 <i>Procedure – Study 1</i> .....	80
3.7.2 <i>Procedure – Study 2</i> .....	81
3.7.2.1 <i>Sampling procedure – Study 2</i> .....	83
3.7.2.2 <i>Methodological problems</i> .....	85
3.7.3 <i>Procedure – Study 3</i> .....	86
3.7.3.1 <i>Method of data collection – Study 3</i> .....	86
3.7.3.2 <i>Informants</i> .....	87
3.8 ANALYSIS – STUDIES 1, 2, AND 3 .....	87
3.9 SUMMARY .....	87



## **CHAPTER 4 PERCEPTIONS OF HEALTH WITHIN THE DEAF**

<b>COMMUNITY .....</b>	<b>89</b>
<b>4.1 INTRODUCTION – STUDY 1 UNIVERSITY STUDENTS</b>	
(DECEMBER 1996) .....	89
<i>4.1.1 Procedure.....</i>	<i>89</i>
<i>4.1.2 A visit to the doctors.....</i>	<i>90</i>
<i>4.1.3 Use of interpreters – Creating dependency? .....</i>	<i>92</i>
<i>4.3.4 Understanding medication .....</i>	<i>93</i>
<i>4.3.5 Practising safe sex.....</i>	<i>94</i>
<i>4.3.6 Sex education in schools .....</i>	<i>96</i>
<b>4.2 CONCLUSION .....</b>	<b>99</b>

## **CHAPTER 5 DEAF PEOPLE’S HEALTH, ACCESS AND CONTACT WITH**

<b>HEALTH PROFESSIONALS .....</b>	<b>102</b>
<b>5.1 INTRODUCTION – STUDY 2 ONE-TO-ONE INTERVIEWING (1997).....</b>	<b>102</b>
<b>5.2 BACKGROUND TO HEALTH AUTHORITIES PROVISION .....</b>	<b>103</b>
<b>5.3 SAMPLE DEMOGRAPHICS.....</b>	<b>105</b>
<b>5.4 MEDICAL ENCOUNTERS .....</b>	<b>107</b>
<i>5.4.1 Communication issues.....</i>	<i>108</i>
<i>5.4.2 Use of sign language interpreters .....</i>	<i>110</i>
<i>5.4.3 Consequences of communication issues.....</i>	<i>111</i>

5.5 HEALTH TRAUMAS .....	112
5.5.1 <i>The expectant mother</i> .....	112
5.5.2 <i>The man who did not know his medical history</i> .....	113
5.5.3 <i>Other disempowerment issues</i> .....	114
5.6 COMMUNICATION ISSUES .....	115
5.6.1 <i>Reinforced dependency</i> .....	115
5.6.2 <i>Sign language interpreters – Lack of choice?</i> .....	117
5.6.3 <i>Confidentiality</i> .....	118
5.6.4 <i>Interpreter’s professional ethos</i> .....	119
5.6.5 <i>Consequences - Misdiagnosis</i> .....	120
5.7 ATTITUDES TO HEALTH .....	121
5.7.1 <i>Are people healthier in the UK than before?</i> .....	123
5.7.2 <i>Illnesses affecting daily life</i> .....	124
5.8 INFLUENCES ON HEALTH .....	126
5.8.1 <i>Positive influences on health</i> .....	126
5.8.2 <i>Negative influences on health</i> .....	127
5.8.3 <i>Does a good income mean better health?</i> .....	129
5.9 HEALTHY LIFESTYLES .....	130
5.9.1 <i>Exercise</i> .....	130
5.9.2 <i>Diet</i> .....	131
5.9.3 <i>Alcohol</i> .....	132
5.9.4 <i>Smoking</i> .....	133
5.10 MEASURING DEAF PEOPLE’S ATTITUDES TO HEALTH .....	134

5.11 EDUCATING DEAF PEOPLE .....	141
5.11.1 <i>Being taught by a deaf person</i> .....	141
5.11.2 <i>Being taught by a hearing person</i> .....	143
5.12 HEALTH RESOURCES.....	145
5.13 STUDY 2 - CONCLUSION .....	147
<b>CHAPTER 6 DEAF HEALTH PROFESSIONALS.....</b>	<b>149</b>
6.1 INTRODUCTION – STUDY DEAF HEALTH PROFESSIONALS (JANUARY 1997 – JANUARY 1998).....	149
6.2 THE HEALTH WORKERS’ STORIES .....	149
6.2.1 <i>The DWHP Story</i> .....	151
6.2.2 <i>Dissemination of Information</i> .....	152
6.3 RURAL-URBAN COMMUNITY DISCREPANCIES .....	153
6.4 A CULTURO-LINGUISTIC MODEL TOWARDS DEAF HEALTH.....	154
6.5 DEVELOPING A PROJECT – A BOTTOM UP APPROACH.....	155
6.6 PROJECT ISSUES – PIERCING THE JIGSAW .....	157
6.6.1 <i>Confidentiality</i> .....	157
6.6.2 <i>Publicising projects</i> .....	158
6.6.3 <i>Local Deaf issues</i> .....	161
6.6.4 <i>Volunteers</i> .....	163
6.6.5 <i>Importance of venue</i> .....	165
6.6.6 <i>Other health professionals’ attitudes</i> .....	165

6.7 MEASURING EFFECTIVENESS/SUCCESSSES OF PROJECTS.....	167
6.8 STUDY 3 - CONCLUSION .....	169
 <b>CHAPTER 7 THROUGH THE LOOKING GLASS: A PERSPECTIVE ON DEAF HEALTH.....</b>	 <b>171</b>
7.1 SUMMARY OF STUDIES.....	171
7.2 WORKING TOWARDS A MODEL OF DEAF HEALTH .....	174
7.2.1 <i>Community intervention work</i> .....	174
7.2.2 <i>Strengthening communities</i> .....	176
7.2.3 <i>Service provision – Reducing structural barriers</i> .....	178
7.3 FUTURE RESEARCH .....	181

## **LIST OF FIGURES**

	<b>Page</b>
Figure 1.1 External influences on the Deaf community	16
Figure 7.1 Factors to consider when undertaking intervention work	172
Figure 7.2 Factors to consider when planning an appropriate health programme for the Deaf community	173

## LIST OF TABLES

	<b>Page</b>
Table 5.1 Provision of sign language interpreters	104
Table 5.2 Data for informants	106
Table 5.3 GP visits	107
Table 5.4 Mode of communication with GPs	108
Table 5.5 Situations where an interpreter may be used	110
Table 5.6 Deaf people's view of their own health	121
Table 5.7 Deaf people's responses to statements linked with health	136

## **LIST OF APPENDICES**

	<b>Page</b>
APPENDIX 1      Study 1 – Focus Group Schedule (University Students Discussion Schedule)	196
APPENDIX 2      SF-36 Schedule	201
APPENDIX 3      Study 2 – Semi-Structured Open-Ended Interview Schedule (Deaf Community)	205
APPENDIX 4      Study 2 – Section 5 of Questionnaire Raw data for Measuring Deaf people’s Attitudes to Health	215
APPENDIX 5      Study 3 – Semi-Structured Open-Ended Interview Schedule (Health Professionals in the Deaf Community)	218

## GLOSSARY

**Sign language** – refers to the indigenous language used by Deaf people in a country.

Every country (which has a deaf group) has its own sign language, which has developed spontaneously within the Deaf group.

**BSL** – British Sign Language, a distinct and separate language from English.

BSL refers to the language of the British Deaf community.

**ASL** – American Sign Language, a distinct and separate language from English.

ASL refers to the language of the American deaf community

**SSE** – Signed Supported English refers to a signed English use of sign language that is based on the English Language.

**Deaf** (with capital D) – refers to a person who uses sign language as their primary means of communication, identifies him/herself with other Deaf persons and usually does not hear.

**deaf** – Throughout this thesis the term deaf is used to describe both those who identify with the culturally deaf community and those who, while audiologically deaf, do not identify with the culturally deaf community. While the author is fully aware and supportive of the use of the notation Deaf to refer to those who describe themselves as culturally deaf, in preference to the author assigning cultural status to one or the other, the term deaf will be used throughout the thesis to prevent any bias arising. Contextual reference to cultural allegiance will be embodied within the text.

**Hard of hearing** – commonly used to describe people who are partially deaf and have acquired their hearing loss following the acquisition of speech, especially in later life.



**hearing impaired** – has a broad meaning which can refer to all groups of deaf and hard of hearing or just to the hard of hearing. It has been agreed between the World Federation of the deaf and the International Federation of the Hard of Hearing that the terms deaf and hard of hearing should be used, but the reader may come across the vague expression ‘hearing impaired’ (EUD, 1997).

**Mainstreaming** – the name given to placing deaf children in hearing schools, whereby they are usually located in a PHU or HIU, or in isolation.

**PHU** – Partially Hearing Unit, set within a mainstream educational setting.

**HIU** – Same as PHU, but referred to as Hearing Impaired Unit, this term is more in use nowadays

**Minicom** – A telephone used by deaf people who type their conversation which can be either read and answered by another with a minicom, or can be relayed through the Typetalk relay service, to a normal telephone.

**Typetalk** – Is the national telephone relay service which enables deaf, deafblind, deafened, hard of hearing and speech-impaired people to communicate with hearing people anywhere in the world. It is run by the RNID and funded by BT. A third person (a relay officer) is used to relay this conversation using appropriate technical aids and voice.

**BDA** – The British Deaf Association is the UK’s largest national organisation run by Deaf people, for Deaf people. They represent the Deaf community, a community united by shared experiences, history and, above all, by a common language: British Sign Language. The BDA's vision is of a world where Deaf people who use sign language enjoy the same rights, responsibilities, opportunities and quality of life as everyone.

**FDP** - The Federation of Deaf People was launched in early 1998. Frustrated by the lack of political movement in the Deaf community, they wanted to take action and influence change. The FDP is a Deaf campaign organisation and has the following aims: to empower Deaf people, to act as a pressure group and to act as a watchdog.

**NDCS** – The National Deaf Children’s Society is the UK’s leading charity for deaf children and their families. NDCS aims to support parents in enabling their child to maximise their skills and abilities; and works to facilitate this process by every means possible. Its fundamental role is to advocate for parents and carers as and when appropriate, whilst at all times ensuring the child's welfare is paramount. It campaigns for improvements in services aimed at families with deaf children, working with central and local government, health authorities, education professionals, social services, manufacturers and other voluntary organisations.

**RAD** – The Royal Association for Deaf People strives to meet the individual needs of deaf children and adults and deafblind people through the provision of services and the use of RAD Centres for Deaf People.

**RNID** – The Royal National Institute for Deaf People is the largest charity representing deaf and hard of hearing people in the UK.

**SIGN** – This UK charity focuses on the mental health of deaf people. It aims for a world where there is little risk of deaf people developing preventable mental health problems and that equality, respect and fulfilment are enjoyed by deaf people experiencing mental health difficulties.

**CACDP** – The Council for the Advancement of Communication with Deaf People is a registered charity that is raising standards of communication between deaf and hearing people. They do this as a UK awarding body recognised by the Qualifications and Curriculum Authority offering a wide range of nationally accredited qualifications. It is also the registration body for professional British Sign Language/English interpreters (for England, Wales & N Ireland).

# **Chapter 1 Establishing the Target Group under Study**

## **1.1 Introduction**

This thesis looks at the experiences of deaf people in the health system, and the consequences of this, whether they are positive or negative. It also researches the issues and concepts surrounding deaf health and the subsequent health strategies that have been practised. Current research is largely based within the larger field of minority groups and health. This way of interpreting other people's experiences stems from wider research carried out with Black and Minority Ethnic communities and is published in wider literature.

Focus is placed upon two aspects – medical encounters and deaf people's understanding of their own health. Research undertaken describes in detail how a group of deaf people understood these issues by asking them questions in an interview, in addition to a group situation. This understanding is then compared with already reported attitudes and ideas explored in the literature review. Differences between current findings will be examined through a set of defining issues tied into the experience of being deaf/from a minority group.

Attempts at defining what the Deaf community means in literature has focused on the very nature of how deafness is perceived. This tends to link in with the medical definition in lay literature, which has traditionally looked at how deaf people perceive medical terminology and to a lesser extent, their experience of health care systems. However, in recent years there has been a shift towards a community based approach, which has been brought about by deaf people as a result of their life experiences. For example, the following quote appears to be the 'norm' for traumatic experiences:

One instance in particular, a lady complained that she had been visiting her GP complaining of pain in her stomach and was being treated with antacids. She felt that the GP was not taking notice of the severity of what she was telling him. We got an interpreter involved, but within a few months she died of cancer of the stomach.  
(Gill, 2004)

An exploration is also made of differing data collection methods that could provide some validity towards proposing that deaf people have an understanding of their own health. This offers an insight into a framework of intervention that follows a bottom up approach, and is appropriate to deaf people's health needs.

The literature review has indicated that deaf people are at an increased risk of suffering from poor health. Thus it is necessary to understand deaf people's experiences, in the context of community life, to identify the underlying reasons behind what health promotion means to deaf people. This in turn assists towards formulating a theoretical framework of what health might mean to deaf people. The identification of deaf people as a linguistic/cultural minority has brought about some changes in the way that some governmental/statutory services have been organised, particularly during the last decade.

An exploration of the origin and underpinnings of seeing deafness as a pathological condition will be outlined in this chapter. The research has focused on adopting a more holistic approach to the concept of health promotion taking into consideration social, economic, political and environmental factors and their subsequent impact on the health of deaf individuals. This offers a way of thinking that differs from the traditional medical model, which seeks to address the symptoms as opposed to the causes.

In this context, the next section will explore how the Deaf community is perceived as a language-using minority, in contrast to the disability models, which generalise around the medical and the social model.

## **1.2 Deaf community – numbers and definitions**

It is useful in the first instance to look at the demographics of the Deaf community. There are an estimated 50,000–60,000 deaf people whose first or preferred language is British Sign Language (BSL) (Brien, 1992). Every year 840 babies are born deaf in the UK with a severe/profound hearing loss (Davis *et al*, 1997).

One of the first things service planners ask is, ‘How many deaf people are there?’ and, ‘How much will it cost?’ This is a particularly grey area and is not further helped by the fact that deaf people are usually ‘invisible’ in national statistics.

Planning services requires knowledge of how many deaf people there are and where they live. There are many differing figures, and this is not further helped by the statistics being unable to differentiate between those who are classified as deaf from those classified as hard of hearing.  
(SIGN, 1998, p8)

In 1995, 25,993 deaf adults (aged 18-64) were registered with local authority social services in England. The Department of Health points out:

Registration of disablement with the Social Services Department is voluntary and is not a condition for the provision of any social services. It is therefore unlikely that these statistics measure the true prevalence of hearing impairment in the population. Doubts also exist as to the regularity with which these registers are reviewed. Deletions due to deaths and amendments due to migration for instance may not be reflected in these figures. Because of these difficulties the statistics should be used and interpreted with care.  
(Department of Health, 1995, p9)

The best estimates of the size of the Deaf community in the UK are between 19,000 and 25,000 people (SIGN, 1998). However, this level of inaccuracy about the numbers and distribution of deaf people will not assist greatly with any local or regional planning.

Ladd (2003) notes that ascertaining the size of the community has also been affected by the confusion of medical and cultural criteria. Prior to the mid 20th century there appears to have been a higher incidence of deafness during childhood, thereby offering a larger pool of potential community membership, along with the absence of hearing aids, which meant that more partially deaf children were also placed in the deaf education system.

Deafness has been poorly understood in respect of the status of BSL users as a minority community with its own distinctive culture. Writings have tended to focus on the medical perspective rather than the social and cultural perspective. For example,

deafness has traditionally been measured through clinical or functional tests. The functional tests ask questions such as, 'Can you hear someone whispering?' (Schein and Delk, 1974).

This placement of deafness in medical discourses and settings shapes the public perceptions of deaf people. Interventions focus on the environment as well as the individual, and the perspectives of deaf people influence defining the experience of being deaf. The judgement and behaviour of professionals is subjected to the same scrutiny as that of deaf people. Social attitudes and popular culture are typically studied in order to better understand the sources of prejudice and stereotypical images of deaf people (Foster, 1996).

Thus there have been various attempts at defining the Deaf community. Consequently, the literature is divided over whether the Deaf community is regarded as a linguistic, ethnic, social or handicapped community. Deaf people who consider themselves as part of this community often have a different perception of what membership of the community means. Despite the 19th century descriptions of deaf social structures, the accounts of British Sign Language, the identification of the preferences among deaf people to choose deaf marriage partners, the recognition of the existence of a British Deaf community and so on. The first description of its cultural and community characteristics have only taken place in the last 25 years (Lawson, 1981).

Theories on the criteria for community membership vary, but most often specify a shared sign language, and identification with other deaf people. Hearing loss is not itself seen as a defining feature, and many audilogically deaf people for example, those deafened later on in life tend not to be considered members of the Deaf community since they do not use sign language or socialise with those that do (Kyle and Woll, 1985).

Lane (1992) presents this paradigm shift, he believes that sign language and the increasing recognition of the Deaf community's own perspectives are changing these perceptions, in particular deaf people seeing themselves as a linguistic minority rather

than as a disabled group (Lane *et al*, 1996). Traditionally sign language has been thought of as an inferior system of gesture and mime with no grammatical structure (Kyle and Woll, 1985), which goes some way towards explaining prevailing attitudes.

Deaf and hearing researchers have described the history, language and culture of deaf people (Sacks, 1990; Padden and Humphries 1988; Groce 1985; Lane 1989). This research has been conducted with a goal of understanding the experience of deaf people from the 'inside out' i.e. through their stories and words. Ethnographic research methods have been used to explore the experiences of deaf people in a variety of areas. Such notable examples are Higgins (1980) and Becker (1980) who have described different aspects of the community life of deaf people.

Ladd (2003) coined a new label of Deafhood, which moves away from the static medical condition such as 'deafness'. He describes this as a process whereby it illustrates the struggle by each deaf child, deaf family and deaf adult in order to explain to themselves and to each other their own existence in the world. He goes on to explain that this is identified through sharing their lives with each other as a community, and enacting those explanations rather than writing books about them. Deaf people are then engaged in a daily praxis, a continuing internal and external dialogue. This dialogue not only acknowledges that existence as a deaf person is actually a process of becoming and maintaining being 'deaf', but also reflects different interpretations of Deafhood and of what being a deaf person in a Deaf community might mean.

### **1.3 How the Deaf community is perceived**

This section explores the three different models by which deafness is categorised, and how it is perceived by society at large. The first is the purely medical or audiological model. The subsequent two models are the social model and the culturo-linguistic model. Each of these will be looked at in turn.



### ***1.3.1 The Medical Model***

The medical model has been described as a personal deficit model, within which the condition of deafness is defined as a physical deficiency or abnormality that interferes with the individual's ability to function. Whether the focus is upon physiology, personality, education or employment, the individual is considered disabled by his or her hearing loss, and the problems associated with the condition reside with the individual (Foster, 1996). The language of the medical model reflects this perspective and includes such terms as 'hearing impaired', 'disabled', rehabilitation, 'prognosis' and 'stages of adjustment'. Research following the medical model of deafness is generally conceived with the goal of preventing, curing or at least diminishing the effects of hearing loss by changing the deaf person. Research in audiology and speech therapy plays a major role, for example, Myklebust (1964).

When it is suspected that any child for whatever reason may have some degree of deafness, the initial step for the family usually involves a visit to the local hospital Ear, Nose and Throat (ENT) department. In recent years the induction of Universal Neonatal Hearing Screening (UNHS) has been rolled out across the UK.

UNHS is the screening of all newborn babies for deafness during the first days of birth. The initial test usually carried out in hospital before mother and baby return home, is the first step in a screening and assessment procedure which leads to identification of most deaf children in the first two weeks of life, possibly by two months of age... The Newborn Hearing Screening Programme, based in Nottingham, aims to implement a hearing screen for all newborn babies in England. It is expected that Health Authorities across England will be participating by the end of 2004. The implementation programme is being carefully evaluated as it is rolled out.  
(RNID<sup>1</sup> and NDCS<sup>2</sup>, 2002)

The implementation of UNHS will lead to an increased demand for early intervention/support services for deaf children and their families. This will give multi-disciplinary services the opportunity to examine existing practices and explore the ways

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<sup>1</sup> Royal National Institute for Deaf People

<sup>2</sup> National Deaf Children's Society

in which services can be developed to ensure that all newly diagnosed deaf babies and their families receive the appropriate support to meet their individual needs (NDCS, 2002).

Due to the fact that a higher proportion of deaf babies will be identified within the first two months of life, it is apparent that families will require support for a longer period of time. Some expansion of services will be required, particularly in the first two years following implementation of the new screening procedures, and following a family friendly focus.

Another implication of UNHS is that children with moderate hearing losses will be picked up very early and will be represented in caseloads in greater numbers. This is the population most at risk of being missed or picked up very late by current screening arrangements. Working appropriately and in partnership with the families of very young deaf babies brings new challenges for professionals. The professionals also require shifts in knowledge and skills to support the early establishment of communication and language in developmentally appropriate ways. Lane *et al* (1996) notes that parents have the right to professional advice that forms a balanced decision of the possible futures for their deaf child.

A review of literature illustrates the time delay in the diagnosis process prior to the roll out of the UNHS. In a study carried out in Canada, Freeman (1977) reported an average time lag of about a year between the first parental suspicion and the professional confirmation of the hearing loss. About one-third of the doctors refused to refer the parents to a specialist. Meadow (1967) reported similar findings in California; more than 60 percent of parents had at least four medical consultations before a diagnosis was made.

Prior to UNHS being implemented in the UK, a series of tests took place to diagnose or establish the child's degree of deafness. This diagnosis of hearing loss classifies the degree of deafness into one of several categories called audiological descriptors (Knight

and Swanwick, 1999). This means that the child will be diagnosed as mildly, moderately, severely or profoundly deaf. As a general rule those children whose deafness falls within the categories of mild, moderate and less severe will be thought of as a ‘partially deaf’ child, while those whose deafness is more severe will be considered to be a ‘profoundly deaf’ child. Efforts will also be made to find out the cause of the problem, and to provide appropriate amplification devices (hearing aids) to compensate for the degree of deafness as far as possible.

This way of describing and defining deafness reflects a medical perspective. Emphasis is placed on appropriate medical treatment and the provision of hearing aids. Both of these actions are to cure or minimise the effects of deafness (Knight and Swanwick, 1999).

At the other end of the spectrum, disability theory achieved a breakthrough in the 1980s when disabled people identified attitudes towards them as originating in a belief that they were not full human beings because of the absence of, or damage to, a physical fault and termed this a medical model of disability, which in effect ‘blamed the victims’ for their inability to achieve equality (Ladd, 2003).

### ***1.3.2 The Social Model***

The previous section illustrated how the disability movement coined the term ‘medical model’, societies were constructed for the benefit of non-disabled people, and that any attempt made to gain equal access and rights was seen as an ‘adding-on’ process which left disabled people at the mercy of benevolence and charity (Ladd, 2003).

Instead they proposed a radical social model, which asserted their fundamental equality as human beings with entitlement to full citizenship. Societies should be seen as being built and managed with all its members in mind, taking collective responsibility in order to ensure equal access and full citizenship for all, and so that refusal to do so would then be seen as social and political discrimination.

Ladd (2003) has commented on the fact that this radical approach has made some considerable progress in several domains. He notes that the 1990s saw the beginnings of processes to ensure comprehensive legislation to enforce this model. However powerful medical and scientific sectors continue to pursue their own model, as can be seen in the current genetic engineering discourses.

In the last decade Deaf communities have participated widely in the social model movement mainly because they lacked the power to make their own views known. Many are uncomfortable with their inclusion in the disability social model because the criterion used for including deaf communities is that of physical deafness – in other words the medical concept. Ladd (2003) notes that this social-model legislation is suitable for the needs arising over specialist equipment required, such as flashing doorbells, textphones, and subtitles on the television, which also applies to deaf and deafened people. However, these are not issues that are specific to sign language communities, nor do they address their own deeper needs. The irony of this situation is that the medical model is condemned; yet physical deafness is almost a prerequisite of cultural membership.

### ***1.3.3 The Culturo-linguistic Model***

This third concept concerns the widely held belief among Deaf communities – that their existential situation is primarily that of a language minority rather than a disabled group (Ladd, 2003). This move from seeing deafness not as a medical condition but a cultural one is also noted by many recent writers, including Luterman *et al* (1999).

In respect of the children of this language minority Knight and Swanwick (1999) conceive this belief to then focus on the linguistic needs of the deaf child i.e. where consideration is given to the language (spoken or signed) that the deaf child will most easily develop to a level related to their age and general development. They identify several external influences affecting the linguistic development of that deaf child, such as the hearing status of the family, social, environmental and economic factors. They conclude that the focus should be placed on the child's specific language requirements

and the language that they would acquire most easily and appropriately for their age group. This can be thought of as the child's first or preferred language.

The most common indicator of a deaf child's developing their preferred language will be their degree of deafness.

It is accepted that those children who are partially deaf will probably have enough residual hearing to develop a spoken language as their preferred means of communication. A child who is diagnosed as profoundly deaf is more likely to develop sign language – the visual/gestural language of the Deaf community – as their preferred mode of communication.  
(Knight and Swanwick, 1999, p23)

This means that the language development of deaf children falls into two distinct categories; deaf children who use spoken language as their first means of communication and develop sign language as a second language, and others who whose sign language as a first language and English as their second language. Effectively this replaces the medical model where children are categorised by their degree of deafness. There is a shift away from focusing on deafness as a medical condition, with the onus placed on the language needs of the deaf child arising from their specific patterns of deafness and their language preferences.

Ladd (2003) notes that sign language users know that they cannot find a 'home' within the majority society, until the day when that society is able to use their language (Groce, 1985). Consequently, the Deaf community is their natural 'home', and is referred to as such. Deaf people will make efforts in various ways to ensure that strong communities are built and foundations are put in place that will sustain deaf adults throughout their daily lives.

He also notes that the community members require that deaf children leave school with literacy skills, and be aware of their own Deaf community. Only then can they have an opportunity to run clubs, sports, cultural events and political organisations, which characterise 'Deaf community' life. He terms this oppression as *double oppression*.

For the past two centuries Deaf community members have argued that to enhance the quality of deaf children's future lives, the focus should be placed upon education. The priority should not be focused upon gaining increased disability allowances, or access to buildings, but for deaf children to receive an appropriate deaf-centred education in their own language, so that the quality of life within the collective culture can be maintained and enhanced.

At the heart of this model is the belief that the driving force in social relations is power, including the ability to define a situation and to direct its outcome. Historically hearing people have held more power than deaf people, and have therefore been able to impose upon deaf people their definitions of deafness as a disability (Foster, 1996). The political model for understanding deaf people suggests that, no matter how benevolent their intentions, hearing people cannot fully understand the experience and culture of deaf people any more than Caucasians can comprehend the experience of being black in the UK. Language used in the political model includes: oppression, emancipation, civil rights and control.

This model calls for political empowerment of the Deaf community by appointing deaf people to positions of authority, especially with regard to control of resources and programs for deaf people. Research grounded in a culturo-linguistic perspective of deafness has examined the history of deaf people through the lens of oppression and relative power. For example, Lane (1992) suggests that the relationship between the Deaf community and those who would provide services to them can best be characterised as 'oppressed and oppressor', resulting in the dehumanisation of the Deaf community and profit for the service providers.

Consequently, it can be seen in the context of health, that the concept of the Deaf community as its own resource is affected by the negative effects on individuals. Ultimately they are seen as belonging to certain categories imposed by the various professionals. Further analysis of the culturo-linguistic model has shown that deaf people can be seen as part of a minority language group and also as a cultural group. Much of

what happens where health issues for minority groups are concerned has similar parallels to those for the Deaf community.

#### *1.3.3.1 Language and cultural affiliation*

This culturo-linguistic perspective is based on a living language and a unique community, where being deaf is defined in terms of a way of life, not in terms of a medical condition. Deaf members are therefore valued for their own cultural identity in their own right, and are not seen as impaired versions of hearing people (Lane, 1992). Society's lack of recognition of the linguistic status of deaf people has left deaf people at a disadvantage:

The Deaf community can now be identified as a linguistic minority, rather than as individual handicapped people whose problem is the inability to hear sounds, and who are themselves a problem. This has made the issue a question of discrimination against a language-using group and society's attitude has become the problem.  
(Ladd, 1988, p41)

Those that belong to the Deaf community have made a choice to mix with and be with others from a similar background to themselves. The Deaf community is unique because they form a community that does not live together in a community grouping, although 90% tend to marry other deaf people. Deaf people tend not to work together, and they usually use their language in interaction with situations, which are of a social nature (Kyle and Woll, 1985). The community usually meet at Deaf clubs, although there has been a gradual decline in recent years as a result of mainstream activities and opportunities, along with technology. In more recent years transient deaf social gatherings have become more common, mostly made up of young deaf people, and track an itinerant Deaf club around various pubs and clubs in the UK (Kyle *et al*, 1997).

This social interaction ensures that those who make this contact and have no skills in sign language, quickly learn to sign and become members of the community. These latecomers tend to consist of post-lingually deaf, orally educated deaf and mainstreamed deaf people (Lawson, 1981). However, language usage is heavily dependent upon on

factors such as late diagnosis of their deafness, late entry into the Deaf community or special school settings.

When looking at sub groups within the Deaf community we can recognise that minority ethnic families with a deaf child are not a homogeneous group. Socio-economic differences, as well as religious and cultural diversity, mean that people's understanding and attitudes towards deafness are not the same (Chamba *et al*, 2000). Studies conducted with young deaf people from minority ethnic groups reveal that many individuals grow up knowing very little about their cultural traditions and heritage (Badat and Whall-Roberts, 1994). Parents' accounts also highlight problems in transmitting cultural knowledge to deaf children from a young age, often leaving children feeling isolated within the home (Gregory *et al*, 1995). The situation is not helped by their contact with professionals who are often unaware of the cultural and religious implications of their advice. Schools have also been criticised for providing a 'white' environment and having limited resources to teach young children about their own religious beliefs, values and customs. As one Bangladeshi mother of a young deaf child remarked, "I send my son to school and he comes back an Englishman" (Ahmad *et al*, 1998).

To address this problem, efforts are being made to raise awareness of cultural and religious diversity within the deaf world. The employment of more minority ethnic people to work with deaf people and their families has been one way of ensuring that organisations are better equipped to address the needs of parents. Indeed over the past decade, there has been an increase in the number of African Caribbean and South Asian professionals such as teachers, social workers and British Sign Language interpreters working with families of deaf children (Darr *et al*, 1997).

All of the aforementioned factors have implications for understanding the make-up of the Deaf community. In order to obtain a better understanding of what impacts upon community collective behaviour, the consequences of individualist and collective cultures are investigated in more detail in the next section. These cultural theories offer an



understanding as to how the western culture operates in the context of health and its subsequent impact on the Deaf community.

#### **1.4 Collectivism and Individualism**

Mindess *et al* (1999) identified that 70% of world cultures can be labelled collectivist or group orientated – they include much of Africa, Asia and Latin America. In all such cultures members of a group (family, work group, tribe, caste or even the entire country) help each other to survive. Individuals subordinate their personal goals to the group. Mindess *et al* (1999) sees American deaf culture as qualifying as a collectivist culture, with its emphasis on pooling resources, the duty to share information, the boundary between insiders and outsiders, and loyalty to and strong identification within the group. Further exploration of how such initiatives work in the context of health and deaf people will be made in the analysis of data in later chapters.

In collectivist cultures rules for group membership are rigid, and one must essentially be born into and grow up within that culture to qualify as a member. It is said, for example, that even if foreigners can speak perfect Japanese, they will never be able to think like the Japanese (Mindess *et al*, 1999). We can see the similarity in deaf culture:

Deaf people seem to agree that a hearing person can never fully acquire that identity and become a full-fledged member of the Deaf community. Even with deaf parents and a native command of ASL, the hearing person will have missed the experience of growing up deaf, including attending a deaf school, and is likely to have divided allegiances.  
(Lane, 1992, p17)

Thus insider/outsider distinctions are crucial to determining behaviour in collectivist cultures. Another facet of collectivism is the preference of the members of such a culture to engage in many activities together, and in this way deaf people feel strong ties to the Deaf community.

By contrast, in individualist cultures such as the United States, Australia and most of North West Europe, the basic unit of survival is the individual. The onus is placed upon being encouraged to be independent, self-reliant and always ready to take responsibility for one's own actions. Heavy emphasis is placed upon personal choice, opinions and creativity. Group membership is flexible and one can be a member of several groups simultaneously. However, Mindess *et al* (1999) notes that identification with these groups in individualist based societies are relatively weak, and no one group can completely define the identities of its members.

In deaf culture the most respected leaders are felt to be responsible for other deaf people in a personal way. They must not only work for the betterment of the community but are expected to be open to all its members, giving them time, attention and help.

(Smith, 1996, p30-31, cited in Mindess *et al*, 1999, p42)

Individual success in deaf culture is applauded with the proviso that one must not distance oneself from the Deaf community. In various health initiatives and particularly in Chapter 6, when looking at the data of deaf health professionals, the impact of this responsibility on the deaf professionals in these areas can be seen.

## **1.5 External factors that affect the Deaf community**

There are several factors that affect enculturation into the Deaf community; these are illustrated in figure 1.1. The underpinnings for each of the factors are explored in further detail in this section.

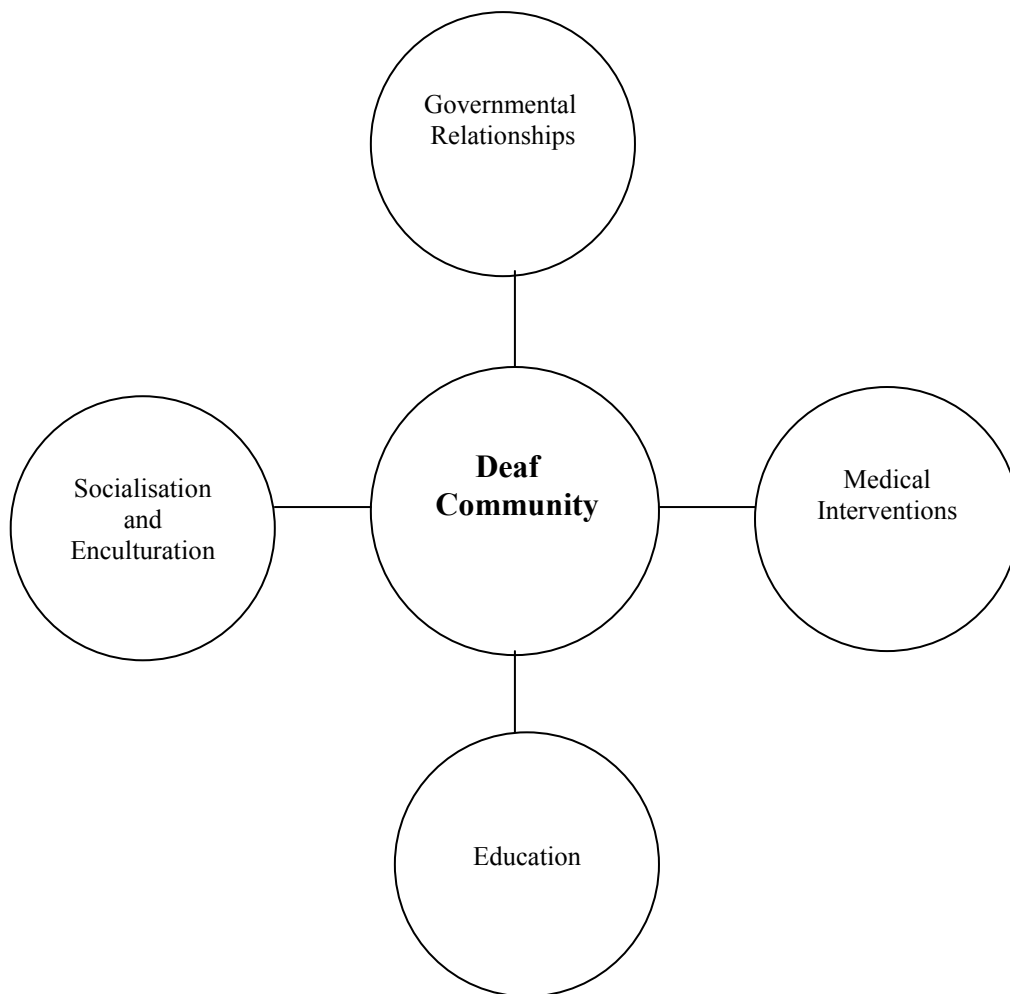


Figure 1.1 – External influences on the Deaf community

### ***1.5.1 Deaf community and governmental relationships***

Deaf organisations have to operate with the three main levels of government in the UK in order to influence public policy. The first is the British government at national policy level. The second level is at a regional level, in the countries that have assemblies with legislative power, for example, Scotland and Wales. The third sector is local government who have responsibilities for the elected local authorities, whose remit includes social

Services, Education and Transport. There are also unelected bodies with responsibilities for Health, Police, and Law courts.

The breakdown of influence at different levels means that there are restraints for local deaf organisations. The cost of contribution to policy development has been seen as a heavy burden on local deaf organisations and it was felt that this was best left to the national deaf organisations (RAD<sup>3</sup>, 2002). At a meeting with the chief officers of local deaf organisations, part of the Kaleidos project looked at best practice in a European wide context and at the experience of how public policy has been influenced. The general consensus was that there was some unwillingness to criticise the funder – whether it be local or national government – a case of not biting the hand that feeds you and staying within the criteria for funding. As a result, local deaf organisations felt constrained in being critical of public policy in order not to jeopardise their funding prospects. However, this scenario is commonplace with small organisations representing small communities, who experience similar problems with obtaining funding.

At a national level the legal framework in which the rights of deaf people are incorporated at governmental level includes the Disability Discrimination Act (1995). This covers the provision of goods and services, employment and premises, requires ‘reasonable adjustments’, but currently excludes education, transport, military, and small employers. In education the Special Educational Needs and Disabilities Act (2001) is in practice. Finally, the Disability Rights Commission (DRC) is a body that monitors and advises on application of disability rights legislation, and has certain powers to enforce the legislation. Some concerns have been expressed at the government proposals to streamline the DRC in line with the Racial Equality Commission Board to become a Single Equalities Commission – the fear of disability rights as an umbrella term being lost in the weight of the work on disability and gender issues.

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<sup>3</sup> The Royal Association for Deaf People

It was generally felt that local deaf organisations tend to be effective at local and regional and moderately at national level. National organisations tend to be effective in proportion to their size and resources. The BDA<sup>4</sup> and the FDP<sup>5</sup> have traditionally been the only national organisations of the BSL community, and the small size of their funds is noticeable in comparison to those who embrace the medical and social welfare models for the D/deaf. Major cultural or resource changes are difficult to achieve at any level, and several organisations tend to be bogged down with bureaucracy.

The evidence clearly demonstrates that this has impacted several areas in deaf people's lives, especially in education, social services, and in particular, health. It can be seen that governmental policies conflict with deaf culture; the policies determine that individuals are seen as taking responsibility for their own health in an individualistic rather than a collective way.

#### *1.5.1.1 Funding and its implications*

Funding sources and constraints have had important implications for service development, user involvement and systems of accountability. The short-term nature of funding for 'special initiatives', has made long term planning difficult for projects (Ahmad *et al*, 1998).

It was found that pressure was placed on the project workers to demonstrate that their work was deserving of continued support. This could only be achieved by creating a balance between the monitoring and evaluation of the project, to support claims for continued support and efforts for new funding. The project effort was often diverted from the actual work, and focused on its presentation and evaluation for the benefit of the funders.

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<sup>4</sup> British Deaf Association

<sup>5</sup> Federation of Deaf People

The limited knowledge of funding sources and underdeveloped skills in securing funding in the voluntary sector were difficult to overcome. This means that deaf workers have had to rely on hearing allies who had experience of dealing with such funding proposals for support in securing funding.

Additionally, restrictions on how the funding could be spent created tension with workers having to accommodate user-defined needs into funder-defined remits. Where such restrictions were not imposed, there was more flexibility in the scope of the project and allowed for greater user involvement in decision making. Attempts were made by the workers, often deaf, to develop portfolios of funding to support different aspects of their work. This both offered greater flexibility within the portfolio and added appreciably to the burdens carried by workers, in order to maintain a constant flow of funding from various sources (Ahmad *et al*, 1998).

### ***1.5.2 Deaf community employment***

Deaf people occupy the lower socio-economic groups in society in terms of jobs and status (Kyle and Pullen, 1984). This is a pattern that is also repeated in Europe (Jones and Pullen, 1990) and in the USA (Schein and Delk, 1980).

This is surprising insofar as deaf people's intelligence is distributed normally; although it is compatible with the fact that deaf people achieve fewer school qualifications.  
(Kyle *et al*, 1997, p25)

Deaf people tend to be 'underemployed' rather than unemployed (RNID, 2006). Generally they hold jobs in the unskilled and semi-skilled occupations; very few are found in professional or managerial jobs. There are also a significant number of white deaf people in employment compared to non-white deaf people. Jones and Pullen (1990) discovered in their study of deaf lives in European countries that there was evidence of underemployment, lack of opportunities and even occupational segregation. They found

that jobs for deaf people were usually acquired through personal contact, rather than on the open market or through rehabilitation or job finding agencies.

Sainsbury (1986) reported that the incomes of deaf people are likely to be disproportionately low, because they are underemployed and they are more likely than the general population to be dependent on social security benefits. For example, 70% of Sainsbury's sample in private households lived on the margins of poverty. Dye and Kyle (2000) commented that married and cohabiting deaf couples report a lower than usual gross weekly income than their hearing peers.

Sainsbury's (1986) study also found that deaf people are more likely to live in unsuitable housing. A later study (Dye and Kyle, 2000) found that deaf people's housing choices tended to be consistent with less affluence, with deaf people less likely to live in detached houses and more likely to live in terraced housing.

Deaf adults tend to be over represented in the lower social-economic status (SES) groups at least in the United States (Schein and Delk, 1974). Deaf employees tend to be overqualified for their jobs and earn significantly less than their hearing peers.

Given the positive relationship between employment and psychological well-being (Department of Health, 1999), there is some concern that the evidence suggests that deaf people are more likely to be unemployed, particularly deaf women. They are less likely to be employed within the professional and management sphere (Dye and Kyle, 2000; RNID, 2006). The difficulties experienced by deaf people in accessing professional education in the social and health care field fits with this pattern. This means that mental health services encounter problems in recruiting a group of people vital to high quality provision (Klein and Kitson, 2000).

### ***1.5.3 Limited enculturation through parents***

Enculturation has been defined as the ‘socialisation of children to the norms of their culture’ and also as ‘the process by which human infants learn their culture’.

It is important to look at the factors that affect the general mental well-being of deaf people. Like other minority communities, the make-up of the Deaf community characteristics tends to vary. Ninety percent of deaf children are born to hearing parents (Kyle and Allsop, 1982). Many deaf people from hearing families make the transition from the hearing environment of their families to a cultural affiliation with the Deaf community particularly during adolescence. This is probably the most significant external factor that affects deaf communities and culture.

Although 10% of deaf children inherit their sign language and culture and are able to pass them onto other deaf children, the process of enculturation for the majority is always vulnerable to ideological interventions. Using the medical model Ladd (2003) identified key areas such as oralism, mainstreaming, cochlear implants and genetic engineering. These issues control the Deaf community’s access to the parents, convey a medically orientated account of deafness, and reiterates that ‘normality’ can only be achieved by not exposing deaf children to deaf adults from the Deaf community.

#### ***1.5.3.1 Diagnosis***

In order to understand the external influences of the medical model, it is necessary to look at literature describing the diagnosis process. The vast majority of literature has focused on the ‘grief’ model, the emotional impact experienced by all families when they realise that their child is deaf (Knight and Swanwick, 1999; Moores and Meadow-Orlans, 1990; Marschark, 1993).

It can be very daunting for families when they are contacted by a number of different professionals, particularly if the families are not clear about their different roles and



functions. It is essential that families know who their key worker is, the person whom they should contact about problems in the first instance. It is also important that the families know what function the various professionals fulfil. Families also need to feel confident that the different professionals are working together, providing a seamless service, and thus the contact between different professionals should be described and emphasised whenever appropriate. However, it is of immense importance that early detection and early intervention takes place; this will ensure the best possible language competency and development (Luterman *et al*, 1999).

The values of hearing professional people affect how parents see the birth of a deaf child as a regrettable event (Lane *et al*, 1996). These parents may then adopt the hearing professional's perspective, especially since the specialist education, background and status seem to give their views extra credibility. From the outset they are expected to negotiate a plethora of professionals, many of which give conflicting messages (Gregory, 1995).

The fact that 90% of deaf children are born to hearing parents will mean that many families will not have met a deaf person or child and they will also have to face the difficulties of communicating with their deaf child in the absence of a common (spoken) linguistic system (Moore and Meadow-Orlans, 1990).

Children acquire their language, or languages largely through conversation with others. Language is not merely a vehicle for thoughts and a tool for learning, but is inextricably bound up with a person's identity and role, as perceived both by self and by others.

(Gallaway and Young, 2003, p1)

The language that is accessible to deaf children is not one that is used by their parents at home. Gallaway and Young (2003) acknowledged that the most important context for an infant's earliest learning is the home and the family. Young *et al* (cited in Gallaway and Young, 2003) identified a number of family intervention projects in the UK involving deaf adults, and emphasised that the introduction of deaf adults into the child's life, can have a number of beneficial effects at an early stage. This in turn would ensure that their

chances of developing language are maximised, with an adequate and age appropriate language system. Subsequently this is seen as a prerequisite to successful learning.

Schlesinger and Meadow (1972) noted that in the absence of a shared culture and language, parents of deaf children reported a constant concern about whether they were being overprotective or under protective. These parents used a narrower range of discipline techniques with greater reliance on spanking and exhibited more frustration with respect to their children. Meadow (1980) concluded that the protectiveness that most families exhibit towards their deaf children inhibits the children's social development. This suggests that the socialisation of the deaf individual can be restricted by the parental 'over protectiveness' and has an impact on their development, particularly towards adulthood.

#### *1.5.3.2 Oralism and the Deaf community*

The more vulnerable the parents, the more reliant and dependent they will be upon the professionals. There is evidence that the professionals appear to put their own values first when it comes to advising about methods of communication. More often than not professionals have suggested that oralism is the best approach for deaf children (BSMHD<sup>6</sup>, 1998). This one-sided approach does not consider whether it disadvantages the deaf child, impedes their learning and restricts access to educational achievements. Oralism places deaf children in such a way that hearing professionals use it to justify their own involvement. Beazley and Moore (1995) argue against spoken language as something that deaf children simply have to have because it helps them to be 'normal'. They suspect that this may not reveal the real reason behind resistance to other approaches, in order for professionals to reaffirm their sense of their own authority (Beazley and Moore, 1995). This approach effectively excludes deaf adults from being involved with the education and development, of future generations of deaf children.

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<sup>6</sup> British Society for Mental Health and Deafness

In raising a child, language is essential, and particularly so for deaf children. Humans require language and this fulfils their social existence. Communication is also a central issue for families and many aspects of daily life, social skills and routine established depend very much on its early and successful establishment within the home. Delaying this will only impact on the social and emotional well-being of the child.

#### ***1.5.4 Deaf education***

Studies in the education area illustrate that not much has changed since the Conrad report. The average deaf school leaver leaves school with an average reading age of less than nine years, speak unintelligibly and have limited lip-reading skills (Conrad, 1979). Because the system of deaf education fosters low self-esteem, being deaf is viewed negatively in society. Parents are often ill advised by these professionals not to use sign language with their deaf child because this is reputed to delay the acquisition of English, when in actual fact the opposite is the case (Kyle and Woll, 1985). Gregory (1995) found that 10% of her young deaf adults sample had to be excluded because they were described as having 'limited language' skills and the deaf interviewer could not communicate adequately with them.

No later studies have adequately demonstrated that there is any improvement. Research is patchy but findings on reading ability (Wood *et al*, 1986) and speech intelligibility (Markides, 1983) show similar results. Such results are not unique to the UK and have been confirmed by similar research throughout the western world, including the USA, Holland, Denmark and Sweden. Two recent reports on deaf pupils' attainments have concentrated on exam results. In the first Powell (1995) collated the published 1993 and 1994 GCSE results of pupils in special schools for the deaf in England and Wales, which were significantly lower than the national average. In the second report (Powers 1996), a questionnaire was carried out with Year 11 pupils (16 year olds) deaf pupils in mainstream schools in England in 1995. This is the only recent research in the UK that has attempted to investigate a range of background variables on pupils' attainments. Powers repeated the exercise in 1996 to improve the response rate. Predictors for success

included the age of onset of deafness, the socio-economic status of the family and the presence of any additional learning difficulties. The hearing status of the parents and the language used in the home were less important but nevertheless significant factors.

Historically it was the case that the majority of deaf children were placed in residential schools. This marked for some the beginning of their integration into the Deaf community (Lane *et al*, 1996). For deaf children that are placed in a hearing school, the parents may be reassured but this is likely to add to the delay in learning and language acquisition. This denial and placing their child into mainstream education may mean that the deaf child will spend much of the school day isolated in a group of hearing children and lacking the social support of others who are deaf like themselves.

Deaf adults have continuously spoken of their relief when they were first able to meet and mix with other deaf people, either at another school, at work or at the Deaf club. They discovered that they were not imperfect copies of hearing people; rather they were deaf with a culture and community (Lane *et al*, 1996) and felt they had 'arrived home'.

Schlesinger and Meadow (1971) reported that adolescence is a time of particular stress for deaf children and their parents. The gap between the deaf child and the hearing child widens at this point. The socialisation patterns may begin to differ. Adolescence is a time of uncertainty for the young person undergoing various physical and emotional changes, who is no longer a child but not yet an adult. This strain can become greatly intensified for a deaf child who may experience greater difficulty in establishing a personal position within the family structure.

For instance, the deaf child may miss out on understanding conversations and discussions indirectly, which helps them to learn the mores, values and behaviour that the family and culture consider desirable or undesirable. Incorporating all these favourable environmental factors enables the personal and social development of the deaf child to be on a par with their hearing counterparts. As the deaf child gets older they are able to

engage in discussion with their parents, for example, why it's time to go to bed, and why there is no school today (Lane *et al*, 1992).

These are all meaningful exchanges that enhance the child's development, and further assist their *worldview* and conceptual thoughts. This enables deaf children of deaf adults to become adults with a strong sense of who they are, and a positive sense of their ability to accomplish what they set out to do. When this is not in place then young deaf people feel excluded from general information within the family and the decision making process. Gregory (1995) reports that the majority of parents (76%) describe their main problem with their deaf child to be communication. In her follow up study a few years later, 75% of the original sample and over 50% of parents still claimed to be concerned about their son's or daughter's communication skills. Often the responsibility for communication lies with one family member, usually the mother or a sibling. In many families the father had poor communication with the young deaf person (Gregory *et al*, 1995).

In 1995, 93.7% of deaf children were placed in mainstream schools compared to 64% in 1981 (Walker, 2000). The different figures can be accounted for by the fact that the Government does not collate data on the number of deaf children nationally. Until 1981 disabled children were divided into 11 different categories. This all changed with the 1981 Education Act when they were all placed in one category, Special Education Needs (SEN), on the advice of the Warnock Report (1978). Since then, Deaf organisations have taken responsibility for collating their own data.

This experience often has a significant impact on any young deaf person, as it is usually the first time that they meet their deaf peers and exposed to sign language. Although they may not sign fluently upon leaving school, development of a rudimentary sign language would be utilised even at an oral school for the deaf.

#### *1.5.4.1 Resistance of belief in existence of the Deaf community and its language*

Initially the medical and audiological group of professionals will play a leading role in family life, followed by those at nursery, infant school, primary school, and then secondary school. Deaf adults, who could present to hearing parents a positive view of their child's prospects, are very rarely to be found in any of these groups. Indeed, many professionals appear not to appreciate the full value of the resources that deaf professionals can provide. Many focus on their limited academic achievement, inability to speak, the limited value of BSL, and the deaf world as isolated and ghettoised. This adds to the parents' trauma and exacerbates their fear of the unknown. It is not surprising then that these parents go through a process of denial that their child is deaf, which may last for many years.

Stereotyped beliefs about the limited mental capabilities of deaf people and the inferior status regularly assigned to them have had a considerably negative effect on the self-confidence and self-esteem of deaf people. This is a typical phenomenon of oppression. As a result there is an internalisation of oppression, whereby a person starts to believe what is said, thought and written about them. (Ladd and John, 1991, p44)

It is suggested that one of the responsibilities of oppressed groups is to educate their own members on how to develop plans to change the order of things. We have seen evidence of a response to this through various pressure groups run wholly by deaf people such as the National Union of the Deaf (NUD) formed in 1976. Its successes not only brought into question the appropriateness of hearing people's control of deaf affairs, but also questioned the suitability of deaf leaders who were content to operate under such systems (Ladd, 1998).

#### *1.5.5 Further negative interventions*

Much of the positive culturo-linguistic research is relatively recent, and has not been incorporated into the training of many of the health professionals. Deaf adults are rarely to be found in the professions consulted by the hearing parents. The health care

professionals are naturally orientated towards a health care perspective, one that emphasises the latest medical and prosthetic technology. Their approach is not with the cultural perspective but lies with the clinical approach. The perspectives that professionals choose to put forward are supported by a climate of ‘expertise’ surrounding their work. Professionals tend to communicate with families using highly abstracted information and academic theories that are often bewildering.

The diagnosis of deafness and its ‘treatment’, if any, is conducted by medical staff – health visitors, general practitioners, ENT or audiological scientists, physiological measurement technicians in audiology, and hearing therapists. All these are medical staff based in hospital or community health settings (Ahmad *et al*, 1998). This means that having a hearing aid fitted is not seen in the same way as having an eye test. One of the consequences of this medicalisation of deafness is that technological solutions may be given a high profile. Surgical interventions such as cochlear implants are examples of hi-tech fixes. Cochlear implants are:

Electrically assistive hearing devices that process and deliver an electrically amplified signal directly to the acoustic nerve, unlike the acoustic hearing aids, which amplify sound to the ear.  
(Hindley, 1997, p113)

Despite the many ethical dilemmas (Hindley, 1997) cochlear implants are on the increase. One piece of independent research concludes that the benefits offered by implants over conventional hearing aids are at best slight (Allens *et al*, 1993, cited in Hindley, 1997), and the costs are great (estimated at £24,000 for an adult, followed by £1,000 maintenance costs a year, and for the child £28,000, with annual maintenance costs of £2,500 a year) (Hollins, 1997).

Professionals involved with cochlear implants programmes commonly do not explore alternative approaches to rehabilitation. Lane (1992) reports on a meeting between the representatives of the Deaf community and medical professionals involved with cochlear implant surgery. A deaf leader asked whether they informed parents whose children were

candidates for surgery, about the Deaf community and American Sign Language (ASL) as alternatives to implantation. The reply given was that 'we tend to present things from our point of view' (Lane, 1992, p24).

The Deaf community tend not to object to cochlear implants for consenting deafened adults, who are old enough to decide for themselves. Ethically it is considered immoral for 'such' experiments to be carried out on deaf children (Ladd and John, 1991).

More recently, cochlear companies' research and medicine has been exposed as a billion-dollar industry, thus creating conflict between business interests, shareholders, and the best interests of the patients. Evidently the cochlear implant market was growing faster than the businesses servicing it and the challenge was to market effectively to consumers and professionals as illustrated by this quote in 2004.

BIONIC ear-maker Cochlear expects to boost profits back to about \$50 million after a year chairman Tommie Bergman describes as "miserable". He told yesterday's annual meeting the 2003-04 net profit of \$36.7 million – down from \$58.2 million – was "disappointing and clearly not acceptable".  
(Thurs Oct 21, 2004, Adelaide Now)

There are also associated medical risks with cochlear implants. In 2002 it was reported that at least 56 people contracted meningitis as a direct result of Cochlear Implant surgery. Fifteen of them subsequently died from associated complications. Preliminary information from investigations of Cochlear Implant Centres suggests that many additional unreported cases of meningitis exist. Corporations suppressed this information; it took many years of campaigning before the American FDA put out a press release showing the possible dangers of cochlear implantation (Deaf Liberation Front, 2002).

However, proponents of the medical model dominate within the professional body, which 'service' the Deaf community, and consequently they often command enormous power (Griggs, 1998). This process is highlighted by Lane (1992, p24) where the medical professionals 'medicalise the child's difference into deviance'. It is only when the child



is subsequently presented to various hearing experts that the medical or the ‘infirmity model’ (Lane, 1992) is perpetuated and the child acquires an ‘infirm’ label.

For both parents and professionals, the psychological link between deafness and illness is also exacerbated by the fact that contact between deaf people and professionals is predominately hospital based, a location associated with illness (Griggs, 1998).

## **1.6 Summary**

There have been various attempts to define the Deaf community and to determine the criteria for membership by identifying the number of BSL users. There is a wide disparity in the figures quoted in the literature review, which has made it difficult to ascertain the exact number of BSL users in the Deaf community.

Society’s perceptions of deaf people were explored in this chapter using the three different models – the medical model, the social model, and the culturo-linguistic model. The research undertaken adopts a culturo-linguistic approach, which is considered to be more appropriate for describing the experiences of people in the Deaf community, particularly when discussing health issues. This bottom up approach helps to lay the foundations towards intervention work that is best suited to sign language users, who belong to a community with its own culture, and sees itself as a linguistic minority.

Distinguishing between collective and individualistic cultures gives an insight into how the Deaf community functions. The Deaf community can be described as operating at a collective level, but functioning within a western collective model. This has an impact on defining how health is viewed within the Deaf community. For example, deafness is seen as a medical problem. Deaf people come into contact with these attitudes in a medical setting, at a very early age starting with diagnosis. As a result deaf people have a tendency to avoid contact with health professionals. The data collection has focused on the underlying reasons for this, as well exploring reasons for their lack of health knowledge.

An example of this is outlined in section 1.5.1, when looking at how the government operates at different levels. This western approach of setting the funding criteria has an impact on quality control and service deliverance, and doesn't allow for the benefits of a community intervention approach. This has implications for delivering community projects within health care that require a bottom up approach.

Baseline assessments are frequently used to compare deaf people's health with that of hearing people. The literature review in the next chapter looks at deaf people's health in the context of medical assessments, and their health knowledge.

## **Chapter 2 Health Issues and Health Care Systems**

### **2.1 Introduction**

The linguistic and cultural Deaf community (approximately 25,000 people) in the UK has clear and distinct needs where health provision is concerned. Clinicians and researchers have identified various factors in the assessment and treatment of deaf clients, which need to be given special consideration. The main issues are:

- The lack of health knowledge
- Barriers with various health professionals

It is likely that there are cultural differences in the expression of illness, especially due to communication differences. It is equally likely that normality is perceived differently from hearing people. There is evidence that the Deaf community may apply a different concept of, for example, 'mental health' or 'physical health' to that held by the hearing majority. For example, Griggs (1998) found that her deaf informants equated mental health with 'coping', whereas hearing people tended to use more positive descriptions, such as 'a happy, fulfilled, good marriage'.

In relation to the hypotheses set out in the introduction of Chapter 1, further exploration is made in this chapter of mainstream literature available regarding barriers in health for specific communities, and how this in turn has formed a model of inaccessibility based on structural and cultural issues for the Deaf community. The literature review goes some way towards explaining the current structure of health and access, or more pertinently the lack of it for deaf people and the community. In addition exploration is made of any intervention work carried out to date, and its merits.

## 2.2 Health Promotion

In the first instance it is necessary to look at the wider literature available on health. The term 'Health Promotion' refers to a movement that has gathered popularity over the last two decades. It challenges the medicalisation of health that has been covered historically in literature, and is an important force in improving the quality of people's lives and their longevity. There are varying definitions of health promotion but all incorporate the idea that both individuals (lifestyle) and structural elements (environment) play a critical part in any health promotion strategy (Whitehead, 1993).

Health promotion differs from health education, in that it is not solely focused on the responsibility of the individual and behavioural change. Instead, progressive health promotion strategy aims to change or introduce public policy to support health across all health related sectors. It also emphasises that the foundation for any change comes with community awareness and action (Whitehead, 1993).

In the early decades of this century many international health bodies were created culminating in the creation of the World Health Organisation (WHO) in 1948, shortly after the end of the Second World War. Although the nature of health promotion and strategies for health has changed since that time, the WHO's ultimate aim has still since remained as:

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.  
(WHO, 1946)

Health therefore has two common meanings in everyday use, one negative and one positive. The quote given above can be seen as a positive definition of health. We also have the negative definition of health, which is the absence of disease or illness. This tends to be defined as the meaning of health within the western scientific medical model (Naidoo and Wills, 1994).

However, the significance of these initiatives led by the WHO in the 1970s and 1980s should not be underestimated. On their own each one was modest but lacked the practical detail useful for action and policy-making at the grassroots level. For example, these policies did not take into consideration the health needs of different cultural groups, and tended to generalise all their needs as being the same. Evidently this led to problems due to a lack of understanding of the needs of certain communities.

It is safe to say that there are a number of difficulties associated with the WHO definitions. Firstly, it suggests a state that very few people aspire to. Secondly, it assumes that there is one particular state that equals being healthy, a case of 'one size fits all', which makes it limited in its scope. A more balanced approach would see attempts to move away from concepts of health that focuses solely on the physical aspect. In addition, added weight should be given to mental and social aspects, suggesting that there is more to being healthy than just not being sick. Instead of experts and professionals diagnosing problems, people need to take on responsibility for identifying and being offered a say regarding health issues relevant to them in their local community.

When looking at deaf people's understanding of health and health care systems it is useful to look at the differing definitions of physical and mental health.

### ***2.2.1 Health and well-being***

Health and well-being can be described as the absence of physical illness, disease and mental distress, which is a negative definition. At the other extreme, a positive definition would see health and well-being being described as the achievement and maintenance of physical fitness and mental stability. There is also a holistic approach, which is the result of a combination of physical, social, intellectual and emotional factors.

Ideas about health and well-being do change over time and vary between different cultures. In Chapter 1 exploration was made of the difference between collective and

individualistic cultures. Further examination of the literature review in this chapter will look at how this focuses on the individual.

What factors are a risk to health and well-being and how do they have a damaging effect? Lifestyle has a major influence on an individual's health and well-being but is something that most people have some degree of control over. There are also genetic, social and economic factors which people may not be able to change. Health and well-being can be affected by:

- genetically inherited diseases and conditions
  - substance misuse (including misuse of legal and illegal drugs, solvents, tobacco smoking and excessive alcohol intake)
  - an unbalanced, poor quality or inadequate diet
  - too much stress
  - lack of personal hygiene
  - lack of regular physical exercise
  - unprotected sex
  - social isolation
  - poverty
  - inadequate housing
  - unemployment
  - environmental pollution
- (QCA, 2003)

Some indicators of physical health can be measured, such as assessing the state of an individual's physical health including: blood pressure, peak flow, body mass index, resting pulse and recovery after exercise. In addition, a person's age, sex and lifestyle also needs to be taken into account.

In Chapter 5, a revised health questionnaire was developed to identify which of these factors affected deaf individuals, and explored experiences that stemmed from a cultural viewpoint.

### **2.2.2 Mental health**

Mental health is more than the absence of mental illness. There are many different definitions of mental health, including:

Mental health is the emotional and spiritual resilience, which enables us to enjoy life and to survive pain, disappointment and sadness. It is a positive sense of well-being and an underlying belief in our own, and others' dignity and worth. (Health Education Authority, 1997, p7)

Mental health is essentially about the way we think and feel about ourselves and about others, and how we interpret the world around us. It affects our capacity to manage, the ability to communicate, and to form and sustain relationships. It also affects our ability to cope with change and transitions such as life events – for example having a baby, going to prison, and experiencing bereavement. Mental health affects how we think and feel, and as a consequence has a strong impact on physical health. There is an abundance of data that demonstrates the importance of mental health and well-being to overall health and productivity. Mental well-being, like physical health, is a resource we need to promote and protect (Department of Health, 2001).

Mental health promotion involves any action that enhances the mental well-being of individuals, families, organisations and communities. It is important to recognise that everyone has mental health needs, regardless of whether they have a history of mental illness or not. Mental health promotion programmes that target the whole community will include and benefit people with mental health problems, and are concerned with the following:

- how individuals, families, organizations and communities think and feel.
- the factors which influence how we think and feel, individually and collectively.
- the impact that this has on overall health and well-being. (Friedli, 2000)

Mental health promotion works at three levels. Each level is relevant to the whole population: to individuals at risk, vulnerable groups and people with mental health problems.

- **Strengthening individuals** - or increasing emotional resilience through interventions designed to promote self-esteem, life and coping skills, e.g. communicating, negotiating, relationship and parenting skills.
- **Strengthening communities** - this involves increasing social inclusion and participation, improving neighbourhood environments, developing health and social services, which support mental health, anti-bullying strategies at school, workplace health, community safety, childcare and self-help networks.
- **Reducing structural barriers to mental health** - through initiatives to reduce discrimination and inequalities and to promote access to education, meaningful employment, housing, services and support for those who are vulnerable. (Department of Health, 2001, pp.31-32)

### 2.3 Community Group's Role in Health Promotion

The community development approach is concerned with helping people to re-examine critically the society they live in, to understand ways in which various political and administrative systems work, and to acquire more skills in self organisation and more specific skills relevant to self-chosen topics (Pike and Forster, 1995).

Community groups and voluntary organisations are less well known as a setting for health promotion because:

They belong to the lay system and are not regarded as a resource for activities and interventions relevant to health. They seem to have no clear health-damaging effects and many of these groups, organisations and associations are neither known to the public nor to researchers and politicians because the groups are overshadowed by the large institutions of society. (Trojan *et al*, 1991, p441-442)

Another explanation as to why the significance of community groups and voluntary organisations for health remained undiscovered for a long time, is the dominance of the medical disease model, with its overemphasis on natural science and technological



methods in diagnosis and therapy, and on the work of the health professionals. We can only begin to understand the relevance of the health of community groups if a social model of health becomes more widely known and accepted. It is not difficult to relate the principles of health promotion to community groups and similar small networks for the following reasons:

- Most community groups actually support or wish to support emotional and social well-being, personal growth and their members' or clients feelings of self-esteem.
- Community groups try to change the physical, social and political living conditions that commonly cause social problems and disease.
- Community groups, which often belong to a grassroots movement are indicators of the many forms of mutual health, of social and political participation and of involvement of the local population in its own affairs.
- Community groups are a means of enabling and empowering people to increase control over, and to improve their health (Trojan *et al*, 1991, p442).

In promoting community involvement in health, Brearley (1990) notes that people have not always been encouraged to think and choose for themselves. It has been argued that many World Health Organisation initiatives for community participation have been ineffective, partly because people are so used to solutions being imposed on them by experts that they are reluctant to become actively involved themselves. Health orientated health education programmes should therefore be planned according to opportunities identified within a community (Downie *et al*, 1990). As a result, it can be seen that a holistic life context format for health education is more likely to be sensitive to the needs of particular individuals in their community setting.

### ***2.3.1 Empowerment***

In order to determine a people-centred health promotion strategy, it is necessary to ensure that health promotion is driven by a viewpoint that starts with the actual subjective experience of ordinary people, rather than the objective view of social scientists looking at abstract data (Raeburn and Rootman, 1998). Empowerment is seen as first and

foremost as having to do with control, in order to gain this Raeburn and Rootman (1998) recognise the category of 'Community Control':

The term community control refers to sectors of the population represented by ordinary people, as distinct from official, political, professional bureaucratic or institutional power structures. Communities may be geographically based, or they may be interest based. What counts in this definition is that they are groupings of people who do not have a lot of ready made power in terms of existing organisational strength. The primary *raison d'être* of such groupings is the strength that the people in them actually or potentially get from other people with whom they are in immediate contact through the virtue of their membership in the same community.

(Raeburn and Rootman, 1998, p22)

Since by definition, the kind of community that is alluded to currently does not have 'a lot of power' when compared with other power blocs in society, it is very easy for professionals and officialdom to feel that they have 'power over' that community.

Raeburn and Rootman (1998) recognise that community control requires four main steps. The first is that *constitutionally* (agreed on, written down form), a commitment is made to community control, and the structures are described to make sure that this happens. The second is that *organisationally*, attention is given to how the enterprise will run in practice, so that the control is unambiguously in the hands of the community concerned. The third is that, *developmentally* the project is evolved with careful checks and balances in place to ensure the maintenance of community control. Finally, *evaluation* systems need to be in place to ensure that community control, is fully established and continues to happen.

In different parts of the world, many community based health promotion programmes are underway which seem to operate via a mode of intervention, and these are achieving greater recognition in terms of their value. One example of a special community is the Gypsies (Hawes, 1997) who face difficulties in accessing and health and welfare services, as with other ethnic and cultural minorities. This resulted in a dedicated mobile unit being set up as part of the Bristol Traveller Health Project travelling around various sites.

Another example is the Regional Race Programme (Department of Health, 1994) where the starting point was recognising that certain populations, within the context of care in the community, need to receive better mental health services if their needs are to be properly met. The aim of the project was two-fold. In collaboration with the local black communities this programme would listen to what black people had to say about mental health care delivery in their local areas. Secondly, the objective was to facilitate a dialogue between health and social service managers who were the purchasers and providers of services, to ensure that the agenda regarding race and mental health was appropriate to the needs identified.

An important consideration is that these programmes target a geographical community (MacLachan, 1997), which should be taken into account when considering the needs of the Deaf community.

Finally, Ashton and Seymour's description below partially explains why health promotion works within communities:

Health Promotion works through effective community action. At the heart of this process are communities having their own power and having control of their own initiatives and activities...health promotion supports personal and social development through providing information, education for health and helping to develop the skills which they need to make healthy choices.  
(Ashton and Seymour, 1988, p26)

This demonstrates that the focus of health promotion places a heavy emphasis on communities and is critical to the changes in the Deaf community.

### ***2.3.2 Evaluating a community health programme***

In any evaluation the most fundamental decision that is made is the choice of questions to ask. Pirie (1990) presents a list of questions that could be useful in asking about a community health promotion programme, with regard to the planning, implementation and outcome approaches.

Planning:

- Should this programme be developed at all?
- Are the available educational materials appropriate?

Implementation:

- Is the programme being implemented as planned?
- Is the programme reaching its target audience?
- Who is the programme failing to reach and why?
- Are the programme participants satisfied with their experiences?
- Are the participants complying with the actions requested of them?

Outcome:

- Is the programme having the effect it is designed to have?

These provide a useful blueprint for the way community centred programmes should be run.

## **2.4 Health Inequalities**

Health has been described as a social category that depends on social support for the individual and on good living conditions; an environment without pollution, a society that enables the development of self-esteem amongst many other factors (Trojan *et al*, 1991).

Naidoo and Wills (1994) describe health as:

A broad concept which can embody a huge range of meanings, from the narrowly technical to the all-embracing moral or philosophical. The word “health” is derived from whole, hale and healing, signalling that health concerns the whole person and his or her integrity, soundness or well-being.  
(Naidoo and Wills, 1994, p4)

Inequalities in health are defined as differences that are unnecessary, avoidable and judged to be unfair and unjust (Whitehead, 1990).

Discussion has been made of various definitions of health and theories in relation to a community centred approach that attempts to explain the models of change behaviour.

## **2.5 Indicators of Deaf Health**

It is important to consider why deaf people may be at an increased risk of suffering from poor health. Good prevalence data is scarce; existing data is difficult to interpret and compare because it comes from different study designs and sources, using different definitions and instruments (Van Oyen *et al*, 2001). Research indicates that deaf people are marginalised and ignored in hearing society. Subsequently this has led to major difficulties in having the confidence to access services and in using the available information for themselves.

Research to date has indicated that the predictors of deaf health are:

- Low social economic status (Kyle and Pullen, 1984; Jones and Pullen 1990; Schein and Delk, 1980)
- Poor circumstances (Sainsbury, 1986)
- Underemployment (Jones and Pullen, 1990, RNID 2006)
- Low wages (Sainsbury, 1986)
- Poor health status (Zazove *et al*, 1993)

A more detailed exploration of the underlying reasons can be found in Chapter 1 when looking at the various external factors that impact on deaf people.

By looking at these predictors it can be seen that the eventual outcomes will be:

- Poor health
- Early death
- Mental health problems
- Poor social and economic status
- Lack of awareness about health information

It is useful to look at the structural issues that result in barriers to health for deaf people. These originally stem from the idea of the 'traditional' structure of the health service, powerful medical discourse, existing training, and current service provision. Specialist services represent a cultural barrier in that they stand in direct opposition to an alternative health framework.

## **2.6 Structural Barriers to Health**

There are several indicators as to why there are structural barriers in place for deaf people and their access to health.

### ***2.6.1 Planning of Health Authorities training***

There is little or no training of hearing health workers, and this is linked to the planning and organisation of training by hearing educators. There are no established training courses that specifically cover health issues in relation to deafness. Only one medical undergraduate training programme in deaf awareness exists in the UK. This was set up in 1987, and the one-day programme on deaf awareness and communication skills is run as part of the fourth year public health course at Leeds University (Smith and Hasnip, 1991).

Although doctors graduating from Leeds may not necessarily remember specific details or retain any signing skills, they would have been exposed to the communication difficulties they may face with deaf clients and how these can overcome. If Leeds

graduates are indeed the exception to the rule, it can be assumed that knowledge and awareness for the majority of doctors comes only from chance meetings or family involvement with deaf people.

According to the Commission of Enquiry into Human Aids to Communication (HAC) report (Panel of Four<sup>7</sup>, 1992) many health authorities in the UK felt that they had discharged their duties if the deaf person had access to the local social worker for the deaf, and is provided with hearing therapists, speech therapists or audiology services. Very few mentioned how deaf, deafened, hard of hearing and deaf-blind patients would be able to use their services. Some realised that specific policies and budgets were needed to address the issue of how deaf users could access mainstream health services. The report concluded 'the use of social workers or hearing family members to aid communication can pose problems of confidentiality in medical consultation.'

In addition, concern was expressed at Social Service Departments using social workers for the deaf as interpreters. Many reported that they switched between both roles, even though this contravened the policy of some social service departments.

A damning report carried out by the inspectorate for the social services in the UK (Department of Health, 1997) documented inspections of services to deaf and hard of hearing people in eight local authorities. Services were found to be patchy in all areas, with the exception of a generally satisfactory picture in one authority. Only 18% of the social workers with deaf people were qualified in British Sign Language at CACDP<sup>8</sup> level III or beyond. This is deemed to be the minimal fluency in BSL and the figure was the same in 1988. This means that 80% of social workers working with deaf people may experience communication difficulties in some situations. It is common for social workers with deaf people to be placed under considerable pressure from the public and

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<sup>7</sup> A collaboration between The British Association of the Hard of Hearing [now Hearing Concern], The British Deaf Association, The National Deaf Children's Society and The Royal National Institute for Deaf People

<sup>8</sup> Council for the Advancement of Communication with Deaf People

colleagues to provide an interpreting service. Social services in some areas have no policy for separating the dual roles.

A SIGN report (1998) confirmed that facilities for contact with deaf clients tends to be poorly developed in social services departments, and there was little evidence to show that there are adequate assessment and placement procedures at social service level.

Over half of those inspected had made successful efforts to appoint deaf staff to their specialist teams, and three-quarters of care managers or social workers with deaf people had a social work qualification. The report also found that some social workers with deaf people tended to work in a way that encouraged people to be dependent on them.

### ***2.6.2 Deaf people's health status***

Deaf people with mental illness are far more likely than hearing people to stay in hospital. There is a higher incidence of emotional, behavioural and adjustment disorders among deaf people than hearing people. Studies have shown that 40% to 50% of children who are deaf have these problems compared to 25% of children in the general population (Hindley *et al*, 1994). Recent studies, which looked at deaf people's mental health problems in the community (Checinski, 1991), found high rates of problems such as depression or anxiety, and a low take up of mental health services within the Deaf community. Checinski (1991) estimates that 90% of the deaf population's mental health needs remain unserved.

Van Oyen *et al* (2001) looked at data from a national health survey in 1997 in Belgium ( $n=8560$ ). The aim was to discover how deafness impacted on negative health outcomes, how they developed their subjective health perspectives as well as looking at mental health and social well-being. Face to face interviews were carried out with trained interviewers and self-administered questionnaires filled in. They concluded that the prevalence of subjective ill health was higher in people with hearing difficulties (45%) compared to hearing people (20%). The data illustrated that deafness did impact on



health and well-being, and that research/intervention should focus on strategies for prevention.

There is a growing awareness of needs that have not been met and deficiencies in the services offered to deaf people with mental illness. Deaf people have found it immensely difficult to gain access to services and to information about the existence of these services. Communication difficulties were reported (SIGN, 1998) at a primary care level. This report indicated that few deaf people can communicate their health concerns to their GPs, and are not aware that GPs can act as gatekeepers to mental health services. This weak provision can lead to misdiagnoses. These findings are backed up by the RNID report (2004) titled 'A Simple Cure' which surveyed the experiences of 866 deaf and hard of hearing people. This report concluded that despite the frequency with which deaf and hard of hearing people use the NHS, the service they received in both GP surgeries and hospitals falls short of what they would reasonably expect

In 1977 the US National Health Interview Survey (NHIS) revealed that deaf and hard of hearing people used the medical service more than hearing people. They see physicians twice as often, have more bed days due to illness or injury, and see themselves as less healthy. Preliminary results from the 1990 survey are similar (Ries, 1982, cited in Zazove *et al*, 1993). They conclude that the lower educational and economic status of these people may also play a role; and people of lower socio-economic status see physicians more frequently. Zazove *et al* (1993) found that deaf and hard of hearing people have a higher prevalence of medical problems, poorer health status, and utilise the health care system more frequently than hearing people. Zazove and Doukas (1994) concluded that communication problems appeared to play a large role in difficulties that deaf people may have in obtaining health care. Obstacles to communication have had a significant negative effect on the ability of the health care system to address the deaf population's health care needs adequately.

### ***2.6.3 Deaf people's status as health professionals***

Deaf people's participation in health provision has been limited, and there is little evidence to suggest otherwise. Although authorities believe that they are making sufficient provision, the view of many deaf people is that often nothing is offered, and the use of health provision is avoided because of the potential stress caused by factors such as communication difficulties.

Deaf people working in health tend to occupy low paid, low status jobs with unqualified positions. They are usually not in a position to influence decision making. The position of deaf people as an undervalued minority means that they have internalised much of the attitudes of those around them. Deaf employees also tend to have a lower socio-economic status than their hearing counterparts (Montgomery and Laidlaw, 1993; Young *et al*, 1998).

The challenge for deaf people is to hold high expectations in the face of hearing people's low expectations.  
(Kendall, 1999, p18).

Within the field of mental health, deaf sign language users are being employed in specialist psychiatric services to deaf people. This employment comes in response to growing concerns that deaf people with mental health problems are both misdiagnosed and under reported (Denmark, 1994). Deaf people are still seldom visible in a professional capacity within the mental health services on a national scale. Indeed, Klein and Kitson (in Hindley and Kitson, 2000) point out that deaf people working in the mental health field have traditionally been employed in the fields of entertainment or recreation, rather than in any more qualified positions.

Deaf people as advocates have been used in various situations, including health (Collier, 2000). Many difficulties were experienced in recruiting deaf advocates. Most of the information about advocacy and rights tends to be in English not BSL. Lack of a strong volunteering tradition in the Deaf community was cited as another explanation. Helping

other deaf people to claim services and rights was seen as problematic because many deaf people have to cope with their own oppression and inequality. Therefore they may not have the confidence and the time to become advocates for other deaf people (Reid, 1994).

In order to be successful advocates deaf people must be aware of which channels they need to go through to address their grievances, for example, local authority procedures. Deaf people must know how to tackle these issues before they can become citizen advocates for others. The deaf person will experience difficulty when supporting their partner in dealing with statutory agencies and other services. It is almost inevitable that barriers will be faced due to the lack of accessible information and the difficulties in obtaining sign language interpreters for meetings. This can have a significant impact on the volunteer's morale as well as reducing their effectiveness as an advocate. It was found that the role of citizen advocate was frequently confused with the role of a social worker for deaf people or a befriender.

Hawcroft *et al* (1995) concluded that the lack of investment in the Deaf community in the past diminishes the contribution that deaf people can make today. Agencies need to work together with local communities and explore how the resourcing of outreach and development work to specific groups can work. They noted that in order to build effective partnerships between deaf service users and local agencies significant investment in training is required, for both deaf people and their agency partners.

#### ***2.6.4 Demographic limitations***

The demographics of the Deaf community mean that deaf people face greater distances to travel and see specialists. This causes additional stress and has the effect of causing apathy among health professionals towards the training of deaf issues. As a result there is a lack of choice and lack of a range of health provision.

Confining the advocacy project to one locality was difficult because of the dispersed nature of the Deaf community who tend to be concentrated in large urban areas. (Reid, 1994)

#### ***2.6.5 The interpreter effect***

Chilton (1996) argues that effective communication in medical settings can be achieved only through the use of a qualified sign language interpreter. The failure of health care providers to provide qualified interpreters is disturbing, when there is a critical need for accurate, immediate and effective communication in medical settings. Many studies have indicated that a lack of sign language interpreters, and the resulting communication problems that occur in medical settings, has had a negative impact on the health of the deaf population as a whole. Without the benefit of interpreters, deaf patients often find communication in medical settings frustrating, difficult and even frightening. Due to their position within the Deaf community, interpreters face additional dilemmas and pressures because they are more culturally aware about deaf people's needs than health professionals.

Consequently, deaf people may be fearful of having to interact with health care workers who are insensitive or uneducated about the needs of the Deaf community. Chilton concludes that this seems to have caused a marked 'chilling effect' on the willingness of deaf patients to seek appropriate medical care and health information.

To counteract this, it has been argued that in the consultation process interpreters affect the flow of the consultations and indeed its dynamics, causing conflict of interest in trust, embarrassment, and the added pressure of role conflict. This leads to skewed relationships with the client and possible misdiagnosis through lack of cultural awareness.

Health services add to this unnecessary stress for the deaf patient, because they do not know how to request interpreters, how to pay for them, how to work with them, and are restricted by health authorities budgets which are fixed.

Deaf parents using hearing children as interpreters in medical situations is well documented in various deaf health literature (Mohay and Kleinig, 1991). Collins (1996) reports on a ten-year-old hearing daughter who went to the hospital with her deaf mother who had breast cancer. As an adult this girl recounted that she had to interpret for her mother, which was very difficult for her emotionally with her limited understanding of the English language. Such dependency is not only demeaning to deaf adult but can also result in undue emotional trauma for the child.

Wright (1993) found that deaf people, who took 'interpreters' with them when they used the health service, also had problems with communication. In one instance, a woman took her mother who she named as her 'interpreter' to an outpatients appointment. The mother did not use BSL, and although the deaf woman reported that she and her mother communicated adequately, she failed to understand 'medical words' that her mother was trying to relay to her. Similar stories are documented by Gregory *et al* (1995). This scenario is illustrated in a European survey carried out by Jones and Pullen (1990) who interviewed deaf people from 12 countries in Europe with regard to their health care experiences and health knowledge. The use of families and friends as interpreters was the only option available for most people in a medical setting, in all the countries surveyed with the exception of Denmark.

Friends or relatives may not be reliable interpreters because they edit patient's statements or interject their own conclusions without offering an objective view. Impartiality is not assured. Moreover, ethical standards, particularly that of confidentiality, adhered to by qualified sign language interpreters may not be observed by friends and relatives.

### ***2.6.6 Mode of communication in health care settings***

Writing was the most frequent method for physicians communicating with deaf clients in a US survey conducted by MacKinney *et al* (1995). However, only 18% of the controls considered themselves fluent in written English.

This is also emulated in Schein and Delk's Survey (1980), a postal questionnaire sent to 128 American deaf leaders. In this survey 76% reported that writing was the most common mode of communication used by medical staff in outpatient situations. Writing (83%) was reported to be the most common mode of communication used in in-patient situations. Although only 8% of the respondents had interpreters available at some time during their hospital stay, they preferred this to writing notes back and forth. What was most disconcerting about this research was the fact that deaf leaders had higher educational levels than the average deaf person in the Deaf community, and they tended to be more aggressive and better communicators (Schein, 1990).

Collins (1996) also discovered in her survey that 65% of deaf women go to medical consultations on their own and communicate by writing or speech, even those that would have preferred to communicate in sign language. This is consistent with Graham (1984) who reported that women often visited the doctors on behalf of others, especially children.

### ***2.6.7 Specialist equipment***

Health professionals have a lack of knowledge in the use of specialist equipment such as minicomms and videophones, which are deemed vital by deaf people to access health services, and also a lack of awareness of communication aids. Moreover, several are unused to new technology such as email or sms/text messages on mobile phone as a means of communicating with deaf people.

In 'Access to Health Services: Falling on Deaf Ears?' Lomas (1998) interviewed 56 deaf women who used sign language. All the deaf women interviewed were articulate in their own language, BSL, so they did not feel that they had a problem in expressing their needs. Rather there was a general feeling that the problem lay with the health services because doctors and staff were unable to communicate with deaf people. One particular story in the survey raises a number of issues:

A deaf man was admitted to Greater Manchester Hospital. His wife was also deaf and had two young children under three years of age. He was an in-patient for 16 weeks. The hospital concerned had six minicomms available. They were aware of the situation and also of the availability of sign language interpreters.

In the early hours of the morning the hospital rang for the wife to go to hospital immediately. The older hearing child, under three years old had to wake her mummy. When the woman tried to use the minicom there was no answer, the child had to act as an interpreter, it was an emergency and Mum was needed immediately at the hospital. A short time later there was a further call from a Deaf club several miles away asking her to go to hospital at once. The club had received a call via Typetalk from the hospital. The wife arrived just in time before her husband died. At no time in sixteen weeks had access been facilitated by minicomms available in the hospital.  
(Lomas, 1998, p5)

Serious issues arise from this, including the lack of deaf awareness by front-line hospital staff, using the hearing child as an interpreter, using Typetalk directly to the wife, and phoning the Deaf club via Typetalk. Appropriate training at the hospital concerned would have overcome these problems. The report emphasises that the health authority has a responsibility to deaf people and that under the Patient Charter (Department of Health, 1992b), they should enable deaf women to have access to and be able to communicate with the health services.

In the report, the local health authorities are urged to work in partnership with the local Deaf community and with communication support units to address these issues.

### **2.6.8 Misinformation**

In a pilot study in New Orleans, USA, (Lass *et al*, 1978) deficiencies of medical understandings were found among deaf adults. There was a high level of misunderstanding of the use of medical jargon and the roles played by medical specialists such as paediatricians, psychiatrists and the like. Prescriptions also confused deaf patients. Doctors expected deaf people to have a 100% comprehension of their prescriptions but the real figure was 59%.

More recently, the RNID ‘A Simple Cure’ report (2004) concluded that profoundly deaf patients were at a greater risk of inadvertently taking an overdose than hearing patients.

## **2.7 Cultural Barriers**

There are several reasons why deaf people may be at a disadvantage in a medical setting. One is their poor understanding of written English. Like other minority populations, deaf people have a poorer health status than the general population, this can be attributed to cultural and communication differences.

### **2.7.1 Access to Health Information**

Health information is not readily available to deaf people. Much of the literature is written in a form suitable for hearing people and does not take into account the literacy levels of the majority of deaf people.

For example, sexuality programs are sporadic in schools for the deaf (Fitz-Gerald and Fitz-Gerald, 1976). In the past, many deaf people attend residential schools for the deaf where the establishment would act as both academic institutions and as *in loco parentis* for students in their care. The duality and quantity of these programs are difficult to estimate. Kleinig and Mohay (1990) suggest that educators of deaf students typically spend little time focusing on health education issues, which are viewed as less academic



than the acquisition of language and other skills. This could be attributed to poor teaching or signing skills on the part of the teacher.

Jackson (1990), and Powers *et al* (1999) reinforce this argument by stating that hearing children acquire much of their worldview and knowledge through *incidental learning* (my emphasis). They listen to radio and television, and overhear adults discussing health matters. This avenue is not open to deaf children when they become adults; they often cannot give a health history because they were never told that they had measles or chickenpox, only that they were sick. Furthermore, the deaf child is often not included in conversations between health care professionals and parents. This not only deprives the child of learning about their own health but also encourages an attitude of complacency towards participation in his or her own health care.

Mohay and Klenig (1991) note that as a result of deaf people's limited language use, their educational and linguistic skills are impaired. Consequently, this precludes deaf people from acquiring information incidentally from books, casual conversations, television or any other source unless it is *specifically* (my emphasis) targeted at them. Effective utilisation of the medical services is dependent on an understanding of proper hygiene and nutrition, an awareness of basic health care procedures, knowledge of common diseases and medical terminology, and familiarity with the health care system. An absence of this type of information may well threaten the well-being of many deaf people, as they may not know how, when, or where to seek appropriate medical care.

Many deaf people communicate with their contemporaries to obtain the health information they require, and this hinders the introduction of suitable health information more appropriate to their needs. This leads to misinformation spreading within the Deaf community because external sources are not readily available to provide accurate information.

Birmingham City Council (Farmer and Timmins, 1995) carried out a weekend residential programme with young deaf people in the Birmingham area. The programme consisted

of discussion-based activities, developed in response to a needs assessment survey carried out with young deaf people from the Birmingham area. Activities that proved successful include: presenting information visually with diagrams and pictures, role-play, using a video camera to record role play situations and feedback from the group, using videos with sign language, subtitles or diagrammatic explanations, and minimising the amount of reading and writing required.

### ***2.7.2 Principle of autonomy/informed choice***

One way that an individual exercises their autonomy is through voluntary informed consent. For consent or refusal to occur freely, the patient must have all the necessary information about their health status and the available treatments. An informed decision can only then be made based on a patient's own values and beliefs. This concept is reliant on the individual culture of the western world. Whether health professionals adequately address the autonomy needs through the provision of informed consent from these deaf people is questionable (Zazove and Doukas, 1994).

It appears that deaf people, because of the communication barriers faced, do not receive full disclosure of their medical situation and the alternatives are not discussed with them. Even when disclosure does occur, many deaf people may not fully comprehend the options available to them because of communication difficulties with physicians. Zazove and Doukas (1994) urge the health care system (both institutions and physicians) to respect the bio-ethical claims of deaf and hard of hearing people, and reassess their ethical responsibility in treating these people. Some deaf college students have been known to confuse the terms 'constipation' and 'diarrhoea' or believe them to be identical. Others have been unable to respond to the question, "Do you have any allergies?" because they did not know what the word allergy meant (DiPietro *et al*, 1981).

### ***2.7.3 Attitudes of health professionals***

Historically deaf people have a long-standing distrust of hearing people in general and the medical profession in particular. This distrust is in part based on the medicalisation of deaf people by the medical profession (Lane, 1992). In contrast to deaf people seeing themselves as a cultural model, they have been viewed throughout history from the infirmity model perspective. That is, they have been viewed as having a medical condition in need of a cure.

Lane (1992) has written extensively on the infirmity model perpetrated by health care professionals. Starting from childhood, the lives of deaf people have been punctuated with diagnoses from an array of hearing professionals including physicians, audiologists, etiologists, speech and language pathologists, psychotherapists and surgeons. Few of these professionals are able to communicate with their deaf patients directly, and most have little or no awareness of the Deaf community. The tendency of the medical profession is to evaluate and diagnose deaf and hard of hearing people from an ethnocentric perspective. This perpetuates the view of deaf people as disabled, handicapped or hearing-impaired (Lane, 1992). Hence, a hearing professional who maintains this ethnocentric view may mistakenly perceive a deaf person as non-communicative and unresponsive, if he or she refuses to engage in communication efforts that require speech and lip-reading skills (Phillips, 1996).

An undergraduate project (Naish and Clarke, 1997), from the department of Public Health and Epidemiology final year at Birmingham University, assessed the means and quality of communication of profoundly deaf patients and GPs. The results of the questionnaire distributed to 46 GPs indicated that 52% stated speaking 'loud and slow' as a means of communication with potential deaf clients. Experience of professional interpreters was limited, and doctors saw the provision of interpreters as the patient's responsibility. This highlights poor knowledge and the need for medical training to include deaf awareness training.

The asymmetry of the medical relationship between deaf people and medical professionals is widely cited in literature. In this context, patients have difficulty raising topics of interest to them and/or providing information that they see as relevant. It is doctors who ask most of the questions and patients who respond most of the time (Mishler, 1984).

#### ***2.7.4 Cultural viewpoint***

Health professionals do not commonly acknowledge cultural perspectives on health and mental health. Deaf people are compared to hearing people and are therefore homogenised. Patterns of support in health are seen as culturally inappropriate. The most frequent request of the health care system is to provide care for deaf patients when the patient's complaint is unrelated to deafness (Mindel and Vernon, 1971; DiPietro *et al*, 1981). The health care system tends to focus on one aspect where deaf people are concerned – the ear and its dysfunction.

The assessment and diagnosis process is commonly fraught with difficulties when two languages (English and BSL) are used. Culturo-linguistic features of sign language are misunderstood and misinterpreted.

#### ***2.7.5 Communication barriers***

Communication difficulties arise in times of additional stress and can result in deaf people being unable to participate in treatment or therapy. Reeves *et al* (2003) found that deaf people have substantially poorer access to primary care, and Accident and Emergency services, and experience difficulties at all stages of the health care process. The study focused on the experience of 98 deaf patients in the North West of England as well as Practice Managers and found provision to be extremely patchy.

In medical encounters deaf people are usually subjected to procedures they do not understand and even worse, ignored when they need medical attention. These create

significant communication barriers at the onset of the medical examination. Many deaf and hard of hearing persons fear that their physicians will administer incorrect treatments because of misunderstandings. Consequently, they are less likely to ask doctors to repeat themselves when instructions are not understood (Zazove *et al*, 1993).

Many deaf people do not know their own medical histories. There is a simple explanation for this – all the information interchange has largely occurred between the parent and the physician. Later no one takes the effort to explain to the child what the illness was (DiPietro *et al*, 1981). It is not unusual for a deaf adult to have to contact their own parents or an official for information about their own past medical history. Sometimes there is no source of information leaving them at a complete loss.

The low tolerance of the medical profession staff to writing down information causes further stress for the deaf client, and hinders them from understanding issues related to their health (Lotke, 1995).

Deaf patients frequently nod, suggesting that they understand, or express a reluctance to repeat themselves. Consequently, no effective communication has occurred due to the communication barriers in place and deaf people's lack of knowledge of medical terminology or even names for bodily parts and functions (DiPietro *et al*, 1981).

It is worth examining the role of the head nod in British Sign Language and how it is generally understood by deaf and hearing people. It is widely understood to mean 'yes' (Sutton-Spence and Woll, 1999). Significantly, it does not only have grammatical meaning in BSL, in that it means 'yes' it also functions as a discourse feature. This means that there are functions associated with the nod and not just meaning relating to 'yes'. For example, Sutton-Spence and Woll (1999, p92-93) explain that the nod can be used to indicate:

- the first person;
- the truth of a statement; or

- a grammatical marker in a topic-comment sentence.

With respect to the deaf person nodding, it needs to be established whether this person was actually saying ‘yes’, or using the nod as a discourse feature. It may be that even though a nod was used in the signed discourse, the deaf person may have been trying to say something quite the opposite, thus creating further misunderstandings.

Ebert and Heckerling (1995) noted that physicians might be tempted to abbreviate messages, resulting in incomplete communication with their patients. This is an area for grave concern when considering that the hearing population consult their GP for everyday problems such as anxiety, depressive illness and for physical ailments. If half of the deaf population have difficulties in communicating with their doctors, then where do they go to in times of stress, and are the voluntary agencies helping?

Huntington *et al* (1995) in conjunction with the Cheshire Deaf Society surveyed deaf women’s health needs in Cheshire. After distributing questionnaires to 134 women they discovered that only seven percent of the survey said that they usually fully understood what was said to them when they visited a doctor on their own. In the survey, 76% of women said that they always or sometimes had problems in the waiting room when attending hospital or visiting their GP. The responses from the women in the group discussions were varied. Many felt that they had a lack of health information on issues such as sex education and childbirth. Of the 81 women who had received information on smear tests and healthy eating, 25% had difficulty in understanding it, and 40% in understanding cancer. Nearly half felt that it would help to have simple leaflets. One-third thought that subtitled videos would be useful, and around one-fifth thought personal visits would help.

Haffner (1992), in discussing her role as a Spanish interpreter, sometimes observed physicians and nurses who knew a little of the language to be able to converse in Spanish with their Hispanic patients. This was a practice that she always encouraged as it was felt that this made a patient feel more comfortable and helps build up a rapport. When

making this effort, it was important to remember not to overestimate language abilities and that a lower skill level of communication is required for ‘chatting’. Even if a question appears to have been understood by the patient, the answer may not be fully understood by the health care professional to form the basis for a medical decision. This scenario has parallels with the situation faced by deaf people in the medical setting.

## **2.8 Community Health Projects**

A number of projects have been carried out in the UK that looked at deaf people’s health needs. One of the most notable examples is the Deaf Women’s Health Project (DWHP), which was formed in 1998. It aims to give deaf women access to health information, and gives them the opportunity to make decisions about their health and to receive health care by communicating in their preferred language – British Sign Language. The members are all deaf women who act as volunteers, and some coordinators are paid through contracted funding. The history of this group is explored further in Chapter 6.

The British Deaf Association Health Promotion Department was set up in 1997 under the umbrella of ‘Aids Ahead’ and ‘Deaf Mesmac’. The original aim was to meet concerns that deaf people were missing out on information relating to HIV transmission and its prevention. Since then, the department branched out by offering information in various formats: easy to read leaflets on drugs, smoking, alcohol, healthy eating, women and men’s health issues, safe sex, and sex education in schools. More recently in 1999, the focus has shifted to counselling. A survey conducted by the British Deaf Association (BDA, 1995) looked at the health habits of deaf people. The report complemented the government white paper, ‘Health of the Nation’ (Department of Health, 1992a), by identifying that special consideration is required when considering the health promotion needs of people with physical and sensory impairment. A high proportion, 86.6%, of the respondents did not feel that they had received or understood enough mainstream health information.

The overall picture regarding health access for deaf people nationally does not appear to have shown any improvement. The British Deaf Association, the London Borough of Hackney, and the City of London (Depledge and Meyer, 1996) commissioned a report, which looked at the current provision for access to health services. A dismal picture of 'current access provision' was painted. The rudimentary level of awareness among health service professionals was identified as the main cause of poor access provision.

## **2.9 Ethnic Minorities**

It is important to consider the health of ethnic minorities in conjunction with deaf people, and take into account those who come from an ethnic minority background. There is less reluctance by ethnic minorities to use some of the health services than might be expected. Community based outreach services, which have an understanding of the needs, language and culture of ethnic minorities, have been a more successful approach (Scambler, 1991).

### ***2.9.1 Double discrimination***

The Royal Association in Aid of Deaf People (Sharma and Love, 1991) funded by the Department of Health carried out a study on the needs of deaf people from black and ethnic minority communities. They concluded that black deaf people felt that their cultural identity was ignored, and overtly discriminated against. Some white deaf groups were seen as defensive in not allowing black members to join them, or making them feel uncomfortable if they attempted to become involved.

Special mention is made of the aspect of parenthood and the family in a western context with the eventual aim of independence and a gradual reduction in the obligation of children to their parents. It is commonplace in Asian families to witness a sense of assumed inter-dependency based on cultural values. The children are seen as an extension of their parents, with shared responsibility for the well-being of the family, rather than as separate entities. The rights and responsibilities of Asian children are integrated into their family life, and there are clear expectations of their roles in



community life (Sharma and Love, 1991). This creates further difficulties for deaf members of Asian hearing families in terms of culture conflict, language, religion, marriage, and history of their ethnic background.

Black people, who were interviewed for the research project, experienced limited employment and career prospects, and these were perceived as being worse than those for their hearing contemporaries. Contacting women in the Muslim community proved to be difficult for some people, due to the fact that Muslim women are very home centred. Marriages were often arranged with hearing people that further compounded their isolation (Sharma and Love, 1991).

A report, commissioned in West Yorkshire (Badat and Whall-Roberts, 1994), found that many deaf Asian people had almost no knowledge of the services provided by local authorities and other agencies. This concluded that a significant number of these people were not receiving the help that would enable them to access services, such as social workers and communication support. Communication facilities for deaf Asian people were found to be poor. Finding a person with sign language and Asian language skills was extremely difficult. In addition, Asian hearing people and community groups were not always aware of the needs of deaf people, and therefore were not in the best position to offer support to them within the Asian population.

The project concluded that many young deaf people from ethnic communities might have two or three languages in their life. At home they may use their mother tongue, and English and BSL at school. As the child got older they were more likely to question which culture they belonged to. Also deaf adults were rarely in touch with their local Deaf clubs or other services used by deaf people in general. Therefore they do not have access to the mutual support and information that is available within the Deaf community. These findings are supported by Ahmad *et al* (1998).

Chowdhury (1999) observed that ethnic minority people are disadvantaged in accessing various services. The Asian Deaf Women's Association was set up to counteract this

isolation, and is an example of a community based approach enabling statutory services to reach a previously isolated user group.

## **2.10 Summary**

Literature on deaf people and health covers *whether* deaf people have the health knowledge, which is of course necessary. More importantly, there is very little mention made of *why* the lack of knowledge has occurred along with recommendations. Very little research has been carried out on the activities in the Deaf community and even less carried out by those with an ‘insider’ perspective. Many deaf people do not have sign language as their first language, and the outcomes of these community based developments are not often available in written English.

When deaf people become more acculturated they start taking the same level of responsibility for their own health that is routine for most other people. However, this is very much an individualistic assumption. Exploration was made in Chapter 1 of collectivist values inherent in the Deaf community, and it is these values that they practise best. Language and cultural issues are also a factor, and service providers need to incorporate these into their strategies for a better understanding of deaf people’s health needs within a culture-linguistic framework. The following chapter introduces the methodological framework for the studies.

## Chapter 3 Methodology

### 3.1 Research Questions

In health theories, the emphasis is on empowering people and improving their ability to cope with their daily lives and their personal health. There have been many opportunities (Duran and Duran, 1995; Hawes 1997) for other ethnic minority groups to talk about their health needs in relation to their community and ethnic culture. For literature that uncovered deaf people's health knowledge (Kleinig and Mohay, 1990; DiPietro *et al*, 1981), much of it has traditionally used sample methods without consideration for the population being studied. No attempt is made to explain why deaf people lack this health knowledge. A lot of work using the bottom up approach is carried out in the Deaf community in the form of community health projects. Yet these events are often not written about in academic literature that concerns deaf people and their lives.

To explore the above limitations in more detail three studies were undertaken that incorporate the three main research questions, which are:

- What is the impact of being deaf on health?
- What are the strategies that can assist in the prevention of poor health?

In attempting to establish an appropriate methodology for the focus groups for Study 1 the main selection criteria were:

- The methodology should allow for discussion away from all established concepts of health categories.
- The methodology should allow for the cultural viewpoints and beliefs to be elicited from the both the individual and collective perspectives to examine how the Deaf community sees health per se.

Study 1 explored the cultural context of the Deaf community and offers an insight into how young deaf people construct their social views. It was decided that the use of focus groups were the most appropriate means of data collection. Study 2 looked at the development of a health questionnaire appropriate for deaf people, in order to determine the value of such a measurement combining both quantitative and qualitative methods. Finally, Study 3 gave an insight into working as a health professional in the Deaf community, and the open response interview allowed for further exploration of thematic issues.

### **3.2 Research Methodologies**

In Chapter 1 exploration was made of the three models – medical, social, and culturo-linguistic. The third model, culturo-linguistic, plays a more prominent role in recommendations for better health service provision. The qualitative research approach best helps us to understand the needs of the community from a collective point of view.

The research undertaken had to take place from an ‘insider’s’ perspective. Stinson (1993) acknowledges that he gives additional weight to reports written by deaf scholars even if he disagrees with the writer’s perspective. While he considers that hearing scholars can make noteworthy contributions, there remains:

A potentially dangerous tendency for oversimplification and stereotyping when researchers from the dominant culture try to describe and understand a minority culture.

(Stinson, 1993, p18)

Therein lies the crux of interpreting data, which gives some guidance for understanding the subject matter in this thesis. Writings by deaf people on research strategies with theories to guide research are very thin on the ground. The lack of deaf researchers can be attributed to the fact that, in acquiring training and establishing one’s position as a researcher, the deaf individual is likely to encounter significant barriers and receives little or no support. There has been and still is a demand for deaf people to work within the

discipline of social science, and to assume the positions of leadership and control in research involving deaf people.

This has had an effect in establishing and conducting the research questions from an ‘insider’s’ perspective. However, it is important to try and define the methodologies chosen, and their validity in conducting each of the studies.

The aim of this thesis has been to learn about the experiences of deaf people from their perspectives, and to reflect these through the analysis of recorded field notes, interviews and focus group discussions, where the informants describe and interpret their lives. The next section discusses the value of quantitative and qualitative research used with the Deaf community to best describe their community life and culture.

### **3.3 Which Approach?**

#### ***3.3.1 Quantitative research***

Quantitative research, unlike qualitative research, relies on a fixed questionnaire that should be administered the same way, word for word, for each respondent to obtain a reliable measure of the chosen group to study (Dobney Corporation, 2003). For reliable conclusions to be drawn from the research, samples for quantitative research must be representative of the target group (MORI, 2004).

Although not hard to design, questionnaires require a few basic rules to be followed so that ambiguous results are avoided. These include examples such as avoiding double meanings or leaving the respondent unable to answer. This type of research concentrates on measuring and counting facts, the relationships between variables, and seeks to describe observations through statistical analysis of data. It includes experimental, non-experimental, and descriptive research. The latter describes the characteristics of a sample or population (Dobney Corporation, 2003).

### 3.3.1.1 Snowball sampling

It is particularly difficult to carry out the random sampling approach with the Deaf community, as no concrete data or register of deaf and hard of hearing people exists. Records that do exist are sporadic, and may depend on registration with the local social services department, which is done on a voluntary basis. The snowball sampling method was utilised for all of the studies; this approach is a valuable tool in studying the lifestyles of groups often located outside mainstream social research.

While some may seek to characterise the topics for which snowball strategies have been used as being trivial or obscure, the main value of snowball sampling is as a method for obtaining respondents where they are few in number or where some degree of trust is required to initiate contact. Under these circumstances, techniques of 'chain referral' may equip the researcher with characteristics associated with being an insider or group member and this can aid entry to settings where conventional approaches it find difficult to succeed (Atkinson and Flint, 2001).

Snowball sampling is used most frequently to conduct qualitative research, primarily through interviews. Snowball sampling can be used for two purposes. Firstly, it can be used as an 'informal' method to reach a target population. If the aim of a study is primarily explorative, qualitative and descriptive, then snowball sampling offers practical advantages (Hendricks *et al*, 1992). Secondly, snowball sampling may be applied as a more formal methodology for making inferences about a population of individuals who have been difficult to enumerate through the use of descending methods such as household surveys (Faugier and Sergeant, 1997).

Quantitative analysis was used to measure deaf people's attitudes to health in Study 2. The questionnaire design, in some parts, incorporated the qualitative method. This allowed for greater flexibility and elicited valid views from the deaf informants. Adopting this method gives an insight into the social life of the Deaf community, and helps to understand the reasons for the informants' behaviour. It is also orientated towards understanding human nature, and allows the researcher to get close to the research subjects.

### **3.3.2 *Qualitative research***

Qualitative research focuses on the experiences, interpretations, impressions or motivations of an individual or individuals, which seeks to describe how people view things and why. It also relates to beliefs, attitudes and changing behaviour. This approach includes research such as focus groups and in-depth interviews, the results of which cannot be statistically applied to a population as a whole, but can provide a valuable insight into certain aspects of the population.

It is useful to look at ethnographic methodologies as this approach can be used to explore deaf people's experiences of health. Ethnographic methodologies are helpful in that they encourage and capture the perspectives of 'other' cultures. Ethnographic research methods augur well for studying 'special populations' because they allow the people being studied to define what is being studied (Akamatsu, 1993).

Although not all questions can be answered through ethnographic research, the qualitative approach is ideally suited to studies where the goal is to describe the experience of people in their own words, and from their perspectives.

Ethnographic research is built on the premise that human behaviour is a product of how people interpret their world. Instead of surveys or controlled experiments the ethnographers research tools are observation, and open-ended or semi-structured in depth interviews.

(Bogdan and Biklen, 1982, p28)

The study of the Deaf community's cultural and belief system is more suited to the qualitative rather than the quantitative approach.

More credence has been given to qualitative research. Once thought to be lacking in objectivity, academic rigour, reliability and validity by the 'scientific community', it is now thought to represent more the real life, lived experiences of those who would not otherwise be in a position to inform the wide academic community about their experiences. It has also enabled d/Deaf people to both

undertake research, which affects them, a necessity if service provision is to be appropriate to users needs.  
(Hawcroft and Jones, 1998, p5)

This offers an insight into how service providers may wish to research ‘special populations’, and gives some consideration towards a developing a methodology in data collection.

Qualitative research seeks to answer the ‘what’ question, not the ‘how often’ question (Black, 1994). A qualitative approach – interviews, observation of activities, and interpretation of written materials – is the most revealing when the variables of greatest concern are unclear. However, quantitative research can assist qualitative work by identifying the appropriate variables to be measured. Too often people start analysing results before they fully understand the underlying issues, and thus may not target the appropriate factors (Black, 1994). The questionnaire design of Study 2 permitted exploration of the main factors affecting deaf people and their understanding of health using a qualitative approach.

Qualitative research is descriptive. Results that are written up contain quotations from the data to illustrate or substantiate their presentation. The underlying premise is that systematic enquiry must occur in a natural setting rather than an artificially constrained one such as an experiment. Although, it could be argued whether focus groups are a ‘natural’ way of studying a population. This research approach, which is used in Study 1 provides a starting point and establishes a platform for exploring further themes in Studies 2 and 3.

Qualitative researchers are concerned with process rather than simply with outcomes or products.  
(Bogdan and Biklen, 1982, p28)

This method allows the researcher to visit the area of study by collecting the data without any specific questions to answer or hypothesis to test, or to assess preconceived models. By conducting research in this manner there is a marked difference from quantitative



research, in that data or evidence is not investigated to prove or disprove any hypotheses that the researcher has prior to the study. The direction that the research takes comes after the data has been collected and time has been spent with the subjects.

The following criteria provide some useful guidelines in starting research according to Bogdan and Biklen (1982, p48):

a) The question of informed consent – the researcher must ensure that all informants enter the research/projects voluntarily. The informants must be made aware of the nature of the research, and any dangers or obligations that are involved.

b) Protection of subjects from harm – the researcher must ensure that the subject is not exposed to risks that are greater than the gains that they may derive.

c) The identities of subjects should be protected so that the information collected does not embarrass them or harm them by using pseudonyms. Anonymity extends not only to writing, but also in transcribing information into quotations. There will be times in the research when the subject's identity is difficult or impossible to hide.

d) Subjects should be treated with respect in order to seek their cooperation in the research.

e) In negotiating permission – it should be made clear to those you are negotiating with what the terms of the agreement are. The contract should be abided by; if you have agreed to do something in return for permission, it should be followed through and done. Above all, it is important to be realistic as a researcher when making such negotiations.

f) The truth should be told when writing up research findings. For ideological reasons you may not like the conclusions you reach, and others may put pressure on you to show certain results that your data does not reveal. It is important to show what the data reveals.

### **3.4 Focus Group Techniques**

This section explores the effectiveness of ‘focus groups’ – the method by which the material was collected in Study 1. This illustrates how different focus group discussions are from open group discussions.

Group interviews often provide us with unexpected interactions, insights, ideas and information. The importance of doing a group interview is to bring informants with different views into contact. This situation usually consists of six to eight people; to find out their opinions, feelings, and knowledge in response to the researcher’s line of inquiry. A script is followed to provide a structure for the questions being asked. Some researchers prefer to use the term ‘focus group’ to refer to the group interview that emphasises dynamic group interactions, amongst other things (Krueger, 1994).

Focus groups offer many advantages for both the researcher and the group informants. In essence, the group interview is an opportunity to observe a selected number of people discussing the topic of most interest to the researcher. In naturalistic observations the participant observer may not be fortunate enough to see a discussion of his or her research question. This chance is possible through focus groups (Krueger, 1994).

In the group interview the informants have an opportunity to listen to each other’s contributions, and this may spark new insights, or help them to develop their ideas more clearly. Information that may not have been contemplated or shared in the individual interview may emerge in the group process. In this way, researchers are sometimes able to ‘see’ people thinking through their interaction and can gain fresh insights into how people construct their worlds (Krueger, 1994).

### 3.5 Semi-Structured Open-Ended Interviewing

This approach was adopted for Studies 2 and 3. In-depth interviewing follows the qualitative approach, but it is in many ways a different research approach. There are many different types of interviews, attitude surveys, opinion polls and questionnaires, which cover a large group of informants or subjects. Qualitative interviewing is quite different from structured interviewing.

By in-depth interviews we mean repeated face to face encounters between the researcher and informants directed towards understanding informants' perspectives on their lives, experiences and situations as expressed in their own words. The interviewer, not an interview schedule or protocol, is the research tool.

(Taylor and Bogdan, 1984, p77)

The researcher is intent on obtaining a detailed understanding of how people think, and how they arrived at their perspectives. Often in-depth interviewing goes hand in hand with participant observation.

Open-ended questions allow the subjects to answer from their own frame of reference rather than one structured by pre-arranged questions. Because of the nature of the detail sought most studies incorporating this approach have small samples (Taylor and Bogdan, 1984).

Spradley (1979) offers an insight into ethnography research describing it as the work of describing a culture. The essential core of this activity aims to understand another way of life from the native point of view. He describes ethnographers working with informants to produce a cultural description:

Informants are first and foremost native speakers. Informants are engaged by the ethnographer to speak in their own language or dialect. Informants provide a model for the ethnographer to imitate. Finally informants are a source of information; literally they become teachers for the ethnographer.

(Spradley, 1979, p25)

An important part of interviewing is being non-judgmental when the informant talks about something embarrassing, particularly if it is illegal. In-depth interviewing requires a great deal of patience, but does allow exploration of several issues that might not be possible in a quantitative approach. It means communicating a sincere interest in what informants are saying, and knowing when and how to probe and ask the right questions.

### **3.6 Factors Affecting Methodologies and Choices**

Exploring the validity and reliability of the data is essential to provide an 'honest' account of the research and the samples undertaken. The following section looks at some of the methodologies chosen which have impacted the research process.

#### **3.6.1 Written surveys**

Standard data collection methods present communication, language and cultural barriers that make it difficult to collect quantitative data amongst deaf people (Lipton and Goldstein, 1997; Lipton *et al*, 1996).

Written surveys have been used amongst deaf people (Joseph *et al*, 1995; Zazove *et al*, 1993), but they are difficult to implement because of the low levels of English language reading ability (Conrad, 1979). Minicomms could be used for telephone surveys, but this also requires a written English language literacy and is a cumbersome technique for data collection (Berman *et al*, 2000).

Sign language can be used for data collection, but the lack of written forms precludes their use in paper-and-pencil questionnaires or telephone (minicom) interviewing. Sign language can be used for signed in-person interviews (Schein and Delk, 1974; Hindley *et al*, 1993). However, their use raises important issues; unlike written questionnaires the signed interviews are interpersonal and informants may have concerns about confidentiality and privacy, particularly if the survey is collecting information on sensitive topics. Zazove *et al* (1993) observed that when interpreting health behaviour

data in the Deaf community, one must bear in mind that they are often secretive about their lifestyles. The Deaf community is comparatively tight-knit, and members may be reluctant to admit to their behaviour for fear that others will find out.

The absence of a standard way for different individuals to interpret a written questionnaire into sign language raises issues of inter-interviewer reliability and consistency. Repeated administering of an interview is demanding and labour intensive for an individual or a team of interpreters, and skilled interpreters are in short supply (Berman *et al*, 2000; Lipton *et al*, 1996). In addition, the use of sign language may not meet the needs of all deaf people especially those who choose to communicate by lip-reading.

From a reliability viewpoint, the use of different signers/interviewers in one-to-one situations would yield an intolerable amount of uncontrolled variation. This would result in too much inconsistency in the content of questions, in sessions, and with interviewers. The content of sign language communication would not be standardised and the survey instrument would be communicated slightly differently by each person. This would be deemed unacceptable from a research standpoint (Lipton *et al*, 1996).

For all the studies conducted, it was felt that the validity of written questionnaires would offer no value to understanding deaf people's concepts of health. For this reason, 18 interviews were carried out for Study 2. Although a small number, this group yielded rich data and explored issues that would not have been obtained from a written survey among deaf people.

### **3.6.2 Ethics**

Ethics are important in considering the difference between right and wrong by a particular group, when conducting research. Jones and Pullen (1992) researched the benefits and challenges of collaboration between deaf and hearing researchers. Foster (1996) noted that researchers need encouragement in thinking about potential

conflicts that may arise in their interactions with deaf people, and to make adjustments that empower rather than alienate their subjects. Contemporary cross ethical principles and practices in cross cultural research are also important aspects to consider and incorporate into research in deafness. The Deaf community has been defined by Pollard (1993) as a 'collective entity' which has the same rights as individual research informants, i.e. the right to information, consent and protection from harm.

At times the research can go beyond the individual and affect the entire host community, sometimes quite negatively. Host communities in Alaska, India or Australia have banned or severely curtailed outside research activity after an investigation agenda, data collection methods or published results proved detrimental to them.

### ***3.6.3 Difficulties with sampling procedures for Deaf populations***

There is no regional or national sample from which to draw stratified random samples of deaf people. Census data is available from which one can obtain some descriptive statistics and some health data can be derived from general household samples, but nobody has compiled a sampling frame of the deaf population to date (Lipton *et al*, 1996). In a recent survey this also proved to be difficult due to the absence of a register containing all the name and addresses of all members of the Deaf community. Moreover, the Deaf community does not exist in a geographical location, as it is a linguistically and culturally defined group (Dye and Kyle, 2000).

It is not surprising that survey research amongst deaf people has been limited, or that information specific to deaf people is rarely reported from general population surveys. Few descriptions of the steps required to tailor data collection to the needs of deaf people are available (Berman *et al*, 2000).

### ***3.6.4 Developing a cultural and linguistic approach to data collection***

It is necessary to develop a culturally and linguistically appropriate data collection instrument as part of any health related survey. In recent years, a larger body of research

began to look at the need for both linguistic and cultural knowledge, and understanding within the field of deafness and mental health (Hindley *et al*, 1993).

Berman *et al* (2000) identified an innovative strategy to overcome traditional barriers of data collection techniques among deaf people by using the Interactive Video Questionnaire (IVQ), an interactive multimedia computer and video technology used for surveying deaf people. This is essentially a signed questionnaire that is presented on a standard desktop computer and monitor using digital video. Three language options are offered: ASL, signed English and lip-reading, and written English. The user chooses a language format; options for questions and answers are signed on the video monitor in the selected language. As the option for each response is signed, the corresponding button with an appropriate word prompt appears and is retained on the touch screen monitor. This approach offers an insight into collecting sensitive information amongst the Deaf community and considers various sign modalities.

In Study 1, a video narrative was created in order to gauge and spark off responses from the informants. In Study 2, a health questionnaire was developed that was appropriate for deaf people and health issues in the Deaf community, particularly with regard to access. An attempt was made to consider the cultural experiences of the Deaf community as well as their experiences in accessing health for the interviews in Study 3.

### ***3.6.5 Insider researcher issues***

Just because a researcher is deaf does not mean that they will carry out research that is appropriately sensitive to the views of various deaf people. For deaf researchers in the Deaf community, there is the potential influence of what is known as the ‘Observers Effect’. It is a desirable attribute for deaf interviewers to become skilled in listening and communicating with deaf informants who have different communication preferences (Kannapell, 1989), and to involve other deaf people in the research such as including a deaf advisory group (Foster, 1993). In the context of this research the following quote

illustrates that consideration needs to be shown towards special populations during research:

Those researching sensitive topics may need to be more acutely aware of their ethical responsibilities to research informants than would be the case with the study of a more innocuous topic.  
(Lee, 1993, p2)

The Deaf community tends to be a closed community. That is, most deaf people are reluctant to share information that might embarrass them or bring shame on the community. A large proportion of interpreters are known to most deaf people within the community thus their willingness to share information about clandestine behaviour in a one-to-one session with an interviewer, with an interpreter present, could be compromised by the apparent threat to personal confidentiality (Lipton *et al*, 1996).

### ***3.6.6 Cross cultural conflict***

Cross cultural conflict needs to be taken into account when interpreting data where language is a consideration. If sign language interpreters are used in interviewing deaf subjects, we must ask whether the appropriate cultural meaning of the response will be relayed. This is well documented in Elton (1994), when she poses the question of cross cultural misinterpretation. She argues that communicative competence is required in

order to understand rules for communication and shared interaction, as well as the cultural rules and knowledge.

In order to extract culturally appropriate data it is essential that deaf people interview other deaf people. For example, Akamatsu (1993), a hearing researcher, recognises in herself and other hearing researchers in the Deaf community, the potential limitations of the majority group writing about a minority group and also in carrying out this research.



The recruitment of deaf people to answer questions on drug use would be difficult for any research initiated by hearing people. Kannapell (1983) states that in general the deaf people do not trust the hearing community. This has an impact upon the disclosure of any behaviour in closed settings, particularly if the information is sensitive. Lipton *et al* (1996) employed deaf researchers as recruiters and researchers in their research on drug use. This can be seen an example of best practice to implement in research with deaf people.

The value of hearing researchers is important. However, building up a relationship between researchers and informants necessitates getting involved in the community, and is a significant step in increasing the sensitivity of the research. As with ethnography, the ethnographer tries to find examples of shared experiences. Foster argues that the insider's perspective is necessary, but it is healthy to have an outsider's perspective (Foster, 1993).

Stinson argues that there is a real need for more hearing researchers to make such efforts and to check their work with deaf people. Hearing researchers have greater credibility if they can sign well, when they have deaf friends, and get involved with the activities of the Deaf community. Foster (1993) questions whether a person can do research in 'someone else's backyard'. She argues that it is possible for hearing people to do responsible and high quality research in the area of deafness, providing that steps are undertaken to include deaf people in the design and/or review of the work.

A good example of when the researcher has interpreted data wrongly is documented in Freeman's (1996) book on Margaret Mead's famous anthropological research in Samoa. She had set out to research the culture of the Samoans and claimed that free love flourished, while jealousy and adolescent turmoil were unknown. Embarrassed by her persistent questioning, the young girls told Mead a series of exaggerations, claiming that they lived in a sexually promiscuous paradise. This was the society that Mead had portrayed in her best-selling work, 'Coming of Age in Samoa'. This book became the key text in the nature-nurture controversy and a reference point for the social and sexual

revolutions of the 1960s. Freeman proved beyond doubt that Mead was wrong, leading to one of the greatest controversies in the history of anthropology.

Problems arise over the issue of informed consent, where the majority of deaf people are concerned, when it requires written English proficiency beyond the participant's ability. It is possible to translate the consent form from English into British Sign Language. However, problems arise over the different language levels of the deaf informants and what it means to them to give consent. The potential issue of harm has to be considered if informants have given consent, but are unaware of the nature and the implications of the research. In addition, they are often unaware of what happens to the research after the data collection has been conducted.

Baker-Shenk and Kyle (1990) note that deafness research has largely bypassed deaf people. They attribute this to the apathy of the Deaf community, instilled in them by years of exclusion from decision making processes that affect them. Additionally, the reports that are distributed are disseminated primarily in Higher Education settings which deaf people have had limited access to. These reports require a high level of English literacy.

This brings up the issue of how the research should be disseminated back to the Deaf community. Pollard (1993) suggests a variety of ways: distributing the research report in deaf magazines, local and regional television programmes, or through public lectures or meetings that are accessible to deaf people. This should ideally be distributed and led by a deaf person. Such costs should be anticipated and added to research and conference budgets.

An exploration of the theoretical design of Study 1 will be made in the next section.

### **3.7 Theoretical Background to the Research Design of Studies**

The 3 studies undertaken essentially followed a qualitative approach. The exception is Study 2, which incorporates some elements of quantitative data in order to investigate the consequences of asking deaf subjects closed questions.

#### ***3.7.1 Procedure – Study 1***

Prior to commencing Study 1, a small-scale discussion group was held at a college for the deaf in the UK, and matched the criterion of young deaf people still experiencing the ‘transitional stage’. Informants from both focus groups were of a similar age and shared other socio-economic features such as occupational status.

The emphasis of the discussion focused upon the student’s perceptions of their self-image and how they saw themselves in terms of their deafness. The findings have not been included in this thesis, however it later supported the development of recent research studies and was helpful in deciding which population and which research method not to use.

A decision was then made to approach young deaf people in an older age group, who were studying or had studied at University. This was done specifically to gauge their conception of health topics, to provide some clues towards their decision making process, to find out whether they were influenced by their peers, and where they obtained their health information. If an older group of deaf people were chosen then it was felt that they would be more informed and knowledgeable about various health issues, and the emphasis of this study was to find out the status quo for deaf youths.

It was decided that a video narrative would be created in sign language. A videotape containing two different stories narrated in sign language that covered various health issues was used to generate discussion. The aim was to place the responsibility of problem solving on the group.

People found it difficult to be subjective in their answers and the opinion was that if the video acted as a separate entity to the facilitator, then the group would relate to the topics better. At this stage it was also important to consider conceptual expression, which would be best served by a qualitative approach and the decision was supported to undertake the research in the form of focus groups and open-ended interviews.

Deaf people who have had inadequate communication models at home and school can struggle in answering probes or questions, for example, when commenting on a hypothetical situation. Adults of normal intellect and mental health may have difficulty with formal questions such as 'how?' and 'why?' even in sign language (Thacker, 2002). This might be because they are more accustomed to being told than being asked.

The focus group discussions were recorded on video and later transcribed into written English. This offered a unique way of eliciting responses concerned with decision making directly from deaf people at the prompts of the facilitator. In each case a deaf BSL user crosschecked the written English transcription against the video recording. Pseudonyms have been used throughout to protect the identity of the informants. The script utilised can be found in Appendix 1.

### ***3.7.2 Procedure – Study 2***

The researcher was faced with the dilemma of persuading the informants to express their feelings. At this stage it was felt that this might provide some insight into their lay beliefs that encompassed health, and development of a questionnaire was necessary to elicit these views. General health questionnaires utilised within the general population were reviewed, and the SF-36 Health Survey was regarded to be the most suitable template to produce a questionnaire tailored for deaf people to be used on a one-to-one basis.

The SF-36 Health Survey was developed for the Medical Outcomes Study (documented in Appendix 2), and has been tested and validated extensively. A 36-item short-form (SF-36) was constructed to survey health status and designed for use in clinical practice and research, health policy evaluations, and general population surveys.

The questionnaire assesses eight health concepts:

- 1) Limitations in physical activities because of health problems
- 2) Limitations in social activities because of physical or emotional problems
- 3) Limitations in usual role activities because of physical health problems
- 4) Bodily pain
- 5) General mental health (psychological distress and well-being)
- 6) Limitations in usual role activities because of emotional problems
- 7) Vitality (energy and fatigue)
- 8) General health perceptions.

(Medical Outcomes Trust, 1994)

The aim of this questionnaire was for it to be filled in by persons 14 years of age and older, and for administration by a trained interviewer in person or by telephone. The SF-36 has been described as a promising new instrument for measuring health perception in a general population (Ware and Sherbourne, 1992). The questionnaire in its current form was unsuitable for sending out to deaf people for completion due to the low levels of literacy.

This was used as the basis for developing a culturally appropriate General Health Questionnaire for deaf people, to enable comparisons to be made with hearing baseline assessments whilst at the same time offering an insight into discovering any cultural viewpoints. The literature review in Chapter 2 touches on the importance of this in respect of eliciting experiences, rather than just asking open and closed questions. The aim of the modified questionnaire was to analyse the health status and the experiences of health of the deaf informants. The approach used was a semi-structured questionnaire, in order to examine deaf people's knowledge of their health and social situation. This modified version can be found in Appendix 3.

Although the questionnaire followed a systematic health approach, it was necessary to determine whether deaf people would be receptive to such a sampling method, and if it would be successful.

#### *3.7.2.1 Sampling procedure – Study 2*

In total, 18 interviews were conducted. For the interviews based on the modified SF-36 questionnaire, the quota sampling method was chosen as a means of recruiting informants. It was apparent over time that this approach was not entirely suitable for a small community. For example, it was not easy to find a male aged 18-21 who lived in the East London area that would take part in the research, although at least five people were approached who satisfied this category.

East London boroughs rank among some of the most deprived areas in the UK. In April 1998, the British government announced which areas had been selected as 'Health Action Zones' (HAZs) as a strategy to tackle these deprived areas. Money was given to those areas to modernise services, tackle inequalities and to improve the health of local people. Frank Dobson, then Health Secretary, spoke about the HAZs developing ways of involving patients and the public in making decisions about local priorities, with the aim of promoting local partnerships to tackle pollution, homelessness, unemployment, and poverty. Eleven new zones were announced and one was the East End of London covering the boroughs of Hackney, Newham and Tower Hamlets. The total population for the three boroughs was 580,000 and it had the greatest concentration of poverty and poor health in the whole country.

The East London and City Health Authority (ELCHA), covers these three boroughs. In 1991 The Office of National Statistics (ONS) reported on the 30 most deprived areas in England using the index of deprivation; Newham was listed as the most deprived district in England, Hackney in third place and Tower Hamlets in seventh place. Haringey was in tenth place.

Two geographical areas were covered in Study 2 when interviewing individuals:

- Bristol and the surrounding counties in what was formerly the county of Avon.
- Three London boroughs: Hackney, Haringey and Tower Hamlets.

These areas were selected in order to provide some useful comparison between an inner city area and a regional city area.

The Centre for Deaf People in Bristol was set up in 1876, and serves the needs of deaf people from Bristol and its surrounding areas. The recruitment process of deaf informants in Bristol was bolstered by the fact that the Centre is open most nights to deaf people. Interviews could be arranged at the informant's own convenience at appropriate venues, times and dates.

The Centre for Deaf Studies at the University of Bristol was established over 20 years ago, and extensive research work has been carried out with deaf people nationally as well as locally. This was an added advantage in that many informants had at one time or another encountered or experienced deaf researchers, and participated in interviews or group discussions. As a result they had some understanding of their role in the research process.

Visits were made to Forest Gate Community Centre in East London. The Deaf club meets at this location on Friday evenings and has a predominately Asian membership. Another means of recruiting local informants from the area was made possible through the Asian Deaf Women's Association, set up in Newham in 1991. This project works closely with Asian deaf women, bringing them out of isolation in their homes to meet up together, with the aims of improving their confidence and self-esteem. Contact was also established with the deaf health advocate at ELCHA in order to identify suitable informants to interview.

### *3.7.2.2 Methodological problems*

Many service providers were reluctant to provide names and addresses of potential informants due to confidentiality. In some cases they needed the agreement of their clients before giving out personal details. If the informants were registered with the social services or their details were recorded on a database at, for example, the Deaf club then this proved an easier way of recruiting potential informants, because information could be sent to them via the service providers.

In an informal group session on 'Healthy Eating' deaf Asian women were approached on a one-to-one basis after the session. Many were reluctant to be interviewed; common responses were that they felt they had nothing interesting to say in an interview, and that they were not capable. "Not clever enough", was a uniform response given by at least four Asian women. In addition, some did not want the interviews to take place in their homes because they would have to obtain permission from their husbands. Finding Asian men was another obstacle; many worked during the daytime and tended to stay at home with their families in the evenings.

With hindsight it can be seen that because the researcher was Caucasian this was a contributory factor in the low response rate from the deaf Asian community, especially from young males. Evidence of this can be demonstrated by the fact that a successful response rate was obtained on a different research project in Bradford when using a deaf Asian person, as a research assistant, to recruit informants.

The revised questionnaire was administered by myself in sign language to ensure consistency. In order to eliminate any researcher bias and to ensure the interview could be reviewed at a later stage it was also recorded on video. One of the advantages of this method was that many of the informants had learnt sign language later on in life, for example, after they had immigrated to the United Kingdom. This was particularly true for the London interviews. Consequently, the tapes could be used as a means of backup



to double-check their narratives. The full questionnaire utilised is documented in Appendix 3.

Pseudonyms have been used throughout to protect the identity of the informants.

### ***3.7.3 Procedure – Study 3***

Studies 1 and 2 looked at the issues facing deaf people in order to establish a framework of issues that impact the Deaf community. However, it was felt necessary to investigate further the viewpoints of the professionals that work in the Deaf community, and how different issues impacted on their work to build a more comprehensive picture of how the framework would look. For this reason, Study 3 adopted an open-ended interview approach to obtain a greater understanding of the situation of people working as health professionals in the Deaf community. This offered a unique insight into what their work entailed, the barriers in their work, and an understanding of the issues facing deaf people in the health context.

Therefore the aims were to look at:

- 1) The status of health professionals in the Deaf community.
- 2) The beliefs of the lay views of deaf people in the community in more detail.

#### ***3.7.3.1 Method of data collection – Study 3***

In keeping with ethnographic research, it was necessary to undertake an in-depth interview that focused on the issues within the Deaf community and health, but also allowed for flexibility to perform probes where appropriate.

Having researched the attitudes of young deaf people, to build up a representative picture of deaf health, it was necessary to meet those people who work in the Deaf community or who provide information in the health arena. Young deaf people often mentioned not

having access to health information, and this offered an opportunity to discover if certain health initiatives were working at a community level.

All of the interviews were carried out by the means of semi-structured open-ended interviewing (See Appendix 5 for the interview schedule). These interviews were conducted in sign language by myself, recorded on video and later transcribed into English. Pseudonyms have been used to protect the identities of the informants.

#### *3.7.3.2 Informants*

Six informants (all female, five deaf, one hearing – as she was instrumental in setting up the DWHP) working as health professionals in the Deaf community were interviewed over the period of one year on a one-to-one basis, in order to investigate topics that had surfaced. Their work in the voluntary sector covered a wide variety of jobs: health volunteers, committee members of a voluntary women health organisation, deaf health workers, deaf advocates, and Health Promotion officers in the Deaf community.

### **3.8 Analysis – Studies 1, 2, and 3**

After the focus groups were conducted and the one-to-one interviews carried out with deaf professionals, full transcripts were produced and analysed. The creation of these transcripts meant procedures had to be followed and there were rigorous checks on validity. A deaf sign language user checked all the data against the filmed narratives. Initially a computer software package was considered but it was felt that it was necessary to obtain a full and complete narrative in the ethnography tradition. Furthermore, it was important to collate the information to identify certain trends that appeared. The information was collected in sign language and it was fundamental that the linguistic and cultural meaning of the narratives was not lost.

### **3.9 Summary**

This chapter highlights several issues when undertaking research with deaf people and the Deaf community. An exploration of the research methodologies and their ethics helped us to define the most appropriate method to use. What is clear is that deaf people need to be involved with research involving their community – at both the design and the review stages. In addition, the research tools created need to be culturally and linguistically appropriate to utilise with deaf informants.

Generally speaking the two types of research approaches, quantitative and qualitative, do not work well together. However, when looking at health it is useful to use the two approaches to look at certain issues from different viewpoints. The qualitative approach enables deaf people's views to be explored. The quantitative approach will provide reliable information with regard to health habits, which allows comparisons to be made with other populations.

## **Chapter 4 Perceptions of Health within the Deaf community**

### **4.1 Introduction – Study 1 University Students (December 1996)**

The discussion aimed to elicit the student's views on various subjects of a topical or controversial nature in the Deaf community. This chapter covers many aspects of deaf people's experiences, and provides testimonies from deaf young people, their life experiences and perceived factors that have had an effect on their health and well-being. An attempt was also made to gain an insight into their general knowledge and their views on health to build up a health framework from a Deaf community perspective, by covering issues that have impacted on their lives. It provides us with an opportunity to enhance our understanding of the Deaf community and helps to define health behaviour in accordance with cultural norms outlined in Chapter 2.

Many obstacles have to be overcome to ensure that the deaf individual has a good grounding for well-being. The barriers mentioned in this study include enculturation, education, and making the transition to meeting deaf peers. Issues arose over deaf people's access to health information, sexual behaviour, and the subsequent impact on their health, self-esteem and well-being. If these positive environmental factors are not in place then it can be suggested that this has an adverse impact on the health and well-being of the deaf individual.

#### ***4.1.1 Procedure***

The emphasis of this group discussion concentrated on two stories told by a deaf BSL user. The first narrative looked at a deaf person being prescribed the wrong medication, and the second narrative related to a new couple practising safe sex. This approach of video narratives was used to elicit the views of the informants on their decision making process. Contact was established with deaf students in a city in the North of England inviting them to attend.

#### ***4.1.2 A visit to the doctors***

The first case study looked at a deaf man's experience with his GP, who did not understand him and was not helpful. The story ends in the deaf man being prescribed some medication and picking it up from the chemist without understanding why he was required to take it, or any potential side effects.

The informants were quick to tell their own stories of the discriminatory attitudes of their GPs, and often felt under pressure to leave the room as quickly as they entered. An interesting aspect of the discussion revolved around whom they attended their surgery sessions with. One male confessed that he still attended with his mother:

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

(Ian, 24 years)

Raj came from an Asian background, however he felt that people from his community still lacked basic awareness:

My experience is similar but it is the same with Asian people. They are not deaf aware themselves either. When I go to the doctors I have to write things down, it puts me off. Sometimes my mother and father go with me, and help me – that is all right.

(Raj, 23 years)

The ever-prevalent influence of the mother in attending the son's surgery appointments seems to be a consistent theme in the focus groups discussions. Evidently this is one aspect of their lives that some deaf people feel that they have no control over. The maternal instincts from childhood are extended into adult life, and once again the deaf adult is excluded from making their own decisions.

A key theme in the discussion was the existence of a support network. For several of the informants this was provided by their family unit. An example of a deaf person that was seen to be acting in a non-assertive role was given:

I know one deaf person who waited for two hours for their turn at a GP surgery. I don't know how that person had the patience to watch people arriving after him, leaving to see the doctor, and just sit there. When that person felt that they had waited for a long time, they went up to the receptionist and explained the situation. The female receptionist just said, "I'm sorry, I forgot." The next time that person brought an interpreter with them. It was much better for them.  
(Jo, 27 years)

One way of coping with this scenario was put forward by Jack:

You have to be forward, pushy.  
(Jack, 24 years)

No mention was made of whether the service providers should make their service more accessible for deaf people. The informants felt that the onus of responsibility lay with them. This is not surprising given that the medical model was predominately seen as insurmountable, stemming from years of experience growing up deaf.

An account of encountering good practice of deaf awareness in a medical situation was given:

I only went into hospital for one day. They wrote down that I was deaf. I slept most of the day and my friend came to pick me up at 6pm. They provided me with a teletext television and a minicom. I did not really need it but it was useful to have a teletext television. I was only there for one day but the provision was really good – excellent I thought. The equipment makes a big difference.  
(Jo, 27 years)

Clearly such a situation allowed informants to feel valued and assimilated into the health care system rather than feeling socially excluded and isolated

Thoughts about the medical view were very much interwoven with the informant's own life experiences. Having established what would constitute better practice in GP's attitudes, another view that generated mixed feelings among the group was some deaf

people should be more assertive, and demand their rights as deaf people. However, the general opinion was that not many deaf people would be confident or comfortable asserting themselves in such a situation.

#### ***4.1.3 Use of interpreters – Creating dependency?***

Several informants were not keen on using a sign language interpreter in a consultation session. The group consensus developed along the lines of privacy being of utmost importance, being able to have a one-to-one consultation, even if pen and paper had to be resorted to. Another concept brought up was that interpreters were seen to have an interfering role. These young deaf people did not want to be seen to depend upon a ‘third person’.

I don’t need an interpreter because I have the confidence to approach people and be forward.

(Ian, 24 years)

This false belief and independent stance can be attributed to group and peer pressure throughout the focus group’s session. Of the seven informants, six were male.

While some had this attitude, Jo explained her experience of using an interpreter:

At hospitals I have used interpreters twice, because doctors there cannot be bothered to make an effort to talk to me. The second hospital visit I made I brought an interpreter and it made a big difference. My interpreter was demanding. I think the doctor was a bit stunned. I did not say a lot myself but thought it was great! Now my doctor is making progress quicker. I realised before that I had wasted a lot of time so having an interpreter there is really useful. Now if I go to the hospital I will always book an interpreter. It is worth it and useful.

(Jo, 27 years)

Jo had realised the potential and usefulness of having an interpreter present. However, the general utilisation of interpreters is misconstrued. Jo saw the interpreter as doing the

talking for her, which meant she took on a more passive role. This led Jack to comment that using interpreters was most appropriate in times of serious illness.

I will use interpreters if it is a very serious illness. I would be able to get full information that way. If I have to write down or lip-read I won't understand what they (doctors) are talking about. I do not want to miss out on important information about my health for my future.

(Jack, 24 years)

Interpreters were seen to be part and parcel of access to any information, whether it is health, education or mainstream information. However, the group felt that this disempowered them in their medical appointments. At best it could be described that their experiences with interpreters were either not positive or limited. The need to look confident and be assertive was seen as a way of coping. Health appointments were seen as a necessity, and best avoided unless it was essential, although this lack of access to information could have a knock on effect on an individual's health in the long term.

#### ***4.1.4 Understanding medication***

In most situations people do not ask about any side effects or symptoms arising from taking prescribed medication. The group felt that deaf people were at more of a disadvantage and cited the following reasons: language and communication barriers, a lower level of understanding of English, a lack of confidence, and the ever prevalent medical attitudes of the health professionals. As a result they would not attend a health appointment unless it was absolutely necessary. Jo explained that she checked her medication when she got home:

When I get home I look in my medical dictionary. It tells you what the side effects are. I never ask my doctor because they find it difficult to explain to a deaf person. I check it out in the dictionary before I go to the chemist.

(Jo, 27 years)



The general view of the group was just to take the medication without asking any questions. Raj even asked his parents to ring up and check for him:

I ask my mother to phone afterwards and ask what it is, to check it out or to change it if it is the wrong prescription. I don't bother to ask at the appointment.  
(Raj, 23 years)

I never check. I just take it and see if it works or not. (laughs)  
(David, age 21)

Similar themes emerge, particularly around over-reliance upon parents. This was not challenged in the group discussion, and was accepted as the norm. Consequently not using interpreter's means that deaf people, in general, are at greater risk of inadvertently being misdiagnosed or taking the wrong medication when compared to hearing people because of the communication barrier.

#### ***4.1.5 Practising safe sex***

The literature review in section 2.7.1 documents that sexuality programs are typically sporadic in schools for the deaf. In order to examine the attitudes of the group towards safe sex, a video was shown of a deaf couple in a newly formed relationship. The female asks the male to use a condom but the male refuses to do so and walks out on his girlfriend.

Discussion centred on differing attitudes towards sex after watching the narrative. Jo felt that peer pressure influenced people's views within the Deaf community:

Friends like to follow their friends. I think that it is linked with pride. Some deaf people are like that; they never admit that they have a problem. They have an, 'I'm all right', attitude. They want to be the same as their friends – not think about themselves. Like when deaf males get together in the Deaf club, in a group they may ask other people do they use condoms, and they all say no. They are denying that they use a condom themselves. I have seen it happen. They do not think about the girl. It also depends on the age group and that person's education.  
(Jo, 27 years)

The informants maintained that their attitude was not similar to the account given by Jo. Agreement centred on the fact that it was acceptable to use contraceptives during sex. An additional perspective was that the groups saw themselves as a different group from those who frequented the local Deaf club, as being more educated. Ian described how he saw Deaf club members locally:

Like – having no brains. They just have sex, a fuck, and don't think anything of it, and the effects like pregnancy, HIV. They just think about sex. If a man is not too smart, sees a woman as a sexual conquest and she gets pregnant by him, then they don't care. But, on the other hand they are happy to tell their friends when they get laid!  
(Ian, 24 years)

We are mature, sensible. We have the brains. It is up to individuals to accept the responsibility. Couples should talk to each other and discuss whether they should use a condom or not. Not just the 'Fuck it' attitude, and not have respect – that is not good. An agreement should take place first between both adults.  
(Raj, 23 years)

Although there was an attempt by the facilitator to try and gear the group discussion around more intimate issues and dilemmas that might arise in their sexual relations, there was little discussion of these issues. The general consensus was that nobody would have any objections to using condoms, but there was a time and place to discuss this. This can be attributed to peer pressure and a lack of understanding of the consequences of unprotected sex. When challenged by the facilitator as to how they would explain the use of condoms without appearing 'sex mad', the following comments were made:

I would explain to them afterwards that I would not want them to think that I was sex mad – that it was for safe sex.  
(David, 21 years)

I know that I am healthy. If anyone else has AIDS or VD then that is their problem. I believe in looking after myself.  
(Raj, 23 years)

Categorising and labelling others was seen as harmful and negative. The importance of the video narrative gave an insight into how ‘closed’ issues are discussed and debated among peers from the same social group:

It is good to talk about it with each other, to help each other. I think that we all need that sometimes, to understand each other and the world better.  
(Raj, 23 years)

Indeed some members of the group members commented afterwards to the facilitator that this was the first time they had had a discussion on an adult level about health or sexual issues, and that they would have liked the opportunity to explore these issues further.

#### ***4.1.6 Sex education in schools***

All secondary schools are required to provide sex education for their pupils, but schools can decide on the content of the lessons, which results in patchy provision across the country. Some special schools have reported resistance from parents to their disabled children receiving sex education and there is a general reluctance in society to acknowledge disabled people’s sexuality (Fitz-Gerald and Fitz-Gerald, 1976).

For the majority of the informants in Study 2, sex education had been patchy or non-existent in schools. There was an overriding feeling of not being aware of basic information, such as understanding their bodies or sexual relationships.

When I lost my virginity, I thought that it was brilliant, but as time went by I learnt more about condoms, AIDS, etc. Those issues were there all the time but I never noticed it or thought that it was nothing to do with me. The more I learnt, the realisation hit me that the same issues affected me too. I was ignorant before – just wanted to have a good time. I changed and became more careful.  
(Jo, 27 years)

Common anecdotes came from informants who did not know about sex at all until they were about 13 or 14. Such a belief system is not surprising, considering that many deaf

children lead sheltered lives and are less exposed to mainstream information around them.

My hearing friends at home told me that they had learnt about sex in junior school and safe sex in secondary school. I went to a boarding school in Scotland and they did not say one word about sex during my education there – nothing at all. If someone talked about it they would get smacked and called a bad boy and sent out of the classroom.

(David, 21 years)

Many of the informants discussed similar feelings and agreed that this was the status quo for many young people especially school leavers. It was felt that those who had gone through the mainstream system had a worse time because they were the object of ridicule, being the only deaf person among hearing pupils, and lagged behind in their social skills and sexual knowledge at adolescence.

In contrast, in deaf schools it was more a case of ‘ignorance is bliss’, and sexual experimentation was rife:

I learnt at school. I did not know what condoms were, I was about 13/14 at that time and everyone laughed at me. I knew nothing about sex. My mother told me about the ‘birds and the bees’, the difference between men and women. This was because at the time I had watched a science programme at school and a couple were having sex on it. I did not understand it and a few weeks later I tried to do the same thing myself.

(Jack, 24 years)

While some informants described incidents where they were taught sex education at a school for the deaf, parents usually took on the role of explaining to their children about the ‘birds and the bees’ to their children. Deaf friends were another source of information, but it was agreed that this was not entirely accurate and lacked sufficient detail. Teen magazines were a further channel of obtaining information, giving teenagers the opportunity to learn and understand more about themselves and their sexuality.

The notion that one day deaf pupils would become adults and experience sexual relationships was seen as a subject that was embarrassing to broach and beyond the comprehension of staff. They could not envisage their deaf pupils growing up and leading 'normal' lives. David recounted a story from his schooldays:

One time four boys and four girls were having sex in a bedroom. The school found out and they were angry with them. They did not explain to them what the dangers were – just suspended them for two weeks. The teacher said how very bad it was to the rest of us. They did not give them any sexual advice before or after the incident. They had not been practising safe sex. All the girls could have got pregnant!

(David, 21 years)

Conflicting messages and being denied access to information provoked feelings of confusion:

When I look back, if I was watching television with my mother and father, for example, a 'Carry On' film and watching the woman's boobs, my mother would change the channel and say to me that was bad and smack me. When my mother and father kissed each other I would say to them, "That's bad", then they would tell me that it wasn't. They kept saying a lot of things were bad and I became confused. When I was about nine or ten I realised that my mother instead of saying that things were bad to me, should have explained things to me.

(David, 21 years)

David's incidental learning about issues of growing up and sex came from his deaf peers, not his parents. The majority of the group felt that they could not compare their own experiences, on the pace of learning and acquiring sexual knowledge, with their hearing peers, simply because no comparison model was available. Jack believed that he was held back when growing up with his hearing peers, and harboured mixed emotions:

I was about 11 at the time; I did a paper round. I bumped into one of my hearing friends when I delivered the papers at his house. He asked me if I wanted to join him in pulling some girls. I was not sure about what would happen but he told me that it was good – that I would have a good shag. I was like all up for it, dropped my paper bag and cycled to this place to meet a girl. I was not sure what was happening but I knew she said yes to whatever would take place. They were all talking, I did not understand what was happening, but the girl looked really keen.

We went to a hut in the field. The girls started to take their clothes off and get into sexual positions. I thought to myself, I haven't got a clue about what I am supposed to do. I pointed to the girl's vagina and said, "What's that?" I was not quite sure what to do; it was the first time that I had seen one. I knew nothing about sex at that time.

(Jack, 24 years)

While Jack felt anger and embarrassment that he was always 'one step behind' his hearing peers, he agreed that no one person was to blame. However, he maintained that he could have received better access to such information at school.

Channels of help sought included close friends, partners, going to the doctors for advice, or seeing a specialist. Nevertheless, no one could name a specific type of specialist. At a time of crisis when more information is required, all said that they would seek professional help although it may seem somewhat embarrassing.

## **4.2 Conclusion**

From all the data, a structural framework begins to emerge for the issues that affect deaf people in general, which were explored in Chapter 1.

The use of the video allowed for a group narrative, instead of questioning by the facilitator, to further explore the issues raised in the literature review in Chapter 2. The discussion revolved around what factors would affect their decision making or influence other deaf people. Common themes emerged including reluctance in booking appointments with GPs and in using specialist services, as a result of not knowing where to go, and frequently using parents in medical situations. This was accepted as the status quo. Using interpreters meant that the discussion was no longer private, and there was a preference in having a member of family present to help with communication for confidentiality reasons.

A consistent theme in running through Study 1 is that young deaf people are heavily influenced by their peers, more so by their deaf peers. This is not surprising but can be

explained by the process of going through the second stage of transition in meeting deaf peers and using sign language for the first time and perhaps having more access to information around them. It was the first opportunity for many that they were able to discuss issues that affect teenagers and young people with their deaf peers.

It is clear from the comments made by both of the focus groups that deaf people settle into a routine, which avoids the stress of contact with hearing people. When the surrounding community is not easily accessible, people retreat into structures, which they are familiar with. The home environment and meeting deaf peers in a neutral setting are understandably non-threatening.

All contact with hearing people in a medical setting is potentially stressful and can have an impact on their health and well-being. If they lack the confidence to pursue appointments due to these communication barriers, then what is important is that there are systems in place available to provide the necessary information and guidance.

The fragmentation of the structure of the Deaf community with respect to Deaf clubs gives some cause for concern. The individualistic attitude expressed by the group very much follows western bias, but community and cultures tend to only work best on collective terms.

It would have been ideal to carry out staggered focus group discussions with the same people over a period of time, to explore several themes further, particularly the issues that they felt had an impact on their general health, and their understanding of health care systems. This would have allowed more exhaustive analysis of several themes and stronger thematic issues may have emerged. In addition, setting up several further focus groups meetings may have allowed some quieter group members to build up confidence in discussing issues, with some of the more dominant group members.

Chapter 5 looks at the views of deaf people in two urban areas in order to elicit their viewpoints via the means of a modified health questionnaire. This looks at cultural references and offers an insight into the best way of meeting deaf peoples health needs.

In addition, this chapter builds on the themes that constitute a framework towards deaf people's understanding of health and health care systems.



## **Chapter 5 Deaf People's Health, Access and Contact with Health Professionals**

### **5.1 Introduction – Study 2 One-to-One Interviewing (1997)**

The previous chapter looked at focus groups as a technique of identifying themes that are consistent in the Deaf community. This chapter covers Study 2, which looks at one-to-one interviewing as a means of drawing out the thematic issues further. This approach was taken to find out which themes were consistent with the findings in Chapter 2, around deaf people's access to and understanding of health. It also allows us to probe further in order to develop a framework for understanding health as well as identifying suitable community intervention.

A standard questionnaire (SF-36) was modified to measure the status of health amongst deaf people. Several questions were semi-structured in order to allow for probes, when necessary. Further details around the modification of this questionnaire can be found in section 3.7.2.

Ten interviews in Bristol, and eight interviews in London were carried out on a one-to-one basis, in order to make a comparison of deaf people living in different urban health authority areas. Unforeseen problems arose from working with ethnic minorities and, in particular, in dealing with people with minimal language skills. Generally these people had poor language skills in both English and BSL, and this was further compounded by the fact that several had been raised in ethnic minority families. These were contributory factors in being unable to gain a representative sample of the three boroughs under the deaf advocate's boundaries of Hackney, Newham and Tower Hamlets. Difficulties of sampling deaf populations were explored in more detail in section 3.6.3. In order to make up the numbers, two of the informants came from two other neighbouring boroughs in East London – Haringey and Havering.

Two interviews were incomplete. The reason for this was that one informant had been invited via her Social Services department in Hackney to be interviewed for this research project, not understanding fully why she had been invited. When she had some conception of what the interview was for, she was reluctant to take part. An explanation for this could be that her visits to the social services were invaluable to her; they assisted with everyday tasks that she encountered difficulties with, such as letters that she may have received and not have understood. Another interview with a male from Hackney was also incomplete. He was unable to answer many of the questions, and it was decided to cease the interview halfway through the session.

Twenty one-to-one semi-structured interviews were carried out. Two were incomplete. This leaves 18 complete interviews, which will be analysed in this chapter.

## **5.2 Background to Health Authorities Provision**

Different health authorities have different levels of interpreter provision for deaf people in health care situations. For example, Avon Health Authority is contracted with the local RNID service to provide sign language interpreters in health care situations, such as appointments with hospitals and doctors. Any deaf person has access to this service living in what was the former county of Avon. This now makes up the four separate counties of Bristol City Council, North Somerset, Bath and North East Somerset, and South Gloucestershire as from April 1996.

East London and City Health Authority (ELCHA) provide a deaf health advocate for deaf people who use BSL and are resident in one of the three boroughs to meet their health needs. In inner city areas, with a high proportion of ethnic minorities, health advocates are often appointed for each ethnic group. For example, a Turkish person works for ELCHA as a health advocate, and their role includes working as a Turkish interpreter.

The ELCHA health advocate is deaf and unable to fulfil the role of a sign language interpreter. The deaf advocate acts in an advocacy/relay role at hospitals or GP surgeries

for deaf people. After receiving the GP's written response the deaf advocate will convey the proceedings and the information to the deaf client via sign language, and vice versa.

Table 5.1 illustrates the sign language provision available in the areas at the time the interviews took place (January 1998).

Area	Interpreting Service?	Deaf Health Advocate	Special Services
Bristol, North Somerset, Bath and North East Somerset, South Gloucestershire. (Former county of Avon)	Yes – via RNID Wessex	No	Social worker for the deaf and Deaf Services Team.
Tower Hamlets	None	Yes	Social Worker for the deaf (interprets for clients)
Hackney	None	Yes	Social Services for the deaf, currently seeking funding for deaf people to use sign language interpreters
Newham	One full time Community Interpreter	Yes	Deaf Services Team based at Social Services Department Asian Deaf Women Association
Haringey	None	No	No social worker for the deaf. Drop in service once a week at Winkfield Road
Havering	None.	No	No Social Worker for the deaf

Table 5.1 Provision of sign language interpreters

### **5.3 Sample Demographics**

Section 3.3.1.1 explores the merits of using the random sampling approach with the Deaf community, as no concrete data or register of deaf and hard of hearing people exists. Instead the snowball sampling approach was utilised, the main difficulty in using this method is that the final group of deaf people researched will not be 100% representative of deaf people as a whole. Those who participated in this study were known members of the Deaf community or known to their social worker. Not all deaf people will fit into either of these categories.

The sample was proportionally split 50% for the male to female ratio. The group were split into five age groups, and there is a good even distribution across the statistical breakdown (18-21 yrs – 3, 22-30 yrs – 4, 31-40 yrs – 5, 41-50 yrs – 4, 51-60 yrs – 2).

In the Bristol sample, eight of the informants were White and two were Black Caribbean. For the London sample, the ethnicity of the informants was: 3 White, 2 Black Other, and the remainder were Black African, Pakistani or Bangladeshi.

Out of the total sample of 18, 72% were born deaf. The results showed that 11% saw themselves as being partially deaf and the remainder (89%) saw themselves as profoundly deaf.

Seven of the sample (39%) did not have any deaf members in their families. Seven (39%) had deaf parents, and a further eight (22%) had deaf siblings. This percentage is particularly high for a sample, when it is considered that 90% of deaf people have hearing parents. One explanation is that active members of the Deaf community tend to have deaf parents and these people were easier to recruit for interviews. However, this may make the sample demographics slightly weighted in favour of active members of the Deaf community and the assumption can be made that these members would have more access to information via the community.

Eleven of the sample (61%) had attended a deaf day school and six (11%) had attended a mainstream school. One informant had not attended school until the age of 11, because he was living in India prior to this. With regard to their secondary education six (33%) continued to attend a deaf day secondary school until aged 16. Nine (50%) went to a residential deaf boarding school. Three (17%) attended a mainstream school.

Name	Gender	Age (yrs)	Current place of Residence	Ethnicity	Deaf Family Members
Emma	Female	18-21	Bristol	White	3 <sup>rd</sup> generation deaf, 1 sister, 2 brothers
Scott	Male	18-21	Bristol	White	3 <sup>rd</sup> generation deaf, 2 sisters, 1 brother
Tara	Female	22-30	Bristol	White	None
Matthew	Male	22-30	Bristol	Black Carribean	None
Madeline	Female	31-40	Bristol	White	Sister
Harry	Male	31-40	Bristol	White	2 <sup>nd</sup> generation deaf, brother
Leah	Female	41-50	Bristol	White	2 <sup>nd</sup> generation deaf, sister
Simon	Male	41-50	Bristol	Black Carribean	Uncles (2), brother, wife
Sophie	Female	51-60	Bristol	White	2 <sup>nd</sup> generation deaf, brother, 2 sons
Julian	Male	51-60	Bristol	White	Wife
Irene	Female	18-21	Hackney	Black African	None
Sumita	Female	22-30	Newham	Pakistani	Sister
Ali	Male	22-30	Tower Hamlets	Bangladeshi	None
Kate	Female	31-40	Hackney	Black other	None
Clive	Male	31-40	Hackney	Black other	None
Eric	Male	31-40	Tottenham	White	2 <sup>nd</sup> generation, sister
Abigail	Female	41-50	Hornchurch	White	4 <sup>th</sup> generation, husband and daughter
Bruce	Male	41-50	Tower Hamlets	White	None

Table 5.2 Data for informants (*n*=18)

## 5.4 Medical Encounters

The informants were asked how regularly they visited their GP, in order to determine whether they frequently visited the doctors. Studies frequently demonstrate that deaf people avoid medical situations as much as possible. The findings are illustrated in the table below.

How often do you see your G P?	
More than once a month	11%
Once a month	22%
Every three months	28%
Every six months	6%
Once a year	33%

Table 5.3 GP visits ( $n=18$ )

A high proportion of females visited their GP. A possible explanation for this is that women are often expected to be responsible for the health of the family; therefore they are more likely to see the doctor on the family's behalf (Abbott and Wallace, 1990).

When asked who accompanied them to their last appointment, a high proportion of 13 said that they went alone (63%). Others (37%) reported having been accompanied by a member of their family, partners, or their social worker who signed for them. The situation of each interviewee was very diverse. However, one consistent theme remained, that they tended to bring people in with them who they trusted. Significantly, none of the sample had used an interpreter at the doctors at any point in their lives. Table 5.5 illustrates that that 61% would like to use interpreters, but they were not aware of how to access them. If deaf people are not comfortable or at ease in GP or medical consultations the likelihood is that they will not make further enquiries or access the necessary information. By missing out on access to information this consequently has an adverse effect on their long-term health.

### 5.4.1 Communication issues

The various methods of communication used when visiting the GP were explored.

Mode of Communication	Percentage of Informants
Only wrote	50%
Spoke	17%
Lip-read	11%
Brought family, friend or partner	22%

Table 5.4 Main mode of communication with GPs ( $n=18$ )

The most common method of communication was writing for the informants.

Surprisingly nobody used sign language interpreters. It is necessary to be cautious with some of the responses; for example, only 11% lip-read. At best, the majority of deaf people would still not obtain all the information solely by lip-reading:

It is not satisfactory to write things down all the time. I know that you can bring an interpreter but it is not really the same, although you know that it is a confidential service. If you have a medical problem, like with your private parts, then I am not really comfortable with the interpreter being there. I do feel a bit discriminated against because of the communication. I don't feel as an equal if I am writing things down all the time.  
(Scott, age group 18-21)

Some informants were not clear when questioned whether their family used sign language or not. When probed further it was clear that these were family home signs, not sign language per se. The experience of parents having an overriding influence over the deaf child as illustrated in Study 1 is shown again below:

My mother goes with me to the doctor, she does it all for me, speaks and everything. Then I go to the chemist to pick up the prescription, they have all my information there on the computer. My parents never explain anything to me. If the doctor tried to explain the side effects to me I would not understand the reply.

I really need an interpreter there to make things clearer for me.  
(Clive, age group 31-40)

Clive is unaware of his rights and is clearly in a position of diminished control, not by choice. As recently as last year, Clive was diagnosed with sickle cell anaemia, and admitted that he knew little about sickle cell and its symptoms.

Sumita, an Asian female, in particular felt overly restricted by her family strict religion and over-protectiveness:

My mother talks for me. I am quiet and I never speak. My mother knows what is wrong with me. I never communicate with my GP myself and I remain silent. All I understood was to take medication three times a day. I read the note on the prescription, I do not ask about side effects.  
(Sumita, age group 22-30)

Sumita explained her frustration at being in this situation:

I don't understand; it is difficult communicating with the doctor. He explains nothing to me. I am fed up and he is not interested in communicating with me, only with my mother. I want to ask but I have been told to forget it by my mother, that I cannot speak as communication is too difficult. I do not understand what is going on, it is not clear, but I need to know why!  
(Sumita, age group 22-30)

This no doubt reinforced Sumita's low self-esteem and unwelcome feelings of inferiority. She wanted greater control over her life but felt that her mother acted as a gatekeeper in her interaction with others. Some informants used their children to interpret at the doctors:

Sometimes my 12-year-old son comes in to interpret for me at the doctors.  
(Bruce, age group 41-50)

The distinction between using the social worker and his family clearly has blurred boundaries for Bruce. This was a consultation with a heart specialist, and if there were



any bad news, his son was expected to relay this. The consequences of this was explored in section 2.6.5, for example (Collins, 1996)

Some informants mentioned that they were not happy to resort to written communication all the time and expressed the need for doctors to be able to use sign language. Despite their misgivings it is evident that using independent interpreters would allow autonomy away from their parents.

#### ***5.4.2 Use of sign language interpreters***

The incidence of interpreter use in everyday situations was investigated.

<b>SITUATION</b>	<b>YES</b>	<b>NO</b>
Hospital	78%	22%
GP	61%	39%
Educational Lecture	100%	
Meeting	100%	
Job Interview	72%	28%
Legal Situation	94%	6%

Table 5.5 Situations where an interpreter may be used ( $n=18$ )

A high proportion of the informants wanted to have an interpreter at the hospital rather than at their GPs. This is not surprising when you consider the different communication requirements for each situation, on a one-to-one basis compared to a busy hospital. It should be noted that there was a 100% response rate for having sign language interpreters in meetings and in educational situations. Again this is not surprising as these encounters offer the opportunity to learn about information on neutral grounds.

### ***5.4.3 Consequences of communication issues***

Many of the informants claimed that they understood why they had been given their prescriptions. A common response was that their doctor had prescribed it because they ‘knew what was best for them’. Few, if any had any concept of asking further questions about the medication, including any possible side effects.

Yes the doctor gave me tablets last time, I asked what it was for, he told me that it was to make me feel better, for my back and throat. I understood why then, and how many times a day I had to take it.  
(Madeleine, age group 31-40)

A common view began to emerge of one that was very heavily reliant upon the patient/professional relationship. The informants saw doctors being at the peak of the medical profession whose role were to ‘cure’ individuals.

A striking finding was that all of the informants attended appointments without an interpreter. Several informants saw the appointment as a burden and attempted to spend the minimum time possible in attending them, largely due to the communication difficulties. During the consultation session they had often wanted to ask questions. However, they encountered negative attitudes such as health professionals shouting at them, or refusing to write anything down.

Many expressed a preference for nurses rather than doctors; nurses tended to have time to talk to them, explain things fully and use alternate means of communication. This ‘secondary’ relationship with nurses reinforced any important medical information that they may have missed in the original consultation session.

One of the effects of this miscommunication was afterwards, many tended to resort to asking family or a close friend to explain to them what their prescription was for. This clearly demonstrates that there is a breakdown in communication during the diagnosis process.

## 5.5 Health Traumas

### 5.5.1 *The expectant mother*

During pregnancy deaf women feel particularly vulnerable in the medical consultation and in hospital due to communication issues. Abigail was ten weeks pregnant when she had a miscarriage. She went into hospital complaining of feeling ill and dizzy; the doctor did not appear to believe that she was pregnant. Eventually the doctor agreed to let her stay overnight for a 24-hour period:

I did not feel well all night and told the nurse that I wanted tablets. I did feel that I was being a nuisance to them. I took a tablet. I lost the baby a few hours later in the toilet. When I came out of the toilet I held the embryo wrapped up in tissue, found the nurse and gave it to her. She thought it was a sanitary towel and indicated that she would throw it away. I screamed, “No, don’t!” I pointed at it for her to look. That was when she saw the embryo; it looked transparent like a fish. She was in a panic. I thought to myself finally now they believe that I was pregnant! My frustration was gone. It made me feel better.  
(Abigail, age group 41-50)

Although she had survived such a traumatic experience, Abigail was insistent on proving her point that she was pregnant, as no one seemed to believe her. Abigail went on to describe her confusion when she was asked to sign a D and C (dilation and curettage) form the next day:

Next morning the nurse came up to me and asked me to sign for something, a D and C. I did not know what it meant, they never explained. I was 25. I remembered that my mother had a miscarriage twice and talked about a D and C. I asked them whether it meant a clean out, a scrape. They replied, “Yes”. Nothing was explained clearly. My mother and sister both of who are deaf came to visit that day. They asked how I was; I told them that I had lost the baby. They were shocked that I had been pregnant. The nurse had not told them, nor did they tell my husband before seeing me. That was 18 years ago.  
(Abigail, age group 41-50)

Fortunately the trauma of this experience did not put Abigail off having two more children. The irony was that despite losing the baby this was replaced by her relief that

she had been vindicated in her belief that she was pregnant. She also felt very frustrated with communication at the hospital. The situation of signing a D and C form was another worrying incident:

That word was confusing; I did not know what it meant at all! It could have been mistaken for a Death Certificate! I was very confused about what I was signing on paper.

(Abigail, age group 41-50)

Even though Abigail signed this paper form, she was not entirely sure what it was until she had a discussion with her mother the next day. This negated her opportunity to exercise her autonomy and make an informed choice as illustrated by Zazove and Doukas (1994) in Chapter 2, section 2.7.2.

### ***5.5.2 The man who did not know his medical history***

Many hearing families with a deaf child will perhaps have not taken the time and effort to explain to the deaf child about issues in the family such as illnesses (DiPietro *et al*, 1981). Consequently many deaf adults are unaware of their family medical history, and even their own as DiPietro *et al* (1981) identified. Unfortunately Bruce discovered after his heart diagnosis that there had been a history of heart disease in his family:

I did not know until it happened to me, my mother told me – that was when I was in my early 40s. I thought why are you telling me now about this, not before. I could have been prepared for this.

(Bruce, age group 41-50)

There may be a communication breakdown because of the language used. In Bruce's case he was a BSL user whereas his family did not sign. In Study 1 the informants felt sign language interpreters did not have to be used until the situation had worsened. In both the examples just discussed, it can be seen that there is an over reliance on parents to help out in the consultation, or to 'fill in the gaps' of their medical history.

### ***5.5.3 Other disempowerment issues***

As seen in Study 2, the upbringing of the deaf person, education, and the over reliance on parents has contributed toward passive decision making. For some deaf adults, when they are exposed to communication in sign language within their own community, they will at last be in a position of being able to access information around them in sign language, either in the form of health information in BSL or having an interpreter present in consultation sessions. For the majority, it is the first time since leaving the family unit that they may have to deal with life decisions. Deaf people are unable to either access radio or television easily, nor read to a proficient level. This means that they will tend to rely on direct information from the Deaf community, which was true in Madeleine's case. She had refused to have a smear test for years:

I have had a smear test done by a nurse in the last six months. It was the first time for me; I refused before because I did not have the right information. Deaf people told me that they were horrible. It made me worried. People said that you could get AIDS from it; I had an immense fear of it. Luckily one person explained to me what it was. I went for a smear test and after that I felt like, "What! Is that all?"

(Madeline, age group 31-40)

Once Madeleine had the information, she felt that she was able to make an informed decision. Not surprisingly, she had felt confused with receiving conflicting information. It is notable that Madeline went for her first smear test in her 30s, at an age where she was able to access information around her, without depending on her teachers or parents. The importance of receiving health information at an earlier age is crucial, to enable early diagnosis and to prevent any major illness such as cervical cancer, and allows informed decisions to be made.

## 5.6 Communication Issues

### 5.6.1 *Reinforced dependency*

From the earliest documentation, the experiences of deaf people have been narrated through their relationship with hearing professionals, as teachers, guardians or pastoral carers. In addition to this, social workers evolved primarily from the church dominated heritage, which started with missionaries to deaf people at the beginning of the 19th century. Many accounts have described the power attached to the welfare worker within the context of the evolution of a professional role. Although this understanding has often led to a call for redefinition of the role of the social worker for the deaf (Hynes, 1988), there is resistance to such change.

Informants gave accounts of the role that the social worker for the deaf played in their lives. Bruce made regular visits to a heart specialist, but felt that he could not cope without a social worker present:

I usually go with my social worker to the heart specialist. The doctor does not talk to me much only via the social worker. Once I went on my own without the social worker. That was really difficult; the doctor was in a hurry and there were a lot of patients outside waiting for him. Writing anything down was a waste of time, it takes too long. I told my social worker after that it was best if she came with me all the time. It is impossible by myself with the heart specialist. I can't cope. Sometimes my 12-year-old son comes in to interpret for me at the doctors. (Bruce, age group 41-50)

However, when looking at Sophie's response there is an element of compliance and a positive desire to be nurtured:

Hearing people always let me down. I am not happy with the social worker. Old-fashioned social workers were better, they explained more, were good. They used to interpret for us too. (Sophie, age group 51-60)

Several informants spoke of a feeling of lack of control in their current dealings with health professionals, which left them with a feeling of disempowerment. Harry reflected on his past experience with his doctor, although it was over 20 years ago:

When I was 18, I was feeling depressed at that time. I was not happy at work. I felt ill. I was coping but ignoring it at the same time. I went to the doctors and complained that my knee was painful and that my head was sore. The doctor was frustrated because he could not communicate with me. Next time I went, I took a social worker to help me communicate, as at that time there were no interpreters available or adequate training for them. On this occasion I was surprised because the doctor told me to go out of the room, leaving him and the social worker. I thought that was very cheeky. They both sat in there talking about me while I waited outside.

(Harry, age group 31-40)

While the social worker and Harry's doctor discussed him, thoughts raced through his mind:

I was annoyed at this! "Why?" They were talking about me, this was about me, my problem! When the social worker came out, I expected to go back in with her but that did not happen. The social worker told me that I was worried and that I just needed to rest. I felt that I should have been sent to see a specialist. When I look back now I realised I needed counselling because feeling very depressed and I had no access to information at that time.

(Harry, age group 31-40)

An explanation for this would be that Harry came from a generation that was systematically oppressed, and this social worker had acted as a gatekeeper to his well-being. A consequence of this was being overwhelmingly dependent upon the help of hearing people, starting off a vicious circle of internalised oppression.

The informants had differing views ranging from a feeling of dependency and disempowerment, to one of feeling empowered and making their own decisions in choosing sign language interpreters. A common comment was the choice of gender, for example, male sign language interpreters for deaf male clients to avoid embarrassment.

### ***5.6.2 Sign language interpreters – Lack of choice?***

Some informants expressed a wish to know who the interpreter would be at their appointment beforehand. Choice was deemed to be of utmost importance and for some, they were adamant about which sign language interpreters they would not work with:

Yes, I must choose myself because there are some sign language interpreters or communicators I refuse to work with. There are two I will not work with. Once I had an appointment and found out who they had booked. I cancelled it straightaway. I did not want that person to know my business.  
(Eric, age group 31-40)

Clive felt that his contact with health professionals was stressful. He wanted more access to sign language interpreters:

When I meet health professionals and when they talk to me I cannot understand them. It makes me feel stressed. I feel lost and uncomfortable. It is a relief if I have an interpreter there. The only difficulty is that you have to book two weeks in advance. I cannot wait that long.  
(Clive, age group 31-40)

Often there is a lack of awareness on the part of service providers where they provide an interpreting service. They are often unaware of the professional skills and qualifications of sign language interpreters. Those deaf people who have autonomy, and are aware of local sign language interpreters and provision, will recognise that they have a choice of which sign language interpreters they wish to work with.

Many studies (Section 2.6.5) have indicated that a lack of sign language interpreters, and the resulting communication problems that occur in medical settings, has had a negative impact on the health of the deaf population as a whole. For many deaf people there is a conflict between what is deemed to be their private business and giving up some control over their own matters, when an interpreter is present. Some felt vulnerable having a new interpreter or one that they had not formed the basics of trust with yet. The implications for their health is that they will not benefit fully from their medical



consultations and may be misdiagnosed as a result, or any concerns they have may not be picked up on until it is too late.

### **5.6.3 Confidentiality**

The issue of trusting sign language interpreters was paramount on two levels; relaying the correct information and placing trust in the interpreter to keep the client's names confidential as well as the nature of the appointment. Tara commented:

When you work with an interpreter, it is important to know what their training is, really important to have that background, and whether they know their boundaries. Too often they try and have a chat with me before the appointment and ask lots of personal questions. I find that unprofessional.  
(Tara, age group 22-30)

However, the waiting room chat is invaluable for medical appointments. It may be the client's first visit to the particular doctor, and it gives the interpreter the opportunity to find out about the events leading up to the appointment. If the patient and the doctor have a long history together, it may be more difficult for the interpreter to catch the context of the discussion without any background knowledge. It is useful for the interpreter to have a mental picture of the timeline of events and the purpose of the visit.

Other informants questioned the confidentiality issue:

To be honest with you I don't trust them (sign language interpreters), not really, I don't know? They may give me all the good information but what about when they get home? Will they keep it confidential or tell someone else that they worked with me, and the nature of the appointment, I do not know?  
(Kate, age group 31-40)

How can we be sure that they will be totally confidential? The Deaf community is small, so is the sign language interpreter's community. I know they talk to each other about dilemmas, how can I be sure that names are not dropped into the chat, and that includes my own!  
(Leah, age group 41-50)

There is still an element of mistrust amongst deaf people on using sign language interpreters, especially those who are not accustomed to using them on a regular basis. Evidently, more training is needed both with deaf people and sign language interpreters particularly where interpreting in a medical situation is concerned.

#### ***5.6.4 Interpreter's professional ethos***

It is important to understand the difference between sign language interpreters (registered or trainee) and communicators who tend to be at CADCP II or III level. In small intimate situations some deaf people may feel more comfortable with a familiar person who has qualified at CACDP level II or above, who are normally called Communication Support Workers (CSWs). They will assist them in their communication rather than having what is seen as a growing stream of professional sign language interpreters who treat the job professionally and some do not provide a level of support. Qualified sign language interpreters tend to be seen as being more clinical and aloof:

I was involved in a car crash and am lucky to be here today. I found it difficult to move my shoulder joints afterwards. I went to see the physio and I brought a communicator, a friend of mine. He clarifies things for me afterwards that I may have forgotten in the session. An interpreter would not do that.  
(Eric, age group 31-40)

Eric disliked using sign language interpreters as he felt that they operated in a businesslike manner, whereas he felt that communicators have deaf people's best interests at heart. Leah commented on how she saw the interpreting profession had developed:

Some sign language interpreters are really too professional and detached. They rush off after the appointment to their next booking; that is especially true if they are freelance. I need to have the opportunity afterwards to clarify some of the issues from the consultation. Even if they do not have to dash off, you can see that they are not prepared to extend themselves to spending a little time with you to reassure you. Quite frankly I think 50% are just in it for the money!  
(Leah, age group 41-50)

We have seen a growing stream of ad hoc training set up in addition to established university courses for sign language interpreters in the UK. Without knowing about the content of these courses, it is fair to say that the standards vary and there are differing levels of ability in using BSL after finishing the course. There is a demand for flexibility from the community particularly in situations where there may be a lot of jargon. Flexibility in most cases comes with years of lay experience and allowances should be made for this cultural adjustment. Mindess *et al* (1999) explored this further by identifying where the cut-off point was for when the interpreter no longer has responsibility for the client. She concludes that for the sign language interpreter to leave as soon as the appointment is finished, and to refuse to wrap up the transaction with the deaf client borders on the culturally insensitive, if not the unethical.

#### **5.6.5 Consequences – Misdiagnosis**

Misdiagnoses can occur in interpreting situations, as in the case of Eric:

Six months after my diagnosis the doctor found out that both side of my shoulders were painful not just on one side. My original sign language interpreter had got it wrong and said that the pain was on one side only.  
(Eric, age group 31-40)

These mistakes aggravate the symptoms, and had a detrimental effect on Eric's health. The deaf person has no way of checking what has been relayed in the interpreting process. Therefore, it is not surprising that the issue of trust was brought up frequently in the interviews.

## 5.7 Attitudes to Health

The informants were asked to evaluate how they viewed their own health on an overall self-assessment basis in terms of well-being:

Excellent	-
Very Good	5%
Good	67%
Fair	28%
Poor	-

Table 5.6 Deaf people's view of their own health ( $n=18$ )

Very few of the informants (5%) rated their health as very good. The majority (67%) rated their health as good. The informants had different interpretations of the term, 'feeling healthy'. Examples given included:

- annual holidays
- having a break away from the mundane existence of everyday life
- feeling full of energy
- not tired
- enjoying life
- being happy
- having fresh air
- going out for a meal
- being in a good mood
- feeling relaxed, can do anything.

The informants often repeated these responses. Very few mentioned exercise in the physical health context, which included their own physical health as well as looking after themselves by taking regular exercise.

It was also important to divert from the word ‘healthy’ to distinguish what they felt this meant in a linguistic context and how communication barriers impacted on achieving a good healthy state. The informants were asked if they ‘felt healthy inside’. This was done in order to probe further into their feelings about social and emotional well-being. It was interesting to note that several said they had to meet other deaf people, as it was an important part of their lives:

I just stayed at home; it felt like a prison in Pakistan. We came back here when I was 22. A lot of things I did not understand. My English was not good. I did not improve it was very poor. I stayed at home mostly. A deaf woman came and picked me up, took me to the Deaf club, they supported me, helped me, explained English words and what they meant. I improved and things became better. Before I just stayed at home, all the time.  
(Sumita, age group 22-30)

Sumita went on to explain what ‘healthy’ meant for her:

Being confident, improving myself, can go out of the house, learn information. I can go on red bus by myself now. Before I was tense, I could not go out by myself. I went to the Deaf club; I got it out of my system to my friends there.  
(Sumita, age group 22-30)

To Sumita, being healthy meant that she was able to leave the house more frequently and to have the confidence to do so. Her family were overprotective and this impacted on her self-esteem and the activities that she was able to do. Other people may define this differently, for example, Griggs explored the different concepts of wellness (Griggs, 2000). She mentions that deaf people are collectively assessed in comparison to hearing people and are thought to be worse off in terms of mental health. However, she found in her research that the most meaningful points of reference for mental health were other deaf people, not hearing people. The findings from the informants appear to support this social aspect of being able to socialise within the Deaf community, in order to share experiences and to reconfirm their own knowledge.

### ***5.7.1 Are people healthier in the UK than before?***

The informants had differing views on how society had changed, advances in medicine, more information about diseases, and the contents of food.

Half of the informants felt that people were less healthy now than in the past. Closer examination of the results discovered that six out of the nine informants were over the age of 30, and would therefore be more informed to comment and reflect on the past. Other factors cited for people being unhealthy included: increased pollution, stress, money worries, too many cars on the roads, food scares, poor diets, and the increased use of drugs.

How life had improved for deaf people was also discussed. Significant advances in technology and society would perhaps mean some changes for some of the informants:

I noticed that a long time ago, everyone looked fit, healthy and strong. People looked well, their faces too. Now people are getting thinner, ill. Being healthy means that you have to be careful about food that did not happen before, a big difference now. Before we used to butter our bread thick, eat chips. The flu injection, I thought that it was new, but I was told that it had been around for a long time, I did not know that. I do not want an injection, frightened to spoil inside my body.

(Madeline, age group 31-40)

Others commented on the richness of community life, and how the community culture around the Deaf clubs was stronger. Previously, deaf people generally met through activities organised by the British Deaf Association. Ali felt that there was nothing on offer for deaf young people now:

Now it seems worse, nothing for deaf youth. We need more deaf people to get together, holidays and things like that. No groups here for deaf involved with sport in this area. A few years ago deaf people used to play each other in sports league. Now it is all focused around the pub. I like it but not all the time, we should encourage them back into Deaf clubs.

(Ali, age group 22-30)

Ali lives in Tower Hamlets, and was unaware of whether there was any specific youth provision available for young deaf people. He did not appear to have any access to the internet, or other written deaf media, due to low levels of literacy. Access to this information would have improved his knowledge of what was available in terms of youth provision for deaf people in and around his area. As a result his view of the world was limited and this impacted his access to various activities.

### ***5.7.2 Illnesses affecting daily life***

The informants were asked about everyday things that had an impact on their lives, to determine what factors were important to them. Stress was constantly cited:

When I get stressed, it is like it is locked inside me, and I do not know how to unlock it.

(Madeline, age group 31-40)

When things get on top of me, I get a knot in my stomach and feel anxious inside. I can't explain it, but I have to slow down and take things in moderation. Talk to my deaf friends and calm down.

(Leah, age group 41-50)

Hearing standard measure assessments are sensitive to indicators of stress. A deaf cultural 'baseline' would assume a certain degree of stress and would rate the ability to cope or not with that stress as a positive indicator of adjustment (Griggs, 2000). From the above quotes, the informants acknowledged that they were stressed and identified their strategies for coping.

For informants who had been diagnosed with health problems, they were able to express the changes that had been made in their lives. For Bruce, having heart problems reinforced how unhealthy his life had been prior to the heart attack:

Now I get short of breath, and find it difficult to climb the stairs. My life is now controlled by drugs. Every day I wake up with pains in my chest, painful, feel dizzy, wait until I calm down. I use my inhaler, if I run, after 100 yards I am

completely out of breath. I ate too much before, piled my plate high. Now I have cut down on fried food, egg, bacon, cut out all the white bread and salt. If I go to a party or a friend's house, they give me food; I eat it reluctantly, but do not feel very well afterwards.

(Bruce, age group 41-50)

His heart problems affected his everyday life and he expressed regret at not looking after himself prior to diagnosis. However, it was in a sense a wake-up call, and he maintained he would have continued to be unhealthy if this had not occurred.

Clive talked about his devastation when he discovered that he had sickle cell anaemia:

I was told that I had sickle cell. It can be dangerous, it can kill and very few people live. I was shocked. I did not know that I had it. My balance gets worse in the evenings when it is dark, and I cannot go out at night. People think I look drunk because I cannot see properly. I am frightened, better to stay at home. When I walk it makes me feel tired and weak.

(Clive, age group 31-40)

Clive had been ill for some time, and commented that he had no system of social or emotional support. All of his family were based in Jamaica, but he had decided to stay behind and utilise the health care in the UK because he felt that there was better provision. He felt isolated and lonely without anybody close to him who understood his illness.

The implications of not having access to mainstream health information, and a support network, meant that the informants, particularly for Bruce and Clive meant that they felt isolated, and consequently developed their own coping strategies for their illness.



## 5.8 Influences on Health

### 5.8.1 *Positive influences on health*

A pattern began to materialise where the informants defined what they saw as a healthy state, which tended to relate to the social aspect of communication and being able to share information with deaf friends. The implication is that informants were relying on their peers to achieve a sense of positive well-being; however, they did not relate this to the wider picture. For instance, the right to receive information and to access health information in order to make an informed decision could perhaps have been considered equally important.

It was important to allow for the informants to define their own deaf cultural interpretation on what would constitute a positive influence on their own health. Several informants reported different factors that influenced their health. For example, Madeline saw smoking as a something that helped her to relax – this may be seen as a bit of an abnormality in terms of what would constitute a healthy physical state:

Smoking! But I find it relaxing, same as drinking tea. I enjoy a cigarette with a drink. I have a problem with tea; if I drink nothing all day then I will become stressed, or aggressive. I drink about 20 cups a day.  
(Madeline, age group 31-40)

For Matthew, he felt that his environmental conditions were important:

My house is near the river; the air is fresh and good and clean. No cars or pollution there. I like to jog around there. It is beautiful and clean.  
(Matthew, age group 22-30)

Career paths and the future was a constant worry for some informants. Ali and Sumita commented on the Deaf community, the importance of the Deaf club and being able to continue learning:

For my future I must think of my home, and future work. Being able to go to the Deaf club and being in contact with other deaf is important too. I cannot live without that; it is very important for me.  
(Ali, age group 22-30)

Going to the Deaf club, continue learning. I do not understand the conversation at home, important for me to be confident and happy. Also to continue to become more aware from deaf friends to improve myself.  
(Sumita, age group 22-30)

On several occasions the interviewer (myself) had to give the informants prompts such as holidays, relaxing, or seeing friends. This question left several stumped and many found it hard to think of positive aspects of their lives. Naturally they started to explain the bad aspects first, before the interviewer pointed out that the question *actually* (my emphasis) necessitated a response based on the positive effects on their health.

### **5.8.2 *Negative influences on health***

In two instances, the informants were separated from their family and had moved to Britain at a young age. They felt that this did not help them in terms of social and emotional support:

I miss my family back in India. I have not seen them for seven years and I am living by myself here. If they lived over here they could help me to sort out my problems. Some are coming over in two months time. One is staying with me for a few months and check on me, that I am going to college and things like that, and advise me on my future.  
(Ali, age group 22-30)

Ali felt isolated without his immediate family support; it was interesting to note that his correspondence with them was extremely limited in between visits. He relied very much on these to keep him going, and the longer he lived in the UK, the more distant he felt

from them. Clive expressed similar feelings:

My family went back to Jamaica last October, I am here by myself. My father is coming over to England next week; he will go back in a year for good. I have only been over there three times.  
(Clive, age group 31-40)

In Clive's case, he felt dependent on his family especially since he discovered that he had sickle cell anaemia. Study 1 illustrated the over reliance by deaf people on their parents to help out and support them, and this dependency can also extend into adulthood.

Sumita felt overtly excluded and oppressed by her family as she was very seldom allowed out of the family home, and had found her way of coping via the Deaf community:

Staying at home all the time, it is wrong. My mother and father are wrong to be so strict. They have closed minds like Pakistani people, they don't know or understand the English way. They do not communicate or support me at all. They leave me alone, not help me. I feel angry and upset. My family are not a very nice family. I am deaf, lonely, and they argue with me non-stop. I go to the Deaf club; my friends support me better there.  
(Sumita, age group 22-30)

This is an extreme situation, but there is no doubt that this perpetuates further to Sumita's own negative image of herself. Her own family, who prevented her from carrying out daily tasks, contributed to her cycle of oppression.

Subconsciously, deaf people have developed a coping strategy where they have low expectations of themselves, or manage by just 'getting by'. Griggs (2000) identified this as coping to allude to the existence of internalised oppression, and a tradition of oppression having created low expectations amongst deaf people with regard to mental health.

### ***5.8.3 Does a good income mean better health?***

Mixed responses demonstrated that the informants had different perceptions of how their lives would change if they had more money. In some cases, the informants cited that more money would be connected with eating more:

I believe if you have the money the more rubbish you will eat. If you have money you would spend more on sweets and cakes etc. I can't see myself being happier with a lot of money. I would spend it all on food. Become depressed and end up in debt, you never know. I would rather have a comfortable income, knowing that money is in the bank to pay off my bills.  
(Tara, age group 22-30)

An additional option would be access to private health care:

Perhaps if I had more money, one thing I would do is see a private doctor. I go to the hospital practically every month for a different problem. I would have gone private if I had the money.  
(Leah, age group 41-50)

Career progression was also mentioned, in terms of salary and status. There was an overwhelming consensus that deaf people have still not reached the same level and obtained the same career opportunities as hearing people, due to the 'glass ceiling' effect:

Yes, it's true; a good income would mean better health. Deaf people have not reached the same level as hearing people in earning a high salary, there are not many deaf people in the 35-40K earning bracket.  
(Harry, age group 31-40)

Due to internalised oppression we can suggest that this leads to low expectations in terms of career aspirations. Through this cycle of negativity deaf people in general tend not to aspire to better paid jobs, in part due to low expectations by society as documented in section 1.5.2. The implication is that deaf people will continue to be underemployed and risk not reaching their potential in the employment market.

## 5.9 Healthy Lifestyles?

### 5.9.1 Exercise

Only one person reported exercising on a regular basis, Matthew exercised two to three times a week. Informants frequently cited lack of motivation for not having the incentive to exercise. Other factors included gym membership being expensive, being out of work or being on a low income. This is consistent with deaf people earning a low wage as mentioned in section 2.6.3.

Nothing, but in the summer I use my bike at the weekends. Last summer I went swimming a few times. At the moment it is too cold; it is better to do it in the summer time.

(Irene, age group 18-21)

No, I go for walks sometimes. I hate exercising. I am thin, that's good enough. I clean the house and do the ironing and cooking.

(Sophie, age group 51-60)

Deaf people due to their low levels of literacy, and education, are more likely than their hearing counterparts to be on a low income and this will affect their access to leisure.

This vicious circle means being trapped in a spiral of poverty. Disabled people are around five times as likely as non-disabled people to be out of work (Delin, 2003).

I feel embarrassed to go and exercise, for example, swimming. I have to take my hearing aids out and worry that someone might talk to me. I would not be able to understand them. There are also communication barriers with following an instructor, for example, and its hard work having to lip-read all the time, for which you pay a lot of money.

(Sumita, age group 22-30)

Communication barriers in sports coaching can have an impact on a deaf person's self-esteem. It has been traditionally difficult for deaf people to access mainstream sports, and this may have an impact on their awareness of the benefits of exercise later in life. It has also been suggested that lack of exercise adds to deaf people's social isolation.

Due to communication issues deaf people avoid participation in sport unless it is within the Deaf community. Provision of BSL trained coaches and instructors in communicating with deaf people is very limited, and local authorities do not appear to have made much progress in terms of enabling deaf access to sporting facilities and opportunities (Fagan and Cameron, 2004).

Better utilisation of time management was seen as a way of becoming healthier with an emphasis on greater participation in sport, or some kind of activity to keep fit. A change in diet was also cited as a positive move forward.

I should do more sports, every fortnight, or once a month. Become more active. It would help me to get rid of the stress; I need to switch off.  
(Madeline, age group 31-40)

Exercise more, should go to the doctor rather than avoid going.  
(Abigail, age group 41-50)

The responses indicated that in the context of physical health the informants tended to focus on their experiences from a physical well-being perspective. They failed to recognise that there were other factors that contribute to health such as lifestyle, exercise, good mental health and positive well-being. Due to their lower levels of education and income they may not have the financial means to aspire to a healthier lifestyle. This could have long-term repercussions for their health and put a greater strain on the health service.

### **5.9.2 Diet**

Most informants had some awareness of what a healthy diet consisted of. However, it was interesting to note what their perception of healthy food was, and where they obtained their information:

Sweetex is bad, someone told me that it gives you cancer, it is too sweet, more so than sugar. Orange juice too, I think because it makes you feel full.  
(Madeline, age group 31-40)

I know that white bread is healthier than brown, it has less fat. I am not sure, can't remember.

(Tara, age group 22-30)

Ali reported his typical diet, and did not show any awareness of what would constitute good food:

I like vegetables, but it is hard to improve my diet. I eat a lot of curries, if I get bored with the same food, all the time then I will buy pizza. I just live to eat.

(Ali, age group 22-30)

Eating convenience food is generally consistent with being on a low income. However, some people expressed a willingness to learn more about healthy eating:

I learnt at a talk given last week by a deaf person, not to use so much oil when cooking, grill instead of fry. It's better when people explain. I become more aware and gain more information. I am getting fat. I eat too many sweets and cake. I am worried that I eat the wrong food.

(Sumita, age group 22-30)

Sumita mentioned that this talk had made her very keen to improve on her health knowledge, and wanted to attend further talks. The informants were generally more receptive to information given by a deaf person, because it is given to them in BSL and is considered to be culturally and linguistically appropriate. The information they obtained made them more enthusiastic about learning similar topics via sign language. They were keen to explore avenues where they could access information via this method. This demonstrates that there is a need to look at a variety of ways in which information needs to be delivered, whether it is face to face or through the use of technology.

### ***5.9.3 Alcohol***

The majority of the informants were unaware of the difference between regular drinking and occasional drinking. Guidelines for the recommended limits state that a female should drink 14 units a week whilst men drink 21, spread throughout the week with two or three drink free days. If men drink 36 units or more in a week then damage to their

health is likely; for women the figure stands at 22 units or more. There is little difference in the awareness of alcohol unit levels between the deaf informants and any results from the general hearing population in a survey.

None of the females exceeded the recommended units of 14. Six out of eight informants drank on a weekly basis, and the other two were non-drinkers. However, the average weekly consumption for the males was about 34 units, which is in excess of the recommended guidelines. Matthew showed his lack of awareness:

I drink about two to three times a week, sometimes less. I usually drink on weekends, mostly Saturdays. In the last week I drank on Wednesday three to four pints Thursday two pints, Friday four to five pints, Saturday five to six pints; that's about ten units altogether.  
(Matthew, age group 22-30)

Matthew had actually consumed between 28-34 units in one week. Most of the informants consumed the majority of their weekly alcohol intake at weekends. Binge drinking is not usually recommended, and government guidelines advise spreading the alcohol intake throughout the week rather than limiting it to the weekend. There has been much media coverage about this. Binge drinkers tend to be in their 20s, and there has been a fall in binge drinking, partly due to health awareness and the ageing of the UK population.

#### **5.9.4 *Smoking***

Statistically about one-third of any group will be smokers, (29% men, and 28% women) (Department of Health, 1992a). However, there are various factors that may skew this average, some groups are likely to have a higher than average incidence of smoking (e.g. socio-economic groups C2, D and E) or a very low incidence of smoking (e.g. older Asian women).

Only five out of 18 informants smoked regularly, which is consistent with the average for the general population. The average amount consumed was between 10 to 15 cigarettes



per day, and reasons for smoking ranged from stress and being nervous. There appears to be little difference between the incidence of smoking between deaf and hearing people, due to a paucity of research work in this area.

The implications are that deaf people appear to be no different from hearing people in terms of their smoking and drinking habits. However there still needs to be information made available in BSL covering these topics to ensure access to information is on par with the hearing population.

### **5.10 Measuring Deaf People's Attitudes to Health**

Section 5 of the questionnaire was used to assess deaf people's attitudes to health. The informants were asked for their views on statements linked with health, in order to build up a picture of preconceived ideas and assumptions and to develop a greater understanding of factors that impacted on their health views. Further background to the procedure as why this questionnaire was developed can be found in section 3.7.2.

The five possible answers were: strongly agree, agree, don't know, disagree, and strongly disagree. The respective scores for these outcomes were 10, 7.5, 5, 2.5, 0, for positive statements (one and eight). The reverse was true for the remainder, which were identified as negative statements. The scores ranged from 0-100, with the maximum possible score representing the most positive attitude to health. This is illustrated in several spreadsheets in Appendix 4, one for Bristol and one for London.

The mean scores calculated for each area were as follows:

$$\bar{x} = \sum x / n$$

$$\text{Bristol} = 602.5/10 = 60.25$$

$$\text{London} = 307.5/8 = 38.4375$$

$$\text{Combined} = 910/18 = 50.556 \text{ (to 3 s.f.)}$$

There is a significant difference between the two areas. Eight informants from the Bristol sample scored over 50 compared to two for the London sample. There are a number of possible explanations and these will be explored in more detail.

*Table 5.7 looks at deaf people's responses to statements linked with health. The results are displayed for both the Bristol and London samples, as well as the combined sample.*

Statement	Bristol sample (n=10)		London sample (n=8)		All informants (n=18)	
	Agree %	Disagree %	Agree %	Disagree %	Agree %	Disagree %
1. To have good health is the most important thing in life.	60	40	87.5	12.5	72.2	27.8
2. <i>I really don't have time to think about my health.</i>	40	60	62.5	37.5	50	50
3. <i>I am more reluctant to go to the doctors because of communication problems that might arise.</i>	30	70	75	25	50	50
4. <i>Deaf people die younger than hearing people because of limited access to health care or to information.</i>	30	60	62.5	25	44.4	44.4
5. <i>Deaf people earn less than hearing people.</i>	60	40	87.5	12.5	72.2	27.8
6. Hearing people are more intelligent than deaf people.	10	90	37.5	50	22.2	72.2
7. <i>I would rather go to a deaf doctor than a hearing doctor.</i>	50	50	37.5	50	44.4	50
8. <i>It is sensible to do exactly what the doctor says.</i>	40	30	37.5	62.5	38.9	44.4
9. Being able to hear means that information can be better understood.	40	60	87.5	12.5	61.1	38.9
10. The National Health Service is responsible for my health.	30	70	75	12.5	50	44.4

Table 5.7 Deaf people's responses to statements linked with health

*Statement 1: To have good health is the most important thing in life.*

A high proportion of informants believed that this statement was valid. This view was more marked for the London informants (seven out of eight). The fact that most of them came from one of the most deprived areas in the UK was probably a contributory factor in that they placed a greater value on their health. Further exploration of this question might have discovered other aspects that were important such as having regular holidays or an emphasis on the health of their own children.

*Statement 2: I really don't have time to think about my health.*

The results were skewed. A high proportion of the Bristol sample disagreed with this statement. This indicates that they thought their health was important. In contrast, most of the London informants agreed with this statement. This highlights their ignorance about keeping healthy and affects their overall health status. On the other hand it might suggest lack of time and being unaware of important health information.

*Statement 3: I am more reluctant to go to the doctors because of communication problems that might arise.*

There was a disparity in the answers given by both groups. Most of the informants from the Bristol area were willing to visit their doctor despite any potential communication problems. This was in complete contrast to the London informants who were more reluctant to visit the doctor. It is clear from the mean scores that the Bristol informants have more confidence and a higher self-esteem than their London counterparts. There is a well-established Deaf community in Bristol, which may have an effect in that the doctors in the area are more aware of deaf people's needs. In London the Deaf community is dispersed over a much greater area. The implication of this is that when deaf people have better access to communication, their confidence and self-esteem appear to be higher.

*Statement 4: Deaf people die younger than hearing people because of limited access to health care or to information.*

More than half (62.5%) of the London informants were of the opinion that deaf people die younger than hearing people. In contrast this was true for 30% of Bristol informants and may help explain their confidence in visiting the local GP hence their higher levels of confidence and self-esteem.

*Statement 5: Deaf people earn less than hearing people.*

A high proportion (72.2%) believed that deaf people earned less than hearing people. Research has established that deaf people have a lower socio-economic status than their hearing contemporaries as illustrated in section 2.6.3. This consequently has an impact on their self-esteem and confidence in accessing information, in this case health information.

*Statement 6: Hearing people are more intelligent than deaf people.*

The majority of the informants disagreed with the statement that hearing people are more intelligent than deaf people. This indicates that they are aware of the capabilities of deaf people. While the London informants experienced oppression and had low self-esteem this had little influence on their belief that deaf people were the equal of hearing people if given the opportunities.

It is not surprising is that a high percentage (90%) of the Bristol informants opposed this statement. The presence of the Centre for Deaf Studies at the University of Bristol has played a major role in increasing the profile of deaf academics in the area.

*Statement 7: I would rather go to a deaf doctor than a hearing doctor.*

This was viewed as a negative statement because this part of the research focuses on deaf people's attitudes to health. In health terms, all doctors should be accessible regardless of whether they are hearing or deaf, this question tested their awareness of whether there were any deaf doctors available.

Opinion was polarised over whether a deaf doctor was preferable to a hearing one. Almost half the informants (44%) would use a deaf doctor. The main reason for using one was ease of communication. This is understandable as a deaf doctor will have greater empathy and will give them full access to information by communicating in their preferred language. On the other hand, 50% preferred a hearing doctor. Reasons given were: confidentiality, more experience and knowledge, better information and trust. The first point is probably the most pertinent. Due to the small nature of the Deaf community, confidentiality is paramount especially where health matters are concerned.

*Statement 8: It is sensible to do exactly what the doctor says.*

This question was asked to determine how much emphasis informants placed on medical advice. The responses to this statement were mixed, with a few 'don't knows'. In retrospect this question could have been better worded, for example, 'It is sensible to follow the doctor's advice'. It could be argued that there is little point in visiting the doctor if you do not follow his/her advice and take the appropriate medication. If they don't do exactly as the doctor says then that could be negative and have dire consequences.

Agreement with the statement can be construed as a positive statement for their health and subsequent well-being. The informants are aware of their health needs and that the doctor does indeed know best. On the other hand it depends on the context of the question and how the informants interpreted it. For example, the doctor is the fount of all knowledge and whatever he or she says must be right. This would indicate a dependency

culture with a reliance on the medical experts and low self-esteem (e.g. I am deaf, they are hearing, therefore they are more intelligent). This interpretation would mean that it is a negative question rather than a positive one.

Despite the best efforts of the researcher (myself) this statement is open to interpretation and is dependent upon the informant's mode of communication and their experiences in a medical setting.

*Statement 9: Being able to hear means that information can be better understood.*

It is significant that the informants (61.1%) considered that being able to hear meant that information was better understood. This was particularly true for the London area (87.5%). A possible explanation is that a large percentage of the informants came from ethnic minorities. English may not necessarily be the first language so they may experience more communication difficulties than normal. As a result they may conclude that being able to hear would reduce these problems.

*Statement 10: The National Health Service is responsible for my health.*

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

In summary, the statistics clearly indicate that deaf people in the London area have a low self-esteem hence the low attitude scores. The scores for the Bristol sample were

somewhat surprising, but this can be accounted for by the fact that there is a stronger Deaf community and activities for deaf people are set up in the area. As a result, the informants had a stronger Deaf identity and were more immersed in Deaf culture and the Deaf community.

## **5.11 Educating Deaf People**

### ***5.11.1 Being taught by a deaf person***

It was important to establish the best way of delivering health information to deaf people, and the reasons behind their preferences. In recent years we have seen a growing stream of deaf professionals teaching subjects other than sign language. A good example is that more deaf people are teaching health as a topic. For Irene this was a revelation:

I have a deaf tutor; she explains about health issues. I understand her. I have misunderstood a lot of things in the past. I never realised that things could happen, like cancer, sickle cell or knew anything about healthy eating. I did not realise that there was more information, compared to what I used to know. I find it very interesting and want to learn more  
(Irene, age group 18-21)

An overwhelming 55% of informants wanted to have deaf tutors, and 22% wanted hearing tutors. The remainder of the informants (23%) requested both. A number of reasons were cited for requesting deaf tutors, understanding each other's culture and using the same language:

I went on an Ushers course, a hearing doctor there explained about the eye, in technical terms. I did not understand; it went over my head. A deaf person explained to me visually in graphic detail in sign language – it was fantastic! With deaf people you learn just like that, quickly. The doctor used difficult words; no signs exist for them!  
(Abigail, age group 41-50)

Several informants felt that being in a group with other deaf people meant they were confident enough to ask questions and ask for further clarification in sign language, rather



than worrying about how their question might be perceived. This group dynamic made for a more relaxed situation where they could relate to one another more easily.

They also felt that the teaching methods and the examples used by the deaf tutors related to deaf people's way of learning on a linguistic level:

I am between two worlds. Newspapers teach me more, but both are the same.  
Deaf knowledge is by sight. Some deaf very clever, they have knowledge.  
Hearing are lazy, listen to the radio, deaf miss out. Deaf community tend to help each other, deaf people always ask a lot of questions.  
(Abigail, age group 41-50)

This illustrates the importance of the community network, and that the informants did not believe that hearing people were poor teachers; it was more a case of understanding the culture and language levels of deaf people. The general opinion was that deaf tutors were better at doing this, rather than using a hearing tutor with an interpreter.

Irene relayed a situation where she derived more benefit from a deaf tutor in college:

Usually I have a hearing English teacher, but she was ill so the other day we had a deaf person teaching us. It was different like the deaf teacher explained about plurals, i.e. man, males, men. But the hearing teacher only corrects our writing, wrong verbs, grammar with a red pen!  
(Irene, age group 18-21)

Increased opportunities in education means that courses and qualifications are more accessible now. Deaf people have wider access to a variety of courses, due to funding provision for communication support. Informants were asked how they felt about being taught by deaf people younger than themselves. Madeline commented on why some people might object to this:

If young deaf people teach older deaf people, the older deaf people get jealous. They think, "How come they are smart, younger and teaching me?" They don't want to know. They prefer to go to a hearing tutor, who they don't know. It comes down to pride, really!  
(Madeline, age group 31-40)

Perhaps being anonymous was an attractive option; having a hearing tutor that did not know you, rather than being faced with one's own internalised oppression.

Because it is such a small community maybe deaf people don't want a deaf course, but an outside (hearing) course so that they can be anonymous as health is quite a personal thing. I think for myself I would prefer an outside course.  
(Tara, age group 22-30)

### ***5.11.2 Being taught by a hearing person***

One of the dilemmas when hearing tutors are used is that information can get lost in the translation process. Scott describes this:

If I have a hearing person then I would need an interpreter. Maybe I trust the hearing person, but whether the interpreter gives me the full information, that is another question.  
(Scott, age group 18-21)

Others had the same dilemma and maintained that they would check out the information for themselves afterwards, for example, checking out the details on the internet or in a book. Emma had negative thoughts about deaf tutors, due to her own underlying perception that deaf people could not teach other deaf people:

It is very hard to find a deaf tutor who has specialised health knowledge, and be able to teach that at a level, to be knowledgeable and sign well. I really think that hearing tutors are better; they have the knowledge, the skills and hear information via the TV and radio, so are more up to date than deaf tutors.  
(Emma, age group 18-21)

A possible explanation could be that Emma answered the question mirrored on her own perception of herself – a case of internalised oppression. The reasons for this are complex but can be attributed to various factors: education, the learning process and the lack of deaf role models in the system. More detailed explanations on these factors and its effects can be found in Chapter 1.

Ali explained why he thought deaf people might only want hearing tutors:

The problem is that they are depressed. Deaf people have been oppressed all their lives. Parents are not happy with having a deaf child so they ignore them. The deaf child remembers this and feels more at home in the Deaf community. I want to see the Deaf community encouraged; I do not want to join the hearing community. Deaf people are not confident and have problems in communication with hearing people.

(Ali, age group 22-30)

Ali's comments raise a number of issues; his family were Muslim and spoke their native language at home excluding Ali. He had not attended school until he was 12 after moving to the UK from India. Consequently he had to rely on other means of obtaining information about his world.

Bruce expressed similar sentiments of deaf people being unable to achieve success:

If deaf achieve then I would praise them, think that it was good for them, oh I will! But I know that it is impossible for deaf people to achieve because of oppression.

(Bruce, age group 41-50)

Evidently low self-esteem manifests itself when we look at the common responses of deaf people who have low self-esteem and apply the same label to other deaf people. Some of the informants found it easier to revert to the passive model in which they saw hearing people as powerful and knowledgeable, and in doing so perpetuated their own cycle of negativity, and internalised oppression. This is evident from Harry's quote:

Some say having a deaf doctor would be impossible, that they would not keep things confidential. Deaf society is the same as hearing society except its people are deaf. Deaf have to accept it, that the deaf society is small.

(Harry, age group 31-40)

If deaf role models were publicised more, this would enable deaf people to see that they can aspire to greater things. Clive, who had recently been diagnosed with sickle cell

anaemia, maintained that his doctor knew everything, even though he received most of his information from his deaf health advocate:

I thought that doctors knew everything – they know a lot about sickle cell. I was surprised when I met a deaf person who knows about health issues. The deaf health advocate explained to me about sickle cell in BSL, that was the very first time, I understood well. I need to know the information in order to understand my illness better.

(Clive, age group 31-40)

The conclusion was that deaf people have a long way to go before accepting deaf tutors. However, greater exposure of deaf role models in a positive light was seen as the way forward in the Deaf community, working together, and sharing information, both informally and formally.

## **5.12 Health Resources**

A number of different health resources were presented to the informants to obtain their opinions; these ranged from BDA and Health Education Authority leaflets to BSL videos. Other alternatives were suggested such as one-to-one and group discussions.

A high number (72%) of the informants had never seen any of the British Deaf Association videos, and 55% had never seen the BDA Health Promotion department leaflets. Over half of the informants maintained that they would not fully understand the HEA<sup>9</sup> leaflets if they read them on their own. The clarity of the information was important, and preferences were expressed for plain language that was easy to read and simple pictures or diagrams. Over 60% expressed a preference for a drugs poster supplied by the HEA, with photos of different drugs and explanations underneath them, rather than the BDA poster which was in the form of a cartoon and appeared to be too wordy.

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<sup>9</sup> Health Education Authority

An overwhelming 55% felt the best way of learning health information would be through a deaf discussion group, and a further 16% wanted this approach with leaflets to take home afterwards to reinforce their learning.

In watching a television programme about healthy eating more than half of the informants (55%) said that they would watch it in sign language with a deaf presenter without subtitles. However some informants (28%) felt subtitles were essential to aid their understanding of health programmes, in order to check any words that were finger spelt:

If a particular word is being mentioned that is crucial to the programme, then it should be finger spelt, for example, *PROZAC* (my emphasis). We know that terminology can be full of jargon, and it's essential that the deaf audience understand the word. Subtitles can help to back up finger spelling of words, particularly for those deaf people who do not have good receptive finger spelling skills.

(Harry, age group 31-40)

Significantly, not one informant wished to see the programme with a hearing presenter and a sign language interpreter. An ideal solution would be to develop television programmes geared towards deaf people covering health issues on a regular basis, or to utilise technology on the internet. The general feeling was that it was complicated trying to fit everything for deaf people in half an hour such as 'See Hear!' The coverage of controversial topics such as Aids, counselling, and cancer was believed to provide better exposure to the Deaf community, if it was shown on mainstream television.

The informants were asked about their views on the only current programme for deaf people called 'See Hear!' a weekly deaf magazine style programme. The format of the programme uses different presenters each week and this can result in confusion as regional signs may dominate. Some informants found it difficult to follow the BSL and preferred to watch it in conjunction with subtitles or relied solely on the subtitles.

If the presenter is from say Manchester, then I would find it quite tricky to follow the signs, they sign in a different way. I have never been to Manchester. None of my friends are from there, so how would you expect me to understand a presenter straightaway on the television. The subtitles are there as backup; I need them.  
(Ali, age group 22-30)

To keep up to date with changes in sign language it was felt that socialising in the Deaf community and going to the Deaf club helped. Unfortunately some of the informants did not have the opportunity to do this regularly:

They use different sign language; I do not understand it. I have my own signs, they use ones I have never seen before, and I only understand half of it. Deaf people go to Deaf clubs or pubs to improve their signing. I cannot do that as I stay at home a lot with my illness (sickle cell). They cannot be bothered to explain the new signs to me. I am a strong BSL user.  
(Clive, age group 31-40)

Clive felt that he was missing out on developing his BSL skills further. He was unable to travel outside his own locality, and this affected his ability to meet and hold conversations with deaf people. He was not able to chat with his neighbours as they were hearing and could not sign. BSL is a living language, which needs to be constantly utilised in order to maintain skills and adapt to changes or trends in signs; and is completely different to a spoken language. Clive can therefore be seen as socially excluded and oppressed through his lack of mobility.

### **5.13 Study 2 – Conclusion**

Strong patterns emerged across the data, especially in relation to how the informants viewed their health and the community around them. The data offered an insight into their belief systems and their conceptualisation of health information.

In this chapter, the use of a questionnaire enabled the researcher to find out whether using the SF-36 as a template for further developing a questionnaire would work with deaf people. It provided the opportunity to look at beliefs on what or what did not constitute a

normal healthy state, and to determine whether this would differ from comparative studies for hearing people.

One thing is clear, and has been evident in this chapter; deaf people cannot be collectively assessed in comparison to hearing people on opinions. Closed questions, which relate to certain aspects of health such as drinking and smoking, can be topics that are comparable in behavioural terms. However, the deeper underlying questions with regard to accessing health information and the barriers that exist for deaf people, in the context of oppression, cannot be compared. General health questionnaires do not look at the responses from a collective viewpoint, they are set up and designed for analysis from the individual perspective.

There is a danger of allowing the dominant culture to determine what constitutes a healthy state, and how deaf people fit into this model. A proactive service is far more valuable than a reactive service.

Generally it was found that the most relevant points of reference concerning health came from deaf people and not hearing people. Also some deaf people actively sought out the community as a resource, to maintain their lifestyle, or as a means of sharing information with each other, either formally or informally.

None of these findings are particularly surprising. A consistent theme is that the majority of deaf people wish to discuss issues at a community level, which helps towards a framework, for community intervention in terms of health.

Chapter 6 looks at the views of health professionals to obtain viewpoints from the 'other side of the coin', and expands on the themes that constitute a framework towards deaf people's understanding of health and health care systems.

## **Chapter 6 Deaf Health Professionals**

### **6.1 Introduction – Study 3 Deaf Health Professionals**

**(January 1997 – January 1998)**

This section explores the belief system and the roles of a sample of health professionals in the Deaf community. An attempt was made to elicit views on the situation of health for deaf people in the community and its implications. Particular emphasis was placed on looking at best practices in delivering health information, what barriers had been put in place by their funding body, and the ethos of the authority they worked for. The interviews also looked at the support systems in place to carry out their work.

### **6.2 The Health Workers' Stories**

The informants were familiar with the dilemmas and issues of working in the Deaf community. The range of jobs was diverse but they all worked in the health sector. Beth explained her role as a health advocate in London:

If deaf people want health information that they don't understand then I can explain it to them. They may want me to come with them to the doctors for clearer information; if that is the case then I can act as a relay interpreter for them. I run health workshops when necessary for deaf people in the East London area. In addition, I also work with health professionals, give deaf awareness and campaign for better access in hospitals and with GPs for deaf people.  
(Beth, deaf)

Carol worked for a major deaf organisation as a health promotion officer and her responsibility covered all the London boroughs in the mid 1990s:

After being in the job and being responsible for the health promotion in the organisation, I then realised that being part time did not enable me to do my job effectively as I had to cover all the London Boroughs, so my job then became full time. My role is very diverse from liaising with clients, carrying out workshops, exhibitions, to information sharing. Consequently, there has been no time to do



any research, develop any initiatives or focus on new areas, which is rather disappointing.  
(Carol, deaf)

It appears that Carol had a lot of responsibility for providing information to a large catchment area. Looking at the national picture, we can see that health workers have been assigned to certain areas and healthy living centres have been set up specifically for ethnic minorities. At present the moment there are some discussions about setting up one for deaf people in London. The plan is that it will be modelled on the Chinese Healthy Living Centre; the planning of the structure is in progress but has not yet been implemented.

Many of the deaf informants commented on feeling undervalued in their profession, often working in isolation, and away from contact with the health service:

It seems that all those people who are involved in health work alone; I find teamwork valuable. Although I work on my own, I do get the feeling that it is a waste of time if you work on your own. I wonder whether it is because health is a taboo area or has a stigma is attached to it. I have worked in various jobs for many years in the Deaf community and always have been part of a team, its brilliant. Health seems to have a particular barrier.  
(Liz, deaf)

Several informants felt that they were giving more to the community than what they got back in terms of job satisfaction. There was an underlying feeling that they were tied down by narrow funding restraints, and that some of the funding bodies needed greater awareness of the issues in setting up a project in the Deaf community. In addition, several had to follow funding criteria that did not necessarily follow deaf people's needs, but had no alternative due to the need for establishing the project in some form.

For Carol working in the voluntary sector and following contract specifications impacted on her work:

I feel restricted by the specifications of my contract. I work alone a lot of the time with a secretary and it is impossible to cater for everyone by myself. It would be good to have staff trained in specialised areas and then the quality of the information would become better, for example, cancer. Bringing in deaf role models as speakers in order to give other deaf people confidence. If they always see hearing speakers then they will never gain confidence in themselves.  
(Carol, deaf)

This created extra responsibility and put them under undue pressure to spend some of their time obtaining additional and future funding in order to complete projects, rather than concentrating on the work at hand. It can be seen that the support issues in the health sector are limited at best, and these workers are the exception to the rule. They are also in the position where there is no national funding body for liaising with, specifically over support for deaf health staff, which impacts on their ability to deliver the community aspect of their project.

### ***6.2.1 The DWHP Story***

One of the most noteworthy health projects in the Deaf community was set up on a voluntary basis, the Deaf Women's Health project (DWHP), to meet the needs of the community. It is worth exploring the origins of this group and the issues affecting the composition of the group:

The Deaf Women's Health Project originates back to 1987, it was a voluntary organisation and workers did not begin to get paid until 1991. The five co-founders of which four were deaf and one hearing had gone through the experience of having cancer. Their suffering was worsened by the feeling of isolation. In addition they had experienced immense difficulties in gaining health information. They felt throughout their illness that they had wanted to get their information from deaf people, but this was not available at the time.  
(Sharon, hearing)

The Deaf Women's Health project consisted entirely of volunteers, until 1991. Funding enabled them to continue and expand their services to deaf women all over the UK. Prior to this project, few initiatives had been set up by existing projects in the health sector, and consequently there was a real need for deaf people to establish a voluntary project in the field of health.

### ***6.2.2 Dissemination of Information***

Shirley explained how the DWHP was set up:

At that time we were not thinking on a big scale with concern to the DWHP. We just needed a service – to change awareness and attitudes of the hearing medical profession. Open meetings were arranged all over the UK with deaf females. We then conducted a small project and recruited deaf women as volunteers to interview other women through a health questionnaire asking about a wide range of issues covering knowledge, experience and service provision. In particular, focus was placed on the best way of disseminating health information.  
(Shirley, deaf)

This was the first time that a survey had been undertaken by deaf people that looked at the health needs of deaf people away from the medical perspective. At the time there was a growing trend towards making information videos available in BSL. Some surprising results came to light:

Information via video came down as seventh in order of popularity from the list of nine options of gaining health information. The most popular choice was to meet and get information from another deaf person. We had to reject our original plan of making a video; information had to come directly from deaf people themselves. Deaf volunteers had to be recruited and trained through weekend courses to become information officers.  
(Shirley, deaf)

The Deaf Women's Health project set a precedent for further health projects to be set up in the Deaf community, which has led to a more widespread acceptance in discussing health at a community level. Beth reiterated the importance of one-to-one contact:

At the moment we have the patient charter, made into a video. That's fine but we have a lot of leaflets. Deaf people say that they don't understand the information, and that they want something better. How to resolve that, I am not sure. There is not enough funding to make a video for each leaflet, that's why it is useful to have my job, advocacy. Deaf people who do not understand health information, then I can explain it to them rather than something expensive being created.  
(Beth, deaf)

This illustrates that the DWHP is an invaluable project with a lot of potential for further development. However, the drawbacks are the incessant demands placed on volunteers and its dependency on funding to further develop resources.

### **6.3 Rural-Urban Community Discrepancies**

In the interviews a common theme began to emerge of behavioural norms and values between rural and urban areas, in terms of deaf people's attitudes and their approach to one another. As a result Liz, a Development Officer, felt that she had to develop a different health agenda:

The aim of the project is to encourage deaf women to get together, empower them and to promote health awareness. In this area, it is rural and rather isolated. Deaf women living in urban areas are more progressive in their attitude and outlook and as a result have more confidence in themselves. When they have meetings together, the differences are exacerbated because they split into two groups. I have had to develop two different health programmes to meet each group's needs.  
(Liz, deaf)

Liz went on to explain how she achieved this:

When drawing up a programme I have to try and think what deaf women really need. I bring in hearing speakers and give information using other health organisations' leaflets. I rarely use deaf speakers because so few of them have had the opportunity to train to become health tutors or are knowledgeable enough

to run a health workshop. Often they live some distance away and as we are a voluntary project we do not have the money to pay for them to come.  
(Liz, deaf)

Ana also commented on bringing in deaf speakers:

There is some suspicion of deaf women teaching...nothing has changed that much in the last ten years. This is especially true with deaf rural women, you have to build up the trust with them, but they are still vulnerable. Because I worked at the University they found it difficult to see my job separate from my role in the project. They had an attitude problem then but now it seems to have changed for the better, they are more accepting.  
(Ana, deaf)

This distrust of having deaf tutors appears puzzling. This may stem from deaf people's negative image of themselves, and their belief that knowledge is best from a hearing professional. This theme consistently emerges in Study 2 when informants were asked whether they would prefer to be taught by a deaf person or a hearing person. The lack of confidence in having deaf tutors was a recurring topic. Perhaps a more plausible explanation would be the lack of deaf role models, particularly deaf teachers amongst deaf adults.

#### **6.4 A Culturo-Linguistic Model towards Deaf Health**

What was particularly striking was the continuous emphasis from these deaf health professionals who see themselves as part of a language minority rather than as an integral part of the disability movement. This was explored in Chapter 1 when the three models of viewing the Deaf community were analysed. Beth highlights this viewpoint:

Although I am based in a disability advocacy team, they are not fully aware about deafness. My supervisor is blind, so I have to a sign language interpreter there all the time, which makes communication difficult. I feel as if I am in the wrong organisation. I want to be in the health advocacy service, which covers different languages and nationalities such as Urdu, Hindu, and Turkish. They understand language barriers a lot better.  
(Beth, deaf)

For Beth, being in an organisation without any regard for assessing the social and cultural aspects of deafness and sign language is apparent and impacted on her work. This was an all too common story, and concern was expressed by several at being ‘lumped’ into a category without any consideration or much understanding of deaf issues.

## **6.5 Developing a Project – A Bottom Up Approach**

Several informants recognised the difficulties in establishing new projects in the Deaf community. Working in a small community resulted in a reluctance to embrace and accept new projects run by deaf people. An element of trust had to be built up over time and volunteers also had to be recruited. The roll out of such projects took time and a rapport had to be established with the participants. Sharon commented on a best practice view of how deaf people would become health professionals by working alongside other health professionals:

It is very important to train deaf people as health workers. I believe that the next step is to encourage Local Education Authorities to employ deaf people as part of their health promotion team. There is a real need for the professional health service to have links with the Deaf community.  
(Sharon, hearing)

Others informants managed to publicise the project by visiting their local Deaf club on social nights hoping to recruit participants or clients. Beth found this approach unsuccessful because club members were unable to distinguish between her job and her standing as a club member. She was finding it increasingly hard to promote her project because the Deaf club members still saw her as ‘one of them’ – not someone who was running a project and working as a deaf professional:

I visited Deaf clubs myself on social events to publicise the project; no one seemed to take it seriously. It was difficult for them to see me in a professional role distinct from my own personal role. I wanted to explain that I was there for work, but it was complex.  
(Beth, deaf)

There are certain difficulties associated with being a volunteer health worker, and the level of mistrust from the Deaf community impacted the success of their projects. Shirley commented on the DWHP volunteer situation and how there had been a drastic decline in volunteer numbers:

A couple of years after the set up of the DWHP the volunteer numbers had dropped from 50 to 20. The deaf volunteers said that they did not feel confident to teach deaf people as health volunteers because they found that deaf people were critical, very negative. They did not feel that they could handle such criticism from their own community. They knew the health information, but were often subjected to the criticism of, “How do you know that you are right?” when they disseminated the information to deaf groups. Basically they thought why bother doing this as voluntary work when people don’t want to learn and were not appreciative of their efforts.  
(Shirley, deaf)

There was a strong feeling among the deaf informants that working and socialising in the Deaf community had blurred boundaries. When a deaf person started a project and had the role of supplying information, it gave the impression that they had been elevated to a status where they controlled all the information and knowledge. Liz described feelings of being ‘thrown in at the deep end’:

When I started my job I was well known in the Deaf community, they were suspicious of me, as they did not know me. I had to build up the trust. Once they accepted me it meant that they could accept the project. They tend to think I know everything about women’s health, I try to explain to them that I am just the same as them, that I am learning too.  
(Liz, deaf)

Liz gave her own explanation as to why there is mistrust in the community:

Culture is vital when working with the Deaf community. I don’t think many are bicultural. If they do not have these skills then they become difficult and establish barriers, i.e. jealousy. I believe if you are bicultural, you are more confident, can accept people for what they are, approach them, talk to them and at the same time give them confidence.  
(Liz, deaf)

Not only do deaf health professionals face a barrage of criticism from other deaf people, meeting their hearing colleagues presents its own set of problems:

They were also faced with the difficulty of meeting hearing medical professionals, who use a powerful language. They did not have the skills on how to confer with them. We had not taught issues deep enough, it was all done on rather a superficial level. We have had to review the situation, and teach some confidence-building courses. Since then some areas have gone from strength to strength – especially the North West.  
(Shirley, deaf)

When starting a new project there are a number of obstacles that need to be overcome before further progress can be made. Several examples are low self-esteem and the lack of trained deaf health professionals. The participation of the Deaf community is critical to the long-term success of projects and relies on an element of trust between the project co-ordinators and the participants.

## **6.6 Project Issues – Piecing the Jigsaw**

### ***6.6.1 Confidentiality***

Confidentiality was deemed to be of utmost importance:

Confidentiality is a problem; you need to gain their trust, because the Deaf community is a very small community. It's a worry when we recruit volunteers because we have to be really sure that they can keep things confidential, because once they tell someone it can really affect us as an organisation for a long time. It can be difficult for professionals to socialise with the Deaf community because clients may be there and they will say hello and come to talk to you for ages, unaware of what the boundaries are, some overstep them.

(Carol, deaf)

The Deaf community is small and it is critical that confidentiality is maintained at all times. Deaf people may interpret this in different ways depending on their self-esteem and the perceptions of the Deaf community.



### **6.6.2 Publicising projects**

Sharing information was seen to be more effective towards encouraging group participation rather than relaying information ‘parrot fashion’. If this was effective as a learning tool then it contributed towards deaf people having a better understanding of health.

Liz managed to overcome the dilemma of reaching deaf people who did not attend the Deaf club regularly, by asking the local Deaf club to include her newsletter in their regular mailshots. However, this left her with another problem, which remained unsolved, of how to reach those deaf people who were not members of the local Deaf club:

To publicise the project, I went along on club evenings, and coffee mornings but it was not successful. The local deaf association sent out a newsletter on a regular basis so I asked them could I include my newsletter in their mailings. In that I included a programme of events. At first the deaf women were really suspicious of me as well as the project. Once they knew where the office was they started to come regularly.

(Liz, deaf)

For a project to be successful a wide range of participants is needed. Liz’s dilemma was how to reach out and publicise the service to a wide range of deaf people, and to ensure that the service was fully utilised. She felt that the declining membership of the Deaf clubs had a knock-on effect on her work and alternative means had to be found. Also, both the mainstream Deaf community and the major deaf organisations are seen as predominantly ‘white and middle class’ by deaf ethnic minorities.

Religious beliefs further complicated things when trying to recruit members of ethnic minorities. Many ethnic deaf people were restricted by the time they had available. This was especially true of females whose role is seen to be within the home. In addition, some religions placed restrictions on external activities outside the home.

I have tried to negotiate with the Asian Deaf Women's group, as some may be refugees. They told me that most women stay at home in the evenings, they are only allowed out in the afternoons to pick up the children from school and they have to be back before their husband comes home.  
(Beth, deaf)

As with any project ensuring access for ethnic deaf people was seen as an enormous challenge, and all the informants were keen that they reached out to a good cross section of the Deaf community. People from these groups tended to miss out on access to health information for several reasons. Their background at home means that English is not the mother tongue, and strict adherence to cultural practices may be the norm and cause further barriers. This illustrates the importance of ensuring that there is access to health information for ethnic deaf people.

Different informants had their own views of how health information was best understood by deaf people. Some commented that the demands made on them by the users of the project were unexpected:

When we asked deaf women what they wanted from the project they said that they wanted training and outside speakers. In addition, they wanted day trips to places, even though that wasn't relevant to health. So we had to match the project criteria and we said that it was linked to stress, even though it was not wholly appropriate!  
(Ana, deaf)

It seems recently from evaluation after workshops, a lot of people have said that they needed both the social aspect of the group as well as the information. I have planned a trip to France. Maybe it is a move on their part to say to their husbands that the trip is organised and that they feel obliged to attend. Perhaps it is an ulterior motive to get out of the marital home?  
(Carol, deaf)

This cultural affiliation with other deaf people was seen to be an important factor in establishing the projects. For these deaf women the health part was considered important, but the social network and meeting others more so. It also offered the opportunity to build up trust with other deaf people. This was particularly important for

those women who were isolated at home, and who did not usually meet other deaf people.

The best way of disseminating health information, from the wide range of options available, was explored in the interviews, and the effectiveness of groups came up frequently:

When someone tells their own experience to the group that has the biggest impact. If you just give out leaflets or videos, they just take it, not read it and put it into their bags. Leaflets may be visual and simple but it still has no impact. Discussion does, you may find out someone's experience, when it crops up, and the others have no prior knowledge of that, they will remember it afterwards.  
(Beth, deaf)

The impact of the deaf media provides good publicity, and is most effective in raising health awareness:

Two deaf women were on 'See Hear!' It was just a brief clip about breast cancer but as a result four or five deaf people in the UK found out that they had breast cancer. They have been through surgery and said if it was not for the programme, they would not have known. They thought that a lump in the breast meant nothing. The media is such a powerful tool; we need more of it.  
(Liz, deaf)

Not surprisingly, a striking pattern began to emerge providing evidence that more deaf led projects need to be established. These allow deaf people to make their own judgements on how they can assist other deaf people in the community to achieve effective learning. Ana mentioned how she modified information from a hearing course to suit a deaf audience:

My main interest is breast care. I used my training experience to pass on the information to deaf women in the area. I would make it more visual, draw lots of pictures. The feedback was amazing, deaf women said they preferred my talk to the hearing speakers because it was more visually appealing. It was then that deaf women started to realise that deaf people could give health talks. You have to give them time to get used to deaf speakers, some of them are do not have any

idea and would prefer a doctor or a health worker to give them information, because they see the medical professional as knowing everything.  
(Ana, deaf)

Clearly there is a need to re-evaluate the effectiveness of health information resources, and to look at areas of best practice in more detail. The project needs to be given time to develop from a bottom up approach via the input of deaf people, rather than being dictated by funding.

### ***6.6.3 Local Deaf issues***

One crucial factor in setting up any project is to evaluate the response to the provision of services for deaf people in the area. Ana provided an insight into how an area with a University Deaf Studies Department was viewed:

When I give talks in other places, like Leeds, I have noticed that deaf people are more down to earth and relaxed; they meet up a lot. One of the problems with this area is that the culture here is different. It is a unique situation where you have a mixture of deaf academics, researchers and ordinary people coming together in the Deaf club and locality. In other locations they have 'ordinary' deaf people. They come home from working all day with hearing people, go to the social evening at the Deaf club, relax and use sign language. That's their social life, and it is very important to them to be able to switch off. In addition, the health project is very important to them, especially for the wives to get together.  
(Ana, deaf)

Ana went on to explain that having an academic deaf studies department impacted on deaf people's attitudes to participating in projects at community level:

In this area they would prefer to stay at home, seeing as they have been exposed to a deaf work culture where they have communication in all aspects of work. Some spend all day with deaf people so the need to meet at the club is not so great. You cannot force people to come and participate in the project; they must make that decision for themselves.  
(Ana, deaf)

Emphasis was placed on the importance of setting up a project to look at local community issues, and being aware of any other local organisations or initiatives that may have a direct or indirect impact. Promoting a new idea was one of the biggest obstacles faced due to the fact deaf people are slow to embrace new ideas and initiatives. Beth expressed this view:

I feel that when deaf people see something new developing they never bother to try it or use it. They should make use of it, and should try and be more motivated. Even when the project finishes it does not matter because they will have gained some experience and knowledge through being involved in it. They wait until something happens to them like getting a terminal illness, and then need to use the project but what if the support is no longer there anymore? Projects don't last forever.

(Beth, deaf)

This can be attributed to the dependency or apathy culture prevalent in our western society. This situation of transference appears to stem from deaf people's life situations in education and family – a case of learnt helplessness (Seligman, 1992). As a result they expect this to extend into their adult life. Beth sums this up:

I have noticed that deaf people do not like letting go of their social workers. If they have a problem then they will go to the social worker. They do not like the idea of independence. To them having an advocate means that they will have to make decisions for themselves. They want someone else to decide for them. It stems from school, either special or mainstream, everyone tries to run their lives, and it becomes a habit. When they leave school they still want someone to run their lives.

(Beth, deaf)

Knowing about the complaints procedure is important in improving access to local resources:

There is a complaints procedure for the local health authority, but deaf people do not know how to use it. It is important therefore to explain to them deaf people's backgrounds, that they suffer from barriers because of the poor education that they received.

(Liz, deaf)

It was felt that working with a mainstream organisation would overcome the problem of scarce resources, but the small nature of the Deaf community needs to be taken into consideration:

We wanted to link in with a network, i.e. a helpline. We visited the breast cancer care headquarters in London, but realised after discussion it would be hard. They had a list of contacts so a person can ring up, and they put them in contact with a person who has gone through the same experience of cancer. In this way they can share their experiences and give advice. We had originally hoped to set up a network for deaf people so that they could talk about shared experiences. It would be totally confidential, and they would be put them in contact with others living near them who were going through the same experience. Contact could carry on via the minicom or meeting in person and sharing or giving information. If you wanted to go to hospital, then that person could be prepared to go with you to give you moral support.  
(Shirley, deaf)

The crux of this situation is that the key to changes comes with training, trust and confidentiality. Deaf women needed this in order to progress and feel comfortable with discussing such issues.

#### **6.6.4 *Volunteers***

Knowing how to continue fundraising for projects after funding ran out was considered a useful and important skill to have. However, the reliance on a few deaf people for fundraising left them 'burnt at both ends of the candle' due to the pressure and high demands involved. Another added responsibility was to recruit volunteers, which was not without its difficulties:

A lot of people did not understand what commitment was needed to become a volunteer. I had to set up training to show what being a volunteer meant. I found that they were not aware; they did not want the responsibility. They thought that if they became a volunteer they would be on the committee, which was not true! The women were not motivated, although they had originally made a demand for this project and the service; the money was there. I felt really stuck!  
(Ana, deaf)

Ana found it difficult to recruit volunteers, and felt that this was because they were unaware of what voluntary work actually entailed. Typically the project was funded for a limited period of time, with specific objectives. The disadvantage is that it does not allow the community to grow with the project and understand the nature of such work:

Some of these organisations have funding for training days, and recently one was held in this area. They did not have any deaf representatives? Deaf organisations need to get more involved in this area and have representatives. The current situation is it has to be a motivated deaf person who has a real interest and personal drive to become a volunteer.

(Liz, deaf)

However, several activities in the Deaf community are dependent on volunteers in different areas, for example, deaf sports. As a result there are never enough volunteers. Shirley reiterated the point that community resources could be very stretched at times:

Deaf people who teach sign language become tired and they cannot channel their energies elsewhere. This is why it is difficult to get volunteers for the project.

(Shirley, deaf)

Although community action usually occurs within voluntary groups, deaf people were beginning to tire of being volunteers, particularly in a sector that usually advocates the medical model. Sharon's vision was of an approach to set up a community led regional structure with paid workers:

A lot of people are tiring of the pressure of work and its voluntary nature. We really need a project director, and more deaf health workers in health promotion. Ideally this should be a regional structure with deaf women as community workers. They need to address special groups such as young deaf women. The grassroots deaf people could then become the professional health workers.

(Sharon, hearing, in talking about the DWHP)

Deaf people at all levels, teach sign language to the wider hearing community. However, the underlying feeling is that any project set up specifically for deaf people is at a disadvantage. There are restraints on project volunteers' time, as several will also be paid

for working as BSL tutors. The Deaf community needs awareness amongst professionals from the health sector and relevant external organisations of its culturo-linguistic needs.

#### ***6.6.5 Importance of venue***

Deaf clubs were not considered as suitable venues to run health workshops for a variety of reasons; the main one being that people using the facility were instantly recognisable in a small community:

Before the project was based at the local Deaf club, because it seemed like the best location for deaf people to access it at that time. No rent to pay or anything. However, people do feel more exposed there, that other members outside the room see them, and think that they have a problem. The social services are based upstairs, which adds to the situation. It would be nice to have one room, like at a Health Centre, where deaf people can get information related to health issues.  
(Liz, deaf)

The deaf women felt the Deaf club as a venue was not private enough and in addition to this the deaf men teased them. I set up a self-defence course, one course at the Deaf club and one course outside. The outside venue was more successful because it was private and safe, so the Deaf club as a venue is not always ideal.  
(Ana, deaf)

Several informants saw better understanding and greater tolerance by other members of the club towards the use of facilities as crucial. Interaction with other deaf people clearly was of importance and the club provided this.

#### ***6.6.6 Other health professionals' attitudes***

Earlier in this chapter, mention was made of working continuously in isolation or as part of a team. Several commented on the attitudes of the health professionals they encountered and how this impacted their work:

Health professionals may go to university or medical school, get promoted, have high status jobs but no one taught them about disability and deafness. They are



not aware of different cultures, they tend to be white middle class. I feel that medical training should teach them deaf awareness and include it in their qualifications. They only teach them the medical knowledge to become a doctor.  
(Beth, deaf)

Hearing people do CACDP stage one, two or three, pass and get jobs, but deaf BSL tutors are still at a subordinate level. It would be far more effective to teach doctors and nurses, people who work in the medical field sign language. We would have something to exchange with them – and receive something back for the Deaf community in being able to communicate with them in BSL.  
(Shirley, deaf)

With health professionals, it seems I have to make the first move to arrange to meet with them. They get a lot of information from deaf people when they meet us, more so than we get from them. If the project was for some time then I would consult with them, and amend their resources, create them, make them appropriate for the Deaf community. One step I have made forward, is involving the local health authorities in consultation about developing appropriate resources of deaf people.  
(Liz, deaf)

Women such as Liz, Shirley and Beth commented upon feeling doubly discriminated against. Firstly, their situation meant that the medical profession categorised them as being part of the medical model rather than as a cultural group. Secondly, they felt that they had to overcome these barriers to provide a cultural model of deafness to health professionals, which they found an uphill struggle at times. Thirdly, their opportunities for career progression are limited, because they are not recognised as being on an equal footing with their hearing contemporaries in terms of their job status.

Sharon explained the dilemmas that deaf people faced working in the health area:

The health authorities need assertive deaf women to work with them. It takes time to do this kind of work. A proper campaign needs to be established in order to meet many professionals and counsellors.  
(Sharon, hearing)

The next section looks at measuring the effectiveness of projects.

## 6.7 Measuring Effectiveness/Successes of Projects

The DWHP is unique in that it is the first of its kind in Europe; a community initiative that grew from the needs of deaf women, through a grassroots approach. Many of the informants reported success in their work and projects. They managed to work out what was the best way of disseminating information based on a trial and error system:

Seeing deaf women build up their confidence, being eager to come to the workshops. The newsletter seems efficient, but I still have concerns over whether the language is appropriate for them. It can't be too highbrow; if we try to simplify it then they would think that we are insulting their intelligence.

(Liz, deaf)

The DWHP, a national project, has gone from strength to strength and has allowed the community to determine their needs:

The DWHP has saved women's lives. Deaf women have been through confidence building courses, and have become leaders in the health area. This is different from just being a BSL tutor; they have diversified into other areas.

(Sharon, hearing)

Shirley explains:

The DWHP has achieved a lot I must say – the fact that it exists and is there for deaf women. If you compare it to Europe they really have nothing. Britain is advanced really. One example is that Finland have invited me to give a talk next week as they want to implement a policy for their own country's women's group. We are a group that really started from nothing. We have enabled deaf women to gain confidence, feel positive about themselves and awareness of information thorough the DWHP. These kind of achievements are not visible or measurable from the outside, but when they all get together it is very apparent. I just feel that it is important for deaf women to meet as some feel really intimidated by men. If the group became mixed – it would be difficult. Some women are afraid of their husbands, being beaten up or stuff like that.

(Shirley, deaf)

It can clearly be seen that the strength of grassroots community organisations is in its members. A bottom up approach of learning and growing in confidence together has resulted in an excellent community initiative through the DWHP.

In the interviews the informants were asked what they would like to see happen in the area of deaf health. A constant topic was the roll out and utilisation of deaf people as speakers, to deal with the issues of confidence and mistrust. They felt that information would be delivered that was culturally and linguistically sound, and who better to do this than trained deaf people themselves. Beth had some concerns over the direction that the field was moving into:

I have a feeling, although there are a lot of opportunities for deaf people, at the moment things will somehow go downhill. There are a lot of cuts in social services, health authorities and local authorities, how can that area improve? It means that things will focus on communication support rather than the service itself. Interpreters are a business; they are not there for deaf people. I do not see the future as being rosy at all.

(Beth, deaf)

This perhaps has some resonance in view of the current DDA legislation, which places responsibility on the service providers. Service providers, who lack understanding of the cultural approach, will tend to set up the provision for deaf people by using interpreters, rather than training deaf people to become health workers. This would result in deaf people returning to the medical model and receiving information via a third party, rather than in their own language. This approach ignores the culturo-linguistic model and presupposes that all information can be given via sign language interpreters.

Shirley also saw that the onus of responsibility lies with health professionals in learning sign language, and making an effort to understand the Deaf community and its cultural differences:

For the year 2000 onwards, deaf people want the information there straight from the professionals in sign language not through interpreters. You want to be able

to walk in, and have a consultation, this way it is your own private business and no body knows.  
(Shirley, deaf)

This approach negates the need for interpreters and highlights the recurring issues of confidentiality that have been common themes throughout Studies 1, and 2.

## **6.8 Study 3 – Conclusion**

The issues discussed by the informants in this chapter covered a whole spectrum of issues in deaf health, particularly from the medical model paving the way towards an understanding of the culturo-linguistic model of deaf health.

There is a real need for health professionals working with deaf people to understand the language minority nature of the Deaf community and what initiatives work well. This training and understanding needs to be incorporated into the medical studies courses. In Studies 1 and 2, themes consistent with the socialisation process, the enculturation process, and the education process frequently reoccur. These factors have an impact on and influence deaf people in accessing health systems, particularly their lack of confidence in the system and mistrust of professionals.

In Study 3, community projects were set up but due to funding restraints they were unable to follow a holistic community approach from the bottom up perspective. In addition, deaf people have been influenced by the ethos of health service providers, which tends to follow the medical approach. There is a requirement for a national plan of health delivery to be incorporated into mainstream health provision. One example of an organisation working towards this is the Reaching Deaf Minds Campaign set up by Sign. Reaching Deaf Minds is a key part of Sign's work to make health and social care providers aware of the need to promote positive mental health for all d/Deaf people, parent/carers, educators and employers. It aims to enable d/Deaf people to gain access to appropriate primary care services, so from the onset, they are less likely to feel distressed and isolated, and therefore, at less risk of developing mental health problems. National

funding and policy makers need to recognise the needs from both a community and a culturo-linguistic perspective.

The informants working as health professionals in the Deaf community have had to constantly challenge these notions, by working in collaboration with the service providers and reasserting themselves as deaf professionals in their own right.

Each of them, in their work, has gradually introduced a cultural way of working with the community, following the grassroots approach and consultation. The DWHP is seen as a successful example of this.

The examples given in Study 3 give food for thought in considering new avenues for disseminating information in a culturally appropriate manner.

The issue of confidence and mistrust can be linked with the lack of resources in using deaf speakers in community discussions. Deaf speakers are necessary to ensure that deaf people can empathise with them, benefit from their knowledge, and have trust and confidence in the delivery of information. It is more beneficial for group members to assimilate information in this way rather than through an interpreter, which has no linguistic meaning.

More modern facilities at Deaf clubs, covering a variety of support services under an umbrella organisation, would help provide a setting for establishing and running different courses, in addition to working with mainstream organisations. Another alternative worth considering would be a Health Resource Centre specifically for deaf people, with deaf trained health workers delivering information that has been adapted as culturally specific.

## **Chapter 7 Through the Looking Glass: A Perspective on Deaf Health**

### **7.1 Summary of Studies**

Several themes emerged from Study 1, which followed a developmental research approach, the sign language video narrative. Many of the young deaf people participating had never had the opportunity to discuss these issues before. This explored the concept of decision making, placing the onus upon them and allowed for a wide-ranging discussion of issues that can be difficult to talk about. These issues may be of a sensitive nature and helped explore their perceptions of health. The findings act as a precursor to the model for deaf health, and offered an insight into what health means to deaf people and the influences of enculturation, education and the transition to the Deaf community that shaped their views. This has implications for future planning and research.

For Study 2 a questionnaire was used to evaluate the health of deaf people, and to determine their attitudes to health. This was modelled on the short form 36 questionnaire. Consideration was given to the design to ensure that it was culturally and linguistically appropriate for deaf people. Its purpose was to allow them to express their views and to enable the researcher to probe further when possible. The format of the questionnaire asked open ended questions, which revolved round Deaf community life and their access to information.

Study 3, which is covered in Chapter 6, set out to explore the issues facing members of the Deaf community who also work in the field of deaf health. The interviews illustrated the pitfalls and obstacles of working in the Deaf community and ensuring that health information is disseminated to deaf people.

The findings from all the studies formulate a framework for understanding deaf people's access to health and its implications. This helps to establish a rationale as to what intervention work will be of benefit for the Deaf community, in line with the hypotheses outlined in section 3.1.

Figure 7.1 illustrates the factors that were explored in order to define how an intervention programme could work. Each study in this research project looked at these factors and covered issues that have a direct impact on deaf people's lives.

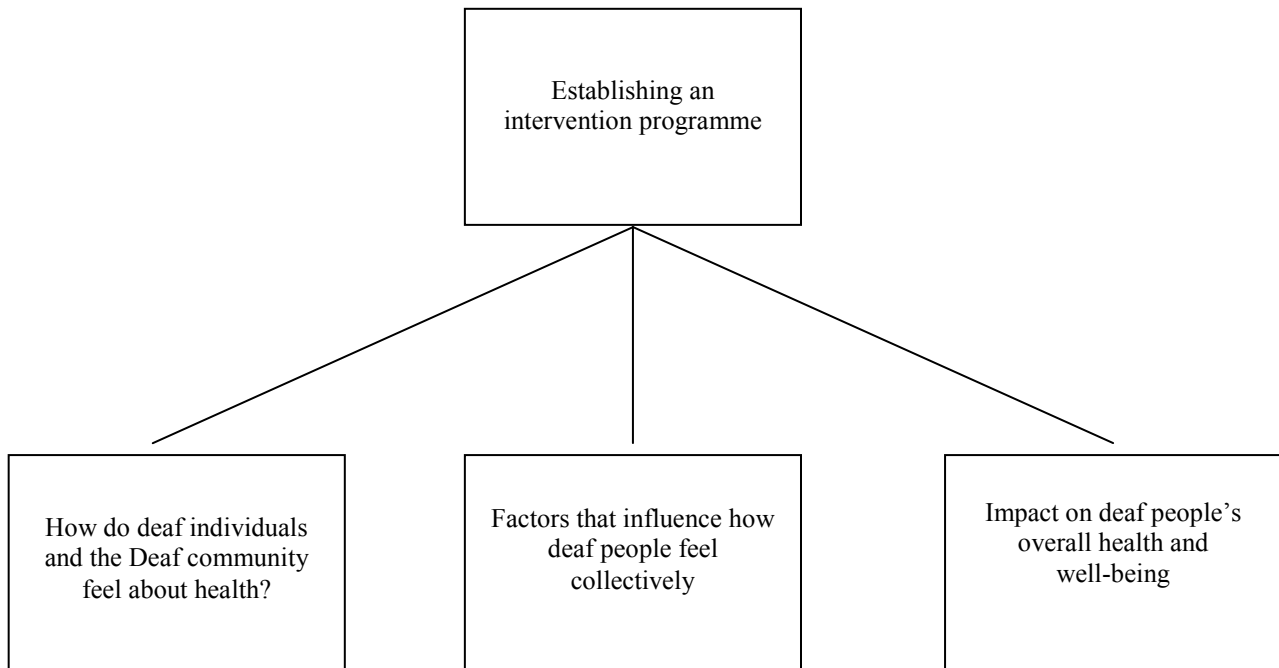


Figure 7.1 – Factors to consider when undertaking intervention work

From these themes a framework can be derived, as shown in figure 7.2, which explores deaf people's experiences of health and their understanding of health care systems. The flowchart displays how intervention work can be undertaken and the dominant ideologies that impact upon the deaf individual's health. This leads to the construction of a potential health intervention programme:

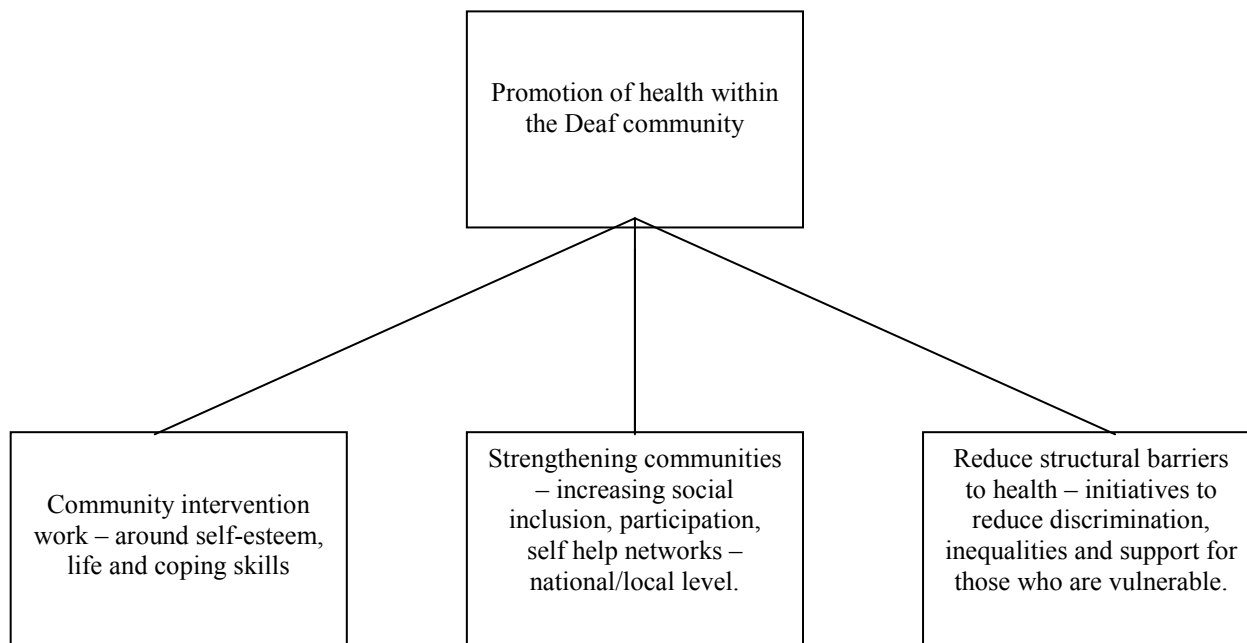


Figure 7.2 – Factors to consider when planning an appropriate health programme for the Deaf community

The key elements centre around three concepts: community intervention work, strengthening communities, and reducing structural barriers in health service provision. Each of these will be explored further in this chapter.



## **7.2 Working Towards a Model of Deaf Health**

### ***7.2.1 Community intervention work***

There is a need for greater grassroots consultation at community level. This process ensures that there is a discussion on health and explores how the community feels about it. The service model will differ from area to area, particularly from rural to urban areas.

Community work is essential in delivering services in order to work on life skills, self-esteem and strategies for coping. This only works by implementing a model that encompasses the whole community. However, it is true to say that in terms of a free market economy a system where users pay doesn't work for deaf people, because the cost of equity is more than the costs of the service to the average person on the street, i.e. effective specialist services are more costly than mainstream services. For this reason, extra funding is needed to cover this cost, as there is no short-term monetary profit to be gained from investing in the Deaf community.

It can prove difficult to obtain funding, when being restricted by following the criteria outlined by the funding bodies who do not always understand the concept of the community approach. There is an obvious need for a national holistic plan to deliver a model of health that is appropriate to deaf people, and funding should be provided to fit in with this. One current example is the Department of Health report called: Towards Equity and Access 2005 (“TEA”). This report highlighted the difficulties d/Deaf people have in receiving equitable healthcare. There were 26 recommendations for improvement, and £2.5 million per year is given to Primary Care Trusts enabling these to be implemented. Recent announcements in the way health care will be delivered locally will further impact on deaf people unless the recommendations are fully implemented. SIGN is determined to make change happen; two Implementation Officers have been recruited to work with Primary Care Trusts and the Deaf community to ensure that the recommendations are followed. Many Primary Care Trusts are unaware of the report, and

do not realise they have been given extra money for improving access for deaf people. (Department of Health, 2005)

Currently there is a lack of community resources available that utilise health information in BSL. When setting up a project it would be useful to contract deaf professionals as consultants to utilise their expertise and knowledge. This would ensure better use of funding because there would be no need for someone with limited knowledge to come in and spend hours attempting to understand the needs of the Deaf community. They would also provide an objective view thus allowing cultural variables to be considered, which are critical to the success of the project.

Many of the difficulties in running health centred projects are compounded by the health agencies themselves. Service delivery is problematic, but is by no means an impossible task. One of the first things to be considered is to ask the Deaf community what is important, and then this information to be relayed back to the service providers. This is the first step in empowering the Deaf community to make a difference, and projects will not be effective without community support. In the first instance, the service provider should get together with some of the skilled leaders of the Deaf community, and work towards designing a project that caters to the needs of the community. By assimilating the leaders into the project process it has positive benefits for the community as a whole.

In assessing the needs of the community, there must be some impetus from people who understand the background to the issues that need to change within that community. There have been a variety of assessments performed on deaf people, some of which are not valid; for example, standard health questionnaires are not culturally and linguistically appropriate to use in data collection with deaf people. For this reason a questionnaire was modified for Study 2, which enabled exploration of the issues that are relevant to the Deaf community and, sign language users in particular.

For community intervention to be meaningful, it is necessary that a holistic approach is conceptualised. This should be at the individual as well as the collective level, and

enable the various services to exist within the community. These should be designed, led and managed by deaf people. This model can work well for both deaf people and the service providers in maintaining a high level of service and adhering to quality standards as to how this is best delivered.

Clearly there are some difficulties in implementing this model such as convincing the medical establishment that there are different ways to address the health problems of the Deaf community. Another consideration is that the composition of staff can undermine the success of deaf related health projects. When implementing relevant health projects, it is critical that deaf people are adequately represented at various staffing levels, and play an active participation throughout its life cycle.

The other alternative is that the Deaf community is left to its own means and the same issues remain unchanged or even worsen. Although the majority of grassroots deaf people intuitively know what is needed, many of them do not have academic qualifications that enable them to take responsibility for the design and development of projects. The power base continues to lie with establishments responsible for policy making and officials who are unaware of the needs of deaf people, which makes it difficult to implement strategies that are culturally appropriate to the Deaf community. To address these issues, the Deaf community must have an integral part in designing any service that caters for the community.

### ***7.2.2 Strengthening Communities***

The community development approach to health within the Deaf community needs to be re-evaluated. Empowerment is crucial, and deaf people need to reclaim autonomy away from the medical profession. Responsibility for health needs to be shared by working in partnership among community groups as well as mainstream statutory and voluntary organisations. For example, the primary care trusts, social services and the local health resource centres could play a key role as agents of change. They could then include deaf

workers in this process in providing needs led services. This would pave the way for providing multi-agency and multi-professional community services.

The education system and teachers also have a role to play, in ensuring that their deaf pupils have the necessary education and develop strategies for coping with the profusion of information around them. Education providers should explore ways of making adult education fully accessible to deaf people.

From the literature review in Chapters 1 and 2, there is clear evidence that there is a tendency to focus upon the illness symptoms rather than on physical and positive health. There are some misconceptions surrounding the minority nature of the Deaf community and its culture. Consequently, there are difficulties in moving towards a community based approach for deaf health, which is culturally and linguistically appropriate.

In contrast to hearing people, deaf people are assessed on a collective basis. The general outlook is that their health appears to be much worse. There is also a long history of the dominant medical ideology, which focuses on the hearing mechanism, and the potential for measuring and correcting deafness. In medical intervention, the needs of deaf individuals centre upon the acquisition of speech, lip-reading and making use of their residual hearing. A deaf person's skills in these areas are highly valued by hearing medical professionals and focuses on success in education and society at large.

These principles of oralism suggest that deaf people who do not conform and use sign language are socially isolated, and that they lack the appropriate skills to 'participate' in the hearing community. It ignores the benefits and the diversity of the Deaf community as a resource that enables deaf people to feel valued and part of community life on collective terms. The inherent attitudes of the medical profession make deaf people reluctant to approach them. There is a need for the medical profession to be sensitive to the cultural and communication needs of people who are deaf and learn to sign. This would enable sign language users to feel more at ease in medical settings.

A positive aspect in all of the studies undertaken was the frequent discussion of the dramatic shift from the mother culture to affiliation with other deaf people. If the idea of community participation is to be put into practice, then the Deaf community groups (e.g. DWHP) and similar social networks are central settings. They provide an important resource in the process of enabling deaf people to increase control of, and subsequently improve their health.

There needs to be a re-examination of society's perceptions of the Deaf community. One way in which this can be done is through increasing the visibility of deaf people as co-workers, which will improve hearing peers fluency in sign language, and in turn correlates with the amount of interaction made with the cultural group (Jankowski, 1997). Along with this view of deaf people as 'peers', there is the potential for greater respect to be established. Jankowski (1997) sees this process as valuing their views, their experiences and consequently trusting them in leading their own community. One example would be to allow deaf people to lead community projects from the outset that concerns the Deaf community.

### ***7.2.3 Service Provision – Reducing Structural Barriers***

It is clear that deaf people are at a particular disadvantage when accessing health services. Information and education are necessary in order to increase public understanding of their situation. Duran and Duran (1995) conclude that most of the attempts in providing services to Native Americans ended in failure. Most of the blame for this has been apportioned to the patient, instead of the delivery system steeped in policies.

The majority of health service providers are only trained in delivering services to the general population. They are usually unaware of the background of their patients and the circumstances that have shaped their lives.

There continues to be a discussion on integrating western and traditional approaches to health. The logic behind this is that it offers a potential solution to improving deaf

people's understanding of health. However, this discussion has mainly remained within the realm of academia, as demonstrated in various studies explored throughout Chapter 2.

It is vital that a bridge is built between the medical profession's worldview, their lack of understanding and the Deaf community, particularly those whose preferred language is sign language. This can be further helped by increasing professional training opportunities for deaf people, in order to pass information back to the Deaf community. Finally, more deaf people need to undergo training as facilitators and as professionals in all aspects of health.

An attempt needs to be made to explore the perspectives of the Deaf community, moving away from the factors that affect deaf individuals being categorised by their 'deafness'. Whenever a person finds it difficult to express feelings of frustration or anger due to living in an oppressive environment, these feelings become internalised. Paulo Freire (1990) outlines the notion of internalising the oppressor as one of the by-products of colonialism. The oppressed group by internalising the oppression may have a tendency to become like the oppressor, because they have no outlet in which to express this emotion. Thus it becomes impossible for the oppressor to liberate the oppressed, and the oppressed function in a way that fits within the oppressor's frame of reference.

The bottom up approach provides a useful research tool towards community control rather than the trickle down paternalist approach. A community led initiative works best for sustainable projects, and deaf people need to define what it means for them to be healthy. Health should not be compartmentalised as, "Let's talk about problems with your GP". The discussion, under health promotion initiatives, needs to be set in the context of contact with hearing society, as well as employment, housing and social interaction. From the studies, it is clear that identification and social interaction with the Deaf community contributed towards good health. The strategies and policies imposed by the service providers do not work because of its inherent paternalist approach.

Another consideration is to develop a needs led assessment for health questionnaires that are culturally and linguistically appropriate for deaf people, in order to derive valid analytical data. This could include: expert panels, focus groups of the target population, developing research that is culturally appropriate, and an analysis of the needs of different sub groups within the Deaf community, for example, ethnic minorities.

The socio-economic dynamics of the Deaf community should also be taken into account. Deaf clubs are no longer the traditional power bases that they once were and it is becoming increasingly hard to target deaf people who rarely attend the Deaf club. Other options should be explored around technology, in terms of disseminating information.

Interpreters and health professionals can act as potential barriers to improving the health of deaf people. They can retain power and prevent the deaf person from taking responsibility for their own health care. Deaf people tolerate using their families in medical encounters, but prefer to discuss health issues with other members of the Deaf community. Good communication support is fundamental towards improving deaf people's health. Training programmes should be developed around interpreting in medical settings to address these issues. In addition, learning about the Deaf community and sign language should be a compulsory component of medical courses.

The majority of the proposals put forward in this chapter centre around inclusiveness, which is demonstrated by the various approaches outlined in figure 7.2.

The overall implications for planning health promotion means that consideration needs to be given to producing a service with no barriers, and ensuring a continuum of influence to ensure that service provision is on par with the standards that the general population would expect to receive. Recent trends in governmental strategy have made provision for user feedback and it is essential that deaf people are part of this process. The thesis adopts a holistic approach in addressing the needs of deaf people by identifying key themes through research undertaken. It also offers the opportunity to look at delivery of service provision both regionally and nationally. Without access to good quality

information deaf people are more likely to be placed in a position where they are unable to make informed choices. The consequence of not having this access means that there is more potential for deaf people to put themselves at risk when accessing health information.

### **7.3 Future Research**

These studies pave the way for future research. The main strands of research that have been identified are:

1. There is a need to implement community work within the Deaf community with deaf researchers. It would be useful to present the findings and the implications for deaf health to the Deaf community. This would allow further exploration of a model of positive deaf health, and helps to establish good working practice for future projects.
2. Issues that centred on deaf people's understanding of health were developed throughout all the studies, from the focus group discussion with deaf people and interviewing on a one-to-one basis. It would be of great value to ensure that this exercise is repeated across the Deaf community, particularly for different sub groups, to identify any demographic trends and any significant differences. Possible examples are rural and urban areas, or focusing specifically on deaf gay men, to allow for further comparisons.
3. The theoretical framework for deaf people's understanding of health needs further investigation. This would then be presented as a working model in everyday language, to deaf people as well as service providers who are already working or considering working with the Deaf community.



4. The findings show that the Deaf community approach differs from both the approaches of the service providers and the government. Further exploration of these issues, both positive and negative, would assist in the implementation of future projects.
5. Although deaf health professionals were interviewed, it would have been useful to obtain the viewpoints of health service providers to provide a balanced view.
6. There is a need to investigate on a greater scale the health resources available to deaf health professionals and to define resources that are most effective for service delivery. Future research should encourage further exploration of best practice and to specifically focus on the development of suitable resources.

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## **APPENDIX 1**

### **Study 1 – Focus Group Schedule**

#### **University Students Discussion Schedule**

## **Study 1 – Deaf University Students**

### **Introduction**

- Explain structure – BSL video to generate discussion.
- Timescale
- Confidentiality
- Some personal details needed: age, gender, deaf or hearing people in family, schooling

The transcripts of the two scenarios were used to produce a BSL video for the focus group to watch and aid as a stimulus to discussion.

### **Scenario 1**

#### **A visit to the doctors**

Jim had an appointment at the doctors. He had not been feeling very good recently. On approaching the receptionist he gestured that he was deaf. She gave him a piece of paper to write down his name, which he did. The receptionist wrote back, “Sit down, and I will tell you when it is your turn to see the doctor”.

Jim sat down, and picked up a magazine. It was not particularly interesting but he needed something to read to pass the time. After a while the receptionist motioned to him, to go and see his doctor. Jim got up, and walked down the corridor, looking at each doctor’s name. His was Dr Taylor, he found the door, and walked in.

He realised straightaway that he was going to have problems. Dr Taylor had a thick bushy beard. Jim sat down opposite him. Dr Taylor spoke. Jim did not understand a word that he said and could not lip-read him. Another problem



he thought, my life is full of problems. Dr Taylor carried on talking. Jim tapped him and pointed to his ears. But, Dr Taylor still carried on talking. Jim could feel the fury building up inside him. He gestured again for a pen and paper this time.

He wrote down,

“I DEAF, I NOT UNDERSTAND YOU. I NEED HELP.”

He could see the puzzled look on Dr Taylor’s face who wrote back,

“WHAT CAN I DO TO HELP YOU?”

Jim was getting exasperated with all this writing. He just wanted to get out of the room. He wrote,

“I DEPRESSED, I FED UP WITH LIFE, I FEEL SAD A LOT OF TIME”.

Dr Taylor, then wrote out a prescription, handed it over to Jim, nodded and gestured for him to leave the room. Jim wanted to get out anyway, nodded back and quickly departed.

Next stop was the chemist where he collected his prescription. The medication word on the packet was very long, but as far as he understood he was to take the pills three times a day.

Later that day, Jim had arranged for Dave, a friend to come over, he had not been to the deaf club recently. Dave had rung up and they arranged to meet at Jim’s. After they greeted each other, Dave asked Jim why he had not been to the deaf club recently. Jim explained about how he had been feeling lately, and how his visit to the doctors had been appalling. He showed Dave his tablets.

Dave looked at the tablets and signed, “Do you know what these are for? And what the side effects are?”

Jim nodded to indicate no and signed back, "I just follow the doctors orders."

"You should check what tablets are for, before taking them!" he told Jim.

"I never thought," was Jim's reply.

## **Questions**

How could Jim improve communication between him and his doctor?

*(Probe: first point of contact, waiting time, consultation session, after thoughts)*

Was Dave right to tell Jim to check before taking tablets?

*(Probe: why? How overcome?)*

## **Scenario 2**

### **Practising Safe Sex**

Steve was staying the night with his new girlfriend Karen. He wanted to have sex with her. Karen asked him if he would use a condom. Steve laughed and signed back that he did not want to use one. "Do you think I have AIDS?" he asked Karen aggressively.

Karen tried to explain about wanting to practise safe sex. Pete laughed again and signed, "Real men don't use condoms!" Karen was frustrated with trying to explain to Pete about safe sex. Pete simply did not want to know. He got dressed quickly, and promptly stormed out of the flat.

## Questions

Was Karen right to ask Steve to use condoms?

*(Probe: How deal with situation?)*

What would you have done if you were in this situation?

*(Probe: Why?)*

## **APPENDIX 2**

### **SF-36 Schedule**

## Standard Form-36 Survey Subjective Functional Outcomes Assessment

The S.F.- 36 Form is one of many outcomes assessments designed by the Medical Outcomes Trust in Boston, MA. It is designed to approximate the improvement in health status from a medical intervention.

INSTRUCTIONS: This survey asks for views about your health. This information will help keep track of how you feel and how well you are able to do your usual daily activities. Answer every question marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is: (Circle one)

Excellent . . . . . 1  
 Very good . . . . . 2  
 Good . . . . . 3  
 Fair . . . . . 4  
 Poor . . . . . 5

2. Compared to one year ago, how would you rate your health in general at this time? (Circle one)

Much better now than one year ago . . . . . 1  
 Somewhat better now than one year ago . . . . . 2  
 About the same as one year ago . . . . . 3  
 Somewhat worse than one year ago . . . . . 4  
 Much worse now than one year ago . . . . . 5

3. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

ACTIVITIES	Yes, limited	Yes, limited	No, not
	<u>A lot</u>	<u>A little</u>	<u>limited at all</u>
a. Vigorous activities, such as running, lifting heavy objects, or participating in strenuous sports	1	2	3
b. Moderate activities, such as moving a table, vacuuming, bowling, or golfing	1	2	3
c. Lifting or carrying groceries	1	2	3
d. Climbing several flights of stairs	1	2	3
e. Climbing one flight of stairs	1	2	3
f. Bending, kneeling, or stooping	1	2	3
g. Walking more than a mile	1	2	3
h. Walking several blocks	1	2	3
i. Walking one block	1	2	3
j. Bathing or dressing yourself	1	2	3

4. During the past 4 weeks, have you had any of the following problems with your work or other regular activities as a result of your physical health? (Circle one number on each line.)

	YES	NO
a. Cut down on the amount of time you spent on work or other activities	1	2
b. Accomplished less than you would like	1	2
c. Were limited in the kind of work or other activities	1	2
d. Had difficulty performing the work or other activities (for example - requiring an extra effort)	1	2

5. During the past four weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

(Circle one number on each line.)

- |   | YES | NO |
|---|-----|----|
| a. Cut down on the amount of time you spent on work or other activities | 1   | 2  |
| b. Accomplished less than you would like                                | 1   | 2  |
| c. Didn't do work or other activities as carefully as usual             | 1   | 2  |

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups? (Circle one)

Not at all ..... 1  
 Slightly ..... 2  
 Moderately ..... 3  
 Quite a bit ..... 4  
 Extremely ..... 5

7. How much bodily pain have you had during the past 4 weeks? (circle one)

None ..... 1  
 Very mild ..... 2  
 Mild ..... 3  
 Moderate ..... 4  
 Severe ..... 5  
 Very severe ..... 6

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)? (circle one)

Not at all ..... 1  
 Slightly ..... 2  
 Moderately ..... 3  
 Quite a bit ..... 4  
 Extremely ..... 5

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks: (circle one number on each line)

	All of the time	Most of the time	A good Bit of the time	Some of the time	A little of the time	None of the time
a. Did you feel full of pep?	1	2	3	4	5	6
b. Have you been a very nervous person?	1	2	3	4	5	6
c. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
d. Have you felt calm & peaceful?	1	2	3	4	5	6
e. Did you have a lot of energy?	1	2	3	4	5	6
f. Have you felt downhearted and blue?	1	2	3	4	5	6
g. Did you feel worn out?	1	2	3	4	5	6
h. Have you been a happy person?	1	2	3	4	5	6
i. Did you feel tired?	1	2	3	4	5	6

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

(Circle one)

- All of the time .....1  
 Most of the time .....2  
 Some of the time .....3  
 A little of the time .....4  
 None of the time .....5

11. How TRUE or FALSE is each of the following statements to you?

	Definitely <u>True</u>	Mostly <u>True</u>	Don't <u>Know</u>	Mostly <u>False</u>	Definitely <u>False</u>
a. I seem to get sick easier than other people	1	2	3	4	5
b. I am as healthy as anybody I know	1	2	3	4	5
c. I expect my health to get worse	1	2	3	4	5
d. My health is excellent	1	2	3	4	5

The Standard Form 36 should be filled out by patients/clients and is a subjective measurement of how they are responding to a particular treatment (in our case, exercise and wellness). Be familiar with this form and be ready to answer questions that may arise from its completion.

## **APPENDIX 3**

### **Study 2 – Semi-Structured Open-Ended Interview Schedule**

#### **Deaf Community**



## Deaf People's Access and Contact with Health Professionals

### Reinforce confidentiality with informants

#### Section 1: Background

1. What is your Name? (optional)

.....

2. Where do you live?

.....

3. What is your gender?

Male ☐ Female ☐

4. What age group are you in?

18 - 21 ☐ 22 - 30 ☐ 31- 40 ☐ 41-50 ☐ 51 - 60 ☐

5. What is your ethnic origin?

White ☐ Black Caribbean ☐ Black African ☐

Black Other ☐ Indian ☐ Pakistani ☐

Bangladeshi ☐ Chinese ☐ Asian Other ☐

6. When did you become deaf?

At Birth ☐ Before 2 years ☐ Before 5 years ☐

Before 16 years ☐ After 16 years ☐

7. Are you?

Deaf ☐ Severely Deaf ☐ Partially Deaf ☐ Hard of Hearing ☐

8. Are any of your family deaf? Who?

Yes ☐ No ☐

.....

9. Where were you educated between the age of 3 - 11 (School you attended for the longest time)?

Day Deaf School ☐ Deaf Boarding School ☐

Mainstream with PHU ☐ Mainstream without PHU ☐

10. Where were you educated between the age of 11 - 16 (School you attended for the longest time)?

Day Deaf School ☐ Deaf Boarding School ☐

Mainstream with PHU ☐ Mainstream without PHU ☐

## Section 2: Medical Encounters

1. How often do you go see your GP?

More than once a month ☐ Once a month ☐ Every 3 months ☐

Every 6 months ☐ Once a year ☐ Never ☐

2. When you last saw your GP, did you:

Go alone ☐ With a friend ☐ With your partner ☐

With your family ☐ With an interpreter ☐

Other ☐

.....

3. How do you communicate with your GP?

Write down ☐ Talk ☐ Lip-read ☐ Sign ☐

Bring family (To help or sign) ☐ Bring friend (To help or sign) ☐

Bring partner (To help or sign) ☐ Use an interpreter ☐

Other ☐

.....

4. The last time you received a prescription or medication, did you understand what it was for and why you were prescribed it?

.....

5. Have you been in contact with any health professionals in the last year?

	In the last month	In the last 6 months	In the last year
Midwife			
GUM Clinics			
Well Women Clinics			
Community Nurse			
Health Tutors			
Health Visitors			
Sister/Nurse			
Health Advocate			
Other (Please Specify)			

6. How did you feel when you met them? Was there anything that you would change about the experience?

.....

7. Have you ever had any bad experiences with doctors, nurses or interpreters in a medical situation? Perhaps an experience where you felt you were badly treated or let down?

.....

### Section 3: Using an Interpreter

1. Would you use an interpreter in a medical/health situation?

*(Probe: Explain why or why not)*

.....

2. You have a choice of which interpreter you can use. How do you choose your interpreters?

.....

3. In what situations would you would use an interpreter?

- |   |                          |
|---|--------------------------|
| Hospital  | <input type="checkbox"/> |
| GP  | <input type="checkbox"/> |
| Educational Lecture                                 | <input type="checkbox"/> |
| Meeting   | <input type="checkbox"/> |
| Job Interview                                       | <input type="checkbox"/> |
| Legal Situation – Interview with Police or in Court | <input type="checkbox"/> |
| Other   | <input type="checkbox"/> |

.....

*(Probe do you feel that you trust the interpreter to give you full information?*

*100% 75% 50% 25%?)*

.....

4. For question 3, if you said no to all the situations then please explain your response.

.....

### Section 4: Attitudes, Questions and Measures.

1. Do you feel that your health is:

Excellent    ☐    Very Good    ☐    Good    ☐    Fair    ☐    Poor    ☐

2. People are more healthy some times, and other times less healthy. What do you feel like when you are healthy? *(Probe)*

.....

3. I am going to give you a statement 'People are more healthy now in UK, more than before'. Do you agree or disagree with this? Why?

.....

4. Have you had any illnesses? What was it? How did it affect your life on a daily basis?

.....

5. What kind of exercise do you do? When and how often? Is there any sport that you would like to try? What stops you from doing this?

.....

6. What does a good diet mean?

.....

7. Do you feel that you eat well? What things have you done to improve your diet?

.....

8. Are you a:

Non-drinker	<input type="checkbox"/>
Drink only on very special occasions	<input type="checkbox"/>
Occasional drinker	<input type="checkbox"/>
Regular drinker	<input type="checkbox"/>

9. Did you drink any alcohol in the last week?

(Go through respondents drinking diary: amount of alcohol, type of drink, time of day consumption, where?)

.....

10. Do you smoke cigarettes regularly? How many every week roughly?

.....

11. What things in your life do you feel have a good effect on your health?

.....

12. What things in your life do you feel have a bad effect on your health?

.....

13. 'Good income, means better health.' Do you agree or disagree with this statement?

Agree ☐      Disagree ☐

14. Is there anything that you feel you should do to keep yourself healthy?

.....

**Section 5: Statements**

1a. Do you agree or disagree with the following statements:

	Strongly Disagree	Disagree	Don't Know	Agree	Strongly Agree
1. To have good health is the most important thing in life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I really don't have time to think about my health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I am more reluctant to go to the doctors because of communication problems that arise.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Deaf people die younger than hearing people because of limited access to health care or to information.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Deaf people earn less than hearing people.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Hearing people are more intelligent than deaf people.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I would rather go to a deaf doctor than to a hearing doctor.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. It is sensible to do exactly what the doctor says.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Being able to hear means that information can be better understood.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. The National Health Service is responsible for my health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

1b. Please explain your choices.

.....

.....

## Section 6: Do hearing people know better?

1. If you go on a course, or get a qualification do you prefer to be taught by deaf person or hearing person? Why?

.....

2. Do you feel that you can trust information/content given by a hearing professional than from a deaf professional?

.....

3. Some deaf people do not want deaf tutors in health issues, they only want hearing tutors, why do you think that this happens?

.....

4. Any idea/comments how resolve this situation?

.....

5a. Gaining and Understanding Information (show examples). What resources do you use to find out more about health issues? If you have never seen some of these please say.

Resource	
Leaflets (normal)	
Leaflets (BDA)	
Magazines	
Posters	
Lectures with health professionals	
Group discussions with deaf people	
Talk to a friend	
Discuss with a health professional	
Other (Enquire what other is)	

5b. Please explain your choices, and say which is the best way for you to learn about health issues.

.....

.....



6. When you watch a TV programmes made specifically for a deaf audience - for example, 'See Hear!' do you understand information/content or feel that you want more information?

.....

7. Would you prefer to watch a TV programme for example on Healthy Eating:

- |   |                          |
|---|--------------------------|
| In sign language with deaf presenter                              | <input type="checkbox"/> |
| With a hearing presenter with sign language interpreter (Hearing) | <input type="checkbox"/> |
| With a hearing presenter with sign language interpreter (Deaf)    | <input type="checkbox"/> |
| With subtitles  | <input type="checkbox"/> |
| Other (Please explain)  | <input type="checkbox"/> |

.....

***Thank you for your help, your co-operation is very important and much appreciated. All your answers are completely confidential.***

## **APPENDIX 4**

### **Study 2 – Section 5 of the Questionnaire**

#### **Raw Data for Measuring Deaf People's Attitudes to Health**

## Raw Data for London

	Abigail	Ali	Bruce	Clive	Eric	Irene	Kate	Sumita	Question score (40)
1. To have good health is the most important thing in life.	7.5	2.5	10	10	10	7.5	10	7.5	<b>65</b>
2. I really don't have time to think about my health.	0	2.5	10	7.5	7.5	0	0	2.5	<b>30</b>
3. I am more reluctant to go to the doctors because of communication problems that arise.	0	0	0	7.5	2.5	2.5	7.5	0	<b>20</b>
4. Deaf people die younger than hearing people because of limited access to health care or to information.	7.5	0	10	5	2.5	0	0	2.5	<b>27.5</b>
5. Deaf people earn less than hearing people.	0	7.5	2.5	2.5	0	2.5	0	0	<b>15</b>
6. Hearing people are more intelligent than deaf people.	10	7.5	2.5	5	10	2.5	10	0	<b>47.5</b>
7. I would rather go to a deaf doctor than to a hearing doctor.	0	0	10	7.5	5	7.5	10	0	<b>40</b>
8. It is sensible to do exactly what the doctor says.	2.5	0	10	2.5	2.5	10	10	0	<b>37.5</b>
9. Being able to hear means that information can be better understood.	0	0	0	2.5	10	0	0	0	<b>12.5</b>
10. The National Health Service is responsible for my health.	0	0	0	0	5	7.5	0	0	<b>12.5</b>
<b>Informant score (out of 100)</b>	<b>27.5</b>	<b>20</b>	<b>55</b>	<b>50</b>	<b>55</b>	<b>40</b>	<b>47.5</b>	<b>12.5</b>	

### KEY

SA Strongly Agree

A Agree

SA Strongly Agree

DK Don't Know

SD Strongly Disagree

Informant Average = 38.4375

Questions 1 & 8 are positive

## Raw Data for Bristol

	Emma	Harry	Julian	Leah	Madeline	Matthew	Scott	Simon	Sophie	Tara	Question score (100)
1. To have good health is the most important thing in life.	7.5	10	10	7.5	0	0	2.5	7.5	2.5	10	<b>57.5</b>
2. I really don't have time to think about my health.	2.5	0	7.5	7.5	2.5	10	7.5	2.5	7.5	10	<b>57.5</b>
3. I am more reluctant to go to the doctors because of communication problems that arise.	10	10	10	10	0	2.5	2.5	7.5	7.5	10	<b>70</b>
4. Deaf people die younger than hearing people because of limited access to health care or to information.	10	2.5	10	10	2.5	7.5	10	5	0	10	<b>67.5</b>
5. Deaf people earn less than hearing people.	10	7.5	0	2.5	0	0	7.5	0	7.5	2.5	<b>37.5</b>
6. Hearing people are more intelligent than deaf people.	10	10	7.5	10	7.5	7.5	10	7.5	2.5	10	<b>82.5</b>
7. I would rather go to a deaf doctor than to a hearing doctor.	2.5	0	10	7.5	10	0	0	7.5	0	10	<b>47.5</b>
8. It is sensible to do exactly what the doctor says.	5	10	2.5	5	5	10	7.5	10	2.5	2.5	<b>60</b>
9. Being able to hear means that information can be better understood.	10	0	7.5	2.5	2.5	10	7.5	7.5	0	7.5	<b>55</b>
10. The National Health Service is responsible for my health.	7.5	10	0	10	2.5	10	7.5	10	0	10	<b>67.5</b>
<b>Informant score (out of 100)</b>	<b>75</b>	<b>60</b>	<b>65</b>	<b>72.5</b>	<b>32.5</b>	<b>57.5</b>	<b>62.5</b>	<b>65</b>	<b>30</b>	<b>82.5</b>	

### KEY

SA Strongly Agree

A Agree

SA Strongly Agree

DK Don't Know

SD Strongly Disagree

Informant Average = 60.25

Questions 1 & 8 are positive

## **APPENDIX 5**

### **Study 3 – Semi-Structured Open-Ended Interview Schedule**

#### **Health Professionals in the Deaf Community**

## Health Professionals in the Deaf Community Interview Schedule

Topic	Question	Probe
<b>Background</b>	Can you explain your role and aim(s) of any projects that you are involved in?	<i>When set up, location, support network?</i>
<b>Health Issues for Deaf People?</b>	Important areas/issues in health for Deaf people? Any problem areas? Success areas?	<i>Information, understanding, access?</i>
<b>Contacting Deaf People</b>	Publicising the project/role? How contact deaf people? Recruiting method? Venue? Any difficulties encountered?	<i>Any particular groups difficult to reach out to?</i>
<b>Health Information</b>	Means of distributing health information used to deaf people.	
	Best way of learning?	<i>Value of group discussions Vs written English leaflets</i>
<b>Networking/ Partnerships?</b>	Any contact with other health groups/organisations?	<i>Good? Worthwhile? Create Network/Partnerships?</i>
<b>Beyond 2000?</b>	Where do you see your role/project beyond 2000?	<i>Same, or different?</i>