

An initial study on Deaf parents with children aged 0-11 years in San Francisco Bay Area, USA.

SW307: International Social Work: Dissertation

Student No: 9801023 May 2001

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SYNOPSIS:

This initial research project focuses on Deaf parenting and is one of the first of its kind highlighting issues around Deaf parenting. There has been little or no previous research so far on these issues only occasional articles on deaf parents and their experiences, such as have appeared in Disability Pregnancy & Parenthood International (DPPI) magazines.

This research project aims to highlight the huge gaps in access to information and services which exist for deaf parents, throughout the period of pregnancy and as the child is growing up, both in the USA and the UK. Much change has happened in the last twenty to thirty years in terms of technology advancement, legal rights, empowerment, recognition of American Sign Language and British Sign Language and improved deaf awareness. Reviewing the literature shows that there is a range of information and resources targeted at hearing parents of deaf children, but little for Deaf parents of deaf, hearing or disabled children. The research found that many of the common themes/ issues affecting deaf parents remain unchanged. The fact remains that 90% of deaf children are born to hearing parents. They will, one day, grow up to become deaf parents and are 90% likely to have hearing children, yet, little or no specific information is available to them. What is being done about this?

It was hoped that the report and the project findings would highlight the issues around deaf parenting, so encouraging deaf parents and services providers to work together to develop information and services in an accessible format. Examples of service providers include Social Services, Education, Community, Health and so on. These offer/provide services to Deaf people, including Health Care during the pregnancy, child development, child education (including playgroup/ nursery), and parent support groups etc.

Service providers may find this a challenge because of their legal responsibility under the Disability Discrimination Act 1995 (UK) and the American with Disabilities Act 1990 (USA). The legislation requires them to make their services accessible to deaf people, clearly not the case here, as many deaf parents were in the dark, often isolated and relying on friends and family for information and support.

Though the project was carried out in USA I had some support from Becki, an information officer at Disability Pregnancy & Parenthood International (DPPI), based in North London. DPPI runs an information services for disabled parents, similar to Through the Looking Glass (TLG), in USA. Like TLG, they have had many enquiries from deaf parents and health professionals (i.e. midwives) requesting information on deaf parenting.

However, because Becki is hearing but has deaf grandparents, she realised that there was a huge gap in services to Deaf parents. As DPPI do not have an information pack, she was looking to have parenting videos subtitled with a view to developing an information pack/video for deaf parents in BSL. In the light of this project, DPPI has agreed to help out by setting up a working party to develop an information pack on parenting for deaf parents and professionals.

It is hoped that the research will serve as a useful source of information for Deaf parents and service providers encouraging dialogue between them.

SECTION 1: Background to the Project:

1.1 Introduction – Deafness & Diversity:

There are an estimated 28 million deaf people in the USA with various levels of deafness (including deaf, hard of hearing and deafened). More than the approximate figure of 250,000 were born or became deaf at a very young age (pg.250, Preston, 1994) and yet between 500,000 and 2 million deaf people use American Sign Language (O'Rourke, 1975 in Preston, 1994; Padden & Humphries, 1988). To examine the picture further, there are over 355,000 people with various levels of deafness in the San Francisco Bay Area (Hearing Society, 1999). Many researchers have acknowledged the difficulty of obtaining accurate and reliable data on the total deaf population. Because of this, the figures need to be treated with caution (Padden & Humphries, 1988; Preston, 1994). However, the fact remains that of the 28 million deaf people in USA, the majority at some stage in their lives will plan to be or will become parents. The research aimed to explore issues concerning them and the information/ services available to them.

Although the above description is brief, the area of research on parenting is vast, as the area of interest covers issues around:

- 1) pregnancy/birth, ranging from the natural biological growth inside the womb to the medical science of test tube babies i.e. IVF,
- 2) parenthood, raising children, including the perspectives of biological parents and carers i.e. foster parents & adoptive parents.

Therefore, because the research was of a small scale, it focused on Deaf biological parents from the pregnancy stage to raising a child. However, further research on the above subjects should be encouraged.

Before embarking on the rest of the report, it is important to clarify the terminology, especially the use of the term 'deafness'. The above opening paragraph outlined difficulty in obtaining data on the deaf population and relates to how deaf people are categorised. There are two main models which show how deaf and hard of hearing people are perceived. The distinction between these groups is important because the descriptions are not used consistently and have very different implications regarding how service providers identify and respond to need (c.f. Corker, 1996a; Chowdry, 1999). Therefore it is important to define deafness for the purpose of this research.

First is the medical/pathological model where deafness is perceived by society as an impairment, an inability to function in response to sounds. Therefore, this system sees:

"...deaf and hard of hearing people as having impaired hearing. It uses 'objective' medical classification based on audiology (how much sound can be heard) and speech pathology (how much 'normal' spoken language can be understood...)". In addition, "because the ability to hear and to speak is seen to be 'normal', services concentrated on the provision of hearing aids, cochlear implants and particular approaches to educating deaf and hard of hearing children which aim to restore them, as far as is possible to 'normality'" (Chowdry, 1999).

However, it is important to note that though, the term 'hearing-impaired' has been generalised by hearing people to include all people with all levels of deafness, 'many deaf people find the term stilted, even offensive...' (p.g.245, Preston, 1994).

Second, is the social model where people perceive deafness as a form of self-identification or linguistic minority. Using the example of the social model of disability:

"...the classification systems acknowledges people's physical, sensory and intellectual impairment, it regards disability as something completely different. Disability refers to a group of social rather than medical categories, which result from the different ways in which society erect barriers, which oppress people with impairment. In other words, individuals with impairment are disabled by society, this is the social model of disability, which emphasis the right of deaf and hard of hearing people along with other disabled people to be included in society as full citizens..." (Chowdry, 1999).

With the above description of the social model of disability, it is important to be aware that many Deaf people do not see themselves as disabled and like the term 'impairment' consider the label 'disabled' to be offensive. In addition, because society continues to erect barriers which to date oppress deaf people, putting them to great disadvantage, they are therefore disabled by society. Padden & Humphries (1988) went further with the social model and deafness, using the Woodward's conventions (1972) which stated that the term

"deaf (lower case) [should be used] when referring to the audiological condition of not hearing, [including hard of hearing and deafened] and the uppercase Deaf when referring to a particular group of deaf people who share a language – American Sign Language (ASL) – and a culture."

(Padden & Humphries, 1988)

This not only applies to American Deaf people using ASL, but to Deaf people all over the world, who use sign language as a first or preferred language and who prefer to affiliate with other deaf/hard of hearing people of similar disposition. However, for Deaf people, it is not just a case of not being able to hear but more importantly it is:

"... 'attitudinal deafness' and the ability to sign, ... though actual competence and fluency in sign language may be irrelevant". Furthermore, "the concept of impairment means little because Deafness is seen as a 'normal' condition. Moreover many Deaf people are very supportive of social and educational segregation e.g. through special education [Deaf school/college/university] and Deaf clubs, believing that the more opportunities Deaf people have to come together, the more Deaf culture and language will flourish." (pg. 2 Chowdry, 1999).

In order for readers to explore this area further, reference to the account in Deaf culture, Deaf community and Deaf World would be found useful (Padden & Humphries, 1988; Lane, Hoffmeister & Bahan, 1996).

Therefore, the self-identification Deaf or deaf, depends on the deaf individual and the deaf group. 'Markowicz and Woodward (1978) have suggested...[that] the deaf group and skill in ASL should be important diagnostics factors in deciding who is Deaf. But the bounded distinction between the term Deaf and deaf represents only part of the dynamic of how Deaf people talk about themselves' (Padden & Humphries, 1988). For the purpose of the research, 'Deaf' will be used constantly to refer to Deaf parents, for these individuals were already part

of the Deaf community as described above, prior to participating in the research. However, issues around how the Deaf parents identified themselves came up during the research and their views will be expressed in a later section. Accounts on identities, including the diversity of Deaf identities, can be found from Bat-Chava, 2000)

These Deaf people live within the wider community and cultures, which are also enriched with languages, beliefs, behaviour, identification, belonging and cultural values which are just as important. This is particularly true for those within the racial/ethnic minority communities. The San Francisco Bay Area has a large diversity of communities, this includes a large Mexican Spanish/Latino (or Latin American/Hispanic) community and is home to one of the largest Asian communities in the USA (Chowdry, 2000a; Census Bureau, 2000). It is also important to note that the term 'Asian' is perceived differently from USA 'as people who are from South East Asia/ Far East (Chinese, Vietnamese, Japanese, Korean, Malaysia etc) whereas in UK, Asian people are mostly from South Asia, namely India, Pakistan, Bangladesh etc' (Chowdry, 2001).

1.2 Aim & Scope of the project:

As outlined in the proposal (see Appendix 2), the project entitled 'Deaf Parenting: Raising a Child' is very much small-scale exploratory research, an initial study, on Deaf parents and their experiences in raising a child aged 0-11yrs old. The importance of this research is in examining the themes that arise from the study and establishing whether there are services available to Deaf parents who have deaf/hearing/or disabled children.

Prior to the research project, some interest had been expressed in this study, by Disability Pregnancy and Parenthood International (DPPI) in the UK and by Through the Looking Glass (TLG) in the USA. The primary aim of the research was to produce this dissertation as an essential part of the university course. However, because little scattered information and research has been found in this area, it was of utmost importance that this research should serve as a pilot study. In addition that it should particularly encourage further in-depth and more ambitious research on the subject of Deaf parenting on various levels from regional/state-wide to national and international levels.

The project was carried out with the support of two agencies - Hearing Society/ Hearing Impaired Program (HIP) in San Francisco and Through the Looking Glass (TLG). TLG is an organisation for Disabled Parents, which is currently undertaking a three-year USA-wide project on disabled parents with teenagers. The TLG organisation is very interested in the outcome of this research project, so that they can plan further research on Deaf parents with teenagers.

The majority of the research was done to find out Deaf people's experiences of being a parent from the late stages of pregnancy to raising a child. The importance of including the pregnancy stage was to highlight experiences of joining in parenthood for the first time and to discover whether the pre-natal/maternity care services were accessible to Deaf parents. Furthermore, the experiences of Deaf parents in raising a child were to provide a useful resource for future parents in identifying gaps in information and service provision. Such findings from the research will be explained in subsequent chapters.

Though there are gaps in information and services, it is important to note that the services available, including their system of education, health and social services in San Francisco Bay Area were found to be different from the provision in the UK. Because of this, it is vital

that the findings are not assumed to apply to all states in the USA or other countries where the systems are different. However, it is hoped that such findings can still be used locally, and the concept transferred to the rest of USA and to the UK, to highlight other gaps in services locally and nationally with a view to developing and improving services

Therefore, in summary, the aim of the research was to:

- i) Explore Deaf people's experiences of being a parent, including the common themes of communication, education, parenting skills and access to information and services.
- ii) Identify gaps in information and service provision for the Deaf parents and where appropriate, provide a list of resources of places they could contact for further information and support.

1.3 Structure of the report:

With the above aims in mind, the next section focuses on the importance of the current research. This includes highlighting the gaps in previous research on the area of Deaf parenting, and focusing on the outcome of the small-scale pilot study that the researcher carried out in the UK prior to departing to the USA. After this comes the Project Target/ Methodology section, which discusses how the current research was carried out, including the methodology, how the sample of Deaf parents was selected, the research methods chosen and any dilemmas/ problems that may have arisen.

The findings from the research will be presented in three main sections. The first section highlights the general findings, the key characteristics of the interviews with the two focus groups of Deaf parents, including the access they had to information/resources and services and how times for the older Deaf parents differed from that of the current Deaf parents.

The second section will focus on the key findings from the Deaf parents with a child aged 0-11yrs. The findings will include the common themes of: their relationship with their family and children, parenting skills, access to information and services during their pregnancy, the birth and the period raising their child, and their advice to future Deaf parents.

The third section will focus on the key findings from the older Deaf parents with grown up children, including the above common themes relating to their previous experiences of childrearing and how times have changed.

The report will then conclude with brief feedback from the Deaf parents, a summary finding of the research and recommendation for future development/ research. Furthermore, a resource list of various organisation/ services in both USA and UK can be found in the appendices, in case if any deaf parents, professionals working with Deaf parents and/or anyone interested to find out more about them, may wish to contact them for further information and support.

1.4. Previous Research

A search was made bearing in mind the figures namely that approximately 90% of deaf children are born to hearing parents (Schien& Delk 1974; Preston, 1994). These deaf individuals will grow up to become Deaf parents and are 90% likely to have hearing children. (Preston, 1994).

It was extremely hard to find empirical research on Deaf Parenting whilst searching for

research materials and literature in relation to this project on Deaf parents. The search was concentrated on various categories including 'deaf people' and 'families and deaf children' in the hope that there might be some material on Deaf parenting written in small sections/ chapters/ articles.

However, the previous literature search in the UK (see proposal in Appendix 2), found a vast number of materials and literature on the subject of family and deafness. These largely focus on deafness from the medical/pathological and educational perspectives rather than the social and linguistic perspectives. These books discuss deafness in depth as a medical condition, offering information on communication methods, (Schwartz, 1996) and the Statement of Special Educational Needs (Knight & Swanwick, 1999; Marschark, 1999). These books were written with the issues of deaf children within hearing families, in mind, providing useful resources for hearing parents of deaf children (Adams, 1997; Luterman & Ross, 1991).

In addition, the above materials make little or no mention of deaf parents and the issues they face in raising their deaf/hearing children. However, there is still some scattered information about Deaf parents and their experiences of having hearing children, in the form of:

- 1) Short articles, (Cundy, 1987; Walter 1990,) on their personal experiences of raising hearing child; and the issues facing Deaf mothers from both a personal (DPPI, Newsletters 1995; 1998; 2000) and a professional view (DPPI Newsletter, 1998);
- 2) Literature reviews, (Singleton & Tittle, 2000), with a specific section on 'Communication Patterns and Parenting Issues in Families with Deaf Parents and Hearing children';
- 3) A few books: (Preston, 1994) carried out extensive narrative research, a nation-wide study on hearing adults who have deaf parents. This has lots of specific references including daily living and their relationship with their deaf parents. Further references highlighted the experiences of the Deaf parents themselves. For instance, Preston gave a picture of how one Deaf parent, from a three-generation deaf family, expected to have a deaf child but was shocked and upset to discover their child was hearing. This mirrors the feelings and expectations of hearing parents, when having a deaf child.
- 4) An Information pack, (BDA, 1997) which has leaflets entitled: 'Hearing Children with Deaf parents', 'A Deaf mother's View' on a child's education, 'Deaf Adults in the school community' on the role of being a Positive Role Model for Deaf children and 'Home/School Communication', encouraging clear communication between home and school.

It was clear that most of the above literature had been written from the perspective of the hearing child of deaf parents. These issues included communication, identity, culture and the role of the hearing child in a deaf family. Thus, this proved extremely useful as background information to supplement this research. It was disappointing, though, to find that very little material focussed on the experiences of deaf parents themselves in raising their children, irrespective of whether the child was deaf or hearing.

This remained true in further searches of literature in the USA. Subsequently, a few research reports related to parenting were used as a guide in developing the research design.

The first report was one carried out by TLG who produced the report using the results from a recent National Survey of Disabled Parents (TLG, 1997). This highlighted the experiences of disabled people and the barriers they face around:

- 1) parenting, including attitudinal barriers/ discrimination (such as pressures to have abortions, reported attempts to remove their children and discouraging them from adopting a child),
- 2) access to transportation (affecting the routines of parent-child activities),
- 3) personal assistance,
- 4) adaptive parenting equipment to enable them to carry out their role as a parent,
- 5) housing (not being accessible or adapted to meet their needs) etc.

However, whilst the report proved extremely useful for the current research, especially the underlying themes of attitudinal barriers/discrimination, which many Deaf parents face, it focused on parents with various disabilities. Many of the issues, other than the attitudinal barriers do not apply to Deaf parents.

Also the research was carried out on a national level, using a postal survey, through both disability organisations and individuals. The survey was also available on-line via the Internet. The research design aimed at getting general data or an overview of the Disabled parents population. Many of the questions asked were not appropriate for Deaf parents i.e. personal assistance, issues of access to transportation, adaptation to housing.

However, TLG acknowledged the difficulties in obtaining data from Deaf Parents using this method of survey, and was looking into different ways of obtaining the information. In the meantime, resulting from the National Survey of Disabled Parents (TLG, 1997), a three-year national research project is being carried out, with specific focus on Disabled Parents with Teenagers. Furthermore, this Deaf parenting project is working in partnership with TLG with a view to referring, to them, Deaf parents who have teenagers as identified from the current research. TLG can then plan and carry out their study on Deaf parents with Teenagers in the summer of 2001.

Moving from the National level onto the local level, the report was carried out on Deaf Parents and the issues they face in raising their children - see Bunde, L.T (1979) 'Deaf Parents-Hearing Children: Toward a greater understanding of the unique aspects, needs, and problems relative to the communication factors caused by deafness'. Here, Bunde carried out large-scale research on adult hearing children of deaf parents. Through his work, as a minister of a local church, he had come into contact with many deaf parents with hearing children and noticed many aspects of communication that put Deaf parents at greater disadvantage, hence the title. Preston (1994) acknowledged that Bunde's work "represented an important first step in delineating some features of this population and in suggesting future research directions"

Clearly, this research provided useful insight, however it was carried out on both Deaf parents and their adult hearing children thorough mail survey. There are questions concerning how the survey was designed and how the sample was selected, as it was 'largely derived from persons who work as interpreters' (pg. 22, Preston, 1994). Information that was gathered from the deaf parents was subsequently shared and discussed in the group of adult hearing children of the deaf parents, whilst the deaf parents shared the information from the adult children. This approach was seen as a good idea but because the current research is of a very small scale it therefore has only one focus: Deaf parents and their experiences. Thus, it is important to be aware of the limitations of the scale of the research, such as not being able to interview both the deaf parents and their children and adopt Bunde's approach.

Nevertheless, Bunde had still made some important points and these were certainly relevant to the current research. For instance, Bunde acknowledged that many families of Deaf parents with hearing children felt isolated, thinking they were the only ones with problems and 'thus frequently postpone seeking help until a crisis has developed' (Bunde, 1979). However, it is important to be aware that the research was carried out over 22 years ago, and as far as the literature search went, there was no other similar research carried out following up Bunde's work. There have been many changes since Bunde's report came out and they include:

- changes in advanced technology, especially with communication: such as the increased growth of ASL sign language interpreters available, captioned programmes on TV, videos and DVD, the use of TTY/Minicom (electronic text phones for deaf people using telephone lines), the global use of computers including emails and the Internet.
- 2) changes to legislation, including the American Disabilities Act 1990, which strengthens the rights of deaf people, along with other disabled people, to be included in society as full citizens requiring service providers to make their services accessible to Deaf and disabled people.

Therefore, this report will aim to highlight the findings and to conclude whether the issues affecting Deaf parents are the same as those found in Bunde's report 22 years ago.

There remain many stories/cases which have gone unreported of Deaf parents and their experiences of parenting, lack of access to needed information and services (including access to parenting classes, ante-natal classes; information on pregnancy, parenthood and child developmental stages) (See proposal in Appendix 2). A one-year study carried out by Preston and Lou (TLG, 1997) on Intervention Models for Deaf Parents and their children proved useful as an insight on issues faced by high-risk families with deaf parents. The study took place as a result of undocumented cases of deaf parents who were generally seen as 'unfit' parents and which resulted in inappropriate intervention from professionals and hearing members of the extended families. Preston (TLG, 1997) explained, "Many deaf parents have raised their families successfully and are inappropriately stigmatised because of misguided presumptions about their parenting capabilities. However, some deaf parented families are vulnerable to dysfunction, child abuse and/or neglect because of risk factors comparable to those within hearing families...for those deaf parents who need information or services, resources are virtually non-existent"

Clearly, in light of the review above of previous research/literature, the current research can be seen as unique and as one subject that has received little attention from previous research and literature.

Pilot Research in UK

Also because of the insufficient literature on Deaf parenting, a pilot study was done in the UK with a view to identifying further information and resources on Deaf parenting before embarking on the current research.

The study took place using a short simple questionnaire (see appendix 1), which includes a section on resources. There is a specific question asking people whether they are aware of any existing research/materials and books on Deaf parents. The questionnaire was circulated at one Deaf event, and distributed on a Deaf website where the questionnaire could be downloaded and printed out before completing and posting it off.

18 questionnaires were completed and returned (see result on Appendix 2). Yet, only 33% suggested materials from a few Deaf organisations namely:

- Bristol Centre of Deaf Studies, which is doing a research project on deaf children who are
 in need of short breaks/respite care, with a view to developing services including
 recruiting Deaf Carers.
- National Deaf Children Society, London, which provides a range of services to deaf children and their families where many of the parents/siblings, are hearing.
- British Deaf Association, London which provides a range of services to Deaf Adults and
 has produced an information pack 'Deafinetly worth thinking about' (BDA, 1997). Some
 of the leaflets in the pack include a 'Deaf Mother's View' on her child's education,
 'Hearing Children of Deaf Parents' often referred to by the acronym CODA, Children of
 Deaf Adults and 'Deaf Adults in the School Community' where Deaf adults can be seen
 as positive role models for deaf children.
- Forest Bookshop, which sells books, CDs etc on Deaf-related issues. Many of their books/materials on children & families are geared more to hearing parents of deaf children.
- Local library, which provides books on loan.

Clearly, at these stage, insufficient information is available on Deaf parenting, however the pilot study proved useful as it enabled the researcher to have a fuller picture of Deaf parents in the UK and their experiences in terms of raising their child and their future family planning.

1.5. Project Target & Methodology

Leaving apart the above pilot study undertaken in the UK, the actual research design, at the beginning of the research project, required lots of planning and liaison with Paul Preston and Nancy Grant providing useful guidance.

With the aims of the project in mind, even though it was a very small-scale study, it was originally thought that the research interviews would be carried out with three focus groups.

The first focus group, interviewing **young Deaf adults** aged 14/16yrs onwards. It was considered that the interview would be in the form of a group-work exercise involving those who were not yet parents. The exercise was to find out the group member's views in general on their future, focusing on careers, marriage, family life and how they would feel about becoming a Deaf parent – assessing their level of awareness and knowledge of sex education.

The second group, interviewing *Deaf adults*, who were pregnant and/or had children, to find out their experiences of being a Deaf parent, to assess their level of awareness and their access to services.

The third group, interviewing **Deaf Senior Citizens** (aged from 50 years onward), who had grown up children, on their experiences of being a Deaf parent. The aim of this interview was to find out about their experiences of parenting and their access to services and look at how these have changed over the years.

However, it was realised over a period of time during the project, that the timescale was very limited and that it was not realistic to carry out interviews with all three separate (though important and inter-related) focus groups. In the end it was thought that the young Deaf

adults, who were not yet parents, would not be interviewed since they had no relevance directly to the issues of Deaf parenting. In addition, for this group, parental permission was legally required for the workshop, since the young Deaf adults were under 18yrs of age. Instead of disregarding this group altogether, it was thought best only to consider the young Deaf adults who were pregnant instead and to include them as part of the focus group of Deaf parents who were pregnant and/or had children. As a result, two main focus groups were established, one of Deaf parents with young children (including those who were pregnant) and the second focus group of Senior Citizens/Deaf parents with grown up children. To avoid confusion, the terminology used throughout the project for the two groups, Deaf parents with young children and Senior Citizens/Deaf parents with grown up children is *Deaf parents* and *Senior Citizens* respectively, unless otherwise specified.

The Process of the three stages:

The first stage: The first few weeks of the placement were spent networking and visiting various agencies within the San Francisco Bay Area. It was important to carry out this first stage, in order to understand and assess, in general, the level of services available to Deaf people (including Deaf children of Deaf/hearing parents). It was during this process that many Deaf people, including young Deaf adults were identified. Those identified were either pregnant and/or parents with Deaf/hearing/disabled children and gave their contact details including email addresses as a main point of contact.

56 Deaf people were identified as parents, including 19 senior citizens with grown up children and three young Deaf adults who were pregnant. The parents were from various racial/ethnic groups and from various geographical backgrounds within the Bay Area. As a result, these parents were seen as a large sampling frame. Criteria were established in order to select approximately 10-12 Deaf parents. In order for Deaf people (excluding Senior Citizens) to meet such criteria, they had to be:

- 1) A Deaf parent and/or a pregnant mom-to-be (minimum age 14+)
- 2) With a child aged 0-11yrs old
- 3) And the child must live with the Deaf parent in their own home.

The list of criteria was important for the selection of Deaf parents, but it did not specify mother or father, it could be either or both, it was left open. However the wording, pregnant mom-to-be clearly had a gender bias, as it is only women who physically go through the pregnancy stage. However, the interview itself was open to either parent (including those who were pregnant) or both, as long as they met the above criteria.

Secondly, the child's age group was restricted to 0-11 years old for the following two reasons:

- a) it was vital to find out about Deaf parents experience during the time the child first goes to school, in order to see whether there were any issues around communication between the parent and the child's school. The child usually attends their first school between the ages of 5-11yrs old.
- b) And, the TLG's current research project on Disabled Parents with Teenagers will be interviewing Deaf parents with teenagers (aged 11-17yrs) in the summer of 2001. Therefore, it was not a good idea to overlap/duplicate work with TLG in interviewing Deaf parents.

Finally, a comment on the criterion, which says that the child must live at home with their Deaf parents, it was discovered after meeting parents identified during the first stage that quite a number were separated or divorced and did not have their child living with them all

the time.

Emails were the preferred means of communication for most parents, for the rest of the parents, letters/telephone calls via TTY (textphone) were appropriate. Contacts were made with 37 Deaf parents (not including the 19 Senior Citizens), asking if they were still interested in the project and asking for basic details to be provided, including the ages of their children. Also if the child was more than the 11yrs of age, the parents were then asked if they were interested in having their names referred to Paul Preston, for TLG's future research on Deaf Parents with Teenagers. If the child was grown up, then the parents were re-grouped into the second focus group of Deaf parents with grown up children.

There were 37 Deaf parents from the responses received, of which only 46% (17) met the criteria. This included the young Deaf adults identified during the first stage. Of the 54% (20) parents who did not meet the criteria:

- 70% (14) were identified as having teenagers and gave permission to be referred to Paul Preston for TLG's research on Deaf parents with teenagers
- 15% (3) were identified as having grown up children and re-grouped with the Senior Citizens Focus group.
- 15% (3) were identified as Deaf parents but because of their circumstances their children were not living with them. One of the parents mentioned that he had his children staying with him every fortnight for a weekend and this was not sufficient to meet the criteria.

The second stage: was to carry out interviews with the 17 Deaf parents already identified from the first stage. The research method chosen was by interview, in the form of an in-depth semi-structured questionnaire on a face-to-face basis. There were reasons behind choosing this method. Previous research and the past experiences of the current researcher showed that posting questionnaires to Deaf parents (i.e. postal survey), for many Deaf parents would not be an efficient method. There were two main reasons:

- Taking into account the many deaf people, fluent in ASL, who may have limited access to English and the diversity of deaf people from various communities whose first language may not be English.
- The questionnaire itself was designed to get in-depth information; as a result it was lengthy with a mixture of open and closed questions.

It was also highly likely that on receiving the questionnaire, parents would be de-motivated by its length. They may have been tempted to write simple rather than the in-depth information required for this research. The length would also be likely to result in a low response rate. (Chowdry, 2000b)

Whilst designing the questionnaire (see Appendix 7) it was important to obtain comparable factual information from the respondents (namely Deaf Parents). The questions types from the pilot study held in the UK (see appendix 1) and the framework of questionnaires used by the TLG's Disabled Parents with teenagers were considered and used as guidance. The final questionnaire (see Appendix 7) asks for in-depth information about their parenting experiences dating from the time the pregnancy was discovered, with an emphasis on the final stages of pregnancy, to the period of raising their child. It aimed to assess the level of access to information/services. The questionnaire was carried out by face-to-face interview and invited reflection on their previous experience, asking them to give opinions on parenting, their support network of family, friends and agencies, their education prior to

becoming a parent and their access to information/ services. Furthermore, while the majority of the questionnaire applies to all Deaf parents, there was a section on pregnancy that was devoted to Deaf Parents who were expecting a child for the first time.

With the questionnaire tested and approved, a letter requesting the parent's permission for young Deaf parents (under 18yrs) to participate in the interview was sent out (see Appendix 5). Once the letter was signed, further contact was made with all 17 Deaf parents to set up interviews. Prior to commencing the interviews, a consent form for the interview had to be signed (See Appendix 6 for Deaf Parents under 18yrs at school at the time and Appendix 7 for Deaf parents). The whole process of continuing contacts with the 17 Deaf Parents resulted in:

- 41% (7) interviews successfully completed
- 6% (1) interview half completed
- 12% (2) interviews, which were arranged but didn't take place/no longer interested
- 18% (3) interest in participating in the interview but unable because of difficulty in arranging appointments at a time to suit both parties.
- 12% (2) no response to the second follow-up and subsequent contact by emails/TTY
- 12% (2) interviews arranged but cancelled. These were at the last stage of their pregnancy and had to be detained in hospital as a safe measure. Hence it was not appropriate to pursue further, for they had to concentrate on their health and the well being of their baby.

From the above, eight Deaf parents were interviewed. The eighth person was unable to complete the follow up session on two occasions because she had to deal with an emergency at work both times. Because of the tight schedule, completing 8 whole interviews, it was not possible to arrange a follow up session for a third time. Therefore it was considered unsuccessful and not included with the seven completed interviews.

The third stage of the proposal (see Appendix 2), depending on the schedule, was to interview Senior Citizens. During the research there was a short space, so the third stage was carried out in form of a workshop.

Twenty-two Senior Citizens were identified from the first stage and were contacted by email, with an invitation to participate in a workshop on two dates at two different Deaf Centre locations. The locations were chosen out of a mutual convenience, as they were well known to the Senior Citizens for weekly activities. As a result, altogether 59% (13) of them attended, including 41% (9) who came on the first date and 18% (4) who came on the second date. Like the Deaf parents, the Senior Citizens were required to sign a consent form before participating (see appendix 9). Both of the workshops were facilitated by the researcher, and discussion took place on the common themes/issues that came up from the interviews with the Deaf parents. Senior Citizens were invited to reflect on their experiences of parenting and their access to services and on how things had changed over the years. They also offered their advice to younger parents and made suggestions for improvements on service delivery. At the end of each workshop, the Senior Citizens were given a simple questionnaire to complete. The simple questionnaire consisted of basic information about themselves, their awareness of information/resources in the Bay Area and an evaluation of the workshop (see Appendix 10).

Issues on Research Designs

Numerous issues came up whilst deciding on the research method i.e. the semi-structured questionnaire interview and whilst carrying out this research project:

- 1) Differences in the systems for providing services: Gaps in literature on Deaf parenting highlighted by the previous research/pilot study and previous work the researcher did with some Asian Deaf women who were pregnant (see proposal in Appendix 2) formed the basis for the research design. However, the systems, agencies and services in the USA and UK are different, for example many of the social services provided by USA are under voluntary organisations. Those same organisations are listed under the information/resources section separately from the Social Services (also listed under this same section!). This created some confusion during the interviews since many of the Deaf parents (respondents) thought the Department of Social Security meant welfare benefits.
- 2) Attempts to cover all issues of parenting: It was during the process of designing the questionnaire to be used as interview, that this was seen as an important element of the research. Also, because the research was new and seen as one of the first to focus on the issues of Deaf parenting, attempts were made to cover all issues of parenting. Issues included: looking at the relationships that the Deaf parents had with their own parents, the type of education they had during their childhood before becoming a parent, their relationships with their own children and their access to information/services. Being a parent meant from the time the Deaf parents discovered their first pregnancy to the time of raising their school age child (of under 11yrs). Obviously, this resulted in a very lengthy questionnaire. All Deaf parents were informed that the minimum length of the interview would be 2-3hours. This often required more than one session at a time at their convenience. An evaluation of the interview was included in the questionnaire, as their feedback on how the interview was carried would be invaluable and enable the researcher to improvise where appropriate in subsequent interviews. For example, the first parent, like all the Deaf parents interviewed, found the interview extremely valuable as it helped her to recall information she thought she had forgotten. However because, she live far (not easily reached by public transport), it was extremely difficult to schedule another session. It was agreed to complete the interview in one long session, this stretched from the planned 3 hours into 6 hours (no video camera was used). As a result, she admitted during the evaluation, that the interview was a bit too long, and suggested that in future interviews that parents complete the simple questions themselves. She realised the benefit of having a video camera to record the interview because she had to wait for the researcher to write things down before proceeding with the interview. Though she made some good points, it was not possible to ask parents to complete the questions themselves. However the use of video camera was encouraged, (and, obviously, with the parent's permission) it became integral part of the interviews. In most cases, it speeded up the process to varying degrees, (depending on the pace of each individual). Clearly, the evaluation had served as a useful and important tool for future research design.
- 3) *Confidentiality*: was a big issue throughout the research because of the depth of the questions asked during the interview. It therefore had to be considered at all times. However, the researcher was consciously aware (bounded by social work ethics and values) and throughout the project, reassured the parents. Such reassurance was made directly through ASL and prior to the first day of interviewing, parents were required to sign a consent form (See Appendix 4 & 5). They were also informed, at the start of each

interview, about the confidentiality of the interview. Every effort was made to make them feel comfortable during the interview and they were empowered to skip over questions that they were uncomfortable with.

- 4) *Means of Recording information:* Furthermore, because of the lengthy questionnaire, the interviews took longer than expected. The use of a video camera was an issue and teething problems were expected. However, Deaf parents were offered the opportunity of accepting or declining the use of the video camera as a means of recording data. In fact it was no problem, all the Deaf parents accepted it as a means of speeding up the interview. Like the above issues on confidentiality, parents were happy to be videoed. Also because the interview was conducted in ASL, the researcher had 6 weeks to master the language (Chowdry, 2001a) and needed to double-check what was being said during the interview to avoid any misunderstanding. Therefore, in addition to the written keynotes on the questionnaire during the interview, playbacks of the videotapes were used to doublecheck the notes for accuracy and ensure the validity of the research. In addition to the one-to-one interviews with Deaf parents, the video camera was used to record the discussion during the workshop session with the Senior Citizens (they were required to sign the consent form too). Clearly, it was an advantage using the video camera, it was a great support during the interviews and meant the workshop with the Senior Citizens went without interruption. However, the down side of using the video camera was the writing up of transcriptions and data analysis from the video, which was time-consuming.
- 5) Difficulty of including all the information collected. Finally, the lengthy questionnaire, covering a broad range of issues on Parenting (see item 2 above), resulted in much information being collected. The data from the closed questions was easy to organise, it was the open-ended and in-depth responses of the Deaf parents experiences that were difficult to categorise, as every individual had their own different life experiences. All the information was valuable and it was better to have more information than needed rather than insufficient information. However, it was not possible to include or summarise it all for this dissertation, but the information will still be useful for future writing up after the dissertation, maybe in a book or an in-depth report!

SECTION 2: Deaf Parents & Senior Citizens: Key findings (general):

This section focuses on the statistical information collected from the interviews. Figures 2.1-2.10 (Deaf Parents) and 2.1a - 2.10a (Senior Citizens) describe the personal, social, cultural and communicative characteristics of the research sample in relation to:

- Gender (Fig 2.1 and 2.1a)
- Age (Fig 2.1 and 2.1a)
- Race/Ethnicity (Fig 2.2 and 2.2a)
- Religion (Fig 2.3 and 2.3a)
- Preferred Language used (Fig 2.4 and 2.4a)
- Parents & Siblings (Fig 2.5)
- Children (Fig 2.6 and 2.6a)
- Language used with their parents/siblings Fig 2.7 and 2.76a)
- Language used with their deaf/hearing children (Fig 2.8 and 2.8a)
- Educational Attainment (Fig 2.9 and 2.9a)
- Current employment and/or educational status (Fig 2.10 and 2.10a)
- Awareness of Services on Deaf parenting (Fig 2.11 and 2.11a)
- Awareness of research projects/ materials/ books on Deaf parenting (Fig 2.12 and 2.12a)
- Information, they wished they had, when raising their children (Fig 2.13)
- Information, they requested on raising their children (Fig 2.13a)
- Preferences regarding information format (Fig 2.14 and 2.14a)
- Preferences regarding information to be available through the computer (Fig 2.15 and 2.15a)

Illustrations taken from the interviews with Deaf parents and Senior Citizens are presented in italic type. Further analysis of these figures, supplemented by examples from the in-depth interviews with Deaf parents are revealed the following findings:

- All of the Deaf parents are female with 57% of them married or with a partner, whereas the Senior Citizens had a majority of females (69%), more than half of the Senior Citizens are married or with a partner, while 39% are not (31% divorced and 8% widowed).
- The majority of Deaf parents were from European American (43%) and Latin American/ Hispanic (29%) background. The Senior Citizens showed a similar pattern (see Fig 2.2&2.2a). An unusually high proportion of these identified themselves as Native American (40%) as compared White American (23%) and European American (15%). This may suggest confusion between the two classifications of Native American and White American.
- The majority of Deaf parents live in a suburban area (71%) and a relatively equal proportion of them either live in privately-owned accommodation (43%) or rented accommodation (43%). The Senior Citizens though, showed a different pattern, living in a large city (56%) and in a suburban area (23%). They are more likely to be living in privately-owned accommodation (69%) as compared to 15% in rented accommodation.

• Both the Deaf Parents and Senior Citizens showed similar patterns regarding religion (see Fig 2.3&2.3a)). 43% of the Deaf Parents reported that they are not actively involved in religious activities, whilst 29% attends on weekly basis and 14% attend on special occasions.

"I used to go to church with Deaf friends but now, very few of them goes to there. So now, either Mum or myself would only take my children to the Sunday school, but only if their friends goes there"

Deaf Parent with 2 hearing children.

• Though all of the Deaf Parents (100%) and 85% of the Senior Citizens identified themselves as 'Deaf' compared to Deafened (15%). 29% of the Deaf parents were born deaf to a hearing family and have deaf siblings, thus have a Deaf identity. Another 29% of Deaf parents were born deaf (including hard of hearing) and yet another 29% became deaf at a very young age, equal proportions of Deaf parents but identifying themselves as Deaf for different reasons. 58% of all Deaf parents grew up orally in a hearing family, and it wasn't until they were in their teens/early twenties that they adopted their Deaf identity.

"I'm Deaf but other people often seen me as Hard of Hearing because I spoke so clearly that they didn't realise I'm really Deaf"

Deaf parent from a hearing family with Deaf/Hearing siblings

"I was born Hard of Hearing but became deaf at age of 3years. I grew up orally however I believe I'm culturally Deaf. That is because I faced the same challenges as other Deaf people i.e. Communication with hearing people...and despite this, I have strong Deaf identity...I went to hearing school with Deaf program and met lots of Deaf kids there and mixed very well with them. I don't call myself Hard of Hearing because I don't have the 'issues' that hard of hearing people have i.e. limited social skills, isolation with deaf and hearing people etc'

Deaf parent from a hearing family with hearing siblings.

"Me, born deaf and happy with Deaf identity. My parents tried various treatment to make me hearing when I was young but when I got older, I told them that I'm happy being Deaf and didn't want any treatment i.e.: cochlear implant in [Asia].

Deaf parent from a hearing family with Deaf/Hearing siblings

• Senior Citizens showed similar patterns on Deaf Identity, and there are significant numbers of them mentioning ASL as one of the factors for self-identification.

"Being a proud Deafie!"

Male Senior Citizen from a hearing family with Deaf/Hearing siblings

"Born deaf and brought up as an oralist. Started ASL at 16yrs old and an advocate of ASL!"

Male Senior Citizen from a hearing family with hearing siblings

"I grew up orally and learnt ASL later in life."

Female Senior Citizen from hearing family with hearing siblings

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"[Came from a] six generation of deaf families including deafened and Hard of Hearing"

Female Senior Citizen from Deaf/Hearing family with Deaf/Hearing siblings

- While the majority of Deaf parents and Senior Citizens come from a family where their parents and siblings are hearing (57% & 62% respectively- see Fig 2.5), both groups generally showed a preference for American Sign Language (ASL). However, there was a significant difference between them (see Fig 2.4&2.4a), with the Senior Citizens tending to be using more ASL & English (69%) or English only (8%) as compared to using ASL only (23%). Whereas the Deaf parents prefer to use ASL only (71%) as compared to ASL& English (5%) and English only (5%).
- In addition to the above, it was also found that 31% of the Senior Citizens have Deaf siblings in their families with a further 39% of them with Deaf members in their extended families. Only 8% had one Deaf and one Hearing parent. The majority of the Senior Citizens' parents/siblings used spoken English with them (33%), though this is not a good indicator of the fluency of such communication. The Senior Citizens reported that it was often a mixture of a spoken language, either English or another language with visual cues such as home signs/gestures (24%), fingerspelling, lip-reading and written English (see Fig 2.7a).

"All my family were influenced by A.G Bell's oral program [at the time this prohibited the use of ASL & marriages between Deaf people]"

Female Senior Citizen of Deaf/Hearing family with Deaf/Hearing Children

"Before I went to school, all [of my family] used home signs [to communicate with me] but when I started school and learnt English, then they [my family] all stopped using home signs and used written English instead".

Female Senior Citizen of hearing family with hearing siblings

• Likewise, the Deaf Parents showed a similar pattern but with a broader range of methods of communication with their parents/siblings, (see Fig 2.4). A significant number of parents/siblings were using spoken languages such as English (26%), Spanish (16%) with the siblings more likely to use the visual languages such as ASL (21%) and Asian Sign Language (11%). Furthermore, there was less need for visual cues i.e. home signs/gestures (5%) to supplement such communication between the Deaf Parents and their parents/siblings. This was due to the increased use of 'Total Communication' (a mixture of spoken language and sign language).

"I communicate fine with my family, but mostly it was on a one-to-one basis. We spoke in English and never used ASL or any home signs/gestures. Especially in the family/ group discussion, it was very hard to communicate with them as I didn't understand what was happening"

Deaf Parent of hearing parents with hearing siblings

"Being an eldest child, I was brought up orally but once I learnt ASL from school, I taught to all my brothers/sisters and now we use ASL fluently. My parents still spoke orally and if we use ASL in front of them, they told us to use Total communication instead for their sake!" Deaf parent of hearing parents with Deaf /hearing siblings

• Whilst the majority of Deaf Parents and Senior Citizens are from hearing families, they also raised a family of their own, with a high proportion of their children being hearing (75% & 71% respectively - see Fig 2.6&2.6a). Deaf Parents were more likely to communicate with their children using either Total Communication (43%) or ASL on its

own (28%), compared to Senior Citizens who used more of ASL & English (54%). Though the Deaf parents used the term 'Total Communication' more often, they argued that Total Communication and ASL & English are both seen as relatively the same!

"Using a mixture of ASL and, ASL & English etc. Really... it depends on the child's needs. If I talk to my Deaf child, then I would use ASL only, but to talk with my children, one is hard of hearing and one is hearing, then I would use spoken English and we can lip-read each other."

Deaf parent with Deaf/Hearing children

"I use ASL only while talking with my Deaf child, and use ASL & English while talking to my hearing child"

Senior Citizen with Deaf/Hearing Children.

- Equal numbers of Senior Citizens (38%) either went into *Deaf education* (attending Deaf day/residential school, Deaf College and Deaf University) or into *Deaf and mainstream education* (Deaf day/residential school and mainstream College and University). 15% had a mainstream education. Out of those who had Deaf & Mainstream education, some received communication support and some went without yet 53% of them achieved beyond the AA degree level.
- On the other hand 71% of Deaf parents went into Deaf & Mainstream education. These included 29% who had an ASL interpreter all the way through and 29% who had no communication support and went without an ASL interpreter until college/university. None of the Deaf Parents attended Deaf education and 29% went into mainstream education, they only had communication support through college/university. Similar to the Senior Citizens, 57% of Deaf parents achieved beyond the AA degree level. (See Fig 2.9&2.9a)
- Just under half of the Deaf parents are in full time paid employment, whilst the rest (57%) are working part-time, still in education or staying at home as a parent to care for their children (see Fig 2.10). This includes one Deaf parent who does both at the same time working part time while pursuing further education. Only 57% are in receipt of more than \$1300 a month household income, while the rest receive \$900-\$1000 a month (29%) or below \$500 a month (14%), in addition to their receipt of state benefit, Social Supplementary Income (SSI) & MediCal (health insurance for low income). Almost all of the Senior Citizens, in contrast, are retired, with 29% of them continuing work on a voluntary basis and 14% are not retired but unemployed, seeking work and also pursuing further education.

SECTION 3: Deaf Parents & Senior Citizens: Key findings (Services):

The in-depth questionnaire given in Appendix 7 was used as a guide for interviewing Deaf Parents and the Senior Citizens in the workshops. This was done to discover experiences and common themes relating to information, awareness and access on:

- Parenting
- Health Care (during pregnancy and birth)
- Education
- Awareness of Other Agencies
- Request/Suggestions for Information and services

With reference to the following themes of:

Communication, Support Network, Gaps in information and services, advice for future parents

- Awareness of Services on Deaf parenting (Fig 3.11 and 3.11a)
- Awareness of research projects/ materials/ books on Deaf parenting (Fig 3.12 and 3.12a)
- Information, they wished they had, when raising their children (Fig 3.13)
- Information, they requested on raising their children (Fig 3.13a)
- Preferences regarding information format (Fig 3.14 and 3.14a)
- Preferences regarding information to be available through the computer (Fig 3.15 and 3.15a)

3.1 Parenting:

- A majority of the Deaf parents came from hearing families, and while the rating system on relationships ranges from poor (1) to excellent (5), all of them rated their relationships with their families between average and very good (see Fig 3.1). They all explained and felt that support and communication were the major factors in rating their relationship.
- Many indicated that they had received lots of support during their childhood and throughout their pregnancies. A significant number of them felt closer to their mothers and siblings, as a result of such support.

"I talk to my mum about anything...also my sister was very supportive during my pregnancy and always interpreting for me"

Latin American/Hispanic Deaf Parent of hearing family with hearing siblings

"All our family are very close, we talk about anything, we care very much for each other. Mom is always supportive, interpreting for me and taught me values...Dad is soft-hearted, often worried about me and making sure I'm ok."

Asian Deaf Parent of hearing family with Deaf/hearing siblings

"With my mom, I'm very close to her. She was a single parent and brought us up single-handly. Now I'm a single parent, Mom helped me a lot with all of my pregnancies. However, she moved out of state so we are not as close as before, but still keeping in touch regularly."

Euro American Deaf parent of hearing family with Deaf siblings

"I rated my parents as average. For Mom, that was because she get worried or overwhelmed so easily. She also misunderstood everything and get frustrated easily too. Therefore, I had to be caution, only sharing appropriate information with her on the need-to-know basis. On a positive side, she was very resourceful and always making sure I had good education. As for Dad, he was a disciplinarian, gave me a physical punishment when I was young. He was very strict and was always working. He was never at home, Therefore, the family environment at home was poor. But now, Dad is more supportive, especially when I went through my divorce.

Euro-American Deaf Parent of hearing family with hearing siblings.

• In addition to the above, Fig 3.1a have indicated that all Deaf parents are more closer to their children, rating their relationship as 'excellent' as compared to their relationship with their parents. Many explained the importance of being close to their children and are very actively involved in their lives.

"We are very close family. My first kid is interested in sport so I encouraged and supported him to sign up for activities. Same goes for my second kid who is very much into music and drama and I supported her..."

Deaf parent with hearing children

"I say all my relationship with my kids are all excellent! I just love them all! Really, all of my children have very different characters. My first kid always tells me everything and anything that bothers him. My second kid is more easy-going and laid-back, affectionate and loves sport. My third kid is very cute and chatty and always wanted to get lots of attentions"

Deaf parents with Deaf children

• While, many parents learnt or became aware of the parenting role when they became a parent, some Deaf parents found their experiences of caring for their siblings a useful source for gaining parenting skills as one explained:

I remembered when I was 16/18yrs old. I was very close to my youngest deaf brother who was about 10 years younger than I was. At one time, he was suddenly became very seriously ill and remain so for the next 4 years. As I was already so close to him and because my parents were elderly, I told my parents that I will become the main carer and cared for him like he was my own child, 24 hours a day for a long while until I got married. So, the experience of caring for him, with my family values influenced on how I cared for my own children."

Asian Deaf Parent with hearing children.

Like parents in general, both the Deaf parents and Senior Citizens shared the same feelings of anxiety and excitement when bringing baby home, and also shared the common concerns around whether they would make a good parent. While the majority of Senior Citizens received no support in the home, many Deaf parents reported that they got support from their mother or their partners. However, both groups said that they managed just fine, but there is still a lack of peer support and social networks for Deaf moms as one Deaf parent explained:

"It was fine, no problem. Enjoyed looking after my baby very much. But one problem – there was not many Deaf moms around here. I knew of one Deaf mom but she lives far away. So I just turned to my mom for support instead."

Another Deaf parent added: "I relied on my mom for support through pregnancy and after birth as we (my husband and I) were living with Mom through the first eighteen months [temporary accommodation]...I was isolated and knew no-one in the area."

• One Deaf parent managed to obtain information from her friend on Parenting Class, thinking it was a perfect source for support but it was not enough, even without any sign language interpreter provided as she explained:

".....I thought [it was] all Deaf [parents] but turn out to be all hearing [parents]. I was disappointed as I couldn't understand what was happening....been thought that there should have been a sign language interpreter there but nothing..."

Deaf parent with three hearing children

• Almost a half of Deaf parents received information and support from their doctor on Parenting and reported that it was very basic information on the pregnancy stage. In addition, almost three-quarters of both the Deaf parents and the Senior Citizen had no information or knowledge of the whole process in raising their first child, particularly the Senior Citizen who reported they had no Sex Education at school. And though, all reported that they experiences varied a lot between each child, but they felt calmer and know what to do and learnt so much from their first experiences. As a result, they felt an increased sense of confidence when having their second or subsequent child as it became easier for some of them:

"I felt more experienced. I knew exactly what to do and what to expect during the pregnancy stage....my experiences of pregnancy onto the labour/birth was very much the same as I had with my first child"

However, the experiences are not always the same, especially if there is a change in circumstance. One parent explained:

• "When I had my first child, I was married and had support from my husband and my mother in law. By the 3rd child – I was divorced. I had to adjust myself to being a single parent and was very lucky to have had support from a very good friend of mine. When my 3rd child was born, he was born too soon and as a result, he swallowed some fluid from the womb, which can be very dangerous. I was lucky that he survived"

3.2 Health Care

- All of the Deaf Parents and most Senior Citizens reported that though their pregnancy were not planned, all of them were shocked after completing self-pregnancy test and later confirmed by local doctor. A small proportion of them was unhappy and upset and was offered the option of having an abortion. One had an abortion while one of the others, after a long thought and under pressure from her family, she decided against it, all of them reported that they had very little or no information or support from any health care professionals.
- More than half of the Deaf parents had normal worries as expected to the general population, on their pregnancy. Such concerns they had included the process of going through the labour and birth, feeling scared of the pain, unsure of what are the best methods or choices available on pain reliever and the birth, and more importantly, the concern of the baby's health & well-being throughout the pregnancy.

[&]quot;Oh yes, I was so worried because I had no knowledge at the time, of how pregnancy works."

I had no knowledge of English and ASL, having come to this country a year before the birth of my child, so I didn't have any access to information".

Asian Deaf Parent with two hearing children

"I was so worried because I was so ill for three months and had medication before I found out that I was pregnant [with my first child]. Does that means my baby will be affected by the medication and result in disability?"

Deaf parent with Deaf children

• And yet, with the above worries in mind and over half of them were not aware of any outside agencies for support. 43% of all Deaf parents reported that they turned to their local Doctor for support (some with the use of sign language interpreters or using a family member to interpret), while 29% prefers their husband/partners, parents/siblings (14%) and social worker (14%).

"My local Asian doctor for support. My relative found him in a large city [out of the state] and I used to live one and half hours away in other state, so I just relied on my relatives to support me, take me to all prenatal appointment with my aunty, not exactly as an interpreter but she was there to tell me what was happening.

Asian Deaf parent with hearing children

"I prefer my boyfriend because I felt so comfortable with him. He knows how I felt, we talk about everything"

Deaf parent, currently pregnant.

• All of the Senior Citizen, but one never attended the Antenatal/ Lamaze Class and only had basic information on pregnancy from their local doctor. However, they reported that they communicated with their doctor either by lip-reading/spoken English or writing everything down that was said and despite this, they found their doctor providing useful advice. Other source of support can be found from a well-known book, at the time, called 'Dr. Spock' which provided information and advice on pregnancy and parenting, a very popular choice among the Senior Citizens of all of them had treated it as their bible!

3.3 Education

• 85% of Deaf parents were generally informed on the key stages of child development. Most of them reported that they learnt from their area of work of which half of them works with children, and another half of them found out more information by reading a highly recommended parenting book entitled: "What to expect when you are expecting". "Though I am aware of the Child Development, but really, I knew very little. For example, at 6 months, a baby should start crawling, baby talk [babbling] and by Iyear old, the baby should start walking, you know. I just learnt a bit from my friends who are young moms as well as my teacher and my doctor"

Deaf parent, currently pregnant.

• From the interview with all the Deaf parents and the observation of their interaction with their children, all Deaf parents, even without realising, have showed clear awareness of their roles and working with their child, which is seen as very positive. They all have used all the relevant child behaviour management, for example: time-out, rewarding, talking with their child, open up communication with them, negotiating, explaining to the child of the reasons for their actions, finding out what wrong if the child get upset or angry etc. They raise their children with no problems, and are fully aware of their needs

for nurturing, emotional development and fully encourage all their children to participate fully with their education as all of them saw education as of an utmost importance for their children in term of their confidence, to gain their independence and to achieve whatever they set out to do.

"It was very important to explain to the children everything I do to them to justify my decision/action"

Deaf parent with three hearing children.

- A majority of the Deaf parents found it really hard to participate in their child's school (71%), especially the school events and keeping in contact with the other parents whose child goes to the same school as their (Deaf parents) children. This includes liasing with the (hearing) parents to arrange for children to sleep over. Many felt so isolated and as a result, become less involved in their child's school eg: as a board governor of the school or at least help out with the school activities. Half of the Deaf parents reported that many of those events were carried out without sign language interpreter, and as a result, the Deaf parents felt left out. However, at the same time, some Deaf parents felt that they didn't want to be a burden onto the school to provide interpreter as the money would come out of the school funds which the parents felt were really designed in educating the children.
- All of the Senior Citizens reported that they had little or no involvement with their child's education because of communication and there was no sign language interpreting services at the time. However, they believed that education was very important and as a result, they approached to education to have their children enrolled to nursery at the very early age of 2 years instead of the usual age of 3½ years old.
- Only 43% of the Deaf parents helped out with the school now and then, with the preschool classes, driving car/ bus whilst taking the children on trips and half of them have stopped now because of their work commitment and looking after their subsequent baby/children.

3.4 Other Agencies

Awareness of Services:

• More than half of the Senior Citizens and just over a quarter of the Deaf Parents were aware of the possible services/resources on Deaf parenting and suggested many places/agencies, particularly DCARA and UCCD, which provide further information/services to Deaf parents (see Fig 2.11&2.11a). There was a similar pattern showing the level of awareness on research projects/books/materials on Deaf parenting (see Fig 2.12&2.12a), with significant numbers of Senior Citizens sure that there were plenty of projects on the issues of Deaf parenting but were unable to recall the names (44%). However, a few Deaf parents (14%) suggested TLG for their research on Deaf parenting in high-risk families (TLG, 1997).

3.5 Access to information and Services

+

• The Senior Citizens reported, after discussion on the common themes, on the lack of information they had in their time. 46% of them looked back and wished they had more information on *Parenting* (46%), followed by the area of Pregnancy/Birth stages including: *Pregnancy* (38%), *Labour & Birth* (38%), *Antenatal/Lamaze class* (31%). The

information on Education was just as important for them including: *Helping your child to read* (38%), *Choosing the right school for your child* (38%), *Issues relating to the Nursery* (31%). This also applied to the other areas of raising the child in the home including *Child Development* (31%) and the technology to enable them to carry out their role as parents such as *the equipment for Deaf/Hard of hearing people* (31%).

- Deaf parents showed a similar pattern to the above, although fewer wanted information on the Lamaze Class, Nursery, and the equipment for Deaf/Hard of Hearing people. Though the range of information requested by Deaf parents was not as broad as the Senior Citizen, the information on Education was voted the most needed resource. For example, 86% of them said they wanted information and support in relation to *the issues arising from the child's school*, followed by *helping your child to read* (86%) and *choosing the right school for your child* (71%). This was followed by the need to know more about *child development* (71%), *parenting* (71%). More than half of them wished they had more information at the time on *Pregnancy* (57%) and the *Labour & Birth* (57%).
- Both Deaf Parents and Senior Citizens showed a similar pattern on their preferences for various formats in accessing the above information (see Fig 2.14 & 2.14a), with popular demand for hearing videos to be subtitled/captioned (77% & 100% respectively). However, because of the Deaf parents' preference for ASL, compared with the Senior Citizens' ASL & English, Deaf videos in ASL with Deaf people involved i.e. Deaf presenters was a favourite choice among the Deaf parents (85%) rather than the Senior Citizens (54%). The very same pattern applies to their choice on information in books (85%& 54%). They gave no indication of their preference in relation to the type/size of books and/or how they were presented i.e. visual or written or both.
- All of the Deaf parents were keen to have information on Deaf Parenting available through the Internet (100%), email (100%) and to have Internet chats (100%) with other Deaf parents as a means of sharing information and supporting each other (see Fig 2.15). 14% of them suggested the use of a videophone in addition to the Internet chat, as it provides an accessible means of communication with the other Deaf parents using their preferred language namely ASL. More than half of the Senior Citizens felt the same on the use of each facility- preferring to access information through the Internet (54%) and use Internet Chat (61%) to communicate with each other. However a small number of Senior Citizens reported that because they were new to using the computer, they preferred to receive information by emails only (30%).
- The Deaf parents had a various and individual experiences throughout their pregnancies and births. Many were positive and some negative but comparable to the general population. However, at some stages of their pregnancy and birth, some experienced complications but didn't have access to much needed and specific information currently available to the general population such as, pre-eclampsia/ectopic pregnancies, family planning, abortion, miscarriages, IVF, breastfeeding etc.
- Fig 3.4 showed that the Deaf parents had received a significant more information at the time when they had their recent child as compared to their first child.
- The majority of Deaf parents complained at the lack of resources for Deaf parents in general as one parent explained:

"I noticed that those Deaf parents with Deaf children already got support from one Deaf school's Early Learning Center for children aged 1-3yrs. In the Center, they also have a

parent support group for Deaf parents but it was designed only for Deaf parents with Deaf children. Therefore, if you are a Deaf parents with hearing children, then you can't access to the program or the parenting support group. As a result, you are isolated!"

- Whilst asking the Deaf parents what they would like to see available for Deaf parent, a majority of them preferred to see more support groups for Deaf parents to reduce isolation, have better access to parenting class especially the advanced level as existing Deaf parenting classes are very basic and doesn't cater for all Deaf people. Quite a number of them have came forward with one specific vision that they would like to see achieved for all future Deaf parents from all ranges of background. And that is a one-stop agency which can provide a variety of support and services to all Deaf parents including Deaf parenting class, support group, counselling, information and advice, peer support, social network, encourage hearing children of Deaf parents to mix together with Deaf children of Deaf/ Hearing parents, advocacy etc with view of expanding the services to a national-wide.
- As a small number of Deaf parents are young adult, and because they have different needs from adult Deaf parents. The young Deaf parent put forward suggestions for more information on teenage pregnancy, providing support to Deaf young parents as they felt the current general parenting information was too much focus on the adult whereas the information for teenagers were more geared on the prevention of teenage pregnancy, rather than providing useful information, advice and support to those Deaf teenagers who are already pregnant.
- Also a few of the Deaf parents reported the needs for more information for Deaf parents whose first language is not English or ASL as one Deaf parent explained:

"When I got married and moved to USA, I had no green card, therefore can't afford health care. So, when I got pregnant, I had to rely on my husband and my relative to pay for my health care through out my pregnancy and birth. I knew nothing of interpreting service and not even used ASL, but my Asian sign language. It was very hard and isolating for me and I want to see more Deaf parents from similar backgrounds to get the support they needs."

Asian Deaf Parent with hearing children

SECTION 4: Conclusion and Recommendation:

The overall research project have clearly indicated that the Deaf parents, like the general population of parents, are very much a capable parent who loves and nurture their children. They have gone through the experiences of pregnancy and raising their child, with lots of worries and anxiety that are similar to the general population. This had thus challenge the society's assumption that Deaf parents can't be a parent (Preston, 1994).

It is interesting to note that the difference in relationship rating between Deaf parents and their parents/siblings (mostly between average to excellent) and Deaf parents with children (almost all excellent). This may suggest that because of the Deaf parents' experiences with their parents/siblings, coupled with the oppression toward Deaf people within the society in areas of education, employment etc, they have forged a better relationship with their children. Furthermore, Deaf parents are communicating with their children in their first/preferred language (mostly ASL) and there was better understanding between them as compared to Deaf parents' level of understanding with their parents/siblings. Evidences of the Deaf parent's view in child's education as of an utmost important demonstrated that they wanted to bring the best in them with view of bringing them up to be a well-responsible citizen, contributing to the society as a whole.

Whilst for many hearing parents who were shocked to have deaf children, it took them a long time to overcome and to learn appropriate means of communication. However, for Deaf parents and Senior Citizen, a majority of them were not shocked (at least not beyond the initial shock/reaction) and accepted their child are hearing (even a few of them had Deaf children). These also challenge the assumptions of the society that to communicate with the hearing children of Deaf parents, it was best for Deaf parents to use spoken language, for that it would prevent the child's language development. While this is not the case, ASL is seen as a language in its own right There was no significant evidence that Senior Citizen and Deaf parents who use ASL with their children, that any of those child had any language developmental delay. These was due to the fact that they were able to pick up the auditory skill from the environment around them such as TV, radio, neighbours, hearing extended families, hearing friends, hearing school etc. In addition, because Deaf parents were able to communicate with their Deaf/ hearing children fluently, they were able to discuss anything and every thing, just in the same way as any other parents and their child communicate with each other in their own languages.

Furthermore, whilst there are evidence suggesting that Deaf parents had more information on pregnancy and parenting as compared to Senior Citizens, there is a consistent theme through out the research that the Senior Citizens are just like the Deaf Parents, capable of raising their own children. This is particularly true, for Senior Citizens have brought up their own children without much support or access to information and yet, their children have grown, well-educated, good employment, had family of their own and still maintaining close contact with them.

With the advanced technology developing in the last 20/30years, an increasing number of people are using electronic means of communication such as internet, emails, TTY (textphone), pager etc. For Deaf Parents, they found the technology, especially the equipment for Deaf/ Hard of Hearing people useful, particularly the baby alarm clock. Senior Citizens

explained that they were amazed by the changes and felt that the Deaf parents today are more lucky than they were at the time, for they had to rely on the home-made baby alarm to alert them if their child were crying.

There was also, no interpreting service in the old day, and many Senior Citizens relied on their family, neighbour and/or even used their hearing children to interpret for them. As a last resort, they had to use pen and paper to write down everything that is being said to facilitate the communication. With the Deaf parents today, it was interesting to find that many of them are aware of interpreting services and had access to them during their antenatal/lamaze class, labour/birth. These was because many Health services had contract with the interpreting services and are required to call out interpreter if Deaf person come in for an appointment. Bearing in mind of the national and international shortage of sign language interpreters, there was no indication on the length of time between the date of booking and the actual appointment and whether an interpreter can be found at a short notice i.e.: emergency. Though for many Deaf parents interviewed, had access to interpreter in hospitals, this may not always be the case for all Deaf parents in USA and in UK as there are cases of Deaf parents who went through their pregnancy and labour/birth without any access to communication.

As for the Education, the issues that Deaf Parents and Senior Citizens faces, in not being able to participate fully with their child's education or being involved with the child's school remains the same. Not only it applies in USA, but also it happened in UK, Australia and many part of the world. Preston (TLG, 1999) acknowledged: "...over the course of several research projects, deaf parents repeatedly told me how they're excluded from active participation in the hearing child's education. Many school systems never provide interpreters for routine parent-teachers meetings or other school functions. For their part, many school administrators are uncertain of their legal obligations to provide communication access to deaf parents". Bearing in mind that 90% of Deaf parents are highly likely to have hearing children and the fact remains that Deaf parents like the Senior Citizens will still be left out if something is not being done about it.

Communication is seen as one of the major central theme throughout this research, and not only this applies to the dialogue between the Deaf parents and the other person, but in term of access to information and services. The findings showed that the services to parents in general are made inaccessible for Deaf parents and thus put Deaf parents at a greater disadvantage, resulted in an increased isolation with no peer support, etc. Despite these, many Deaf parents had more resilience than any other parents, for they have coped and raised their children. Senior Citizen have also raised their children through the period of time where there were no support, parenting classes for Deaf parents, no advanced technology was available the time, and neither was the sign language interpreting services. Resilience is not the best answer as though many Deaf parented families have managed just fine, there are still many other Deaf parented families who would experience some forms of isolation, lack of awareness/understanding of parenting skills, difficulties in finding schools for their children, and thus may lead to family breakdown.

In these case, the suggestion from Deaf parents on the idea of having a 'one-stop' agency would be very useful as it can be seen as a central source of information and support for all Deaf parented families. This agency could provide a range of information on pregnancy, labour/ birth, parenting issues, child's education, advocacy, counselling, and even run various activities for all Deaf/Hearing Children of Deaf parents to encourage social network and peer support among themselves. Nevertheless, the fact still remain that there is a huge needs for

the information and services from Deaf agencies and the agencies for parents needs to be developed and more readily accessible to them all. Especially the existing resources that were given to all parents from mainstream agencies, especially in the UK, are not readily accessible to Deaf parents, i.e.: many of the parenting videos were not captioned nor have any BSL/ASL in them. The services providers would find the findings with the specific references on their level of awareness on services available in the Bay Area and the Deaf parents and Senior Citizens' preferences of how information should be developed and distributed, extremely useful whilst designing and developing services to Deaf parents.

In overall, it had been a very much worthwhile piece of research. There are few issues that came up during the research but the research method of interviewing Deaf parents and Senior Citizens were appropriate to the research. Like one parent mentioned in the methodology section that the interview itself was too long. Yes, it was the case and in addition to video recorded interviews, it took longer than expected and thus, became difficult to sort out the data and analyse them. It was thought that the research design of the questionnaire should be better improved and to be made shorter. Also because the Deaf parenting remains a broad subject to study, this research was hopefully seen as a successful attempt to cover as much as possible around the issues of Deaf parenting and to demonstrate how much have changed over the years between the Senior Citizen and the Deaf parents. In answer to that very question, some areas have changed in term of economic and social environments e.g.: technology advancement, the availability of interpreting services, the changes in disability legislation, more women into employment, etc but in term of services to Deaf parents, very little had changed!

Recommendation:

Though, this report can be considered as one of the first piece of research that focus on Deaf parents with children aged 0-11yrs. It is vital that the interest of Deaf parenting must NOT stop here, but the report can be used to encourage further research in this area. Furthermore, for the Deaf parents themselves and the services providers, should they require any further information in relation to Deaf parenting or similar issues, would find the resource list in appendix, useful and hope this would prove a good starting point! The following recommendation for further research are resulted from the issues arising from this research and some were suggested by the Deaf parents themselves in USA and in UK:

- 1. Information/ Services around Pregnancy, Parenting and especially Education should be made accessible format to Deaf parents, to enable and empower them to make choices and decisions that are affecting their and their children's life.
- 2. There are lots of interests from Deaf parents (including Senior Citizens) in USA and Deaf parents in the UK on fostering and adoption to care for Deaf children but no information are available. They are not aware where to go for information/advice.
- 3. There are lots of issues around pregnancy, especially the pregnancy complication many Deaf parents remains unaware on the risk of such complications
- 4. Whilst there are high percentages of teenage pregnancies in USA and UK, with high publicity campaign on the prevention of teenager pregnancies, there are still little or no information and support available to Deaf pregnant teenagers.
- 5. For all Deaf parents in USA and UK, they felt it is of utmost important to have social

- network of Deaf parents with peer support to reduce isolation and to encourage exchanges of information/ ideas on all aspect of parenting.
- 6. It is also important to ensure that all Deaf children and all Deaf/Hearing children of Deaf parents have opportunities to interact with each other and have access to social/recreation activities. In addition to Deaf Parents support Network, the idea for all children to get together and get peer support can be achieved by the creation of signing family support group where hearing families with deaf children can meet Deaf parented families with Deaf/ hearing children informally in safe signing environment.

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Appendix 1: Pilot Questionnaire for Deaf people in UK on Deaf parenting

	Gender:	Males		nales \square				
	hnicity: nguage used	Irish: BSL:		ite Jewish: □ ne specified: □		k African: □	None stated: □	
	You as a deaf p Are you pregna		,	Yes [] No			
If	ves, is this your ves, go to quest no, please cont	ion 2c)		☐ Yes ☐	No			
<i>b)</i> (Children:							
		mplete	the child	dren's details				
Ch	ild first name	Age	Gender	Deaf (Please tick)	Hearing (Please tick)	Other disabilities? (Please specify)	Does the child go to p group or school i.e. primary secondary?	olay o
1. 2. 3. 4.							•	
2. 3.								
4.								
Co	b) Do you h Family: □ Deaf organisa Hearing orga mment on ac	ation: [nisation] n: 🗆	ParentsInterprOther: □ pl	Il Services: □ s Group: □ eting Services	s: □		
	You are aYou have	aware of tware be access please s	of above so that you hat to above state:	ervices: d no informati services but the	on on how to hey are not de		ve services: □	
			20 40010					

experience of having your first child. 3) Are you having a first child? Yes: □ No: □ a) Do/Did you receive any information/ support on parenting? Yes b) If yes, who from? c) Are/were you anxious either about the process of pregnancy or the period leading up to the birth of your first baby? Yes \square d) If yes, where would/did you go for information/ advice/ support? e)Are there or were there any concerns around your child being born or later becoming: Deaf Yes No 🗌 Hearing Yes \square No \square With disabilities (if any) Yes \square No \square f) If yes, what are/were the concerns? 4) Not a parent? YES: □ *NO*: *□* a) Any issues or concerns if you or your partner decide to have children? YES: □ *NO*: □ b) If yes, what are the issues/concerns? c) Where would you go for information/ advice/ support? 5) If given opportunity to improve/ develop services for Deaf parents, what would you suggest? Comment to above services

For Deaf Parents only - You may want to complete this section if you can recall your

6) Resource	s:
-------------	----

a) Are you aware of any services currently available to Deaf parents in UK? YES: \Box NO: \Box

If yes, please list them

b) Any research project/ material/ books around Deaf Parenting? YES: \square NO: \square If yes, please list them and where they are based.

Appendix 2: The result of the Pilot Study

Result of the Pilot study held in UK

1) Gender: 7 Males 11 females

Ethnicity: Irish: 2 White Jewish: 2 UK: 12 Black African: 1 None stated: 1

Language used BSL: 17 None specified: 1

2) Already a parent? YES: 12

a) Deaf/Hearing Children? 11 parents have 22 hearing children between them and 1 parent has a deaf child.

b) Had access to or received support from:

• Family: 9

• Deaf organisation: **3**

• Hearing organisation: 1

• Council Services: 3

• Parents Group: 2

• Interpreting Services : 3

Other:

- Relatives: 3
- Social Worker with Deaf people: 1
- "I wasn't there at the time when baby was born (adopted my wife's existing children after we got married)": 1

Comment on access to above services:

- Had support from my Deaf family
- "My hearing children support me if I need them no problem"
- "Used RAD interpreting services in Surrey"
- "Nil, nothing like Parent Line, parent evening at school/clinic"
- "25 years ago, we didn't have any sign language interpreting service. I used to rely on my mother to support me".
- "No provision of sign language interpreter when I needed one"

c) If no access to above support, was it because:

- You not aware of above services: 2
- You are aware but you had no information on how to access to above services: 3
- You have access to above services but they are not deaf friendly: 1
- Other: Sought help but no-one interested 1

Comment to no access to above services

• "I went to Mother & Toddler group, had chat about our children in hearing group but they not interested. Got no support from anyone, not even from the NDCS,(as they only targeted to Deaf children). What about the services to Deaf parents of hearing children – no support available.

- 3) **Having a first child? YES: 0** However, some parents completed this section as follow, having recalled their experiences when they had their first child:
- a) Received information/support on parenting? YES: 2 NO: 5
- b) if yes, who from?
- One parent said: "My husband's aunty used to support me a lot"
- One parent said "My social worker!"
- c) Anixous on the process of pregnancy or process leading up to the birth? YES: 1 NO: 4 Other: Mixed response of both yes/no: 1
- d) Where would you go for info/advice/ support?

 One parent who said yes, she said she would go to her social worker
- e) Any concern if child is born or later become:

 Deaf:
 YES: 2
 NO: 2

 Hearing:
 YES: 0
 NO: 2

 Disabilities:
 YES: 1
 NO: 2

f) If yes, what are the concern: *Deaf*:

- "My 3rd child, I was worried when he was about 2yrs old, one of his ear was full of wax, then he had a meningitis but he was fine afterward. Now, still had perfect hearing!"
- "I worried about my child, especially if born deaf and that was because of my experience with my hearing family"

Hearing: 0 Disabilities: 1

- "Not knowing what to do or expect or even not to be in control of the situation worried me the most".
- 4) Not a parent? YES: 6
- b) Any issues or concerns if you or your partner decide to have children?

YES: 2

NO: 4

- b) If yes, what are the issues/concerns?
- "The process of adoption, being gay/lesbian there is difficulty in being accepted as a Deaf parent!"
- "Finding education/ schools for Deaf children"
- c) Where would you go for information/ advice/ support?
- One Gay parent who wanted to adopt said she would not go anywhere. "None, because of the dilemma on confidentiality and trust"
- One parent said she would go to CAB whilst another said she would go to NDCS.

5) If given opportunity to improve/develop services for Deaf parents, what would you suggest?

- Parent Skills
- Know Parent's right
- Parent Support Group
- Discussion Group
- Women's Health services
- Plenty of well-balanced information
- Men's health services
- School & Clinic
- Access to Minicom services
- Understand, recognise and respect BSL as preferred language for Deaf people
- Deaf Equality Training to be involved
- Deaf Parents Advocacy Group

- More information needed to be available in rural areas
- "In the past, it was not the same. Now, need to see more improvement hope to see more BSL videos for Deaf parents about it"
- "Ensure that all Deaf organisation/ schools/ medical services are up to date with relevant information by having regular open days and send out newsletter"
- Need for Deaf parents to mix together
- More access and more awareness of what all Deaf people "needs to know"
- Midwifery
- CAB

6) Resources:

c) Are you aware of any services currently available to Deaf parents in UK? YES: 2 NO: 8

If yes, please list them

- NDCS: 8
- FYD: 1
- Enfield Deaf Children Associaton: 1
- BDA: 1
- Via Social Services: 2 (Through Deaf Services Team?)
- Local Deaf organistions: 1
- Deaf Centres in UK: 1

- Oak Lodge Deaf School: 1
- Gover House School: 1
- Doctor: 1
- Dept of Social Security (DSS): 1
- School: 1
- "Hidden services Deaf parent group run by the Deaf parents who meet in their own home"

d) Any research project/ material/ books around Deaf Parenting? YES: 6 NO: 12

If yes, please list them and where they are based.

- Bristol Centre of Deaf Studies: 1
- NDCS London: 1
- BDA they have information on hearing children of deaf parents, also known as KODA Kid of Deaf Adults
- Forest Bookshop: 4
- Local Library: 1

Appendix 3: Research Project Proposal

<u>Deaf Parenting: Raising a Child - An initial study on Deaf parents with children aged</u> infant to eleven years old.

Topic and Scope of proposed project

This project is of a small scale; the aim is to undertake an exploratory study of Deaf parents and their experiences in raising a child and to examine themes that arise from the study. This includes establishing whether there are services available to Deaf parents who have deaf, hearing and/or disabled children.

Thus, the title clearly reflects the proposed area of study to the lay reader, it signifies that the research focuses on a particular group of Deaf parents and their experiences of raising a child. The title includes the term '*initial study*', this is to demonstrate that the research itself is a very small study and one of very few pieces of research that focus on this subject.

Though the proposed research project will lead to a dissertation as an essential part of a university degree course, there have been some expressed interests in this study both in the UK and the USA. As a result, this local research project will serve as a pilot study with a view to encouraging further in-depth and more ambitious research on the subject of Deaf Parenting. This research will be on various levels ranging from regional/state-wide to national and international levels. A three-year national project in the USA, on disabled parents with teenagers, which is based in the same area as that chosen for this project, is very interested in the outcome of the project, so that they can plan further research on Deaf parents with teenagers.

In the proposed area of study, the majority of the work will be to initially find out Deaf people's experiences of being a parent from the late stages of pregnancy to raising a child. The importance of including the pregnancy stage is to highlight experiences of joining in parenthood for the first time and to discover whether the pre-natal/maternity care services are accessible to Deaf parents. Furthermore, the experiences of the Deaf parents in raising a child would provide a useful resource for future parents in identifying gaps in information and service provision available to such parents.

It is important to note that the information and services, referred to above, will depend on what is available in the local area where the study takes place. Also the study will briefly look into services provided by Deaf agencies and mainstream agencies, including education, health and social services. However, outcomes from the study on gaps in information and services locally, could be used in the USA and the UK, to highlight other gaps in services locally and nationally with a view to developing and improving services.

Therefore, the aim of the study is to:

- Explore Deaf people's experience of being a parent, including the common themes of communication, education, parenting skills and access to information and services
- iv) And to identify gaps in information and service provision for the parents.

Methodology

The research will take place through three stages, bearing in mind still, that it is a very small-scale study.

First stage:

Networking and visiting, in the local area various Deaf agencies, including social services, voluntary organisations, Deaf/mainstream schools and Deaf clubs to familiarise the researcher with the services that are currently available to Deaf people in general (including Deaf children of Deaf/hearing parents). It is during this process that many Deaf people have been identified as Deaf parents with Deaf/hearing/disabled children.

Second stage:

Interviewing the Deaf parents identified from the first stage. Set criteria will be used to select from a large sampling frame, the 10-12 Deaf Parents who have children aged 0-11 years old. The interview will be carried out in the form of an in-depth questionnaire on a face-to-face basis. The questionnaire design will aim to find out comparable factual information from the respondents about their parenting experiences dating from the final stages of pregnancy to raising their child and will aim to assess their level of access to information/services. The questionnaire would also invite them to reflect back on their experiences and to give opinions about parenting, their support network of family, friends and agencies, their education prior to becoming a parent and their access to information/ services. Furthermore, it is important to include interviews with Deaf people who are expecting a child for the first time.

Also the researcher initially considered carrying out a group-work exercise with young Deaf adults aged from 14/16yrs onwards, who are not yet parents, to find out their views on their future in general, focussing on careers, marriage, family life and how they would feel about becoming a Deaf parent – assessing their level of awareness and knowledge on sex education. However, due to the time-limited nature of the project, it was thought best only to consider young Deaf adults who are pregnant instead. Resulting from the first stage, three Deaf teenage mothers-to-be were identified from one school. In this particular case, the interview to find out about their experience of becoming a young Deaf parent for the first time, will be carried out in the form of a group-work exercise, since the teenagers have a pregnancy support workshop every week at school. The workshop is specifically run for the three teenage mums-to-be. It was considered a good idea to carry out the exercise within the group where they have peer support and rapport with their facilitator, who is also a Deaf mum. However, individual interviews could be arranged instead of the group work exercise should they prefer this.

The group-work exercise will be done using a list of questions, which will invite them to discuss: their experiences of going through pregnancy, their current support network, their access to information and services (particularly in relation to pre-natal care and a plan for post-natal care), their plans for after the birth of their child and their own future. Some of these questions are similar to those on the questionnaires that target Deaf parents with children who are 0-11yrs old.

Third Stage (time permitting):

To interview Deaf parents who have grown up children who are senior citizens (aged from 60 years onward) on their experiences of being a Deaf parent. The aim of this interview is to find out about their experiences of parenting and their access to services and look at how these have changed over the years. This comparison will be done by discussing the common themes resulting from the second stage interviews of Deaf parents with young children and inviting the older Deaf parents to reflect on their experiences and asking them what advice would they offer the younger parents.

Findings:

The results of the findings of the proposed project will be incorporated into the dissertation as essentially required for the university degree course. Furthermore, it is hoped that this valuable information will be disseminated, via the national Deafhood conference, (to be held in July 2001) to Deaf parents, the Deaf Community, professionals/researchers working in deaf-related and parent-related fields and service providers.

Relation of proposed project to previous research in this field

It was extremely hard to find empirical research on Deaf Parenting whilst searching for research materials and literature in relation to this project on Deaf parents, However, on looking under the category of 'families and deaf children', particularly in the Mail Order catalogue which list books, videos and CD-ROMs about 'Deafness and Deaf Issues' (Forest Bookshop, 2000/01) available in the UK, in the hope that there might be some material written in small section/ chapters/ articles available on Deaf parenting, a vast number of materials and literature on the subject of family and deafness were found. These largely focus on deafness from the medical/pathological and educational perspectives rather than the social and linguistic perspectives. These books discuss deafness in depth as a medical condition, offering information on communication methods and the Statement of Special Educational Needs. The books were written with the issues, in mind, of deaf children within hearing families, providing useful resources for hearing parents of deaf children. For example, see the works of Knight & Swanwick (1999) 'The care and Education of a Deaf Child – A book for parents'; Adams (1997) 'You and your Deaf Child: A Self-Help for Parents of Deaf & Hard of Hearing Children'; Schwartz (1996) 'Choice in Deafness: A Parents' Guide to Communication option'; Marschark (1999) 'Raising and Educating a Deaf Child: A Comprehensive Guide to the Choices, Controversies and Decisions faced by Parents and Educators' and Luterman & Ross (1991) 'When your child is Deaf: A guide for Parents', to name but a few

In addition, the above materials make little or no mention of deaf parents and the issues they face in raising their deaf/hearing children. However, there is still some information on Deaf parents and their experiences of having hearing children, in the form of short articles, literature reviews and a few books. Most of them are written from the perspective of the hearing child of deaf parents, including issues on communication, identity, culture and the role of the hearing child in a deaf family. For example, see works written by a few authors such as Goodstein (1981) 'Three Generation of loving memories'; Cundy (1987) Hearing Children of Deaf Parents: Patronizing Attitudes'; (Walter (1990) 'The Ties That Bind: Hearing children and deaf parents talk about being a family'; Preston (1994) 'Mother Father Deaf: Living between sound and silence' and Singleton & Tittle (2000) 'Deaf Parents and Their Hearing Children'. All of the above works were carried out in USA and likewise, there are some similar resources in the UK, but very little material was found to focus on the experiences of deaf parents themselves in raising their children, irrespective of whether the child was deaf or hearing.

Many experiences and perspectives of Deaf parents' around parenting and their lack of access to needed information and services (including access to parenting classes, ante-natal classes; the information on pregnancy, parenthood and child developmental stages) are undocumented.

Also two organisations providing information services to disabled parents, one in the UK and

one in the USA, have received lots of requests for information from health professionals, particularly midwifes who are at a loss as to how to relate to deaf parents going through the pregnancy stages. However, these two organisations are unable to provide information, as they unaware of exactly what the Deaf parents' needs are. Clearly there is a large need to provide such information to service providers and hopefully this research project will be seen as a starting point, encouraging ideas and dialogue between the service providers and Deaf parents on service delivery.

Justification of the proposed study

The topic of the proposed study itself is unique and one of the subjects that has received little attention from previous research and literature.

There are many factors that prompted the researcher to explore this subject and come up with the proposed study, including her personal experience as an Asian Deaf Woman who, one day, will become a Deaf Parent. In addition the researcher has also worked with Asian Deaf People and their families, both during a previous project on their access to council services and as a social worker. Many of these Asian Deaf people came from other countries, and were illiterate, communicating in their home-generated signs and as a result, they became isolated and were unable to access local services.

It was during her work with some Asian Deaf women who were pregnant, most with their first child, that she realised the gaps in literature on Deaf parenting and the lack of access to much needed services in an accessible format (sign language) i.e. parenting classes, antenatal classes, parent support groups and information on child developmental stages.

The researcher communicates in British Sign Language (BSL) and works with many BSL interpreters, some of whom have Deaf parents (referred to often by the acronym CODA, Children of Deaf Adults). It was through her contact with interpreters that she gained more insight into their experiences of growing up with Deaf Parents.

She learned from her Deaf Studies Course at Bristol University in 1997, that 90% of deaf children are born to hearing parents. They will grow up into Deaf parents and are 90% likely to have hearing children. Yet, there is literature available for hearing parents (i.e. general parenting books), hearing parents with deaf children and hearing children of deaf parents but insufficient information available targeting deaf parents themselves.

The researcher attended an Asian Deaf Conference in the USA in March 2000, meeting lots of Asian Deaf people, including some CODAs and noticed that there were no information workshops that targeted Deaf Parents. There was however a workshop targeting parents (many of whom were hearing) of Asian Deaf children. It was there that she met a Deaf Asian Social Worker whose agency agreed to host her during her proposed study.

In addition, through her contact with one of the BSL interpreters (now with her on the proposed study), she was introduced to Preston, a writer of the book 'Mother Father Deaf: Living Between Sounds and Silence'. Preston is also a CODA and is working on the three-year national project on Disabled parents and he was keen to know the outcome of the proposed study.

Finally, the researcher is fully aware that during the proposed study, she will be working with

Deaf Parents in the USA, most of whom are American Sign Language (ASL) users. She has to learn and adapt from BSL to ASL and prepare herself for some individual interviews where she is expected to use ASL fluently to ensure the validity of the research. She has brought her BSL interpreter for ease of communication whilst networking and visiting the numerous agencies many of which have hearing staff.

Timescale and work plan for the proposed project

DATE/MONTHS	<u>ACTION</u>	DONE	STAGES 1, 2 or 3 of Research Study? For Dissertation
Nov 2000:	Pilot questionnaire survey of Deaf Parents in UK	YES	Pilot Stage
	Establish a email-discussion group for Deaf parents to share their views, information and support with each other.	YES	This need is resulted from the Pilot survey
Nov-Jan 2001:	Literature search in UK and update with information on parenting, deafness and family, pregnancy.	YES	Stage 1
16 th Jan 2001 – 8 th Feb 2001 :	3 weeks of familiarisation involving various agencies in San Francisco and identifying Deaf parents.	YES	Stage 1
	Continue with literature search but in USA with particular reference to American writers.		On-going
Feb 2001	Research design of in-depth questionnaire for face-to face interview with 10-12 deaf parents, and a similar list of questions for a group work exercise with teenage mums-to-be.	Started on 30 th Jan and is on- going	Pre-Stage 2
Feb 2001 – March 2001	Arranging a schedule and interviewing Deaf Parents (approx 4-5weeks)	Started on 6 th Feb and is on- going	Stage 2
March 2001	Themes arising from the interviews will be discussed with a group of 15-20 senior citizens (approx few days/ 1 week)		Stage 3
March 2001 - April 2001	Data Analysis, some will be done in USA and some on return to the UK (on 24 th March 2001)		Post Stage 3
April 2001 – May 2001	Write up the research project for the dissertation		Complete Dissertation, the final stage.

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Appendix 4: Proposed Timetable to carry out the research project

DATE/MONTHS	<u>ACTION</u>	DONE	STAGES 1, 2 or 3 of Research Study? For Dissertation
Nov 2000:	Pilot questionnaire survey of Deaf Parents in UK	YES	Pilot Stage
	Establish an email-discussion group for Deaf parents to share their views, information and support with each other.	YES	This need is resulted from the Pilot survey
Nov-Jan 2001:	Literature search in UK and update with information on parenting, deafness and family, pregnancy.	YES	Stage 1
16 th Jan 2001 – 8 th Feb 2001 :	3 weeks of familiarisation involving various agencies in San Francisco and identifying Deaf parents.	YES	Stage 1
	Continue with literature search but in USA with particular reference to American writers.		On-going
Feb 2001	Research design of in-depth questionnaire for face-to face interview with 10-12 deaf parents, and a similar list of questions for a group work exercise with teenage mums-to-be.	Started on 30 th Jan and is on- going	Pre-Stage 2
Feb 2001 – March 2001	Arranging a schedule and interviewing Deaf Parents (approx 4-5weeks)	Started on 6 th Feb and is on- going	Stage 2
March 2001	Themes arising from the interviews will be discussed with a group of 15-20 senior citizens (approx few days/ 1 week)		Stage 3
March 2001 - April 2001	Data Analysis, some will be done in USA and some on return to the UK (on 24 th March 2001)		Post Stage 3
April 2001 – May 2001	Write up the research project for the dissertation		Complete Dissertation, the final stage.

Appendix 5: Consent letter for parents of teen moms-to-be

8th February 2001

Dear Parents/Guardian,

<u>Deaf Parenting: Raising a Child - An initial study on Deaf parents with children aged infant to eleven years old.</u>

Please allow me to introduce myself; my name is Sabina Chowdry, a Deaf Social worker from England. At the moment, I am studying for a UK degree in International Social Work and as part of the course I am required to carry out a three months research project in a different country.

I have chosen to come to San Francisco because of the Deaf services available in the area. I thought it might be interesting to know how the Deaf services work in the SF Bay Area and whether they are similar or different from the Deaf services provided in the UK.

Furthermore, I am doing a research project on Deaf Parenting, finding out whether there are any services or information available to deaf parents who have a hearing/deaf/disabled child or children. In addition to interviewing 10-12 Deaf parents who have children 0-11 years old, I would also like to meet any young deaf moms-to-be to find out their views about their pregnancy and any issues/concerns they may have in relation to becoming a new mom. There will also be discussion about their plan/vision of their future after the baby is born, in terms of parenting, employment, the child's education and family, with particular focus on parenting.

The aim is for me to meet the group, that regularly gets together every Tuesday morning at California School for the Deaf in Fremont, to find out their level of awareness and understanding of their pregnancy, the responsibility that results from bringing up their child, and of the services and information required in bringing up a family. This will include a discussion about the personal social development and sex education that they learnt at school.

I would like an opportunity to meet your daughter and need your permission for your daughter to participate when I meet this group. We plan to discuss their views about life in general, with particular focus on their access to information and services for Deaf parents.

For this project, I co-work with the Hearing Society in SF and Paul Preston (writer of 'Mother Father Deaf') of Through the Looking Glass (an agency, providing information and support services to disabled parents) in Berkeley. I'm based at the Hearing Society's main office for three months from 16th January to 24th March 2001.

I would appreciate if you could complete a reply slip to be returned by <u>Tuesday 20th</u> <u>February 2001</u> on whether you would agree for your daughter to participate in the group discussion for the project. This is an opportunity for the Deaf students to consider their future carefully and to think about the responsibilities of the individual in relation to having a

family. I assure you that all information given during the group discussion will be confidential and only be used for the purpose of the research project.

If you agree for your daughter to participate in the group discussion, please feel free to talk to her about any of the issues arising from the discussion. Also, support will be available from the school, should your daughter need information or need someone to talk to.

Should you require any further information or have any questions about my project, please do not hesitate to contact me at the above numbers or by e-mail:

sabina.chowdry@rocketmail.com
Many thanks for your time and I look forward to hearing from you by Tuesday 20 th February 2001.
Yours sincerely,
Sabina Chowdry Social Work Researcher
X Reply Slip (Please complete this section and return it to Frank Lester, the Guidance Counselor or the child's teacher by Monday 12 th February 2001)
I/We would/ would not (delete where appropriate) be happy for my daughter (name) to participate in the group discussion about Deaf Parenting as part of the research project 'Deaf Parenting: Raising a Child'
Parent/Guardian (over 18yrs):
Signature:
Full Name (BLOCK CAPITAL):

Appendix 6: Consent form for Deaf teem moms-to-be to participate in the interview

Consent Forms to Participate in an interview for the project:

'Deaf Parenting: Raising a Child - An initial study on Deaf parents with children aged infant to eleven years old.

I am being asked to participate in a study conducted by Sabina Chowdry, the researcher. The study is a three months study on Deaf parents with deaf/hearing/disabled children. My family and I have been selected as possible participants in this study because I am either a Deaf expectant mom or a Deaf parent with child(ren) aged 0-11 years old.

As a participant in this study I understand that the interview will take place at my home or at a place that I feel comfortable in agreement with the researcher.

The interview will take at the minimum of about two hours, with the flexibility of breaks. Further appointments may be needed to complete the interview. Each meeting will be facilitated by the researcher who has been trained in issues of confidentiality. The purpose of the interview is to discuss topics relevant to Deaf parents and their experiences of raising a child aged 0-11 years old.

Consent for Videotaping

I am aware that the interview may be videotaped. The purpose of the tape is to help the researcher more accurately recall what was discussed during the interview. The tape will be identified by date only, with no names or identifying information attached. The tape will be kept for a maximum period of five years after the completion of the project or publication of the project study, whichever comes later, after which time it will be destroyed.

Benefits:

By participating in this interview, the potential benefits to me are:

I will have the opportunity to participate in a research project, which aims to explore families, which include Deaf parent with at least one child, aged 0-11 years old living in the home. My participation in this research may provide me with the experience of sharing ideas and perspectives with other Deaf parents who are raising a young child. Further, through my participation, I may gain a clearer understanding of my role as Deaf parent and I may be introduced to a supportive community, which may lead to an increased sense of empowerment. My participation will help the researcher better understand the issues facing Deaf parents.

Risks

By participating in this interview, the potential risks to me are:

I may experience feelings of anxiety or distress in response to topics brought up. If I experience any undue anxiety or distress as a result of my participation in this research I can contact Frank Lester, Guidance Counsellor of the CDSF Counselling Department for an appointment or further information/resources. His contact number is (510) 794 2522 and his office is based in Cottage 17 of CSDF.

Confidentiality:

I understand that after the interview, the completed questionnaires will be kept in a locked file cabinet for the maximum of five years after the completion of the study (or publication of the final project report, whichever comes later), after which time they will be destroyed by shredding.

Limits to Confidentiality

If any information is brought to the attention of the project researcher that leads her to think that I might be at

risk of significant harm to myself, may harm someone else, or there is reasonable suspicion of child, elder, or dependent adult abuse, they are required by law to report these to the appropriate authority.

As a participant in this study, only the researcher will know my full name and specific responses on the survey. I also understand that all papers with my name on them will be kept in a locked file cabinet and will be destroyed as stated above.

I have the right to refuse participation in this study. If I agree to participate in this study I may choose not to answer certain questions that make me uncomfortable or invade my privacy. I may feel free to withdraw my consent to participation at any time with no consequences to myself or family and my data will be shredded.

If I have any questions now or at a later point, I may call the researcher, Sabina Chowdry on (415) 834 1005 (TTY) or email her on sabina_chowdry@hotmail.com. I have been given a copy of this consent form to keep.

	owledge that I have read and understood the sterview and that the interview may be videota	
Participant's signature	Date Researcher's signature	Date

Appendix 7: Consent form for Deaf parents to participate in the interview

Consent Forms to Participate in an interview for the project:

'Deaf Parenting: Raising a Child - An initial study on Deaf parents with children aged infant to eleven years old.

I am being asked to participate in a study conducted by Sabina Chowdry, the researcher. The study is a three months study on Deaf parents with deaf/hearing/disabled children. My family and I have been selected as possible participants in this study because I am either a Deaf expectant mom or a Deaf parent with child(ren) aged 0-11 years old.

As a participant in this study I understand that the interview will take place at my home or at a place that I feel comfortable in agreement with the researcher.

The interview will take at the minimum of about two hours, with the flexibility of breaks. Further appointments may be needed to complete the interview. Each meeting will be facilitated by the researcher who has been trained in issues of confidentiality. The purpose of the interview is to discuss topics relevant to Deaf parents and their experiences of raising a child aged 0-11 years old.

Consent for Videotaping

I am aware that the interview may be videotaped. The purpose of the tape is to help the researcher more accurately recall what was discussed during the interview. The tape will be identified by date only, with no names or identifying information attached. The tape will be kept for a maximum period of five years after the completion of the project or publication of the project study, whichever comes later, after which time it will be destroyed.

Benefits:

By participating in this interview, the potential benefits to me are:

I will have the opportunity to participate in a research project, which aims to explore families, which include Deaf parent with at least one child, aged 0-11 years old living in the home. My participation in this research may provide me with the experience of sharing ideas and perspectives with other Deaf parents who are raising a young child. Further, through my participation, I may gain a clearer understanding of my role as Deaf parent and I may be introduced to a supportive community, which may lead to an increased sense of empowerment. My participation will help the researcher better understand the issues facing Deaf parents.

Risks

By participating in this interview, the potential risks to me are:

I may experience feelings of anxiety or distress in response to topics brought up. If I experience any undue anxiety or distress as a result of my participation in this research I can contact Barbara Bell, Supervising Clinical Social Worker at Hearing Society for an appointment. Her contact number is (415) 834 1005 (TDD) and her business card can be obtained from the researcher.

Confidentiality:

I understand that after the interview, the completed questionnaires will be kept in a locked file cabinet for the maximum of five years after the completion of the study (or publication of the final project report, whichever comes later), after which time they will be destroyed by shredding.

Limits to Confidentiality

If any information is brought to the attention of the project researcher that leads her to think that I might be at

risk of significant harm to myself, may harm someone else, or there is reasonable suspicion of child, elder, or dependent adult abuse, they are required by law to report these to the appropriate authority.

As a participant in this study, only the researcher will know my full name and specific responses on the survey. I also understand that all papers with my name on them will be kept in a locked file cabinet and will be destroyed as stated above.

I have the right to refuse participation in this study. If I agree to participate in this study I may choose not to answer certain questions that make me uncomfortable or invade my privacy. I may feel free to withdraw my consent to participation at any time with no consequences to myself or family and my data will be shredded.

If I have any questions now or at a later point, I may call the researcher, Sabina Chowdry on (415) 834 1005 (TTY) or email her on sabina_chowdry@hotmail.com. I have been given a copy of this consent form to keep.

In signing this consent form I acknowledge to I am agreeing to participate in an interview are			wing information, and that
Participant's signature	Date	Researcher's signature	Date

Appendix 8: In-depth Questionnaire for the interview with Deaf parents

arent	(s)	No:	
arent	(S)	No:	

Deaf Parents: Interview Questionnaire

I am currently doing a research project on Deaf Parents in order to identify common themes/ issues and their access to services. This is part of my degree in International Social Work Studies.

I'd like to begin by having you tell me a little bit about yourself and your family.

1) Personal Details a) Gender/Age:	
	r date of birth (DD/MM/YY):
b) Race/ Ethnicity/ identity: Which of the following best describes your race or etl African American or Black Latin American or Hispanic Asian American/ East Asian Pacific Islander Other: (please specify)	
How do you identify yourself? Deaf Deafened Other: (please specify)	Hard of Hearing
Any comment about your identity?	
c) Your preferred language used: Sign language:	
ASL user Other sign languages	s (please specify)
Spoken language: English Chinese [Other communication methods (please specify)	Spanish
 d) Religion: What is your religion? How often do you participate in religious or spiritual Daily	activities either at home or with others?

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Married	aship status: your relationship s or with a partner please specify):		separated, divorced, widowed	i
Keys: 0= Not at all			Deaf University; 4= Mainst Other (please specify)	ream School; 5=
Type of school (use above keys)	Was it Full/Part Time	Was it Residential or Day/Evening?	Did you receive any Communication Support?	How many deaf students there at the time out of total student?
	highest grade you	have completed so far?	No	
If yes, pleas	e specify:			
Type school (use above keys)	Is it Full/Part Time	Is it Residential or Day/Evening?	Do you receive any Communication Support?	How many other deaf students are there?
In U: U: U: A A O: No	paid employment, paid employment, nemployed, seekin nemployed, NOT s Homemaker, if so Student Volunteer	, part-time g work seeking work , do you stay at home a	as a parent □, or are you retin	
h) Housing Are you livi				
A Large	City	A Small Town	A Rural Area	A Suburban Area
State pro	y owned accommodation	ation	Rented accommodation shared ownership according	

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Is your home located: Near local shops? Near the local transport i.e.: MUNI/ BART/ AC TRANSIT etc? Near the local deaf schools? Near the local mainstream schools? Yes No Don't know Yes No Don't know Yes No Don't know Yes No Don't know Yes No Don't know									
<i>i) Your finance</i> What is your		househol	d income ap	proxi	mate	ıly:			
☐ Below \$50 ☐ \$900-\$100	_	\$500-5 \$1000	\$600 [-\$1100 [_	00-\$ 100-	700 [\$1200 [\$700-\$8 \$1200-\$		800-\$900 er \$1300
SSI MediCal (s Other (plea	MediCal (state health insurance for low income people) Other (please specify): j) Your parents/ family background:								
Their relation			Hearing		Dea	af	Other (p	lease specify)
How do you c	ommun	icate with	your family	? (Tio	ck all	l boxes tha	t apply)		
How do you communicate with your family? Name of ASL Other Sign Family Language, please specify		Eng		Chinese	Spanish	Other spoken language, please specify	Other communication method		
								specify	
								вресну	
								specify	
								spectyy	
								specify	
								spectyy	

Any further comments on communication with your family?

Using the rate from 1 to 5 (1=poorly, 2= not well, 3= average, 4= quite good, 5= very well)

How do you rate your relationship with your parents, siblings, partner etc as follow:

Their relationship to	How do you rate your	Any comments:
you	relationship with this person?	Any comments.
you	Use above keys	
	Use above keys	
2. You as a deaf parent:a) Are you pregnant now?	☐ Yes ☐ No	
a, the you prognant now!		
If yes, is this your first preg	nancy? Yes No	
If yes, go to question 2c)		
If no, please continue to 2	b)	
b)Children:		
How many children do you	hove?	
riow many children do you	nave:	

i) Please complete the children's details as follows:

Child first name	Age	Gender	Deaf (Please tick)	Hearing (Please tick)	Other disabilities? (Please specify)	Does the child go to play- group or school i.e. Kindergarten or Elementary?
1.						
2.						
3.						

Child first name	Age	Gender	Deaf	Hearing	Other	Does the child go to play-
			(Please tick)	(Please tick)	disabilities?	group or school
					(Please	i.e. Kindergarten or
					specify)	Elementary?
4.						
5.						
6.						
7.						
8.						

b)	Pregna	ncy:

e) Tell me about your experiences of pregnancy with your first chi	cy with your first child:
---	----------------------------------

How did you find out you were pregnant? (Self - pregnancy test or from doctor or both?)

How did you feel? (Including your feelings on first discovering that you were pregnant)

f) Was this pregnancy planned? Yes/No Any comment?

g) When you discovered that you were expecting, what did you do next? (did you share the news with your family/partner, have a check-up, pay a routine visit to the GP etc?)

	Do/Did you receive any information/ support on parenting? Yes \(\square \) No \(\square \) yes, who from?
i)	Are/were you anxious either about the process of pregnancy or the period leading up to the birth of your first baby? Yes _ No _
j)	If yes, where would/did you go for information/ advice/ support?
k)	How do/did you know where to go for this information/advice/support?
viii)A • •	re there or were there any concerns around your child being born or later becoming: Deaf Yes No Hearing Yes No With disabilities (if any) Yes No
If	yes, what are/were the concerns?
d) Pre	paration for birth/labor (for current pregnant moms only)
i) To	ell me your plan in preparation for birth/labor.

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••\	TT71 1	1 , , •,1		•	· · ·	110
111	Who do you	have contact with	สมหาคล พลม	• ทะงสมสมสมาเจ	n <i>vonavatiou toi</i>	いいひいい しのわのかり
ii)	m no ao voa	have contact with	. uuring voui	Diegnancy in L	n evaration ivi	vour tubor.

	Check boxes if you have contact with following people	_	Were they supportive?
Local doctor			
Doctor/clinician at hospital			
Midwife			
Other (please specify)			

iii)	If you receive support from the	above people, wha	et kind of support o	do you receive
iv)	Will you plan to have anyone w If yes, who?	vith you during the	labor? Yes ☐ No	•□
	If no, any reason why not?			
	Any other comments?			
v)	Will your baby be born in: ☐Hospital ☐ At Home	□ Other	(please specify) _	

vi)

How will you want your baby to be born by:

Other (please specify)

☐ Natural delivery ☐ Caesarean Section ☐ Birthing pool

i)	Tell me your experiences of birth/labor:	ice of having their first clind)
e)	Actual Birth/Labor (applied to all Deaf parents and their experier	nce of having their first child)
	Any comments:	
vi)	Are you aware of the different choices on birth delivery, in	preparation for your birth?
	Whose decision will it be for you to accept or decline pain r	elievers?
	If no, any reason why not?	
	If yes, please explain:	
	Will you plan to have any pain reliever during the labor?	Yes No No

••\	1171 1 1 1 4 4 14	during vour pregnancy and labor?
ii)	W NO AO VOU NAVO CONTACT WITH	auring vour prognancy and labor?

	Check boxes if you have contact with following people	Were they supportive?
Local doctor		
Doctor/clinician at hospital		
Midwife		
Other (please specify)		

iii) If you received support from the above people,	, what kind of support did you recei	ve?
---	--------------------------------------	-----

Did you have anyone with you during the labor? Yes [] If yes, who?	No 🗀
If no, any reason why not?	
Any other comments?	
	If yes, who? If no, any reason why not?

v)

Was your baby born in:

☐ Hospital ☐ At Home

| Other (please specify) ______
|

vi)	Was your baby born by:
	☐Natural delivery ☐Caesarean Section ☐ Birthing pool
	Other (please specify)
	Did you have any pain relief during the labor? Yes \(\subseteq No \subseteq \)
	If yes, please explain:
	If no, any reason why not?
	Whose decision was it for you to accept or decline pain relievers?
v)	Were you aware of the different choices on birth delivery before your baby was born?
	Now, you know, would you have made a different choice?
	Any comments:
Δ D.*	noing habe have for the Great times
f) Bri	nging baby home for the first time:
How	long was it from the birth of the baby to bringing the baby home?

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How did you feel about bringing baby home?
Did you have any equipment installed in the home? Yes No
If yes, what equipment?
If no, why not?
How do you feel becoming a new parent for the first time?
tion do you reer occoming a new parent for the moveme.
How did you cope in the first few months after you brought your baby home?
Where do you go for information and support?

i)	How is your experience of having a recent child similar or different from your first cl

h)	Child Development
i)	Are you aware of the key stages of child development? Yes \ No \
Wł	nere did you learn this information from?
Wa	as it useful?
ii)	If appropriate, do you feel your child is meeting all stages of child development for their age? (Using the Child Development Stage Chart for children aged 0-5yrs – see attached on back of questionnaire) Yes No
An	y comments?
;) (Child's Welfare:
i)	Are you aware of any vaccinations required for your child from the age of birth to 11yrs old? Yes No If yes, where did you get the information?
	If no, how come?

ii) Tell me wha	at do you normally do if your child
	Any example?
cry?	
Becomes ill?	
Has tantrums	
Becomes naughty	
Behaves well/laughs	
Wants something	
Wants to play?	
Other: please	
specify	
i) Is any of yo	on with your child/children ur child(ren): Hearing Deaf with disability Hearing with Disability
How did you fin	
,	
How do you fee	l about this?

sing the rate from 1 to 5 (1= poorly, 2= not well, 3= average, 4	= quite good, 5= very well)
If applicable, how do you	rate your relationship with your child	dren as follow:
Their relationship to you	How do you rate your relationship with this person? Use above keys	Any comments:
First Child	Ose above keys	
Second Child		
Third Child		
Fourth Child		
Fifth Child		
Sixth Child		
		1

How do you communicate with your child(ren)?

k)	Child's Educat	ion:		
i)		Does your child(ren) rother groups)?	now attend school (including Yes	g playgroup/kindergarten or
	If no, why not?			
	Any further cor	nment about why your	child(ren) is not in school?	
ii)	If yes, how long	g has your child(ren) be	een attending?	
iii)	How do you thi	nk your child(ren) is ge	etting on at school?	

iv)	Is the school for your children: Deaf Mainstream Other (please specify) Other (please specify)
v)	Why did you choose this school for your child(ren)?
V1)	Where did you find out information about this school?
vii)	Think back to the day you took your first child to school for the first time, tell me what happened on the first day? How did you get on? (Include any feelings of excitement? relief? Happiness? Sadness? Fears/Worries? Frustrations? etc)

viii)	And how do you feel now that your first child has been attending school for a while?
iv) H	lave you met with any other parents whose children go to the same school as your child?
1X) 11	Yes No No
	If yes, then please describe your contact with other parents:
If no,	why not?
x)	Are you in any way, involved with the school? Yes \(\subseteq \text{No } \subseteq \)
	If yes, in what way?

If no, wh	ny not?
xi) Ar	ny further comments about your child(ren)'s education?
xii) Wha	t is your view on education in general? (Discussion about importance, values, beliefs)

l) Awareness/Access to information and agencies

Only applicable to the first-born child of the Deaf parents who have children between the ages of 0-11yrs

i) Was any of the information below available to you when you were expecting your first-born

child?				
Information on:	Yes	No	Where from?	
Pregnancy				
Labor and Birth				
Ante-natal Classes				
Parenting Classes				
Parenting				
Access to GP				
Access to Maternity healthcare				
Access to Child Development				
Center				
Child-Care/ baby sitting				
Services Equipment for Doof/HOH				
Equipment for Deaf/HOH parents				
Interpreting Services				
Other (please specify)				
outer (preude speerly)				
Was the information you were g Only applicable to Deaf parent children in addition to their fit ii) Was any of	ts who are eit rst-born child	:	•	t child
Only applicable to Deaf parent children in addition to their fin ii) Was any of	ts who are eit rst-born child the following	her expecting:	a baby now or have a recen	t child
Only applicable to Deaf parent children in addition to their fit ii) Was any of Information on:	ts who are eit rst-born child	her expecting	a baby now or have a recen	t child
Only applicable to Deaf parent children in addition to their fin ii) Was any of Information on: Pregnancy	ts who are eit rst-born child the following	her expecting:	a baby now or have a recen	t child
Only applicable to Deaf parent children in addition to their fin ii) Was any of Information on: Pregnancy Labor and Birth	ts who are eit rst-born child the following	her expecting:	a baby now or have a recen	t child
Only applicable to Deaf parent children in addition to their fit ii) Was any of Information on: Pregnancy Labor and Birth Ante-natal Classes	ts who are eit rst-born child the following	her expecting:	a baby now or have a recen	t child
Only applicable to Deaf parent children in addition to their fin ii) Was any of Information on: Pregnancy Labor and Birth Ante-natal Classes Parenting Classes	ts who are eit rst-born child the following	her expecting:	a baby now or have a recen	t child
Only applicable to Deaf parent children in addition to their fin ii) Was any of Information on: Pregnancy Labor and Birth Ante-natal Classes Parenting Classes Parenting	ts who are eit rst-born child the following	her expecting:	a baby now or have a recen	t child
Only applicable to Deaf parent children in addition to their fir ii) Was any of Information on: Pregnancy Labor and Birth Ante-natal Classes Parenting Classes Parenting Access to GP	ts who are eit rst-born child the following	her expecting:	a baby now or have a recen	t child
Only applicable to Deaf parent children in addition to their fin ii) Was any of Information on: Pregnancy Labor and Birth Ante-natal Classes Parenting Classes Parenting Access to GP Access to Maternity healthcare	ts who are eit rst-born child the following	her expecting:	a baby now or have a recen	t child
Only applicable to Deaf parent children in addition to their fin ii) Was any of Information on: Pregnancy Labor and Birth Ante-natal Classes Parenting Classes Parenting Access to GP Access to Maternity healthcare Access to Child Development	ts who are eit rst-born child the following	her expecting:	a baby now or have a recen	t child
Only applicable to Deaf parent children in addition to their fin ii) Was any of Information on: Pregnancy Labor and Birth Ante-natal Classes Parenting Classes Parenting Access to GP Access to Maternity healthcare Access to Child Development Center	ts who are eit rst-born child the following	her expecting:	a baby now or have a recen	t child
Only applicable to Deaf parent children in addition to their fin ii) Was any of Information on: Pregnancy Labor and Birth Ante-natal Classes Parenting Classes Parenting Access to GP Access to Maternity healthcare Access to Child Development Center Child-Care/ baby sitting	ts who are eit rst-born child the following	her expecting:	a baby now or have a recen	t child
Only applicable to Deaf parent children in addition to their finii) Was any of Information on: Pregnancy Labor and Birth Ante-natal Classes Parenting Classes Parenting Access to GP Access to Maternity healthcare Access to Child Development Center Child-Care/ baby sitting services	ts who are eit rst-born child the following	her expecting:	a baby now or have a recen	t child
Only applicable to Deaf parent children in addition to their fin ii) Was any of Information on: Pregnancy Labor and Birth Ante-natal Classes Parenting Classes Parenting Access to GP Access to Maternity healthcare Access to Child Development Center Child-Care/ baby sitting services Equipment for Deaf/HOH	ts who are eit rst-born child the following	her expecting:	a baby now or have a recen	t child
Only applicable to Deaf parent children in addition to their finii) Was any of Information on: Pregnancy Labor and Birth Ante-natal Classes Parenting Classes Parenting Access to GP Access to GP Access to Child Development Center Child-Care/ baby sitting services Equipment for Deaf/HOH parents	ts who are eit rst-born child the following	her expecting:	a baby now or have a recen	t child
Only applicable to Deaf parent children in addition to their fin ii) Was any of Information on: Pregnancy Labor and Birth Ante-natal Classes Parenting Classes Parenting Access to GP Access to Maternity healthcare Access to Child Development Center Child-Care/ baby sitting services Equipment for Deaf/HOH parents Interpreting Services	ts who are eit rst-born child the following	her expecting:	a baby now or have a recen	t child
Only applicable to Deaf parent children in addition to their finii) Was any of Information on: Pregnancy Labor and Birth Ante-natal Classes Parenting Classes Parenting Access to GP Access to GP Access to Child Development Center Child-Care/ baby sitting services Equipment for Deaf/HOH parents	ts who are eit rst-born child the following	her expecting:	a baby now or have a recen	t child

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iii)		ion you were given the same or ere expecting your first child?	different from the inform YES/NO	nation you were given			
	Please explain						
iv)	support from: (if y Ke 2= You we 3= You had	During the time your child or children was/were born till now, did you have any access or support from: (if yes, please tick boxes) Keys 1= You were unaware of above services 2= You were aware but you had no information on how to access the above services 3= You had access to the above services but they were not deaf-friendly 4= Other (please specify)					
		Name and address of person/organizations (if possible)	What kind of support/services?	Reason for not getting the support, (using the above key)			
	Your family [une user one negy			
	Your friends						
	DCARA 🗌						
	CHIP (SF)						
	St. Joseph's Church						
	UCCD [
	Deaf Counselling Services						

Hearing Counseling services		
Child Development Center		
Social Services		
After School Programs:- HIP:		
Project Insight:		
Child's school:		
Other: [(please specify)		
HIP/Hearing Society		
SF Library Deaf		
Center		
Deaf Services Network North		

Other Deaf		
· · ·		
organizations		
Hearing		
Treating		
organizations [
Otl. D		
Other Parent		
groups		
groups		
C 1.C . \square		
Council Services		
T / /		
Interpreting		
Services		
Services		
Other (please state)		
o mer (preuse state)		

Any other comments on the above services?

issues? Please list as mud	ch as you can.			
Pregnancy:				
Labor & Birth:				
Pre-natal Classes:				
Pre-natal Clinic:				
Nurseries:				
Schools:		_		
Child Development:				
emia Development.				

Parenting:	
Equipment for Deaf/ Hard of Hearing Parents:	
Other (please give details):	
(premse g. (e armins).	
Any other comments?	
Any other confinents?	
) Resources:	
Are you aware of any services currently available to deaf parents in the San Francisco and Bay Area? Yes No No	
If yes, please list them and state where are they based. (Please include contact details if possible).	

i)

	parenting? Yes No No	nat cover this area of in	iterest i.e. Dear
	If yes, please list them and state where are they based. (Ple	ease include contact de	etails if possible).
V(iii	What subject would you like to have information on?		
111)	Pregnancy		
	Labor and Birth		
	Antenatal Classes		
	Antenatal Clinic	Ц	
	Nurseries Schools	\sqcup	
	Child Development stages & Behavior		
	Parenting	H	
	Helping your child with reading/writing etc		
	Choosing school for your child		
	Equipment for Deaf/ Hard of Hearing Parents		
	Other (please give details)		
	What formats would you like information to be in?		
	Written		
	Leaflets		
	Information Sheets		
	Books		
	Posters		
	Video with captions		
	Video with ASL interpretation		
	ASL Video		
	Other format (please give details)		
n)	Internet/Email Information Services		
11)	Would you like information to be available via the Interne	et? Yes No No	
	Would you be interested in an email group for Deaf Paren	ts? Yes No No	
	Would you be interested in an internet chat group for Dea	f Parents? Yes	No 🗌
	If yes to the above, would you like to leave your email add	dress?	

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o) Evaluat	tion:
i)	Any comments about the interview as a whole?
ii)	Is there anything you wish to add that has not been covered by the interview? (i.e. plan for future, health, social, education, family, career etc)
iii)	Is there any advice you would like to offer to future Deaf parents?
iv)	If you has one wish, what would you want to have available for Deaf parents?
v)	Your child will become a teenager, is there anything you wish to discuss about raising a teenager?
Looki	Would you be interested in knowing about future research on Deaf Parents with teenagers, which will start sometime in the Summer of 2001? Yes No No would you agree for me to pass on your contact details on to Paul Preston of Through the ng Glass?

Questionnaire Appendix – Child Development Chart: Chart 1 DEVELOPMENT: BIRTH TO AGE 5

Chart 1

Every child may not match the chart. A child develops a skill when he or she is ready

Age	What the child learns	What the child Does
Birth - 3 months	Trust, cooperation, personal power (such as effects of crying)	Gains head control; grasps and holds; makes sounds. Smiles in response to others . Shows distress, delight, boredom. Is forming routine for eating, sleeping
3-6 months	To affect the environment through body movement	Sits with support. Reaches; grabs objects suddenly. Imitates sounds; uses sounds to show likes, dislikes. Recognises familiar objects. Is very social.
6-9 months	More awareness of consequences of behavior	Sits up, stands with help, crawls. Uses thumb and fingers to grasp small items. Drinks from cup. Is growing more independen. Imitates behaviour. May say "Mama" and Dada". May recognise own name and word "no". Notices others feelings - joins other children if they cry, laugh. Is anxious about strangers; may be fearful, even of what is familiar.
9-12 months	More awareness of consequences of behavior	May crawl up and down stairs. Stands. Is better at grasping, holding. Often cooperates in getting dressed. May say a few words. Shows and recognises moods. Is aware of unspoken communication. Is often loving; is more assertive. Fears strangers, being separated from parents.
1-2 years	Beginnings of self- confidence	Walks (usually by fifteen months). Explores; empties, fills things; drops, throws things. Feeds self. Wants to be both independent, dependent. Uses clearer language. Becomes a toddler.
2-3 years	More self confidence	Grows more independent- wants to do things own way. At times wants to return to babyhood. Moves around without bumping into things. Speaks in sentences o 2-4 words. Asks "what?" and "why?". Has longer attention span, memory. Likes to help. Plays beside other children. Gets grater bowel and bladder control
3-4 years	More sociability	Cooperates more. Improves in coordination. Is talkative; enjoys hearing stories. Wants to be like parents. Recognises sex differences. Chooses clothes; dresses self. Likes to be with same age children. Learns to take turns, share. Begins to understand ideas of yesterday today tomorrow.
4-5 years	To grow in abilities already learned	Pefers children over adults. Has make believe friends. Has firm sense of home, family. Is very active-runs, jumps, climbs. Is increasing in fine motor-abilities. Likes to talk, express ideas, ask complex questions. Likely to have good bladder bowel control; may have accidents. Is growing in awareness of time.
5-6 years	To adapt to the world of childhood and to be ready for school	Begins to care about other children's opinions. Has more advanced reasoning powers. Has good control of hands, legs; eye-hand coordination not fully developed-has accidents involving hands. Becomes right or left handed. Is talkative, has good vocabulary. Is loving, helpful to parents. Likes to make friends. Plays with both sexes. Develops sense of fairness. Wants to be independent, trated like an adult.

Source: UCCD University of California Center on Deafness, Child Development Chart provided by Judith Fruge 'Chart 1 Development: Birth to Age 5' San Francisco California USA

Appendix 9: Consent form for Senior Citizens to participate in the workshop

Consent Forms to Participate in workshop discussion for the project: '<u>Deaf</u> <u>Parenting: Raising a Child - An initial study on Deaf parents with children aged infant to eleven years old.</u>

I am being asked to participate workshop discussion as part of a study conducted by Sabina Chowdry, the researcher. The study is a three months study on Deaf parents with deaf/hearing/disabled children. My family and I have been selected as possible participants in this workshop discussion group because I am a Deaf parent who already had grown up children.

As a participant in this discussion group, I understand that the discussion meeting will take place in a group of deaf parents like myself. The meeting will take at the minimum of about two hours, with the flexiblity of breaks. The researcher who has been trained in issues of confidentiality will facilitate this meeting. The purpose of the meeting is to discuss topics relevant to Deaf parents who already had grown up children and their previous experiences of raising a child in the old days.

Consent for Videotaping

I am aware that the meeting may be videotaped. The purpose of the tape is to help the researcher more accurately recall what was discussed during the meeting. The tape will be identified by date only, with no names or identifying information attached. The tape will be kept for a maximum period of five years after the completion of the project or publication of the project study, whichever comes later, after which time it will be destroyed.

Benefits:

By participating in this interview, the potential benefits to me are:

I will have the opportunity to participate in a research project, which aims to explore families, and the service provisions for deaf parents. My participation in this research may provide me with the experience of sharing ideas and perspectives with other Deaf parents who already have grown up children. Further, through my participation, I may gain a clearer understanding of my role as Deaf parent and how it changes from old days to now. Also, my participation would offer the benefit of my experiences to the future Deaf parents and may lead to increased sense of empowerment. This group will also discuss any new ideas and suggestions for development/ improvement of service delivery. My participation will help the researcher better understand the issues facing Deaf parents.

Risks

By participating in this interview, the potential risks to me are:

I may experience feelings of anxiety or distress in response to topics brought up. If I experience any undue anxiety or distress as a result of my participation in this research I can contact Barbara Bell, Supervising Clinical Social Worker at Hearing Society for an appointment. Her contact number is (415) 834 1005 (TDD) and her business card can be obtained from the researcher.

Confidentiality:

I understand that after the meeting, the information on flipchart and/or recorded on videotapes will be kept in a locked file cabinet for the maximum of five years after the completion of the study (or publication of the final project report, whichever comes later), after which time they will be destroyed by shredding.

Limits to Confidentiality

If any information is brought to the attention of the project researcher that leads her to think that I might be at risk of significant harm to myself, may harm someone else, or there is reasonable suspicion of child, elder, or dependent adult abuse, they are required by law to report these to the appropriate authority.

As a participant in this study, only the researcher will know my full name and specific responses on the survey. I also understand that all papers with my name on them will be kept in a locked file cabinet and will be destroyed as stated above.

I have the right to refuse participation in this study. If I agree to participate in this study I may choose not to answer certain questions that make me uncomfortable or invade my privacy. I may feel free to withdraw my consent to participation at any time with no consequences to myself or family and my data will be shredded.

If I have any questions now or at a later point, I may call the researcher, Sabina Chowdry on (415) 834 1005 (TTY) or email her on sabina chowdry@hotmail.com. I have been given a copy of this consent form to keep.

(111) of chian her on saoma_enov	vary concumanteens. I have been given a copy	or this consent form to keep.
e e	owledge that I have read and understood the aterview and that the interview may be videota	•
Participant's signature	Date Researcher's signature	Date

Appendix 10: Simple Questionnaire for Senior Citizens

Deaf Parents with grown up children Discussion Group

I am currently doing a research project on Deaf Parents in order to identify common themes/ issues and their access to services. This is part of my degree in International Social Work Studies.

Please complete the following questions about yourself. All information will be kept confidential.

2) <u>Personal Details</u>	
Your name: (optional)	
a) Gender/Age: Male	:
b) Race/ Ethnicity/ identity: Which of the following best describes your race or ethnicity African American or Black Latin American or Hispanic Asian American/ East Asian Pacific Islander Other: (please specify)	
How do you identify yourself? Deaf Deafened Hard of Hearing Other: (please specify)	
Any comment about your identity?	
c) Your preferred language used: Sign language: ASL user Other sign languages (please specify) Spoken language:	
English Chinese Spanish Other communication methods (please specify)	
d) Religion: What is your religion? How often do you participate in religious or spiritual activities either at home or w Daily Monthly Not at all Weekly Yearly Other	
 e) Relationship status: What is your relationship status? Married or with a partner Other (please specify): Single, separated, divorced, widowed 	

f) Education History: Did you receive any educ	eation? Yes No				
☐ Deaf School	Mainstream School				
Deaf College	Mainstream College				
Deaf University	Mainstream University				
☐ Not at all	Other (please specify)_				
What is the highest grade	you have completed so far?				
Are you still in Education	n now? Yes	No			
If yes, what are you study	ring now and where?				
Unemployed, s Unemployed, N	rment, part-time seeking work NOT seeking work , if so, do you stay at home as pecify)	s a parent □, or are you ret	ired □		
h) Housing Are you living in:					
A Large City	A Small Town	A Rural Area	A Suburban Area		
Is your home: Privately owned accommodation Rented accommodation					
☐ State provided accommodation ☐ shared ownership accommodation					
Other (please specify	·)				

i) Your parents/ family backgrou	una:
----------------------------------	------

Were your parents and brothers/sisters?

Their relationship to you	Hearing	Deaf	Other (please specify)	

How did you communicate with your parents and your brothers/sisters? (Tick all boxes that apply)

Name of	ASL	Other Sign	English	Chinese	Spanish	Other	Other
Family		Language, please	_			spoken	communication
member		specify				language,	method
						please	
						specify	

Any further comments on communication with your family?

i)	Your	child	child	lren
----	------	-------	-------	------

i)	Is any of your child(ren):			
	Deaf	Hearing	Deaf with disability	Hearing with Disability

ii) How do you communicate with your child(ren)? (Tick all boxes that apply)

Name of your children	ASL	Other Sign Language, please specify	English	Chinese	Spanish	Other spoken language, please specify	Other communication method

k)	Resources:	
i)	Are you aware of any services currently available to deaf parea? Yes No No	parents in the San Francisco and Bay
	If yes, please list them and state where are they based. (Ple	ease include contact details if possible).
ii)	Are you aware of any research projects/ materials/ books to parenting? Yes \(\square\) No \(\square\)	hat cover this area of interest i.e. Deaf
	If yes, please list them and state where are they based. (Ple	ease include contact details if possible).
iii)	What subject would you wish you had information on? Pregnancy Labor and Birth Antenatal Classes Antenatal Clinic Nurseries Schools Child Development stages & Behavior Parenting Helping your child with reading/writing etc Choosing school for your child Equipment for Deaf/ Hard of Hearing Parents Other (please give details)	
	Written Leaflets Information Sheets Books Posters	
	Video with captions Video with ASL interpretation ASL Video	
	Other format (please give details)	

l) I		Email Information Services you like information to be available via the Internet? Yes No No
	Would	you be interested in an email group for Deaf Parents? Yes \(\subseteq \text{No} \subseteq \)
	Would	you be interested in an internet chat group for Deaf Parents? Yes \(\scale \) No \(\scale \)
	If yes to	the above, would you like to leave your email address?
m)	Evaluat vii)	ion: Any comments about the meeting as a whole?
	viii)	Is there anything you wish to add that has not been covered by the meeting? (i.e. plan for future, health, social, education, family, career etc)
	ix)	Is there any advice you would like to offer to future Deaf parents?
	x)	If you has one wish, what would you want to have available for Deaf parents?
	xi)	When your child was a teenager, were there anything you wish you knew about raising a teenager?
Th	ank you	for your participation in the interview.

SECTION 6: Resources for Further Information/ Support:

BDA, British Deaf Association (1997) 'Deafinitely worth thinking about' Information pack (1997), BDA, 1-3 Worship St, London, EC2A 2AB, UK Tel: 0207 588 3520 Voice/minicom, Fax: 0207 588 3527

DCARA **Signing Families Playgroup**, for Deaf parents with hearing children (KODA), CODA with their hearing children, Deaf grandparents and grandchildren of Deaf adult (GODA), all nieces/nephews of Deaf adults and Hearing parents with deaf children (including relatives/siblings) www.dcara.org

DPPi, **Disability, Pregnancy & Parenthood International** National Centre for Disabled Parents, Unit F9, 89/93 Fonthill Road, London N4 3JH UK Tel: 0800 018 4730 (Helpline) 0800 018 9949 (Text) 020 7263 3088 (admin) 020 7263 6399 (Fax) e-mail dppi@eotw.co.uk web: freespace.virgin.net/disabled.parents

FamiliesFirst Deaf Foser Care Program: Information pack, including articles and a specification for recruiting Deaf Carers, Oakland CA USA (www.familiesfirstinc.org)

FamiliesFirst Deaf Foser Care Program: **Recent information pack, including leaflet and newsletter,** Oakland CA USA (www.familiesfirstinc.org)

Gallaudet University Laurent Clerc National Deaf Education Center Information pack including: **Shared Reading Project: Keys to Success Training for site Coordinators** and Shared Reading Project and workshop leaflets, Gallaudet, Washington, USA www.clerccenter.gallaude.edu

GURC, Gallaudet University Regional Center (2000) Information on Training Workshop, Reading to Deaf Children and Read It Again and Again Workshop Ohlone College, Freemont, CA, USA

Hearing Society for the Bay Area Inc (2001): Information Pack, Programs and Services Leaflets including information on HIP, Hearing Impaired Program and Oakland Deaf and Hard of Hearing Youth Project, San Francisco, USA

IMPACT, Independently Merging Parent Associations of California Together for Deaf and Hard of Hearing Children (2000) information sheet

Midwifery Today (1993) 'Birth and Disability' Midwifery Today and Childbirth Education Autumn 1993

Oakland Deaf and Hard of Hearing Youth Project, part of HIP, Hearing Impaired Program/Hearing Society for the Bay Area Inc: **Mission statement; services offered and Family Support Program Services**, San Francisco, California, USA

Project Insight (2001) **After School Program Information Pack,** Recreation and Park Department, City and County of San Francisco, California, USA

RNID, Royal National Institute for the Deaf' A GOOD SIGN Goes a Long Way The experiences of some Deaf Mothers' by Veronica Lewis, Available from the Royal National Institute for the Deaf, 19-23 Featherstone Street, London, EC1Y 8SL UK Tel: 020 7296 8000 (voice) 020 7296 8001 (text) 020 7296 8199 (FAX)

South West Community Health Centers Inc. (1982) Information booklet 'Growing Up, an introduction to human growth and sexual development', Ohio, USA

Teen Pregnancy Prevention Program (DCARA): **Information leaflet** San Leandro, CA USA www.dcara.org

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