

CHAPTER ONE

The young deaf people and their families

I want hearing people to learn about deaf people

Isabel

In your wildest dreams you cannot imagine the way I feel

Isabel's mother

Isabel is an articulate young deaf person. She has a good command of English, though not everyone could understand her speech. She uses English with her parents and hearing friends, and sign language with her deaf friends. In an interview, she described how she signed in her dreams and explained 'It's something to do with having a signing mind'. When she was young she thought that when she grew up she would be hearing as all the adults she knew could hear. She and her deaf friends used to discuss this at school, looking forward to the time when they would talk as quickly and easily as their parents did. However, by the time she was seven or eight years old, she realised she would always be deaf. She was always educated alongside other deaf pupils but she felt it was worse for her deaf boyfriend who went to a school with all hearing pupils, as he was very lonely and thought he was 'the only deaf person in the world.'

As an adult, Isabel explained 'I am happy to be deaf', though she also added that if there was an operation that was successful in restoring hearing she would consider it. She described her relationship with her boyfriend as 'beautiful' as they cared for and helped each other. She felt it would be difficult with a hearing boyfriend because, although when they were alone together they could probably communicate easily, in a group of hearing people she would find it difficult to follow the conversation and that could lead to problems. She said:

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I once had a hearing boyfriend, and if we were out and I couldn't understand he'd say 'I'll explain later'. Then when we got home I'd ask but he could never remember. That upset me. I've been through all of that. It was a terrible time, I was really hurt.

At the time of the interviews, Isabel was working as a personal assistant in a large company, a post which required only a good general educational background and which offered no further training. She would have preferred to be a teacher and hoped to go to college at some time in the future to train for a position that would be more demanding. She said she was happy at work and found the job interesting, particularly when she detected errors in the bills that were sent in. Her mother was not so sure.

I don't think Isabel's talents have been fully tapped, but I think it's the deafness again. () She thinks it is totally boring what she is doing, but she realises the money is good and that she is lucky to have a job because she is disabled. This is not the way I feel, but how she feels. She hears of so many friends of hers that are out of work because nobody really wants to know them. () With Isabel being deaf, promotion is not easy. () There are not many jobs you can do without using the telephone.

Isabel was two months old when her parents first noticed that she did not seem to respond to sound, although it was not until she was two years old that the doctor finally confirmed she was deaf. Her mother reported that the doctor said:

'Mrs A... you've definitely got a problem. Isabel is deaf.' That was all. That was all I was told at the clinic, and I was very upset.

Isabel was a lively, alert child who was rarely miserable. She enjoyed drawing, writing, her climbing frame and her swing. In an interview when Isabel was nearly four years old, her mother said she enjoyed Isabel because 'she's her' and said she would not swap her for anything. Decisions that had to be made about Isabel's education were difficult. Should she go to the local school, or a specialist school for deaf children some distance away? Should sign language be used in her education, or should it be strictly speech- and English-based? Ultimately she went to a specialist boarding school, which used a spoken language approach, at 11 years of age.

In a second interview with this mother, when Isabel was 21 years old, she said:

I could never see the light at the end of the tunnel. I think that what it is, I could never see Isabel developing into the person she is today. () I felt she would be always and for ever needing help which she doesn't.

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In both these interviews Isabel's mother talked of the lack of information about deafness, of not knowing what to expect. In the interview when Isabel was a child she said:

I would like to know more about deaf children and possibly meet more deaf children – more deaf people as far as that goes.

She felt that people did not understand about deafness, and said:

*People are not quite sure what to do about her. It's not that they mean to be, they don't mean to be that way, they don't know how to go on. The truth of the matter is that there is not enough known about deafness. The general public, they don't know enough about it.
(DCF, p. 196)*

In the later interview, Isabel's mother again spoke of the lack of general understanding and awareness of deafness, this time with respect to parents of newly diagnosed deaf children:

I have been saying this for 21 years. There should be someone they can talk to who has probably had and brought up a deaf child. Yes. Because I know that would have helped me. But when I suggested it once it was pooh-poohed and they didn't want to know. And as I said to the surgeon, an ear nose and throat surgeon, 'in your wildest dreams you can't imagine the way I feel. That's true.'

Isabel herself felt that most hearing people did not understand about deafness and deaf people. She said:

I want hearing people to learn about deaf people. Hearing culture is different from Deaf culture and hearing people don't understand that.

This book is an attempt to provide insights into deafness, to describe what it is like to grow up as a deaf person and to consider the experience of hearing parents with deaf sons and daughters. Rather than being written from a professional perspective, it seeks, by using interview data, to reflect the views of deaf young people and their families. It is based on three sets of interviews. The families were originally interviewed in the 1970s, when their deaf sons and daughters were six years old or less. Further interviews were carried out with the same families, and with the young deaf men and women themselves, in the late 1980s, some 18 years later. The study reported here considers the whole period of growing up, and the way in which attitudes have changed over that time. It also examines the continuities and discontinuities between early behaviour, experience and later life. Such personal accounts allow a consideration of more general

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issues in deafness, as well as challenging commonly held assumptions in the hearing world.

The information is also particularly significant for hearing families with deaf sons and daughters. One of the enduring memories of the research interviews with the parents was that at the end of the interview they were offered the opportunity to ask any question they liked. Many asked 'Are we like other families?'

Isabel and her family were part of the group that was interviewed for this book. We have started with a description of their experiences, not because they are necessarily typical of all those interviewed, for as we shall see the lives of the young people and those of their families are diverse and varied, but because her experiences illustrate many of the issues that arise for young deaf people and their families and which are the concern of this book. She talked of her own feelings about being deaf, her developing identity as a deaf person, her hopes for the future in terms of personal life and career. Her family described the shock of finding out she was deaf, their fears that she may never be able to cope, the difficulties they experienced in bringing her up, and their feelings about her growing independence. They also talked about the decisions that had to be made concerning language and communication, discipline, education and work. Her mother spoke on a number of occasions about the lack of information generally available about deafness, something which we hope this book will remedy.

The account of Isabel and her family illustrates one of the major themes of the book: language and communication. While Isabel is linguistically competent, like many deaf people she finds it difficult to understand spoken English and her speech is not easily understood by those who do not know her. This has implications for communication within the family, for education, work and social life, all of which are considered in the book. Some of the deaf young people described in the book developed spoken language, some sign language and some both; with varying degrees of competence. Because of the difficulty in accessing spoken language and because sign language was not widely available to them, particularly when they were young, some of the young people in the book do not have Isabel's linguistic competence, and the implications of this are discussed.

After the shock of the initial diagnosis, Isabel's family gradually came to accept that she was deaf. For other families it was much more difficult to come to terms with the deafness, and some families felt their lives to be blighted. One mother, for example, when asked what she enjoyed about her son, said, 'there's never been a good day with him, not one'.

Isabel had an active social life with both deaf and hearing friends, although she generally preferred the company of deaf people. Isabel

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identified with other deaf people, and felt she was a member of a Deaf community which she felt differed from the hearing world. Other young deaf people whom we interviewed elected to spend most of their time in the hearing world, some feeling that their deafness made little difference to their lives. As one young woman said, 'I have never regarded myself as different'. Yet others felt that they belonged nowhere. As one deaf young man said, 'I don't fit into a hearing world and I don't fit into a deaf one'.

The young people differed also in the extent of their hearing loss. Isabel would be described as severely deaf, meaning she could hear loud noises such as a large lorry passing by, but not the sound of the human voice. Others could hear voice and use the phone, while others could hear almost nothing at all. Although the extent of the hearing loss cannot be disregarded, we ourselves are not happy with a classification of this group simply in terms of what they cannot hear, for reasons to be explained later in this chapter. It is the consequences of deafness, rather than the degree of hearing loss, that are more important.

However, there is one important element that these families have in common. The young people were all born deaf, or became deaf very early in life. This sets them apart from people who become deaf later in life, when they have already learnt the spoken language of their community. Most people's experience of deaf people will be of this latter group, for while in the UK at present there are 50 000 to 70 000 individuals who were born deaf, the total population with a hearing loss is around 7.7 million, and for 2.3 million of these, the loss is likely to have a significant effect on their day-to-day lives (Institute of Hearing Research quoted by the Department of Health and Social Security (DHSS), 1988).

This chapter introduces the book, identifies some of the issues that will be discussed, and describes changes in society which have affected the lives of deaf people over the past 20 years. It also looks at the research methodology in some detail and discusses the use of interviews as a research tool. The second chapter focuses on the issue of communication by looking at communication within the family. In the following three chapters we move into the public domain by looking at school and education, work, and communication in the wider context. In Chapter 6, we return to more private worlds and consider the social lives and friendships of the deaf young people. Chapter 7 discusses what it is like to grow up as a deaf person, how the deaf young people feel about themselves and their developing deaf identity. Chapter 8 examines the impact of deafness on family life and explores in some detail the relationship between early experience and later life. The final chapter presents an overview of the whole book and returns to the major themes and issues raised in Chapter 1.

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THE CONTEXT OF THE STUDY

One of the important characteristics of a book such as this, is that it provides an opportunity to look at the way in which childhood experiences, attitudes and behaviour relate to later life. Yet the period of time covered by this book has been one of great change in attitudes to deafness, and in the legislative structures and social policy that affect the lives of deaf people. Although in the book our focus is on personal experience and we hope for the most part to allow the contributions from the parents and young people to speak for themselves, it seems necessary in this first chapter to consider aspects of the wider context in which deaf young people grow up and the changes over the period of time covered by this study.

Language, communication and deafness

A major issue for hearing parents, with daughters and sons who are born deaf or become deaf early in life, is the development of language and communication. Although for some of this group hearing aids do much to make spoken language accessible, for others access to spoken language is difficult. At the time when these families were first interviewed, the dominant ideology was oralism. Parents were encouraged to use speech with their children and to try to develop their speech through the use of hearing aids and attention to lip-reading skills.

Since that time there have been conflicting influences on our approach to deaf children. The oral approach appeared to fail a significant number of children. In a classic study reported in 1979, Conrad demonstrated that for half of all those leaving educational provision for deaf children at 16 years of age, their speech was effectively unintelligible or very difficult to understand, their lip-reading skills were no better than those of hearing pupils who had not had specific training in the skill, and the median reading age was nine years (Conrad, 1979). At the same time, sign languages, which until then had been seen by many as crude systems of mime and gesture, came to be recognised as having the full linguistic properties and potential of other spoken languages. Different countries have their own unique sign languages and the sign language of the UK is British Sign Language (BSL), a term that was first used in 1975 (see Brennan, 1976). In 1988, the European Parliament recognised all European sign languages. This developing understanding of the status of sign language, together with research findings indicating that deaf children of

deaf parents were more successful in language development and some academic measures, led to increasing attention being given to the potential role of sign languages in the early development of language with deaf children.

However, during this time, developments in hearing-aid technologies meant that the goal of spoken language development for deaf children through speech and hearing seemed all the more possible. Moreover, the development of cochlear implants, a sophisticated form of hearing aid which is actually implanted into the inner ear providing a perception of sound, has focused attention on the remediation of deafness. Although cochlear implants are currently limited, both in the population for which they are appropriate and in their ability to restore normal hearing, their development and the ensuing publicity with its claims of a 'bionic cure for deafness' have had an impact on debates about the appropriate language for deaf children and young people.

Education

Attitudes to sign languages have had an impact on educational policy with deaf children, as have more general changes in the educational arena in terms of general changes in educational policy and practice. The types of educational provision available for deaf children throughout this period were:

- (a) Special schools, where all pupils are deaf and the approach may be oral or incorporate sign language.
- (b) Partially Hearing Units (PHUs) or resourced schools, which involve groups of deaf children being educated in ordinary (mainstream) schools. In a PHU they are educated in a class group, although most spend time in classes with hearing children. In the resourced school, the deaf pupils are seen as part of the main school, but with support from specialised staff and with special provision for withdrawing them for some of the time. The approach may be entirely oral or include sign language.
- (c) Integration, in which deaf pupils attend their local mainstream school or another suitable school and are educated alongside hearing pupils, usually with visits from teachers of the deaf. We have used the term 'integration' here and throughout the book, as it is the term used in the UK and by young people and parents. However, it cannot be assumed that because a deaf pupil is receiving integrated education they are fully involved with the hearing pupils, as the term itself may seem to

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imply. The approach is almost always oral, although a minority of integrated deaf children are educated in sign language through the provision of an interpreter.

- (d) A few deaf children are educated in other special schools or units, for example those designed for children with physical disabilities or learning difficulties.

During the period covered by this book there has been a shift from placing deaf children in special schools to placing them in mainstream schools, firstly through PHUs and more recently through integration. The initial shift was from special schools to PHUs, and while in 1970, in England and Wales, there were 212 PHUs, by 1980 there were 500 (National Deaf Children's Society, 1971, 1982). The number of pupils in special schools declined in this period from 5781 in 1972 to 4847 in 1980 with a further steep decline to 3808 in 1983 (quoted in Lynas, 1986). The 1980s saw a shift to integrated education not only for deaf pupils but also for all those with special needs, formalised in the 1981 Education Act, which was implemented in 1983. It established the principle that 'all children for whom the Local Education Authority (LEA) decides to determine that special educational provision be made () are to be educated in ordinary schools in so far as is reasonably practicable' (Department of Education and Science (DES)), 1981. While in the early 1970s it was unusual for a deaf child to be integrated, a survey for the NDCS in 1987 showed that nearly three-quarters of deaf children of school age, supported by Teachers of the Deaf, in England Scotland and Wales, were educated in mainstream schools.

Not only the location of the education of deaf children changed over the period, but also the educational approach. There has been a shift from the strong oral policy of the period until the 1970s, to the greater use of sign language in schools. The first move was to Total Communication, described by Denton (1976) as comprising 'the full spectrum of language modes, child directed gesture, the language of signs, speech reading, finger spelling, reading and writing () the development of residual hearing for the enhancement of speech and speech reading skills'. In practice this has often been realised as an approach where speech and signs are used together, sometimes known as Sign Supported English (SSE). Here English is spoken and signs taken from the vocabulary of BSL are used at the same time. The results of this approach in education have been equivocal and more recently approaches using full BSL have been developed, taking a bilingual approach to the education of deaf children in which both English and BSL are seen as having a unique and separate contribution to make.

All these changes were occurring as the young people in this study

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passed through the education system, and these affected both the events that happened to them and the way they were described by both parents and young people.

The Deaf community

Within society as a whole, deafness is usually seen as a major handicap or disability. Deafness is viewed primarily as the inability to hear, to participate in conversations, to appreciate music or birds singing or to be aware of sound warnings of danger. This is not surprising, because most people with a hearing loss come from the group of people who become deaf with age and gradually have more and more difficulty hearing. The book describes a different group, who are born deaf or become deaf early in life, and the issues are different. They are not a group who have lost the ability to hear the spoken word or music or the birds singing – these things may have never been part of their lives or have functioned in a different way from that in the lives of hearing people.

While for some adults who were born deaf, understanding of their deafness is also based on notions of loss or impairment, for others, however, being deaf is an integral part of their being. They do not see deafness as impaired hearing, but see themselves as having a Deaf identity, as part of a community that has its own language, in this case, BSL. The recognition of BSL has given Deaf people not only a pride in their own language, but also a sense of their own identity as Deaf people, as part of a community with its own history, culture and customs (Gregory 1993). As in other minority groups, the Deaf community has recently been reconstructing its history from within (Jackson, 1991). Some members of the Deaf community now reject the idea that they are disabled and assert that they are members of a linguistic minority group. To emphasise this cultural identification, they refer to themselves as ‘Deaf’ rather than ‘deaf’. The implications of these different notions of deafness for deaf young people and their families will be discussed in the book.

INTERVIEWING DEAF YOUNG PEOPLE AND THEIR FAMILIES

Interviewing is not an unproblematic way of obtaining information about people’s lives and experiences. Even when a language and culture is shared, people’s views and opinions do not exist pre-formed and ready to emerge in answer to the interviewer’s questions. Interviewing deaf young people,

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even in their preferred language and modality, can reveal misguided assumptions on the part of the interviewer and misperceptions on the part of the young person. The remainder of this chapter and the related appendices (Appendices I, II, III) set out in some detail the issues involved in re-contacting a group of families after 18 years and in carrying out interviews with them. We felt it necessary to do this in some detail for, while superficially a consideration of research methodology may seem simply to concern procedural matters, in essence the section addresses issues that are critical to the study and to an understanding of the results.

In this section, we look in some detail at the families involved in the study, how they came to be selected, how contact was re-established after some 18 years and who was lost through this process. We also look at the construction of the final sample, and the procedures for carrying out the interviews. We consider which interviews were able to be included in the formal, quantitative analysis and those that were excluded from this, with the consequence that some of the young people are not fully represented in the results. Unlike other similar studies we have decided not to describe the young people in terms of their hearing loss and we examine the factors that contributed to this. The young people are described by their preferred form of communication and we discuss what is meant by this. We also present some basic information concerning the communication competence of the young people. A summary of this information and demographic details of the sample are presented in Appendix II.

Contacting the sample

The research study is based on interviews with 82 parents of young deaf people and 71 young deaf people themselves. Not all the interviews are included in all the quantitative analyses for reasons which are outlined below. However, the discussion and quotes utilise all of them.

The parents

In the early 1970s one of the authors, Susan Gregory, interviewed 122 mothers, and sometimes fathers, of preschool deaf children. The sample was drawn from all children, in five local authority areas, diagnosed as deaf at the time of the study.

In designing the present study it was decided to attempt to contact 101 of the original sample, the initial contact being made with the parents. The reasons for excluding 21 of the original sample are discussed in detail below. Of the 101 families, 91 (90%) were traced. Contacts were made in a