Visually handicapped children and their families.

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A Sheffield Hallam University thesis

VISUALLY HANDICAPPED CHILDREN AND THEIR FAMILIES

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ABSTRACT

VISUALLY HANDICAPPED CHILDREN AND THEIR FAMILIES

Aims of the Study

1. To collect information on the needs and problems of families rearing a visually handicapped child, and to examine the extent to which their needs are being met by existing services.
2. To study the impact of rearing a visually handicapped child on family life.

Method of Study

The study was divided into two parts: Part I, to ascertain needs and problems and Part II, to study the dynamics of family life.

Fifty families, having a total of fifty five visually handicapped children took part in the first part of the study. The families were interviewed using a semi-structured interview schedule, the interviews being audio-taped and transcribed, with tapes being kept for reference.

An "Illuminative approach" (see Jamieson et al 1977) was applied during the analysis of the data.

In Part II, four families were selected to take part in an in-depth study of family dynamics. Each family member constructed models, using miniature dolls and other tactile materials to illustrate the changes in the functions of family life brought about by the diagnosis of blindness and the rearing of a blind child.

Content of the Study

The study is divided into seven sections, topics covered including: Visual handicap in a social setting; the impact of rearing a blind child on family life; the education of the visually impaired; doctor/patient relationships and client/professional communication. The work is illustrated throughout with quotes from the sample group regarding their experiences.

Some Main Findings

Under 25% of the eligible sample group were registered as blind or partially sighted. This under representation of the problem makes planning for the future difficult.

There were communication difficulties between many professionals and clients with associated differences in the perceptions of need. Professionals tend to work within their own "ivory towers" and do not communicate with professionals of other disciplines. This leads to patchy and uneven services.

Low ratings of satisfaction were awarded to some groups of professionals, and these low ratings were often associated with communication difficulties. High ratings of satisfaction on the other hand tended to be awarded where the client had: an on-going relationship, with the same named person, who is an expert in the field, all three of these inter-linked factors being necessary for client satisfaction.

The dynamics of family life are disturbed and disrupted by the diagnosis of blindness and the rearing of a severely visually impaired child in the majority of instances.

Passage through crisis, however, does not inevitably lead to family breakdown and it is worthy of note that a number of the families studied, although severely tested, appeared to emerge from the crisis, not merely intact but actually strengthened.

ACKNOWLEDGEMENTS

FOREWORD

Although this thesis is essentially about visually handicapped children and their families, it is also concerned with wider issues such as the ways in which the families function in society and the reactions of society to families who are rearing a visually impaired child. Just as it is impossible to study a blind infant in isolation of his parents, so the family has to be considered against the backdrop of the society which supports and sustains it.

A great deal of what has come to be termed 'social research', whether the collected data be predominantly 'hard' or 'soft', is concerned to discover **what** happened and **how** it happened. Fewer researchers, it seems, are particularly interested in finding out **why** it happened in the first place, and, more importantly, **why**, in spite of efforts to improve matters, the situation often remains unchanged or actually deteriorates.

During the study of the Sheffield families, social survey techniques were utilised to discover **what** happened to the families during their passage through crisis, and the 'Minisculpt' technique was designed to find out **how** the families coped during the process. The question **why**, in the late 20th century, such things are still **allowed** to happen, is however much more difficult to answer. It was whilst considering the reasons why things happened that I began to explore the history and evolution of some of the professionals concerned to heal and help the blind.

Throughout recorded history, certain themes and ideas have recurred, have been discarded, and have resurfaced again after varying periods of time. To take an example from the field of education: during the mid 19th century there were more blind children integrated into mainstream schools than there are at the present time. During the early and middle part of the 20th century however, due to changes in philosophy and the balance of power between the medical profession and educationists, segregation became the norm and the 'ideal'. Segregation remained the 'ideal' until once again the balance of power shifted and with it, the philosophy underpinning special education, thus paving the way for the 'new' movement for integration.

This thesis then is made up of several different kinds of data. First there are relatively 'hard' or 'stable' data mostly concerned with what happened, for example, the type of eye defect suffered, the process of diagnosis and the social backgrounds of the families. Second, rather softer and less 'stable' data largely concerned with how it happened, for example, the consultation process, the passage of the families through crisis and the ways in which they coped with grief. Third, underpinning the 'what and the how' lies a mass of background information, in which is embedded, often very deeply, some of the answers to the question of **why** it happened.

Some readers will no doubt question the importance or relevance of the 'why'. Other readers, seeking answers to the more pressing questions of what and how, may not at this stage be concerned with why. It is my thesis however that why, is of equal importance to what and how and I cite as an example the judicial system. In a court of law, the judge and jury are concerned with **what** the offender has done. The police are concerned with **how** he did it, but few, it seems are interested in **why** he committed the crime. It is probable however that in the answers to the question, 'why?' lie the means of preventing him from committing future offences and thus, indirectly benefiting a much wider section of society.

I am aware that some readers concerned to find out what visual impairment is and how they can best help clients will become impatient when confronted with long sections of medical history which appear to lead nowhere. For these readers, not interested in or concerned with the why, who wish only to pursue the main argument, I have presented much of the historical and background material in an alternative style, thus:

> with a note to the effect that the appropriate passage can be omitted by those readers who, for whatever reason are 'speed reading' or interested only in certain aspects of the thesis.

A note indicating the page for such readers to rejoin the main argument is added and the previous typeface resumed.

As with the alternatively presented passages, poetry and other literary quotations printed in italics can be similarly omitted if so desired. Italicised passages have been used to illustrate, to underline or to

comment upon some of the issues under discussion. For example, A A Milne's Pooh and Binker illustrates the topic of play and the poetry of Walt Whitman shows that the 'process of mourning' was known to poets and 'story-tellers' long before psychologists made the 'discovery'. In the final pages of the thesis, Biblical passages and poetry are utilized as a kind of 'Greek chorus', commenting as it were 'off stage' or 'in the temple'.

Although the historical and background material can be omitted without detracting from the main argument, the reader is here forewarned that on reaching the concluding section s/he will not find a concise set of 'Conclusions and Recommendations', but instead will be directed to return to the beginning of the work to consider again and reflect upon the issues raised because, as I have tried to show, often through history and poetry, embedded in the past lies the future, and much of our present already lies discarded in the past. But then, this has already been said by the poets, although it does not form part of the 'main argument':

> *"Time present and time past*
> *Are both perhaps present in time future*
> *And time future contained in time past".*
>
> T S Eliot: Four Quartets, Burnt Norton I

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CHAPTER 1

ORIGINS, BACKGROUND AND AIMS

BACKGROUND TO THE STUDY

Although concerned in essence with visually handicapped children and their families, this study, like Tolkein's (1969) narrative, 'The Lord of the Rings', "was a tale which grew in the telling", as things, "higher and deeper and darker than the surface" began to emerge.

Because of my professional background (a general and ophthalmic trained nurse) I had an inherent interest in children with visual impairment. However, after working for a few years in the community as a health visitor I began to realise that my background was in many respects unusual. I had for example had prior experience of working with the visually handicapped and had acquired a knowledge of screening procedures for visual defects and of the techniques of vision testing. Although health visitors in Sheffield are required as part of the child health surveillance programme, to check for squint and to test the visual acuity of pre-school children, few had received any training for this. Stycar single optotype charts are provided for the testing of visual acuity but it is noteworthy that instruction booklets are not provided as part of the package, nor is in-service training in the technique provided unless the health visitor herself requests this. (In view of this and bearing in mind that the problem is not confined to Sheffield, the finding of the Hall Committee (1989) to the effect that the routine screening of pre-school children for visual defects is not worthwhile in terms of case finding, is hardly surprising).

Data obtained from a survey of the health visitors in Sheffield (Bennett, 1981) revealed that 88% of them felt that the education and training they had received in aspects of ophthalmology and techniques of vision screening did not meet their requirements. Thirty four percent did not in any case have a complete set of equipment to enable them to carry out a full screening programme, had they felt competent to do so. Only 6% of the health visitors interviewed felt they had had a reasonable amount of experience in caring for people with eye defects and 4% of the

respondents had received no formal training whatever in the field. In view of these findings it was not surprising to find that 50% of the health visitors surveyed had never advised parents on any aspect of visual development or handicap. It also emerged that many health visitors did not in any case feel that advising and supporting the parents of a visually handicapped child formed part of their role. They felt that this was "a job for the experts" and that it should be undertaken by the hospital. It was therefore disturbing to find that, where health visitors had such families on their case loads, in 70% of instances she was the only professional person involved with the family.

From the findings of the health visitor survey (Bennett, 1981) it was obvious that there was a need for further research into the problems surrounding children with severe visual impairment. It seemed probable that the children and their families might have needs which remained unmet - perhaps to a large extent unknown. It was also apparent that the population of visually handicapped children in Sheffield was an unknown quantity, probably grossly under-reported. In order to try and answer some of the questions posed in the 1981 survey, I planned the present study with three broad aims in mind:

First; to attempt to enumerate the population of children with visual handicap in the city.

Second, to collect information about the needs and problems of families rearing a blind or partially sighted child and

Third, to find out in what ways family life was affected by the birth and rearing of a visually handicapped child.

Before embarking on a research study, it is necessary to establish the 'state of play' in the field by carrying out a search of the relevant literature. This however proved to be a somewhat unrewarding exercise. Literature concerned with the social aspects of blindness and visual impairment is sparse by any standard. Such as there is tends to be contained within highly specialised journals, which are not, as a rule, available to professionals of other disciplines. Many of these articles

are also written from a very narrow perspective and are therefore of little help to researchers studying the wider field of visual handicap. Turning to books, (which some would criticise as 'being out of date before they are published') proved to be equally unrewarding, there being no previous studies of the family life of blind children with which to compare the Sheffield sample group.

It was therefore necessary to widen the scope of the literature search to include the social aspects of handicap in general. It is also interesting to note that whilst social scientists and psychologists have, to a large extent, eschewed the study of blindness in society, the same cannot be said of poets, painters and musicians. Many of these 'artists' impressions' are in fact, first hand experiences of blindness. For example, in the hazy, sunset blur of Turner's later paintings we experience the world as through the eyes of a man suffering from cataracts, and in the writing of 'Samson Agonistes', Milton expresses the feelings of a man whose world has been 'totally eclipsed', "all dark amidst the blaze of noon". Storr (1992), writing in a similar vein with regard to music, points out that whereas the views of the ancients with regard to science have been superseded by present day discoveries, great works of art from the past are just as meaningful today.

Milton also reminds us, in his introduction to Samson Agonistes, that it is through works of art, for example the 'Greek Tragedies', that we learn about the real thing, and are able to experience to some extent, and to, as it were, 'rehearse' and 'learn our lines' for the actual role in life. This need to 'rehearse' for a future role is perhaps even more important today than in earlier times because, nowadays, serious illness and death are much less common, particularly in children and young adults. If, for any reason, access to works of art and literature is denied, (as is sometimes the case today, particularly with children undertaking a 'special' school curriculum), then, what may be the only opportunity to 'rehearse' certain life events is lost. Earlier generations were able to learn such roles as parent of a seriously ill child or the young widow from within their family or peer group circle. Today however this is no longer the case, and those who have to adopt such roles are set adrift without guidelines or role models in a largely uncharted ocean.

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It is my thesis therefore, that the wider literature of poets and 'storytellers' is as important to our understanding of the impact of handicap and crisis as is the 'knowledge based' research to be found in the professional journals. I therefore make no apology for including quotations from these wider sources in my study. However, as I pointed out previously in the foreword, the reader is under no obligation to include these extracts and they are, as I explained earlier, either printed in italics or presented in an alternative style.

The range of literature utilized in the study is wide, both from 'lay' and 'professional' sources (Milne to Milton and Fraiberg to Foucault). I also have to point out that I can lay no claim to 'scholastic learning' in any of the literary fields covered. Neither have I selected from the literature on the grounds of 'taste' (which is a matter of opinion – nearly always somebody else's) nor what is today regarded as 'good' or 'profound'. Extracts have been selected for 'effect' rather than for 'education' or 'edification', and have been used to illustrate or to underline certain topics in the essay.

The scope and ways in which data have been presented in the study are set out in the following pages.

SCOPE AND PRESENTATION OF THE STUDY

The study was, of necessity, exploratory in nature. The methodology utilized has been described by Jamieson et al (1977) and others, as 'illuminative' (see Chapter 2). Although basically 'client centred' or rather, 'client orientated', the scope is wide. Children, as I have argued, cannot be studied in isolation of their families, and by the same token families cannot be studied without giving consideration to the society which supports and sustains them.

The study can be thought of as being divided into two parts, each consisting of different kinds of data. The early sections, i.e. those concerned with the diagnosis of the defect and the early development and socialisation of blind children, contain relatively 'hard' data and the findings can often be compared with empirically based 'knowledge' and with

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the findings of other researchers. Later sections, for example those concerned with client/professional relationships, with grief, or with acceptance and coping, are much less tangible in nature, the data being therefore much 'softer' and less easy to compare with the studies of others.

At the heart of the study, and connecting these two portions is the bridging section which is concerned with education, curriculum and knowledge. The section concerned with education is therefore the pivotal point of the study, for, within knowledge lies power, and to be denied knowledge is therefore to be denied power.

The second portion of the study is devoted to relationship issues, to power and conflict and to the ways in which knowledge (and therefore power) is often withheld from clients. The final pages are concerned with the empowerment of clients and the study concludes with a consideration of some of the ways in which this might be achieved.

The Study in Outline

The thesis is divided into six sections, each having a different emphasis and purpose. Each section is divided into several chapters and these are numbered consecutively throughout the thesis. Sections begin with a short introduction and end with a summary of content and conclusions.

Section 1   Forms an introduction to the study, describes the methodology used and presents a summary of the findings.

Section II   Is concerned with the rearing and socialisation of visually handicapped children.

Sections III   Explores some of the issues surrounding the education of the blind.

Section IV   Is concerned with the evolution and education of doctors and ophthalmologists.

The sections and their relevance to the literature are outlined below.

Section I. Introduction and Overview

The introductory section is divided into four chapters. The background,
aims and evolution of the study are discussed, the methodology is described
and the main findings are summarised.

Chapter 1 In the first chapter the background and aims of the study are
described along with the scope and presentation of the work.

Chapter 2 deals with methodology. The 'illuminative' method, as utilized
by Jamieson and colleagues (1977) is discussed, and the way in which the
study was actually carried out is described. The 'Minisculpt' technique
is described together with its evolution and practical application.

Chapters 3 and 4 are concerned with facts, figures, findings and fallacies.
Some facts about blindness and visual handicap are presented and some
common fallacies explored. The families forming the sample group are
presented in their social settings. The main findings from the survey and
the 'Minisculpt' models are summarised in Chapter 4.

Section II. The Rearing and Socialization of Blind Children

This section is divided into five chapters and deals with the rearing and
socialization of visually handicapped children. The ways in which their
special needs impact upon the family as a system and family life in general
are considered.

Chapter 5 deals with the discovery and diagnosis of the handicap and is
largely given over to the parents who describe their experiences. In many

instances there was a delay between the discovery and the actual diagnosis of the condition, sometimes amounting to many months - a finding borne out by Walker and colleagues (1992) in the RNIB study. Some of the explanations for this situation are explored and related to the literature. For example, the spoiling of identity is discussed with reference to Davis (1982) and stigmatization in relation to the work of Goffman (1963).

Chapter 6 considers the ways in which the rearing of a visually handicapped child can alter the structure and functioning of the family unit. Subjects explored include: the marital relationship, family limitation, parental health, extended family support networks and the ways in which siblings might be affected. As in the previous chapter, the parents are allowed to tell their own stories with the use of quotes from the interviews.

The 'life-cycle' and functions of the 'normal' family are defined and described from a sociological point of view. References include: John and Elizabeth Newson (1968), Carter and McGoldrick (1980) and Duval and Miller (1985). Where appropriate, data from the sample group are compared and contrasted with those of other relevant studies of disabled children. Examples include: Gregory (1976) - deaf children, Gath (1978) - children with Down's Syndrome, Hewitt (1970) - cerebral palsy victims and Glendinning (1983 and 1986) - general disability.

Chapter 7 deals with the early cognitive and motor development of the blind infant and the ways in which these pathways deviate and diverge from those of the seeing child. Works of reference include Fraiberg (1977) and Bower (1977 and 1982).

Chapter 8 is concerned with aspects of socialization of blind children. The 'first relationship' - that of infant and mother is explored and the ways in which the blind infant's 'image' of his mother differs from that of the sighted child are discussed. Other subjects introduced include: the influence of extended family networks on rearing practices, independence and disability, and issues surrounding sex, gender and body image. Again where appropriate, comparisons are made with other relevant studies eg.. Gregory (1976) and Hewitt (1970) and with normal four-year olds (Newson and Newson 1968).

Chapter 9 is concerned with play. Topics include: role learning, turn taking, rites and rituals, the acquisition of life skills through play, and the use of play as a coping strategy for dealing with fear and anxiety, and play as a form of therapy.

Among the sources of reference for this chapter are: Garvey (1977), The Opies (1959, 1969 and 1985), The Newsons (1979), and Axline (1947 and 1964). Quotes from the interviews are also used to illustrate the topic where appropriate.

Section III Education and Visual Handicap

Section III consists of six chapters and is concerned with the origins and development of special education for the blind and the ongoing dilemmas associated with it. The special curriculum and the development of literacy in the blind population are given special emphasis. The issues are discussed in a sociological context and are set against a historical backdrop.

Chapter 10 forms an introduction to the subject, introducing the concepts of power, conflict and mystique in special education. The historical origins and evolution of education for the blind are explored. Work by historians (eg.. Pritchard 1963 and Hurt 1988), and sociologists (eg.. Tomlinson 1982) show that today's dilemmas in special education are not in fact new, but were also faced by the pioneers of special education. These works also show that present day 'solutions' have been tried before, and, more seriously, that educationists throughout the ages have failed to take account of and learn from the mistakes of their predecessors.

Chapter 11 is concerned with stigma, stereotyping and attitudes towards the disabled. Erving Goffman (1963) has written extensively on the subject of stigma, as has Scott (1969) and both these texts are used as references in this chapter. Thomas (1978) also provides useful background information on stigmatization and attitudes towards disabled children. Quotes of parental experiences with regard to stigma are utilized to illustrate the chapter.

Chapter 12 enters the 'segregation/integration debate'. Although the drive towards full integration of all handicapped children into mainstream education is fairly recent, integration itself is not a new idea. Jamieson and colleagues (1977) for example, note that there were more blind children in ordinary schools in 1889, (albeit for different reasons) than there are today. The text is illustrated with quotes from parents and children in both special and mainstream schooling and their educational careers are compared. Texts used for reference include Cole (1986), Fish (1985), Anderson (1973 and 1982) and Madge and Fassam (1982).

Chapter 13 explores the process of 'assessment' through the eye of the client utilizing quotes from the sample group. Topics discussed include: power, conflict and vested interest, and the ways in which powerful groups are able to categorize weaker groups as being in "need" of "special" treatment. Oliver's (1988) account of the nature of disability helps to provide some insight into the philosophies underpinning such processes as assessment, labelling and categorization into or out of special education.

Chapters 14 and 15 are concerned with the special curriculum, giving emphasis to the development of literacy in the blind. The careers of two pioneers, Louis Braille and Thomas Rhodes Armitage, without whom the blind might never have achieved literacy, are outlined alongside the development of reading and writing systems for the blind. Once again issues of power and conflict are discussed in relation to the transmission of culture and knowledge through literature. The section is illustrated and concluded with the experiences of the clients.

Section IV the Healers

Section IV is divided into three chapters and focuses on the medical profession in general and the ophthalmologist in particular. The aims of this section are, to examine the philosophies which have underpinned the treatment of the blind throughout history, and, parallel with this, to trace the evolution of the present day ophthalmologist from the quack and the empiric of previous centuries. Section IV also seeks to examine some of the reasons underlying the low satisfaction ratings awarded to some types of healer by the clients. As in previous sections, the clients

relate their experiences by the use of quotes from the sample group. In addition, in section IV, some of the material is presented from the point of view of the doctor, making use of studies which have examined the careers and personalities of doctors.

Chapter 16 provides a brief 'Freidsonian' overview of the development of medicine as a profession and briefly touches on the changing philosophies underpinning the healing 'arts'. The main themes of the following chapters are outlined and some current issues and dilemmas are introduced.

Chapter 17 is concerned with the development of medicine from a craft into a profession, and with the evolution of the craftsman into a surgeon. It is also concerned with what Freidson (1970) has termed the "clinical mentality", and the ways in which doctors cope with and protect themselves from the hazards of their profession. The idea of the "wounded healer" is explored, and the contribution s/he could make to society and the healing professions. To conclude the chapter, some of the clients describe their experiences of and with healers. The main works of reference for this chapter have once again been histories of medicine and surgery, including Haeger (1988). The work of Bennet (1979) is used to present a "doctor's eye view" of medicine. The early part of Chapter 17 as marked may be omitted as, again, it is historical and not concerned with the main argument.

Chapter 18 is concerned with the education and socialisation of doctors past and present. Some of the reasons for the perpetuation of the nineteenth century system of education are explored. In a recent study (Allen 1988), doctors comment on their careers, job satisfaction and the stresses and strains of medical practice, with some disturbing results. The aim of the chapter is to draw together the threads of previous chapters in the section and to illuminate some of the "backstage" areas of medical practice. The chapter is illustrated by the comments of clients caught up in what might be termed the "welfare web". Works used for reference include: Abel-Smith (1964) and Foucault (1973) who, in different ways, describe the development of the teaching hospital. Hull (1991) – a blind man –, presents a client's view of some philosophical issues concerning blindness, whilst the works of Turner (1987) and Freidson (1970) have been

used to illustrate the sociological viewpoint. Again much of the early part of the chapter may be omitted if desired.

Section V. Passage Through Crisis

This section contains six chapters and is concerned with communication and with relationships. Communication is essentially a social process. However, where a person is disabled or suffers from a long term illness, quite a high proportion of the communications made, and the relationships established, will be with helping professionals and within a clinical setting. Research (see for example, Davis [1982], Stimson and Webb [1975] and Freidson [1970]), has shown that in this type of situation, the dice is loaded against the client, the power being virtually all on the side of the professional.

Section V is concerned to show how the 'clinical processing' of the 'patient' impacts upon family life, and the ways in which the smooth running of the family system is disturbed and disrupted.

In this final section, the study is brought full circle. A return is made to previously presented data in order to re-examine events leading up to and culminating in the diagnosis of blindness, but from a different perspective. The crisis which the diagnosis brings about, the passage of the family into and through this crisis and the coping strategies adopted are now reviewed in a situational context. A modified form of "Crisis Theory" as used by Davis (1963) in his study of polio victims is used as a framework for this. Other studies using a similar approach, for example: Harrisson (1977), studying long term and terminally ill children, and Speedling (1982) studying heart attack victims, are used as 'controls' and for comparison. Chapters 20 to 24 reflect the four stages of the crisis framework as used by Davis (1963):

I. The Prelude Stage. From the time the parents became aware of something unusual in the child's visual behaviour until they realised the child probably had a serious defect.

II. The Warning Stage. From the decision to seek professional help, through the GP consultation to the referral to a specialist.

III. The Impact Stage. The stage at which the diagnosis of blindness is communicated to the parents.

IV. The Inventory and Adjustment Stage. The period during which the families assess the situation and formulate coping strategies.

Chapter 25 is concerned with grief and the ways in which the mourner can be assisted during his passage through crisis.

In this section some of the quotes used in previous chapters will be re-examined from this different perspective.

Section VI. Conclusions and Implications for Practice

On reaching the concluding section, readers are referred back to the beginning of the work to re-examine the implications in the light of what has gone before. Readers are then invited to consider some ideas for solving dilemmas which have been adopted by other authorities or institutions. It is hoped that they will then be able to form their own 'conclusions' and perhaps formulate strategies of their own for dealing with situations in their own areas of practice.

EVOLUTION AND AIMS OF THE STUDY

The original aims of the study were:

1. To enumerate the whole population of visually handicapped children in Sheffield.

2. To collect information on the needs and problems of families rearing a visually handicapped child, and to examine the extent to which their needs are being met by existing services.

3. To study the impact of rearing a visually handicapped child on family life.

For reasons which will become clear later, (see method of study), the first aim - the enumeration of blind children in the city - proved to be impractical at the time and had to be abandoned. However, since completion of the Sheffield study, two recently published works (The OPCS survey of disability in children - Bone and Meltzer [1989] and the RNIB survey of blind and partially sighted children - Walker et al [1992]) have made it possible to make an estimate of this population based on figures from the country as a whole.

Because they were from a large representative sample of the whole population of Britain, the figures of the OPCS survey (Bone and Meltzer, 1989) are probably more accurate than those of the RNIB survey which were obtained from notifications to defined LEAs. If we take the OPCS figure of 1:500 as being reasonably accurate, and given that Sheffield has an annual birth rate of 6,500 to 7,500, and that the rate of vision defects remains constant until after the age of 16 years (see Figure 3.1, page 45), this would give approximately 224 children between 0 and 16 being severely visually impaired. Some allowance should also be made for blind children moving into the city to be near specialist services, and for the fact that Sheffield is a regional centre for the treatment of very premature infants, many of whom will have retinopathy of prematurity. This probably means that, at any one time, there will be between 230 and 250 blind and partially sighted children in the city. This is a very different figure from the one which would be obtained by using the estimate of the Hall Committee (1991) of 2 to 4 per 10,000, resulting in around 25 such children.

Before setting out to collect information on the needs and problems of the families rearing a visually handicapped child, it is necessary to question whether such families actually experience major problems (i.e. is there a need for such a study?). As I pointed out earlier, searching the literature for the answers to these questions proved unrewarding, there

being (at the time) no previous studies of the family life of blind children to use as a base line or with which to compare the Sheffield families.

The question however remained: Why was there so little literature concerning the blind child in a social setting? Blindness, after all, is a condition known since the dawn of mankind. While some types of disability, eg.. mental handicap, attract researchers in great numbers, the major forms of sensory impairment, blindness, deafness and deaf-blindness, remain virtually unstudied. Why should this be so?

The simplistic answer might be that there is no literature because there are no problems. And, in fact, this appeared to be borne out by the opinions of many workers involved with these families. As an example, in the small-scale (unpublished) study by the author, previously referred to (Bennett 1981), health visitors were asked what problems they felt parents rearing a blind child were likely to encounter. The majority said that the families did not appear to have any particular problems or that their problems would be no different from those of families rearing 'normal' children. Many of the health visitors said that they felt the problems these families might have to deal with would be very minor ones compared with those of families rearing a severely mentally or physically handicapped child. It became obvious from later collected data that many doctors, particularly GPs and ophthalmologists shared this opinion.

The study however, was already underway, and data already collected overwhelmingly supported the view that the families did indeed have problems. Many of the problems were similar to, but some very different from, those of families rearing children with other physical or mental disabilities.

Thus, although the families did have needs which were largely unmet, because these problems were not perceived as such by caring professionals, the families' needs remained unknown and therefore unmet.

Why was there this discrepancy between the viewpoints of the professionals and the parents? Was it naivety and lack of insight on the part of the

professionals? This seemed unlikely as the opinion was held across the board regardless of the age or experience of the worker. Many of the health visitors interviewed had over fifteen years of service and had encountered several families with visually impaired children.

An alternative explanation might be that the family actually 'presents' this view to the professional. But why should families present such a facade when it prevents them from obtaining the help they need? Does the answer to this question lie in the perception of blindness as a stigmatizing condition, and the attachment of a "courtesy stigma" (Goffman 1963) to the rest of the family? But is blindness stigmatizing? Surely the blind, particularly blind children, are innocent victims, deserving only help and compassion?

If blindness does not carry a stigma, why do professionals feel the need to continually alter the 'labels' for blindness and partial sight? It is interesting here to note that it is professionals rather than clients who use these terms, and that certain professionals make more use of them than others.   Teachers and social workers for example use the altered terminology frequently, nurses only occasionally and doctors hardly ever. The respondents in the sample group seemed to prefer the 'old' terminology, nearly always referring to their children as blind or partially sighted. If these new labels are meant to change attitudes towards blindness, the ploy is unlikely to succeed, as the stigma is attached to the condition rather than the name given to it.   The stigma will therefore remain, regardless of the altered label.

Thomas (1978) discusses the phrase, "the spontaneous revulsion to the deformed". Was there, Thomas asks a spontaneous revulsion to disabilities in children, or did such conditions evoke a more compassionate response? In his preface, Thomas continues:

> "If there was this negative reaction, was it not possible to explain it more accurately by reference to social conditioning rather than to biology? How were those who were reacted to in this manner affected, and why were there some people who actively sought contact with those who were supposed to excite instinctive hostile reactions?".

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According to Goffman (1963) the stigmatized are 'accepted' only when they "know their place". "He who adheres to the advocated line is said to be mature and to have achieved a good personal adjustment; he who does not follow the line is said to be an impaired person, rigid, defensive, with inadequate inner resources".

Goffman's (1963) explanation of 'good adjustment' begins to illuminate some of the reasons why families should present a facade of "coping splendidly" (Voysey 1975), to the professionals who hold the keys to the helping services. It does not however explain why there are, as Thomas (1978) notes, some people who actively seek contact with those who are supposed to excite instinctively hostile reactions, nor does it explain why these people should act in this manner. And here, yet another question is raised. Why, when people have deliberately chosen to work in this field, are so many of the clients so dissatisfied with the service they offer?

Although Cartwright (1967) and Stimson and Webb (1975) have shown that most patients stay with the same GP for many years, and according to Cartwright (1964), patients are, on the whole, satisfied with the care they receive in hospitals, data collected from the blind sample reveal very low levels of satisfaction with the services provided by GPs and ophthalmologists. On the other hand, the service offered by the peripatetic support teacher was rated very highly by the sample parents. The paradox here is that, on the whole, people like their GP but are unhappy with the service he provides for the blind child, yet they do not necessarily have to like the support teacher in order to be well satisfied with her services.

It will be apparent from the foregoing paragraphs that the research was raising far more problems than it could possibly solve.

Ethical problems also began to arise. For example, can any 'good' come from the uncovering of these problems? In Tolkien's (1969) tale, Gollum, through delving into matters which did not concern him, almost brought about the complete destruction of 'Middle Earth'. Gollum was also shunned by his peers and family.

The dilemma here was that if no improvement in client care was likely to accrue from laying bare family 'secrets' and exposing the inadequacies and short-comings of the Health Authority, was it ethical to proceed with the research?

Many researchers have uncovered inadequacies in hospital and community services, and revealed large holes in the welfare net. Studies include, for example: Oswin (1971) and (1978), Cartwright (1964), Hewitt (1970), and Glendinning (1983) to name but a few. All the contributors to Hall and Stacey's (1979) volume provide evidence that children are still suffering unnecessary trauma within what they term the "treatment environment". Hall and Stacey (1979) point out, however, that as social scientists:

> "(Their) concern was not simply with improving conditions (though this is important and necessary) but also with analysing the reasons why such problems should exist in organisations dedicated to the improvement of health, and why changes, when proposed, should meet with such delays as did the Platt Committee and their report of 1959 - still not completely implemented (in 1979)".
>
> (See Hawthorn [1974] and NAWCH [1975])

Although the above paragraph was written over a decade ago, accounts of the experiences of many of the blind sample show that it could just as easily have been written yesterday.

Obviously a small scale study cannot possibly cover all the questions posed above. The study would need to be focused, but on which particular problems?

Finding the Focus - Towards an Illuminative Methodology

Central to the study are the needs and problems of families rearing a visually handicapped child. That many of their problems continue to be

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unrecognised and their needs therefore unmet is a core concern of the research. Three elements seem to be at work here forming a vicious circle, or perhaps, more appropriately, an 'eternal triangle'.

The families present a "coping splendidly" facade; ---
      --- The case-worker takes this at face value; ---
            --- The families' needs remain unrecognised ---
                        --- and therefore unmet.

In addition to ascertaining the problems encountered by the families, it was also necessary to find out where the 'power source' driving the vicious circle is located. Is it for instance within the family system itself, in the attitudes of carers and professionals, or more remotely in the mores of society in general? Another question which needs to be answered is why the discrepancy of viewpoints between client and worker, referred to earlier, should exist. This discrepancy has been noted by other researchers, eg.. Fisher et al (1986) and Cunningham and Davis (1985). Cunningham and Davis used Kelly's (1955) theory of personal constructs, as outlined by Bannister and Fransella (1971), to develop frameworks of collaboration with parents.

Studies of an exploratory nature do however require a highly flexible methodological approach geared to the needs of the clients. The roots cannot be fixed in any one particular discipline as the design needs to be able to evolve during the course of the study rather than being fixed in advance. A similar approach was required by Jamieson et al (1977) when they collected information for the Warnock Committee (1978) on how best to educate children with visual impairment. Jamieson and colleagues chose to apply an 'illuminative' approach to their research. A rather similar line was taken by Fisher et al (1986) in their study of families with children in care. The 'Illuminative' approach is outlined in the following chapter.

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CHAPTER 2

AN EVOLVING METHODOLOGY

THE ILLUMINATIVE APPROACH

Although the 'illuminative approach' seems to have been utilized mainly in
the field of educational research, the method has obvious advantages for
studies within the field of the social sciences. Jamieson et al (1977)
point out that studies using this approach tend to be holistic. They are
often process rather than product orientated and they are carried out under
naturalistic or 'field' conditions, rather than under more controlled
'laboratory' type conditions. They utilize observational and interview
techniques extensively and they often give less than usual prominence to
quantitative measurement procedures. Illuminative researchers are
concerned to study the phenomena and processes in their chosen field within
a wider social and institutional context.

The illuminative approach lies within what has been called the "social
anthropology" paradigm. This reference to "social anthropology" is not
meant to imply a close identity with anthropological theory and method, but
to provide a general framework and research philosophy. Jamieson et al
note that the connection with anthropology is through emphasis on
interpreting, "on building up explanatory models of existing practice; on
drawing out patterns of coherence and inter-connectedness that otherwise
go unnoticed".

Jamieson and colleagues (1977) point out that illuminative researchers,
like social anthropologists pursuing ethnographic fieldwork, actually
immerse themselves in the working worlds of those they are studying:

> "they seek to build up an overall picture or model of the system
> in question, and they look for relationships between beliefs and
> practices, and between organizational patterns and customary
> response of individuals. The end product therefore is not a set
> of findings as such, nor a catalogue of facts and figures, nor
> even an extended description, but rather an interpretive
> commentary of a series of interconnected ... issues and phenomena
> that are carefully documented".

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Parlett and Hamilton (1972) utilized the 'illuminative' method in the field of education to evaluate innovation in curriculum. They distinguish the 'social anthropology' paradigm from the 'agricultural-botany' which was until fairly recently, much used in educational research. This 'agricultural-botany' paradigm still dominates research in the medical and allied professions. In 'agricultural-botany' types of research the emphasis is on methods which favour experimental and testing traditions. Such research is closely allied with statistical method. The concerns of investigators working within such a traditional framework are, as Jamieson et al (1977) point out, to operationalise variables, match samples, measure outcomes numerically, hold constant some variables while varying others in precise ways, or to correlate sets of dimensions across different and usually large populations.

The agricultural-botany paradigm is highly appropriate for testing fertilisers and crop yields. In the medical field, it is much used for drug trials and the testing of treatments and surgical procedures. It can also be used by nurses in areas such as wound healing and infection control. Although the traditional paradigm can be used successfully with studies in the social science field (eg. Gath 1978 in her study of children with Down's syndrome and their families), it is not, as Parlett and Hamilton (1972) point out, particularly suitable for examining structures, institutions, individuals or practices in ways that preserve them intact. As they note, rather than thinking in terms of parameters, factors, variables and the like, the illuminative researcher is concerned with reactions, theories, assumptions and events.

Parlett and Hamilton (1972), it will be remembered, were using the illuminative process to evaluate innovation in the curriculum. They point out that, "Illuminative evaluation is not a standard methodological package but a general research strategy". The choice of research tactics follows not from research doctrine, but from decisions in each case as to the best available techniques. Thus the problem defines the methods used, not vice versa. Equally, no method is used exclusively or in isolation, different techniques being combined to throw light on a common problem. As Parlett and Hamilton note, "Besides viewing the problem from a number of angles,

this 'triangulation' approach ... also facilitates the cross-checking of otherwise tentative findings".

At the outset, as Parlett and Hamilton point out, the researcher is concerned to familiarise himself thorough with the day to day reality of the setting he is studying. In this he is similar to social anthropologists or natural historians and like them the illuminative researcher makes no attempt to manipulate, control or eliminate situational variables. Instead he takes as given the scene he encounters along with all its complexities.

The 'illuminative approach' as utilized by Parlett and Hamilton is characterised by three stages: the investigator first observes the situation, second, inquires further and finally seeks to explain it. Obviously as they point out;

> "... the three stages overlap and functionally inter-relate. The transition from stage to stage, as the investigation unfolds, occurs as problem areas become progressively clarified and re-defined. The course of the study cannot be charted in advance. Beginning with an extensive data base, the researchers systematically reduce the breadth of their inquiry to give more concentrated attention to emerging issues. This 'progressive focusing' permits unique and unpredicted phenomena to be given due weight".

A Client-Centred and Problem-Orientated Approach

Illuminative research practice has been criticised as being useful only for small scale non-quantitative studies. But, Jamieson and colleagues (1977) point out, this is not wholly accurate, as illuminative researchers do not altogether eschew quantitative data and methods. As they note, they have their place in an array of possibilities. However, a most important feature of the approach has to do with its being client-centred, i.e. it is essentially applied research that concentrates on its clients.

Illuminative research is however influenced somewhat by values and assumptions drawn from medicine and psychotherapy in that it is essentially diagnostic-therapeutic. The diagnostic inquiry begins with a presented problem, proceeds by exploratory investigation, draws inferences, and as

Jamieson and colleagues inform us, "culminates in the discovery of often unacknowledged and contextual determinants that form the basis for interpretations. If these are aptly and sensitively expressed they may change self-knowledge in beneficial ways: at the very least the taken for granted may be viewed in a new light".

Illuminative researchers do not claim to be "value-free", nor to be capable of "total objectivity". They do however hold the value that every effort must be made to represent the different value positions, ideologies, and opinions that might be encountered in the course of the research, and moreover, to represent them in ways considered fair by those holding such positions.

This commitment to being as non-partisan and impartial as possible has been criticised by those who favour a committed political stance. It has also been criticised by those who feel it is impossible to be impartial, and that one should not pretend to be. 'Illuminative researchers', on the other hand, believe that although it is difficult, it is not impossible to be fair to differing points of view. However, it has to be accepted that this, in itself, represents a stance which is 'political'.

Jamieson et al (1977) noted that illuminative research can be regarded as applied, and also as interventionist, in that it seeks to promote change. However, they point out that it is not 'action research' in the usual sense, generally, although not invariably, stopping short of making policy recommendations - especially where to do so would be to advance the views of one interest group over those of others.

Illuminative research seeks to challenge conventional assumptions, to disentangle complexities that are usually left in a muddle and to isolate significant processes from those that are less so. In short, it seeks to provoke thought and to unsettle established ways of thinking.

Jamieson and colleagues (1977) point out that illuminative research does not 'fit' within any one existing discipline or speciality. In the same way, the study of the "world of the blind person" requires an

inter-disciplinary approach which can integrate elements of method and theory from many different fields and disciplines.

Hall and Stacey (1979), editors of a collection of research studies concerned with children in hospital, describe their approach as "psycho-social" because of the mixture of psychological and sociological interpretations. The study of visual impairment requires in addition a medical framework. It could be said therefore that blind children and their families have been studied within a "medical psycho-social framework". This approach has also been termed "triangulation", and triangles, of one kind or another, have formed a recurring theme throughout my study.

Ethical and Political Considerations

Jamieson and colleagues (1977) point out that there are many potential hazards for research workers conducting illuminative style research studies. Quite often they are using more intrusive methods than are usual in general survey research or observational studies. This means that the ethical and professional responsibilities are correspondingly greater. There is a necessity to study what Goffman (1959) termed the "back stage" areas as well as what is 'on display' for the audience. The dilemma here is, how far should the investigator invade the privacy of individuals and institutions? Having obtained this private information, the researcher has a responsibility to the client, to respect confidences and protect individuals. Therefore s/he needs to consider very carefully the implications of reporting certain material.

The writing up of an 'illuminative' study also presents problems. These are concerned with: the extent to which it is appropriate to distort descriptions of situations in order to disguise the identity of individuals; how to report material which, quoted in isolation, could have pronounced negative repercussions; and how confidences can be preserved while reporting as fully as possible what has been said.

As with all research, there is obviously scope for abuse. As Jamieson and colleagues point out, researchers can increase conflict in unproductive

ways, or they can misrepresent a study as impartial while working towards a private objective. Such concerns underlie all research which is basically 'diagnostic', 'clinical' or 'client-centred'. Although all researchers must give high priority to the accuracy and usefulness of their work, there are certain guiding principles which should always be taken into account.

Three simple but cardinal guidelines have, I hope, been applied throughout my study. The first is taken from the 'Hippocratic Oath', and the second and third from the study by Jamieson and colleagues (1977) into the educational needs of visually impaired children:

1. To help where possible or at least do no harm.

2. Not to investigate others in ways that I would not like myself to be investigated.

3. Those studied should afterwards feel they have been enhanced rather than diminished by participating in the study.

METHOD OF STUDY

"In illuminative studies, problems define methods; discoveries up-date the design; and the expanding knowledge base defines the current strategy".

Jamieson et al (1977) Towards Integration, NFER

Defining the Problem

One of the original aims of the study was to attempt an enumeration of all the visually handicapped children in Sheffield. An early problem was therefore to define "severe visual impairment". Other problems were, where to find these children, and, how to select the sample group. It would seem obvious that a search of the blind and partial-sight registers should provide the solutions to all three problems. In practice however, this was not a fruitful exercise as only 13 Sheffield children aged 0 to 16 were actually registered as blind or partially sighted. I had, however already collected over 300 names of children felt to have severe visual problems

by health visitors, teachers, school nurses and other professionals. It was clear therefore that something was wrong with either the criteria the professionals were using or with the statistics.

The ophthalmologist is responsible for the registration of a person as blind or partially-sighted, and by law, he is the only professional allowed to do this. The ministry form 'BD8' is the document used for certification and registration. The guidelines on the BD8 form state quite categorically that the principal condition to be considered when registering a patient as blind, is the visual acuity, as measured with the Snellen test chart. The problem for the ophthalmologist is, how to ascertain the visual acuity of a baby or young child visually impaired from birth. I should add here, that the BD8 form has recently been revised to make it easier to register young children. However, as all the sample children were registered under the old system, this is the one which will be considered in the study.

Because of the difficulties of accurately assessing visual function in children - particularly those who have additional mental and/or physical disabilities - and the uncertainty of the prognosis or the outcome of surgery, many ophthalmologists, (even with the new BD8 form) delay the registration of children until the age of five or over when special education needs to be considered.

Thus, the general assumption that "Because visual impairment is a state which is identifiable and medically acknowledged, national statistics of incidence must be quite straight forward to compile", is as Jamieson et al (1977), the Vernon Committee (1972) and the RNIB National Survey (Walker et al [1992]) found, completely unwarranted.

There is, in any case, no advantage either to the pre-school child or the parents in registration. Later in life there may be actual disadvantages, for example, stigmatization and discrimination in the job market. Registration is not compulsory and many parents actively choose not to have their child placed on the register.

Many blind children have additional handicaps, and it may be that s/he is included in a different category for statistical purposes. The statistical

problem is compounded by the continuing trend towards integration, with perhaps the majority of visually impaired children now being educated in mainstream schools rather than together in special schools and units. Yet another reason for this statistical 'unknown quantity', is as Jamieson and colleagues (1977) point out, that a sizable number of children with visual defects do not show up in the statistics because their problem has not been detected. This remains so until, as one of their respondents said, "one trips over them and sees they are under-achieving".

The children who form the statistics are therefore the tip of an iceberg of unknown size. But even this tip is not recorded on one single register but spread over many different ones.

Identifying the Sample Group

The sample of children for the study was collected from a wide variety of sources and although, in theory, almost all the children should have been included on more than one register, there was surprisingly little overlap.

The "Handicap/Observation Register" kept by the Health Authority proved to be the most fruitful source of information and yielded 40% of the total sample. Other sources of information were the peripatetic teachers for the visually impaired, the head teachers of the blind school and partial sight units and the blind and partial-sight registers. The remaining children were discovered during field work, i.e. they were the siblings of the target children or extended family members who were also visually impaired.

As previously stated, over 300 names of children aged 0-16 years felt by professionals to be severely visually impaired were collected. A sample of this size is obviously unsuitable for a small-scale study. A pilot study, N=6 including three multiply handicapped children and three 'merely blind' children was carried out. It was found from this pilot study and from the case records of mentally and multiply handicapped children, that the vast majority were adequately covered by services from the 'Rygate' Centre. The children in most need and receiving fewest services (quite often the only professional involved being the generic health visitor) were the children of normal or near normal intelligence, with or without

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additional physical handicaps. Because of this, all children attending 'Rygate' were excluded from the study. This left a total of 68 families with children of normal or near normal intelligence. Sixty two of these families were traced and contacted. Four could not be interviewed because of language difficulties, two refused to take part in the study and in a further three cases an interview was not achieved despite several appointments. A further three were excluded following the interview because they did not meet the research criteria.

A total of 50 families having 55 visually handicapped children of normal intelligence was successfully contacted and interviewed. The interviews took place during the period October 1983 to August 1985.

The definition of "severe visual handicap" for the purposes of this study ranged on a continuum from total blindness (unable to distinguish between light and dark) to 6/36 Snellen or its assessed equivalent in the better eye.

I have endeavoured, where practicable, to utilize the International Classification of Impairments, Disabilities and Handicaps (ICIDH) proposed by the World Health Organisation (WHO) throughout the study, rather than the current 'politically correct' definition of 'visual impairment'. Impairment, as defined by the WHO (see below) merely means that a part of the body or mind does not function properly and by this definition, almost every person over the age of 50 could be classified as 'visually impaired'. The 'politically correct' terminology therefore to a large extent negates the magnitude of the disability or handicap suffered by the children in the sample group. It has to be said however that the use of the WHO classification presents other problems, not least because there are no definite boundaries between the groups. Some children will only become 'handicapped' as their condition deteriorates and others as they reach maturity. By this I mean that, whilst the degree of impairment remains static, the child may be merely impaired as an infant, becoming disabled as a school child and handicapped as a mother. Most difficulty is

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encountered when using the classification for the sample group as a whole, and here, it has to be admitted the definitions have sometimes been used interchangeably. The WHO classification is as follows.

Impairment

"Any loss or abnormality of psychological, physiological or anatomical structure or function". This means parts of the body or systems which do not work properly.

Disability

'Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being'. This means the things disabled people are unable to do because of the impairment.

Handicap

'A disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role (depending on age, sex and social and cultural factors) for that individual'. This means a handicapped person is unable to fulfil to the full his/her expected role/s in society.

Data Collection and Analysis

In order to ascertain the needs and problems of families with a blind child, a semi-structured interview schedule was designed and piloted on five families rearing a child with special needs from my own general health visiting case load. Where appropriate questions were pre-coded for analysis by computer. Where this was not possible, boxes were left open for coding at a later stage and plenty of space left for verbatim replies. The form, see Appendix, was modified slightly before use with the visually handicapped sample group. All the interviews were audio-taped and transcribed onto the schedule itself. The actual tapes were also kept for later reference. The length of interview varied between 40 minutes and 190

minutes, most interviews taking 1½ to 2 hours. The mother was the main respondent, fathers taking part in less than 8% of cases. Children were present in 70% of cases and those old enough contributed to the interviews.

The ensuing field work yielded a rich harvest of 'messy' and untidy data, plus long verbatim accounts of experiences, many of which defied codification and quantification. Attempting to squeeze this rich qualitative material into codings for the computer would have completely destroyed the objectives of the illuminative method. It was therefore decided to utilize these verbatim accounts to enable the families, where possible to tell their own story. Quite a high proportion of the study therefore is given over to the parents' own accounts of their experiences. The small size of the sample group (50 families) in any case militates against complex quantitative analysis.

Towards a Working Model of Family Dynamics

The final aim of the research was to study the impact which the rearing of a visually handicapped child might have on family life.

As the fieldwork progressed, it became obvious that the birth of a blind child had indeed altered not only the structure of the family system but also the dynamics of family life. However, because of what I have termed the 'Voysey effect' (the presentation by the families of a facade of normality) (see Voysey [1975]), some of the impact was being disguised and/or denied.

The problem then was, how to devise a method sensitive enough to uncover what was 'really going on' within the family, without being unduly invasive. It was also important that the family system should not be damaged by the technique and that coping and protective mechanisms should be left intact. The evolution of the 'Minisculpt' technique is outlined below.

Barker (1986) draws attention to the use of the 'genogram' (sometimes called a geneogram) as a useful adjunct to both assessment and treatment of families needing therapy. A genogram is a family map, showing the family's current composition and salient features of its history. Some family therapists prepare the genogram on their own using information they have obtained during therapy sessions. Others, including Barker himself, prefer to involve the family in their preparation. An example of a genogram, taken from Barker (1986) is shown in Figure 2.1 overleaf.

Genograms however, could not be utilized in the case of the blind sample because of the high proportion of parents who were also visually impaired. (A high proportion of visual defects are genetically transmitted and this included 64% of the sample group). The impact of genograms is wholly visual; their use by severely visually impaired people was therefore ruled out, at least in the original format.

Another method which can be used to illustrate family dynamics is family 'sculpting'. This family therapy technique was developed by Duhl et al (1973). As Barker (1986) relates, the essential feature of family sculpting is the placing of family members in positions and postures that represent aspects of their relationships and interactions with each other. Family sculpting requires a 'sculptor', whose view of the family will be revealed in the sculpture; a 'monitor', usually the therapist, who guides and supports the sculptor, and the 'actors', usually family members, who portray the sculptor's system.

As with genograms, however, vision is required for sculpting, and the technique cannot be used by the blind and the sighted on an equal footing.

A method whereby both blind and sighted people could sculpt genograms by making use of tactile symbols was required.

Figure 2.1

The Green Family - 1985
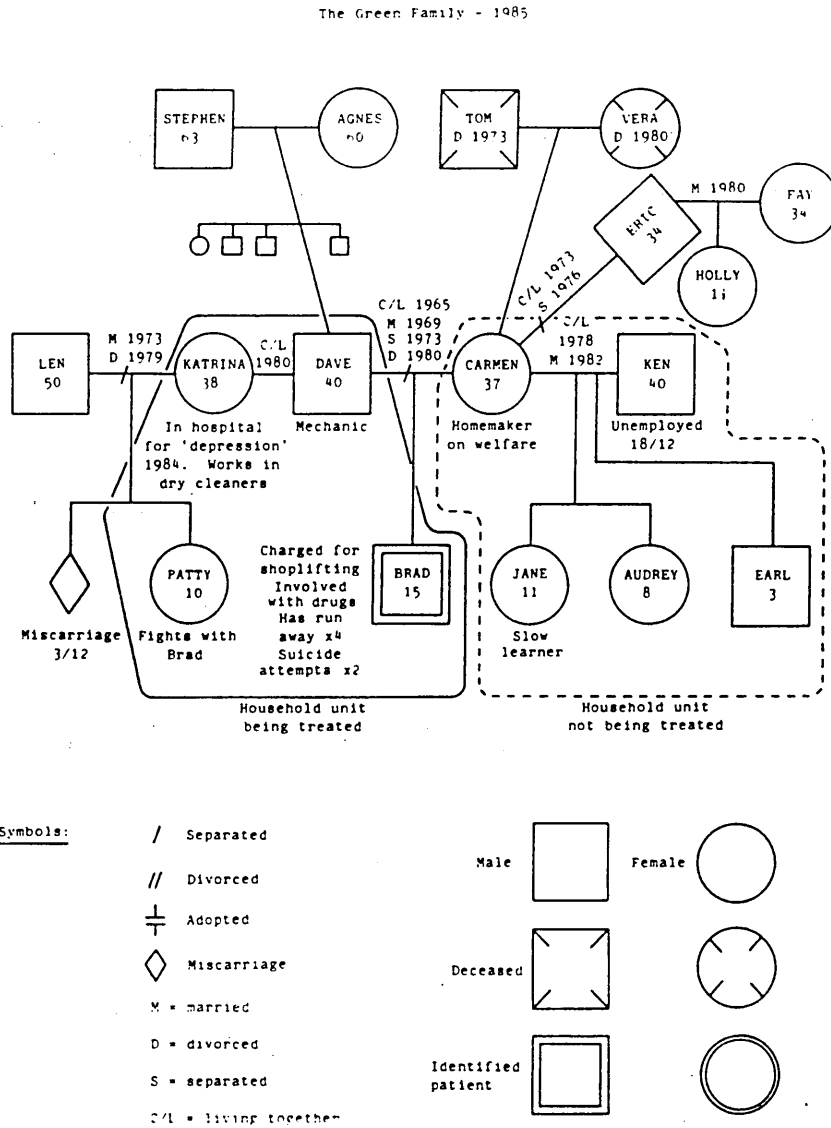
An Example of a "Genogram"; from Barker, P., Basic Family Therapy (1986)

A solution to the problem was found by utilizing the methodology of play therapy (Axline [1947], and see also, "Dibs", Axline [1964]), as a kind of bridge to combine the two systems. Thus, using 1/16 scale dolls-house dolls and different textured ribbons to join them in various patterns of hierarchy and closeness, family members, both blind and sighted, were enabled to sculpt their own genograms.

Piloting the "Minisculpt" Technique

The "Minisculpt" technique was first piloted with the help of two families rearing a sighted child with special needs from my own case load, and two families rearing a multiply handicapped blind child.

Using dolls of their own choice, each respondent was asked to sculpt three models:

A) Their own family of origin at a point in time of their own choosing.

B) The family prior to the birth of the target child.

C) The changes in structure and dynamics brought about by the birth and rearing of the handicapped child.

Once again, all interviews were audio-taped and the models were reproduced diagrammatically using symbols and coloured pencils. The materials used are shown in Plate I.

Those taking part in the pilot study found the process enjoyable and also in many instances, therapeutic. The main criticism was that it was somewhat time consuming. (Each respondent was asked to set aside two hours and the actual interview times ranged from 95 minutes to 210 minutes per family member). Quite a high proportion of time was spent in reproducing the models diagrammatically and this also interfered somewhat with the smooth running of the process. A polaroid camera would, (had I though of it before completing the fieldwork), have been a useful addition to the equipment.

Using the 'Minisculpt' Method in Fieldwork

All of the families surveyed in the first phase of the study were asked if they would be willing to take part in an in-depth study of family dynamics and relationships (Phase II of the research) at a later date. Of those who agreed, four took part in the piloting stage and a further four were selected for the study sample group. Those selected were chosen to represent as wide a range of family size, structure and social background as possible with such limited numbers. Each family member was interviewed on his or her own so that they did not 'contaminate' each other's sculptures. Target children and their siblings over the age of ten were also invited to participate.

Materials Used for the Minisculpts

The materials utilized for the sculptures are shown in Plate I. They consist of:

> One sixteenth scale dolls house dolls in family groupings. These can be purchased from toy shops or from specialist catalogues. At least 20 dolls will be required or three family groups of eight dolls if purchased from a catalogue.

> One quarter inch width ribbons, in red and white of differing textures, i.e. velvet, satin and cotton. Two metres of each are required, cut into lengths of 6 inches and 3 inches.

> Two metres, each one inch wide, of the following to represent 'frames' or 'boundaries': rigid petersham, elastic and stretch lace or open weave elastic.

> One piece of green felt, three feet square for use as a working surface.

Method of Use

<u>The Dolls</u>

These were used to symbolize family members, each person being allowed to select dolls of their choice to represent themselves and other members of the family. Interestingly, the visually impaired appeared to enjoy this process as much as the seeing. For example, one blind father on selecting a doll to represent himself said, "This one's me because he's got a leather jacket and I always fancied having a leather jacket". Once chosen, the dolls were, it seemed, often imbued with the nature and characteristics of the person they represented. This was evident from the ways in which respondents touched and handled the dolls. Mothers particularly would sometimes 'cradle' a child doll in their hand prior to placing it in position in the sculpture. Occasionally a respondent would cast a doll carelessly into a low hierarchical position with a comment such as, "he's my older brother, but we never got on". On occasion, the dolls also seemed to be used as intermediaries or 'shock absorbers'. This occurred when respondents were describing experiences which were painful or distressing to them. In such instances they might stroke the doll's hair or limbs, straighten its clothing or simply stare at it during gaps in the conversation.

An interesting feature of the completed sculptures was that all respondents whether male or female, child or adult, seeing or visually impaired, placed the father of the family in the same position, i.e. on the left hand side of the sculpture when facing the model. This 'rule' applied even where the mother was the 'dominant' partner and placed higher up the model in the hierarchy. It also held true across the generations, i.e. Grandfather and Grandmother were placed in the same relative positions. Only when there is no father in a family or the family breaks up does a mother occupy this position. If she takes another partner, she usually allows him to occupy the 'traditional father's position', she herself moving back to the more usual 'mother's place'.

The Ribbons

Ribbons were used to model closeness of family members to each other or, 'the ties that bind'. Velvet represented a very close relationship, satin a moderately close or 'normal type' relationship and cotton a loose bond or relationship. Two colours, red and white were used. Red represented positive, so that red velvet stood for a very close, very loving relationship; red satin a 'normal' or 'average' family bond and red cotton a loose but nonetheless loving relationship, eg.. a grown up son or daughter not seen very often. The colour white represented negative bonds. Therefore white velvet stood for a close but negative relationship, for example a husband and wife who while hating each other felt bound to stay together for some reason. White satin, (rarely used) could represent a couple always arguing but never to the point of break up. White cotton, (again rarely used) might stand for a couple who lived together but led separate lives. Respondents could also, if they wished, use both coloured ribbons together, so that, for example red and white velvet would represent a 'love/hate' relationship. It is interesting to note that red and white velvet were used quite frequently in sculpts of families of origin to describe ties between parents (grandparents) who were always arguing, and also relationships between the respondent and a particular sibling. This combination was however used much less frequently in the nuclear family models.

Some readers may wonder why this particular colour choice was made when others would seem more obvious - for example, red/greed or black/white. Because the technique was developed with visually handicapped people particularly in mind, the red/green colour combination had to be ruled out as many people with impaired visual acuity also have defective colour vision, and in monochrome red and green are almost identical. The black/white combination was also considered unsuitable because of its strong association with 'good' and 'bad', added to which black and white are not particularly attractive colours to the seeing and would add nothing to the 'attractiveness' of the method. The red/white combination provided sufficient contrast for both visually impaired and sighted subjects, was visually attractive to those who could see, and was also a fairly 'meaningful' combination. Where a subject was totally blind (which only

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one child was), positive ribbons were placed on the subject's left and negative ones on his right and the model built completely by touch.

Building the Hierarchy

In addition to sculpting closeness bonds, respondents were asked to model the structure and hierarchy of their family groups by placing dominant members towards the top and lower ranking members near the bottom of the model. 'Hierarchy' of course need not be a pyramid, and indeed this particular shape was used in only one subject's model. The most commonly used structures were: linear, inverted (base up) triangle, circular and (in large families) random sub-grouping.

Modelling Boundaries

Following the preliminary examination and analysis of the pilot Minsculpts, it was apparent that the bonds and ties sculpted by the respondents did not give a complete picture of the family group as a system. There were also tangible and intangible boundaries surrounding the families, giving them form and structure and also acting as a kind of 'driving force' for family functions. Parkes (1972) reminds us that, "the skin is not the only boundary around the self and that the home we live in and the people to whom we are attached are, in some sense, ours - they are parts of ourselves". By the same token it could be said that we are parts of our families and our homes and that other more intangible boundaries enclose and surround this whole family system.

Systems theory (as utilized by family therapists) was developed by von Bertalanffy (1968) - see also Barker (1986). According to von Bertalanffy, every system (open or closed, living or inanimate) has a boundary, the properties of which are important in understanding how the system works.

As with all living systems, the family is (to a greater or lesser extent) 'open' otherwise it would cease to be functional. Whether they like it or not, family members have to leave the home to work, attend school, buy food and make contact with other social systems in order to survive. It is by such contact through a permeable interface with other systems that the cog

wheels of social existence are turned. Having said however that all family systems are 'open', there remains a great deal of variation in the 'permeability' of the boundary which surrounds each family. In some cases it seems, these boundaries are tangible and can actually be seen; the high fence or unclipped hedge, the 'Beware of the Dog' notice on the gate for example. Obviously it would be dangerous to assume that these are signs of a 'closed family system' as there are many other reasons for such defences. It is interesting to note however that these phenomena seldom presented in families whose members surrounded their Minisculpt models with a semi-permeable boundary and never in those who chose a highly permeable one.

The 'boundaries', like the ribbons used to sculpt bonds of closeness, were purchased from the haberdashery counter. Rigid petersham was used to represent a (relatively) impermeable boundary, elastic a semi-permeable one and stretch lace a highly permeable boundary. Respondents were asked to surround their family sculptures with the appropriate frame as each model was completed.

Some Advantages of the Technique

The technique proved to be easy to use, non threatening, usually enjoyable, and, in some cases, apparently therapeutic. The dolls, as noted earlier, were imbued with the characters of family members and it seemed that, quite often, emotions such as fear, anger or distress were dissipated, using the dolls as 'actors' or mediators as would a child in play.

Some Pitfalls and Disadvantages

Possibly the main drawback of the method is the time factor, although as pointed out above, the use of a camera to photograph the models could reduce this somewhat.

A second major disadvantage is that, although the method was designed and piloted with children as well as adults in mind, the information obtained from the models made by the children was, on the whole, unreliable. The majority of the children, even those aged over 11 years, spent a high

proportion of the time literally playing with the material. For example, they invented siblings who did not exist and occasionally left out those who did. It was therefore difficult to know where fact ended and phantasy began. Because of this it was decided not to utilize data obtained from any of the children's models.

In recent years, possibly because of its misuse in cases of child abuse, play therapy has suffered a decline in popularity. However, it has to be taken into account that the problems lie, not in the method itself, but with the case-workers who use it and interpret the results.

The method however, needs to be used with caution as it can unleash powerful emotions. The pilot work showed that families could be led to reveal rather more about themselves than perhaps they intended. A major concern was therefore that they might "uncover the cracks" which they had successfully "papered over", and be left vulnerable as a result. With this danger in mind, backup support was enlisted from the community psychiatric nurses. In the event, however, none of the families studied required the service.

In conclusion, it would appear that adults (given the opportunity) are as capable as children of utilizing play material in a therapeutic manner. The idea of entertainment as therapy and therapy as entertainment is, in any case, not a new one. It goes back at least as far as the Ancient Greeks, and possibly much further.

Dallos (1991) noted that, in his experience, many families entering therapy seemed disappointed if they were not given something rather unusual to do such as sculpting or psychodrama. Dallos is resurrecting a very old idea however, when he asks whether psychology and therapy are not, after all to a large extent, entertainments?

VISUAL IMPAIRMENT IN PERSPECTIVE

VISUAL IMPAIRMENT - SOME FACTS, FIGURES AND FALLACIES

"I don't think it had ever before occurred to me that man's supremacy is not primarily due to his brain, as most of the books would have one think. It is due to the brain's capacity to make use of the information conveyed to it by a narrow band of visible light rays. His civilisation, all that he has achieved or might achieve hangs upon his ability to perceive that range of vibrations from red to violet. Without that he is lost. I saw for a moment the true tenuousness of his hold on his power, the miracles that he had wrought with such a fragile instrument ...".

John Wyndham, "The Day of the Triffids", 1951

What is Blindness?

A common sense definition of blindness would be, a person who is unable to see, and a common sense definition of partial sight, a person with limited vision or poor visual acuity. Such simplistic definitions can however be misleading as the subject of visual impairment is highly complex. In Great Britain the official definition of a blind person is:

"a person so blind as to be unable to perform any work for which eyesight is essential. Visual acuity of 3/60 or less in the better eye usually constitutes blindness. However, where an individual's field of vision is markedly contracted, then a visual acuity of more than 3/60 can constitute blindness. Blindness is certified by an ophthalmologist. For educational purposes, the Education Act of 1944 defined the blind as 'pupils who have no sight or whose sight is or is likely to become so defective that they require education by methods not involving the use of sight' ".

In Great Britain the official definition of a partially sighted person is:

"one who is 'substantially or permanently handicapped by defective vision caused by congenital defect, or illness, or injury' but not 'so blind as to be unable to perform any work for which eyesight is essential'. Visual acuity of between 6/60 and 6/18 with good or contracted fields of vision can constitute partial sight. Partial sight is certified by an ophthalmologist. For educational purposes, the Education Act of 1944, defined the

partially sighted as 'pupils who by reason of defective vision cannot follow the ordinary curriculum without detriment to their sight or to their educational development, but can be educated by special methods involving the use of sight'".

Definitions from Jamieson M et al, Towards Integration, NFER (1977)

In a study of people who were registered blind during the period 1963-1968 (Sorsby 1972), total blindness, i.e. no perception of light was the exception – affecting only 5% of the group. Just over 10% were said to be "almost totally blind", i.e. having perception of light but not form. Well over half of those registered (53% males and 55.7% females) had "some degree of useful vision". Sorsby (1972) argues therefore that, "the blind population taken as a whole is largely one afflicted with grossly defective vision rather than with blindness in the full sense of the term".

Disorders of the eyes have a variety of causes and they lead, as Jamieson and colleagues (1977) point out, to different effects on what people can see. Children registered as partially sighted in particular, may be misleadingly regarded as a uniform group, when in fact they are strikingly different from one another. A child with retinitis pigmentosa for example will have a restricted visual field and will be unable to see in the dark (night blindness). A child with aniridia (no iris) on the other hand will be over sensitive to light. Medically speaking the two have nothing in common and in the classroom their problems are not the same. They also require different visual aids. Even children with the same defect – for example cataracts – can have completely different needs in the classroom depending, for example on the degree of density of the cataract, the success or failure of operative intervention, the degree to which the child is mobile and whether or not s/he has an added disability. Moreover, one child may use his or her remaining or 'residual' vision better than another and this often depends upon the amount of help and stimulation the child receives in the home environment, which in turn can hinge on the amount of professional input during the pre-school years.

Towards a Functional Classification of Visual Impairment

Because of what has been said earlier, the classification and categorisation of visually impaired children into groupings which can be

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used for comparisons and the compiling of statistics, is exceedingly difficult. An added complication is that, once compiled, these groupings do not remain stable as children can move between them in either direction according to the progression of the disease or the outcome of intervention. The only group which remains constant is the small percentage of the totally blind. Because the research project was not concerned with the visual impairment per se, but rather with its impact upon family and social life, an attempt was made to classify the impairments in a functional manner. This classification is set out as Table 3.1 below.

Table 3.1 Functional Categories of the Visual Impairments Suffered N=55

Type of Impairment	No. of Children
Total blindness (no perception of light)	6
Perception of light only	9
Perception of light and form	19
Defect of central vision	4
Restricted field/difficulty in focusing	4
Severe uncorrectable refractive error	1
Progressive defect	5
Useful vision	6
Unknown (unable to assess)	1

This in fact was not a particularly helpful exercise and did nothing to clarify the situation nor simplify the categorisation. And, as one of my supervisors pointed out, many of the children could be classified under more than one heading.

The search for a simple functional categorisation led eventually to a classification based on social and education *needs* rather than the medically orientated sorting by diagnosis of *disease*. All the children

could be placed under one of three broad headings: Totally Blind; Functionally Blind or as having Useful Vision. These I defined as follows:

1. Total Blindness

Children included in this category have no vision whatsoever. Most will have been born with congenital absence of eyes or have had both eyes removed because of malignant disease. Total blindness, as previously stated is rare and only 6 children from the sample group were included in this category.

2. Functional Blindness

The majority of the children in the sample group (38) were categorised under this heading. It refers to children who retain some vision but not sufficient for them to take part in a normal school curriculum without extensive help, nor to lead a completely independent life in later years. Functional blindness represents in visual terms: perception of light, through perception of light, form and colour to distorted vision and constricted visual fields. Also within this category are children who may eventually move into the totally blind or useful vision categories because of either the progression of the disease or the outcome of medical and/or educational intervention.

3. Useful Vision

The children in this group (11 in the Sheffield sample) are those termed the partially sighted. With help, these children can often take part in a normal school curriculum. They will be able, with the use of various aids, to make use of the print medium rather than braille and most will be able to lead a completely independent life in later years.

This functional classification has been utilised throughout the thesis when quoting the families. It is where applicable followed by the 'name of the disease' or the medical diagnosis. Although a medical classification by type of disease is essential to doctors (who have to repair or treat it), such a classification is almost useless to educationalists and other

workers in the 'real world'. For example, a medical diagnosis of 'cataracts' can mean anything from almost total blindness to near normal vision. A 'scientifically established' visual acuity is equally nebulous to a teacher because, as was pointed out elsewhere, it gives no indication of how well or badly this vision can be utilised under 'field conditions', nor does it take account of the improvements which can be brought about by non-medical types of intervention on the part of parents, teachers and other field workers.

Because the classification was devised after the completion of the data collection, as an aid to its analysis, the approach could not be 'tried out' as it were on the subjects. Although the approach has been briefly described in two papers and a poster presentation at conferences, no formal feedback has been obtained. Whether or not the classification is 'workable' in the 'real world' therefore requires further research.

The Extent of the Problem

As Jamieson et al (1977) point out, the visually impaired represent a small group of children with very special needs. Jamieson and colleagues quote figures supplied to the Department of Education and Science by local authorities in England and Wales which reveal that the visually impaired constituted a mere 2.30% of the total number of handicapped children receiving or awaiting special educational provision as at January 1974. This figure comprised 0.77% blind and 1.53% partially sighted children. Of course, not all visually impaired children attend special schools for the blind or partially sighted. Many are integrated into mainstream schools and others attend special schools for other reasons, for example physical handicap or learning difficulties. Jamieson and colleagues found that of the 1883 *registered* blind children in England and Wales aged 5 to 15 in 1974, only 908 attended a special school for the blind.

It must also be borne in mind that registration represents merely the tip of an iceberg and grossly underestimates the actual population of visually impaired children. Only 38% of the Sheffield sample were actually registered as blind or partially sighted. The findings of the Vernon Committee (1972) and the RNIB survey (1992) confirm this underestimation

of the size of the blind population and show that the problem is a national one and not confined to Sheffield.

The Vernon Committee, reporting in 1972 and Jamieson et al (1977) both noted that, although the main causes of visual impairment had changed over the years, the actual incidence had remained broadly constant. This was also true of the Sheffield sample. Over the 16 year period (1969-1985) the number of *new* cases of visually impaired children with normal or near normal intelligence varied only between four and seven per year. Given that Sheffield has between 6,000 and 7,500 births per year, this gives a very approximate rate of around 1:1,000. Hall (1991), quoting as his reference Smith and Keen (1979) reports that the incidence of severe visual impairment in children is 2 to 4:10,000. He does however concede that this may be an underestimate, "because of the under reporting of vision defects in children with multiple handicaps". There is, as can be seen, a considerable discrepancy between these figures.

The OPCS survey (Bone and Meltzer 1989), based on a representative cross-section of private households, estimated that the number of disabled children living in private households in Britain was 355,000 and that of these 6%, that is 21,000, have a seeing disability (around 1:500). The RNIB survey (1992), whose figures were based on the population as reported by the Local Education Authorities, gives an estimate of 1:1,000. Given that the Sheffield sample comprised only visually handicapped children of normal or near normal intelligence, and that the figure obtained can be at least doubled if mentally and multiply handicapped children are included, the OPCS estimate of 1:500 would seem to be the most accurate. This being so, severe visual impairment in childhood, although less common than other disabilities, can hardly be described as rare. Neither can it be said that the incidence is falling. As can be seen from Figure 3.1 taken from the OPCS survey (1989) the 'curve' for seeing disability remains flat throughout the years of childhood.

**Figure 3.1   Estimates of the Prevalence of Six Types of Disability by
             Age, Showing Continuities and Discontinuities between the
             Children's and Adult Surveys**
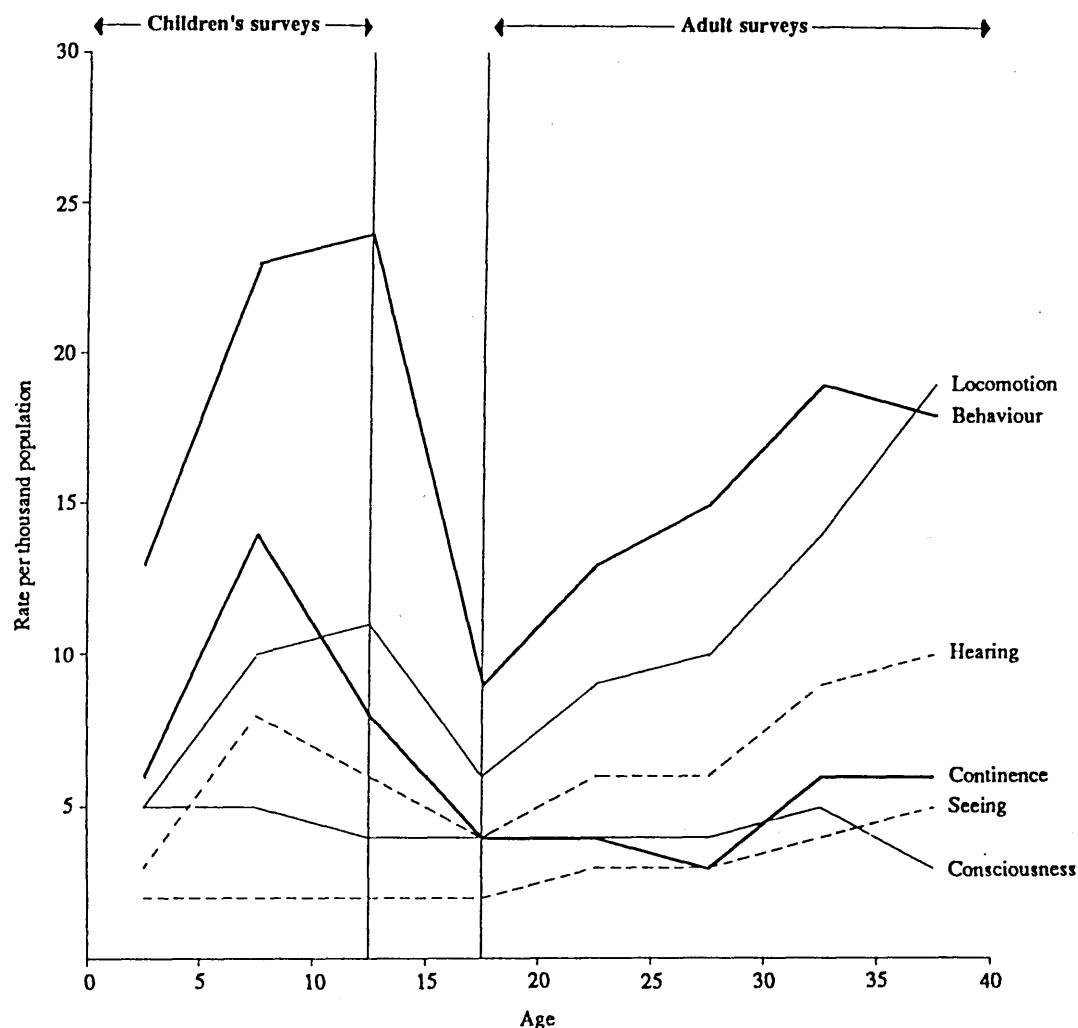
Reproduced from: OPCS Survey of Disability in Great Britain Report 3. 'The
Prevalence of Disability Among Children'. M Bone and H Meltzer, HMSO
Publications (1989)

The Causes of Severe Visual Impairment

The types of eye defects suffered by the children in the Sheffield sample
are shown in Table 3.2 overleaf.

Table 3.2 Eye Defects Suffered in the Sheffield Sample N=55

Ophthalmic Diagnosis	No. of Cases
Retinal dysplasia and optic atrophy	16
Cataracts and other lens anomalies	11
Retinopathy of Prematurity	9
Retinoblastoma	5
Aniridia	4
Microphthalmos and anophthalmos	4
Cortical damage	2
Multiple abnormalities/other	4

As can be seen from Table 3.2, the most common causes of blindness were diseases and anomalies of the retina and optic nerve, none of which are amenable to medical intervention. In all, it was found that 64% of the children suffered from complaints which had been genetically transmitted, but only four of the fifty families had had genetic counselling. Nine of the sample children were suffering from retinopathy of prematurity (previously termed retrolental fibroplasia) and the incidence of this condition is once again rising. This is due to many more babies of extremely low birth weight and earlier gestation surviving due to modern technology. Saving the lives of babies with a gestational age of 26 weeks and a birth weight of 600 grammes is now commonplace in neonatal intensive care units. Saving these lives however is not without cost as it has been found that 100% of babies with a birth weight of under 800 grammes will have some degree of retinopathy of prematurity and a high proportion, although surviving into adulthood, will have other mental and physical defects.

Identification of Children with Severe Visual Impairment

The acuity of vision is tested and persons registered blind or partially sighted in a controlled environment, using a 'scientific' standard testing

procedure (a Snellen optotype chart) recognised by all professionals who test vision in Britain and North America. Jamieson and colleagues point out however that the scientific tests do not give any accurate indication of an individual's ability to read, move around independently or cope with daily living.

Those concerned with education often complain that decisions about school placement are still primarily based on an ophthalmological assessment, and as the educationists point out, ophthalmologists do not see children in the classroom or playground, but rely almost entirely on the assessment of visual acuity in a controlled environment. Such tests, the teachers argue, are inadequate predictors of how well a child can function in the real world and how effectively s/he can use any residual vision.

Jamieson and colleagues (1977) remind us that several of the commonly held assumptions regarding visually handicapped children are incorrect. For example: A) what a person sees will be determined by the extent of their impairment, B) that visual acuity tells us how much a person can see ... and C) that visually handicapped children should be protected from eye strain. From talking to many professionals, Jamieson and colleagues also found that distance visual acuity measurements bear little or no relationship to how well a child may be able to use his near vision for learning. Nor, they found, is there any relationship between measured visual acuity (distance or near) and efficiency in reading print.

In Conclusion

There is, it seems, a huge gulf between the information teachers, parents and other 'field workers' require to help visually impaired children achieve their full potential and the information which is forthcoming from standardised scientific tests of visual acuity performed under optimum conditions.

There is also a danger that once a child's visual acuity has been 'scientifically' established, s/he will be labelled for life as blind or partially sighted, and as we have seen, there are actually no hard and fast dividing lines. Many workers, including Barraga (1970) and Sonksen et al

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(1991) have established that intervention programmes can have dramatic results with regard to helping children make the best use of limited vision, in fact some children have been enabled to convert from braille to print by making use of these methods.

In the real world of daily living then, a scientifically validated visual acuity is of little help to either the client or his helpers. Registration as blind or partially sighted is equally unhelpful, particularly in the case of children as there are no benefits attached. Registration can in fact be detrimental because of the attached stigmatisation and later discrimination in the job market.

Unfortunately however, the homely, everyday methods used by teachers and other helpers to assess the extent of visual impairment in children are held in very low esteem by the medical establishment as they can provide no scientific measure against a fixed standard. That their own measure for very low visual acuity (below 1/60) is even more imprecise and consists of counting fingers, response to hand movements and perception of a beam of light, does not seem to have been taken into account.

Because of the dominance of the medical profession in almost every walk of life, this situation seems set fair to continue. Some of the reasons why this should be so are explored in the chapters of this thesis.

THE FAMILIES AND THEIR SETTING

All the families studied lived within the boundaries of the city of Sheffield. Sheffield is in many respects a typical northern industrial city which in recent years has suffered from the general recession. Unemployment is rising as specialist steel works are closed down and the cutlery and tool manufacturing industries which made the city famous during the 18th and 19th centuries are taken over or amalgamated with larger foreign manufacturers.

Sheffield is still often described as, 'the biggest village in England'. The population remains fairly stable at around half a million inhabitants. Despite its size, it retains its village atmosphere where everybody knows

everybody else (and their business) and it is rare to go 'down town' and not meet someone you know. Family and kinship networks are extensive; many 'Sheffielders' - perhaps the majority, will live the whole of their lives within the same neighbourhood.

There are several large council estates in the city and some of these have been labelled as 'areas of high deprivation'. Not all its inner city areas however could be described thus. In one or two areas within a mile and a half of the city centre, even though the housing stock consists of 19th century terraces and the cobble stones protrude through the thin layer of tarmac applied periodically by 'the council', the residents are proud of their neighbourhood and the crime rate is low.

Although a high proportion of the population of Sheffield could be categorised under the Registrar General's classification, within the III, IV and V brackets, there are a few areas (mainly in the west of the city) where housing density is low and the population could be mainly described as classes I and II.

The Families

Visual impairment is no respecter of class, status or income. It strikes across the board and is as likely to happen to the hospital consultant's child as the unemployed labourer's. There are no correlations between visual impairment and poverty, deprivation or indeed with affluence.

The social class distribution of the blind sample families is shown in Table 3.3 overleaf where it is compared with that of other sample groups, namely: the Newsons' normal four-year-olds (1968), The National Child Development Study [1958 cohort] (1972), Hewitt's (1970) group of children with cerebral palsy and Gregory's (1976) sample of deaf children.

The classification used throughout the study is that of the Registrar General (1970). Classes I and II are those of the professions and include, doctors, lawyers, teachers etc. Class III (white collar) includes office workers and shop keepers. Class III (manual) includes those in skilled manual trades, for example auto-engineers and electricians. Class IV

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consists of semi-skilled workers, for example, fitter's mate, while class V are unskilled labourers. For purposes of this study class V also contains the unemployed.

Table 3.3 The Social Class Distribution of the Blind Sample Group - A Comparison with Other Studies

Sample Group	Social Class					% Unknown
	I&II	IIIWC	IIIM	IV	V	
Newson 1968 (normal)	14	13	50	15	8	
NCD Cohart 1972 (normal)	19	10	44	17	6	3
Hewitt 1970 (Cerebral palsy)	13	10	51	17	9	
Gregory 1976 (deaf)	13	10	51	17	9	
Bennett 1993 (blind)	12	10	28	24	26	

Long term unemployment accounts for the high percentage of blind sample families included in the social class V category. However, if these families are 'regraded' according to the head of household's educational qualifications rather than the job they were employed (or unemployed) in, a somewhat different picture emerges, and as can be seen from Table 3.4 below, this is a much more 'normal' distribution.

Table 3.4 Social Class Distribution of the Blind Sample Regraded According to Head of Household's Qualifications

Sample Group	Social Class (Regraded)					Percent
	I&II	IIIWC	IIIM	IV	V	
Blind Sample Group	14	14	44	20	10	

Several of the blind sample fathers had lost their jobs as a direct result of having a handicapped child. They may for example have been 'sacked' for taking time off work to fulfil family commitments and the needs of the blind child or the family may have been forced to move to a different area to be nearer specialist facilities or so that the child could attend a special school as a day pupil rather than a boarder.

It is interesting to note that a total of five mothers and five fathers in the sample group were themselves severely visually impaired. All the visually handicapped fathers were in full time employment at the time of the survey; one class IIIWC, two class IIIM, and two class IV. With regard to the visually handicapped and impaired mothers however, although all of them wanted to work, and had applied for several jobs, only one had been successful and was working part time as a nursing assistant in a hospital for mentally handicapped children on night duty. Prior to marriage, four of these mothers had been employed in class IV or V occupations such as cleaners and kitchen assistants and the fifth had never had a job since leaving school. All had been employed in jobs well below their qualification levels.

In all, 42% of the blind sample mothers were working part or full time (4% full time), compared with 44% of the mothers of normal seven-year-olds (NCD 1972 cohart), 28% of the cerebral palsy sample (Hewitt 1970) and 29% of Gregory's deaf sample (1976). Taking into account that the mean age of the children in the blind sample was 7½ years, it seems that the mothers of blind children have a much more 'normal' pattern of employment than mothers of children with other kinds of handicap. One possible reason for this is that more of the blind children attended special school as boarders than in the other studies of handicapped children, thus giving the mothers more free time. Another reason however, is that of necessity, as more of the fathers in the blind sample were unemployed compared with those in the other studies.

The Home Environment

The blind sample families were fairly evenly distributed throughout all areas of the city with slightly more living in the south and east than in

the north or west of the city. The majority (54%) were owner/occupiers, 36% were council tenants, a further 6% lived in property rented from a private landlord and the remaining 4% lived in 'tied' or rent free housing belonging to the father's employer.

The Families - Ten Pen Portraits

Because it is impossible to describe the situations of all the 50 families taking part in the study, I have selected ten of those quoted most frequently, as representative of the whole group. Their situations are briefly outlined below. Pseudonyms have been used throughout and certain items of data altered to avoid recognition of the families concerned.

1. The Gill Family

Father age 49 Builder's labourer
Mother age 34 Part time nursing assistant, herself visually handicapped.
Target child Robin: age 7 years, Functionally blind, cataracts which are genetically inherited through his mother's side of the family. There is a family history of three generations of autosomal dominantly inherited cataracts. (One in two children of an affected parent will inherit the condition). Robin attends a special school for the blind as a weekly boarder - this at his own request. He is the second of two children by this marriage, his older sister is aged 10 and unaffected.

There are also four older step-children in the household from the father's previous marriage aged: 17, 16, 14 and 13.

The family live in a large Victorian terrace house in the south-west of the city. They are Roman Catholics and the mother is Irish. The mother's family live in Ireland, but the paternal grandparents live nearby and are seen about twice per month, being reasonably supportive towards the family although they are now elderly.

4. The Jenkinson Family

<u>Mother</u> age 29, unemployed – seeking work.
<u>Target child Wendy</u>: age 4 years, Functionally blind, Cataracts. Wendy attends normal nursery school and will probably be integrated into normal primary school.

Wendy's mother is unmarried, her boyfriend left her as soon as he knew she was pregnant and there has been no contact with him since. The cause of Wendy's cataracts is unknown. She and her mother live in a first floor council flat in the north of the city. Wendy's grandparents are very supportive, and although her grandmother lives and works on the other side of the city, she normally sees Wendy and her mother at least five times per week.

5. The Kent Family

<u>Father</u> age 35, Teacher
<u>Mother</u> age 31, Nurse/midwife works part time
<u>Target child Michael</u>: age 7 years. Totally blind, Pseudo–glioma, Genetically transmitted (X linked recessive) which means that the condition is transmitted through female 'carriers' to male children. Michael attends blind school as a weekly boarder. He is the second child of the marriage, his older sister being unaffected but may be a carrier. There is a family history of three generations; the mother's father, his two brothers and maternal grandfather were all born blind.

The family live in a modern detached house in the west of the city. They are quite isolated as both parents are 'immigrants' to the city. The mother's family come from Wales and the father's from London. Contact with the extended family is therefore infrequent, usually once or twice per year.

8.   The Ellis Family

<u>Father</u>   age 39, Insurance agent
<u>Mother</u>   age 37, Housewife (clerk prior to marriage)
<u>Target child Danielle</u>: age 16. Totally blind, Retinoblastoma – a malignant tumour of both eyes. Both eyes removed at 3 months of age. No family history of the condition, but the bilateral form is usually inherited, therefore Danielle's children will be at risk. The family have not been offered genetic counselling but Danielle would like this for herself before she gets married. Danielle attends a comprehensive school with a support unit for the visually impaired. She will be going on to further education at an RNIB college and hopes to go to university. She is the second of two children, her older sister being unaffected.

The family live in a 1930s semi-detached house in the south of the city. Both the maternal and paternal grandparents live in the same neighbourhood but are not particularly supportive and are seen only three or four times per year.

10.   The Davidson Family

<u>Father</u>   age 32, Solicitor's clerk
<u>Mother</u>   age 33, Part time office worker
<u>Target child Peter</u>: age 11. Functionally blind, cortical damage from a blocked shunt inserted for hydrocephalus. Peter lost his sight age 5 years. He attends blind school as a day pupil. Peter is the second of two children, his older sister has normal vision but suffers from epilepsy and has learning difficulties. The family live in a modern semi-detached house in the south of the city and have daily contact with the maternal grandparents who live nearby.

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22. The Bates Family

<u>Father</u> age 47, Foreman steel worker

<u>Mother</u> age 45, Part time clerk

<u>Target child Samuel</u>: age 15. Totally blind, Congenital anophthalmos (born without eyes). The cause of Samuel's condition is unknown, but his mother thinks it was due to being in contact with german measles during pregnancy. Samuel attends the blind unit at a special school for learning difficulties. He is the youngest of three children, his eldest sister having married and left home. His older brother is twenty years old and still at home.

The family live in a three bedroomed council house on a large estate in the south-east of the city. Both the maternal and paternal grandparents live on the same estate but are not supportive. Samuel's paternal grandmother does not usually talk to him at all when he visits. When Samuel was 10 years old his mother had a severe nervous breakdown and was in hospital for nearly six months.

28. The Carter Family

<u>Father</u> age 54, Unemployed steel worker (retired because of terminal illness).

<u>Mother</u> age 54, Part time railway carriage cleaner

<u>Target child Cynthia</u>: age 16. Totally blind, Congenital anophthalmos. Cynthia attends a special school in Liverpool as a term time boarder. She is the youngest of three children. Her eldest brother, aged 35, is a labourer working for the City Council. He is also blind in one eye and has suffered brain damage as a result of an accident some years ago. Her elder sister is unmarried (aged 29) and still living at home.

The family live in a three bedroomed council house in the south of the city. The house, although sparsely furnished, is immaculately clean and well decorated. Both sets of grandparents are dead and the family have little support from, or contact with, other extended family members.

39. The Whitehead Family

<u>Father</u> age 50, Unemployed steel worker
<u>Mother</u> age 48, Part time cleaner
<u>Target child Winston</u>: age 6 years. Functionally blind, Micropthalmos the cause of which is unknown. Winston attends blind school as a weekly boarder. He is the youngest of a family of seven. The two eldest daughters aged 22 and 21 both have children of their own and live nearby.

The family live in a ground floor maisonette in the east of the city, in which is designated as an 'area of high deprivation'. The family have many problems of a social nature and are receiving help from social service departments. Winston's family are Afro-Carribean and they have no relatives living in England.

42. The Brown Family

<u>Father</u> age 29, Electrician
<u>Mother</u> age 28, Part time shop assistant
<u>Target child Louise</u>: age 6 years. Functionally blind, Retinopathy of Prematurity. Louise attends blind school as a day pupil. She is an only child and was born at 29 weeks gestation weighing 1060 G (2lbs 5oz).

The family live in a small terrace house in what was formerly a mining village on the outskirts of Sheffield. Although Louise's grandfather was a miner, the pit has long since closed down. The village however retains its close knit community. The grandparents live just streets away and daily contact is maintained. Both maternal and paternal grandparents are very supportive.

53. The Winter Family

<u>Father</u> age 36, Electrical engineer
<u>Mother</u> age 29, Part time clerical assistant
<u>Target child Charlotte</u>: died aged 7½ years. Totally blind – both eyes removed for Retinoblastoma. Charlotte attended blind school as a day pupil until a few weeks before her death. She was the eldest of three children.

Although her mother noticed 'something in her eye' from the age of about 6 months, the tumour was not diagnosed until Charlotte was 4 years old, by which time spread had already occurred to her bones and glands and the mother had given birth to two younger children. Because retinoblastoma is genetically transmitted, Charlotte's siblings are also at risk of developing the disease, as are their own children. Charlotte underwent radical surgery and travelled regularly to St Bartholomew's Hospital in London for courses of radiotherapy and chemotherapy. She died at home, in her parents' bed aged 7½ years.

Charlotte's mother and her younger sister and brother live in a semi-detached house in a small village north of the city where most of the inhabitants are employed in the steel making industry. Her father, who left the family shortly after Charlotte's death, has returned to his own parents who live in the same village. Although the paternal grandparents were seen frequently whilst Charlotte was ill, they were unable to accept that she was terminally ill and therefore unable to provide the kind of support the family needed. The maternal grandparents lived much further away and for this reason could not provide adequate support either.

In the pages which follow, the main findings from the interviews and from the 'Minisculpt' models are summarised.

SUMMARY OF FINDINGS

As can be seen from the interview schedule reproduced in the appendix, huge amounts of data were collected on a wide range of topics. Following analysis it was obvious that the study would have to be focused on certain aspects, as the range was far too wide to be encompassed within any one study.

Because the first phase of the study was sponsored jointly by Trent Regional Health Authority and the (then) Sheffield City Polytechnic, quite a high proportion of the interview was devoted to matters concerning health. This information was included in the report of the research (Bennett, 1987) which was circulated to appropriate Health Authority officials. Much of this data however had little bearing on the social and family lives of the children and has therefore been omitted from this thesis.

Examples of such data include possible predisposing factors of visual impairment: for example, exposure to infection or drugs during pregnancy, extreme prematurity and low birth weight. Quite detailed family histories were also taken in order to explore the genetic aspects of visual impairment. Although such data impinge only slightly upon the social lives of the families they take up large amounts of space when analysed and tabulated.

Other data have been excluded on the grounds of unreliability due to difficulties in recall (in some instances the time lag between event and interview was as much as 16 years). Examples include developmental milestones such as smiling and crawling. One exception however was the age at which the child first walked alone, which seemed to have been remembered by most mothers with great clarity, so much so that they were sometimes able to give an actual date even after many years had elapsed.

What follows is therefore a summary of data obtained which are relevant to the social lives of the families concerned, and those which have

implications regarding the professional practice of those involved in their care.

The aims of the interview were to identify the needs and problems of families rearing a visually handicapped child, and to examine the extent to which their needs are being met by existing services.

Method of Study

Permission was obtained from the relevant authorities to search all registers likely to contain information regarding visually handicapped children. Registers searched included; the Blind and Partial Sight registers held by the Local Authority, Abnormality, Handicap and Surveillance registers held by the Local Health Authority, hospital records and the case notes of health visitors and school nurses. In addition, all caring professionals likely to have contact with such children were requested to refer cases for the study. Professionals contacted included health visitors, school nurses, specialist teachers and head teachers of schools likely to have visually impaired pupils.

Approximately 300 names were collected, the majority of these children being mentally and multiply handicapped in addition to having a visual impairment. Following perusal of the case notes, those children who obviously did not meet the research criteria of severe visual impairment, i.e, a visual acuity of less than 6/36 in the better eye, or severely restricted vision for some other reason, eg. constricted fields, were eliminated, leaving approximately 200 names, still of course too large a group for a small scale exploratory study.

A pilot study consisting of 3 multiply handicapped and 3 merely blind children was conducted. On the basis of this pilot study, it was decided to concentrate on visually handicapped children of normal or near normal intelligence or rather, those with no diagnosed neurological defect giving rise to impaired mental ability, as it was found that the majority of mentally and multiply handicapped children were receiving adequate support from the Rygate centre.

Elimination of mentally handicapped and multiply handicapped children receiving support from 'Rygate' left a total of 68 families. A further 3 were later eliminated because they did not meet the criteria for severe visual impairment. In the end, useful data were collected from 50 families having between them 55 visually handicapped children. See Table 4.1 below.

Table 4.1 Details of the Sheffield 'Blind Sample' Group. N=68

Number of families successfully interviewed	50
Not traced	6
Data not obtained because of language barrier	4
Did not meet research criteria	3
Interview not achieved after repeated appointments	3
Interview refused	2
Total	**68**

Interviews were audio-taped and, where possible, transcribed onto the pre-coded computable schedule forms. Where pre-coding was not possible, boxes were left open for coding at a later stage. As explained elsewhere however (see Chapter 2 on Methodology), because of the large amounts of qualitative data, computation was not a feasible proposition, and, as noted elsewhere, 'soft' data do not, as a rule, lend themselves readily to complex statistical analysis.

Identification of the Sample Group

Although, in theory, most of the children should have been included on more than one of the registers searched, in practice there was very little overlap. Ten of the 55 children were not included on any register, these including many of the children with the most serious defects: for example,

two children who died from retinoblastoma and a child blinded because of a blocked shunt fitted for hydrocephalus.

Some families were quite difficult to trace because of their high mobility. Sixteen families had moved once or twice since the birth of the target child and eleven had moved 3 to 8 times since the child's birth. These figures are difficult to compare with the national average because of the widely differing ages of the children involved. It was however found, on breaking down the figures, that 30% of the families had moved more frequently than the average of once every six years. This high mobility of vulnerable families has obvious implications for continuity of care by involved professionals. However, it was not possible to assess the impact of mobility on the sample group because their care was already fragmented by other factors as will be seen in subsequent chapters.

Housing and Area of Residence

Visual impairment being no respecter of social class, families with blind children could be found across the complete spectrum of housing and residential area; 45% were owner-occupiers (about average for South Yorkshire at the time when the interviews were taking place), 36% were council tenants, 6% lived in property rented from a private landlord and 4% lived rent free in 'tied' property.

The high mobility of many of the families referred to above does not reflect the picture of families still trapped in unsuitable housing, but only that of families who have been able to move out of such situations. Seven of the sample families - all but one being council tenants - were so 'trapped' and had been waiting between 2 and 9 years to be rehoused. All of these families felt they had been unfairly and unsympathetically treated by housing officials. Two families had been rehoused **into** high rise flats because "blind children shouldn't be allowed out unaccompanied anyway", and an overcrowded family with five children of different sexes in a two bedroomed house was told to put the blind boy and girl in one bedroom because "they couldn't see each other anyway, so they wouldn't need separate bedrooms".

Social Class and Unemployment

The social class distribution (Registrar General [1970] classification) is shown below in Table 4.2.

Table 4.2   Social Class Distribution of the Families

Class I and II	12%
Class III white collar	10%
Class III manual	28%
Class IV	24%
Class V	26%

The high numbers in class V are accounted for to a large extent by long term unemployment of the head of household (20% unemployed for more than a year, against a regional average of 16%). When the figures were broken down, however, it was found that in half the cases the unemployment could be directly or indirectly attributed to having a visually handicapped child in the family, eg. being 'sacked' for taking time off work to meet the child's needs or moving home to be nearer to specialist resources. If this is taken into account, the 'true' rate of unemployment, due to redundancy etc.. is reduced to 10% which is below the regional average. It is noteworthy also that 5 of the fathers also suffered from severe visual impairment; all were, however, in full time employment at the time of the survey.

Handicap and Family Structure

Twenty three (46%) of the families had more than one handicapped member. Seventeen families had 2 handicapped members, 4 had 3 members and 2 families had 4 members who were handicapped. Many of these people suffered from multiple handicaps, and several had disabilities in addition to a visual impairment. Such conditions included: neurological syndromes,

epilepsy, diabetes mellitus, multiple sclerosis, lung cancer, albinism, hydrocephalus, disability following accident and many more.

The most common reason for several family members to be handicapped was genetically inherited disease, but it is also true that handicapped people tend to live in a somewhat restricted social world and are therefore more likely to meet with and marry other handicapped persons. This increases the chances of the children of such couples inheriting abnormal genes and thus perpetuating rare genetic disorders.

The Inheritance Factor

A high proportion of the defects suffered by the children (64%) were genetic in origin, although relatively few families fully understood the implications of this as can be seen from Table 4.3 below.

Table 4.3   Explanations of Genetic Implications Given to Parents   N=40
Families

Explanation given and understood	7
Explanation given but unsatisfactory or not understood	11
Explanation requested but doctor evasive	8
Mother informed doctor	1
No explanation given	12
Don't remember	1

The genetic implications for future generations are probably among the most difficult of all the problems for the parents of handicapped children to come to terms with, and the topic is loaded with guilt and anger. Few parents had been able to confront the problem directly themselves, let alone explain the implications to their children and help them to come to terms with the issues involved. Table 4.4 overleaf shows the children's awareness of the genetic implications.

Table 4.4 Children's Awareness of the Genetic Implications N=55 Children

Yes, fully aware	3
No, not aware	14
Too young to understand	15
Don't know – not discussed	3
Not asked (child present)	10
Not applicable	10

Intention to Inform

Table 4.5 below shows the parents' intention to inform their children of the genetic implications.

Table 4.5 Intention to Inform Children of Genetic Implications N=50 Families

Child already informed	3
Yes, when old enough	4
Don't know	17
No	0
Parents themselves unaware of genetic implications	6
Not asked	10
Not applicable	10

Table 4.5 shows that all the parents had good intentions and all of them felt that the child had a right to know the truth. They were however all at a loss to know how to go about explaining the situation to the children and had no one to turn to for help. This is shown clearly by the large number of don't knows.

Finding Out - Discovery of the Defect

As with other handicapping conditions, one of the main problems for the parents was getting professionals to listen to their worries. Fifty three percent of the defects were in fact first noticed by family members rather than professionals. This compares with 58% of the defects in the RNIB sample (Walker et al, 1992). The discipline of the first person to notice the defect is shown in Figure 5.1 on page 106 and the subject is discussed in Chapter 5.

Although most of the defects were probably present from birth, only 8 of the children were actually diagnosed before leaving the maternity hospital. In 5 of these cases there was a family history of blindness and medical staff had been alerted to this prior to the child's birth. Of the remaining three, two were born without eyes and the remaining one with microphthalmos - very small rudimentary eyes. The figures from the Sheffield sample are in fact very similar to those of the RNIB national figures (Walker et al, 1992). In the RNIB study, "Some 80% of the children were reported to have had their sight problem from birth, but in only 27% of cases was it actually suspected and confirmed at or soon after birth". In the Sheffield sample, 78% of the defects were definitely or probably present from birth, but only 26% were actually noticed in the first week of life.

Delay Between Discovery and Diagnosis

There was often a wide discrepancy in time between the discovery and diagnosis of the defect. In one case this amounted to 7½ years in the Sheffield sample. The RNIB (1992) national survey shows that this is not

unusual. Figures from this study (Walker et al, 1992) show that in 9% of cases the delay was 3 to 5 years and in 3%, between 5 and 10 years. This subject is discussed in later chapters.

Being Told

For some parents the diagnosis came almost as a relief. At least their fears were confirmed and they could begin to look for help. For the majority however, even though they might have suspected that something was badly wrong, the news that their child was or would become blind was devastating. In some cases parents not only had to come to terms with blindness, but with a life threatening condition which had been passed on by themselves, could well affect their other children and also be transmitted to future generations.

Interviews at which such news was imparted were generally short, about 10 minutes being average. None of the parents could remember a nurse or anyone else being present to pick up the pieces following the interview and none were referred to a social worker or anyone else in a caring or helping capacity. This, it seemed, held true regardless of whether the child was diagnosed in the outpatient department or in a ward situation.

Parents recount their experiences of the impact in Chapter 5 and the subject is explored in detail in Chapter 22.

Who Will Help?

Access to services is shown in Figure 4.1 overleaf.

Figure 4.1 shows how complex finding help can be. The outermost layer of the 'rainbow' shows the 'goals' or the required services. The innermost layer shows the 'gateways' to these services, and the middle layer shows the complex 'web of welfare' through which parents (and professionals) must find their way to achieve their goals. Adding to the complexity is the continually evolving and changing structure of the 'web' as new legislation is imposed and the structure of the NHS changes. As an example, since the study was completed, many GPs have become fund holders and will therefore

have to pay for referrals made by health visitors to specialist community services. In addition, the 'gateway' via the Health Authority clinic system is now effectively closed since GPs have taken over responsibility for child health.

Figure 4.1 Access to Services
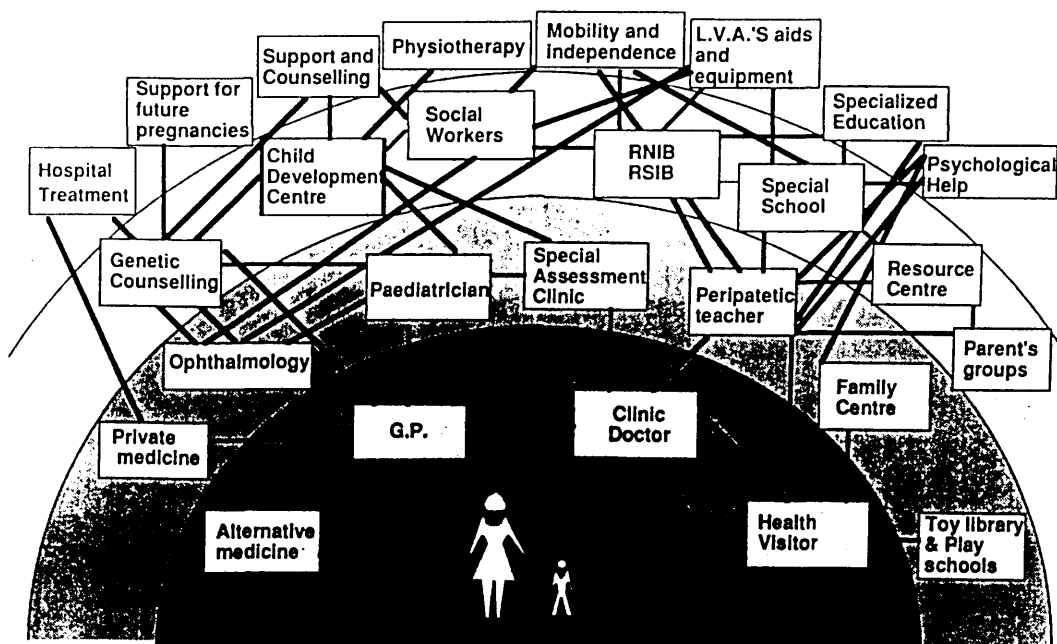
Services and Satisfaction

Ophthalmic Services

It is commonly assumed that children with severe visual impairment will be under regular hospital supervision and that they will therefore receive support from skilled professionals and where necessary be referred to other agencies from the hospital.

Table 4.6 overleaf shows however that 9 (16%) of the children had in fact been discharged from hospital, there being no point in following up children who have no eyes or for whom no treatment is available. Table 4.6

also reveals that the majority of children attend an adult general hospital rather than the children's hospital.

Table 4.6 Hospital Attended for Ophthalmic Supervision N=55

General Teaching Hospital	31	
Children's Hospital	9	
Special School supervision only	3	
Special Clinic in London	2	(both died)
Private consulting rooms	1	
None/discharged	9	

Table 4.7 below shows the frequency of hospital attendance.

Table 4.7 Frequency of Attending the Ophthalmic Clinic N=55

Monthly or more often	1
4 to 11 times per year	10
2 to 3 times per year	11
Once per year or less	16
School supervision only	3
Discharged	9
Don't know - no pattern established yet	3
Died	2

Table 4.7 reveals that most children attend the ophthalmic clinic once or twice a year or less frequently. It does not however show the time spent waiting to see a doctor, for special tests to be completed, for

orthoptists' reports or X rays etc.., as against the time actually spent with the ophthalmologist which averaged around 5 minutes per appointment. The average time actually spent in the clinic averaged 2 to 3 hours per visit. This means that most children have 5 to 10 minutes per year with an ophthalmologist.

Satisfaction with Ophthalmic Services

The parents' satisfaction with the ophthalmic services is shown in Figure 4.2 on page 70 where it is compared with that for other medical services. Parents were asked to award 'marks out of 5', with 5 being excellent and 1 being very poor.

Fourteen parents responded by saying "don't know". This was usually because they had not had time to assess the situation because the child had only attended once or twice and had not established a regular pattern of attendance.

Apart from the waiting time, which was the most common complaint, dissatisfaction stemmed mainly from lack of, or poor, communication between doctor and parent and lack of continuity of care, i.e. seeing a different doctor at each visit.

Paediatric Services

Thirty six of the children had at some stage been referred to a paediatrician at the maternity hospital or the children's hospital. On the whole the paediatric clinic was attended at more frequent intervals than the ophthalmic clinic. Details are shown in Table 4.8 overleaf.

Table 4.8 Frequency of Attendance at the Paediatric Clinic N=36

Monthly or more often	2
4 to 11 times per year	9
2 to 3 times per year	3
Discharged/took own discharge	17
Don't know - no pattern established yet	1

As can be seen from Figure 4.2 overleaf, opinions regarding the paediatric service tended to be polarised towards either the 'good' or the 'bad' end of the spectrum rather than clustered in the middle. Satisfaction was higher where the parents saw the consultant himself or the same doctor at each visit, where they were given information about the child's condition and progress, and where they felt their questions were answered in an open and sensitive manner. There were fewer complaints about the time spent waiting to see the doctor although this was rarely any shorter than the time spent waiting to see the ophthalmologist. There were two main reasons for this difference. Firstly, a larger proportion of the time was actually spent with the doctor - an average of 20 minutes as opposed to 5 minutes with the ophthalmologist, and secondly the waiting area was geared towards children with plenty of toys and space to play. The canteen was also located in the waiting area so that there was less chance of 'missing their turn'.

The General Practitioner

Parents were asked to rate the service given by the GP specifically with regard to the visually handicapped child. In Figure 4.2 the children rather than the families have been enumerated because in some cases each child had a different GP.

70

Figure 4.2 Satisfaction with Medical Services
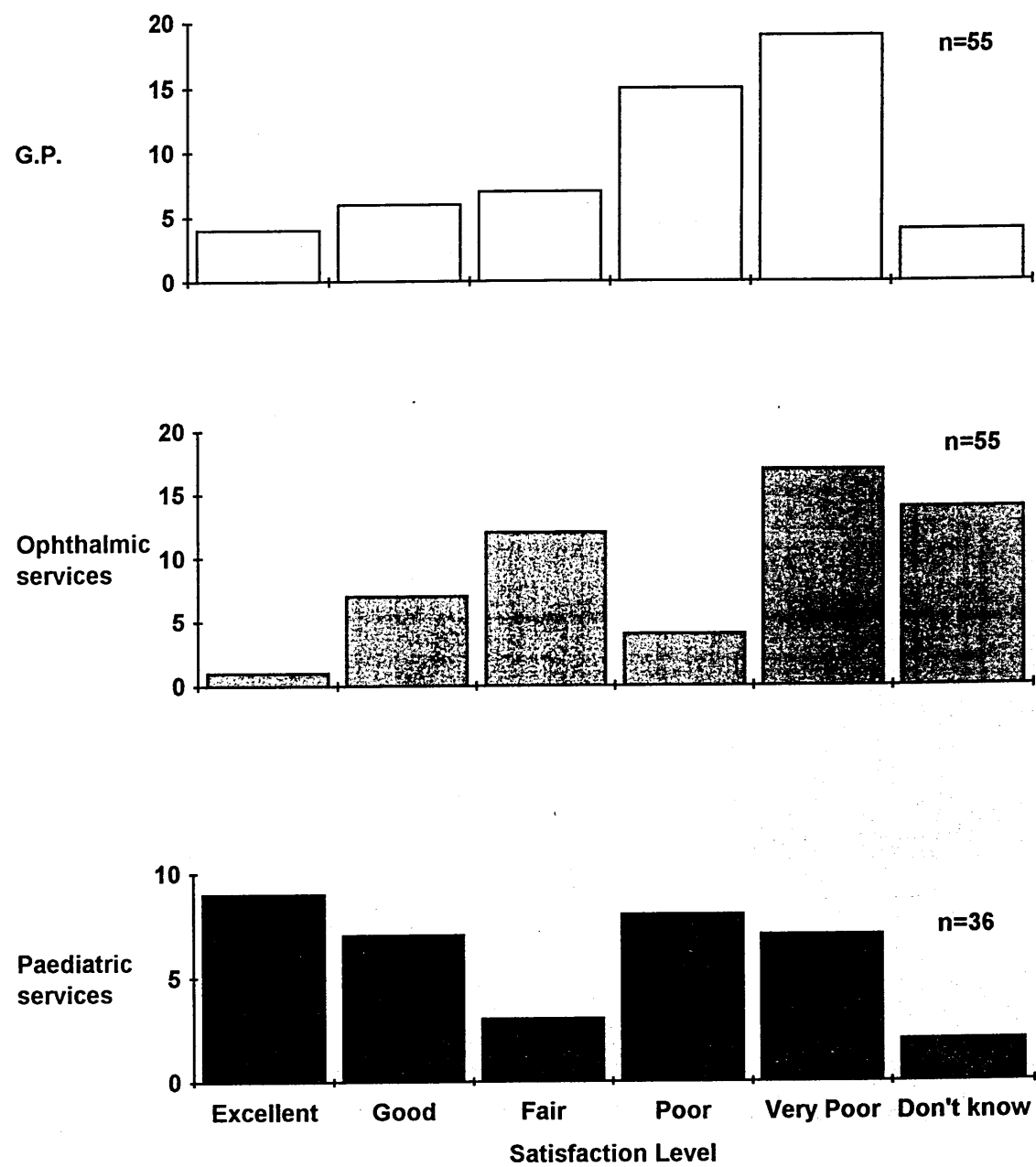
In most instances families had been registered with their GP for a number of years, liked him as a person and were satisfied with the service he had given to other members of the family. The high levels of dissatisfaction shown pertain more often to the service offered to the blind child than to the doctor himself. Although satisfaction ratings for GPs were higher in the RNIB survey (Walker et al, 1992) - possibly because the question was phrased differently - the reasons for dissatisfaction were very similar, i.e. the doctor couldn't help, couldn't or wouldn't answer questions, lacked specialist knowledge, was pompous or dismissive or had no patience with the child. The majority of families did not expect specific help from their GP as they realised that he could not be a specialist in all fields of medicine. On the whole, however, the feeling was that he could have given more general support, and in the cases where this was given it was greatly appreciated.

The Health Visiting Service

Satisfaction with the health visiting service is shown in Figure 4.3 overleaf, where it is compared with that for the social work and support teaching services.

The reasons given for dissatisfaction with the health visiting service were very similar to those for the GP. The majority of those awarding only one mark out of five said the service was unhelpful to them rather than very poor. As with the GP the families did not expect specialised help and advice from the health visitor. They would however have appreciated being referred to someone who could help them.

Many families were under the impression that health visitors did not visit handicapped children, and from the responses, it did appear that families with a visually impaired child were visited less frequently than 'normal' families. According to the parents, only 50% had been visited more frequently than once or twice a year during the pre-school period. These results are similar to those of the RNIB team (Walker et al, 1992) who found that 63% of their sample had not been visited for over a year.

Figure 4.3 Satisfaction with Community Services
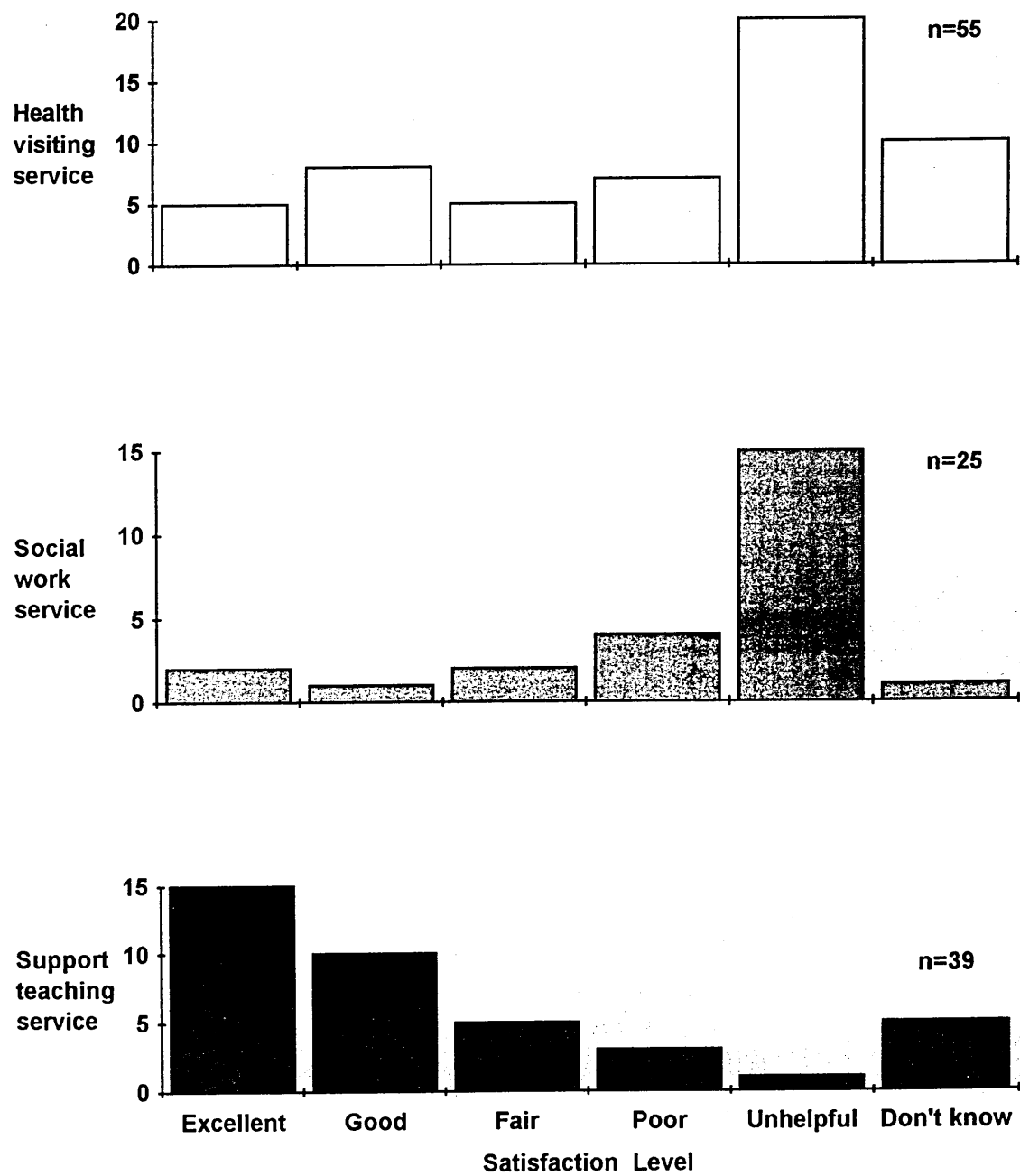
Very few families could remember the name of their health visitor, but this is not surprising as under 25% of the children had had continuity of care from a single named health visitor. Table 4.9 below shows the number of different health visitors involved since the child's birth.

Table 4.9 Number of Different Health Visitors Involved Since Child's Birth N=55

One only	13
Two	13
Three	10
Four	2
Five	3
More than five	1
Don't know	8
Never had a health visitor	5

The Child Health Clinic

Most of the children had (if only occasionally) attended the local child health clinic. Only 7 said they had never attended, all of whom had been followed up by a paediatrician from birth. The frequency with which the children attended clinic is shown in Table 4.10 overleaf.

Table 4.10 Frequency of Attendance at Child Health Clinic N=48

Monthly or more often	20
2 to 6 times per year	5
Yearly or less often	3
Only when sent for	17
Only went once or twice	2
Don't remember	1

Most mothers said they attended clinic less frequently with the visually handicapped child than with their sighted children. One reason for low attendance may have been that the parents felt stigmatised. The comments below are typical.

> "I didn't like going, I must admit. It was very difficult with all the normal children running around and him not being able to join in".

> "I used to go as little as possible. I just used to sit in a corner on my own. Nobody ever used to talk to us".

It seemed to be a fairly general impression that the child health clinic was for normal babies and not for sick or handicapped children. Again the comment below is typical.

> "With him being so small and handicapped, I don't think they wanted to know really. They just used to say, 'Oh well, you're under the hospital aren't you? You'd best ask them".

On the other hand, some parents found the clinic more helpful than their GP, for example:

> "The clinic doctor was the only one interested. The GP just said it was no use seeing anybody because nobody could do anything about it".

"I had more confidence in the clinic doctor than my own GP. At least he took notice of me that something was wrong with her".

The Specialist Support Teaching Service

Seventy one percent of the children had received help from a support teacher for the visually impaired - which of course leaves 29% having had no such input. Figure 4.3 shows that the majority of parents were highly satisfied with this service. Even parents who said they disliked the teacher as a person did not usually complain about the service. The main criticisms were that insufficient help and advice was given with regard to practical aspects of child rearing such as independence skills, feeding and toilet training. Parents answering, 'don't know', had not themselves had contact with the teacher as the child had received help at school with various aspects of work.

Social Work Services

Fifty percent of families had at some time received social work input. Of these, 9 had been area based local authority workers and 14 hospital based. The remaining 2 had received help from specialist social workers with the Malcolm Sargent fund for children with cancer.

The amount of contact with social workers was, in the majority of instances, very small indeed. For those having input from an area social worker, this had usually been one visit at the request of the family. Hospital based social workers were seen by the families as 'almoners' rather than counsellors and most parents had seen the social worker with regard to travelling expenses or other benefits.

Figure 4.3 reveals very low levels of satisfaction with the social work service. Area based generic social workers received the lowest ratings of all. This seemed to be because the service was not geared to the special needs of the families and did not meet their expectations. Parents expected that the social worker would advise them about the services, aids and benefits available and that s/he would help them to obtain these. Families wanted information, practical help and guidance through the welfare maze. Most felt the service had not met any of their needs in this

respect. Two social workers were however awarded an 'excellent' rating and it is interesting to note that both were specialists working for the Malcolm Sargent fund. Another social worker awarded four out of five points was a student.

Services Provided by Voluntary Agencies

Sixty two percent of the children had received no help of any kind from a voluntary agency while some families had been involved with several agencies. The overall satisfaction with voluntary agencies was therefore too complex to tabulate. The voluntary agencies can be divided into two categories – those dealing specifically with visual impairment (the Americans call these 'Blindness Agencies') and those of a more general nature. Among the general agencies with which the families had contact were, local church groups, SKIP (a local play scheme for handicapped and able-bodied children), the Rowntree Fund, Compassionate Friends, Home Start (a local scheme for families with social difficulties), and parents' support groups. The 'Blindness Agencies' included the Royal National Institute for the Blind (RNIB), the Royal Sheffield Institute for the Blind (RSIB) and the Partial Sight Society. On the whole the general agencies elicited higher satisfaction ratings than those specific to blindness.

Only 2 families had been involved with the Partial Sight Society, both finding this unhelpful. Thirteen families had had contact with the RNIB or the RSIB. Although the RSIB is not (as many people think) the local branch of the RNIB, but a completely independent and separately funded agency, families contacting the RNIB in London for help are referred back to the Sheffield Agency unless the service is specific to the RNIB itself – for example the braille library service. Only one family had been able to tap the resources of the RNIB directly and this was the only instance in which a Blindness Agency was given a high satisfaction rating. The remaining 12 families having had dealings with the RSIB awarded very low ratings. It has to be pointed out that the RSIB is not geared to helping blind children, but deals mainly with the elderly blind population. It does not employ qualified social workers and the home visiting service is carried out by untrained volunteers. The RSIB does not provide an educational service as in Sheffield this is the responsibility of the LEA

through the peripatetic support teacher service. Mobility training for children is also the responsibility of the LEA again through the teachers. Should equipment, for example an Optocon or a computer be required for home use, it is usually obtained by local fund raising. When sufficient money has been collected, the RSIB will purchase the equipment on behalf of the family at the (slightly) reduced rate in the RNIB catalogue. Money from voluntary subscriptions and collections set aside for blind children in Sheffield is spent on an annual Christmas party. The comment below is typical of those regarding the RSIB:

> "Well after he'd been registered (blind), this woman comes round from the blind institute (RSIB), pats him on the head and says she'll get him an audible ball. It was a computer we wanted, not a ruddy ball with a bell in. Anyhow we never saw her or the ball again. We got his computer through the church - they've got a special fund for handicapped children in the village".

Private and Alternative Medicine

Fourteen (28%) of the families had sought help from the private sector or from alternative medicine. Eight had seen an ophthalmologist privately and one a paediatrician. Of those who turned to alternative medicine, 3 had seen a faith healer, 1 had written to a Russian hospital regarding a placental implant and 1 to the BBC requesting information about eye transplants. Clients entering the private sector need a letter of referral from their GP. Only 2 GPs willingly gave their support and in 1 of these cases the child's father was also a doctor. In all other cases consent was only grudgingly given and the parents warned that they were wasting their money.

Ten families gave pressure from relatives, friends and workmates as a reason for seeking a second opinion or alternative therapy. Three others said they had paid in order to obtain more information and to have more time with the ophthalmologist. As they remarked, "They never tell you anything on the National Health". The remaining child's father was a doctor and the family invariably sought a private opinion.

While all the parents wanting a private consultation had no option but to request this through the GP, it is interesting to note that none of those

who sought help from alternative medicine asked the advice of their GP on the matter. All felt that it was 'None of his business'.

Satisfaction Ratings in General

If the graphs of satisfaction ratings are compared, it can be seen that only the support teaching service received consistently high levels of satisfaction. In general high levels of satisfaction were found where the client had:

an ongoing relationship - with the same named person - who was an expert in the field.

The specialist teaching service was the only one where this 'essential triangle' was complete. It seems to be necessary for all three sides of the 'triangle' to be present, one or two factors being little better than none at all.

The overall impression gained was that children and families with special needs require special resources and specially trained people to meet these needs, and that in the case of the blind sample at least, these needs cannot be properly met from generic resources.

The Impact on Family Life

The impact from the news that the child is blind can affect not only the immediate family circle but also the extended family and to some extent the neighbourhood and peer groups. The whole family is to some extent labelled and stigmatised as a result. The subject is dealt within depth elsewhere in the thesis.

The Marital Relationship

The impact of the blind child on the marital relationship is discussed in Chapter 6. That the birth and rearing of a handicapped child has an impact upon the marital relationship and family life is not in dispute. However, while 'common sense' and the majority of studies have concluded that this

impact is almost always adverse, a few have come to the conclusion that the problems have been overstated and that the effects are much less catastrophic than many have supposed.

It was not possible to directly compare the results of the Sheffield study with those of others because each researcher has tended to use a different definition of the problem. Even more confusing is the fact that researchers have applied the same definition to different concepts. For example, the terms marital disharmony, marital stress and marital strain seem, in some studies, to be interchangeable, whereas in others they are quite separately defined but not always in the same way.

As can be seen from Table 6.1, the handicapped child did in fact have an adverse impact in the majority of instances. Only 3 couples in the Sheffield sample felt that the child had brought them closer from the beginning and a further 5, although experiencing difficulties in the early period, felt that, over time, the child had had a positive influence.

It would be unwise to try and compare the rate of marital breakdown in the Sheffield sample with that of other studies because of the continued rise in the divorce rate of the general population. This issue is further complicated by remarriage and the combining of step families. It also needs to be pointed out that the handicapped child is not always a 'causal factor' in the breakdown – Furneaux (1988) for example found that in many cases the relationship was unstable prior to the birth of the handicapped child. Although the number of families in the Sheffield sample which had been broken at some time (36%) was around the national average at the time, when only those in which the child was seen as a causal factor are considered, the percentage falls dramatically to 14%, which is considerably below the national average. It would appear therefore that, in the Sheffield study at least, although a great deal of stress was experienced, the majority of families survive intact. It seems therefore that, rather than causing the family to break apart, the blind child actually acts as a binding force holding the family together. This finding also tends to be borne out in the minisculpt models constructed by some of the families.

Parental Ill Health and Emotional Disturbance

When considering the subject of parental ill health, it needs to be taken into account that very few fathers were actually present during the interviews, the data regarding the health of the fathers being almost always obtained from the mothers. The picture is therefore inevitably biased. According to the mothers, 76% of the fathers enjoyed good physical health. However, 64% of the mothers reported symptoms of physical ill health in themselves, such symptoms often being of a psychosomatic nature.

Symptoms of an emotional nature were common in both partners, depression and anxiety being the most often reported. These symptoms (as reported by the mothers) are shown in Figure 6.3. Other researchers have also noted a high prevalence of depression and anxiety among mothers of handicapped children. For example, Gregory (1976) found that 87% of the mothers of deaf children had suffered depression.

Hardly any of the parents had received any kind of professional help in coming to terms with their grief or in coping with the stress. Few had even thought of seeking help as many were ashamed of their feelings and felt unable to admit them to their doctor in order to obtain help. Most parents felt that it was a waste of time talking to their GP about it because he simply did not understand their problems. This is disturbing in view of the finding that 10% of the mothers in the blind sample had seriously considered or actually attempted suicide, while 4% had seriously considered or actually attempted infanticide. This may well be the tip of the iceberg, as no question was asked regarding these matters, the information being volunteered during the interviews.

Emotional Disturbance in the Children

Existing data on the impact of a handicapped child on his siblings are difficult to evaluate, once again because of different definitions and methodological approaches. The National Child Development Study [1958 cohort](1972) finding was that 8% of the general population of children suffered from an emotional or behaviour disorder, "sufficiently severe or

sufficiently prolonged to cause suffering to the child himself or to others" (Rutter et al, 1970).

A number of researchers, for example Glendinning (1986) have found the incidence of emotional disturbance and behaviour disorders to be raised in the siblings of handicapped children. Gath (1978) on the other hand, found that the emotional disturbance was not always directly linked to the handicapped child but had often been present prior to the child's birth. Few studies, it seems, have taken this into account.

Figure 4.4 below shows the incidence of emotional disturbance in the blind children and their siblings.

Figure 4.4 Emotional Disturbance and Behaviour Disorders in the Blind Children and their Siblings Base = 55 Blind Children and 64 Siblings
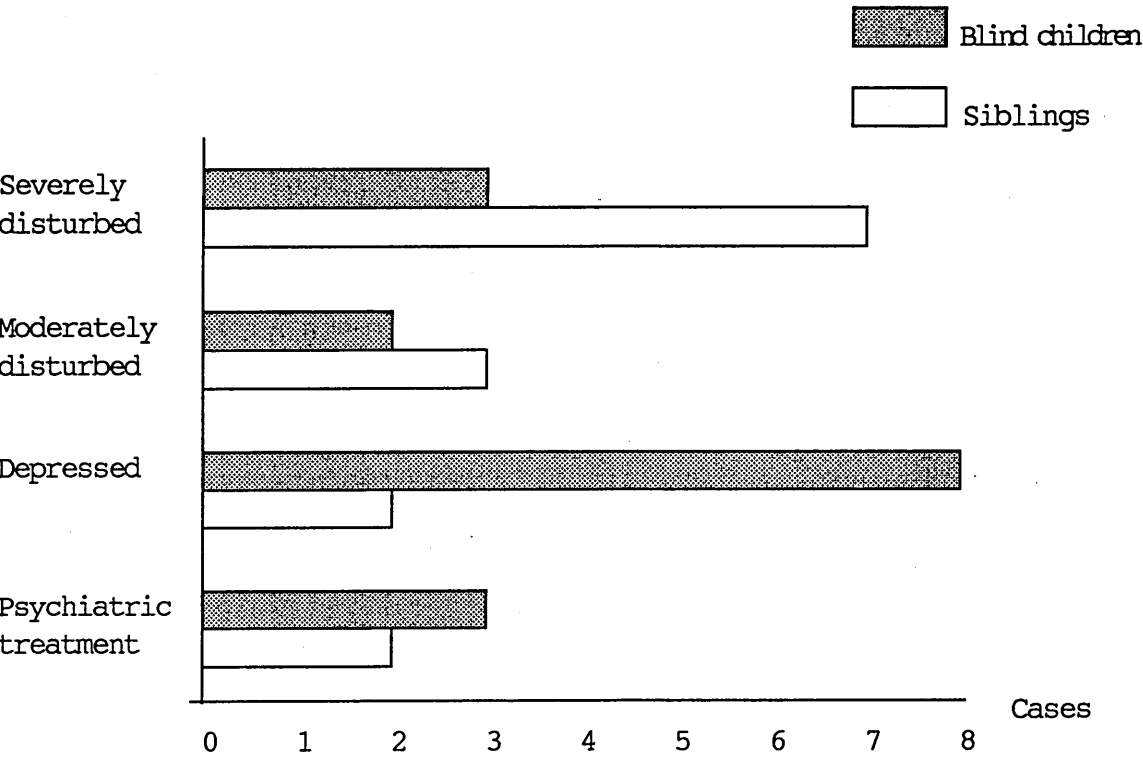
Twelve siblings out of a total of 64 (19%) were felt by their parents to be emotionally disturbed alongside 13 (nearly 24%) of the blind children. Mild forms of sibling rivalry have been discounted as have behaviour disorders present prior to the blind child's birth. In some of the blind children the depression was severe, one child at least having threatened suicide. It will be noted that emotional disturbance in blind children is almost three times the national average, Davie et al (1972) in the National Child Development Study (1958 cohort) giving a figure of 8% of children as being emotionally disturbed.

From Figure 4.4 it can be seen that whilst the blind children suffered more commonly from depression, the siblings were more likely to indulge in aggressive or violent behaviour. Some of the siblings had also resorted to stealing. This difference between the two groups is logical in view of the poor mobility of the blind child and his lack of opportunity to indulge in aggressive or violent behaviour.

The Influence of the Extended Family

In Sheffield the extended family is still a viable system, networks are extensive and the grandparents (particularly the maternal grandmothers) still have a great deal of authority and influence. The majority (84%) of the families in the Sheffield sample had grandparents living in the same neighbourhood. Certain child rearing practices, notably weaning and toilet training were heavily influenced by the grandparents, and because of the lack of professional advice and support given to the sample families, the influence was even more pronounced.

Having the support of their own parents and siblings was often crucial to the emotional well being and sometimes even the survival of the nuclear family as a group. Overall therefore, in Sheffield at least, the extended family can have a powerful influence and should not be overlooked by helping professionals.

Mothers and fathers, it seems tend to experience grief in different ways and therefore adopt different methods of coping. Mothers seem to find it much easier to talk to friends and caring professionals than do fathers. Fathers often play the role of the stronger partner, and are not always able to remove this 'mask' even within the intimacy of the family group.

Another factor to be taken into account is a phenomenon which I have termed the 'Coping Splendidly Syndrome' (see Voysey, 1975). Here, the whole family puts on an act, aimed it seems particularly at caring professionals. A facade is built up which can be very difficult to penetrate. The 'syndrome' is probably much more common than is generally supposed. There are many reasons why families should adopt such a stance and some of these are explored in Section V. One reason was (to me) however somewhat unexpected. There is, it seems, still a deep rooted fear that blind babies are 'taken away' to be cared for in Sunshine Homes and that only mothers who can prove they are experts in coping will avoid this. Fear of the child being 'taken away' was apparently one of the first thoughts to enter many of the parents' minds on hearing the diagnosis.

Understanding, Acceptance and Coping Ability

It was anticipated that acceptance of the handicap would be quite closely linked with the mother's coping ability and with her general understanding of the condition and its effects on the child. As can be seen from Figure 4.5 overleaf however each pattern is different.

Understanding

The majority of parents had little understanding of the handicap or of the ways in which it could affect the child. One reason for these low levels of understanding, regardless of class or educational standard, is the lack of lay literature on the subject of visual impairment. Even when parents actively sought for literature, very little was available. A further reason was the mystique with which the medical profession surrounds itself, "They never tell you anything at the hospital" was a comment made by almost

Figure 4.5   Understanding of the Condition, Coping Ability and Acceptance of Handicap
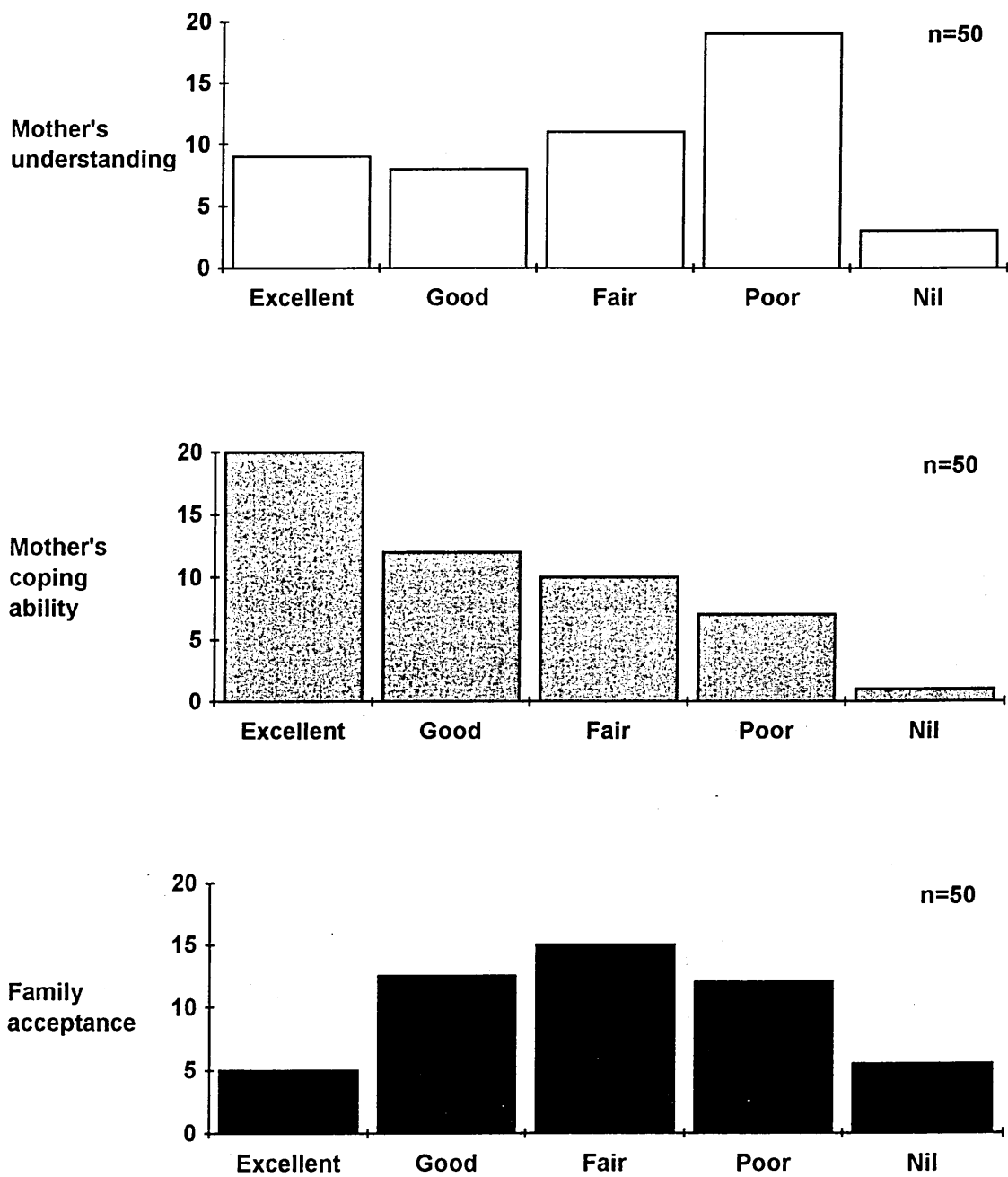
everyone in the sample group. These findings are also very similar to those of Walker and colleagues (1992) in the RNIB national survey.

Coping Ability

Learning to cope with a visually handicapped child is something which happens over time and usually without any input from helping professionals. Although a vast literature exists and high levels of professional time and energy are expended in teaching parents how to cope with normal child rearing, there is a profound lack of help and advice available to families rearing a blind child. In spite of this however, as can be seen from Figure 4.5, most mothers, do in fact, cope very well. This learning is however usually by trial and error, which is time consuming, costly and often detrimental to the child himself and to the family as a group.

Acceptance of the Handicap

Acceptance of handicap like coping ability, appears to be related to time in that the parents of older children showed higher levels of acceptance than those of infants. However, relatively few families ever fully came to terms with the situation. Most 'learnt to live with it' as they said, rather than fully accepting it.

The Achievement of Independence

Common sense would appear to suggest that the achievement of mobility and independence skills would be linked to the degree of handicap. Thus, it was anticipated that the totally and functionally blind children would be less mobile and less independent than those with useful vision. Unexpectedly, no such correlation was found. There was however a relationship between low levels of independence and poor achievement at school and high levels of stress, anxiety and depression in the parents, more particularly in the mothers. There were some exceptions to this, these being cases where the child had lost his or her sight after gaining independence skills. It does appear that such children can override the adverse influence of parental anxiety and depression, not only to retain

their independence but also to become high achievers in the school situation.

Other aspects of socialisation are discussed in Section II. In the main it was found that although the pathways towards socialisation often differ between blind and seeing children, the 'end result' is, it seems, essentially the same.

Education and School Careers

The education of visually impaired children is considered in Section III. Study of the background to, and history of, education for the blind since its inception in the 18th century shows that many of the dilemmas currently facing educationalists are not in fact new. Dilemmas such as whether integration or segregation is best for handicapped children, the kinds of 'labels' (if any) which should be used to describe their conditions, and the balancing of educational need against cost to the tax payer, have all been faced before, sometimes repeatedly. It is also interesting to note from history that the problems and dilemmas facing 19th century educationalists were very similar to those facing present day practitioners, and that many of the same 'solutions' have been tried before with similar results. History, it seems, no longer forms part of the educational curriculum for students in the field of special education. It is likely therefore that teachers and educationalists will continue to fall into the same traps as their predecessors for the foreseeable future.

The educational careers of the Sheffield children are outlined in Chapter 12, see tables 12.1, 12.2 and 12.3. Because the numbers are so small, these tables must be interpreted with extreme caution. It must also be borne in mind that the figures may be peculiar to Sheffield and therefore not applicable nationally. However, the tables indicate that, in Sheffield at least, the children receiving special school education fared rather better than those integrated into mainstream schools. The proportion of integrated children experiencing problems rises progressively as the child gets older with 62% experiencing problems at primary level, 70% at middle or junior level and 100% of integrated pupils having problems at secondary level. Integrated children, it seems, have problems even in schools where

conditions appear to be 'ideal' for children with special needs. Further (client orientated) research is needed in order to ascertain why this should be so. One reason is the difficulty of providing the necessary highly specialised (and expensive) equipment and expertise needed for the teaching and support of these children when they are spread over a wide geographical area. To do this within what could be described as a 'reasonable budget' is even more difficult. It would appear therefore that in the present economic climate, and in Sheffield at any rate, there is a fairly strong case to support the retention of special schooling for children who are severely visually impaired.

Information, Advice and Counselling

As previously stated, all families found it difficult to obtain information about visual impairment and advice on how to rear a blind child. The RNIB survey (Walker et al, 1992) shows that this is a national problem. Sixty two percent of the Sheffield parents had succeeded in obtaining some information about visual impairment from one or several sources. Nationally, it seems, the problem is even greater with only 22% of the (1992) RNIB sample succeeding in this. The sources of information and advice for the Sheffield sample are shown in Table 4.11 overleaf.

The information which was obtained did not, on the whole, meet the parents' needs. It was usually of a very general nature, not specific even to blindness, let alone to the actual condition.

Table 4.11 Sources from which Parents Obtained Information and Advice N=50
(more than one source each)

More than One Each	
None	19
Peripatetic support teacher	23
Sheffield booklet 'Children with Special Needs'	14
Medical books from City Library	11
RNIB	10
Media - radio, television and journals	6
Medical/nursing staff (hospital or community)	2
Partial Sight Society	2
Retinitis Pigmentosa Society	1

With regard to counselling, the position was even worse, only 16% of the national (RNIB) sample and 8% of the Sheffield families having received this. In 2 of the Sheffield cases, the counselling was given only after the child's death. As Walker and colleagues (1992) point out, "There is a miss-match between the desire for help and its provision". Over 80% of the national sample said that what they needed most when faced with the diagnosis was someone knowledgeable to talk to. The Sheffield sample were not asked this question. They were however asked what services they would most like to be made available. Table 4.12 overleaf shows the response.

Table 4.12 Services Parents Would Like Made Available N=50 (More than one source each)

Parents' support group	22
Specialist advisor/teacher/counsellor	11
Holiday camp/play scheme	10
Information on services available	9
Explanation and advice in plain English	7
Named person to contact with problems	6
Parents' workshops	6
Counselling service for child	2
Nothing/don't know	9

These responses from the Sheffield parents also seem to imply that there is an unmet need for counselling as well as for information. By 'counselling' here I mean the assistance of someone knowledgeable for the families to talk to and to help them to work out solutions to their problems as they and the worker jointly define them.

Looking Towards the Future

Parents were asked how they saw the future for their child and whether they had any particular worries or anxieties regarding the future. Again, most parents had anxieties about more than one aspect of the future. Responses are shown in Table 4.13 overleaf.

Table 4.13 reveals that few parents were optimistic about the future. Those who expressed optimism fell mainly into two groups, firstly those for whom visual impairment is the norm, i.e. where there is a family history going back over several generations, and, secondly, the parents of children with useful vision (the partially sighted).

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Table 4.13 Parents' Anxieties About the Future N=50 (More than one source each)

Fear of deteriorating vision or complications	15
Employment prospects	14
Being able to lead an independent life	11
Genetic implications	8
Isolation or social deprivation	7
Short term worries eg.. starting a new school	7
Being unable to plan for the future	7
Old age and death of parents	6
No worries/optimistic about the future	7

It would be interesting to compare the Sheffield sample (in which professional input was very low) with a similar group having access to professional advice and counselling from the very beginning in order to establish what kind of impact this has on the family.

The needs of the families are simple and basic - information and somebody knowledgeable (professional or other parent) to talk to being the most frequent requests. The services they would like could be easily and inexpensively provided, and it is interesting to note that all the services mentioned in Table 4.12 are already provided for diabetic children and their families. The Sheffield survey and the national RNIB survey have shown that the needs of blind children and their families are not less than those of diabetic children, and it is hoped that the attention of service providers can be brought to the results of these studies so that the balance might to some extent be redressed.

Some results from the 'Minisculpt' study of family dynamics are presented in the section which follows.

THE PRACTICAL APPLICATION OF 'MINISCULPT'

The methodology of Minisculpt is described in Chapter 2 together with the ways in which the method was used in fieldwork. In the pages which follow, my aim is to show how the method 'worked' in practice and to present some of the information yielded by the models.

It is said that, during counselling, clients will reveal only such information as they wish their therapist to know. However, this, I think, is not always the case, and during Minisculpt sessions, it was felt that some respondents inadvertently revealed rather more about themselves than perhaps they intended. Much of this information was of a very sensitive nature and it was felt that it could lead to some of the families being recognised should the material reach a wide enough readership. An added problem stemmed from keeping each respondent's models confidential to the 'sculptor' and myself. Sometimes information was revealed which even the sculptor's partner and family were unaware of. Because of this, it was decided to present some of the models as 'snapshots' rather than straight case studies. Thus I have chosen to illustrate some of the information gathered from the sculptures by describing individual models or sequences from several different families rather than joining complete sequences in the form of a case study from any one family.

The families have been given different names from those used in the main text and sometimes other information which could lead to recognition has been altered. For example, the father's occupation, the sex of the child or his siblings or the name of a rare condition to one of a similar nature.

Areas of Use

In this project, Minisculpt has been used successfully under the following conditions: with functionally blind and partially sighted respondents, adults with mild or moderate learning difficulties and people with physical handicaps.

Although the method was designed with children as well as adults in mind, I myself found it less successful (as a research tool) with children

because, as noted previously, they tended, literally to play with the material and thus it was difficult to separate fact from fantasy.

The Minisculpt method was designed as a research tool and this was how it was used during the project. However, as I have pointed out elsewhere, many respondents found sculpting therapeutic, and this seemed to apply to children and parents alike. As with the genogram, Minisculpt could be used as an aid to the diagnosis of family problems prior to starting on a course of therapy. Sculpting could also be used to monitor progress and to records previous scenarios. (The easiest method of keeping such records is probably polaroid photography). Photographs could be kept in case notes and used by client and therapist for comparison with earlier models. Unlike 'real' family sculpting as described by Duhl et al (1973) Minisculpt could be used in either a one to one situation with the therapist or in a family group situation as individual circumstances dictate and according to the progress of the therapy.

Respondents, as noted elsewhere, were asked to sculpt 3 models each: first, their own family of origin at a point in time of their own choosing; second, the nuclear family prior to the birth of the target child; and third, the nuclear family following the child's birth, to include any changes in structure, hierarchy or dynamics which the birth and rearing of the child had brought about. The kinds of information revealed through these models is reported below.

MODELS OF THE FAMILY OF ORIGIN

My original intention when requesting subjects to model their own family of origin was to utilise this model more as a kind of 'rehearsal' for the models to follow than as a prime source of information. I was to discover however that these models often contained vital clues to the understanding of the structure and functioning of the new nuclear family. The kinds of information obtained from these family-of-origin models included, the stability or otherwise of the grandparents' marriage and the ways in which their parenting skills had impacted upon and influenced their children. The size and hierarchical structure of the family system could be seen at a glance, as could the bonds of closeness to other family members. Changes

in structure and dynamics over time could also be modeled and recorded if desired.

Although not immediately obvious from the actual models, other information could be readily obtained by asking the respondent questions as s/he built up the sculpture or by observing the gestures or other forms of non-verbal communication used during the process. Such information might include the social background of the family, whether or not the respondent had had a happy childhood and whether s/he had had any prior experience of disability or hospitalisation.

Of equal importance to the hierarchical structure and the ways in which the family is held together by bonds of closeness or 'the ties that bind', is the permeability of the boundary which surrounds it. This was rendered visible by asking respondents to enclose their model within an appropriate frame as described in Chapter 2.

When each model is complete, the researcher or therapist clarifies any points which are not obvious and respondent and case worker discuss the sculpture. It is then either recorded diagrammatically or photographed for future reference. If the family group is small and sufficient dolls are available, the second and third models can be built up leaving the family of origin intact for comparison.

FAMILY OF ORIGIN EXAMPLES

Large families may be functionally somewhat different from small ones, but as the families chosen to take part in the Minisculpt study had no more than 4 children, further research is needed to establish whether or not this is actually the case. In the Arnold family, Mr Arnold was the eldest of 10 children. His family of origin is portrayed (in simplified form with only important bonds signified) in Plate II.

Mr Arnold is himself registered blind and attended blind school. The model was therefore built up largely by touch. Mr Arnold (Dave) represented himself as the doll on the far left of the picture. He describes some of the features of the sculpture below:
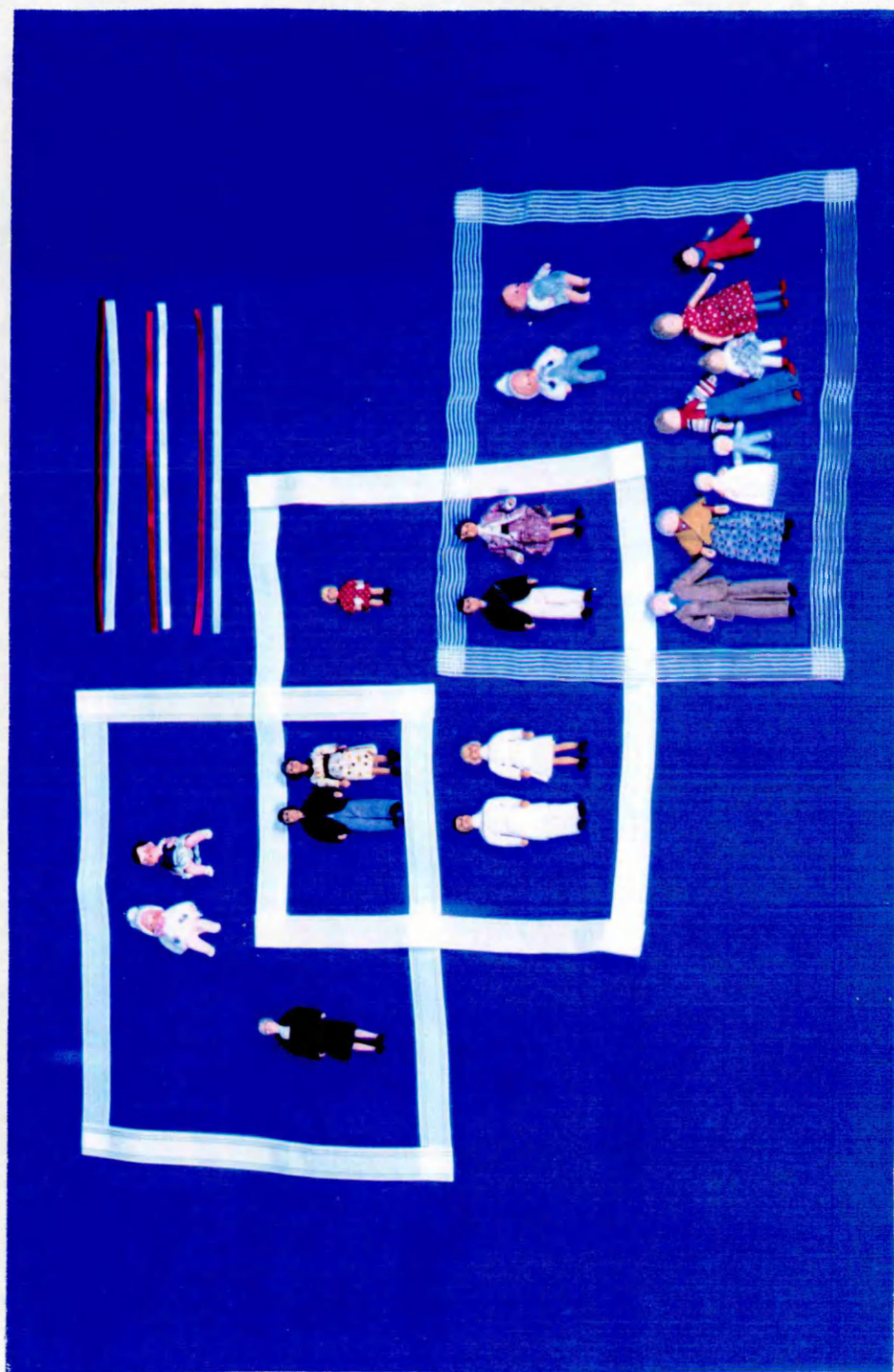
PLATE I

MATERIALS FOR MINISCULPT
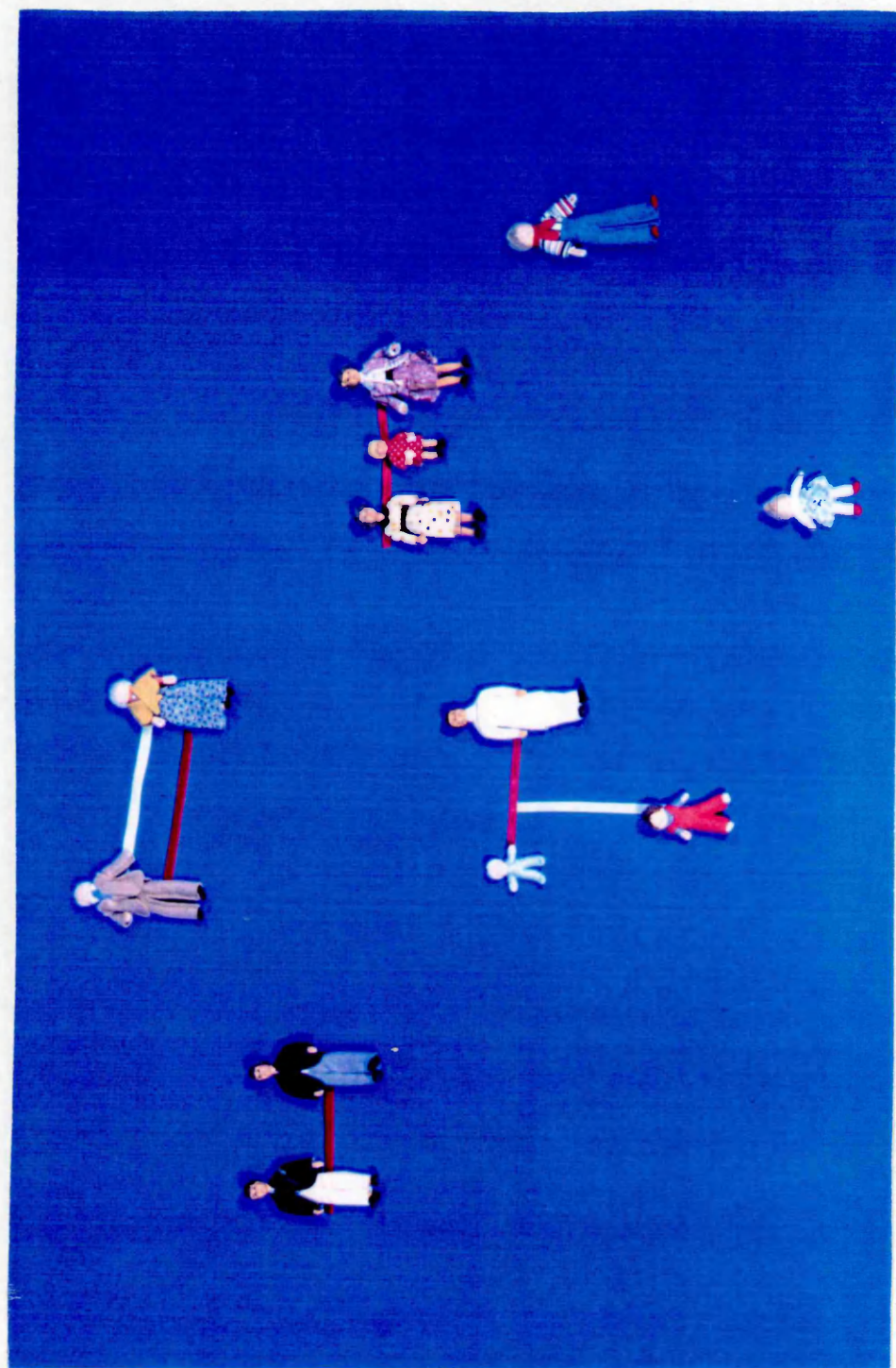
PLATE II

THE ARNOLD FAMILY OF ORIGIN
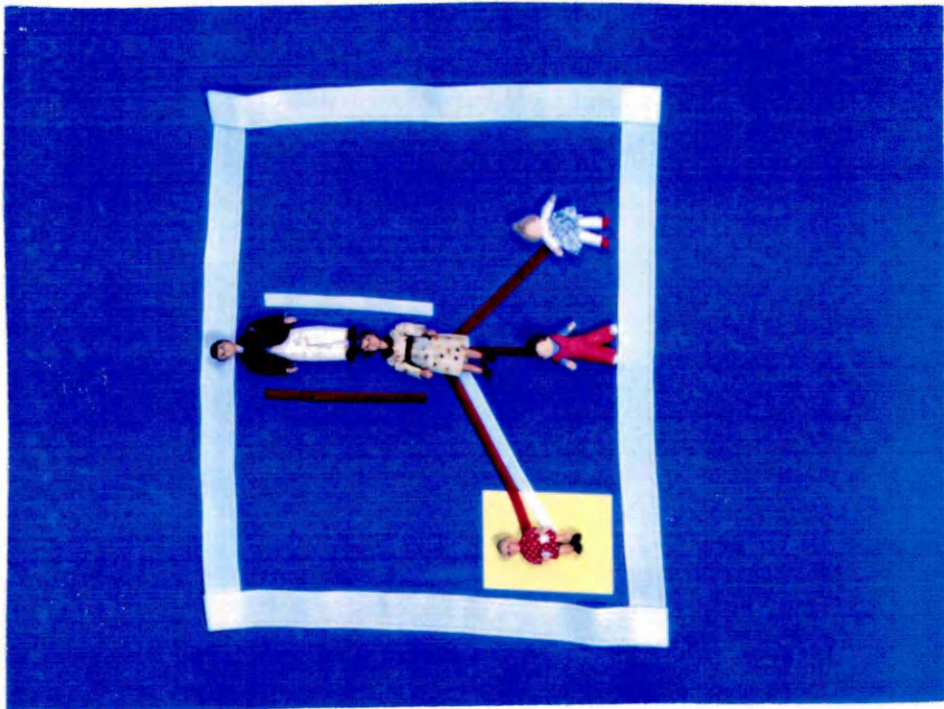
A.   BRITTEN FAMILY OF ORIGIN
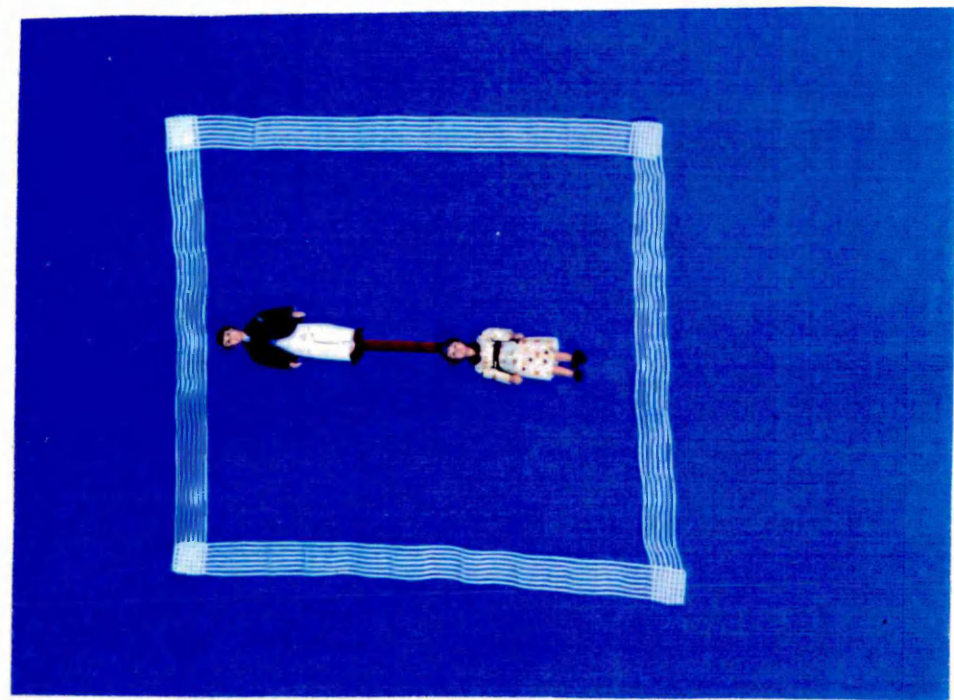
PLATE III

B.   BRITTEN NUCLEAR FAMILY

PLATE IV

A. BRITTEN FAMILY PRIOR TO CHILD'S
DIAGNOSIS

B. BRITTEN FAMILY FOLLOWING
DIAGNOSIS

PLATE V

A.   DICKENS FAMILY PRIOR TO BIRTH OF
      TARGET CHILD
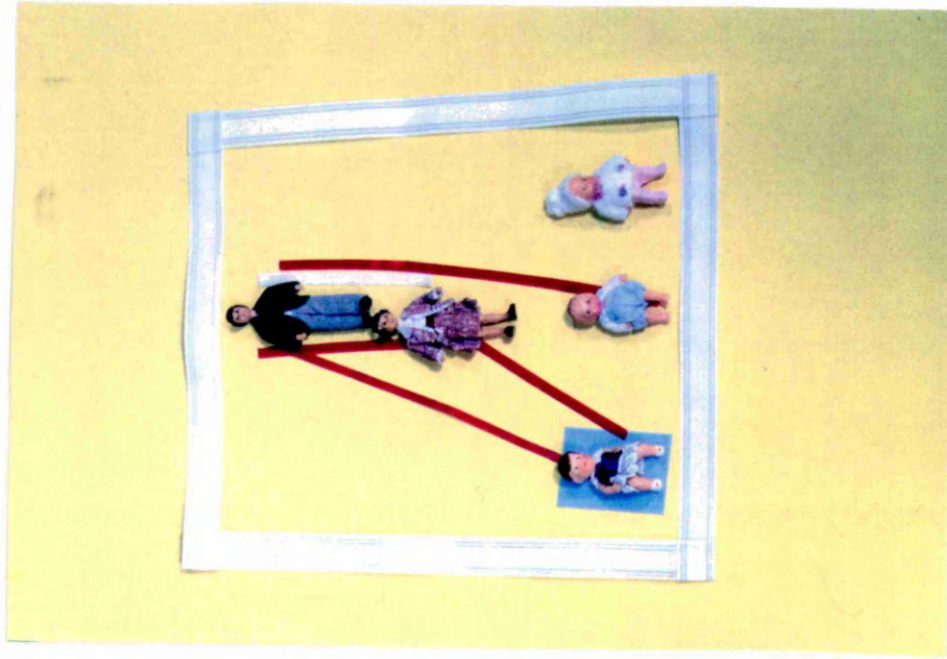
B.   DICKENS FAMILY FOLLOWING
      DIAGNOSIS OF TARGET CHILD

"My mam and dad were always rowing, so I've put them both red and white velvet because, although they didn't get on, there was nowhere else either of them could go - well not then anyhow. They've split up now and Dad's got another woman, but then - well there was all us kids you see.

I've put us all in groups because that's how we were. We didn't all mix in together - partly I suppose because half of us went to blind school and the others to ordinary school. So us that went to blind school didn't see much of the others, except at weekends and holidays.

Me and my brother Eric were very close. The 3 girls who went to blind school (right of the picture) they were another little group, but not as close as me and Eric. Then there was this group (centre) of three boys who went to ordinary school. Sean (right of group) felt he had to look after the youngest one, Garry (left of Sean) but they used to fight with John (lower centre) a lot. These two, Max and Celia, (far right and bottom) didn't belong in any of the groups and they didn't get on together so they kept on trying to break into the other groups. They didn't manage it though and they both got into trouble later in different ways".

(What kind of frame would you put round your family?)

"Well, that's difficult. I don't think really there was one. You see we just came and went as we wanted mostly. I mean, when you've got 10 kids they're difficult to keep track of, especially when both my mam and dad couldn't see well either. Mum had cataracts, but I don't really know what was wrong with Dad's eyes".

(So did you look after each other then?)

"Well sort of, but we weren't really a close family in that kind of way. I mean, we tended mostly to fend for ourselves and just stick together in our groups, if you know what I mean. A lot of us still live round here, and we've got kids of our own, but we don't see much of each other. I still see Eric about once a month and my mam. But Dad and the others, well hardly ever really".

(Does your mum help with Emily - babysitting or anything I mean?)

"Oh no, we look after ourselves in that way. When we see her, she keeps on at Maxine (wife) about when's she going to have another baby, but she doesn't <u>do</u> anything".

(What does Maxine think about that?)

"Well, I suppose I'd like three kids at least, but Maxine's not keen - that doctor at the hospital, he said that they'd all be handicapped, and she thinks it's not fair to have any more. I mean, I don't see that it matters if they have cataracts, we've done all right mostly. I mean, you have the operation and if it works you're OK and go to ordinary school - if it doesn't, well you go to Tapton (blind school) and that's all there is to it, that's what I say".

Mrs Britten's family of origin was smaller and much more compact. She sculpted her parents as having strong ties (velvet) of both a positive and a negative nature. Her father was the dominant partner making most of the decisions but leaving the care of the children almost entirely to his wife.

In Plate III, Mrs Britten used the bottom left doll (mounted on yellow) to represent herself as slightly dominant to her younger brother and sister. Although she was very close to her mother, she felt that the relationship had always been somewhat ambivalent. As she explains:

Mrs Britten's Family of Origin

"Dad was always there if we wanted him, and he'd take us to the pictures and give us pocket money and things, but I think he saw himself more as a provider, you know, he was the breadwinner so to speak, and he left everything else to Mum. With being the eldest, I felt my mother expected an awful lot of me, and she let the others get away with a lot that I didn't. Looking back, I suppose we're very much alike, my mother and me - in character I mean. And I felt that I ought to be the special one, but I thought somehow she thought more about the other two".

(Did you feel particularly close to either your brother or your sister?)

"No, not particularly, just normal I suppose. We don't see much of each other now at all, although neither of them live all that far away. I think, ... well, it's funny, but I feel closer to my dad now than anybody. Since all this happened he's been the one who's stood by me and helped me, more than my mum really".

NUCLEAR FAMILY MODELS

The Britten family Minisculpts are continued below as examples of nuclear family models.

Both Mr and Mrs Britten (Alan and Susan) represented their nuclear family prior to the birth of the children in the same way (Plate III). Both represented Alan as being the dominant partner and the couple as having a strong loving relationship. Both also surrounded their models with a highly permeable boundary. Alan explains:

"Yes, when we were first married I think we had the ideal relationship. I was the one who wore the trousers and that's how we both liked it. We used to go out a lot, together and separately with our own friends. We had a nice house and we both worked so money wasn't a problem. We had what I would call a good marriage".

As with their model of the family prior to the birth of the children, Alan and Susan both presented similarly structured models with regard to the situation after the children were born (Plate IV). Alan remained the dominant partner and the three children were of equal importance in the hierarchy. There were differences however in that the couple had begun to have disagreements as shown by the white velvet ribbon and the system had become less 'open'. In Susan's model, the rigid non-permeable boundary has replaced the open one. The family had become very much more 'home based' and seldom went out either together or separately. Both partners felt that Alan had a special relationship with their son (William) the middle child,

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and that both parents were very fond of Beth the eldest (target child).
Beth is shown on the left of the picture mounted on blue. Alan continues:

> "We were a very close family, we didn't go out a lot, we spent
> our money on the house and the kids. We both idolised Beth, she
> was such a bright kid, always laughing and chattering. She loved
> us all to be together".

I suggested earlier that, where possible, later models can be built up
without dismantling earlier ones so that comparisons can be made whilst
working on the sculptures.   This in fact was done in the case of Mrs
Britten's models of her family of origin and new nuclear family. If Plates
III and IV are compared, it will be noted that the hierarchical structures,
if not the closeness ties, are very similar. Susan's attention was drawn
to this during the interview:

> (Can I ask you a 'deeply psychological question'?)

> "Yes, I suppose so".

> (Well, I was just looking at your two models, and they seem rather
> similar. I was wondering, did it just happen like that or did you
> kind of plan it, if you see what I mean?)

> "Mm ... yes, ... I suppose they are ... I don't know, you and
> your deeply psychological questions. Well we did plan them at
> those sort of intervals, very much like my family. But I don't
> think that I ... we actually consciously tried to reproduce it
> that way. But I suppose it could sort of explain why it all went
> wrong when she got sick".

Susan was asked to sculpt the changes brought about by the diagnosis of
cancer with secondary deposits in the bones. The model is reproduced in
Plate IV.   It can be seen that there was a dramatic shift in the
hierarchical structure, the mother becoming slightly dominant. The bond
between the parents has become weaker, changing from velvet to silk. Susan
described it as a 'working relationship'. William has become the dominant
child in the hierarchy with the bond between both parents and son becoming
even stronger. The bond between Susan and Beth also strengthens, as does
between the siblings.   According to Susan's representation of the
situation, the bond between Alan and Beth has weakened to such an extent

that it has disappeared from the model. The family has become closer knit and the boundary even more impervious.

Alan's model was again strikingly similar to Susan's but with one exception; for Alan, the strong bond between Beth and himself remained intact. Alan continues:

> "I know Susan thinks I stopped caring about Beth after we found out what was wrong but I didn't. I still love her now, and I still can't believe she's not coming back. It's ... you see a little girl with a pony tail running down the road, and I have to stop myself shouting her and running after her. Then she turns round and ... and it's not Beth. I keep thinking ... it's the weekend and she'll be coming with Will and Vicky to my mum's, but it's only Will and Vicky.
>
> I tried to make it work, honest to God I did. But I had to get away for a bit. Susan thinks I ran away, ran out on them, but I didn't, I just couldn't bear to see her suffer, I had to be on my own for a bit to sort things out in my mind. I wrote what I was feeling in a diary. I hoped she'd find it and understand what I was going though. After I'd thought things out a bit I went back, but things got worse and she told me she'd only let me come back because Beth wanted us all to be together.
>
> After Beth died she told me to get lost and that she'd rather cope on her own than have me back. I suppose I did let them down really. You see I'd always been the strong one who said what we were going to do. I thought that's what she wanted and I always put a good face on things for Beth. I think now though that it wasn't real, It was like it was all an act. You put your smiling face on and go to work and carry on as normal. But I think it came over that I didn't care. Some of the time I really thought she would get better in spite of what they said at the hospital, I though the treatment would work, I just couldn't believe she would really die.
>
> It was only at the Parents' Group down in London where we were all in the same boat that I could be myself, like wipe the smile off my face and talk about how I was really feeling. But I only went twice because it was too intense and I had to get away from it.
>
> I think Susan hates me now. I don't hate her but I suppose when something like this happens you've got to hate somebody. With me, I hate the doctors for not picking it up sooner, because if they had, she could have been cured and we'd all have been at home together now".

As I have pointed out elsewhere, actual family breakdown was the exception, most families remained intact and some, it seems, were actually strengthened by their experiences. The Dickens family is one such case.

Both Mr and Mrs Dickens (Peter and Abby) were both themselves handicapped - Peter being registered blind and Abby physically handicapped. Abby also had learning difficulties. Both parents had attended special school, Peter at a school for the blind and Abby one for children with learning difficulties. On leaving school both entered sheltered employment where they met. The couple live in council property on a large estate in an area of 'high deprivation'.

As in many instances, both partners sculpted a very similar model of the nuclear family situation prior to the birth of the target child (Plate V). Both felt that they had an equal partnership with a strong bond of affection between them although Abby admitted that they argued quite a lot when she found it difficult to conceive. Both enclosed the model within a rigid non-permeable boundary. Abby explains:

> "We was really happy after we first got married. We used to help each other with the housework and shopping and that. Pete used to carry the shopping back and I told him where to go. We just shared everything".

(Did you go out a lot together?)

> "Oh no, we never went out much. We didn't have any friends and we'd got nowhere to go and we didn't have very much money. So we stayed in and listened to records and watched the 'tele' and that. We're right home birds".

(Did your family come to see you though?)

> "No not a lot. We kept ourselves to ourselves mostly. We didn't even know what the neighbours was called till we had Amy".

(How did Amy alter things?)

100

"Well ... she made us into a family. You see Pete and me got to arguing a lot because we'd been trying for a baby for ever so long and nothing had happened. Then when we got Amy it was fantastic".

(How did you feel about her being handicapped though?)
Amy is both visually and physically handicapped and suffers from epilepsy.

"Well, I was really upset about that at first 'cos you know the doctor at the hospital said I'd passed it on to her. But then, well, Pete said that having bad eyes wasn't all that important and he's done all right really. And with her fits and that, well, she's only like me isn't she? And she seems really happy and she's doing right well at nursery and she's got lots of friends. They're always coming round to play, her friends - it's open house round here".

(Have you and Pete got more friends now?)

"Ooh yes, since people have found out how poorly she's been, everybody's tried to help. One of the neighbours took us to casualty when she had that convulsion, in his car. They're always in and out now".

(Do you think you'll have more children a bit later?)

"Well, I've thought a lot about it you know, and I don't think it would be fair really. I'm glad we've got Amy, but no ... I think she's all we'll have really".

MINISCULPT - THE WORKING MODEL

In presenting the above short extracts from some of the interviews, my aim was to show, without hurting the families or revealing too many 'family secrets', how the Minisculpt method 'worked' in the field situation.

The number of families taking part in the study was small - 5 taking part in the pilot study and 4 being selected from the main blind sample group - therefore no firm conclusions can be drawn and further research into the situational use of the method is required.

The models did however appear to illuminate a number of facets in the family lives of blind children. The following impressions were gained:

A knowledge of the structure and dynamics of the family-of-origin often helps us to understand the functioning of the nuclear family.

It seems that some people, consciously or unconsciously, attempt to replicate in their nuclear family settings, the structure and functioning of their own family-of-origin. The extent to which this actually occurs requires further exploration and research.

The birth and rearing of a blind child usually brings about changes in the structure and functioning of the family system. There are however exceptions to this 'rule', notably in cases where there is a long family history, over several generations, of severe visual impairment.

Where a family-of-origin setting has been seemingly successfully replicated, the impact of rearing a blind child and the subsequent changes in structure and family functioning can be particularly disruptive.

The invisible boundary surrounding the family is an important part of the family system, which, because of its intangibility, is often neglected by therapists and researchers, Minisculpt renders this 'boundary' both visible and tangible, thus enabling researcher, client and case-worker to explore the area.

The dolls themselves often seemed to have a therapeutic value and were used as 'mediators' or 'actors' upon a stage thus enabling respondents to 'play out' their feelings and emotions as a kind of drama. Unexpectedly, the men (once they had recovered from the shock of being invited to play with dolls!) seemed to benefit from the exercise as much or more so than the women. On average the interviews with fathers took 45 to 50 minutes longer than those with the mothers.

Other fields in which Minisculpt could be used as a therapeutic tool might be marriage guidance and family therapy. Here the method could be used first on a one to one (client/therapist) basis and later, when the client is ready and the situation demands, other family members could be drawn in to sculpt their own individual impressions.

As has been pointed out, Minisculpt could be a useful tool for therapists working with children (both sighted and visually impaired) particularly where there are family problems. It is also possible that the method might be of value as a therapeutic tool in certain cases of child abuse. However, my impression during the research study was that children tend to use the material in a somewhat different way to adults and often present a scenario as they see it or as they would like it to be rather than as it 'really is'. Many children are also highly 'suggestible' and will sometimes model what they think the case worker wants, either to please or to divert her. Further research is therefore needed in order to establish whether or not Minisculpt would be an appropriate tool in such cases.

The method was evolved for use by a sighted researcher (or therapist) and a visually impaired or sighted respondent. It seems feasible however that with slight modification to the material this situation could be reversed to enable a blind researcher/therapist to interview or counsel a sighted client. This is another area which would benefit from further research.

CONCLUDING COMMENTS TO SECTION I

In Section I, I have been concerned to outline the background, aims and evolution of the study and to summarise some of the main findings. The 'illuminative method' of study (Parlett and Hamilton 1972) is described and the practical use of the Minisculpt technique demonstrated. Some of the 'meanings of blindness' have been explored and the functional classification of blindness and visual impairment used in the study is described.

In essence the research was an empirical study, concerned mainly to present and interpret the collected data. It also serves as a contribution to theory in the following respects:

1. It suggests ways of revealing 'meanings behind the masks', by which I mean discerning the 'true situation' from the facade presented by clients to professionals and the world at large.

2. The thesis relates verbatim material to general sociological and psychological theories so that, in evaluation, there is an illumination of what has been defined in theory.

3. The Minisculpt method of investigation develops and illustrates theories about existing data.

4. The research tests out some general theories in respect of their practical application.

In short, the thesis does not initiate new general theories but contributes to 'practice theory' for professional use, and feeds back illustrations on the application of general theories.

It was found from interviewing the families that their needs were simple and basic and could therefore probably be easily and inexpensively provided for. Indeed, many of these same services are already provided for other groups of disabled children. Why they are not also provided for blind children and their families is a question which needs to be addressed.

In the sections which follow, some facets of family life, socialisation and education of blind children are explored in depth. The families are followed in their passage through crisis brought about by the birth and rearing of a handicapped child; and their sometimes stormy relationships with healers and helpers during this journey are examined. It seems that, in the case of visual handicap, the art of helping has not kept pace with the science of healing and in future chapters some of the reasons why this should be so are examined.

Throughout the thesis there is some repetition of the material presented in Section I and elsewhere. There are several reasons for this. Firstly, the introductory section was intended to be fairly complete in itself as a summary of the work, which could be separately presented to health professionals and other interested bodies. Secondly, there are sometimes many pages between the data and tables presented in the introductory section and those explored in later sections. Repetition is here used for the convenience of the reader. Thirdly, the same 'starting point' or table is sometimes used to examine data from a different angle or to trace a different pathway while using the illuminative methodology. Here again, tables and previously mentioned data are re-presented so that the reader does not have to search for the appropriate passage.

INTRODUCTION TO SECTION II

Section II is concerned with the rearing and socialisation of children with severe visual impairment and is divided into five chapters.

Chapter 5 deals with the discovery and diagnosis of the handicap. Because this subject is explored in greater depth in Section V, Chapter 5 has been largely given over to the parents of the sample group who describe their experiences in quotes from the interviews.

Chapter 6 is concerned with family functions and the impact of rearing a visually handicapped child on family life. The implications of genetically transmitted defects are also discussed and the chapter is again illustrated with quotes from the interviews.

Chapter 7 examines the ways in which the gross motor development of the blind child differs from that of a seeing infant and explores the ways in which he is able to discover the world around him.

Chapter 8 deals with aspects of the pre-school socialisation of visually impaired children. Areas where problems were encountered by parents include: meal times and the acquisition of acceptable table manners, acquiring self help skills in daily living, toilet training, building up a body 'image' without vision and the discovery of gender and sexuality.

Finally Chapter 9 is devoted to play and the learning of roles, life skills, and ways of coping with adversity through this medium.

CHAPTER 5

DISCOVERY AND DIAGNOSIS

O first created Beam, and thou great Word,

Let there be light, and light was over all;

Why am I thus bereav'd thy prime decree?

The Sun to me is dark

And silent as the Moon,

When she deserts the night

Hid in her vacant interlunar cave.

Since light so necessary is to life,

And almost life itself, if it be true

That light is in the Soul,

She all in every part; why was the sight

To such a tender ball as th'eye confin'd,

So obvious and so easie to be quencht,

And not as feeling through all parts diffus'd,

That she might look at will through every pore?

John Milton, 'Samson Agonistes'

Although 83% of the defects were definitely or probably present from birth, only 24% were actually noticed during the first week of life. Data collected from the Sheffield sample during 1983/84 are remarkably similar to those obtained during the nationwide RNIB survey (Walker et al, 1992) collected in 1988. Walker and colleagues found that 80% of the children were reported to have had their sight problem from birth, but in only 27% of cases was it actually suspected and confirmed, "at or soon after birth".

With regard to the Sheffield sample, if we exclude the nine cases of retinopathy of prematurity (R.O.P.), which were found during routine screening by an ophthalmologist, only three of the defects were definitely not present at birth, these being the result of accident or conditions manifesting themselves in later childhood. Only eight babies (out of a possible 43) were however diagnosed prior to leaving the maternity hospital, and it is interesting to note that in five of these eight cases there was a family history of blindness to which medical staff had already

been alerted. This leaves three children who were diagnosed soon after birth by doctors without either prior warning that the child might be affected or routine screening on the Special Care Baby Unit. Two of these babies were born with congenital absence of both eyes and the third with microphthalmos (very small rudimentary eyes).

As with the RNIB sample, the majority of the defects (55% Sheffield and 57% RNIB) were first noticed by a parent or other relative, doctors and other professionals combined therefore discovering less than half of all the defects.

The discipline of the first person to notice the defect is shown graphically in Figure 5.1. Here, 'nurses' as a group include midwives, health visitors and school nurses.

Figure 5.1 Discipline of First Person to Notice the Defect
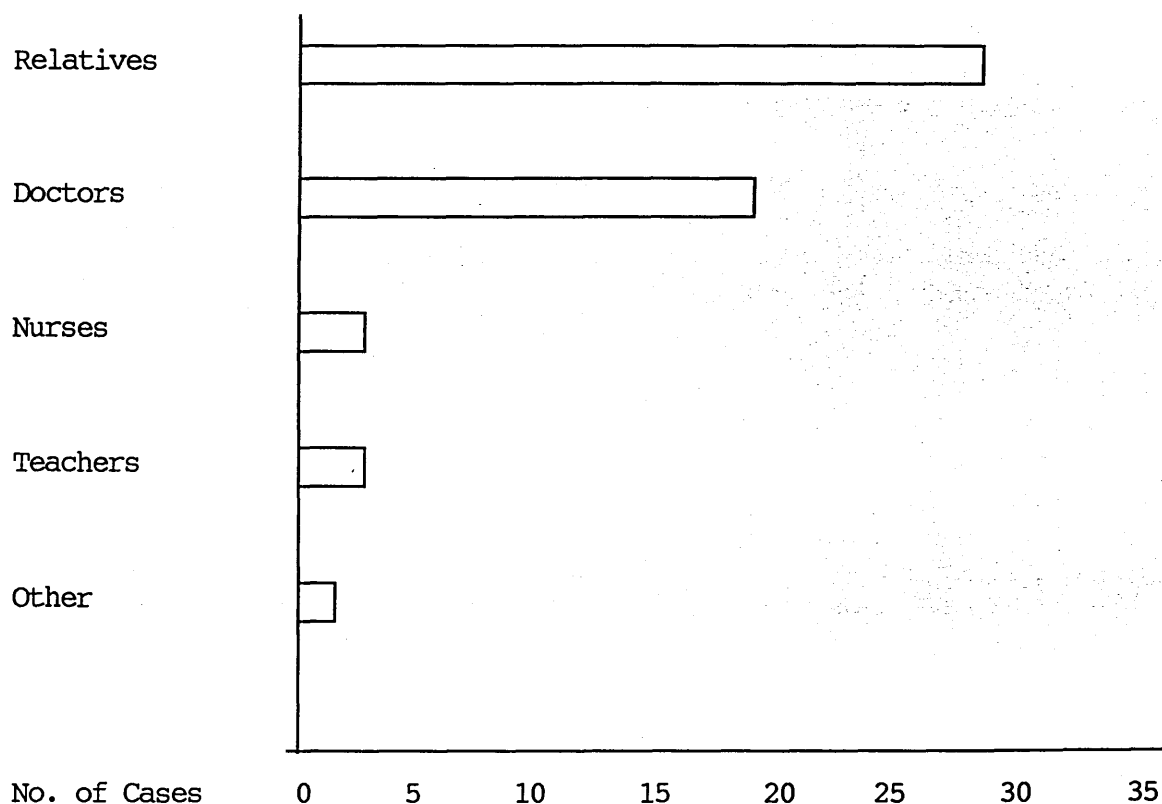
Some of the parents' experiences are quoted below.

1. <u>Robin Gill. Bilateral Cataracts. Noticed from birth. Diagnosed age 3 months</u>

"I knew straight away. As soon as he opened his eyes I saw his pupils were white. I layed awake and cried all night. I never said anything to Ken (child's father - his second marriage, mother's first) and the doctors and nurses never said anything. They said he was quite normal when he was discharged". (Family history of cataracts on mother's side).

2. <u>Matthew Tomlinson. Optic Atrophy. Noticed 6 weeks. Diagnosed 7 months</u>

"Well, we went on holiday with my mum. He would be about 6 weeks old. And she said, 'What's the matter with his eyes? He always looks straight at the sun, he shouldn't be doing that, you should take him to the doctor".

5. <u>Michael Kent. Pseudo Glioma. Noticed from birth. Diagnosed 7 months</u>

(Mother is a trained nurse) "I was practically sure he couldn't see from the first week. He didn't open his eyes very often, and when he did one seemed a lot smaller that the other. I asked the paediatrician to check them but I don't suppose he did. They didn't say anything when he was discharged". (Mother's father was blind from birth but mother was reassured this would not recur in her children).

8. <u>Danielle Ellis. Retinoblastoma. Noticed 1 month. Diagnosed 3 months</u>

"Well I suppose I knew something was wrong right from her being tiny really. She never looked at me and she would only lift her head if there was a really bright light. I took her to the doctor's (GP) when she was about 4 weeks old because the white of her eye had all turned a reddy brown colour. The doctor said it was only due to pressure (from delivery) and I was a young inexperienced mother, and to go home and not worry".

9. <u>Jason Grant. Marfan Syndrome. First noticed - Questionable. Diagnosed 4½ years</u>

"Oh, I don't know, (when first noticed) - he always was clumsy and used to bang into things all the time. And he's always sat with his nose right on top of the tele'. He was being checked at the Children's (hospital) every 6 months and they never said anything. A lady from the Welfare (health visitor) came to check him over for starting school and he couldn't do the things she said (asked). She sent him to the eye clinic".

"He was attending the Children's (hospital) every few weeks because he kept on having convulsions after the meningitis. (Affected age 6 months) I used to say to his dad, isn't he funny the way he feels things instead of looking at them? Like if the dog went past, he used to feel at his fur. We went back for a check up when he was about 18 months and I mentioned it to the doctor that he couldn't seem to pick things up. She held a pencil out in front of him and he couldn't get it. She sent us to see Mr A. at the eye clinic".

Delay Between Discovery and Diagnosis

There was often a wide discrepancy in time between the defect first being suspected and the actual diagnosis by an ophthalmologist. In a few cases this amounted to several years, the most extreme being a discrepancy of 7½ years. Once again these findings compare closely with those of the RNIB survey (Walker et al, 1992): "For the 36% of children where there was a gap between suspicion and confirmation, 50% had had confirmation of the problem within a year, with 3% waiting between 5 and 10 years".

The mean age of the Sheffield children (with the non congenital defects removed) when the condition was first noticed was 9 months, the mean age at diagnosis was 15½ months and the mean discrepancy in time between discovery and diagnosis was approximately 6 months. The ages of the Sheffield sample group at discovery and at diagnosis are shown in graphic form in Figure 5.2 overleaf.

One factor contributing to the delay between discovery and diagnosis was the waiting time for an ophthalmic opinion. In many cases this amounted to several months and added considerably to the stress and anxiety experienced by the families. Other 'reasons' for delay in the diagnosis of severe visual impairment are explored in later chapters. It should be pointed out however, that in addition to the deeper psychological and social 'reasons' discussed elsewhere, there are also considerable practical difficulties for those involved. Not the least of these is the fact that among the most common defects are anomalies of the retina which are not obvious on external examination of the eye. Added to this, in many instances, the long term prognosis is almost impossible to predict. Ophthalmologists often therefore adopt a 'wait and see' policy and do not

Figure 5.2   **Ages of the Children at Discovery and Diagnosis of the Handicap**

Under one week

1 week to 3 months

3 months to 6 months

6 months to 12 months

1 year to 2 years   Nil

2 years to 3 years

3 years to 4 years

4 years to 5 years

Over 5 years

☐ discovery

▓ diagnosis

Number of Children   0   5   10   15   20
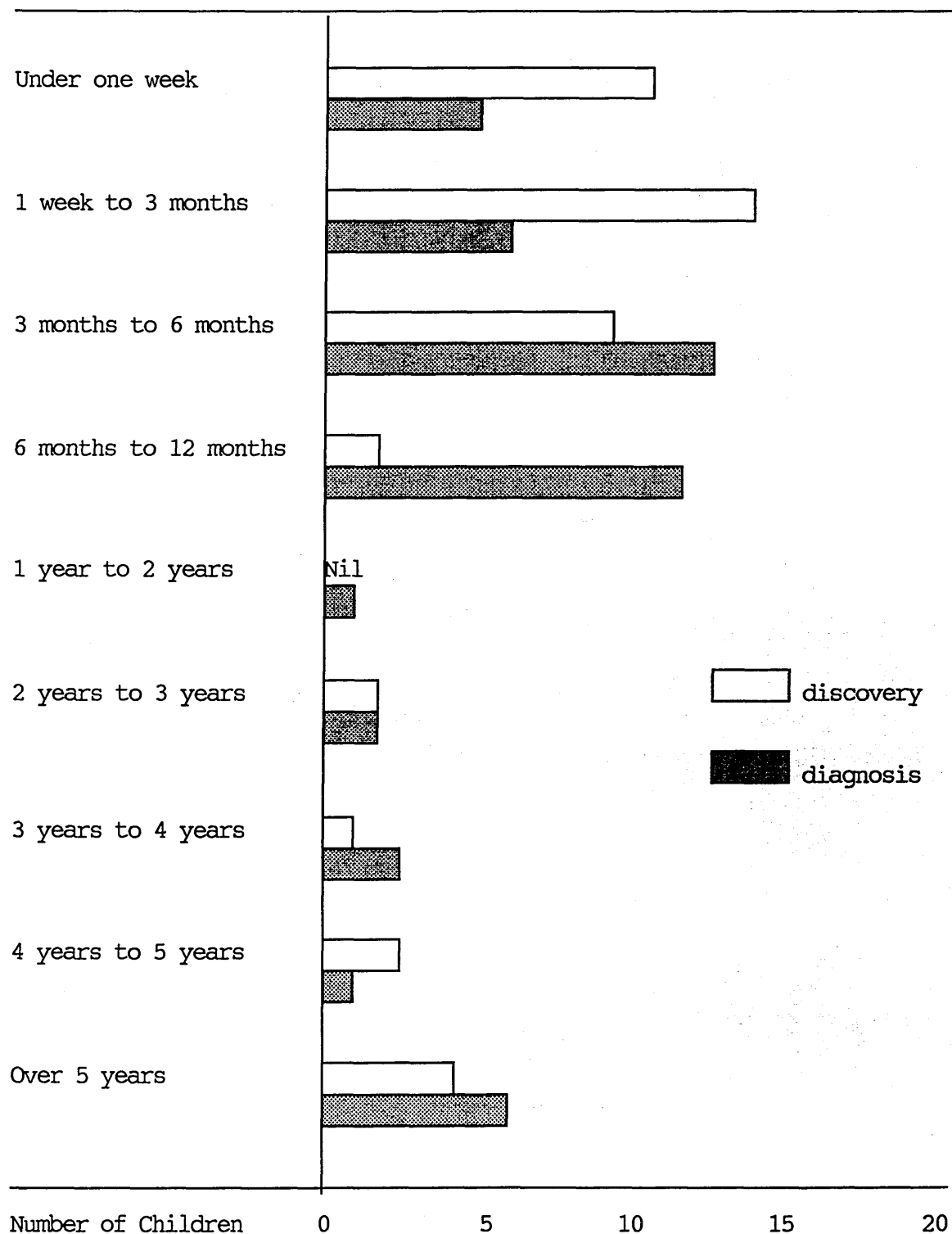
inform the parents of the diagnosis until they are more sure of the ultimate outcome. The reasons given by doctors for adopting such a policy is that they do not want to cause the parents unnecessary distress. Data collected from the Sheffield sample and from the RNIB survey however, show that this strategy is frequently counter-productive and that 'not knowing' often causes more anxiety and stress than being provided with as much information as is available.

The Assault on Normality

Goffman (1963) describes the spoiling of social identity by stigma in relation to those persons marked out in some way as deviants. Scott (1969) takes this further in relation to the (re) socialisation of newly blinded adults. Davis (1982) studied the roles of doctors and parents in relation to children attending various types of clinic. Davies describes the situation of breaking bad news to parents in a specialist neurological clinic:

> "Such bad news fundamentally assaults the normality of the child. It potentially obliterates other identities and common sense dictates it will be destructive for the family. The doctor then is an unwilling and reluctant change agent".

Doctors, particularly those in specialties such as ophthalmology, who only rarely deal with children and their families are ill equipped to make such revelations or to cope with the consequences.

After waiting what is often many weeks for a specialist appointment, parents expect that the doctor will produce a cure, or at least some improvement through the manipulation of medical knowledge and technology. Where such a cure or effective treatment are not forthcoming, as Davis (1982) notes, the viability of any partnership with parents involving care and management is seriously threatened.

Some of the parents recount their experiences around the time of diagnosis below.

8.   Danielle Ellis.   Retinoblastoma.   Noticed 1 months.   Diagnosed 3 months

"I suppose it was the Vicar (Hospital Chaplain) at the Infirmary that made me realise how serious it was. Mr A. (Ophthalmologist) had asked him to come and see me. And he said did I want her christened, and I said yes we would, but not yet. Then he said that Mr A. had told him that Danielle had only a 25% chance of living, so we could have it (christening) done in the Infirmary Chapel. And so we did. I bought her a white dress and the sister and all the nurses came off the ward".

32.   Bethany Hartley.   Retinopathy of Prematurity.   Found on Routine Screening.   Mother Informed age 6 months

"They took her in overnight for an examination (under anaesthetic). Nobody said anything when they brought her back from the theatre. It must have been about half past ten at night and the nurse said would I talk to Mr C. (Consultant Ophthalmologist) on the telephone. He said, 'Oh, I forgot to tell you this morning, we've confirmed your baby is blind'. Wayne (child's father) was away (in prison) at the time so they fetched my sister in because they said I'd gone hysterical. Well, nobody'd ever said she might be blind - just it was a routine check up they had to have".

34.   Jeffrey Howard. Macula Dystrophy.   Noticed 8 years.   Diagnosed as Retinitis Pigmentosa age 9 years.   Diagnosis later changed to Macula Dystrophy

"Well we was in this great big room, I can remember, with all the students round and the other patients waiting to see Mr E. Mr E. just said in front of everybody, 'Well, he has got Retinitis Pigmentosa. He'll get tunnel vision and eventually go completely blind'. And that was the end of it. Jeffrey (child aged 9 years - present throughout the interview) was heart broken. It was 12 months or more before he would go out on his own".

44.   Sally Patterson.   Cataracts + Friedreich's Ataxia.   Cataracts diagnosed 6 months.   Friedreich's Ataxia - Problems began age 7 years.   Diagnosed age 13 years

"Well, I kept taking her to the doctor (GP). She looked like a battered child. She was bruised all over and never had any skin on her elbows and legs. Eventually she got referred to Prof M. (Paediatrician). They did a lot of tests and found nothing wrong with her. She kept on going back and back and eventually he told me to 'stop wasting his bloody time'. Oh yes those were his exact words. He said it wasn't his fault I'd produced a clumsy child and it was obvious it was her eyes that caused her to fall about and bang into things. Well he eventually retired and she got referred to Dr J. (Paediatric neurologist) and he asked me 'Do you know what's wrong with her? And I said, Yes I do, it's Friedreich's Ataxia but I can't get anybody to say so. He said yes it was, but how did I know? I

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told him Alan's (child's father) cousin committed suicide because of it and Sally acted exactly the same as he did".

51. Lucy Baldwin. Optic Atrophy. Noticed 5 months. Diagnosed 6 months

"I took her to outpatients for the results of her EUA. We were in this big room with all the students around and he (Ophthalmologist) said they had confirmed she was blind. I was completely shattered. I walked out in a daze and wandered round town with her for ages. I couldn't cope with their (relatives) reaction. I told everybody she was alright after all. I just sat at home and didn't go out for about 3 weeks after. I just couldn't cope and I didn't know who I could go to for help".

53. Charlotte Winter. Retinoblastoma. First Noticed 6 months. Diagnosed 3½ years. Died age 7½ years

"From her being about 6 months, I kept seeing something in her left eye. I don't know what it was and it didn't seem to be there all the time. I took her to the doctor (GP) and he couldn't see anything. He told me not to worry about it. I mentioned it at the clinic and the doctor said she probably had a slight squint but would most probably grow out of it. It was at Christmas when she was 3½ that I really knew something was wrong. She was standing at the top of the stairs and she looked over the top of my head and sideways at me. She didn't seem to be able to focus at all. I took her back to the doctor after Christmas and he gave me a letter for the hospital but the appointment wasn't until the end of March. I didn't want to wait that long so I asked for a letter to go private. We saw Mr E. (Ophthalmologist) at his rooms on January 19th. He arranged to admit her straight away and she had that (left) eye out on the 23rd (January)".

55. Harry Anderson. Noticed 1st November. Diagnosed 2nd November. Eye removed 5th November

"It all seemed to happen quite suddenly. One day there was nothing wrong and the next I noticed this sort of amber coloured shine in his eye when that table lamp was on - like a cat's eye in the dark. He didn't seem to be able to see out of it and kind of looked sideways at you. I took him to the GP and he said he though it was a cataract. He gave me a letter for a specialist and got an appointment, but that wasn't until 4 months. Well, as we were going out of the door his assistant (Trainee GP) came in. Doctor A. said 'Oh, you'll be interested in this one'. Apparently he had worked in the eye department. Anyway he looked at it and then they had this conflab outside. And Dr A. came back and said we'd to go straight down to the H. (hospital) to see Mr B. (Ophthalmologist) straight away. He admitted him the next day for an EUA and then told me it was cancer. He went back in 3 days later on bonfire day to have his eye taken out".

Conclusion

It seems to be generally assumed by health care workers (Bennett 1981) that severe visual impairment in infancy is easily and speedily diagnosed and that, following diagnosis, a host of highly trained specialist workers will take over the care and educational needs of the child and his family, providing them with all the support they need and thereby reducing or even eliminating the need for input by generic field workers. Empirically however the situation is somewhat different. The delay between discovery of the defect and its actual diagnosis is usually measured in months or years rather than days or weeks, the maximum period of delay being 7½ years in the Sheffield sample and 10 years in the national RNIB sample (Walker et al 1992). The host of highly trained workers is notable only by its absence, and, in the Sheffield sample, most families had to fall back on their own resources. The ways in which they coped with the crisis of diagnosis, came to terms with the handicap, and learned to rear a child with a major sensory impairment are the subjects of succeeding chapters.

CHAPTER 6

THE IMPACT OF REARING A VISUALLY IMPAIRED CHILD ON FAMILY LIFE

INTRODUCTION

> *God bless the Family! God bless this dwelling*
>   *Where so much loveliness and love we know*
> *Like our great cedar-tree, ascending, swelling,*
>   *And ever spreading richer roots below.*
>
> *God bless the Family! God bless the mothers*
>   *Who watched and wept, and guided us along:*
> *They gave their beauty and their youth for others -*
>   *They see the cedar-tree alive and strong.*
>
>   A.P. Herbert, Bless the Bride (1947)

Common sense dictates that the birth of a handicapped child will in some way alter the structure and dynamics of the family unit. Common sense might also suggest that the impact upon family life will be disruptive. The literature on this subject however is far from conclusive. Although most researchers have found the impact to be mainly negative, a few have come to the conclusion that the problems have been overstated and that the damage caused is much less catastrophic than some have suggested.

It should also be borne in mind that impact on various family members might well be different. By this I mean that while the marital relationship might suffer adverse effects leading to disharmony and possible breakdown, the impact on the siblings for example might well be positive, helping them, as one respondent put it, "to be better people and to be able to take more responsibility for others".

FAMILY FUNCTIONS AND THE FOUNDATIONS OF EXPERIENCE

Having stated that the dynamics of family functioning might in some circumstances be altered by the birth and rearing of a handicapped child,

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it is necessary to define those functions prior to considering why and in what ways they might be altered.

Family functions are those tasks which the family performs for other social institutions in society. It is generally agreed that there are six of these functions. They are given below as set out by Kenneth and Patricia Jones (1975).

1. The family provides the setting for the socialisation of the young by conveying values, modes of behaviour and social traditions on the one hand, and attitudes and cognitive content on the other.

2. The family provides provision for and regulation of sexual and parental behaviour or requirements.

3. The family provides a basis upon which private property in the broadest sense can be passed on with the minimum of conflict.

4. The family provides a group of people who are expected to give affection and love.

5. The family provides care and training for the otherwise helpless young.

6. The family is the means by which society passes on its titles or statuses which are ascribed to the young.

These six functions, being general rather than specific, enable sociologists to make comparisons across societies. They also enable comparisons to be made between deviant (including 'handicapped') families and 'normal families').

Some sociologists however, limit the functions of the family to four, namely:

1. The regulation of sexual behaviour and reproduction.

2. The care and training of offspring.

3. Providing role models for the division of labour.

4. Primary group satisfaction.

As the transfer of property and titles were not relevant in this particular study, the simpler set of 4 functions has been utilised to consider the impact of a visually handicapped child upon family dynamics.

Stages of Family Development

Sociologists and therapists have divided the 'Family Life Cycle' into stages according to their own individual and functional needs. A fairly typical example is the scheme proposed by Haley (1973) based on his study of the work of Milton Ericson. Ericson was a rather unconventional but creative psychiatrist. Hayley's scheme comprises the following stages:

1. The courtship period
2. Marriage and its consequences
3. Childbirth and dealing with the young
4. Middle marriage
5. Weaning parents from children
6. Retirement and old age

Variations in Family Development

Family development is subject to many variations, some of which are discussed in "The Family Life Cycle" edited by Carter and McGoldrick (1980). These variations may be caused by the death of family members, divorce or separation, the late birth of a child after the others have grown up or the bringing of new children from another family into a reconstructed family. Chronic illness, financial setbacks, migration, national disasters, war and many other circumstances have their effects, as does the birth of a handicapped child, upon families and how they develop. It is obvious that no model of family development can take account of all possibilities.

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In the final chapter of Carter and McGoldrick's book, Friedman (1980) discusses the family aspects of "Rites of Passage", through which are celebrated various stages of development, notably weddings, funerals and puberty rites. He also considers three other "nodal points" which nowadays have become important in the development cycles of many other families, namely divorce, unemployment and geographical uprooting.

"Marriage and Family Development" (Duval and Miller 1985) 6th edition, is regarded by many family therapists as a standard reference source on family development. It divides family development into eight stages, very similar to those described by Hayley above. Using Duval's stages of development, Barnhill and Longo (1978) defined nine "transition points" which have to be negotiated as the family passes from stage to stage. These are:

0-1   Commitment of the couple to each other.

1-2   Developing new parental roles, as husband and wife become mother and father.

2-3   Accepting the new personality as the child grows up.

3-4   Introducing the child to institutions outside the family, such as school, church, scouts, sports groups and so on.

4-5   Accepting adolescence, with the changed roles associated with this, and the parents' need to come to terms with the rapid social and sexual changes occurring in their child.

5-6   Allowing the child to experiment with independence in late adolescence and early adulthood.

6-7   Preparations to launch, the term used by Barnhill and Longo for the process whereby the parents come to accept their child's independent adult role, including starting his or her own family.

7-8   Letting go - facing each other again, when child rearing is finished and husband and wife are alone again.

8-9   Accepting retirement and/or old age, with the changed life style involved.

Barnhill and Longo (1978) go on to discuss the use of these concepts for therapeutic purposes. They apply the Freudian ideas of fixation and regression to the process of family development, and especially the transition points listed above. So, just as an individual's development (according to Freud) may become fixated at a particular stage, (i.e. has failed to proceed beyond that stage at a time when he would normally have done so) so may a family fail to make one or more of the needed transitions. In addition, a family may regress (that is go back to an earlier transition point) usually when faced with some stress. Barnhill and Longo also use the concept of "partial fixation", when a family life cycle transition has not been made successfully, although partial and even superficially satisfactory adjustment has been made. Such an adjustment is however according to Barnhill and Longo (1978), fragile and precarious. The same authors believe that when a family life cycle transition has not been successfully accomplished, the family is especially susceptible to stress. Many of the families rearing blind children experienced difficulties in negotiating some or all of Barnhill and Longo's transition points, or failed altogether to make the transition. Stages 4-7 proved particularly difficult for many families to negotiate.

Some of the handicapped children also experience delay in being allowed access to rites of passage, particularly those concerned with puberty, adolescence, sex and courtship. For some, certain rites may be withheld altogether.

If, as Barnhill and Longo (1978) believe, families are especially vulnerable, and susceptible to stress when life cycle transitions are unsuccessfully or incompletely accomplished, (the family papering over the cracks to give an impression of normality); it follows that many of the sample group of families will be living in a continual cycle of stress. No sooner is one hurdle surmounted then another presents itself.

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Many, if not all, of the life cycle transitions of a family rearing a blind child will be made at a later stage than those of a 'normal' family. And, as previously stated, many are unsuccessfully or precariously accomplished. As has been seen from the parents' comments in the previous chapter, the birth of a handicapped child affects the couple's commitment to each other by its impact on the marital relationship. It also affects the new parental roles as husband and wife become mother and father.

Other transition stages in the life cycle will be discussed at a later stage, but it will be appreciated that the family may experience some difficulty with almost every stage. Stress may be even more keenly felt where rites of passage are involved. For example, starting school, puberty - particularly for girls, and the sexual and social changes associated with adolescence. Allowing the child independence and finally letting go may be delayed for long periods. In some cases they may never be achieved at all.

Barnhill and Longo's theory may well help to explain why the families in the blind sample experienced stress over such prolonged periods of time.

Difficulties Encountered by Families Rearing a Visually Handicapped Child

Many of the difficulties encountered by families socialising a visually handicapped child are shared by families rearing a child with almost any handicap. For example, many of the children require 24 hour supervision to prevent their coming to harm and to give the extra care and stimulation needed. Most require extra physical care and help with bodily functions beyond the age expected with sighted or non handicapped children.

The family as a unit will often suffer social restrictions with regard to getting around with a handicapped child and the use of public transport. Public transport presents even more problems if siblings, prams or wheelchairs have to be taken along as well.

Problems are also encountered with regard to finding a suitable baby-sitter or child minder when parents wish to go out without the handicapped child.

An extra financial burden may also be imposed upon the family as the child may need more expensive toys or special aids and equipment not provided by the health or social services. Most parents also feel obliged to provide siblings with toys of a similar calibre and other treats in order that they do not feel left out.

To these general difficulties must be added those which are specific to blindness and severe visual handicap, and it is with these that I propose now to deal, beginning with the impact on the marital relationship.

THE IMPACT ON THE MARITAL RELATIONSHIP

For Better, For Worse ...

It has not been possible to compare the present sample group with those of other studies in the field because each researcher has tended to use a different definition of the problem. More confusing still is the fact that researchers have used the same definition for different concepts. For example, the terms 'marital disharmony', 'marital stress' and 'marital strain' seem to be interchangeable in some studies. In others they are quite separately defined but not always in the same way.

The impact of the handicapped child on the marriages of the sample group is shown in the table overleaf.

As will be seen from Table 6.1, the handicapped child had an adverse impact on the marital relationship in a small majority of instances. Only three couples felt the child had brought them closer together from the beginning. A further five had experienced difficulties during the early periods but had surmounted these, feeling that over time, the child had had a positive effect.

Table 6.1 The Impact of the Handicapped Child on the Marital Relationship N=50

Brought closer together	3	6%	)	16% Positive
Difficult at first but closer now	5	10%	)	Impact
No difference (fair/good relationship)	6	12%	)	28% No
No difference (poor relationship)	8	16%	)	Change
Much strain/driven apart	16	32%	)	54%
Never discussed	7	14%	)	Negative
Marriage broken (child causal factor)	4	8%	)	Impact
Not applicable (one parent family)	1	2%	)	2% Not
			)	Applicable

Gregory's results from her study on deaf children and their families are given in Table 6.2 below.

Table 6.2 The Effect of a Deaf Child on the Parents' Relationship (Gregory 1976)

Closer	23%
Strain	24%
Varies, sometimes closer sometimes strain	25%
No difference	28%

Gregory however did not approach the subject will all respondents as she felt it to be too sensitive an issue in many cases. It is interesting to note that the percentage saying it had made no difference is exactly the same in both samples (28%). It seems probable that those with whom the subject was not discussed were the most likely to be experiencing problems. Had Gregory's results been complete, they may have been very similar to the blind sample. Other researchers finding a negative impact upon the marital

relationship include; Glendinning (1983) and Gath (1978). However, Burton (1975) like Gregory found no significant difference. In Burton's case, however, this may have been due to the methodological approach used.

Marital Breakdown

It was not possible to compare the rate of marital breakdown in the sample group with other studies or even with the national average because of the yearly rise in the divorce rate of the general population. The issue is also further complicated by the re-marriage and combining of families. It is also most important to note that the handicapped child was not always a causal factor in the breakdown. As several parents in Furneaux's (1988) study pointed out, the marital relationship was already unstable prior to the birth of the handicapped child. In some cases the birth of the child merely hastened an already irrevocable process. The broken and re-combined families in the sample group are shown in Table 6.3 below and 6.4 overleaf.

Table 6.3 Broken/Recombined Families - Child a Causal Factor (N=7 14%)

Type of family	Reason	No.
One parent family	Father married. Returned to his wife	1
Step family	Father left	1
Recombined step families	Father left	3
Step family	Mother left Father and children	1
Original family	Father left but returned later	1

**Table 6.4 Broken/Recombined Families - Child not a Causal Factor   (N=11
          22%)**

Type of family	Reason	No.
Mother's 1st marriage Father's 2nd	Mother visually handicapped	1
Unmarried mother	Father left when mother pregnant	1
2nd marriage for both parents	Violence and drinking	1
Recombined and step families	Not compatible	8

As will be seen from Tables 6.3 and 6.4, a total of 18 (36%) of the
families had been broken at some time. This is probably around the present
day national average. However, when only those where the handicapped child
was a major causal factor are studied, the percentage falls dramatically
to 14% which is considerably below the national average.   It would
therefore appear that, in this study at least, although a great deal of
extra strain is placed on the marriage, the majority of families survive
intact. It seems therefore that, rather than causing the family to break
up, in many instances the blind child acts as a binding factor on the
family. However, further study is required before conclusions can be
drawn, as there are many variables to be considered, but the findings were,
to a large extent, confirmed by families taking part in the Minisculpt
study.

Some of the parents' comments on the marital relationship are quoted below.

53. Charlotte Winter. Totally Blind. Retinoblastoma. Died age 7½ years

> "Yes it puts a lot of strain on the marriage. He did actually
> leave me for a few months before she died, but he came back again
> just before she died. After she died, people used to say, 'Well,
> at least you've got each other'. But I don't see it like that.
> I mean, sometimes you make it worse for each other - like if you
> feel depressed but he's having an up day, then it's best to keep

out of each other's way. I think it's something you've got to get over on your own really at your own rate.

He (father) could never accept that she was going to die. He didn't until she actually did die. He would never discuss it at all even after she was dead. He kept a diary of his feelings and I found it after he'd left me. I suppose he actually left it for me to find. But we've never actually discussed it together".

NB This family was followed up approximately 2 years after the first interview as part of the later 'Minisculpt' study. The parents were by then divorced. Both parents were interviewed (separately) and both agreed that it was only the blind child (there are two younger siblings) that had kept them together.

46. Nina McDonald. Functionally Blind. Optic Atrophy

"I think really she brought us closer together. We used to fight a lot before I had her and he used to knock me around. But he's very fond of Nina, he'd do anything for her. A lot of people have said having a handicapped child's split them up, but it hasn't happened with us".

44. Sally Patterson. Functionally Blind. Cataracts and Friedreich's Ataxia

"Yes it puts an awful strain on it (the marriage). But it's just something you've got to learn to live with. We can't talk about it. I mean, he's completely unable to accept that it's incurable. I daren't even mention it to him. He's quite certain somebody can cure her and he gets really angry because they don't".

43. Rachel Cotton. Useful Vision. Retinopathy of Prematurity

"Well it's done both at the same time really, (driven apart and brought closer together) if you know what I mean. It's hard to explain but when I'm depressed I get mad at Luke (child's father) because he doesn't understand. But yet in other ways it's brought us closer together".

42. Louise Brown. Functionally Blind. Retinopathy of Prematurity

"I think in the long run it's brought us closer together. We really work together now. It gave us a nasty knock but we've always been able to talk about things and help each other".

31. Dawn Allerton. Useful Vision. Retinal Dystrophy

"Oh it didn't make any difference luv (to the relationship). I would have left him anyway. He used to knock me about before

Dawn was born and it didn't stop him when I was carrying (pregnant). He just carried on the same after. Her eyes didn't make no difference".

30. Coral Barton. Functionally Blind. Cataracts

"There has been a lot of strain, yes. But I'm not sure it was her eyes caused it, or that she was such a bad baby. She was always fractious and screaming. The hospital side of it caused a lot of trouble because I had to stay in with her each time and there was nobody to get his (husband's) meals and that".

21. Marie Williams. Totally Blind. Leber's Amaurosis

"We just don't ever discuss it. I mean, well, I think that way lies the divorce court. Hugh just wouldn't have anything to do with her at first. Now he idolises her. But he can't accept it's final (child's blindness). He's still trying to find somebody to cure her".

13. Callum Pickering. Functionally Blind. Retinal Dystrophy

(Marriage broken. Child a major causal factor)

"They said at first that he would be completely blind. (Child has perception of light and form). He (spouse) couldn't take it. I hoped we could support each other but three months after we found out he left me. He said Callum couldn't be his child because no child of his could be blind. He said it certainly wasn't anything to do with him or his side of the family".

12. Christopher Peters. Useful Vision. Retinal Dystrophy

"Well I don't know (what effect child had on the relationship). I don't think he accepts it anyway. I think Christopher has probably kept us from splitting up. But then you know, I'm not altogether sure that that's a good thing really".

3. Eleanor Havard. Functionally Blind. Cataracts. Incontinentia Pigmenti and Heart Lesion

(Both parents handicapped. Father blind – cataracts – Mother physically disabled – epilepsy and Incontinentia Pigmenti. Eleanor inherited both)

"Oh yes, she's definitely brought us closer together. It (marital relationship) was worse before I had her. We were trying for a baby for ever so long and I got really depressed. But now I've got Eleanor it's just great. She's made us a real family".

Again it was not possible to make detailed comparisons of the sample group of parents with those of other studies because of differences in methodology. An attempt was made to separate physical from mental and emotional symptoms but inevitably there is some overlap.

It would appear that mothers are far more prone to ill health, both mental and physical, than fathers. As the main burden of caring for the child almost invariably falls on the mother, these findings are not surprising. However, it must be borne in mind that few fathers were actually present at the interview. Even fewer made any significant contribution to the data collection, or contradicted their wives' statements. Data collected on the fathers' ill health were therefore almost exclusively provided by the mothers.

Physical Ill Health in the Mother since the Birth of the Handicapped Child

Approximately one third of the mothers said they mainly enjoyed good (physical) health and that the birth of the handicapped child had not markedly altered this. The most common symptom reported was insomnia (reported by 64% of the mothers). When they did fall asleep, many reported vivid dreams and nightmares. Some said they were almost afraid of falling asleep because of the horrific quality of the dreams. The second most common symptom was loss of weight, reported by 32% of the mothers. Major physical illness (eg. rheumatoid arthritis and angina) and exacerbation of a chronic condition (eg. multiple sclerosis and diabetes mellitus) occurred in 6 cases. One mother is quoted below.

36. Kenneth Barton. Functionally Blind. Buphthalmos (Infantile Glaucoma) and Cataracts

> "I lost an awful lot of weight. I think I went down to under 6 stones. I smoked like a chimney. I didn't have time to eat, I spent so much time trying to feed Kenneth, I didn't want my own food. I couldn't sleep and there was all the frustration of whatever I asked for being turned down. I was frightened to go to sleep, the dreams were worse than the reality. I felt sick most of the time and used to get migraine a lot".

Physical Ill Health in the Fathers since the Birth of the Handicapped Child

According to the mothers, 76% of the fathers enjoyed good physical health. Data were not elicited for 7 of the fathers. None of the fathers were reported to have lost weight. As with the mothers the most frequently reported symptoms were insomnia and nightmares although in a much lower percentage (8%) as opposed to 64% of the mothers. Other symptoms reported by fathers included extra smoking (6%), extra drinking (2%) and weight gain (2%). Two of the fathers suffered from major physical illness (terminal carcinoma of the lung and a leg injury sustained at work).

Emotional Symptoms in the Parents

With regard to mental and emotional symptoms, the differences between the mothers and fathers seemed to be quite clearly defined. Only two mothers stated they had suffered no symptoms of anxiety or depression, and it should be noted that in both these cases there was a long family history of blindness covering several generations. Also, interestingly, both these mothers were themselves visually handicapped[1].

Gregory (1976) found that 87% of the mothers of deaf children were or had been depressed. Other studies of various handicaps have also found a raised incidence of depression in parents, although none were actually clinically evaluated. One study, that of Gath (1978) did attempt clinical evaluation of the emotional states of parents using the Golding (1972) questionnaire. Gath studied the parents of children with Down's syndrome and did not find the scores markedly raised. However, she admits that the questions probably did not pick up the grief reactions suffered by the parents. During her study, Gath carried out six interviews over a fairly long period of time. She found that grief symptoms suffered by these parents had usually resolved within two years of the child's birth. This finding however is not borne out in the experiences of the blind sample group. The ages of the children studied, ranged between 0 and 16 years and

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[1] It is important to remember that information regarding the fathers was second hand from the mothers. The Minisculpt models revealed that many fathers did in fact experience emotional trauma but were more likely than the mothers to keep their feelings to themselves.

most of the parents of the older children were still experiencing many of the same emotions felt in the early months and years following diagnosis. For some parents, the symptoms had actually worsened with time. For example, one mother was admitted to a mental hospital after suffering a complete mental breakdown 9 years after the child's birth.
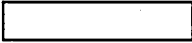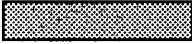
Details of the parents' emotional problems are given in Figure 6.3. It would appear from the data that virtually all the symptoms suffered by the parents are components of the mourning process. It does however seem that gender has some impact on the way in which grief is experienced and expressed. Whilst the mothers tended to suffer predominantly anxiety, depression and feelings of guilt and shame; the fathers most commonly reported feelings tended to be anger and resentment. It is also interesting to note that whilst none of the mothers denied the existence of the handicap, 28% of the fathers apparently did so. (Grief and the mourning process will be discussed in greater depth in later chapters). Again it must be borne in mind that symptoms in the fathers are mainly those reported by the mothers as few fathers were present at the interviews.

The majority of parents had received no (professional) help of any kind in coming to terms with the handicap or coping with the stress. Few had even thought of seeking help. Many were ashamed of their feelings and felt unable to admit them to the doctor in order to ask for help. Two mothers who did ask their GP for help were told it was just "baby blues" and they would soon get over it. Most of the parents felt that it was a waste of time going to the GP because he did not understand. Burton (1975) studying families of children with cystic fibrosis confirmed these findings. Doctor/patients relationships between GPs and their patients are explored in sections IV and V.

Figure 6.3 Emotional Problems in Parents Since Birth of Handicapped Child as Reported by the Mothers

SYMPTOM	PERCENTAGE REPORTED	
Anxiety		(M 96%)
		(F 24%)
Depression		(M 92%)
		(F 6%)
Guilt/Shame		(M 69%)
		(F 4%)
Resentment		(M 68%)
		(F 34%)
Anger		(M 52%)
		(F 34%)
Revulsion/ Rejection		(M 16%)
		(F 12%)
Denial of Handicap	Nil	(M 0%)
		(F 28%)
Agrophobia/ Claustrophobia	Nil	(M 14%)
		(F 0%)
No Symptoms Admitted		(M 4%)
		(F 20%)

Percentage Reported: 0   25   50   75   100
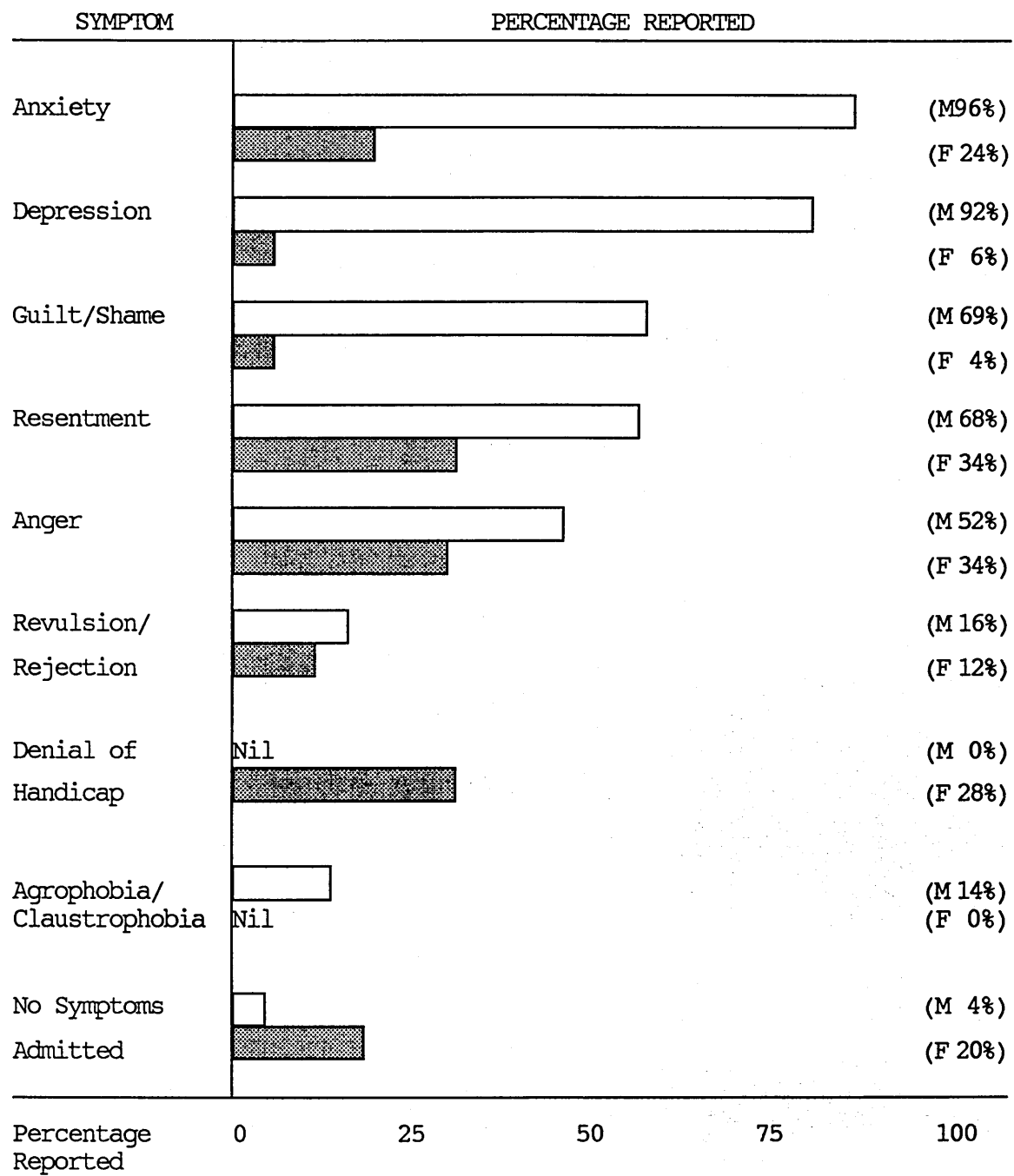
KEY ☐ Symptoms in Mother

☒ Symptoms in Father

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In view of the fact that 6% of the mothers in the blind sample had seriously considered or actually attempted suicide, and that a further 4% had considered or actually attempted infanticide, it seems there is an urgent need for GPs and other professionals to be alerted to the hidden dangers. In fact these figures probably underestimate the problem as parents were not questioned on this aspect, they merely volunteered the information.

Some of the parents discuss their experiences below.

53. Charlotte Winter. Totally Blind. Retinoblastoma. Child died aged 7½ years

"Yes, I am depressed. I don't think that really it will ever go away. I really wish that I could die. Actually I saved a lot of tablets the doctor gave me. I've still got them. I did almost take them on her last birthday. I'm not frightened of death. The only reason I decided not to go through with it was because I though I mightn't be allowed to go straight to her if I took my own life. And I thought about Andrew and Joanne (siblings) and that I had a responsibility to them. So I just keep on living from day to day. I know that one day I will see her again but I do just wish it could be soon".

51. Lucy Baldwin. Totally Blind. Optic Atrophy

"Well I got so as I couldn't go out at all I was frightened to go beyond the front door. I felt I couldn't take her out because I thought everybody was staring at her and thinking 'Oh she's got a blind baby'. I don't suppose they were actually, but that's how it all started (nervous breakdown)".

50. Nicola Porter. Useful Vision. Retinal Dysplasia (Mother a Nurse and Midwife

"Well when you have a straight diagnosis, like say, Down's Syndrome, at least you know what you have to face. But not knowing the prognosis and how things will turn out is terrible. To tell you the truth, I found bonding with her very difficult. I wished I had never had another baby. I wanted to run away and leave her".

44. Sally Patterson. Functionally Blind. Cataracts and Friedreich's Ataxia

"I get terribly wound up about everything. I'm like it all the time. I tend to snap everybody's head off for no reason. I suppose to be depressed and anxious about them (handicapped children) is normal really but I didn't expect to feel so guilty. I don't know why I feel guilty but I do. Everybody says it's not

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my fault and it's actually on Alan's (husband) side of the family anyway. But yet I feel as if it's all my fault. I feel so angry. (Who are you angry with?). I suppose Prof M. mainly. I know he knew what was wrong with her but he never told me. I still hate him. I went out one night and I was looking for him. I never saw him - it's just as well because I swear if I'd got my hands near his throat I wouldn't have let go".

43. Rachel Cotton. Useful Vision. Retinopathy of Prematurity

"Yes I do get depressed, even now. I used to cry for hours when I was on my own. (Did you ask anybody for help?) Oh no. I couldn't could I? Everybody thought I was really happy she was alive, because they all thought she would die. So there's nobody I can tell really, they'd think I was stupid".

42. Louise Brown. Functionally Blind. Retinopathy of Prematurity

"I feel guilty yes, but I feel resentful as well. It really isn't fair. I did everything right in my pregnancy. And yet, people who don't, who smoke and drink and things, they get normal babies".

38. Matthew Windsor. Useful Vision. Retinoblastoma. Died aged 4½ years

"I still feel guilty. Partly because I feel as if I caused it all and because I don't feel as if I looked after him very well before he died. I felt angry with him all the time, but it's not logical is it? How can you be angry with a 4 year old that's dying. I felt angry because I felt it was his fault I'm like I am. (Mental health problems). I wanted to run away. I just couldn't bear to touch it (child had fungating carcinoma of eye socket) it made me feel sick. I didn't want to be near him and yet I wanted to love him because he was dying.

I was frightened of him dying and not knowing what it would be like or what would happen or how I'd cope. You see, I'd never seen anybody die before and I felt I couldn't ask the (district) nurse or the doctor because they'd think I was stupid.

(What was it like for you when Matthew did die?) Well, I can't remember an awful lot about it. (Mother had mental breakdown following child's death). It's only recently I've been able to think about it and kind of sort it out in my own mind. He'd been crying and moaning all night and in the morning I called the doctor out. He brought another doctor with him, (probably a trainee GP) and they stood and talked by his bed. I don't really know what they said. Anyway my doctor said 'I'm going to give him an injection. You come and sit with him. He'll be alright now'. Well he seemed to go off to sleep, but then later he started to moan and cry again, although he still seemed to be asleep. I phoned for the doctor to come back but Matthew died before he came.

I just wish that I had known he was going to die that day because I could have given him all his favourite toys and I could ... well ... I could have said ta-ra to him like".

36. Kenneth Barton. Functionally Blind. Buphthalmos and Cataracts

"At first I just felt numb. Then I was angry - why should it happen to us? Then I got more and more depressed. I was suicidal at one point actually. The doctor gave me librium but I didn't take them. I just kept going back for another prescription. I was saving them up you see. (How long did it take you to get over it?) Humph! (laughs) you don't get over it. It was six years before I even began to feel as if I could cope at all".

35. Lee Davidson. Functionally Blind. Cataracts and Hallermann Strieff Syndrome

"I felt very guilty at first, till I knew it was part of his condition (Neurological syndrome). He was a really mardy irritable baby and I used to think it was just bad temper. So I used to leave him outside in his pram. I though it was being left out in the sun so long that had caused it (cataracts) you see".

28. Cynthia Carter. Totally Blind. Congenital Anophthalmos

"It was quite difficult at first. I didn't want to feed her. I couldn't bring myself to pick her up and love her. She used to lie there screaming for ages. I used to bottle feed her in the cot. I didn't bring her down stairs - I didn't want to look at her. And I just felt I couldn't take other people's reactions (Child born without eyes)".

22. Samuel Bates. Totally Blind. Congenital Anophthalmos

"When they brought him back to me, (baby taken away to special care nursery at birth as born without eyes) I just went berserk. I shouted and screamed at the doctor, 'Why did you let him live? I don't want him, take him away'. I was sure he wasn't mine. I couldn't imagine how my baby could be like that. Well, they put me in this room on my own, away from everybody else. And I thought 'Look at him. He's not going to be any good to anybody'. Well, I got my pillow and put it over his head. You see I was going to kill him and then slash my wrists. I held it over him for ever so long till he went still. But I didn't realise how long it takes. When I took it off he was all mottled and a funny colour. But he started breathing again and he screamed and screamed once he'd got his breath back

My mother came to see me and I told her, I said I didn't want to live. I said, I can't take him home, I wish we was both dead. Well she put some sense back into me. She says, 'Don't you ever say such things again. Of course you want him'. Well then I went the opposite way. You know, I wouldn't let him out

of my sight. I wouldn't let him be put in the nursery with the other babies because I thought he might get mixed up. I mean, it's stupid isn't it? (laughs) getting him mixed up with no eyes. But that's what I thought then".

THE IMPACT ON THE SIBLINGS

The existing data on this subject are difficult to evaluate, once again because of differing definitions and methodological approaches.

The National Child Development Study [1958 Cohart] (1972) found that 8% of the general population of children suffered from behaviour disorders. Many studies of handicapped children have found the incidence of behaviour disorders to be raised in the siblings of target children. Some researchers (mainly those studying mental handicap) have however pointed out that a handicapped child can have a positive effect upon the siblings. Gath (1978) studying children with Down's Syndrome, found that disturbance in the siblings did not appear to be related significantly to the handicapped child per se, but had often been present prior to the birth of the handicapped child. Most studies do not seem to have taken this into account. Burton (1975) found that disturbance seemed to be related to age and family structure, i.e. that the birth of a handicapped child was quite likely to have a positive effect on older siblings but a markedly more negative one on younger children (those born after the target child).

Gregory (1976) found that 44% of the deaf sample of families had experienced problems of jealousy in siblings as against 33% of Hewitt's (1970) sample of children with cerebral palsy. However, neither Gregory nor Hewitt inquired about mood disturbance of behavioural disorders in siblings. Glendinning (1983) in an overall survey of handicapped children did not find disturbance of the siblings to be a problem. She felt at that time that the siblings' problems were mainly of a "restrictive" nature - i.e they had less freedom in many respects than the siblings of normal children. However, Glendinning (1986) later carried out an in depth evaluation and "interventive" type study involving specialist social worker/resource workers. This study revealed that 50% of the families experienced problems with siblings requiring a moderate or large amount of

time devoting to them. Thirty nine percent had required a fair amount of time and 11% had required a great deal of time devoted to them.

In the present blind sample, 12 siblings out of a total of 64 (19%) were felt by the researcher to have an emotional or behavioural disorder "sufficiently severe or sufficiently prolonged to cause suffering to the child himself or to others". (This definition from Rutter et al, 1970). Mild forms of disturbance and normal sibling rivalry were discounted as were behaviour disorders present prior to the target child's birth. It should also be noted that many of the siblings were as yet too young to exhibit symptoms.

It would appear therefore that to be the sibling of a visually handicapped child can have an adverse impact in a significant number of cases.

Some of the parents' comments on the siblings' behaviour are quoted below.

44. Sally Patterson. Functionally Blind. Cataracts and Friedreich's Ataxia

"I don't know what will happen about him (sibling) I'm sure I don't. He's in serious trouble at school. Last week he threw his book at the teacher and swore at her. He smacked another teacher and he's always on report. He's been suspended (from school) twice. And then this morning, like I said that's why I was late for you (researcher) coming, I had to go and see a psychologist at school about him. He said something what should never have passed any child's lips and I just don't know what will happen. He said he wished he was out of it like his uncle B. (committed suicide) and that as soon as he got a chance he'd probably do the same.
     We decorated his room for him a few months back, and what did he do? Got black paint and splashed it all over the walls and everything. I'm really at my wits end. Nobody seems to be able to get through to him any more".

22. Samuel Bates. Totally Blind. Congenital Anophthalmos

"Oh well, what Sam did to them (siblings) was diabolical. But I've got the best kids in the world. It's made them better people. But they had to grow up really fast. And they had to fend for themselves as well as help with Sam whilst I was in hospital". (Mother in mental hospital for several months following a nervous breakdown due to the shock of the child's birth).

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21. Marie Williams. Totally Blind. Leber's Amaurosis

"Mm yes, they did have problems, they still do now as a matter of fact. (Both siblings are child's half brothers, children of the mother's first marriage). Paul got very depressed. He just used to sit in his bedroom and not do anything. Daniel was the opposite. He would hit her if he could get away with it and he used to smash her toys up and things like that. He stripped all the paper off his room and drew all over the walls in felt tip pens. He has problems at school as well. I think he just doesn't turn up there quite often".

16. Felicity Newson. Functionally Blind. Retinopathy of Prematurity

"Ruth is difficult sometimes. She imagines things - like I've taken her to hospital several times because she says she's swallowed something. She's been examined and x-rayed but they've never found anything. She makes things up - for attention I suppose. The school psychologist sees her about it now".

10. Peter Davidson. Functionally Blind. Cortical Blindness due to Hydrocephalus

"She (elder sibling) hates him because he is more intelligent than she is and gets more attention. He always makes a point of rubbing it in and telling her how clever he is at school and how he's got a place at grammar school (for the blind). (Sibling suffers from epilepsy and has learning difficulties). He really does some quite nasty things to her sometimes and she always gets blamed or it if she hits back".

EXTENDED FAMILY NETWORKS AND SUPPORT SYSTEMS

Sheffield is often called "The biggest village in England". The majority of its inhabitants still spend the whole of their lives within the city. Unlike many similar sized urban conurbations, most Sheffield people have extended family connections in the same neighbourhood or elsewhere in the city. As anticipated, this also applied to the visually handicapped children and their families.

Contact with the Grandparents

The majority of the families (37 out of 50 or 74%) had grandparents living in the same city. Twenty one of these, or 42% lived in the same neighbourhood. Of the remaining 13, seven were dead and only 6 lived out of the area.

The majority of families (54%) visited or were visited by the grandparents once per week or more frequently. Most of these families had daily contact with grandparents as they tended to live "just round the corner" or "a couple of blocks away". In most instances the grandparents were the family's main support system. Of those seen weekly or more often, only one family said the grandparents were of no help and in this case it was felt that the grandparents were unable to accept the fact that the child would never regain her sight.

Only 10 families saw the grandparents rarely or hardly ever. Of these, 4 lived in the same city but were not on good terms with the family. In these cases the relationship did not appear to have been affected by the handicapped child as the families had not been close prior to the birth of the child. In one case the maternal grandmother was dead and the family did not see grandfather very often. In the remaining 5 cases the grandparents lived out of the city.

Parents' Contact with their own Siblings

Most of the families lived closer to their parents than to their siblings and other family members, although these networks were still quite extensive. Forty two (84%) of the families had siblings living in the same city, ten (20%) of these lived within the same neighbourhood. The families however saw less of their siblings than of their parents. Only eight (16%) families saw their siblings weekly or more often and a further seventeen (34%) approximately once a month.

As previously stated, the grandparents were the main family support system rather than brothers or sisters as the latter were usually concerned with the raising of their own children.

THE INHERITANCE FACTOR - GENETIC IMPLICATIONS OF VISUAL IMPAIRMENT

A high proportion of the defects suffered by the children (64%) were probably genetic in origin. In 23 of the families there was a clearly defined family history of a genetic eye defect. In a further 9 families the family history was probably significant. In 8 cases the cause of the

defect was unknown and in only 10 cases was the condition definitely not genetic in origin.

Considering the large number of cases where the disorder was known (by the medical profession) to be genetic, relatively few families fully understood the inheritance pattern or the implications for future generations. Although a total of eighteen (45%) of the families had been given some explanation of the genetic implications, the majority had not understood all that was said and were still very confused about the situation. Where the implications had been explained, the information had rarely been given by a specialist in human genetics. Neither had it always been given by a GP or Consultant. In several cases a specialist social worker had given the information and in one case a health visitor. The information being given by personnel other than doctors did not appear to prejudice the chances of the parents' understanding the implications - rather the opposite in fact, as all the parents informed by non medical personnel had a good grasp of the facts. Eight families had asked doctors for information but had been given unsatisfactory or evasive answers. Details of the information received by parents are given in Table 6.5 below.

Table 6.5 Explanations given to Parents of Genetic Implications. N=40 Families

Explanation given and understood	7
Explanation given but unsatisfactory or not understood	11
Explanation requested but doctor evasive	8
Mother informed doctor	1
No explanation given	12
Don't remember	1

Genetic Counselling

Only three of the families were actually offered genetic counselling and it is interesting to note that two of these families refused the offer. A further four families requested the service for themselves. Three of these were granted and the 4th refused by the GP. This gives a total of 4 families who actually received the service. The remaining 35 families were not offered the service and did not request it.

Genetic Implications for Future Generations

The genetic implications for future generations is probably one of the most difficult of all the problems for parents of handicapped children to come to terms with. The topic is laden with guilt and anger. Few of the parents had been able to confront the problem directly themselves, let alone explain the implications to their children and help them to come to terms with the situation. In some instances however the question was academic, as the child was not expected to survive to child bearing age.

When the parents were asked if the children were aware of the genetic implications only three said they had shared the full extent of their knowledge with the child. Three others said they didn't know as the question had not been discussed openly but they felt that the child "probably had a good idea" of the implications. In ten cases the question was not asked. (In four of these the child was present during the interview and in the remaining six, the parents were obviously not aware of the genetic implications themselves). Table 6.6 overleaf gives details of the children's awareness of the implications.

Table 6.6 Children's Awareness of the Genetic Implications N=55 Children

Yes, fully aware	3
No, not aware	14
Too young to understand	15
Don't know - not discussed	3
Not asked	10
Not applicable (not genetic)	10

Parents' Intention to Inform Children of Genetic Implications

The parents whose children were as yet unaware that they could pass the defect on to future generations were asked if they intended to inform the child. Although none of the parents gave a direct 'no' in answer to this question, it was obvious that many were experiencing great difficulty with the problem of how and when to broach the subject. Comments such as, "Well, I know I've got to tell her somehow, yes. But how and when, I just don't know", were common. One mother felt she would like a professional to explain the situation to her daughter:

51. Lucy Baldwin. Totally Blind. Optic Atrophy

"Well, I think it would be better really coming from somebody else. Like a teacher or a social worker. But well, there isn't anybody, is there? So I suppose I'll have to do it myself, but I've no idea how".

Another mother with two handicapped children both with inherited cataracts and the daughter also having inherited a neurological syndrome is quoted below.

<u>44/45. Sean and Sally Patterson. Both Functionally Blind. Son and Daughter Cataracts. Daughter also Friedreich's Ataxia</u>

"Well you know, I would never lie to them. But then again, I can't just come out and say it directly, so if they were to ask, well then I would probably answer their questions with the truth. But I don't think Sean will ask although Sally (daughter) might".

The parents' intent to inform the children of the genetic implications is given in Table 6.7 below.

Table 6.7 Intention to Inform Children of Genetic Implications   N=50 Families

Child already informed	3
Yes, when old enough	4
Don't know	17
No	0
Parents themselves unaware of implications	6
Not asked	10
Not applicable	10

Some parents were very bitter about the way in which they themselves found out they could pass the defect on to their own children. For example, the mother of a child inheriting and X linked recessive disorder who repeatedly asked for information.

<u>5. Michael Kent. Totally Blind. Microphthalmos and Pseudo-Glioma (Mother a Trained Nurse)</u>

"I feel very bitter towards the medics in that respect. I mean, if I had known, I would have planned my family differently and I would never have had Michael.

Right from being very small, I used to ask my mother, 'Will I have blind babies?' She always said she had been told it had died out because none of us (mother and siblings) were affected. But then you see we were all girls. My sister's children were girls as well.

When I was pregnant, I told the GP and Mr N. (Obstetrician) about the history (Grandfather, Father and Uncle all born blind). But nobody was interested. They all said it was nothing to worry about. I was staggered by their indifference and lack of interest. When Michael was born they hardly looked at him and yet the defect was obvious to me. Of course, I realised then that it was X linked and that I was a carrier".

Family Limitation in Relation to Severe Visual Handicap

The majority of couples studied, wanted to limit the size of their family. In most instances this was a direct result of having a handicapped child. Several mothers would have liked more children, having originally planned to have a large family. However, they felt they could not now take the risk of having another handicapped child. In several instances, where the blind child had been the first baby, the parents did decide to have another child. This had however usually required a great deal of courage and parents often said they had done this for the sake of the handicapped child rather than themselves.

In three cases the family was limited more because of maternal illness, (diabetes, multiple sclerosis and pulmonary embolism) than the child's handicap. In eight cases the family was complete in any case. Only five couples said that having a handicapped child had made no difference to their thoughts on family limitation. It is interesting to note that these families (with one exception) were those with a family history of blindness over several generations.

Mrs Kent quoted above, continues her story:

5. Michael Kent. Microphthalmos and Pseudo-Glioma

"Well yes, I would like another child. But it's got to be a girl. I asked Mr N. (Obstetrician) about this and he said I could have an amniocentesis - because of my age. But he wouldn't be willing to do a termination if it turned out to be male, just because it might be blind. He said blindness was only a minor thing and not something I could have an abortion for. I really hate him. Who does he think he is, to be playing God. People like him should be made to bring up a blind child. And he should be made to suffer what Michael's been through. Then we'd see how he felt. It's the parents who should decide these things. After all they're the ones who know what they can cope with, not obstetricians who think they're gods!".

Concluding Comments

In Chapter 6 I have been concerned to show some of the ways in which the birth and rearing of a severely visually impaired child affects relationships within the family circle and impacts upon the functioning of the family as a system.

Because specialist help was not readily available in the majority of instances, it was the family circle rather than the professional sphere which provided the support network. The ways in which the families coped in their 'passage through crisis' is dealt with in Section V of the study.

With regard to the 'telling of bad news', Cunningham and Davis (1985) note that:

> "Reactions of anger and dissatisfaction have been found to be considerably less where parents were told (i) as soon as possible, (ii) together, (iii) sympathetically, but with a balanced honest appraisal of implications which do not just list negative aspects, (iv) in a private place with time to react, (v) in a series of planned discussions of practical and relevant information, and (vi) that there will be continuity of service support".

It is noteworthy, however, that in the great majority of cases in the Sheffield sample, none of the above criteria were met. Lonsdale (1979) has shown that this kind of planned intervention can be highly effective, particularly when it is carried out by a group of professionals working coherently as a team. Such a team approach is discussed in Section VI.

In the chapter which follows, the early development of the blind, as distinct from the seeing, infant is profiled along with some of the ways in which s/he is motivated towards mobility.

CHAPTER 7

THE EARLY DEVELOPMENT OF BLIND CHILDREN

TOWARDS MOBILITY - FIRST STEPS

Gross motor development is directed towards the attainment of stable positions - especially against gravity - and the achievement of movement. Movement itself opens up many new avenues of development. It enhances physique by the effect on circulation and increased muscle strength. It provides practice in the developing sensory skills, co-ordination and balance. Increased learning opportunities are provided by exploration of the near and distant environment. Spatial awareness is achieved and an understanding of object permanence. Communication with other humans becomes more effective and wider in scope.

If a child remains immobile (for whatever reason), he will be unable to explore the world around him. His emotional and social development will also be affected as he is unable to run to his mother for a cuddle or play hide and seek with his brothers and sisters.

Gross motor development culminates in the achievement of the upright position and walking. Walking is the one action parents wait for and acclaim with great joy. In fact, so important is this achievement that many parents remember not only the day and date, but the actual time that the infant took his first steps alone.

The prospects opened up by the development of independent walking are considerable. It is a mature and socially accepted means of progression; considerable distances can be explored; and the hands are free for manipulation and carrying. For the sighted child, progress is visually directed and controlled without difficulty. Walking is also the precursor of other skills such as running, leaping and hopping.

Studies of blind children, eg. Norris et al (1957) and Fraiberg (1974) have shown that congenitally blind children are later than sighted children in achieving many developmental milestones, particularly those relating to

gross motor development. Bower (1977) presents a table summarising some of the findings of Fraiberg (1974). This is shown as Table 7.1 below.

Table 7.1   Schedules of Development for Blind and Sighted Babies

Item	Median age in months		Difference
	Sighted	Blind	
Levitates self by arms, prone	2·1	8·75	6·65
Sits alone momentarily	5·3	6·75	1·45
Rolls from back to stomach	6·4	7·25	0·85
Sits alone steadily	6·6	8·0	1·4
Raises self to sitting position	8·3	11·0	2·7
Stands up, using furniture	8·6	13·0	4·4
Stepping movements (walks if hands held)	8·8	10·75	1·95
Stands alone	11·0	13·0	2·0
Walks alone, three steps	11·7	15·25	3·55
Reaching, visible object	5·0		
Reaching, audible object		11·0	6·0

Reproduced from T Bower: The Perceptual World of the Child. Fontana (1977)

Fraiberg (1977) shows graphically the percentage of her blind sample who were delayed beyond the sighted norm - taken from the Bayley (1969) scales of development. This is shown as Figure 7.1 overleaf.

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Figure 7.1 Percentage of Fraiberg's Blind Sample Who were Delayed Past the Upper Limits of the Sighted Age Range (As Given by Bayley 1969)

Elevates self by arms, prone	80%
Sits alone momentarily	10%
Rolls from back to stomach	10%
Sits alone steadily	10%
Raises self to sitting position	40%
Stands up by furniture (Pulls up to stand)	50%
Stepping movements (Walks hands held)	20%
Stands alone	10%
Walks alone, 3 steps	50%
Walks alone, across room	90%

■ = self-initiated mobility   ▭ = posture (with 1 exception)
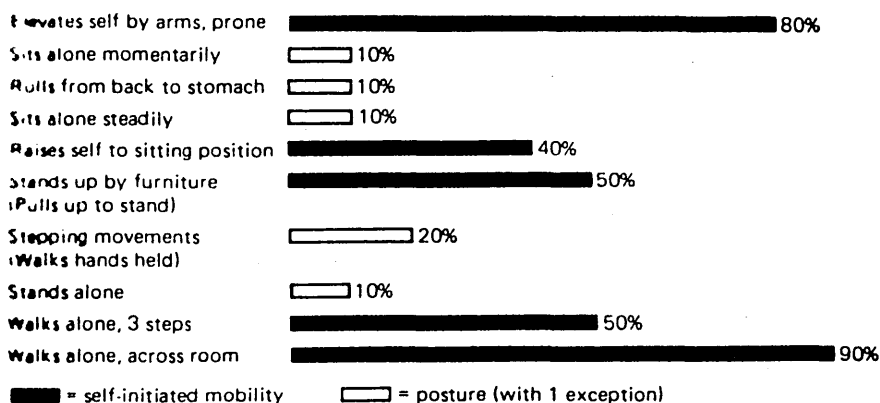
Reproduced from S Fraiberg: Insights from the Blind. Souvenir Press (1977)

The age range in acquiring the skill of walking alone in the Sheffield sample was ten months to four years (48 months), with a mean of 14.5 months. It must however be borne in mind that this sample included children classed as partially sighted as well as blind, whereas the children in Fraiberg's group were all blind from infancy.

As with the acquisition of independence skills, I found no correlation between degree of handicap and the age at which the child walked alone. One child born without eyes (female) walked alone at 12 months - well within the sighted norm. Another functionally blind child with only perception of light, crawled at 6 months and walked alone at 10 months. It is interesting to note, however, that this particular child was from a large Afro-Caribbean family and, although the subject is not well documented, some doctors working in the field of child development have noted that some of these children have precocious gross motor development. And, as his mother pointed out, this child was later than his (6) siblings in achieving both these skills. On the other hand, four of the children with useful vision were between 16 and 19 months when they walked alone. It is important to note that no correction for prematurity has been made in any of the samples quoted.

Although the Sheffield sample is too small to draw conclusions of statistical significance, from the data collected it does appear that there is a positive correlation between the mother's anxiety and depression level and delay in walking alone. It is also evident that walking alone (as with other gross motor abilities) can be achieved within the sighted norm even by children totally blind from birth. However, a level of input by the parents (usually the mother) far in excess of that required for 'normal' children seems to be required in order to achieve this.

Obviously if the mother is depressed, anxious or in poor health, she will be unable to provide the high levels of input required. Add to this the mother's lack of knowledge of the child's needs, her guilt feelings and the tendency to overprotect and it seems surprising that some blind children ever learn to walk unaided.

It does seem however, that the giving of information to parents and the instigation of a programme of intervention can achieve quite high rewards. All the children in Fraiberg's (1977) study received educational guidance from the project from the time of entry into the programme. When Fraiberg's levels of achievement are compared with the Norris (1957) sample of blind children receiving no intervention, it is obvious that Fraiberg's children had an advantage. The results, taken from Fraiberg (1977) are given in Figure 7.2 below.

Figure 7.2   Two Blind Groups Compared: Norris 75%, with Fraiberg 80th Percentile (No Age Correction for Prematurity)
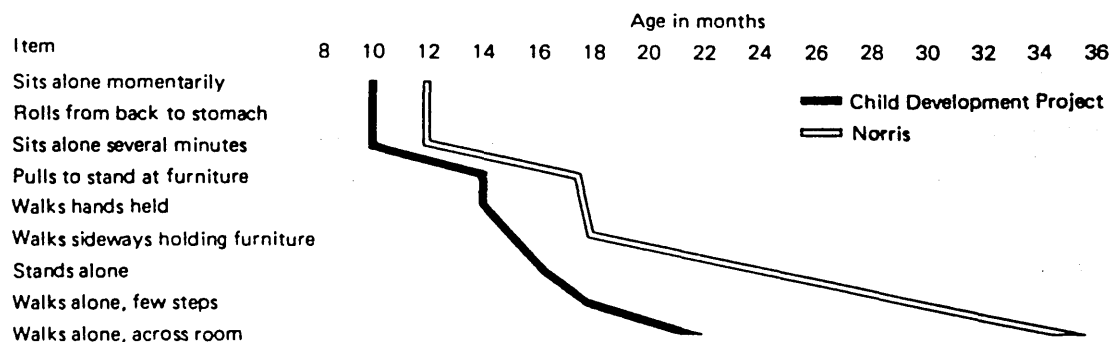
Reproduced from S Fraiberg: Insights from the Blind. Souvenir Press (1977)

The Development of Mobility and Gross Motor Skills

In order to study mobility, it is easier first to look at the development sequence in reverse. We need to know how walking develops from crawling, how crawling develops from prehension and the achievement of balance and how reaching develops into grasping. Having established the sequence in the sighted and neurologically normal child, we then need to consider the special problems to be overcome by the visually handicapped child.

Prehension

The 'wired in' biological programme intends that vision and prehension evolve in synchrony. As Fraiberg (1977) pointed out: "The story of prehension is not the story of the maturational and adaptive functions of the hand alone, but the story of hand and eye, eye and hand".

At around 4 months the sighted baby demonstrates that he can reach for and grasp an object on sight. He has now achieved a co-ordination of hand and eye which evolved in a biological sequence and is assured under all normal circumstances.

For the blind baby at 4 months, there is no equivalence in prehension. There is no adaptive substitution of the ear for the eye available to him. The co-ordination of ear and hand is achieved in most blind infants at around 11 months. In Fraiberg's (1977) sample, where educational intervention was provided, the mean age of achievement was 8.27 months.

The Beginnings of Reaching and Grasping

According to Bower (1982) reaching, like walking begins well before birth. All of the components for reaching and grasping can be elicited in the foetus at a conceptual age of 14 to 16 weeks.

Bower (1982) found that visually initiated reaching can be elicited in newborn infants. Bower (1972) has also demonstrated that the neonate (suitably supported) not only reaches for objects using vision, but

actually matches the size of the object with finger/thumb separation (See Figure 7.3 overleaf).

In the average infant however, this precocious behaviour vanishes, and reaching re-appears when the grasp reflex disappears at around four to five months of age. Humphrey (1969) argues that this, as with walking, (which can also be demonstrated in all normal neonates) is the take over of these skills from the primitive hind brain, by the higher cortical centres. In order to understand how this occurs, we need to study reflex activity in infancy.

Reflex Activity in the Infant

The nervous system of the newborn baby is well developed and capable of complex activities. Many of these activities concern vital functions such as breathing and suckling. These actions are 'wired in' before birth and are termed reflex responses. There are many reflex responses which can be demonstrated using an appropriate stimulation. Holt (1977) describes a reflex action as:

> "... a prompt, stereotyped and often considerable response to a specific and often quite minor stimulus. There is no opportunity for variation or choice of action. The promptness, consistency and predictability of the neonatal reflex responses show that neurological pathways are already established and defined".

Figure 7.3 A Neonate Matching the Seen Size of an Object to Finger/Thumb Separation

From T G R Bower. Object Perception in Infants. Perception, 1, 15-30, (1972)

Holt (1977) goes on to explain that the pattern of reflexes shown by young infants reflects the phylogenetic evolution of the nervous system. Many of the reflexes are evident in other species. For example, the trunk righting reflex is also shown in quadrupeds, (the reason cats tend to fall on their feet). Some reflexes are considered to be remnants of vitally important reflexes in the past. For example, the grasp reflex would serve an essential survival function enabling the infant animal to cling to its mother's fur. Other reflexes are probably unique to man, especially those concerned with the attainment and maintenance of the upright posture.

As the nervous system develops, many of the early reflexes are inhibited, others are modified and later incorporated into more complex actions. These developmental changes are necessary because the continued activity of early reflexes would interfere with the development of other actions. This effect is seen in neurologically disabled children and children with sensory defects.

The A.T.N.R., Precursor of Prehension

As we noted earlier, reaching can be elicited in the immediate post natal period. However, it is fair to point out that this can only occur when certain specific conditions are met. Bower (1972) found that in order to do this, the infant must be wide awake - a state not always easily obtained in the neonate. He must also be in a specific posture which allows him free use of his arms and free head movement. This too is a condition difficult to attain because the infant tends to use his head and arms as supports whilst lying supine. See Figure 7.4 overleaf. Obviously, if the arms are being used as supports they cannot move freely.

Incidentally, the position seen in Figure 7.4(A) is one frequently resorted to by many blind children long after normal sighted children have abandoned it for more purposeful ones.

A reflex which plays an important role in visuomotor development is the Asymmetrical Tonic Neck Reflex (known as the A.T.N.R.). If the infant's head is turned - actively or passively, to one side, the reflex response consists of, extension of the arm on the side to which the head turns and flexion of the other arm. See Figure 7.5 overleaf.

Figure 7.4 A Neonate Lying Unsupported
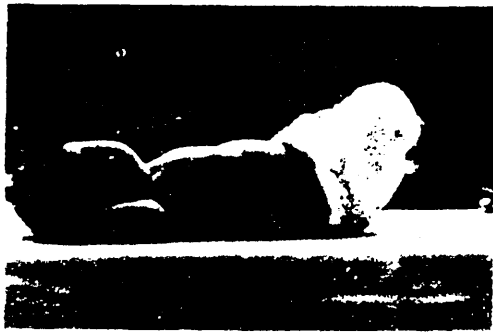
(A)

(B)
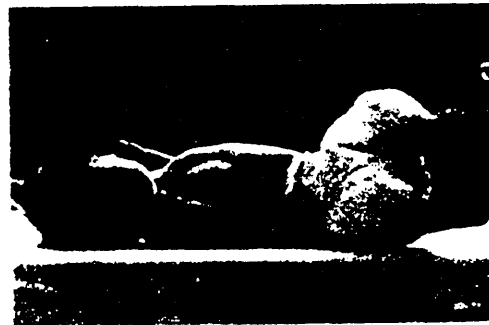
(C)

Note the support role of the head and arms. (A) If the infant moves its arms it is unable to maintain posture (B), save by propping itself on its arm (C). This precludes any attempt to reach.

From T G R Bower: Development in Infancy (1982)

There is some controversy as to whether this reflex is present in the early neonatal period. It is most easy to elicit between the ages of two and four months. This is the time when visual fixation upon nearby objects is developing and it seems as though the nervous system is making sure that the appropriate arm stretches out towards visualized objects. As the hand touches the object, the seeds are sown of awareness of distance ("at arm's length") and hand-eye co-ordination. The A.T.N.R. fades rapidly and is not usually seen after the age of six to seven months except in infants with neurological lesions.

Figure 7.5   The Asymetrical Tonic Neck Reflex

From K S Holt; Developmental Paediatrics; Perspectives and Practice (1977)

Gesell and Amatruda (1947) explain that the A.T.N.R. channels visual fixation to the extended hand and by gradual stages leads to hand inspection, active approach upon an object and to manipulation of that object. And as Fraiberg (1977) points out, "This early alliance of hand and eye, which is biologically insured to promote the later complex co-ordination of eye and hand, is already lost to the baby who is blind".

As the A.T.N.R. begins to fade, the infant's head begins to "prefer" the midline (supine) position. At this time also the range of the sighted infant's vision widens and he no longer needs to use his arms to support himself in this position because of his greater strength. He is now in a position to fully exploit this new found hand-eye co-ordination to make new discoveries and perform new experiments.

In the supine position, the hands will sometimes come across the child's field of vision for close inspection. As Fraiberg (1977) explains.

Now the hands engage midline in mutual fingering and this 'game' leads the baby rapidly on to new discoveries, i.e. he is led to approach objects 'out there' with his hands. The early attempts are often off target, but chance encounters win rewards.

Bower (1982) claims that when neonates reach for objects, they are successful in around 40% of cases, although a high proportion of the misses are within a hand's breadth. it is also interesting to note that although this early reaching behaviour usually dies out to reappear again at around 4 months of age, Bower (1982) found that infants who were given an object to reach for every day from birth demonstrated no decline in reaching behaviour at all.

Reaching, the Precursor of Crawling

Between four and eight months the sighted baby makes rapid strides in becoming mobile. By 6½ to 7 months he can sit independently and steadily. Placed supine he can roll over onto his stomach. At an earlier age he reached out into the visual world with his eyes and his head followed, moving from side to side or up and down. Now he is able to reach out with his arms. His eyes and hands have been co-ordinated since the age of 4½ months. Placed prone he is able to raise his head on his forearms and look around. In doing this he pivots out of his original position. By 7 months he will move ahead to get an attractive toy held out of his reach. One way or another he will get from where he is to where the toy is. He sees it, he wants to hold it and he moves towards it by crawling, creeping, hitching or rolling. The external stimulus provided by vision creates the incentive for reaching and extension of the trunk which initiates the locomotor sequence. Fraiberg describes the progress of the sighted child in the passage below:

> "... But we may overlook, in observing the sighted child, the contribution of vision to his eager self-confident adventuring. Each change in position from sit to stand, or from stand to sit, each step he takes whether supported or not, produces an endlessly varied and fascinating series of visual spectacles.

Wherever he casts his eyes, the space is furnished with a mixture of shadows and textures and patterns and contrasts and 3-dimensional objects, including the people he knows. One glance brings him the entire scene and informs him about his relationship to each element".

What of the Blind Child?

What then of the blind child? It can be seen from the work of Bower (1982), Fraiberg (1977), Gesell (1947) and many others, that hand-eye co-ordination, maturation and mobility are all, to some extent pre programmed and set to run inextricably locked together. The journey is already mapped and the sequence timed so that each stage locks together with the previous one. This has been so since the dawn of mankind; and the overall co-ordinator is vision. Fraiberg (1977) describes the plight of the blind child in the passage below:

"In all those ways, then, in which the hand unites the infant with a world 'out there', in those ways in which the purposeful reach gives intentionality to action and a sense of voluntariness in the formative period of the ego, the blind child is deprived for much of the first year. In cruellest irony, these hands, quite literally groping in the near void of the blind child's world, derailed in their progress by a deficit in the biological plan, must come to serve the blind child as primary perceptual organs - something not 'intended', either, in human biology".

Why should the blind infant be som much later than the sighted child in acquiring gross motor skills? In the children of all three samples quoted - Norris (1957), Fraiberg (1977) and the Sheffield sample - no neurological or developmental defect had been diagnosed which would suggest that their intelligence might be impaired. During infancy, none of the children suffered from neurological defects which would inhibit their mobility and all their other senses were intact. Why then should it be so difficult for the blind child to achieve his gross motor milestones? To begin to answer this question, we must ask another. What is there 'out there' for a blind infant under 6 months of age? Fraiberg answers thus:

"For a perilously long time in the first year of life, the blind child lives in a near-void compared to the sighted child. When he is in his mother's arms he experiences enclosure and tactile intimacy and her voice. When he is not in tactile contact with his mother we infer from his behaviour that she has evanesced

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from him. There are no contact-seeking behaviours, no gestures
of reach. In this world without pictures, persons and things
manifest themselves in random fashion, emerging from the void as
transient tactile or auditory experiences, returning to the void
as they remove themselves, or as they are removed from the near
space which is his 'space'. Sounds and voices register from 'out
there', but sound is discontinuous, intermittent, and the
behaviour of the blind baby in the first 6 to 9 months tells us
clearly that sound does not yet connote a person or thing 'out
there' ...
      His is, then, a world of evanescent objects, a world of
magic, in which persons and things are subject to a capricious
causality".

For the sighted child, a picture unites all the experiences of sound and
touch long before the age of 4 months. At 3 months, the sighted child
turns to a sound source with the expectation that he will be able to see
what is making the noise. This turning towards a sound source can be
elicited in the neonate (see Bower 1982). It begins as a reflex which is
reinforced through visual experience. The reflex is present in totally
blind babies, but because it is not reinforced it dies out and has often
disappeared completely by the age of 6 months.

The blind infant then, does not locate persons or things by sound, neither
can he attribute substantiality to objects that manifest themselves through
sound. The inexperienced blind infant can have no knowledge of whereabouts
in space the sound making object is. The sound gives no indication of size
or graspability. If he should reach out, the chances of his coming into
contact with the object are very, very slight. When the sighted child
reaches for an object and misses, he can see why this happens and
correction possibilities are open to him. When the blind child is
repeatedly unsuccessful, the motivation for reaching simply dies away.

We can see then, that it is vision which lures the sighted child in his
progress towards co-ordinated reach, and it is vision again which lures him
to become mobile so that he can then explore the world 'out there' beyond
his reach.

Held (1965) established with work on kittens that knowledge of and
perception of the world 'out there' can only be acquired actively.

The kittens in the experiment were connected together by the apparatus shown in Figure 7.6 below.

Figure 7.6 Richard Held's Apparatus (1965)
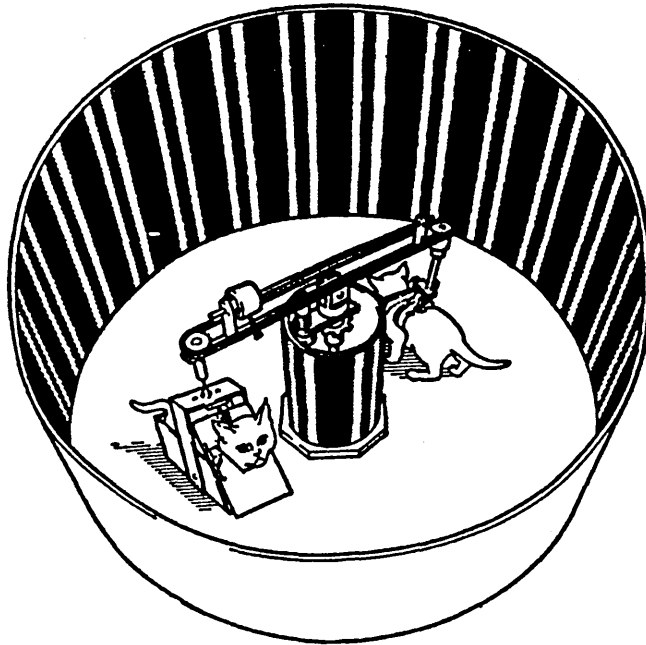
The kitten in the basket can see as much as his companion, but cannot <u>act</u> in a visual context

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One kitten, the active kitten, could move voluntarily anywhere within the limits of the apparatus. If he saw something interesting, he could move towards it. If he saw something unpleasant, he could move away. This kitten could use visual stimulation to control his movements and could use his movements to control the input coming to his eyes. The kitten encased in the basket had no such interactive relationship with his visual world. He could not walk around or even touch the grounds with his paws. The passive kitten saw only what the active kitten allowed him to see. When the kittens were removed from the apparatus and given a series of visual tests, the active kitten was essentially normal. The passive kitten by contrast simply did not react to visual inputs, he remained essentially

blind. Although his visual system was normal, he had lost the capacity to act in a visual context.

Aside from late reaching, there are other factors which influence the achievement of mobility in blind children. It will be remembered that in the supine position the infant is in touch with the floor from head to foot. For the blind infant this is a very secure position and one from which he does not readily move without good reason. When the infant sits unsupported, only half his body (buttocks and legs) rests on the floor. When he finally stands alone without support, he feels the floor only with the bottoms of his very small feet. So we can see that with each postural advance, the infant gives up a major part of his actual physical contact with his real world.

We can see from Figures 7.1 and 7.2, that the blind infant is neurologically ready for progress along the gross motor path at around the same time as the sighted child. However the motivation to explore the world around him is lacking, as this motivation comes almost entirely from visual stimuli. Fraiberg describes the situation thus:

> "In gross motor development lack of vision presents the blind child with a double handicap: he has only one instead of two distance senses and the one he has is the lesser one, at that, since sound does not begin to function as a clue to the presence of an out-of-reach object until late in the first year. Evidently a child who is born totally blind cannot make use of distant sound cues from an invisible object any earlier than a sighted child. He remains in a void until he can seek his own direct contacts with the external surroundings; ironically, until he has an incentive to move into those surroundings he cannot discover their existence. Once 'reach on sound' has been achieved he can soon be lured into motion and can begin to cope with the relatively less difficult problems of balance, speed, and safety.
>   If the blind child is provided with good mothering and the chance to become familiar with many body positions, and if his hands and ears are given months of varied play experience with toys that unite tactile and auditory qualities, he will have found interest and taken pleasure in the space immediately around him. He will then be ready to move forth into a larger space when he becomes aware of the interesting possibilities just beyond his reach".

"If the child is provided with good mothering ...". We have seen that good mothering is absolutely crucial to the development of the blind child. In fact, the mother at this point probably holds the key to the child's whole future. Here in fact nurture must often take over the functions of nature.

At the beginning of her study, Fraiberg (1977) presents two case studies. Toni, who with excellent mothering and the help of Fraiberg's intervention programme, overcomes almost all her difficulties to achieve her milestones virtually within the sighted normal range. Peter, the second study, on the other hand, although again quite normal neurologically, was still immobile at the age of 8½ years. The difference between Toni and Peter lay in their mothering. Although Peter's mother had reared two perfectly normal and well adjusted daughters prior to Peter's birth, according to Fraiberg:

> "The mother became depressed immediately after learning that Peter was blind. She remembered the early years of Peter's life as a kind of bad dream. When her suffering became too great for her she simply withdrew from her blind child. Peter was in the care of servants a good deal of the time; there was a succession of maids, so numerous that their names could hardly be recalled by the mother ...".

Peter also spent many months in foster care in a residential home for blind children with behaviour disorders. The case study of Peter makes compelling, if disturbing reading. There are similarities to 'Dibs', the child studied by Axline (1964). Unfortunately, however, the story of Peter, unlike that of Dibs, does not have a happy ending. In spite of 2½ years of intensive one to one input by Fraiberg herself and one to one psychological help for his mother over the same period of time, and despite considerable improvement in Peter's mobility and other areas of development, Peter finally had to be committed to the full time care of an institution because of his continued severe behaviour disorders.

Fraiberg (1977) also discusses the development of another child "Robbie". On the whole, Robbie's mothering was adequate. However this mother suffered from bouts of depression which she tried to ward off by eating and various other strategies. As long as she was successful, there were no

apparent impediments to Robbie's development. However, Fraiberg describes a 4 month period in Robbie's second year during which the mother's withdrawal and loss of rapport with him showed immediate effects, with a slowing of the rate of development in all areas and particularly apparent in language development. However, with support and guidance, the mother was able to re-establish her relationship with the child and Robbie's language and overall development leaped forward again.

In Conclusion

The findings of Fraiberg (1977), Norris (1957) and Bower (1982) have implications for the ways in which helping professionals deal with handicapped children and their families. It would appear from such work that ability and achievement in handicapped children are linked less with the degree of handicap or disability and more with the attitudes and nurturing abilities of those most closely involved with the children. The mother, it appears, plays the key role but other family members play vital supporting roles.

However, if we consider the 'functions of the family', set out in Chapter 6, and the work of Barnhill and Longo (1978) on the 'transition points' which families need to negotiate, it becomes apparent that the whole family will be in need of support rather than merely the child himself and, to a lesser extent, the mother. It follows therefore, that altering the focus from the usual child-centred type of intervention to a family orientated approach might well reap considerable benefits for all concerned.

CHAPTER 8

ASPECTS OF SOCIALISATION

INTRODUCTION - FIRST STEPS IN THE DANCE OF LIFE

> *Tomorrow shall be my dancing day;*
> > *I would my true love did so chance*
> *To see the legend of my play,*
> > *To call my true love to my dance.*
>
> *Sing O my love, my love, my love*
> > *This have I done for my true love.*
> > > English Traditional Carol

This chapter is concerned with the early socialisation of blind and visually impaired children and with some of the problems encountered by parents in completing their task.

Socialisation is the process by which the child learns to live and interact with other humans in society. The sum total of what makes us human (apart from hereditary factors) is learned from social interaction with other humans. Childhood, or primary socialisation refers to the learning process which takes place in the early years of life - usually the first 10. Adult or secondary socialisation is the learning through social interaction which occurs after childhood. A high proportion of childhood socialisation occurs within the family unit. Certain basic assumptions regarding socialisation are generally agreed. Those concerned with the present study are given below - largely as summarised by John and Elizabeth Newson (1968) at the beginning of their study of 4 year old children.

1. The family is the fundamental social group to which humans give allegiance. Cultures vary as to how far they extend family ties and how rigidly such ties operate, but the family remains the basic unit.

2. Throughout the world it is normal for the process of
    socialisation to be initiated by the parents. It is from their
    behaviour towards him that the child first learns to label his
    actions as 'good' or 'bad'. The network of social relationships
    through which the process continues is gradually extended,
    earlier or later in the child's life according to the structures
    of the individual culture. In our own society, the nuclear
    family excludes outsiders for a relatively long period of time,
    so that for British children, the process of primary
    socialisation tends to be mediated through social interaction of
    a particularly intense and intimate kind, within the family
    often up to the age of 4½ or 5 years.

3. However long the child is restrained from full interaction with
    people outside his own kin, the family itself is always a part
    of some wider community with which it is functionally related.
    This remains true where the family deliberately rejects, or is
    itself rejected by the community and where the relationship is
    therefore one of withdrawal. The family may choose to spurn the
    community, but it cannot choose to deny its existence. This
    like it not involvement means that child rearing does not and
    cannot take place in a social vacuum. Within any society the
    range of available occupations, work roles, income, standards of
    nutrition and housing, educational possibilities and the
    geographical environment all interact to evolve the customs,
    beliefs, attitudes and fashions which make up what has been
    called the 'Web of Culture'. And the individual family's place
    in these systems whether objectively or subjectively assessed,
    can be ignored neither by members of that family nor by anyone
    who tries to understand its internal relationships.

INVITATION TO THE DANCE - THE 'FIRST RELATIONSHIP'

Come, dance, my dear and be my delight!
We two like stars, will spin through the night.
For age may rage, but youth is right.
   So waltz a little way with me.

<div align="right">A P Herbert, 'Bless the Bride' (1947)</div>

Socialisation begins with bonding. In virtually every human culture, 'The First Relationship' is the attachment bond between infant and mother. This relationship has been researched mainly by psychologists although it is of the utmost importance to all who would study the family and society in general.

It is acknowledged that gaze and counter gaze play crucial roles on the formation of the first relationship. Mother and infant 'get to know each other' by gazing, for quite long periods, into each other's eyes.

The adult cultural 'rules' regulating how people may gaze at each other during social interaction, do not apply when we consider how mothers gaze at their infants. An important 'rule' in our culture is that two people do not remain gazing into each other's eyes (mutual gaze) for long periods of time. Mutual gaze in most species, is a potent interpersonal event which greatly increases arousal and evokes strong feelings and potential action of some kind, (the action depending on the interactants and the situation). Mutual gaze rarely lasts for more than a few seconds. In fact, two people do not usually gaze into each other's eyes for more than about ten seconds or so unless they are going to fight or make love, (or are already engaged in one of these pursuits). This is not so with mother and infant. They can remain locked in mutual gaze for 30 seconds or more without any difficulty.

Purely social interaction between mother and infant is sometimes called 'free play'. These episodes are amongst the most crucial experiences in the infant's first phase of learning and participating in human events. In the normal course of events, by the end of the first 6 months of the infant's life, the work of this phase is completed, and as Stern (1977)

states "is considerable". The following quote from Stern (1977) sums up what is accomplished during this phase:

> "The infant has developed schemas of the human face, voice and touch, and within those categories he knows the specific face, voice, touch and movements of his primary care giver – usually his mother. He has acquired schemas of the various changes they undergo to form different human emotional expressions and signals. He has 'got' the temporal patterning of human behaviour and the meaning of different changes and variations in tempo and rhythm. He has learned the social cues and conventions that are mutually effective in initiating, maintaining, terminating and avoiding interactions with his mother. He has learned the different discursive or dialogic modes, such as turn taking. And now he has the foundation of some internal composite picture of his mother so that, a few months after this phase is over, we can speak of his having established object permanence – or an enduring representation of mother that he carries around with him, with or without her presence".

Stern (1977) goes on to discuss how these developmental tasks of this first phase are accomplished, by examining in detail the repertoire of facial, vocal and other behaviours, which the primary care giver provides for the infant as his first experience of human stimuli. He then examines the repertoire of behaviours and perceptual abilities which the infant possesses to enable him to perceive, and to interact with the human world in which he finds himself.

If we examine the above quotation from Stern (1977), it will be obvious that a high proportion of the interaction process is based on vision. In fact, some authorities feel that the bonding process is to a large extent, based on mutual gaze. That mothers of blind babies do experience difficulty with bonding and early relationships with their infants is borne out by some of their comments. Obvious ones can be found in Chapter 6. For example, Case 50, Mrs Porter on page 130, and Case 28 Mrs Carter on page 132, who quite often prop fed her daughter because she disliked picking her up and was unable to hold her close or to cuddle her. Mrs Bates Case 22 on page 132 also experienced a stormy and traumatic early relationship with her child.

Several mothers mentioned an unreal or 'doll like' quality in connection with their children, although they did not give similar reasons for this. Some of their experiences are quoted below:

14. Catherine Vickers. Functionally Blind. Retinopathy of Prematurity

"I don't know whether it was because she was on the Prem Unit so long or what it was, but after we got her home, she didn't seem real somehow. You know, it was more like having one of them sleeping dolls than a baby, she was that quiet. I would feed her and then put her down, and her eyes would close and that would be that till it was feed time again".

42. Louise Brown. Functionally Blind. Retinopathy of Prematurity

"Well at first it was just like having a doll. I suppose part of it was because she was so tiny. Even first size baby clothes were miles too big on her. In fact some of her clothes she was dressed in were doll's clothes. It was difficult because she wasn't a baby you could talk to or play with, if you know what I mean. She didn't cry very much. She just seemed to feed and sleep a lot of the time. And her eyes were closed most of the time even when she was awake.".

22. Samuel Bates. Totally Blind. Congenital Anophthalmos

"I always used to say he looked like a 'trussed up chicken' when he was small. (Mrs Bates' description in fact very aptly describes the posture adopted by many neurologically damaged babies, i.e. prone or semi-prone, with the limbs drawn up close to the abdomen, the back flexed with the spine protruding through the skin). Of course, I didn't allow the others (siblings) near him while he was very small. They've always treated him as something special. Like a fragile china doll. And they've never played rough with him. And they've always tried to shield him from the other (neighbourhood) children".

8. Danielle Ellis. Totally Blind. Bilateral Retinoblastoma

"I suppose I though it would be easier when she got her (artificial) eyes. But it's funny, when she first got them, I didn't like it at all. She didn't seem like my Danielle somehow. She was more ... well doll like somehow. She always reminded me of one of those, ... you know, those lovely antique porcelain dolls. (Danielle and her sister present during the interview, both laugh). To tell you the truth, I used to take them (the eyes) out when we were on our own. Then I felt she really was my baby, but with her eyes closed".

At the time of interview, Danielle was a vivacious 16 year old on the brink of womanhood. She did indeed remind one, rather forcibly, of an antique

doll, with her long dark hair and lashes. The eyes were deep blue and beautifully crafted though slightly too large for their sockets. Later I tried to analyse why it was that Danielle conveyed this impression. In retrospect, two factors seemed to stand out. Firstly, the eyes were very noticeable. As she turned to speak to me, she appeared at first glance to be looking at me, but in actual fact the eyes were focused on nothing. Although her face and voice were animated – sometimes exaggeratedly so, the eyes remained calm and contemplative, staring into space. Secondly (although this did not register during the interview), Danielle probably did not blink very often. (Physiologically this would be unnecessary as the object of blinking is to cleanse and lubricate the cornea). Although I would probably not consciously notice this, it may well have been unknowingly recorded, just as 'messages' flashed on film too briefly to be 'seen' are, (psychologists have found) received and registered by the brain.

It seemed that, in the case of Danielle, the doll like quality was to a large extent related to the artificial eyes. However, this does not explain the phenomenon in any of the other cases quoted. Although Samuel Bates was born without eyes, artificial ones were never fitted as his sockets were rudimentary and could not accommodate eyes without extensive surgery. Catherine Vickers and Louise Brown were both premature babies, and in part the 'sleeping doll' phenomenon could be attributed to their small size and general quietness. In all cases however, the phenomenon would appear to be closely related to the bonding process and the mother/child relationship.

Gaze and counter gaze are obviously not the only factors at play in the first relationship. Mother and infant become acquainted, and later bonded by interacting and playing together. Imitation forms a large part of the infant's repertoire at this (and most other) stages of socialisation. The infant must master basic signals and conventions, so that he can 'perform moves' and run off natural sequences in step with those of his mother. These moves and sequences form the "steps" of what Stern describes as "dances", which we recognise as social interactions. To quote Stern (1977): "This biologically determined choreography will act as a prototype for all his later interpersonal exchanges".

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Stern (1977) goes on to describe these "dance sequences" in some detail.
He also enlarges on "play periods" which are indulged in by mother and
infant purely for pleasure. We humans, in common with many other higher
mammals are extremely playful creatures. Adults as well as children will
play with everything and anything including our own behaviour. We find it
amusing and pleasing to play with our own faces, voices and movements. We
create new variations and elaborations of simple behaviours. Stern (1977)
thinks that song, mime and dance are probably cultural ritualisations of
this play process, (i.e. play with words, movement and time).

Stern (1977) claims that these dyadic play periods, "invariably start with
mother and infant catching each other's eye". He continues:

> "There is a moment of mutual gaze. What immediately follows this
> moment will determine whether or not a period will take off. If
> either mother or baby breaks gaze, for whatever reason, the play
> period is usually aborted, at least for the moment. If they hold
> gaze, then they both must signal to one another their readiness
> to engage in a social interaction".

It is necessary to consider the role of mutual gaze in the emergence of the
'relationship' between infant and mother. Stern (1977) feels that
conceptually, a relationship is "an organisation or integration of past and
present social interactions, but that it is more than just the sum of these
parts". He states that, "One of the central features of the relationship
is an enduring mental image, schema or representation of the other person".

How does a blind infant form this mental schema when he has never
experienced a visual image of his mother? If he is unable to do so, can
he then go on to form a 'relationship' in the true sense of the word?

Study of the older children in the sample group, shows that mothers and
children can and do form apparently satisfactory and 'normal'
relationships. How they achieve this takes us into largely uncharted
territories requiring further research and is beyond the scope of this
study. That it can be achieved, is an excellent example of human
adaptability, bearing in mind just a few of the difficulties which might
be encountered.

For example, it has been shown (see Chapter 6) that many of the mothers were depressed during the period when the relationship is normally being formed. Although the depressed mother is usually able to perform all the practical actions of care giving, her flattened emotional responses mean she will be unable to light up her face, voice and movements to provide a sufficiently intense stimulus to influence the infant's attention. The infant himself will appear to be unresponsive to the mother's efforts, particularly to facial stimulation. Because of her depression, the mother will be unable to respond appropriately to infant behaviours inviting her to play or interact. A vicious circle is set in motion and the stimulus-response schema is thrown completely out of gear. The tenuously formed relationship would appear to be heading irrevocably for the rocks.

However, this does not usually happen. Most mothers, as previously stated, were able to form a normal or near normal relationship with their infants. And they achieved this, in the majority of instances, without professional intervention or help of any kind. In fact, the only 'help' given to those few mothers who approached their doctors, was the prescription of tranquilisers. From the foregoing discussion of Stern's (1977) work, it will be evident that this form of treatment, by dampening further the mother's emotional responses and awareness of infant eliciting behaviours, could hinder rather than help the work of forming a relationship.

It would appear however, that human adaptability somehow enables infant and mother to overcome seemingly insurmountable difficulties. In fact, Stern (1977) sees "miss steps in the dance" and what he terms "messing up", as positive rather than negative influences. By "messing up" Stern means the mother over or underestimating the infant's tolerance boundaries during play and stimulation. When discussing the "Virtues of Messing Up" he says:

> "First of all, only when a boundary is exceeded is the infant forced to execute some coping or adaptive manoeuvre to correct or avoid the situation or signal to the mother to alter the immediate stimulus environment. The infant behaviours, like any others, require constant practice, constant opportunities under slightly different conditions to become fully developed adaptive behaviours. Second, unless the mother frequently risks exceeding a boundary, whether by design or miscalculation, she will be unable to help stretch and expand the infant's growing range of tolerance for stimulation".

(Fortunately) there can be no such person as the ideal caregiver. That is, one who is exquisitely sensitive to all infant behaviours and always responds accordingly. Such a person probably only exists in books on baby care by 'experts in the field', and in popular literature and art. If she were to exist, the ideal carer would no doubt be insufferably boring, not only to her offspring but also to interested professionals.

Mother and infant are constantly adjusting to one another's behaviour. The stimuli that the mother provides for the infant and the infant's level of attention and excitement often fall below an optimal level where interest is lost. They also frequently climb above this optimal level where active aversion or termination are executed. Mother and infant continually adjust their behaviour to bring it within the optimal range.

The process of learning to interact with an infant and getting to know him is fairly similar from one caregiver to the next. However, for each caregiver it is a highly personal and individual experience, seeming to her, exclusive and unshareable. No one has ever written down the 'notes' or the "steps of the dance sequence". No one has ever listed or 'sanctioned' the wide variety of behaviours and stimuli which normal caregivers provide for normal infants, let alone attempted to choreograph a programme for deviant or handicapped interactants. Stern (1977) admits that the difference between "normal messing up" and frankly deviant behaviour is marginal, and that intervention may sometimes do more harm than good. As psychologists including Bowlby (1965) have found, it is better to respond badly than not to respond at all.

Fortunately babies (including those with severe visual impairment) are virtuoso performers, and are able to elicit at least adequate (and often virtuoso) responses from their caregivers. Fortunately also, nature has been perfecting the system of interaction over several million years. And, as Stern (1977) points out, "The (interaction) system is designed to develop individuals, not mistakes".

Augustus was a chubby lad;

Fat ruddy cheeks Augustus had;

And everybody saw with joy

The plump and hearty, healthy boy.

He ate and drank as he was told,

And never let his soup get cold.

But one day, one cold winter's day,

He screamed out, 'Take the soup away!

Oh take the nasty soup away!

I won't have any soup today.

<div align="right">

Heinrich Hoffmann (1809–1894)

The Story of Augustus who would not have any Soup

</div>

As the Newsons (1968) have written, apart from the actual bearing and suckling of children, there is probably no act which better epitomises motherhood than the preparation and serving of food. The offering of food to the family symbolises the nurturing function of the mother across all cultures and in every part of the world. For most women, the preparing and serving of acceptable meals for husband and children is an essential part of being a 'good' wife and mother. As it is intolerable to accept that one is a 'bad' mother, and failing in what is recognised as a primary role, the child who persistently rejects the food his mother offers, stirs it into a mud coloured sludge, or throws it on the floor, will be a potent threat to her self esteem.

Few of the blind sample mothers reported major problems with either breast or bottle feeding during the early weeks of the infant's life. Four mothers encountered what could be termed 'mechanical difficulties'. Two of these children suffered from cleft palate, a third had a tracheostomy and the fourth was a premature baby needing to be tube fed in the early weeks of life. It is interesting to note that in all these cases, skilled help was routinely mobilised as soon as the infant was discharged from hospital, this help being available on a 24 hour basis. The mothers found this service very helpful and within a short time had learned to cope by themselves using the service merely as an emergency back up.

Feeding began to be problematical for a few mothers as they began to wean the infant from breast or bottle onto solid foods. Even at this stage however, the problems experienced were little different from those of mothers rearing 'normal' children. It should be pointed out however that the mothers in the blind sample did not wean 'according to the book', policy at the time the interviews took place being to delay weaning until the age of four months. The majority of visually impaired infants were weaned between the ages of five and twelve weeks, at which time the child can still be regarded as a 'passive receptacle' as far as food is concerned.

The Influence of the Maternal Grandmother

Sheffield has often been described as the "biggest village in England", not least because of its extended kinship networks. The majority of the sample mothers lived close to their own families of origin and therefore received help and guidance from their mothers and older sisters.

In many of the older parts of Sheffield, the kinship systems of today are not radically different from those of Nottingham in the 1960s (Newson J and E, 1963 and 1968) or Bethnal Green in the 1950s (Young and Willmott, 1957). The extended family network is still a highly functional system and the maternal grandmother, particularly in working class families, often has more influence in child rearing than doctor, midwife and health visitor combined.

As civilisation advances, medicine is increasingly taking over large areas of birth and child care which previously were the province of the extended family (mainly grandmother). Not unexpectedly, many grandmothers are reluctant to give up their role of mentor and adviser. They therefore maintain a relationship of thinly veiled hostility towards the midwife and more particularly the health visitor. This hostility towards 'authority' in the guise of the health visitor is quite common in working class areas. In matters pertaining to early weaning and breast feeding, middle class mothers tend to follow their consciences and the baby books. As the Newsons (1963) point out however, "The books themselves simply reflect the established middle class attitudes of their middle class authors".

With regard to infant feeding practices the Newsons (1963) state:

> "Thus working class mothers feel free to suit themselves in the matter of infant feeding; and often, as a result, they are completely out of sympathy with the advice pressed upon them by middle class nurses and doctors who in general try to encourage breast feeding where it is at all possible. In consequence, for many of them, pretending that one intends to breast feed is just part of the ritual involved in having to have babies under predominantly middle-class supervision. That they meekly appear to comply only so long as they are under medical supervision is in line with a traditional working class attitude when faced with middle class authority: direct opposition nearly always involves endless trouble, verbal acquiescence costs nothing and generally gets one out of the situation more quickly".

It would appear that a very similar process operates when the infant is weaned onto solid food. Mothers seldom directly challenge the medical dogma doled out by the health visitor, but then the health visitor is not around all the time. And, as will be seen elsewhere, health visitors tend to visit families with handicapped children less frequently than normal families. Therefore, where the extended family is still a viable system, (which was the case in the majority of the sample families) the maternal grandmother tends to move back into the place of authority and weaning progresses, little altered down the generations.

The process of weaning however does not always run smoothly where the maternal grandmother is not available, and it seems that the paternal grandmother does not readily fill her place. The following discussion on weaning took place between myself and the young mother of a very premature baby whose family of origin lived outside the city. It illustrates the point under discussion.

43. Rachel Cotton. Retinopathy of Prematurity. 26 Weeks Gestation

Researcher: Do you have any difficulty getting her to take solids at all?

Mother: Oh no, she really likes her food. It's knowing what to give her that's the trouble. I've given her all the stuff in the "Bounty Pack", (Bounty Packs are boxes of samples and literature given to new mothers on discharge from hospital. They were not intended to be used as weaning kits, although their use for this purpose is not uncommon) and now I'm a bit stuck really. She likes Instant Whip and chocolate puddings, but I don't know if she ought to be having other things

really. I've asked Dave's mother (paternal grandmother) but she wasn't much help really.

Researcher: Why don't you ask your health visitor about it?

Mother: Well I can't really, you know, 'cos she thinks she's still on just milk. She said I couldn't start giving her rusks and that for at least another 2 months, with her being so premature.

'All the World's a Stage' - Impression Management and the Theoretical Framework of Erving Goffman

The perpetual discrepancy between what 'authority figures' are allowed to see and know and what actually happens in real life can be explained by the use of Erving Goffman's theoretical framework.

Goffman (1959) analyses the structures of social encounters from the perspective of the dramatic performance. He describes how people use "fixed props" such as houses and places of work as a stage. He also shows how people use clothes, combine in teams and adopt discrepant roles to communicate out of character in the many different roles they play in everyday life. We are also taken "backstage" into kitchens, bedrooms, servants' quarters and the regions where "actors" both prepare their images and relax from them.

Using the Goffmanian framework it is possible to gain insight into what is actually happening in case-worker/client relationships. Although some health visitors may be inexperienced or naive enough to believe that Mrs Rachel Cotton above is acting on the advice given, many, perhaps the majority are not. According to Goffman (1959) they (the health visitors) are indulging in what he describes as "protective practices". These protective practices are described in Chapter 6 (The Arts of Impression Management) of Goffman's 1959 essay, a little of which is quoted below.

> ""... access to the back and front regions of a performance is controlled not only by the performers but by others. Individuals voluntarily stay away from regions into which they have not been invited. ... And when outsiders find they are about to enter such a (backstage) region, they often give those already present some warning, in the form of a message, or a knock, or a cough, so that the intrusion can be put off if necessary or the setting

hurriedly put in order and proper expressions fixed on the faces of those present ...

... We often find that when interaction must proceed in the presence of outsiders, outsiders tactfully act in an uninterested, uninvolved fashion, so that if physical isolation is not obtained by walls or distance, effective isolation can at least be obtained by convention".

Thus when the health visitor making an unannounced call is invited into the kitchen, (which in terrace houses often serves as both back and front stage) she may well choose to save the act of her client by turning a blind eye to the evidence of the dish and spoon and the remains of the infant's unfinished pudding, or the stains of beef and tomato dinner on the hastily removed bib. She will choose instead to discuss the problems of breast feeding or the inclement weather. As Goffman explains:

"Audiences are motivated to act tactfully because of an immediate identification with the performers, or because of a desire to avoid a scene, or to ingratiate themselves with the performers for purposes of exploitation".

As can be seen from the quote from the interview with Mrs Cotton on page 171, these protective practices do not, in the long term, help either the case-worker or the client, and we can see that case worker/client relationships are often based, not on mutual trust, but on a stereotypical performance by the client, drawing an expected response from the audience.

The client's dilemma is that if she is to maintain her projected image, she will be unable to ask for help. The health visitor's dilemma is that if she attempts to break down the client's facade, her relationship may cease to be viable. Either way the situation will become stressful for both case-worker and client.

Unfortunately help was not forthcoming for the parents in the sample group. Virtually all the mothers of the functionally or totally blind children (who had reached an appropriate age) had encountered problems with regard to teaching the child to feed himself, use of the correct implements and to have acceptable table manners in the company of strangers. Only one mother had been offered any help specifically related to visual handicap, (as opposed to five offered help for other handicaps). It may well be

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however that the mothers did not receive help simply because they did not ask for it. As with Voysey's (1975) sample of handicapped children, many of the blind sample mothers appeared to the professionals to be "coping splendidly". However as Goffman's (1959) work shows this is often a facade. Goffman also demonstrates that the whole dramaturgical structure is often perilously close to collapse with the "actors" enduring high levels of stress merely to sustain their performance.

Manners Maketh Man

The majority of the mothers in the Newson's (1968) study, particularly the middle class mothers, felt that by the age of 4 years the child should have acquired acceptable eating habits, so that he could be "taken out" without fear of the mother being "shown up" in social situations. 'Acceptable table manners' include: use of the correct implements without reverting to "baby habits", i.e. the use of a spoon or (worse) fingers instead of a knife and fork, and the eating of food in a manner which does not cause offence or embarrassment to others.

For the blind child, learning to feed himself and the acquisition of acceptable table manners are much more difficult than for a sighted child. The blind child learns these skills later than the average sighted child and frequently resorts to baby habits and finger feeding. In the Newson's (1968) study, finger feeding was more strongly discouraged than any other baby habit:

> "... the use of fingers was strongly discouraged, even though the question referred specifically to relatively dry morsels of food. Again, the feeling was that this would definitely be considered a regression, and obviously there are much more practical reasons for being more intolerant of fingers than of spoons. For most of the more tolerant, 'chips, chops and chicken-bones only' was the rule, though peas were sometimes admitted because of their elusiveness to the unskilled fork. The child's persisting impulse to abandon his implements and use an older method was recognised by most parents, but by this time they felt they were beginning to master it and that laxity at this stage would be a mistake".

By contrast with the Newsons' (1968) four year olds, all the young totally or functionally blind children were regarded by their mothers as being

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"very messy feeders". All still needed considerable help with feeding and 3 children over the age of 4 years were still being fed by the mother.

Stigma and 'Passing' or Blind Man's 'Bluff'

When he is eating it is obvious to everyone present that the blind child is abnormal. Blindness is a stigmatizing condition and according to Goffman (1963) a very visible one. Only rarely can a blind person "pass" as normal and virtually never when he is eating in the company of strangers. By "passing" Goffman (1963) means, "The concealment of creditable facts from the audience in order to pass as a normal person". So the visually handicapped child is stigmatized not only for his messy feeding and unacceptable table manners but because of his blindness as well.

Goffman (1963) suggests that those related to a stigmatized person through the social structure, are to some extent stigmatized themselves. So the family of the visually handicapped child begins to build up a protective wall, not only around the child, but enclosing themselves also. If they are unable to pass as normal, they can at least appear to be "coping splendidly" with the situation. This means they will be unlikely to admit that they need help with the basic practicalities of daily living such as feeding, dressing and toilet training and in any case, even if they were to ask, relatively few professionals would be able to give the required help.

Who fed me from her gentle breast,

And hushed me in her arms to rest,

And on my cheek sweet kisses prest?

     My Mother.

When pain and sickness made me cry,

Who gazed upon my heavy eye,

And wept, for fear that I should die?

     My Mother.

Who dressed my doll in clothes so gay,

And fondly taught me how to play,

And minded all I had to say?

     My Mother.

Who ran to help me when I fell,

And would some pretty story tell,

Or kiss the place to make it well?

     My Mother

     Ann Taylor (1782-1866) 'My Mother'

All children are, in varying degrees dependent on adults for their care. The development of 'normal' children is however consistent with accelerating independence. The gradual unfolding of skills and abilities changes the child from someone who cannot do things into a person who increasingly can. Blindness, like many other forms of disability, can imply unchanging dependence upon adults in many areas of personal life.

In discussing the functional independence of four-year-olds, the Newsons (1968) found that children of this age are not usually called upon to do as much as they are capable of, and that often they would be reasonably willing to do more for themselves than is in fact asked of them. It seemed that this was also true of the visually handicapped children, and for many

of the same reasons as will be seen from the paragraph below quoted from the Newsons' (1968) study:

> "Simple habit is one factor which must operate to a greater or lesser extent in a majority of cases. For every child, there has been a time when it was *necessary* to do everything for him. This period lasts for at least a year, but usually a good deal longer; and during this time the mother works herself into a routine of caring for the child. In the normal way, the child gradually takes over for himself the easier jobs, such as undressing, while still continuing to receive help with tasks in which he is as yet incapable or inefficient. In most children's progress towards independence, their mothers will also have the added motivation of having their hands full, literally, as younger siblings arrive, truly helpless in their turn. But if the four-year old is the youngest or only child, then the habit of doing things for him may well die hard, even against the mother's better judgement".

An attempt was made to compare the skills of normal four-year-olds with those of the visually handicapped children using tables from the Newsons' (1968) study. However, because of the wide age range of the blind sample, the differences in the degree of handicap and the difficulties of parents in trying to recall information about the older children, the attempt had to be abandoned.

Dependence and Disability

Information was however collected on the self help skills and degree of independence acquired by the children at the time of the interview.

Common sense would seem to dictate that the most severely disabled children would be the least independent. Surprisingly however, this proved not to be the case and some of the totally blind children with other disabilities were in fact more independent than many of those with useful vision (the partially sighted).

The data collected, suggest a correlation between the amount of emotional disturbance in the mother and the failure of the child to achieve his full potential with regard to independence. Most of the mothers who had suffered from severe forms of emotional disturbance or disordered mourning, i.e. had attempted or considered suicide or infanticide, suffered a

'nervous breakdown', or reported many symptoms of mental ill-health — had children who remained highly dependent regardless of age or degree of disability.

The Overriding of Adverse Influences

> *I never did, I never **did** like "Now take care dear!"*
> *I never did, I never **did** want "Hold my hand";*
> *I never did, I never **did** think much of "Not up there dear!"*
> *It's no good saying it.   They don't understand.*
>   A A Milne, 'Independence' (1924)
>   From 'When We Were Very Young'

There were a few notable exceptions to the above correlation, and it would appear that in certain circumstances the children themselves can override even the most adverse influences.   Children who have already acquired independence skills before losing their sight appear in many instances to be able to retain them under even the most adverse conditions.   For example, despite extremely high levels of anguish in their mothers, both Charlotte Winter, who had both eyes removed for a malignant tumour and Peter Davidson who became blind as the result of a blockage to his shunt fitted for hydrocephalus, were highly intelligent active children, Charlotte retaining her independence until a few days before she died.

It would of course be unwise to attach too much significance to the above findings in view of the small numbers involved.   However, it does appear that the amount of independence achieved by the child in self help skills, depends not so much on the degree of disability as on the parents' (particularly the mother's) emotional well being and attitude when helping him to learn these skills.   The mother who feels guilty and anxious will find it very difficult to allow her child to become independent.

The above findings are in fact somewhat similar to those of Neuhaus (1969) who examined the social and emotional adjustment of 84 deaf children.   The children in the Neuhaus sample were all of average or near-average intelligence, were without secondary handicaps and came from intact families — very similar in fact to the visually handicapped sample.

Attitudes of both mothers and fathers were assessed separately, and the children's adjustment was measured on scales completed by their teachers. Grouping the children into three age bands (3-7, 8-12 and 13+) Neuhaus compared adjustment levels with parental attitudes. The mothers' expressed attitudes appeared to be related to adjustment level in all three age bands in the expected direction, i.e. positive attitudes coincided with emotional and social stability in the children. The fathers' expressed attitudes did not correlate with the adjustment of the younger children, but did influence the older age groups. In some cases as with the visually handicapped sample, it was found that both parents had the same positive or negative attitudes, whilst in others each parent held directly opposing attitudes. Positive attitudes in both parents were associated with superior adjustment in the children, and positive maternal and negative paternal attitudes were associated with better adjustment than negative maternal and positive paternal one. So, with this sample and for this disability, maternal attitudes appeared to be the more crucial ones for the emotional well-being of the children.

As with Neuhaus's sample, the blind children's mothers' attitude and anxiety level appeared to have a greater influence over the child's progress than the fathers' and this also seemed to hold true across the complete age range.

Conclusion

It would appear that there have been few attempts to study this relationship between parental attitudes and achievement in handicapped children. There are, as Thomas (1978) points out, serious problems with regard to method which may explain the reluctance to explore this area. However it seems likely that if parental anxiety can be defused or prevented from building up to dangerous levels, the children might achieve independence at an earlier age.

If we return to the model of Family Transition Stages by Barnhill and Longo (1978) it will be appreciated that many of the families are failing to negotiate the early stages, probably becoming "fixated" between steps 2 and 4.

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The Newsons (1968) found that as the child approached school age, even the parents (of normal children) who had treated their children's lack of independence lightly began to worry that they had left it too late, and that the child would not have acquired independence skills in time for starting school.

Starting school, of course, is not only a life transition point, but requires rite of passage. With families already in crisis, unless the situation is defused, parents may enter a vicious circle of stress and anxiety as the stress of the child's failure to gain independence is added to the stress of failing to negotiate the life transition stage.

PERSPECTIVES ON POTTY TRAINING

> "According to many writers, particularly those of a psycho-analytic persuasion, toilet training is one of the most important and fundamental experiences for the child and one which can have far-reaching repercussions upon his whole personality and future character development".

So say the Newsons in their 1963 study. Potty training, it seems arouses intense anxiety and tension in both mother and child. Often the mother's own deep seated feelings and inhibitions are brought to the surface during the process, particularly those of shame with regard to the naked body and disgust towards its excrements.

Many children also learn, quite early, that performance or non performance on the potty is a potent weapon which can be utilised to manipulate the mother, or at the very least, to gain her undivided attention.

Mothers in western culture still place considerable emphasis on the early completion of toilet training, although the Baby Books (and medical opinion) are in some disagreement as to whether this is either desirable or possible. In general, as the Newsons (1963) found: "... advice seems to vary according to the date of the book, the trend in time being (in the books) towards late introduction of the pot". The books however appear to have made little impression on what happens in practice.

The Newsons (1963) felt that although, in general, the mothers were aware that it was pointless to hope for too much too soon:

> "... they were nonetheless influenced by the subtle prestige attached to early and successful toilet training. This led to a curious process of double-think whereby a great many mothers, while paying lip-service to the official attitude that, for most babies, twelve months was too young to expect control, themselves gambled fairly heavily in time and patience on the chance that their own babies were different. From one point of view, they had little to lose by starting training early: if they were in fact quickly successful, they would be able to claim credit both for having a precocious child and for being patently efficient in this difficult sphere of child management; if they failed, they could fall back on the professionally authorized belief that 'all children are different', and that early success with any particular child is largely a matter of luck".

The conflict between the mothers' actual hopeful behaviour and their less optimistic expectations, was shown in the figures obtained by the Newsons in their 1963 study. Less than 20% of the mothers in their sample were expecting their children to be dry during the day before 18 months of age, and a similar time for becoming clean. Despite, this 83% of the mothers had started toilet training before the child's first birthday and that figure includes 63% who had started before 8 months. Over 20% of the Newsons' mothers had been holding the child on the potty since before he was 2 months old. So, only 17% of the Newsons' (1963) sample had not yet started potty training at the time of their interview.

In the blind sample (and it must be remembered that these interviews took place more than 20 years after the Newsons') 59% had started potty training before the child's first birthday, and this included 22% starting before 6 months. A further 21% started between 1 year and 18 months. One mother could not remember the age she started. Eight percent started between 18 months and 2 years. Twelve percent had not yet started training, but all these children were under 18 months of age. All the mothers in the blind sample had begun training by the age of 2 years and 22% of the blind children were said to be reliably clean and dry during the day by the age of 18 months.

It appears that the pressures to achieve an early end to toilet training, although different to those of the early 1960s were, nonetheless, still present in the late 1980s. Although disposable nappies are now the norm, and terry nappies seldom seen, disposables are bulky, difficult to transport and dispose of and expensive. Skin cleansers and creams for napkin rash are also expensive and mothers and other relatives are probably less rather than more tolerant of mess and smells. Wall to wall carpets and expensively upholstered furniture are now also the norm, these are highly stainable and likely to remain damp and smelly for long periods. The importance of these factors to many of the mothers is shown in the quotes below.

3. Eleanor Havard. Functionally Blind. Started 6 months, not trained yet

"Oh yes, I've got her a little potty and I sit her on it after meals. Sometimes she does a poo in it. It saves an awful lot of washing".

22. Samuel Bates. Totally Blind. Started 9 months, trained 2 years

"People told me I wouldn't be able to train him, but I knew I would. Mind you, he was a bit later than the others (2 years) because I started later. I used to spoil him and I didn't start him till he was about 9 months. I stuck the others on from being a few weeks old. I can't stand dirty nappies".

43. Rachel Cotton. Functionally Blind. Not started training yet

"I've not started yet. (4 months) I can't find a potty small enough. Her bum just slips right into it. As soon as she grows a bit I'll start (very low birth weight infant [850g at birth])".

Another factor which should not be overlooked is the influence of relatives, in particular the grandmothers. And here it seemed the influence of the paternal grandmother was equal to or exceeded that of the maternal grandmother. The influence of the grandmother is illustrated in the quote below.

2. Matthew Tomlinson. Totally Blind. Started 3-4 days. Trained 18 months

"No he was never any trouble at all. In fact he was clean and dry much earlier than Michelle (female sibling). I held him out on the potty as soon as I came out of the hospital. He just transferred to sitting on it himself without any trouble. I always used to leave it under the table and he used to go and sit on it whenever he wanted. (Who advised you to hold him out?) Oh, my mum. She said that was what she did and never had a dirty nappy. And it worked really well with Matthew".

All modern baby books warn of the dangers attached to early potty training, and the bringing of pressure to bear on the infant by making him sit on the potty for long periods against his will. Some psychological studies have shown that training is a waste of time anyway. McGraw (1940) showed that trained and untrained twins achieved reliability at the same age. (It should be noted however, that most of this work has been carried out by male psychologists who have never coped with the mess). In spite of these warnings the majority of mothers in the blind sample started training early

and appear to have 'got away with it'. Few of the blind children presented with potty training problems, even during the transition phase between reflex action and gaining voluntary control. The quotes below are typical.

8. Danielle Ellis. Totally Blind. Started 9 months. Trained 15 months

"They were both quite reliable in the day by 15 months. I got her this special potty chair with arms and a tray on for toys. She would sit there for hours, she really liked it. She used to ask for it as soon as she could talk".

11. Jennifer Roberts. Functionally Blind. Started 3-4 weeks. Trained 2 years

"She was no trouble with that. I used to hold her on the potty from being about 3 or 4 weeks old every hour or two. (Did anybody give any advice on potty training?) Oh no. Well you see I've always looked after children so I knew what to do".

18. Marie Masters. Functionally Blind. Started 10 months. Trained 1 year

"Actually she was easier to train than Cathy (sighted sister). She didn't get off and run around like Cathy. She used to sit on the potty for ages quite content".

These results are in fact not so surprising when we consider the lack of motive for the blind child to get off the potty to do more interesting things. He cannot see anything around him which is more interesting, therefore the potty is as good a place as any to spend his time especially if it is particularly comfortable like Danielle's with a tray of interesting toys.

Whilst the baby books and psychologists all seem to dwell on the fact that the child will be negatively inclined towards potty training, this is by no means always the case. It appears that a few of the blind children were actually ahead of their mothers in their wish to become clean and dry as the quotes below show.

39. Winston Whitehead. Functionally Blind. Started 10 months. Trained 1 year

"I don't know (how he got trained) he did it himself. From being one, he took his nappies off, he couldn't stand them on him. I had lots of potties one in each room, he used to go around

finding them and sitting on them. (Child mobile from age 10 months, comes from a large Afro-Caribbean family)".

45. Sean Patterson. Functionally Blind. Started 11 months. Trained 13 months

"He just trained himself really. He was dry at night before 2. He just threw his nappy off himself - said it smelt. We've never had a wet bed with him since".

46. Nina McDonald. Functionally Blind. Started 2 years. Trained in 2 weeks

"I just put her in panties and said she couldn't have them if she wee'd them. She was dry 2 weeks after starting, it's never been a problem".

12. Christopher Peters. Functionally Blind. Started 9 months. Now age 15 months

"Well I try to catch him when I think he wants to go, but he just gets off and laughs. I think I left it a bit late starting really 'cos he's no idea what his potty's for".

17. Paul Russell. Functionally Blind. Started 16 months. Trained 3 years

"I think really I left it too late starting. I took notice of the books and didn't start till about 16 months. I didn't make the same mistake with Michelle, (younger sister) I started at a few months with her and she was quite reliable by 18 months".

1. Robin Gill. Functionally Blind. Started 15 months. Trained 4½ years

"Oh that! (Potty training). Oh God, he was over 4 when the penny finally dropped. I tried everything. I used to take him with me to the toilet and say 'listen to the water trickling', but no. I tried potties and little toilet seats - everything. He'd sit there for ages and then as soon as he got up he'd do a piddle. He'd say 'Mummy the carpet's all wet again down here'.
    I took him to the doctor's but he just said 'Oh boys are always late, don't worry".

It would appear then, that blind children can be reliably clean and dry at around the same age as sighted children, although possibly not by following the advice of the baby books or current psychological thinking. It may be that blind children (like other handicapped children) feel secure in the ritual of regular potting and actually benefit from this. It is also possible that blind children suffer less psychological stress than sighted

children during training. They perhaps never experience their bowel motion as being "part of themselves", and in any case cannot see this part of themselves being flushed down the toilet. They therefore probably do not suffer the same fears as sighted children that they might be swallowed up and flushed away with their motion, should they happen to fall in.

Robin Gill (Case 1 above) shows that where the connection between the wet carpet or the puddle on the floor and the voiding of urine is absent, potty training is likely to be problematical. Early training in blind children can, it seems, increase the chances of the connection being made at the appropriate time.

We must also take into account that, not only is the visual connection between wet floor and voiding missing, but also that imitation usually plays a large part in training. The blind child is unable to imitate because he cannot see. Although Robin's mother took him with her to the toilet and asked him to listen to the tinkle, he had no way of knowing what his mother was doing to make the sound because he had never experienced it for himself. It is easy to see therefore in retrospect how his training went wrong.

The deaf children in Gregory's (1976) sample were also it seems, relatively easy to train. Gregory does not discuss the subject in detail but merely states that there was no difference in time between the deaf children and normal children. No particular problems were reported to her with regard to the subject. However, Nolan and Tucker (1981) in their book written for parents of deaf children, felt that toilet training was one of the most serious problems parents had to face. Nolan and Tucker however do not recommend an early start which appears to work with blind children:

> "As far as toilet training is concerned, it would seem to us, after speaking to many parents, that one of the most important reasons for difficulty is starting to train too soon. Many mothers have described starting early with the first child, and encountering problems that were difficult to overcome. With their second child they were able more accurately to gauge the child's developmental readiness, and so had a much easier time".

Nolan and Tucker recommend starting at around the age of 20 months, but by this time 36% of the blind children were said to be reliably clean and dry.

As in the Newsons' later (1968) work, there is often a "Coda to Toilet Training", in that, children considered 'reliable' at an early age may relapse or have 'accidents' at a later stage. This often happens when the child begins to establish his independence and goes out to play in the street or at a friend's house and does not make it back to the toilet in time.

Whilst it is easy for the blind child to manage independently in a familiar toilet, it is much more difficult in a strange place, particularly where he cannot ask for help. His dressing and independence skills are still somewhat limited and he may have to wait for someone to escort him home.

Many children, particularly those integrated into normal schools, have difficulties going to the toilet during school time as the following quote shows:

41.　Darren Morton.　Functionally Blind (Normal School).　Started 6 months.　Trained 2½ years

"I just put him in trainer pants and he did it himself. He was no trouble when he was small, but now, he doesn't like going at school. He'll do anything rather than go to the school toilets. Sometimes he comes home nearly crippled".

The final quote is from a mother who after reading the literature, made a deliberate decision to go against the advice. And, according to her, the method worked well.

51.　Lucy Baldwin.　Started 18 months.　Trained in 29 hours

"Well, I read in this RNIB book that they could be 5 or 6 before they were dry and clean. And I thought 'not my child'. So I started that same day (aged 18 months) and I wouldn't let her out of the toilet till she had wee'd and done a poo. She held on to it for ages, but she was fully trained in 29 hours. (29 hours?)! Yes 29 hours, and I've got proof 'cos the Health visitor came and asked what I was doing, so I told her. Anyway it worked, she was even dry at night afterwards as well".

Mrs Baldwin's method in the quote above is in fact not dissimilar from the method described by Azarin and Fox in a book called 'Toilet Training in a Day'. The book is now out of print but was published by Macmillan. Before using this method, the mother first needs to be sure that the child is ready to be trained. She then sets aside a day or two when she can be absolutely free to give her full attention to the training. A model of a doll that wets is a useful aid. The method involves sitting the child on the potty at regular intervals - every 15 minutes at first and for quite long periods in the early stages (around 10 minutes), the child being rewarded each time s/he performs on the potty. The mother also needs to check that the child remains dry between sessions on the potty.

Thus we have seen, there are many methods of toilet training and as the Newsons (1968) point out:

> "... it must be stated that each and every one of the methods quoted (in the 1968 survey) has been known to work with individual children, in the sense that the child became dry shortly after the method was adopted; and this includes smacking and threatening. On the other hand it is easy to find numbers of mothers who have used any of these tactics to no avail".

Later in the same chapter they state: "In achieving success in toilet training, it may be more important that the mother have a relaxed attitude than that she should start at any particular age."

Possibly one reason for the marked lack of problems experienced by the mothers of blind children is that they are so inundated and concerned with more pressing and severe problems, that potty training must indeed seem almost relaxing.

"WHO TOLD THEE THAT THOU WAST NAKED"?

CONSIDERATIONS OF BODY IMAGE, GENDER AND SEXUALITY

This section considers how the blind child acquires a 'picture' or 'image' of his own body and those of other humans, and, closely allied, the acquisition of knowledge regarding gender. Knowledge about sex and reproduction will also be considered although these topics will also be discussed elsewhere together with play and role learning.

The Building of a Body Image

How then does the blind child acquire a 'picture' of his own body, and, more difficult still, the bodies of his parents, siblings and other humans?

The concept of body image is closely bound up with the concepts of self and not self, object permanence and animate versus inanimate. In order to acquire these concepts, as has been shown in a previous section, the child needs to be mobile and 'in touch' with the world about him.

Assuming that the child is mobile and has achieved a knowledge of object permanence, how does he actually build up a picture of what he actually 'looks' like? The terminology used when describing body image is itself purely visual, (image, picture, looks like, sees himself, etc..). In fact, it is difficult to comprehend the concept in terms other than visual. The blind child has, somehow, to use his remaining intact senses to build up an image which the sighted child takes in, 'in the twinkling of an eye'. Which of his senses then are useful to him in this task?

Hearing

Hearing can tell the child when another person is approaching and with increasing experience, whether the person is known to him or not. To some extent he may be able to distinguish what the person is wearing from sounds made by clothing. As he becomes more experienced, he will be able to judge whether the person is male or female. Increasing experience will also

teach him to be able to work out how far away the person is and whether he is approaching or receding.

Once speech has been acquired, hearing will be even more useful. By listening to the other person talking and by asking questions himself he can gain a positive identification of the person, what he is doing and why he is doing it.

Hearing however cannot tell him what the person **looks** like. Neither can hearing give many clues as to what his own body **looks** like.

Smell

It is possible that blind children rely on the olfactory sense rather more than sighted people suppose. Cultivating this sense can be useful if the child is helped to use it from an early age. Many animals, for example dogs, foxes and, to a lesser extent, cats are far less handicapped by blindness than are people. This is because smell is the predominant sense in these animals, whereas in man it is vision. It must however be taken into account that in these animals the sense is far more highly developed than it can ever be in man.

It is possible that the young infant uses the sense of smell to a somewhat greater extent than the older child or adult. If this is so, the infant might well 'recognise' his mother by her smell and (if breast fed) the smell of food, in the early weeks. In the sighted infant, vision will soon take over as a much more useful tool of recognition. In the blind child however, whether used consciously or unconsciously, smell could well retain a role in the recognition of mother and significant other people.

As with hearing however, smell gives no clues as to his own body image.

Taste

Taste itself is probably not used at all in the recognition of other people, that is, unless we include mother's milk in the breast fed infant. Can taste then give the blind infant any clues about his own body image?

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The answer may well be in the affirmative. Because of the flexibility of the young infant's body, many parts of it can be taken to the mouth. These include; hands, feet, fingers and toes. Hand regard has been observed to occur even in totally blind infants (Fraiberg 1975). From this position the hands will probably find their way into the infant's mouth. Feet too can be taken to the mouth and also handled and played with. However, when the infant explores these parts of his body and experiences the different sensations received through his mouth, he is actually using the sense of touch, rather than that of taste. The mouth and tongue contain more tactile nerve endings than almost any other part of the body. Long after the sighted child has ceased to take objects to his mouth, the blind child continues to put everything into the mouth to explore and examine it.

Taste then, is quite useful to the blind infant in identifying objects and also parts of his own body. It will also help him to some extent to distinguish between self and not self. Taste however is of little use to him when trying to identify others, (with the exception described above of the breast fed infant).

Touch

Taste and touch are to some extent bound up together when the infant explores objects with his mouth. Touch is the blind infant's primary sense for exploration of the world around him and the identification of the people and objects within that world. Mobility is the key to the door of this world. Once he is mobile, the blind child is 'in touch' with the world around him and its occupants. Touch informs him about size, shape, hardness, softness, state, (liquid or solid), temperature and when combined with smell and taste, whether the object is edible. To a lesser extent, touch can give information about space and the distance between objects. However, it cannot (nothing can) give information as to light or dark, colour, or distant objects, eg.. the moon. Touch can give only a distorted picture of very large objects such as houses.

Touch then is the only sense which can give the blind child information regarding his own body and those of other people. Unfortunately for this intrepid blind explorer however, although he has no way of knowing in

advance, many parts of his world, particularly the bodies of other people (and even parts of his own) bear the warning "DO NOT TOUCH".

Touch and Taboo

Many games played in the nursery entailing touch and movement together with singing or poetry are useful to the blind infant in helping him to identify parts of his body and build up a rudimentary body image. They also help him to distinguish between self and not self and to establish concepts such as up and down, inside and outside and so on. Games such as 'This Little Piggy', 'Round and Round the Garden' and 'Insey Winsey Spider' come to mind in this respect. However, none of these games deal with parts of the body to which taboos are attached, for example, the sex organs, breasts, anus and buttocks.

How then is the blind child to learn about sex and gender, where babies come from and what is recognised as socially acceptable and unacceptable in his particular family and culture?

From early infancy, exploring his own body (let alone anyone else's) by the only means available to him (touch) is discouraged in most instances by a majority of mothers. Whether the touching is innocent exploration or overt masturbation matters little to the average mother. Both are usually actively discouraged as being unacceptable - possibly even dangerous according to some of the mothers in the Newsons' (1968) sample.

Some of the comments from the mothers of blind children are recorded below.

6. Rowan Davis. Functionally Blind. Retinal Dystrophy. Age 1 year
> "Yes, she likes to have a little poke, but I don't like it. I always put her nappy straight back on".

12. Christopher Peters. Useful Vision. Age 18 months
> "It's mostly in the bath when he does it. He gets hold of it and pulls really hard. I'm scared he'll really hurt himself one day. I usually smack his hand and tell him he'll pull it off".

19. Brett Phillips. Functionally Blind. Age 14

"Well no, I wouldn't say he did it (masturbate) any more than is usual in little boys. But then you see he couldn't see when he was being watched and so he got into trouble for it more often".

Brett above was not the only blind child to be caught masturbating where a sighted child would not. The sighted child quickly becomes aware that this is something one does in private. Unfortunately for the blind child however, he is not always aware that he is being observed.

It is possible that Robin below, was not even aware that his behaviour was unacceptable, particularly in front of persons representing institutions such as the Church.

1. Robin Gill. Functionally Blind. Age 8 years

"Oh he was always doing it at one time. I tried ignoring it like they said but that was disastrous. He was layed on the settee one day when Father D came. He (the priest) was having a cup of tea and I could see Robin fiddling with himself in full view! I said, 'Robin, what are you doing?' 'Nothing he says, and carries on. Father D didn't say anything but he went a funny colour. I said, 'Robin! What _are_ you doing? Well, he just came straight out with it and says, 'Well if you've got to know, I'm only faffing me tail up and down".

Sometimes the mother is obviously aware that the child masturbates but either cannot see him because of her own visual handicap or chooses not to look as in the case of Jason Grant below.

41. Darren Morton. Functionally Blind. Age 9 years

"I don't know whether he does it or not. (Mother blind) I suppose he must do. I suppose all little boys do, don't they? But I don't suppose it'll hurt him".

9. Jason Grant. Functionally Blind. Age 12 years

"I got very worried about it at one bit. He used to get his teddy and put it in there ... (What did he do with his Teddy?) Don't know. I don't want to know either, my mind boggles. I daren't tell his Dad. I used to say, 'Don't put that Teddy in there'. But I don't know what he gets up to on his own, do I? I think sometimes he has to go to sleep like that".

I never did find out what exactly Jason was doing with his Teddy bear because his mother continued to evade the question. It is possible that James was not masturbating, but merely carrying out some kind of comfort or sleep ritual in which many blind children indulge. Marie below was probably using masturbation as a form of comfort habit.

21. Marie Williams. Totally Blind. Age 3 years

> "She sort of rocks on this cushion. I suppose that's what she's doing. But she doesn't do it a lot, only when she's tired. I don't stop her because it's not obvious what she's doing really and it's only a comfort thing. Really I'm more worried about her continually having her dummy in. I find I just can't break her of that".

Several mothers were in fact less concerned about masturbation than about other habits and what are sometimes termed 'blindisms', as was Simon's mother below.

27. Simon Zyskhi. Functionally Blind. Age 18 months

> "Well yes he did (masturbate) a bit, but that didn't worry me. I found his continual head banging and rocking much more difficult to deal with".

In some cases the child masturbates in order to gain parental attention. In this event (as with sighted children) the best policy is probably to ignore the behaviour, as Nina's mother found out.

46. Nina McDonald. Totally Blind. Age 8

> "She used to do it quite a lot, but the more I told her to stop it, the more she did it. So I just let her get on with it and ignored her. She stopped doing it then".

The most usual form of discouragement employed with regard to masturbation, is simply to cover the offending parts with clothing. According to the theories of Piaget (1954) therefore, the blind infant, prior to gaining object permanence may well not realise that his penis is part of himself at all. To him, it will "appear" only when he is in the bath or having his napkin changed, rather like the plastic bath toy duck.

Discovering his body is hampered still further (particularly in winter) by the clothes he wears. Not only is he unable to experience the socially unacceptable parts of himself, but even the acceptable ones are covered by mittens, shoes or bootees and often also a helmet or hood.

Although this is seldom taken into account, the clothing of a blind child can actually contribute to and increase his sensory deprivation. Mittens to a blind child are the equivalent of a blindfold to a sighted one and the helmet to keep out the cold muffles the sound. Thus the blind child already without his primary and co-ordinating sense, is also effectively deprived of touch and hearing, his only available means of orientating himself and keeping in touch which the world around him.

The blind infant then, for a perilously long period of time, remains in what is almost a sensory vacuum, where people, objects and even parts of his own body come and go as if by magic. And, there is seemingly no way in which he can actually control this coming and going.

Discovering Gender

How does the blind child discover that he is a boy, or that she is a girl? For sighted children the most usual methods are; seeing siblings of the opposite sex when napkins are changed or in the bath, seeing parents undressed, where this is permitted and through speech and socialisation, i.e. being told that he is a boy, wearing appropriate clothes and being given appropriate toys to play with. The slightly older child will also no doubt discover the difference when playing "Doctors and Nurses" and "Mummies and Daddies" with peers, and also from what the Newsons (1968) term "Giggling over the Toilet".

Playing "Doctors and Hospitals" will also be discussed in the section on play because as the Newsons (1968) found, children do not always play hospitals in "that" way. The quote below is taken from their 1968 study.

<u>Research Chemist's Wife</u>
> "Her little friend introduced 'hospitals', where that seemed to be the main examination, and the other child's mother disapproved strongly of that. I'm not sure where I stand on this, really,

because Eleanor wasn't guilty about it; but I think she is now, and I think it would be difficult if they went on playing hospitals in that way. They *do* play hospitals - but not always in that way. I have a feeling actually that they shouldn't play it, because I think it worries the other one. I *think* I don't mind; but I'm not sure".

The only senses useful to the blind child in helping him to distinguish between the sexes are hearing and touch. Hearing as we have seen, is not particularly helpful in this respect, although it will inform him that his father has a deeper voice and a heavier foot fall. His father's clothing (unless his mother also wears trousers) may make a different noise from that of his mother, but in no way can sound give him any clues to the 'real' differences between the sexes.

Touch, the only useful source of information in this respect is forbidden for all the appropriate parts of the body. And this taboo, which also includes faces except in the family circle, applies in almost all cultures in every part of the world.

Giggling Over the Toilet

How then is the blind child to learn gender difference? The answer would appear to be, mainly from peers and siblings. It seems to be quite uncommon for the subject to be 'taught' in any formal sense by parents or teachers. Parents in fact are often quite at a loss to know how to go about teaching the subject to a blind child, as the quote below shows.

4. Wendy Jenkinson. Functionally Blind. Age 4 years

> "She loves playing hospitals, it's her favourite game. She mostly plays it with her dolls and teddies, and they have mainly eye operations. But when the little boy from down the road comes round, it's always his tummy or other bits and pieces that have to get examined. (Is she usually the 'doctor'?) Oh yes, he's always the one that gets examined. Well, I've never thought anything of it really, you know, because it seems quite innocent. And besides, how else is she going to learn? (Only child of a single mother) But his mother came to fetch him one day and caught them at it. She was really mad and she smacked him and took him home. She doesn't let him come round now, on his own. It's hard to make people understand really that she has to touch to see".

Even with sighted children, as the Newsons (1968) discovered, mothers vary a good deal as to how far they wish to restrict their children. Some, like Wendy's mother were aware of the nature of the game, but felt it should be allowed, so long as no child was upset or frightened and so long as much older children were not involved. The Newsons (1968) pointed out however:

> "... because these are essentially group games, and because curiosity tends to take this form between friends rather than siblings, a social situation of some delicacy can develop between mothers, especially where they differ in attitude or where one child is considered to have 'led the others on'".

The Newsons (1968) found that "Doctors and Hospitals" and "Mothers and Fathers" were, not infrequently banned altogether from a whole street.

Parents are not given any guidance as to how to go about educating their child with regard to sex and reproduction. The mother quoted below went to considerable expense to acquire a boy doll (not generally available in this country at the time) to use as a teaching aid.

42. Louise Brown. Totally Blind. Age 11 years

> "I wanted to teach her (about sex) myself, but it was difficult to know how to go about it. I asked the health visitor and the specialist teacher, but they both said to leave it, there's plenty of time for that when she starts school. But I think that's wrong myself. I mean, I think all children should know before they start school because otherwise you get all this silliness about toilets and messing about in the garden shed don't you?
>   Well anyway, I thought I'd get a boy doll and use that. But that was easier said than done. I had to send away for it, I think they come from Scandanavia or America or somewhere. Even then, they aren't particularly realistic, but I think it put her on the right lines".

This reticence of professionals with regard to sex education is part of a wider problem – the denial of sexuality and sexual rights to the handicapped by the able bodied. All of the older children with whom the subject was discussed complained about the sex education (or lack of it)

given in special schools. The children who attended single sex schools or special grammar schools seem to have fared particularly badly in this respect:

34. Jeffrey Howard. Functionally Blind. Age 16

"In that respect we were treated as if we were going to end up as monks. It was as if girls didn't exist. Nobody seemed to think we might want to get married and have children. The only time we came in contact with girls was at the end of term, when these sighted girls came to nursemaid us at a dance. I suppose we were some sort of community work for them, but I used to find it quite threatening really".

8. Danielle Ellis. Totally Blind. Age 16

"Sex was never mentioned at school. We were treated as if we were all unisex except that girls got this talk from the school nurse about periods. That was really embarrassing and we all got the giggles afterwards in the toilets. That was where we got most of our (sex) education anyway (in the toilets). But we were really mixed up about how you got pregnant and where babies come from and things. (How did you find out then?) Oh well, for me it was easy because Frankie (sibling) told me. We used to sit in my bedroom for hours talking about boys and having babies. But I really don't know how I'd have found out if I hadn't had a sister".

The granting of equal rights and freedom to blind children with regard to discos, parties and boy friends is however not without problems (particularly for girls) as Mrs Carter points out:

28. Cynthia Carter. Totally Blind. Age 16

"I really hate having to say, no you can't go to this disco or that party all the time. It seems so hard on her and she doesn't get much social life at all really. But then, you know, this estate has got really rough these past few years, and there's some really awful people about. I mean, well she's easy prey really, a sitting target like. And if she was to get harmed, raped or anything she wouldn't be able to get help, and nobody would ever know who'd done it would they?".

Conclusion

In the foregoing section we have briefly discussed the acquisition of knowledge regarding sex, gender and sexuality in the blind child. In spite of many obstacles, the majority of blind children acquire this knowledge

at an age more or less parallel to the sighted child (although by taking
a different path). The majority of children of an appropriate age had also
begun to accept and enjoy their masculinity or femininity.

CHAPTER 9

PLAY AND PLAYMATES, ROLES AND RITUALS

Wherever I am, there's always Pooh,

There's always Pooh and Me.

Whatever I do, he wants to do,

"Where are you going today?" says Pooh:

"Well, that's very odd 'cos I was too.

"Let's go together", says Pooh, says he.

"Let's go together", says Pooh.

"Let's look for dragons", I said to Pooh,

"Yes, let's", said Pooh to Me.

We crossed the river and found a few –

"Yes, those are dragons all right", said Pooh.

"As soon as I saw their beaks I knew.

That's what they are", said Pooh, said he.

"That's what they are", said Pooh.

"Let's frighten the dragons", I said to Pooh.

"That's right", said Pooh to Me.

"I'm not afraid", I said to Pooh.

And I held his paw and I shouted 'Shoo!

Silly old dragons!" – and off they flew.

"I wasn't afraid", said Pooh, said he.

"I'm never afraid with you".

So wherever I am, there's always Pooh,

There's always Pooh and Me.

"What would I do?" I said to Pooh,

"If it wasn't for you", and Pooh said: "True,

It isn't much fun for One, but Two

Can stick together", says Pooh, says he.

"That's how it is", says Pooh.

        A A Milne, 'Us Two', from 'Now We are Six' (1927)

Play has been studied in people and animals from a variety of points of view. For example, psychologists, sociologists, anthropologists, ethnologists and others have all considered the subject. It is generally agreed that play is important, not only in the development of the individual, but also for the survival of the species. Unless they are very ill, disturbed, depressed or handicapped, the young (and sometimes adults) of all higher animals spend a high proportion of their time in play.

According to Garvey (1977):

> "Play is most frequent in a period of dramatically expanding knowledge of self, the physical and social world, and systems of communication; thus we might expect that play is intricately related to these areas of growth.
> ... almost universally, the young of higher species engage in playful behaviour that resembles adult activities but is somehow incomplete or unperfected ...".

The diversity of forms which play takes, coupled with the different approaches to the study of the subject has led to a proliferation of ideas and theories concerning the causes of play and the functions it may serve.

The study of play has, it seems proved rather more difficult than many researchers anticipated. One reason for this is that the presence of an adult, whether she be an observer, researcher, teacher or parent, almost always inhibits certain types of play, particularly play with sexual connotations. Another common occurrence is for children (particularly younger ones) to gravitate towards an adult to structure their play rather than to remain in the peer group.

Despite the interest shown in the subject, many questions regarding the role and functions of play in development remain unanswered. Without an established base line of 'normal' it is therefore rather difficult to put the play of handicapped children in context.

Play and Games

Some researchers, for example Garvey (1977) make a distinction between play and games. Garvey states:

> "(Play) has no extrinsic goals. Its motivations are intrinsic and serve no other objectives. ... In utilitarian terms, it is inherently unproductive".

Games on the other hand have rules, require co-operation with other players and often involve an element of competition.

Piaget (1951) divided play into three types.

1. <u>Sensori-motor Play</u>

According to Piaget, this type of play occupies the period from infancy to the second year when the child learns to control his movements and co-ordinate gestures and his perception of their effects. During this stage the infant masters motor skills by repeating varying motions and he explores and experiments with the world of touch, sight and sound.

2. <u>Symbolic Play</u>

Piaget claims that this type of play predominates from the age of two to about six. During this period the child learns to encode his experiences in symbols. This is the main period of 'pretend play', when a cardboard box can become a lion's den, a house, a fort for soldiers or a nest for birds.

3. <u>Games with Rules</u>

These represent Piaget's third stage of play which, he states usually begins in the school years. Piaget argues that in order to play "games" the child needs to understand the social concepts of co-operation and competition.

My own thesis follows neither Garvey's nor Piaget's formulation. I have chosen to treat play in all its aspects as a learning experience. Garvey's statement that, "Play has no extrinsic goals and is inherently unproductive", does not seem to fit the picture of the little boy creating a fantastic machine from his lego bricks, nor the little girl painstakingly sewing a dress for her favourite doll. Both are clearly playing, but equally clearly both are engaged in a productive learning experience which is not without goals.

Piaget's concept of games with rules being the last type of play to emerge does not take into account the early social play of a mother and her infant. Surely 'Peek-a-boo' is a game with rules which are equally well understood, it would seem, by both partners. Peek-a-boo and other such 'structured' games are understood and enjoyed well before the end of the infant's first year.

I have chosen to discuss the play of visually handicapped children under six functional headings and to compare its development with that of sighted children. Although inevitably there is some overlap, the headings are as follows:

1. Activity Play – the release of energy and aggression.
2. Educational Play – play and the acquisition of life skills.
3. Play as a Coping Strategy – dealing with fear and anxiety.
4. Play as a Therapy.
5. Learning Lore and Language through Play.
6. Learning the Rules – games and competitive play.

ACTIVITY PLAY – THE RELEASE OF ENERGY AND AGGRESSION

Spencer (1896) put forward the theory that the main function of play was the release of surplus energy. Although this theory has now been mainly superseded by others, it is true that healthy children do have a great deal of energy to expend. This "pent up energy" as Spencer described it, is released in activity play which tends to take place mainly in the street or playground. Activity play includes, chasing games such as Tag (known as Tiggy in Sheffield – see the work of the Opies (1969) particularly for

locals names of street games), football, play with toys such as bikes and skate boards and mock fighting or what is generally called 'rough and tumble play'.

Activity play is usually rough and boisterous and, out of school hours, tends to take place in the street. Even when parks and playgrounds are close by, it seems, according to the Opies (1969) that children have always gravitated towards the streets. This happens regardless of danger from traffic and the wrath of residents. It would seem that these factors actually add to the attraction rather than detract from it.

Activity play tends to take place in a social context with peers, usually of the same sex, and, according to Garvey (1977) boys indulge in this type of play more frequently and for longer periods than girls, and this holds true regardless of culture.

Although the majority of the sample mothers (97%) were tolerant or highly tolerant of noisy and messy play, they were rather more protective towards visually handicapped children than their sighted siblings, allowing siblings much more freedom in this respect. Of all the types of play, street play tended to cause most anxiety to the mothers. Relatively few visually handicapped children were allowed to play in the street at all. Almost all of those who were, had to be supervised by an older sibling or special sighted friend. There were good reasons for this. Three children had been involved in road traffic accidents during street play. On more than one occasion a visually handicapped child had been forgotten by his playmates during a game. The other children had wandered off to play elsewhere leaving the blind child to find his own way home. The few children who were allowed unrestricted access to the street were often teased and ridiculed by peers. They were frequently assigned unpopular roles such as being 'on' at tiggy or being the 'piggy in the middle' or 'Tom Tiddler'.

Activity play requires speed of action and good mobility. For obvious reasons the visually handicapped child is unable to compete with his peers in these areas. Many of the toys used in activity play, eg. bikes, skate-

boards etc.. were felt by the parents to be too dangerous for a blind child, although as Mrs Gill discovered, they are allowed at special school.

1. Robin Gill. Functionally Blind. Age 7 years

> "He was always on at me for a skate board. And I used to say, 'no way you'll end up under a bus'. He was really upset because all the other kids had got one. Well, after he was transferred to blind school, I went to an open day there, and what do you think was the first thing met me in the playground? It was him careering round on a skate board. Well, you just can't win, can you?".

Healthy blind children have the same need to let off steam and release pent up energy as sighted children. Their needs in this area however often remain unfulfilled. This may be one reason why blind children so often indulge in repetitive, non productive movements such as rocking, twisting round, head banging and hand flapping - so called 'blindisms'. Blindisms might be less frequent if children could indulge in more activity type play in a safe environment. Tooze (1981) gives several ideas for integrating blind children into mainstream school games. Helping parents to see that with slight modification of the environment, toys such as bikes and skate-boards can be used with reasonable safety by many blind children, could boost not only the child's confidence but also the parent's.

EDUCATIONAL PLAY - PLAY AND THE ACQUISITION OF LIFE SKILLS

This heading includes imaginative and role play games such as house, school, shop, train drivers and bus conductors, hospital and many others. It might be thought that the imaginative and imitative play of blind children would be somewhat stilted and restricted and that they would tend to play subordinate rather than dominant roles. This however was not the case with the Sheffield sample. Almost all the children spent a high proportion of their time in this type of play. Their role play was equally convincing (sometimes more so) when compared with that of sighted peers.

The following action took place during the research interview. Wendy was playing by herself and can be heard in the background of the interview tape.

4. Wendy Jenkinson. Functionally Blind. Age 4 years

Standing on a stool, 'washing up' in sink, real water, doll's dishes.

Wendy (in mother's voice): Oh dear, who's this?

Gets down and opens kitchen door.

Wendy (in deep voice): Tele Missis.

MV: Oh, come in.

DV: What's up wi'it then?

MV: Don't know, can't get a picture.

DV: Oh, I'll go and get me tools.

Brings little doctor's kit and tinkers with a cardboard box.

MV: You want a cup of tea?

DV: Yer, don't mind if I do.

Pours 'tea' from doll's tea set.

DV: Thanks Missus, I've fixed it now.

MV: Oh, thanks. Ta-ra then.

Opens kitchen door.

DV: Bye luv, see yer.

Closes door, climbs back on stool to 'wash the pots'.

(**MV** = Mother's Voice; **DV** = Deep Voice)

As the above excerpt shows, the imaginative play of visually handicapped children differs little if at all from that of sighted children of a similar age.

Research into play, including that of the Newsons (1979) and Garvey (1977) has shown that children, particularly aged 3-4 years enjoy role play and slip easily from one role to another. If no peers or siblings are available to fill supporting roles (patients, pupils, sons, daughters, passengers etc..) children easily substitute dolls, toy (or real) animals or play all the roles themselves as Wendy showed in the above excerpt.

Unlike activity play, where the blind child almost always played unpopular or subordinate roles, when engaged in imaginative play, they were equally likely to play a leading role as a supporting one. Here they were the doctors, teachers, mothers etc.. whilst siblings and peers often played patients, pupils and children.

Blind children played roles of equal diversity to sighted children. They showed the same gender difference with regard to role preference found by most researchers including the Opies (1959) and (1969). Favourite roles for both blind and sighted girls included: mother, nurse, teacher and doctor. They also quite frequently played cops and robbers and bus-driver or passenger. Favourite roles for boys were: racing driver, train driver, policeman, fireman, monster and spaceman. They also played doctors, passengers and patients though less frequently. It was almost unheard of for boys (even where the father played a high profile role in child care) blind or sighted to play the roles of nurse or girl baby. Boys (blind or sighted) were not allowed in the 'kitchen' or baby care areas by girls, even as 'fathers'. None of the blind boys were said to have played with girl's dolls, even as babies, although they did play quite often with action men or play people and other symbolic toys of this nature.

Dressing up was very popular with blind children. Favourite play clothes for girls included: nurse, mother (long dress and mother's shoes), queen and princess (also long dresses) and fairies and witches. Boys preferred: policeman, fireman and racing driver (all mainly headgear). Cowboys and Indians seemed to be out of fashion at the time of the research. The role of doctor seemed to be played almost equally by boys and girls, but doctors tended not to wear special clothes, a toy stethoscope being the main prop for this role.

As with imaginative play, gender tended to polarise dressing up roles. Boys did not dress up as nurses (even male nurses) fairies or witches etc.. Girls tended to encroach on boys' roles (eg.. cops and robbers) rather more than the other way around. Occasionally and for fairly short periods, girls might be policemen/women for example.

All these findings are very similar to those of studies of sighted children. it seems therefore that the development of blind children in this area of play parallels that of sighted children.

"I'm not afraid", I said to Pooh,
And I held his paw and shouted shoo!

The use of play as a coping strategy inevitably overlaps with imaginative play (hospitals, doctors and nurses etc..) and play as a therapy (for which see the work of Axline (1947 and 1964). Just as both blind and sighted children play out family life in intimate detail, so they also play out stressful life events. Although popular amongst all children, hospitals and doctors and nurses were particularly popular with blind children. These games were played more often following discharge as an in-patient and after attending the Out Patient Dept. The roles of doctor and nurse were more popular than those of patients. Dolls and teddies were the most usual patients, although peers and siblings were sometimes co-opted to fill the roles. The most popular procedures performed were instillation of eye drops, injections and ophthalmoscopic examination. Also featured quite frequently were feeding, washing and 'cleaning up sick'.

During the periods following admission to hospital or out-patient attendance, sex and 'that kind of examination' rarely featured in games of hospital. The children tended to act out the roles of people who featured strongly in their care. Dolls and teddies and occasionally pets appeared to have a therapeutic value equal to that of peers and siblings.

Separation Rituals

Wherever I go there's always Pooh.

Toys often have a high profile in separation rituals such as preparing for sleep or going to school or nursery.

It is interesting however, to note that a fairly high proportion of the sample children (18%) did not in fact undergo such a nightly separation as they slept mainly in the parental bed. Five percent of the sample group had never actually slept in their own bed or cot. Most of the children

were allowed into their parents' bed when ill or frightened. One of the children who died, did so in her mother's arms in her parents' bed.

Separation rituals are common amongst blind children regardless of whose bed they sleep in. And it seems that many parents were encumbered not only with the child but also a collection of dolls, teddies and security blankets. Rituals involving dolls, teddies, musical toys and things to suck (dummies and cloths) were the most common. Stories and songs did not feature in the sample group, only one child having a nightly story read. None of the children actually said prayers although many included 'blessings' in their rituals. Night night, God bless, Night night mummy, daddy, nannan and everybody, God bless, God bless, see you in the morning and Night night, hope the fleas don't bite are some examples.

Separation rituals can take 30 minutes or longer and as with the Newsons (1968) four year olds, must be carried out in exact order and intimate detail before the child is satisfied.

It is difficult to say whether blind children indulge in rituals more frequently than sighted children or continue to use them for longer periods. This is because it was not possible to compare a sample group of widely differing ages directly with any other sample group. No major research seems to have been undertaken to ascertain at what age ritual behaviour ceases in normal children. In several blind children, some forms of ritual behaviour persisted well into adolescence.

Binker - what I call him - is a secret of my own,
And Binker is the reason why I never feel alone.
Playing in the nursery, sitting on the stair,
Whatever I am busy at, Binker will be there.
   Oh, Daddy is clever, he's a clever sort of man,
   And Mummy is the best since the world began,
   And Nanny is Nanny, and I call her Nan -
                  But they can't
                  See
                  Binker.

Binker's brave as lions when we're running in the park;
Binker's brave as tigers when we're lying in the dark;
Binker's brave as elephants. He never, never cries ...
Except (like other people) when the soap gets in his eyes.

   Well, I'm very fond of Daddy, but he hasn't time to play,
   And I'm very fond of Mummy, but she sometimes goes away,
   And I'm often cross with Nanny when she wants to brush my hair ...
   But Binker's always Binker, and is certain to be there.
            A A Milne, 'Binker', From Now We Are Six', (1927)

Imaginary friends are also it seems often deployed as a form of coping strategy.

It is difficult to ascertain how many of the blind children had imaginary friends. The data obtained are unreliable because they are coloured by the mother's own views and feelings on the subject. Even though they themselves might remember having had such a 'friend' in childhood, many of the mothers still seemed to regard this as abnormal. Several mothers rejected the question out of hand, refusing to believe that any child of theirs could possibly indulge in such behaviour. Although the majority of mothers said their children had never had an imaginary friend, it is possible that some children, like their parents before them, had managed to keep their friends a secret. Three mothers obviously had no idea what

I was talking about, and gave me the distinct impression that I was the peculiar one.

A total of 9 blind children were known to have had imaginary friends. Six were children of the same sex, one child of the opposite sex, one dog and one snake. Some of the mothers' comments on the subject are given below.

45. Sean Patterson. Functionally Blind. Age 13

"Yes he did. It was another boy called Dave. He seemed to live in the coal shed. It was when Sally went to school and he was left on his own that it started. He often went into the coal shed to play with Dave. Used to stay in there for hours sometimes. (Did he ever bring 'Dave' into the house?) Oh no, it was his secret friend. He always used to go to him. It lasted between 2 and 3 years, till he started school himself".

52. Vincent Green. Functionally Blind. Age 15

"Oh no, nothing like that. Thankfully none of mine did. I don't know what I'd do if they had done. I think it's really weird that sort of thing".

21. Marie Williams. Totally Blind. Age 9

"Yes she had Vicky. It was absolutely fascinating. It lasted almost a year, till Michelle (younger sibling) came along. Then it just stopped. It got to the point where we almost had to buy clothes for her".

17. Paul Russell. Functionally Blind. Age 8

"He had this pet snake called Sid. He used to trail this piece of string along and say it was Sid's lead. If he lost things, it was always Sid what had taken them or eaten them".

7. Robin Gill. Functionally Blind. Age 7 years

"It really worried me, that. (Imaginary friend) I thought he was going mental. I was going to take him to the doctor about it, but the lady across the road, her little boy did it as well and she said it was quite normal, just a phase they go through".

4. Wendy Jenkinson. Functionally Blind. Age 4

"Yes she's got Gemma Minor - she means Jemmima I think. She goes everywhere with her. You're not allowed to sit in her chair 'cos you might squash her. And she has to have a place set at the table and some food saved if she's late coming in. I think she sleeps with her as well".

As with rituals, it is difficult to ascertain whether blind children have more, less or the same number of imaginary friends as sighted children. It does seem however that the 'images' of the friends are no less vivid to blind children than to the sighted. It is also apparent that the friends fade away when they are no longer needed. 'Friends', it appears are a valuable aid to coping and it seems a pity that so many mothers regard them in such a negative light.

PLAY AS A THERAPY

As previously stated, there is a high degree of overlap between imaginative play, play as a coping mechanism and therapeutic play. Play as a therapy will not be discussed in detail as no data were obtained on the subject. It is mentioned briefly here because the Minisculpt models utilise some of the tools and methodology of the discipline. Although the method was developed as a research tool which could be used by adults and children on an equal footing, in the event the data obtained from the children were too unreliable to utilise. This was because the children tended to actually play with the material rather than use it in the prescribed manner. It was not possible to reliably distinguish where reality ended and imagination began. From observing the children (and adults) when engaged in the task it did appear that many of them were using the material as a form of therapy and also enjoying the experience.

Blind children are rarely able to make use of art (drawing and painting) as a form of therapy, nor are they able to use much of the symbolic material employed by Axline (1947) without modification. However, when one considers the high proportion of blind children who are either disturbed or depressed, the benefits might well repay the small outlay required to modify the equipment and the environment.

LEARNING LORE AND LANGUAGE THROUGH PLAY

A great deal of research in this subject has been conducted by the Opies, (1959) (1969) and (1985) are examples. Many of the games they describe are hundreds of years old. More than 200 years ago, Queen Anne's physician, John Arbuthnot, observed that "nowhere was tradition preserved pure and

uncorrupt but amongst school boys, whose games and plays are delivered down invariably from one generation to another". According to the Opies (1959) if Dr Arbuthnot made any notes on his discovery they have not been found. (Apparently he allowed his children to make paper kites of his papers). To quote from the Opies' (1959) work:

> "The curious lore passing between children aged about 6-14, which today holds in its spell some 7 million inhabitants of this island, continues to be almost unnoticed by the other six-sevenths of the population".

Examples of these folklore games are, The Farmer's in His Den and The Big Ship Sales thro' the Alley Alley O and hundreds more. Although blind children do sometimes join in these games with sighted peers, they are (as in other types of street play) at a disadvantage in many of them. Blind children do play many of these games in special school, but they tend to be somewhat modified versions. The main difference however seems to be, not so much that the games are modified but that they are organised and supervised by adults. The Opies (1969) and (1985) found this was not the case with sighted children where the games generate spontaneously. Blind children therefore tend to inherit a somewhat diluted 'more suitable for children' version of most of the games, as adults tend to frown on many of the originals which children enjoy.

The acquisition and use of language and literacy will be discussed in the section on education.

LEARNING THE RULES - GAMES AND COMPETITIVE PLAY

Although all competitive games have rules (otherwise no-one could win or lose) not all games with rules are competitive. If a game has rules and they are not obeyed, the game usually breaks down after a short time into unstructured rough and tumble play.

Competitive games are not necessarily active games, chess, board games and card games are examples.

Although as we have seen, visually handicapped children can take part, on equal terms with sighted children, in imaginative games with rules such as shop or school, wherever there is an element of competition, the blind child is likely to be at a disadvantage. This holds true even when the game is modified as many can be by the RNIB utilising tactile cues.

Active games involving competition and team games with sighted peers present the visually handicapped child with quite severe problems. Although for example football can be played with an audible ball, the competition is really only 'fair' when the game is played with other visually handicapped children.

Even though blind children have problems competing at team games and sports with sighted peers, they are frequently avid supporters and 'spectators' of sport. Football matches were very popular amongst both boys and girls in the sample group. Most children said they enjoyed the atmosphere and excitement. They felt they were able to follow the game quite well with a little filling in of details from a sighted friend.

Conclusion

I have tried in this chapter to give a brief over-view of the visually handicapped child at play. It is an incomplete view and the area would benefit from further research. It is also, once again, of necessity the view of a sighted person and probably lacks insight into some of the problems and strengths of the children.

It must also be added that most of the information was obtained, not from direct observation, but third hand from the parents.

I have not written about adaptation of toys nor about toys which have been specially designed for handicapped children as there is already excellent literature on this subject, eg. Newsons (1979).

It would appear then, that although the visually handicapped child may have difficulties in joining in some kinds of play with sighted peers, there are areas such as imaginative and role play, where the blind child's performance is almost indistinguishable from that of a sighted child. His

intellectual skills in these areas are also often on par with sighted peers.

Many of the problems of integrated play with sighted children could be overcome with a little ingenuity. It seems therefore that, on the whole, the visually handicapped child, "Will get by, with a little help from his friends".

CONCLUSION TO SECTION II

Section II was concerned with the socialisation and rearing of visually handicapped children. The section began with the discovery and diagnosis of the defect. It was found that the majority of defects were first noticed, not by professionals, but by parents or other family members. Many parents then had difficulty in convincing professionals that something was wrong and there was often a long delay between the discovery and the diagnosis of the condition. Following the diagnosis there was no one to counsel the parents nor to help them come to terms with the handicap. Neither did the hospital refer the children to other helping agencies. Although the majority of the defects were genetically transmitted, very few families received genetic counselling and none had received any help with regard to discussing this with their children.

The impact of rearing a blind child upon family life was discussed in Chapter 6. It was found that although the birth and rearing of a visually handicapped child placed great strain on many of the marriages, the majority remained intact, the handicapped child often acting as a binding force rather than splitting the family apart. Failure to negotiate 'transition points' in the family life cycle caused ongoing stress and it was found that almost all the mothers and many of the fathers experienced long term emotional problems; anxiety and depression being the most common. Few parents received any help with these problems. Most did not even ask for help and those that did approach their GP were given tranquilisers which did not help the situation.

In Chapter 7 the early development of blind children is outlined and compared with that of the seeing child. The findings suggest that ability and achievement in handicapped children is linked less with the degree of disability and more with parental attitudes.

Chapter 8 was concerned with aspects of socialisation. The first relationship - that of mother and infant was explored. Bonding is said by many authorities to be based largely on gaze, yet it was apparent that, despite early problems, most mothers were able to bond successfully with their infants. Stern (1977) points out that the 'steps of the dance' of

the first relationship remain unwritten and unchoreographed in normal couples. Virtually nothing is known about the ways in which blind infants bond with their mothers. Further research in this area would benefit psychology as well as blind children because if the ways in which the blind baby bonds successfully with his mother can be established, we may begin to understand the part which vision plays in the bonding of seeing couples. Not only is the blind infant able to bond successfully with his mother, he is also able, in many instances, to overcome adverse influences to achieve and retain independence, to acquire an image of his body, and, despite the taboo of touch, to discover and enjoy his sexuality. In some areas, for example potty training and imaginative play, the blind child is able to equal or to exceed his sighted peers and siblings. From Section II therefore it can be seen that many blind children are truly 'virtuoso performers'.

Section III is concerned with the education of children with severe visual impairment. The ways in which special education for blind children began and has developed from the 18th century to the present day are considered along with the philosophies and attitudes which have underpinned this development. Special consideration has been given to the achievement of literacy in the blind.

The section is divided into 6 chapters as outlined below.

Chapter 10 outlines the foundations of special education in general, and traces the origins and development of special education for the blind.

Chapter 11 is concerned with stigmatization and stereotyping. Attitudes towards the blind are explored and the ways in which society classifies and 'labels' those it assumes to be 'abnormal' are considered.

Chapter 12 enters the segregation/integration debate. The movement for integration is traced to its culmination in the 1981 Education Act. The mainstream/special argument is illustrated with quotes from the sample group and the educational careers of the blind sample children are outlined. The continuing need for special schools is argued.

Chapter 13 is concerned with the assessment process. The ways in which powerful groups select, define and treat weaker groups and 'count them out' of normal education are considered. Issues of power and professional conflict are also discussed.

Chapter 14 considers the special curriculum for blind children. The aims and objectives of the special curriculum are discussed along with its content and the ways in which it has evolved. The ways in which children with disabilities are denied access to certain kinds of knowledge are examined.

Chapter 15 continues the examination of the special curriculum and is concerned particularly with the development of literacy in the blind. The

ways in which this was achieved are outlined and the careers of the two men who made literacy, in the full sense of the word, possible for blind people are briefly described.

The section is illustrated throughout with quotes from the sample group.

CHAPTER 10

EDUCATION AND THE FORMATION OF IDENTITY

THE FOUNDATIONS OF SPECIAL EDUCATION

In this chapter, the education of visually handicapped children will be considered largely from a sociological perspective. Where applicable the chapter will be illustrated with quotes from the interviews of parents and children.

Special education today is permeated by an ideology of benevolent humanitarianism, which provides a moral framework within which professionals and practitioners work (Tomlinson, 1982). However, it is important to recognise that the classification, provision for, or treatment of children who have been defined as "defective", "handicapped" or as having "special needs" is also a social categorisation of weaker social groups.

In all societies, as Tomlinson (1982) notes, powerful groups categorise and classify weaker ones and treat them differentially or unequally. The notion that the powerful groups (in our society often professionals) are solely engaged in "doing good" to the weaker groups (children, clients, patients) is actually something of a rationalisation. Professionals and practitioners have a vested interest in expanding and developing their fields of practice. They also have very real power to affect the lives and futures of their clients - or in special education, the children.

A crucial factor in special education is that the children concerned have no power to speak for themselves. And, despite the growth of parental pressure groups, parents still have very little influence over the process of special education. In fact, as Tomlinson points out, the clients of special education, (children and parents) have the least influence over what happens to them, and are subject to the most pressures and coercions of any group in the education system.

Special education has developed to cater for children who have been categorised out of the ordinary education offered to the majority of children in society. Industrial societies increasingly require qualifications and credentials acquired through the normal education system and as Tomlinson (1982) writes:

> "... to be categorised out of 'normal' education represents the ultimate in non-achievement in terms of ordinary educational goals. Occupational success, social mobility, privilege and advancement are currently legitimated by the education system; those who receive a 'special' rather than an ordinary education are, by and large, excluded from these things. The rationale for exclusion has been that children were defective, handicapped or, more recently, have special needs. The result of the exclusion is that the majority of the children are destined for a 'special' career and life-style in terms of employability and self-sufficiency".

Much of what happens in social life, (special education being no exception) is a product of power struggles between various groups with a vested interest. Each professional group involved in the process, including referral, assessment, treatment, teaching or administration, has its own vested interest and sphere of power and competence. The professionals involved in special education are in a position to mystify others. And special education has evolved as one of the most secret areas of education, partly as Tomlinson (1982) points out, because of the medical connections, and the ideology of 'medical confidentiality'. Tomlinson (1981) found in fact that at times the procedures were so secret that even other professionals were not informed. This secrecy also has to do with the way in which professional people regard parents. Parents are denied access to information pertaining to themselves and their 'special' children, and to be denied knowledge is to be denied power.

Booth (1978) and Tomlinson (1981) both found evidence that many parents whose children are in special education feel inadequately involved and consulted. They also feel mystified by professionals. They are in fact a weaker social group in terms of control over their children's destiny.

Sociology can be used as a tool to analyse power structures and the ways in which power is legitimated through secrecy, persuasion and coercion.

Sociology, as Rex (1974) points out: "... may not be able to influence the powerful - but it may be able to help the alienated and the puzzled".

This chapter then, is concerned with the origins and development of special education for the visually handicapped and the on-going dilemmas in this field.

THE ORIGINS OF SPECIAL EDUCATION FOR THE BLIND

> "Sociologically, the history of special education must be viewed in terms of the benefits it brought for a developing industrial society, the benefits for the normal mass education system of a special sub-system of education, and the benefits that medical, psychological, educational and other personnel derived from encouraging new areas of professional expertise".
>
> > Tomlinson (1982). A Sociology of Special Education, Routledge & Kegan Paul

The treatment of those who have been socially defined as "defective" or "handicapped" is dependent on the values and interests of the dominant groups in each particular society. And societies do not necessarily become more humane as they develop. For example, the Ancient Greeks and the Nazi Party shared somewhat similar values concerning racial purity and both these societies killed handicapped children who were thought to interfere with this purity.

In protestant England, the value placed on productive work has tended to dominate the treatment of the handicapped. In 1601, the Elizabethan poor law provided, "the necessary relief of the lame, impotent, old, blind and such others" only if they were unable to work. The brief of the Warnock Committee (1978) was not only review educational provision for the handicapped, but also to consider arrangements to prepare them for employment.

What is usually taken to be humanitarian charitable enterprise, is related to the values and interests of society and is seldom the product of pure altruism. The early pioneers of special education are often portrayed in highly individualistic and charismatic terms, as if they were acting out

of the social context and counter to prevailing trends. But as Tomlinson (1982) points out:

> "One reason for the charisma surrounding personalities concerned with special education is that their clients have seldom been in a situation to present an alternative viewpoint regarding the humanitarianism of their mentors".

In the early part of the nineteenth century, "education for the masses" was beginning to be regarded as necessary for the control of unrest amongst the working classes and also to produce a literate population for the furtherance of commercial interests.

At that time the education system, such as it was, was privately owned and to a large extent, dominated by the Anglican Church. However, as Archer (1979) points out, the developing capitalist economy was being hindered by the Anglican ways of instruction which placed hardly any emphasis on commercial values. There was however a dilemma in that the ruling groups needed the religious influence as a form of social control for working class unrest.

As Tomlinson (1982) states however, one of the interesting aspects of the development of special education is the lack of interest displayed by all religious denominations. It was mainly businessmen who took the initiative because it made economic sense to make as many citizens as possible (including the handicapped) into a productive labour force. The handicapped were also no doubt a source of cheap and docile labour.

Although the first English school for the blind – The School of Instruction for the Indigent Blind – was opened by a clergyman (Henry Dannett) in Liverpool in 1791, the object of the school was commercial. According to Tomlinson (1982) it was to "render the blind useful to their country by removing 'habits of idleness'. In 1800 the school was re-named 'The School of Industry for the Blind'. Those incapable of any labour were discharged from the school.

Protestantism did not originally have a history of kindness towards the handicapped. Martin Luther for example considered the mentally subnormal

to be "Godless", and Pritchard (1963) states that mental and physical handicaps were frequently taken to be an indication of "divine displeasure". Although Catholicism has been kinder in other countries, as Tomlinson (1982) has pointed out, it was not until 1841 that the first catholic school for the blind (The Liverpool Catholic Blind Asylum) was opened in England.

Hurt (1988) explains that the early founders of Blind Schools concentrated on training their inmates in manual crafts. In doing so they set the pattern of what was deemed suitable training for the blind for many generations to come. Hurt also points out that the inmates of these early institutions, although indigent, also were required to be respectable. They were no doubt the forerunners of the "deserving poor" of the later Victorian era. Applicants for the Liverpool school had to undergo careful vetting prior to admission. Their sponsors had to answer questions such as:

> "Has the blind person been a common beggar, wandering minstrel, a player upon any instrument at ale-houses, within two years before application for admission, such persons being entirely excluded?".

Such standards of morality, industry and respectability were, it seems also demanded of the teachers in such institutions. At the Edinburgh Asylum, opened in 1793, the instructors had to be in their homes by 9pm each night, with the least sign of drunkenness attracting severe punishment. In order to discourage drunkenness at the weekends, workers received their pay on Monday nights! (Hurt 1988).

The first grants towards education were given by the House of Commons in 1833, but according to Tomlinson (1982) none of this money was spent on provision for the handicapped.

However, after the beginning of state education, economic interests in making as many as possible of the blind and deaf self sufficient and employable became more pronounced. There was also, according to Tomlinson (1982) a more overt political interest in the social control of groups which might prove troublesome to the hierarchical order of society, because

of their 'vice, folly or improvidence'. Accordingly the Royal Commission on the Blind, Deaf, Dumb and Others was set up in 1855 and reported in 1889.

> "The blind, deaf, dumb and the educable class of imbecile (Others?) if left uneducated become not only a burden to themselves but a weighty burden to the state. It is in the interests of the state to educate them, so as to dry up, as far as possible, the minor streams which must ultimately swell to a great torrent of pauperism".
>
> Egerton Commission, 1889

Tomlinson (1982) also points out that the Egerton Commission (1889) was to illustrate a crucial and continuing dilemma concerning special education in a society where the work ethic dominated. That is, how to make as many handicapped people as possible productive whilst keeping the cost of any provision low so that the government do not have to use too much of the tax payers' money.

In 1889 the Egerton Commission reported that there should be separate classes provided by the state for the blind and deaf and that after school they should receive training in a suitable trade. In 1893 the Elementary Education Act (Blind and Deaf Children) laid a duty on local school boards to provide appropriate education for blind and deaf children in their area. However, as Hurt (1988) explains, this could require the boarding out of a child and for the school authority to contribute to the cost. As Hurt continues, this kind of arrangement often lead to collusion between parents unwilling to have their child sent away from home and school authorities unwilling to foot the bill. The result, of course, was neglect of the child's educational needs.

In addition as Hurt (1988) explains, other factors militated against the successful operation of the 1893 Act. Magistrates were reluctant to enforce it as the levels of grants offered by the government were £3.3.0d per year for a child attending a certified school (whether residential or not) and a further £2.2.0d for the inclusion of manual instruction. The amount of the grant compared unfavourably with the estimated cost of blind education under the London School Board which had been put at £9.10.5d. And, as Hurt (1988) pointed out, the level of the grant discouraged school

authorities from searching out blind and deaf children and actually penalized those that did so.

The familiar contradiction (which will be discussed in greater depth elsewhere) that whilst handicapped children should be educated separately, it should not cost too much, became evident during the passage of the 1899 Education Act, (Defective and Epileptic Children). According to Tomlinson (1982) the Chancellor of the Exchequer himself expressed fears that too many local authorities 'especially in Ireland'! would discover too many defective children.

In conclusion, as Tomlinson (1982) writes:

> "The interests of political ruling groups were being served by the placement in separate schools and institutions, of children who might eventually prove troublesome to society, given the assumed links between defect, crime and unemployment. Medical interests were supreme in that doctors had control of selection and assessment procedures for special education, but the interests of educationalists in normal schools were served by the removal of troublesome children. The social origins of state special education can certainly be traced to the desire of educators in normal schools to separate out the defective and troublesome, and thus special education can be regarded as a safety-valve, allowing the smoother development of the normal education system".

CHAPTER 11

STIGMA AND STEREOTYPES IN SPECIAL EDUCATION

STIGMATIZATION AND SOCIETY

Goffman (1963) informs us that it was the Greeks who originated the term "Stigma", to refer to bodily signs designed to expose something unusual and bad about the moral status of the signifier.

The Greeks cut or burnt the signs into the body to signal that the bearer was a criminal, a slave or a traitor, according to Goffman, "a blemished person, ritually polluted, to be avoided, especially in public places". In other words, as Goffman states elsewhere, the stigmatized is, "a person who is quite thoroughly bad, or dangerous, or weak. He is thus reduced in our minds from a whole and usual person to a tainted, discounted one". Stigma then, constitutes a discrepancy between virtual and actual social identity.

In later Christian societies, as Goffman points out, two layers of metaphor were added to the term: the first being bodily signs of holy grace taking the form of eruptive markings on the skin and the second, a medical allusion to this religious concept, referring to the signs of physical disorder. The term, as Goffman states, is used today in something like its original sense, although as he points out, it is applied more to the disgrace itself than the bodily evidence of it. And as Goffman also notes, shifts have occurred in the kinds of disgrace that arouse concern.

Thomas (1978) argues that attitudes towards the disabled have changed at quite a rapid rate during the last 40 years or so. He regards the press, TV, and the persuasive power of the voluntary societies as having played a large part in bringing about this change. Much of the research regarding attitudes towards the disabled has been carried out in the field of mental handicap, leaving wide gaps with regard to many other disabilities. Thompson argues that: "Legal changes and new concepts of help, care and support reinforce the conclusion that during this period a more tolerant attitude towards various kinds of disability has developed". He adds

however that despite these positive gains there is still a residue of uncertainty, mistrust and downright discrimination, against which the disabled have to contend.

Stigma, Stereotypes and Attitudes

Stigma is inextricably bound up with attitudes and stereotyping, it being almost impossible to discuss these issues separately.

Although as Thomas (1978) reminds us, there are many definitions of the word, according to Hilgard and Atkinson (1967) an attitude represents both "an orientation towards or away from some object, concept, or situation and a readiness to respond in a pre-determined manner to these or related objects, concepts or situations".

According to Thomas (1978), attitudes, or "orientations and responses have intellectual and emotional components, and the basis of any particular attitude towards an individual or group may be well understood by the person who holds it or may reside at an unconscious level". Attitudes, Thomas continues, are learned in a variety of ways. The attitudes of those who hold key positions in our lives can be internalized. Personal and distinctive attitudes can be acquired from particular personal circumstances, from a single traumatic event, or from the general social surroundings, without any serious reflection. Thomas (1978) argues that, "Some attitudes are so firmly embedded that they can be legitimately regarded as stable elements of the personality", and as such are vigorously resistant to modification.

Attitudes and Culture

Culture wide attitudes towards handicap have been explored by Richardson and colleagues (1961). It appears that attitudes towards various disabilities are shared by "normals" and the handicapped alike and that attitudes to many disabilities cross many culture boundaries.

Thomas (1978) argues that this uniformity of response by handicapped and able-bodied alike, is explained by minority cultures absorbing the values

of the majority. He explains that the uniformity across social and ethnic groups can be explained by the gradual exposure of children to "deprecatory evaluations of persons with physical disabilities". It is interesting to note that advertising also exploits cultural stereotypes of physical beauty which are identified with "goodness".

Stereotypical Beliefs About Blindness

Scott (1969) in his study of adult socialisation of the blind, argues that one of the ways in which a visually handicapped person learns how to be a "blind man", is by interacting with sighted people. When "normals" come face to face with someone who is unable to see, their preconceptions about, and reactions to blindness are expressed as expectations of how a blind person ought to behave. The blind person is also reminded of the social identity imputed to him by the sighted. According to Scott, all blind people respond to this identity in some way, even if only to refute it. He argues that, for those who internalize it, this putative social identity in fact becomes the blind man's actual personal identity. According to Scott's (1969) thesis, there are two principal mechanisms of personal encounters through which the blind are socialized. The first relates to the preconceptions about blindness that sighted people bring to encounters with the blind, and the second to the reactions of the sighted during the encounter.

Scott (1969) describes a number of general beliefs which laymen are held to have regarding the blind. These include notions of helplessness, docility, dependency, melancholia, aestheticism, and serious-mindedness. Whilst it is unlikely that many laymen accept all these beliefs, Scott maintains that the majority adhere to at least some of them. These misconceptions are brought by the sighted to situations of interaction with the blind, where they are expressed as expectations of the behaviour and attitudes of the blind person. Because of them, Scott maintains, "deep and stubborn grooves and channels are created into which all the blind man's actions and feelings are pressed". The existence of these stereotypical attitudes makes it extremely difficult for meaningful communications and unstrained relationships to be maintained between the sighted and the blind.

Scott refers to the work of Gowman (1956) on the impact such beliefs have upon blind people when they react with the sighted:

> "An individual taking up the role of a blind man is conceptually relocated along the margins of the dominant social structure and a peripheral social role is assigned to him. His rights and obligations are redefined in a manner which is believed to mesh with the character of the disability ....
> What distinguishes the blind role from other types of roles is its all pervasive character. Blindness is not an attribute to be put on or cast off as the situation demands, but a constant characteristic which affects the quality of each of the individual's relationships in occupational, recreational and other contexts. When evaluation is thus expanded to cover an individual's entire personality structure, a stereotype is operative. The blind may be assigned a social role which so transforms them that they emerge as a labelled segment of society. Social interaction becomes stunted and artificial under the impress of the stereotype".

Goffman (1963) provides an illustration of a newly blind girl taking up her role as a blind person on a visit to an institution.

> "I could hear the shuffling of feet, the muted voices, the tap-tap-tapping of canes. Here was the safe, segregated world of the sightless - a completely different world, I was assured by the social worker, from the one I had just left ...
> I was expected to join this world. To give up my profession and to earn my living making mops. The Lighthouse would be happy to teach me how to make mops with other blind people, eating with other blind people, dancing with other blind people. I became nauseated with fear, as the picture grew in my mind. Never had I come upon such destructive segregation".

> T Keitlen, Farewell to Fear, 1962
> Quoted in Goffman (1963) Stigma, Penguin

Scott (1969) argues that it is impossible for blind people to ignore stereotypical beliefs and that they have no choice but to respond to them. Responses will vary, but, according to Scott, in a highly patterned way. Some blind people, he maintains, come to concur in the verdict that has been reached by those who can see. "They adopt as a part of their self-concept the qualities of character, the feelings, and the behaviour patterns that others insist they must have". Docility, helplessness, melancholia, dependency, pathos, gratitude, a concern for the spiritual and the aesthetic, all become a genuine part of the blind man's personal

identity. Such blind people, Scott terms 'true believers' by which he means that they have actually become what others with whom they interact assume they must be because they are blind.

According to Goffman (1963) and Scott (1969), blindness is a stigma, carrying with it a series of moral implications regarding character and personality. Stereotypical beliefs lead sighted people to believe that the blind are different. Because blindness carries a stigma, sighted people are lead to regard the blind as their "physical, psychological, moral and emotional inferiors". (Scott 1969). Blindness is therefore a trait which discredits a person by spoiling both his identity and his respectability.

Davis (1964) argues that when a person with a stigma encounters a normal person, barriers are created between them. These barriers, though symbolic are often impenetrable, producing what Davis terms a kind of "moving away" similar to matching the two like poles of magnets. These avoidance reactions are according to Davis (1964) often induced by a fear that direct contact with a blind person may be contaminating or that the stigmatized person will somehow inflict physical or psychic damage. The impact of these reactions on the blind person can be profound. Even though he thinks of himself as a normal person, he recognises that others do not accept him as such and are unwilling to deal with him as an equal. As a result he may feel shame because he possesses a defiling attribute. Thus, writes Scott 1969):

> "The stigma of blindness makes problematic the integrity of the
> blind man as an acceptable human being. Because those who see
> impute inferiority, the man cannot ignore this and is forced to
> defend himself. If, as sometimes occurs, the blind man shares
> the values of the sighted, the process becomes even more
> insidious; for when this is the case, a man's personal identity
> is open to attack from within as well as from without".

Goffman (1963) illustrates this situation with a quote from Henrich and Kriegel (1961):

> "I think the first realization of my situation, and the first
> intense grief resulting from this realization, came one day, very
> casually, when a group of us in our early teens had gone to the
> beach for the day. I was lying on the sand, and I guess the
> fellows and girls thought I was asleep. One of the fellows said,

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`I like Domenica very much, but would never go out with a blind girl'. I cannot think of any prejudice which so completely rejects you".

Similar kinds of prejudice were met with by families in the Sheffield blind sample group:

30. Mrs Barton, Herself Functionally Blind

"Well you know, it's incredible what people think. I mean, they treat you as if you weren't human at all. I was on this bus one day going to town and these two old so and so's were sat behind me. Well, I think they thought I was deaf and stupid as well as visually handicapped. It's as if I wasn't really there at all, as a person, I mean. Well, one says to the other, 'That shouldn't be allowed, that, I mean look, she's blind and she's got kiddies with her. Well I think they should have been taken off her. People like her should be kept in homes not out on the streets, don't you think?".

Another instance of a family on holiday:

21. Marie Williams, Totally Blind, Lebers Ameurosis

"It's not people who know her who are unkind. Really they're very good round here. But when we were on holiday a couple of years ago, she was playing on the beach and another little boy came up and they were playing quite nicely together, you know making sand pies and that like kids do. And suddenly his mother comes up and drags him away saying 'Come away from her, she's a blind girl. You mustn't ever play with blind children, you don't know what you might get from them'. Well, you can imagine that really shook me that did".

An Historical View of Stigma

Thomas (1978) puts an interesting slant on the possible origins of the stigma surrounding childhood disability, whilst discussing attitudes as a cultural phenomenon. Thomas refers to the work of Haffter (1968) whose basic material was folklore of Western Europe which he used to explore changes in popular attitudes to childhood disability. Haffter saw that a constant theme in these folktales, was the changeling, i.e. a normal child exchanged, usually by fairies for an ugly, deformed or crippled one. According to Haffter, these tales were explanatory devices by which illiterate peasant societies could understand the phenomenon of physical or mental handicap. Haffter writes that along with the tales went a body

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of "folk wisdom" for getting rid of the handicapped infant, (exposure, beating, drowning etc..). The tales illustrate the belief in the middle ages that handicapped children were not human creatures at all, but sub-human ones surreptitiously substituted for the real child shortly after birth.

With the spread of Christianity however, the nature of the explanations changed and the handicapped child was no longer seen as a misfortune, but to have been caused by the impiety or misconduct of the parents. In some parts of Europe, the birth of a deformed infant was seen as evidence of involvement in witchcraft which led to the concealment of many of these children. "The transformation of the idea of the changeling by Christian demonology", writes Haffter, "meant that the existence of the child was a public denouncement of the parents' actions and even their thoughts. It ... became a shameful stigma in the eyes of society and a reason for isolation, ostracism and even persecution". Haffter apparently (according to Thomas (1978)), goes so far as to suggest that a residue of these earlier beliefs still actually influences present-day attitudes through what he terms a "societal collective unconscious".

NORMALITY, ABNORMALITY AND LABELLING

When we think of other people, we tend to use convenient conceptual packages or "labels". As Thomas (1978) suggests, perceptions of different social and racial groups and other "outsider" minorities form part of our social education. To be "like us", he continues, is natural and normal, to be "not like us", is to be foreign, unusual and abnormal. Physical disability is perceived as a violation of physical normality that often extends to social abnormality.

"Normal" is a classificatory term and as such can be defined as: most suitable to survive, carrying no penalty, commonly aspired to, most perfect of its class and a statistical distribution with known characteristics (Murphy 1972).

After examining the classifying process of people as having normal or abnormal intelligence Murphy (1973) felt that the demarcation lines were

imprecise. He felt the process to be both "arbitrary and expedient" and compounded by significant errors in measurement or evaluation and also by the intrusion of subjective judgement. Furthermore, Murphy (1973) felt that the line between normal and abnormal is so adjusted as to produce a deviant population of "just manageable proportions". Thomas (1978) questions whether a similar process operates in attitudes towards the disabled. He asks: "is society readjusting its views of the extent of deviance it can tolerate?". This idea is also explored in John Wyndham's "The Day of the Triffids" (1951).

Labelling and Certification

Following the 1870 Education Act, the state began to be formally responsible for provision of education for the handicapped. The acts of 1893 and 1899 enabled blind, deaf, epileptic and defective children to receive state education. However, this followed the pattern of earlier voluntary provision in that it was universally segregated, although not exclusively residential.

The act of 1921 combined earlier legislation and required that children be "certified as mentally or physically defective" before being admitted to special education. As Thomas (1978) comments, this labelling process undoubtedly contributed to the stigma which attached itself to special schools and special education in general.

One of the most notable features of the Butler Act of 1944 was the defining of categories of children needing special help and the placing of a definite duty on Local Education Authorities to discover children with disabilities of body or mind and to provide such special help as they required.

Thomas (1978) writes that one of the dominant themes of British education is the philosophy and practice of classifying, sorting and grouping of children. Thomas terms this both as a "sorting out and a sorting in process". By this he means that normal schools sort out those children who fall outside the restricted variability of behaviour and development which schools establish for themselves, and special schools then sort in children

according to their own criteria. This philosophy of classification is a subject surrounded by controversy and will be discussed elsewhere. As Thomas (1978) writes:

> "It can be argued that special schools by their openness - bring me your blind, crippled and retarded children and I will cherish them - have, as they have grown, provided a validating system for ordinary schools to narrow their version of what are acceptable pupils. This problem has its reverse side, however, since special schools also have their own ideas about their rightful clients, and because pupils do not always show easily classifiable symptoms, judgements about which educational system, ordinary or special, is right for a particular child, give rise to endless boundary disputes".

And as Thomas continues, "The elaborate classification of children by physical or behavioural characteristics following the 1944 Education Act has increased rather than decreased the intensity of this insular and self-perpetuating debate".

As we have seen then, stigma has surrounded special education almost from its inception. However, I do not mean to imply that integration of the handicapped into normal schools is the solution to every child's problem. Quite the reverse, in fact, as integration can pose as many problems as it solves. I propose in the next chapter to explore some of the issues and dilemmas concerned in the segregation versus integration debate.

INTEGRATION/SEGREGATION - THE DEBATE

"In the pantheon of educational mythology the angels are on the side of the integration of the handicapped and the devils are segregationists who would pack the worst handicapped and most maladjusted pupils off to remote residential schools. Perhaps in no area of education are feelings, opinions and practices more confused and ambivalent than in the residential sector.

In England our misnamed public schools are status symbols of privilege, elitism and academic excellence. But, for the majority of the population, residential education carries the stigma of workhouse, reformatory, borstal or Dotheboys Hall. Despite this dichotomy, many parents and voluntary bodies have laboured to set up residential schools for deaf, blind, cerebral palsied and other handicapped or orphaned children so that their needs might best be met. Special boarding schools have been seen as the best way of concentrating specialist resources, aids, therapies and skills upon handicapped children".

> Series Editors' Introduction to:
> Residential Special Education.
> Ted Cole (1986)

THE MOVEMENT FOR INTEGRATION

The segregation/integration debate is a comparatively recent dilemma. As Thomas (1978) points out, until fairly recently there was implicit acceptance of the nineteenth-century philosophy of segregation. That notion however has now been seriously challenged and there is a strong movement seeking to re-examine it. There are now those, writes Thomas, who argue that nothing except financial expediency stands in the way of having every handicapped child, no matter how serious his disability, placed in an ordinary school. As Thomas (1978) states, this has been (historically speaking) a remarkable revolution in attitudes. Over a relatively short period of time, we have come from neglect and indifference, through protectiveness, to an acceptance that the disabled child has a right not only to the best treatment and care, but also that his disability should not be used as a device to separate him from society.

The movement for integration gathered much of its momentum during the 1970s and 1980s. As Tomlinson (1982) informs us, the 1944 Education Act can be regarded as a major effort by educationalists to move as many 'defective'

children as possible out of medical domination and place them firmly under the educational aegis. Local education authorities were required to meet the needs of handicapped children in the form of special educational treatment within their general duty, to provide primary and secondary schools. A new set of categories for children needing special education was evolved, increasing the number of categories from four to eleven. This expansion of categories, continues Tomlinson (1982), was not surprising, considering that for the first time, England and Wales were about to develop a co-ordinated system of compulsory, mass primary and secondary education. Central and Local Education Authorities, having regard to the problems certain groups of children had posed following the introduction of mass primary education, did not wish secondary education to be similarly disrupted. In order to develop a workable system, it was essential to exclude as many children as possible who might obstruct or inconvenience the smooth running of normal schools, hence the need for careful categorisation. In addition, writes Tomlinson (1982) the 1944 Act allowed for a tripartite system of secondary schooling by 'age, aptitude and ability'. Selection by 'ability' sanctioned selection by 'disability'. Thus, the duty was laid upon local authorities to arrange provision for pupils suffering from 'any disability of body or mind'. This requirement, as Tomlinson points out, was vague and general enough to incorporate all children who might conceivably upset normal education. However, as she continues:

> "... the requirements of the (1944) Act did conflict with the egalitarian ideology which became more pronounced after the war; also, provision for such a wide variety of 'disability' was undoubtedly immediately seen to be expensive. The loophole to accommodate this was that less seriously handicapped children could be educated in ordinary schools, either 'normally' or in special classes. But suggestions that children in need of special education could remain in ordinary schools immediately conflicted with two educational interests: the goals of removing the children so that normal schools could function efficiently would be frustrated, and the expanding profession of 'special' education would lose clients. Thus, it was not surprising that provision for special education failed to develop in ordinary schools to any great extent".

Although the movement towards integration, as advocated by the Warnock Committee (1978) and the 1981 Education Act is a comparatively recent phenomenon (gaining momentum during the 1970s and 1980s), the actual idea

of integrating handicapped children into normal schools is certainly not new. Jamieson and colleagues (1977) point out, in fact, that there were more blind children in ordinary schools in 1889 than there are today.

Alexander Barnhill, writing in 1875, argued that more of the population of blind children should be educated, but to achieve this would probably mean their attending normal schools:

> "Much difficulty or expense has usually stood in the way of the admission of blind children into institutions, and many have been entirely neglected. Sufficient indication already appears that the country will not tolerate the education of 50% in institutions, and leave the remainder to grow up uncared for ... Teaching blind children with the sighted has not been advocated for the purpose of withdrawing children from institutions, but to overtake those not being educated, and to give anyone an opportunity of having his child taught at home. Which may be the better education need not be inquired into at present ... The great matter is to get a good education for all".

Barnhill was one of the leaders in what seemed to be a strong movement in favour of educating blind children in sighted schools. The 1889 report of the Royal Commission on the Blind, Deaf and Dumb, showed clearly the extent of integration at the time:

> "The school boards of Bradford, Cardiff, Sunderland and Glasgow have undertaken the education of the blind within their district, and 61 children in all are under instruction in these towns, 28 being educated in different schools in Glasgow alone. In most cases the children follow the ordinary time-table with their seeing companions, and associate with them both in school-time and play-time, Bradford and Sunderland being the only exceptions to this. On the occasion of (a visit) to Glasgow, the school board and their teachers expressed themselves as satisfied with the success of the experiment of educating the blind with the seeing in the board schools. In London the blind children usually attend the ordinary day schools, and share as far as possible in the instruction there given; but they also on specified days, receive special instruction at centres of which there are 18 ... The children are examined with the other scholars at the annual government examinations of the ordinary day schools they attend".

Jamieson and colleagues (1977) from whom the quote was taken, point out in a footnote however, that whilst an appreciable number of quite severely handicapped children may have attended ordinary schools and thus been

integrated, evidence that they actually achieved anything is tenuous. The only alternative to such schooling was often no schooling at all, and perhaps only in this sense was ordinary education considered satisfactory. The main driving force in the late 19th century was to ensure that all blind children received at least some education. None of the advocates of ordinary schooling was opposed to special schooling.

The pressure for integration in the 1870s and 1880s therefore had more to do with obtaining education for those without it than with displacing the special schools. The schools for the blind of that period, being very selective, did not cater for the majority of blind children although the Royal Commission of 1889 recommended compulsory education for the blind. This was enacted in the Elementary Education (Blind and Deaf children) Act 1893:

> "... the fact of a child being blind or deaf shall not of itself
> ... be a reasonable excuse for not causing the child to attend
> school ...".

The Act also enjoined school authorities to enable blind and deaf children in their district 'to obtain such education in some school for the time being certified by the Education Department as suitable for providing such education'.

There were other trends during this same period however which did not favour integration, not least the adoption of a reading method (Braille) which required special instruction. (The adoption of Braille in preference to other reading methods will be discussed at a later stage). It is interesting to note, however, that we have here, as Jamieson and colleagues (1977) point out, an argument very similar to the present day one favouring special schooling for the blind: that it may be less "natural" to attend a special school, but the final outcome (independence in society and a satisfying life as an adult) justifies its non-usual nature.

THE 1981 EDUCATION ACT - A NEW CHAPTER

The passing of the 1981 Education Act initiated a new chapter in the Special Education saga. Following the recommendations of the Warnock

Committee (1978) it gives legal recognition to the parents' right to be consulted when major decisions regarding their handicapped children's education are being made. It also acknowledges the part that parents can and often do play in their handicapped children's education.

Until the 1981 Act replaced it, the 1944 Act (with several amendments and supplementary Acts) remained the legal basis of Special Education. It is interesting to look (as Furneaux 1988 does) at the way in which parents were regarded under the 1944 Act and the role they were expected to play. It was the duty of the LEA to have regard for parents' anxieties about their children aged 2 and above. The authorities also had to give written notice to the parents that it was being considered that their child may need extra help. If the parents objected to the decision that special school placement was required, the authority had to proceed to certify that this was in fact necessary. If this was done and the parents still intended to oppose it, they had to appeal to the Minister of Education, who alone had the right to cancel or approve the certification. In other words, under the 1944 Act, the parents' rights were very limited, consisting solely of:

> "Being able to request a medical examination, which could be refused if the education authority considered it to be unreasonable; being present at the medical examination and the right of appeal to the minister against the authority's decision".

It is also worth noting, as Furneaux (1988) points out, that although the authority had to inform the parents of the decision that had been made, no one was obliged to tell them of their right of appeal. The parents however had a duty to present their child for the medical examination and they could be forced to comply with the decision which had been made.

Many parents reacted to this state of affairs by joining pressure groups and forming mutual aid societies, as it was soon appreciated that far more attention was paid to a body of opinion than to an individual's view. This in turn, led to a growth of public and professional interest. As a result of this interest, there was an increase in the amount of research into the problems of, and possibly undeveloped potential of the handicapped. Public and professional interest thus combined led to the belief that the whole

basis of providing special education should be reconsidered. This in turn led to the setting up of the Warnock Committee in 1974 and the resulting (1978) report.

The Warnock Report

The terms of reference for the Warnock Committee were:

> "To review educational provision in England, Scotland and Wales for children and young people handicapped by disability of body or mind, taking account of the medical aspects of their needs, together with arrangements to prepare them for entering into employment, to consider the most effective use of resources for these purposes and to make recommendations".

The report covered the whole age range from infancy to adulthood and emphasised three main areas as priorities for better provision. These were:

> The pre-school years
> The post-school years
> Teacher training

One of the basic conclusions of the report was that there is no particular point of separation between the handicapped and the non-handicapped, just a continuum. From this it follows that there is no particular point on the scale where children require special education. The Warnock Committee accepted that many more children (1 in 5 rather than the previously accepted 1 in 50) would need special education at some time during the school years. It also recognised that, for educational purposes, it was not appropriate to categorise children according to a medical diagnosis of handicap. The concept of "Special Educational Needs" was proposed in its place. These needs should be determined by a multi-disciplinary and detailed analysis of the child's strengths and weaknesses and should take into account educational, psychological and medical factors. Account should also be taken of the resources and deficiencies of the child's setting, thus emphasising the parental role, and also of the fact that special education should be defined in terms of what it consists of rather than where it takes place. The report also stressed the role of parents

and the importance of establishing and maintaining co-operation with them in everything relating to their child's assessment as having any special needs.

The 1981 Education Act – Emphasis and Influence

As Fish (1985a) points out, the 1981 Education Act does not cover all the Warnock Committee's concerns, only those which the Government was prepared to accept which required legislation. Nevertheless, as he states, it does embody powerful ideas which it is important not to lose sight of while developing new procedures.

The Act recognises a wide range of special educational needs, only some of which may be so severe and complex as to need the safeguard of special procedures for assessment and provision. The definition of special educational needs is not linked to specific causes and is relative to the needs of all children. The Act makes clear the responsibilities of ordinary schools to detect, assess and provide for special educational needs, it cautiously encourages the process of integration, and gives parents increased rights to share information and the decision making process. It abolishes categories and broadens the range of special educational provision.

In summarising the Act, Fish (1985a) points out that it emphasises that there is only one population of children, not two – i.e. the ordinary and the handicapped. Some members of this population may need special help because of disabilities or significant difficulties, but categories based on similar disabilities do not represent groups with the same needs. Thus the new framework endorses the right of all to education, whilst stressing the pre-eminence of common needs. It sees disabilities and significant difficulties as variations in need and not as defining different kinds of children.

Another major theme of the Act is that each child should be individually assessed so that where special education is necessary, it can be planned to meet individual identified needs. There is no longer an assumption that

a particular disability requires a particular curriculum or teaching methodology.

Integration is another major theme. Previous legislation had assumed that separate provision in special schools was the first essential and that arrangements in ordinary schools were a secondary alternative. However as Fish (1985a) points out, the Act recognises that integration requires careful planning as "Placement in an ordinary school is no guarantee of positive interaction between those who are disabled and those who are not".

Finally, the theme of parent participation is strongly endorsed. Parents, and young people who are handicapped are to have more information and to be more involved in making decisions. The education and treatment of the disabled is no longer to be the exclusive concern of the professionals and disability is no longer to imply incompetence in managing one's affairs. Fish (1985a) however concludes his chapter on the 1981 Act with a caution:

> "Although these themes will be recognised by those closely concerned with special education, they are as yet not always understood by other administrators and professionals. Nor are they firmly rooted in the attitudes of the general population. The "does he take sugar?" syndrome is not uncommon. Preoccupation with the nuts and bolts of implementing the new Act should not blind us to the importance of keeping these themes in the public eye".

THE CONTINUING NEED FOR SPECIAL SCHOOLS

Cole (1986) considering the continuing need for special boarding schools, argues that the continued existence of many residential schools will be, "aided by the natural inertia of people employed in the present system". The majority of these people, he continues, will not share the moral fervour of the keen integrationists. These "integrationists", as Cole (1986) states may have won over much of the media, but have yet to convince many experienced practitioners or parents, that in practice, children at present in segregated education would be better served by "mainstreaming". Some professionals may have experienced the difficulties of integrating children with emotional and behavioural disorders, or severe sensory impairments. They might well argue that whatever the moral and egalitarian arguments, it is unwise to disrupt an established special school network

(whatever its faults) for an alternative whose superiority is not established on a firm empirical base.

Supporting the status quo are figures given in the Fish Report (1985b), indicating that the majority of parents are satisfied with their children's placement in special schools. For example, 80% of a sample of parents considered the special school successful or very successful in developing their children's strengths and were pleased or very pleased with their progress. Some parents had actively pressed for their children to attend special schools, believing them to be superior to ordinary school alternatives.

Such research as has been carried out with regard to the integration of handicapped children into normal schools has shown somewhat divergent results. It should also be borne in mind that very few of the parents have had experience of both normal and special schools, thus their choice is hardly informed. Even fewer studies have included the children concerned and actually asked their opinions. Most studies of integration have been concerned with physically handicapped children, examples including: Anderson (1973), Madge and Fassam (1982) and Anderson and Clarke (1982). Although it appears that a majority of physically handicapped children and their parents prefer integration, as in the Fish (1985b) report, most were happy with their present placement whether it was segregated or integrated. Jamieson and colleagues (1977) discuss the issue in some depth, but as the authors state, their report does not claim to provide conclusive answers but reminds us that each case must be considered individually.

Cole (1986) argues that maintaining a choice of integrated or segregated provision is important. As he writes:

> "For the vast majority of children with special needs, day provision, possibly as part of their local comprehensive system is likely to be preferable, but families should not be denied the option of a segregated alternative, sometimes residential, which might in their particular circumstances, better meet their family needs".

In the final chapter of his book, Cole (1986), arguing the case for special boarding schools, presents criticisms sometimes made of special schools along with some of the responses which can be made in their favour. Some of the arguments which are pertinent to the education of visually handicapped children are presented below together with comments made by some of the blind clients from the Sheffield sample and other research studies.

> *"Boarding separates the child from his family and interferes with the natural pattern of a child's growing up with his parents and siblings".*

In some instances this is true, although as Cole (1986) points out, there are many thousands of families whose children attend residential public schools who do not see this as a drawback of overriding importance.

Cole also argues that if the family is under severe pressure with parents and child sharing a relationship full of conflict, then term times apart can help to create a happier more healthy relationship and rekindle dormant affection. This as Cole points out, will be achieved without stigmatizing the child or his parents as much as taking him into the care of the local authority.

39. Winston Whitehead. Functionally Blind. Weekly boarder at Blind School

Child from a large Afro-Caribbean family living in a deprived area of the city.

> "Oh he just loves school, can't wait to get back after the weekends. He's just like a lost soul in the holidays. There's loads you see going off for them to do after school. They have Cubs and pillow fights and all sorts of games and toys like you've never heard of. And lovely meals they have, and the bedrooms, well you've never seen anything like it. He couldn't have nothing like that here at home".

This mother has also solved the problem of separation and extending the family income by working as a cleaner at the school during the evenings.

"Special school isolates a child from his local community".

In most cases as Cole admits, this is true. However, he goes on to pose the question, "... are some children with physical disability every truly integrated into their local community, given the location of their houses and the extent of their handicap?" The Warnock Committee recognised that some severely handicapped children might have to attend special boarding schools in order to receive a reasonable range of "recreational and leisure opportunities". Cole also points out that the handicapped child from a deprived family background who has been stigmatized and negatively labelled by other children and families in his neighbourhood may well also be isolated. Such children, Cole argues can often find companionship in boarding school and make lasting friendships. Even if these can only be enjoyed during term time, Cole asks, might these not better meet the child's needs than a lonely life at home?

42. Louise Brown. Functionally Blind. Day Pupil at Blind School

> "Yes she does miss her friends from (special) school, because there's nobody round here for her to play with. The problem is they all live so far away and a lot aren't from Sheffield at all. We've asked a couple of her best friends round several times but they never seem to be able to make it. Public transport is a bit of a problem out here". (Village on the outskirts of the city).

> *"Boarding school denies a pupil a normal childhood, mixing and growing up with local children in ordinary day school".*

Cole argues that this statement suggests that the child would be happy in an ordinary school and benefit from the experience. But as he points out, many children in special schools have spent several years in integrated settings and have not enjoyed the experience. They have often been isolated, labelled as "failures" by staff and peers, have fallen behind in lessons and played truant. Cole argues that in contrast, many prosper in the small, segregated environment of the special school and have little wish to be reintegrated. If such children had remained in the normal school setting their continuing isolation and rejection could have been

very damaging to their development. And, as Cole writes, "It has yet to be proved that mixing children without handicap with pupils with special needs increases the sympathy and understanding of the former for the latter and some evidence suggests the contrary". (Here Cole cites K P Meadow, Deafness and Child Development, Arnold, London, 1980).

33. Robert Howard. Functionally Blind (Integrated for some lessons from attached Partial Sight Unit

"There was one teacher, Mrs P. I used to dread going into her class. She couldn't stand the sight of me and she put all the other kids against me, showing me up in front of them. One day she got hold of my ear and squeezed it because I hadn't realised she was talking to me. And she said, 'Robert Howard, answer me when I speak to you, or are you deaf and stupid as well as blind?' I was really upset and I could never concentrate on anything she was trying to teach for fear of what she would say. I used to try and get back into the (partial sight) unit for her sessions".

Sometimes it is the children themselves who make the decision with regard to the day/boarding placement. Louise quoted below is one of three children from the sample attending blind school as day pupils, who themselves requested to board on a weekly basis.

51. Lucy Baldwin. Totally Blind (Transferred from day pupil to weekly boarder at her own request)

"Well you can imagine I was really cut up about it. I mean we moved here so she could be a day pupil, and then she comes out with she wants to live in. I really didn't want her to, but she kept on about it and asked Miss B (class teacher) if she could board. I suppose I've sort of come round to accepting it now. I suppose all her friends are there and she was missing out on Brownies and all the other out of school things they have going on there".

"Small special schools cannot provide the width and variety of the ordinary secondary school curriculum, and therefore limit the educational opportunities and achievement of their pupils".

For some children again this may be true, but for bright blind children, generously staffed, larger residential grammar schools exist, such as Chorley Wood and Worcester. In many instances as Cole points out, the well run special school's concentrated special facilities, homogeneous teaching groups and additional staffing enables the curriculum to be more

effectively tailored to individual and self-esteem needs, thus enhancing the pupil's opportunities and achievement.

26. <u>Heather Jameson. Functionally Blind</u> Integrated into normal comprehensive school until age 14, then transferred to a Comprehensive with support unit.

"I really didn't want to go to blind school because I thought I would end up making baskets or something after I left. I wanted A levels and to go to university. I'd like to be a radiotherapist or something like that. When I got to 14 I just had to admit I couldn't keep up with the work. I hadn't got any friends, because I just worked and worked at home trying to keep up. They kept on saying "You'll have to go to Tapton special unit" and eventually I said I'd try. Well, it's been really great. I've got lots of friends, sighted as well as blind and the support teachers in the unit are really helpful with homework and class work. Most of the general teachers are helpful as well, there's only one I really don't get on with. I wish now I'd transferred sooner, because it's the best of both worlds really".

"Special schools can cocoon a child in an overprotected community, divorced from the harsh reality of the outside world".

Again this can be true and Cole suggests that special schools attack this tendency by adopting methods of organisation which keep pupils in touch with the wider world and prepare them for leaving school.

What Cole fails to mention however, is that handicapped children sometimes need a period of 'cocooning' in a special school environment in order to recover their self-esteem after taking the batterings of the outside world – as did the child below.

44. <u>Sally Patterson. Functionally Blind</u> Also physically handicapped, now spends much of her time in a wheel-chair.

"It was like banging your head against a wall, trying to convince them she couldn't cope in ordinary school. She was just so exhausted and unhappy, she just used to cry herself to sleep after she got home at night. Well, it got to the point where I said, 'enough's enough, she's not going back there no more'. So I kept her off school, and pretty soon this welfare inspector comes round. Anyway it got her a place at Oaks Park (Physically

handicapped school). The difference in her since she started going there, it's incredible. She's really settled and happy there".

"Placing a child in a community where all his peers have similar and perhaps worse difficulties surrounds him with unsatisfactory role models, and possibly leads to the exacerbation of his problems".

This is a valid criticism. Children can also become depressed in the special school environment as it is sometimes here that they learn they are not going to "grow out of their handicap", and that it could in fact become worse rather than get better.

Cole however counters the criticism, stating that in busy, happy, well organised schools, the role models presented by peers may well be more desirable than those of 'significant others' in the child's neighbourhood and at his former normal school.

2. Matthew Tomlinson. Functionally Blind

"I suppose starting at Tapton (blind school) was a bit of a shock at first really. I know it's silly, but I think I really thought I would grow out of being blind, sort of learn to see, like you learn to walk. I suppose when I got to school with all the other kids who couldn't see, I realised I wouldn't be cured. Well nobody ever tells you this. The doctors don't even talk to you and it's not something we've ever talked about as a family. I hadn't gone to Tapton I don't know when the penny would have dropped".

"Attending special school might lessen a young person's employment prospects".

As Cole points out, empirical evidence on this topic is lacking. There is however no evidence from my own research to support this view. In fact, of the parents who were themselves visually handicapped, all the fathers were in full-time employment. With regard to the women, however, this was not the case, and some of the mothers, although they had been seeking work for some time, had been unable to secure suitable jobs. It would seem from the sample group, (although the numbers are far too small for significance to be attached to the findings) that discrimination occurs more with regard

to gender than the school a blind person attends. Below, Robin Gill's
mother describes her experiences in the job market.

Case 1. Mrs Gill. Useful Vision

> "When we moved to Sheffield, I expected to be able to get a job
> straight away because I'd had experience as a child care worker.
> I applied for lots of jobs but they all said they wanted
> qualified nursery nurses - but they hadn't said in the adverts.
> I applied to go on the course but they wouldn't accept me - they
> said I wouldn't be able to cope with the writing. I've got a job
> at Rygate (multiply handicapped children) on nights part time,
> but they won't take me on days. I think they think it doesn't
> matter on nights if you can't see all that well. It's not really
> what I want but I can't get anything else".

> *"The expense of placing a child in a special boarding school is
> not justifiable".*

As Anderson (1973) states, this question does not appear to have been
officially investigated, the assumption usually being that ordinary school
placement will be cheaper. In fact figures in the appendix of Anderson's
book, (The Disabled School Child) show that in 1972 the cost per annum for
a physically handicapped child was roughly £571 in a day physically
handicapped school, £532 in a special class and £655 in an ordinary class
where three children are sharing taxi transport and a welfare assistant.
For one child alone she states, the latter costs would be likely to rise
to a total of over £1,000.

The cost of integrating visually handicapped pupils into ordinary schools
does not appear to have been assessed. However as Anderson (1973) points
out, adequate help for severely handicapped children in normal schools
cannot be provided cheaply.

To conclude this section, the educational carers of the sample children are
presented below.

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Pre-school Play Group

Forty five percent of the sample group were attending, or had previously attended a pre-school play group. The majority of mothers felt this had been beneficial to the children and that helpers, other mothers and the children had accepted the blind child well. Only one mother had been asked to withdraw her child because the group "did not cater for blind children". Such problems as were encountered had often been overcome by the mothers becoming organisers or helpers themselves.

Nursery Education

Forty seven percent of the children were attending or had attended a nursery school or day nursery. Additionally two children were awaiting placement in a private nursery school. Although there are nursery places for children with special needs (integrated with normal children) in Sheffield, none of the sample group attended these nurseries, all being integrated into the normal system. One child had attended a special nursery for blind children in London, but the mother had been unable to obtain any kind of nursery placement since moving to Sheffield. Only one child had been refused nursery placement because of the handicap. Apparently the head mistress had expected the child to sit passively and was unprepared for an active inquisitive child. She did not consider the environment to be safe for her. An alternative placement was later found for this child.

Again the majority (77%) of the parents felt the child had benefited from nursery placement and had been happy during this time. Most of the problems which had arisen had been solved within a relatively short period of time. Problems centred mainly around staff being unsure of how to cope at first and the child's initial distress at being separated from the mother.

Primary School

Thirty four of the children were attending, or had previously attended primary school. Nineteen of these attended normal schools. A further 2 began primary education in normal school but were later transferred to special schools. Ten children attended blind school in Sheffield and one blind school in another city. The remaining 2 children attended the partial sight unit in Sheffield. Most of the children (82%) attended as day pupils. Five children attended as weekly boarders (Monday to Friday). The child attending the out of city school came home only during school holidays.

Problems associated with primary school

Over half (56%) of the children were said to be very happy or fairly happy at school and encountering few or no problems. The problems associated with primary school are shown in Table 12.1 overleaf.

Although the numbers are far too small for any conclusions to be drawn, it seems that, for the Sheffield children at least, those in special education fared rather better than the integrated children.

Middle/Junior School

Twenty eight of the sample group were of an appropriate age to be attending or have attended middle or junior school. Of these, the majority (64%) were in special education. Only 10 children were attending normal school by the age of 8 years. This figure includes one child integrated into normal school from the partial sight unit. Four children had transferred from normal to special school, giving a total of 15 children attending blind school and 3 the partial sight unit. At this point in their career, all 28 children were educated within the city.

Table 12.1 Problems Associated with Primary School. N=34

Problem encountered	TYPE OF SCHOOL		
	Normal N=21	P/S Unit N=2	Blind N=11
None, very happy	5	1	7
Fairly happy	3	1	2
Behind with work/not coping	6	-	-
Teased/ridiculed/ stigmatized	4	-	-
Parents happy but not LEA	3	-	-
Homesick/psychological problems	-	-	1 out of city
Don't know (first term)	-	-	1
Total experiencing problems	13	0	1 out of city

The majority of the children (22) attended as day pupils. Three of these had transferred from being boarders (two at the parents' request and one at the child's). At this stage 6 children were boarding, including three who had transferred from day attendance (all at the child's request).

Problems associated with middle/junior school

Again a majority of children were said to be very happy or fairly happy at middle school. Problems associated with middle school are shown in Table 12.2 overleaf.

Table 12.2 Problems Associated with Middle/Junior School. N=28

Problem encountered	Normal N=10	P/S Unit N=3	Blind N=15
	TYPE OF SCHOOL		
one, very happy	2	–	10
Fairly happy	1	1	5
Behind with school work	3	–	–
Teased/ridiculed/ stigmatized	1	–	–
Emotional/behavioural disorder	2	–	–
Lack of parent/teacher communication	1	–	–
Not pushed academically	–	1	–
Happy in unit, not when integrated	–	1	–
Total experiencing problems	7	2	0

Once again, it seems the children in special education, particularly those attending blind school experienced less problems than the integrated children.

Secondary School

Fifteen children were of an appropriate age to have entered secondary education. Six children were fully integrated into normal schools including 3 children who transferred from special education. Four children were attending Tapton comprehensive school with resource unit support from the blind school. This includes one child transferred from normal comprehensive school, for whom integration failed to work. A further 3

children had been transferred to special schools outside the city and the remaining 2 were in special schools in Sheffield. One child was in the blind unit of a school for children with severe learning difficulties having suffered severe emotional disturbance as a boarder in out of city schools, the other attended a school for physically handicapped children as a day pupil. This child had previously been integrated into normal school. She suffered from Friedrich's Ataxia, a progressive disease of the nervous system and was admitted to special school when her condition deteriorated.

Again the majority of children attended as day pupils. One child boarded on a weekly basis in the hostel attached to Tapton resource unit and the remaining three children attended out of city boarding schools, returning home only during school holidays.

Problems associated with secondary school

Problems encountered by the children in secondary education are shown in Table 12.3 overleaf.

It must be stressed that because the numbers are so small, the figures in the tables must be interpreted with extreme caution. However the tables show that the proportion of integrated children experiencing problems rises progressively as the children get older; 62% have problems at primary level, 70% at middle school level and 100% of integrated secondary school pupils experience problems. It would appear therefore that there is a fairly strong case to support the retention of special education (in Sheffield at any rate) for visually handicapped children.

Table 12.3 Problems Associated with Secondary School. N=15

Problem encountered	Normal N=6	Resource Unit N=4	Blind OOC N=3	Physical Handicap N=1	SLD N=1
None, very happy	–	1	–	1	1
Fairly happy	–	1	1	–	–
Behind with school work	1	1	–	–	–
Staff unaware of problems	3	–	–	–	–
Likes school but not boarding	–	–	1	–	–
Severe emotional problems	2	–	1	–	–
Don't know (first term)	–	1	–	–	–
Total experiencing problems	6 (100%)	1	2	0	0

Further Education

Six children had entered or were about to enter post 16 education. Of these, two were continuing in special education – one to Hereford College for the blind and one in the Severe learning difficulty blind unit. A further two children were staying on at Tapton Comprehensive with Resource unit support, to take A levels. The remaining two children were entering normal further education, one to a Sheffield FE College to undertake an office foundation course and the other to university to read Economics. A further three children were awaiting the results of their GCE examinations.

In Conclusion

Whilst in the 'pantheon of educational mythology', the angels may be on the side of integration and the devils the segregationists; once these issues are stripped of their mythology and mystique, it seems there is little empirical evidence and even less hard fact, to support either side in the debate.

In the real world, neither integration nor segregation is wholly good or wholly bad and it must be remembered that the only winners or losers in this educational chess game are the children. However, if each child is considered as an individual with abilities and disabilities, ordinary needs and special needs, and an attempt made in each case to provide for these needs, taking into account the resources available, the debate itself could well be consigned to the pages of history books.

The processes by which children are selected for special education will be discussed in the following section.

ASSESSMENT: THE POWER AND THE PROCESS

THE PROCESS OF SELECTION

The word 'assessment', Withers and Lee inform us, is now commonly used in such a variety of educational contexts that it is easy to forget it has acquired this key role in educational discourse only in recent years. All kinds of qualities and personal traits are said to be 'assessed', yet the use of the term carries with it the implication that the process of selection by assessment is scientific, neutral and benevolent. However, Withers and Lee (1988) continue:

> "Assessment of pupils within schools is the exercise of power by those who arrogate the functions of assessors, yet it is constantly acted out as an unthreatening natural activity. Assessment, which is claimed to be scientific, including the use of special instruments, such as tests, profiles and such procedures is at the same time nothing but an extension of ordinary judgements which any teacher makes of her pupils. A process which alters the future treatment and life chances of children, and which is sometimes the means by which pupils are selected for special provision, is somehow presented as contemplative and advisory, as if the judgement were made elsewhere, independently of the practices of the assessor. The basis of the process, especially the norms on which it is based, is nevertheless inaccessible to those who are 'assessed' and whose futures will be altered as a result".

The threatening and powerful aspects of assessment seem to have been hidden from assessed and assessors alike and as Withers and Lee point out, critics of examination and testing appear to have been disarmed by talk of 'assessment'.

Educators, whilst differentiating the performances of pupils, produce on the one hand those who are "certified successful", and on the other, in extreme cases, those who will be totally segregated from the mainstream system.

It has come to be recognised that tests and examinations are constructed to produce positional results and they are acknowledged instruments of

selection. On the other hand however, assessments of ability or disability, of degree of special need, or of suitability for a particular type of schooling, are seen as being motivated purely by concern for the interests of the pupil.

Assessment itself, assert Withers and Lee (1988) is a profoundly ideological process. They point out that although, "testing and examination are recognised as means of providing restricted gateways to serve a function in a positional society", assessment somehow escapes this kind of analysis and is seen as being completely benign and humane.

Assessments, Withers and Lee argue, are made by using criteria. Criteria are employed to judge something against an example in order to ascertain whether it is similar or different. We all use criteria for picking out objects, and, as Withers and Lee remind us, people. By this means we can recognize whether people are the same as, or different from each other. In this sense it can be argued that assessment is a necessary and natural activity which everyone engages in. However, as Withers and Lee point out, the criteria employed in assessments are means by which judgements are made of how nearly a sample compares to a standard example. Here they use measurement as an example, i.e. checking a sample against the paradigm of the metre measure, which is kept in a case under standard conditions. People obviously cannot be assessed by using methods devised for objects. Withers and Lee argue that in the case of school children, the paradigm will be an idealized model of reading and calculating ability or of coherence in writing. The implication is that people require 'norm-referenced assessment' rather than 'criteria-referenced testing'.

Withers and Lee (1988) point out that the norms used to assess children are imaginary. In other words, each assessor carries in her head the paradigm or 'standard' against which she will judge the children. And, as Withers and Lee argue, this allows them to exercise considerable and uncheckable power. This power is uncheckable and unaccountable because the criteria are imaginary and not accessible to the uninitiated. Thus, as they explain, the 'experts' are able to defend their power and the assessed have no form of redress.

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Children with special needs are assessed according to medical models of disability using paradigms drawn from medicine, where as Withers and Lee point out, the power of the professional to shroud their speculative, imaginary nature from public scrutiny is exceptionally strong. Thus they argue, assessments for special education are able to take on the mystique of diagnosis, the protection of the expert professional and the secrecy and power of the clinician.

In this section, some of the reasons for selecting children to be removed from mainstream education will be discussed, as will the selection process itself and some of the ways in which it is carried out.

Historical Background and Reasons for "Counting Out"

As Tomlinson (1982) informs us, during the 19th century, the medical profession developed and sustained an interest in all kinds of 'defect'. It was medical influence which dominated all the commissions and committees on defective children in the late 19th and early 20th centuries, for example, The Egerton Commission, 1889; The Committee on Defective and Epileptic Children, 1889; and The Report of the Royal Commission on the Care and Control of the Feeble Minded, 1908.

Clinical definitions of various types and grades of defect therefore became the prerogative of medical men. A medical superintendent (Fletcher Beach) of one of the first idiots asylums devised a test for feeble-mindedness. This is recorded in Pritchard (1963):

> "Fletcher Beach, who had been Medical Superintendent of Darenth, had also devised a test of feeble-mindedness. Among other things, he looked for malformation of the head, a V-shaped palate, large coarse, outstanding ears, a fixed stare, a curved little finger and distractibility noticeable by a constant movement of the eyes. Beach felt that his test was more efficient than that of Warner, (another medical man who based his judgements purely on physical appearance) for detecting feeble-mindedness, but agreed with Warner that only a medical man was capable of diagnosing mental weakness. However, he cast some doubt on the practicability of his system when he stated that there were not more than six doctors in England capable of discriminating between imbeciles and feeble-minded children".

Tomlinson (1982) argues that the perspectives of disciplines such as medicine (and later psychology) and the actions of professionals and practitioners are themselves constrained by the structure of society. The structure of an industrial society provides a number of contradictions for those involved in special education to resolve. Until quite recently, the profit motive of this type of society dictated that as many members as possible should be productive and even the handicapped should work if possible. If the handicapped are not productive, contradictions arise as to how much of society's resources should be allocated to them. Similarly, as Tomlinson points out, the preparation of a productive, educated workforce in ordinary schools was, after 1870, seen to be impeded by handicapped or defective children. A contradiction which has yet to be resolved after 100 years is the provision for, and control of potentially 'troublesome' groups of children, whilst at the same time keeping the costs low and encouraging as many as possible to become productive and self-sufficient.

Thomas (1978) argues that the "counting out" or referral process is not just one of applying educational, medical or psychological criteria. The referring school, like all organizations is concerned with survival – even more so, affirms Thomas, when that organization is relatively stable. One measure of stability, he writes, is the degree to which the school has control over pupils who threaten its status quo. If pupils who challenge this stability cannot be dealt with within the confines of the school (by placing them in a special class or unit where their deviance can be legitimized), the alternative is to exclude or transfer them to another school. This means their problems must be defined in such a way as to make them someone else's concern. Children who are counted out and referred, writes Thomas, can then be regarded as heterogeneous threats to organizational stability, rather than as members of clinically defined categories. Within its own confines, he continues, "the school can disperse children with a fair degree of autonomy but in the referral process the school psychologist acts as a deterrent to unrestricted offloading".

Obviously, schools are not unaware that referral and segregational placement can be made easier by expressing a child's problems in terms which legitimate his removal. As Thomas (1978) points out:

> "The elaborate mechanism for removing pupils as against the informal approach to reintegrating them indicates the respective values the institution places on these activities. The procedures are more than devices for responding to perceived needs in children, they are institutionalized practices for getting rid of organizational irritants".

Needs and Categories

Tomlinson (1982) points out that much of the descriptive literature on the development of special education takes for granted that the categorization of handicaps has gradually evolved as though spontaneously over the last 100 years and that the major problem is moulding the categories of handicaps or 'needs' to the children. Tomlinson however, argues that sociological analysis has begun to show that administrative categories, particularly those that remove children from mainstream education, do not mysteriously develop in an evolutionary manner. Categories, she maintains, appear, change and disappear because of the goals pursued and the decisions made by people who control the special educational processes.

The terminology employed in special education to define and categorize handicapped children is constantly changing. This is not accidental, but is the result of the competing interests involved. As was pointed out in a previous section, where there is competition between groups with vested interests in defining weaker social groups, the labels and definitions finally applied are those of the winning group. Thus, as Tomlinson (1982) argues, early medical interests in special education meant that doctors had an interest in making as many categories as possible medically oriented, while educational interests sought to make categories educational where possible. Doctors wanted to apply medical labels so that the skills and mystique of the medical profession could be used to legitimate the placing of children in special schools dominated by medical men.

It is interesting to note in this context, as Tomlinson (1982) points out, that in just over 50 years, from 1893 to 1945 the first two educational categories (idiot and imbecile) had become eleven.

However as Tomlinson explains later, administrative problems over the static nature of the categories and changing post-war ideologies meant that this kind of categorization of children became unsatisfactory. Economic pressures were also important. As it was financially impossible for LEAs to set up special schools for all categories, provision over the country as a whole developed in a somewhat patchy manner.

CASE FINDING AND COUNTING

One of the reasons for this seemingly haphazard and patchy provision for special needs, was, (and still is) that the extent of the problem is largely unknown, and the authorities therefore have difficulty in planning for the future. It is true that attempts have been made (mainly by medical men) to address the problem of identifying children with special needs from the middle of the last century. For example, as Pritchard (1963) relates, in 1888 Francis Warner, consultant paediatrician to a number of children's hospitals in London, was convinced that there were far more children requiring education in special schools than any of the school authorities imagined. And he set out to find out how many. By 1890 he had examined 50,000 children in London's Board and Poor Law schools. He found that 1% had physical or nervous defects, and in addition, were reported by their teachers to be of very low intelligence. Warner maintained that all of these children required special education in separate schools. The results of Warner's survey were published in 1893 by the Charity Organization Society. ("The Feeble-Minded Child and Adult"). He was encouraged by the Congress of Hygiene and Demography (held in London in 1892), to continue his investigation and by 1894 he had examined 100,000 children looking for four classes of defect:

> "Imperfections in bodily development and physiognomy, abnormal neurological responses, poor physical condition due to lack of adequate nutrition or chronic illness, and mental dullness. The one percent which he estimated should receive special education were not only all mentally dull, but also suffered from the first three classes of defect. Thus, if Warner's thesis was to be

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accepted, there were in London alone, over 6,000 feeble-minded children who were also physically handicapped".

<div align="right">Pritchard (1963)</div>

Because of the difficulties of defining and categorizing handicapped children outlined above, attempts to discover the extent of the problem tended to produce inaccurate and misleading results.

The problem of numbers, as Pritchard (1963) relates, was the first that confronted the Commissioners when they turned their attention to the deaf. A census in 1881 had, according to Pritchard, provided valuable information regarding the numbers of blind people, but this was not so in the case of the deaf. Parents of deaf children were unwilling to acknowledge the problem until the child was at least five. Consequently, young deaf children were rarely included as such on the census return. Apart from the inaccuracies so produced, as Pritchard continues, there were other factors rendering census figures misleading and unreliable. In the case of one district in Ireland, the figures for the deaf were so widely at variance with the usual proportion, that the returns were sent back for investigation. It was then found that every child too young to speak had been returned as deaf and dumb.

Despite the unreliability of the census returns however, it was estimated that in 1888 only around half of all deaf children aged 5 to 13 were having any kind of education at all.

Discovering and Enumerating Visual Problems

Jamieson and colleagues (1977) refer to the difficulties involved in obtaining a comprehensive statistical picture of visual handicap. As they point out, a sizeable number of children with visual defects may not show up in official statistics at all because they have not been detected. They remain undetected until, as one respondent in Jamieson et al's survey said, "one trips over them and sees they are under-achieving". The conviction on the part of many of the respondents in their survey was that there exists a large number of school age children who have received no specialist opinion or attention, but who have defects of vision which

interfere with their effective school functioning, and sometimes severe enough to be defined as partial sight.

There is evidence to support this conviction, including data in Section I of this present study. The Optical Information Council, in 1970 screened 1,000 children between the ages of 6 and 15 years. They found that over 20% required further referral for faulty vision. They concluded that as many as 2,975,000 school age children in the UK may be in need of help. They also recommended an urgent review of sight testing in schools and screening procedures. Further evidence has come from the Health Authorities, for example Manchester, York and Liverpool, who have set up multi-disciplinary teams to help children with visual problems. In view of the above evidence, the recommendation of the Working Party on Child Health Surveillance (The Hall Report 1989), to the effect that: (Vision screening in pre-school children) "is of uncertain value, and while it may be continued pending further evaluation, it should not be introduced if not already in use", seems a somewhat retrograde step.

The Hall Report is discussed elsewhere.

The Usefulness of Tests for Visual Acuity

What is often not appreciated when considering the usefulness of vision testing, is that the tests do not give an accurate indication of an individual's ability to move around, or to cope with daily living. Educators frequently complain that school placement is still too often based, primarily on an ophthalmological opinion. Ophthalmologists, they point out, do not see the child in school or at play, but rely almost entirely on test measurements, which are inadequate predictors of how effectively a child will cope with living skills or how well he will use the sight he has.

Phenomena such as these are now more widely acknowledged, and it is therefore argued that appraisal of vision, particularly for educational purposes, should be based as much on 'real life' kinds of tests, as on standard acuity measures. Reliance on medical assessments of vision as Jamieson and colleagues point out, has proved insufficient for making

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educational decisions. One respondent in their research opposed the idea of automatically turning to an ophthalmologist for guidance. "The decision ought to be based on trying both mediums with the child in the classroom, not on acuity with print indicated by a vision chart".

Some educationists and other field workers have devised their own methods of testing functional vision. However, as Jamieson and colleagues point out:

> "An obvious difficulty in appraising functional vision, whether in this relatively crude fashion or in more systematic ways, is in codifying and quantifying it with anything approaching the precision of the Snellen chart".

Because of the difficulties with codifying and quantifying functional appraisals, the medical profession tends to regard these methods as crude, unscientific and therefore unreliable. This lack of mystique and a 'scientific' base also tends to devalue both the test and the person administering it in the eyes of clients and other professionals. "Anybody can do what she did, there's nothing to it", as one parent complained.

POWER AND PROFESSIONAL CONFLICT

Discussing the various viewpoints of sociologists studying special education, Tomlinson (1982) writes:

> "From structural perspectives, questions could be raised about the whole development and purpose of special education in a class-stratified industrial society. Sociologists who used these perspectives would maintain that, since conflict is endemic in all social institutions, special education is no exception. There is conflict in a variety of situations in special education, not least within professions, between professionals, between parents and professions in special schools, and between mainstream and special schooling; and power and coercion play a large part in resolving conflicts".

Tomlinson points out that it is the acceptance of legitimate authority, as well as outright coercion, that ensures the compliance of some groups to others. She reasons that this is an important notion in explaining why

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parents have come to accept professional judgement and opinions as to 'what is best' for their children.

Oliver (1988) in an essay on the Social and Political Context of Educational Policy with regard to special needs, views social policy regarding disability respectively as a humanitarian response, as a social investment, as the outcome of conflict between competing groups and as a form of social control. Oliver (1988) puts forward three accounts of disability, each account carrying with it a basic definition and understanding of the nature of disability.

A. Disability is and Individual Problem

This has been called "the personal tragedy theory of disability". It assumes that becoming disabled is a tragic event and that disabled individuals must adapt themselves, physically and psychologically to society. This description, as Oliver points out, underlies most approaches in the field of professional practice and is adopted by field workers such as teachers, social workers, doctors and psychologists. This view point suggests that it is the disabled person who has the problem and intervention aims to provide him with the appropriate skills to cope with it.

B. Disabilities are Socially Constructed

Oliver terms this the "Social Constructionist" view. This definition has been used by academics and researchers interested in special needs. It has also been used as Oliver points out, by policy makers seeking to solve problems by changing terminology, here he cites the WHO (1981) definitions of impairment, disability and handicap. From this viewpoint, the problems of disability have failed to be solved because the problem was wrongly defined in the first place. According to this argument, the problem lies in the fact that some people define others as disabled and therefore treat them differently. Therefore if we alter the labels and change the way people think about disability the problem is eliminated.

Disabled people themselves criticise both these stand-points. They argue that:

C. Disabilities are Socially Created

This position argues that Society itself disables handicapped people by the way it responds to their impairments. For example, the inaccessibility of buildings stems from decisions to design them in particular ways and not from the inability of some people to walk. The solution to this problem therefore is to create a barrier free environment rather than attempt to provide disabled people with the necessary skills to cope with steps.

In Conclusion

Oliver (1988) argues that notions of conflict and vested interest can also be used to explain the development of special education. He asserts that the power of certain groups to advance their interests at the expense of others, is a crucial part of this explanation. Oliver's argument is that the initial development of segregated special education was a consequence of the vested interest of ordinary schools in ridding themselves of potentially demanding and disruptive pupils. Subsequent trends, he explains, were then shaped by the group power of newly developing professions including school doctors, specialist teachers, psychologists and educational administrators. Oliver asserts that the 1944 Education Act represented the dominance of the medical profession at that time, and that subsequent developments, culminating in the 1981 Education Act, spring from the gradual challenge of this dominance by other groups including psychologists and educational administrators.

Thus, although the 1981 Education Act has perhaps, to some extent, altered the balance of power and (in theory) has included parents as partners in the assessment process, by increasing the numbers of people involved in the process, it has also increased the potential for conflict.

Below, some of the parents give their views on and experiences of, the assessment process.

41. Darren Morton. Functionally Blind (Integrated)

"It's no help at all really (the assessment), because whatever you say they don't listen. They're just too busy fighting each other. It doesn't matter to them he's not coping and won't go to school if he can avoid it. Miss G (support teacher) and Dr E both want him in blind school, but the psychologist just blocks it every time".

36. Kenneth Barton. Functionally Blind (Transferred to Special School)

"It (the assessment was absolutely stupid. This woman (school doctor) says to him 'stand on one leg' and he kept falling over. They said he was spastic because of that. They never asked him to do anything sensible, and not one of them took into account that he couldn't see".

30. Coral Baker. Functionally Blind (Awaiting Nursery Placement)

(Assessment performed in London, not Sheffield) "Yes, it was really useful, they explained why they did everything, and they did special tests for blind children. They said she was up to her age in most things and told me how to help her with toys and that, where she was behind. But since we came to Sheffield there's nothing like that. It's rubbish really. I've got her name down at three nursery schools, but there's no way they'll make a special case for her. She's just got to wait her turn with all the others for a place".

31. Dawn Allerton. Useful Vision (Transferred to Partial Sight Unit)

"Well, she started off at normal school and she seemed to me to be doing OK. I mean, she liked it and there didn't seem to be any problems, or at least nobody said anything to me about any. Then she had the MI the second term, and the school doctor said 'who the hell let you into normal school?' Anyway a psychologist comes up to see her and she got sent to Stradbroke (Partial Sight Unit)".

13. Callum Pickering. Functionally Blind (Transferred to Partial Sight Unit)

"No, they never said anything to me about what they thought. Naturally I thought he would be going to normal school. I was getting him ready the first day when up comes this taxi to take him to Stradbroke (Partial Sight Unit)".

4. Wendy Jenkinson. Functionally Blind (Normal Nursery School)

"Oh yes, she had an assessment. I was furious about that. He (school doctor) implied that she was thick and not very bright. He told her to draw a square and a triangle, and I said 'how can she copy what she can't see?' but it made no difference. Then he wanted her to build things with bricks and she couldn't do that

either. She got really upset about it. I felt like telling him it was him that was thick, not her. I was going to complain about it actually, but what's the point?".

Tomlinson (1982) concludes that:

"Needs are relative, historically, socially and politically. The important point is that some groups have the power to define the needs of others, and to decide what provision shall be made for these predetermined needs. The unproblematic acceptance of 'special need' in education rests upon the acceptance that there are foolproof assessment processes which will correctly diagnose and define the needs of children. But the rhetoric of special needs may have become more of a rationalisation by which people who have power to define and shape the system of special education and who have vested interests in the assessment of, and provision for, more and more children as special, maintain their influence and interests. The rhetoric of special needs may be humanitarian, the practice is control and vested interests".

CHAPTER 14

THE SPECIAL CURRICULUM

Piping down the valleys wild,
Piping songs of pleasant glee,
On a cloud I saw a child,
And he laughing said to me:

'Pipe a song about a lamb'.
So I piped with merry cheer.
'Piper, pipe that song again'.
So I piped, he wept to hear.

'Drop thy pipe, thy happy pipe,
Sing thy songs of happy cheer'.
So I sung the same again
While he wept with joy to hear.

'Piper, sit thee down and write
In a book that all may read'.
So he vanish'd from my sight.
And I pluck'd a hollow reed,

And I made a rural pen,
And I stain'd the water clear,
And I wrote my happy songs
Every child may joy to hear.

<div align="right">

William Blake
Songs of Innocence and Experience

</div>

KNOWLEDGE, POWER AND CONFLICT

Tomlinson (1982) writes that a consideration of the special school curriculum must lie at the heart of a sociological analysis of special education. For, she continues, "it is here that beliefs that the special needs of children are being met can be tested, clarified and appraised by

an examination of what teachers and pupils actually do in special schools and classes".

In order to appraise the special curriculum, information is required on the goals and aims of special education. Also as Tomlinson continues, on what counts as a 'special curriculum', on what kinds of knowledge and skills are offered or withheld, the kinds of activities which are organised and the provision of available resources. Information is also required on the methods used and the types of evaluation employed. As Tomlinson writes, "Special needs in themselves do not generate a curriculum".

Although there is a large literature on practice and method in special schools, the emphasis is on what to teach and how to teach it. Much of this literature is concerned with what Tomlinson (1982) terms "practitioners talking to each other", that is, the emphasis is on what to do and how to go about it, rather than the theoretical considerations of why it is done. As Tomlinson writes:

> "Much of what practitioners and their advisors talk about is classroom practice, provision of resources, and teaching methods - there is virtually no discussion of the overall goals of special education and the values and beliefs that might be implicit in these goals. Special school teachers, like teachers in other parts of the education system, usually go about their work on a pragmatic day-to-day basis. Indeed, much of the teacher's activity is dominated by an ethic of practicality".

Eggleston (1977) points out that, "The teacher who has fundamental doubts about his rights to teach the curriculum is at best regarded as a crank". But, as Tomlinson (1982) argues, teachers in special schools, like their colleagues in mainstream education, are involved, whether they acknowledge it or not, in issues of power and control and therefore their decisions about what comprises the curriculum in their classes do affect the immediate and future lives of their pupils.

Tomlinson goes on to give an example of this power:

> "... in a society in which an increasing amount and complexity of knowledge is needed to function as an independent person, one implicit goal of special education is to seek out and withhold large amounts of what is generally considered by the rest of

society to be important knowledge. If challenged, this selection and withholding may be justified on the grounds that the children 'cannot benefit', 'would not understand', or have 'special needs'".

Musgrave (1972) noted that, "The curriculum stands analytically at the centre of the process whereby any society manages its stock of knowledge". Tomlinson (1982) argues that it is the distribution of different kinds of knowledge and skills through the curriculum to different groups of children, or the withholding of certain kinds of knowledge that largely determines their future social and occupational status. Therefore, she points out, those involved in decisions regarding the curriculum have a great deal of power.

Sociologists have, it appears, taken little interest in the normal school curriculum, and, according to Tomlinson, none at all in that of the special school. Eggleston (1977) pointed out that this has meant that study of the curriculum has lacked adequate considerations of either the social forces influencing it or the implications of deciding on the kind of curriculum to offer to different social groups.

Tomlinson (1982) argues that every society makes different kinds and amounts of knowledge available to different categories of people, and that, "... there are high- and low-status areas of knowledge, and that academic-type knowledge has a higher status than manual or manipulative skills".

AIMS AND OBJECTIVES FOR A SPECIAL CURRICULUM

The Warnock Committee (1978) felt that education has certain long term goals:

> "They are, first, to enlarge a child's knowledge, experience and imaginative understanding and thus his awareness of moral values and capacity for enjoyment; and secondly, to enable him to enter the world after formal education is over as an active participant in society and a responsible contributor to it, capable of achieving as much independence as possible".

According to Tomlinson (1982), curriculum is concerned with learning activities and the transmission of knowledge in a social setting.

Eggleston (1977) considers that curriculum is concerned with the presentation of knowledge and involves a pattern of learning experiences: "... Curriculum involves a number of components, including aims, content, methodology, timing and evaluation, that spring, like the curriculum itself, from the normative and power systems of the society".

Lawton (1975) writes that: "... the school curriculum is essentially a selection from the culture of a society. Certain aspects of our way of life, certain kinds of knowledge, certain attitudes and values are regarded as so important that their transmission to the next generation is not left to chance".

Eggleston and Lawson both make reference to what Tomlinson (1982) describes as a 'hidden curriculum'. By this they mean those unofficial, informal activities which count as learning, but which would not appear on a timetable. Tomlinson cites as an example the learning of implicit standards of appropriate behaviour.

Tomlinson (1982) argues that whether the curriculum is explicit or hidden, the selection from culture, the aims and methods used, and the kinds of knowledge chosen to impart to particular groups of children, all depend on the dominant groups in the education system. These people, with their own particular ideologies and traditions are the ones holding the power to make decisions and to finance resources.

Tomlinson further points out that the 'benevolent humanitarianism' implicit in the provision of special educational treatment makes it difficult to subject the special school curriculum to critical scrutiny. The major perspective on the special curriculum, she argues, is a philosophical one. Special education is 'depoliticised', described as 'good', 'something to which all human beings are entitled', and so on. Any criticisms tend to be expressed in terms of failure to provide resources. Humanitarian and philosophical approaches, as Tomlinson points out, make it difficult to enquire who has the power and expertise to decide what form 'good' shall

take, who controls the special curriculum, what its ultimate aims are and who is able to sanction or withhold resources.

Until very recently there was little agreement on common aims for the curriculum of children in normal schools - as recent controversy has demonstrated. Where there was agreement, the aims were so general as to have little intrinsic meaning.

As Tomlinson (1982) points out, in normal schools there is still little agreement over whether curriculum planning should be aimed at the need to supply trained manpower for industry, or to educate for 'leisure' or possible unemployment. That is, whether to educate an elite few in a high-status academic curriculum or whether a common core curriculum should be followed by all children in normal schools. There is, as Tomlinson writes, "even less agreement on whether education should be aimed at providing credentials or providing access to a richer, more worthwhile life". If, as Tomlinson argues, there is disagreement and controversy over the nature of the curriculum in normal schooling, it is hardly surprising that there should be disagreement over that for special schools.

Tomlinson suggests however, that there are ways in which the aims thought to be appropriate for both normal and special schooling overlap. These are the aims of training pupils for self-sufficiency and productivity, and the aim of producing controlled, moral, social behaviour. However, as Tomlinson argues these aims presuppose that elite groups with power and influence, who have received a superior education can decide on aims for those in mass education.

Throughout history, the majority of special school leavers have followed a curriculum having the general aim of preparing them for some kind of low-status employment. The Wood Committee, (Mental Deficiency) reporting in 1929, stressed that the major aims of special schooling should be social adaptation and conformity, and the ability to earn a living. Tomlinson points out that this aim of creating self-sufficiency and productive employment and stressing the social qualities needed to obtain and hold down a job, still persist in special education.

Of recent years however, many special school leavers have been affected by the recession, and according to the Birmingham LEA Careers Sub Committee Report of 1977, those requiring routine or semi-skilled work found most difficulty in obtaining employment.

Throughout the history of special education, as Hurt (1988) points out, there have been many occasions when policy has outstripped resources. In times of recession, when considering whether to educate for leisure and possible unemployment, the crucial question of finance and resources arises. And, as Tomlinson (1982) asks: "... how much money is society willing to put into the education of children who will not provide any productive returns even via sheltered workshop employment?"

Historically, this has also been a recurring question for severely handicapped children who will require care throughout their lives, and also for those children having a short life expectation. Reviewing this question in the 1920s, the Wood Committee (1929) considered: (As for bad cases of epilepsy) "such persons are too short lived to make it an economical arrangement to spend much on training them for life". Those who consider that in the latter part of the 20th century this has come to be an academic question are referred to Oswin's 1971 study of children in long-term hospital care.

According to Tomlinson (1982), it is in the teaching of handicapped children that theoretical considerations of aims are most subordinated to practical considerations of classroom activity. It seems there is a greater need on the part of teachers to be taught 'how', rather than 'why'. Tomlinson argues that, given the unequal power relations between teachers who define goals and 'appropriate behaviour', and pupils whose intellectual and social behaviour they are attempting to modify, "it should be very important that teachers should be able to clarify and account for their practices".

A CURRICULUM FOR LIFE (THE CONTENT OF CURRICULUM)

Pritchard (1963) relates how in 1833, an almost empty House of Commons voted £20,000 towards the erection of schools, and the state made its first

contribution to education. At this time there were very few institutions for the blind and no new ones had been established since 1805. Those that did exist, writes Pritchard, confined themselves to giving industrial training and there was virtually no education in the usual sense. Liverpool gave a little tuition in music, though even this, as Pritchard points out, was for vocational rather than educational purposes. A certain amount of religious instruction was given by the chaplains, but of reading and writing, there was none.

A few pioneers, including one James Gall, were at this time attempting to produce books in raised type for the blind, and Gall, writing in 1834 recorded that the art of reading and writing for the blind was at a standstill, "so completely had it been forgotten in this country," (if indeed it had ever been attempted), as he continues, "no trace of its existence could be found amongst the pupils of any of our blind institutions".

Pritchard (1963) considers there is little doubt that special education was given, "not for its own sake, but as an aid to securing employment". The Annual Report of The Yorkshire School for the Blind of 1873 quoted in Pritchard (1963) states: "The object of the Institution is to give the pupils such instruction as may enable them to obtain a livelihood; attention being, at the same time, paid to their moral and religious education".

The introduction of education for the blind did not mean the end of industrial training. As Pritchard relates, throughout the 19th century and well into the 20th, it remained of paramount importance. There was, in fact, as Pritchard continues, greater uniformity amongst the various institutions in the industrial pursuits followed than in the systems of teaching the children to read. In fact as Pritchard (1963) points out in a different chapter, as the concentration on industrial work increased, the institutions came to depend, to an ever increasing extent on the profits which came from the workshops. Pritchard cites basket, mat and brush making as being the most popular and profitable lines, "closely followed in popularity by rope, sash-lines and netted articles". According to

Pritchard, Queen Victoria's pictures at Buckingham Palace were suspended by sash-lines manufactured at the Southwark School for the Blind.

Even in the mid 19th century however, some schools endeavoured to provide a well rounded curriculum for their pupils. An example cited by Pritchard is the General Institution for the Blind at Edgbaston, Birmingham. During the school's first year (1847) there were 17 children, the youngest of whom was 6. Each day their teacher, a Miss Allerton, instructed them in the Scriptures and in reading. Once a week she taught them music and geography with the aid of raised maps. She also taught arithmetic both mental and by means of peg boards, general knowledge and history.

Birmingham's remarkably 'modern' curriculum was by far the most comprehensive education available to the blind at the time. For, as Pritchard points out, there were still many institutions which concentrated almost entirely on industrial training. At the oldest school, for instance, (The Liverpool School for the Indigent Blind) the teaching of reading was not introduced until 1862. And it is interesting to note the reason for teaching the Liverpool pupils to read, as related in Pritchard (1963):

> "At the Annual General Meeting of subscribers, the treasurer, after giving his statement of the accounts, 'spoke more especially as to the amount of time expended in having various books and Newspapers read to the pupils'. This, of course, was at the expense of time that might have been spent in the workshops. Therefore, moved the Treasurer, the children should be taught to read".
>
> Minute Book 1856-1880, manuscript account of
> Annual General Meeting, 17.1.1862

Pritchard (1963) gives an account of life in 1813 for the pupils housed in the newly constructed purpose built Southwark school, as related by the school chaplain:

> "It was an extensive and rambling building, containing a large number of rooms, and enclosing two good-sized playgrounds, respectively for girls and boys. Its main features were the chapel, dining-room and basket shop. They were widely separated, and Johns, who was the school Chaplain, has described the last named as being 150 yards long. Even if he meant 150 feet, it was still of prodigious length. Of course, it was the most important

room. One-third of the school's income, which in 1812 was £4,500, came from the sale of goods made by the pupils: thread, sash and clothes lines, baskets and rope and fine mats 'for hearths and carriages'. The life of the school revolved around the workshop. The instruction was devoted to what went on within it. The only exceptions were the twice weekly religious instruction lessons given by the Chaplain, who also conducted the services on Sundays. Of formal school work there was none; and none could there be until books for the blind were produced".

Thus industrial training and religion formed the greater part of the school curriculum for the 19th century blind child. Instructing the pupils in 'their duty to God and man', was a phrase to be found in the aims of most institutions for the handicapped of that period. As Rose (1970) recounts, "If (in the 19th century) a blind child could make baskets and recite the catechism, he was well and truly educated".

Before the introduction of Braille in the last quarter of the 19th century, almost all the books from which the blind learnt to read were reprints of portions of the Bible. On Sundays, virtually the whole of the day would be spent in study of the scriptures or attending public worship in the local church. Nor, as Pritchard relates, were day pupils exempt from the need to attend religious services. Pupils attending the School for the Indigent Blind at Liverpool, be they children or adults, had to produce to the Superintendent certificates of regular attendance at places of worship. Failure to do so entailed dismissal from the school.

Music in the Curriculum

Since the earliest times, music has played a part in the curriculum of blind schools. From its inception, at Henry Dannett's school, (The School of Instruction for the Indigent Blind) in Liverpool, the pupils were instructed in "Music or the Mechanical Arts, and so be rendered comfortable in themselves and useful to their country". (From the Asylum for the Blind, Minute Book, 1791-1803).

According to Pritchard (1963) however, Dannett, whilst canvassing his plan and collecting money for it, encountered some opposition. Objection was made to the teaching of music on the grounds that "we shall have our streets full of Blind Fiddlers". Dannett's reply was apparently, that

violins would be excluded. The intention was to instruct the blind in organ playing, and this would be achieved by practice on the harpsichord. Some critics however considered that the blind would be unequal to any of the arts selected. Time alone, Dannett replied would show this. Time in fact did prove that many of the pupils were equal to the tasks given. However, according to the Minute Book for the asylum 1791-1793, quoted in Pritchard (1963), others had been dismissed for misconduct or being blind minstrels, "long inured habits of idleness and dissipation, had soon become disgusted with useful industry", and had returned to their former lives.

Following the example set by the Liverpool Asylum, the teaching of music to the blind became widespread. The York school established a brass band in 1843, and the Southwark school, at around the same period, had a band of some 30 players – "viola, flutes and brass horns", (no violins are mentioned) which apparently "play such music as one hears from a good German band".

Amongst the earliest pupils at York was William Strickland. His name, according to Pritchard, appears frequently in the Annual Reports of the school. Pritchard quotes from one of the first references in 1840:

> "Wm. Henry Stricland, aged fourteen, who at the date of the last report, was organist at the Church of Acomb, has been elected organist at St. Martin's, and gained the situation by a contest with two seeing competitors. He has lately been made an assistant teacher of music in the school".

Strickland remained at York as music master until 1883. Few children however were as successful as Strickland. Many were failures. Sir Francis Campbell, writing in 1893, (The Musical Education of the Blind), gave his opinion, that prior to 1870, the blind had been poorly taught in music,

> "Consequently, those that applied for organists' posts were those who possessed very little education and refinement, who had no knowledge of reading and writing the Braille musical notation, or the ordinary notation used by the seeing, who had no technical development worthy of the name, and who did not understand voice development and choir training ... of course they failed, but their failure was ascribed to their blindness, not to their lack of education and training".

Prior to 1870, the education of the blind in England, as far as literacy and music were concerned, was in the Doldrums. Education of blind children as we know it today, had to wait for the ingenious idea of a French man – the son of a saddler and harness maker, blinded in early childhood – Louis Braille.

CHAPTER 15

LIBERATION THROUGH LITERACY

THE INFLUENCE OF BRAILLE ON THE ACHIEVEMENT OF LITERACY

The introduction of the braille system of reading and writing was probably the greatest single factor in the emancipation of blind people. Louis Braille, the inventor of the system, was born in the small market town of Coupvrey about 23 miles from Paris on January 4th 1809.

As previously stated, Braille's father was a saddler and harness maker, and, in common with all small boys, Louis enjoyed watching his father at his work, and sometimes lending a 'helping' hand. It was whilst practising the skills of his father's trade that the four year old Louis lost his sight. While using an awl to pierce a piece of leather, the tool slipped and perforated his eye, the sight of which could not be restored. The other eye became blind from what was probably a sympathetic ophthalmia. This is an uncommon condition in which the uveal tract of the uninjured eye becomes inflamed following a penetrating injury in the other eye. Even today, the condition is incompletely understood and several theories are still current. Nowadays, however, it can be treated (although the outcome remains variable) using modern chemotherapy, rest, and quite often, the removal of the exciting (injured) eye. Following removal of the injured eye, the inflammation in the sympathising (uninjured) eye usually settles down and varying degrees of sight are restored.

It is interesting to speculate on whether the blind would ever have achieved literacy in the truest sense of the word had the knowledge and technology been available at the time to restore Braille's sight. Fortunately however for generations of blind people all over the world, the question remains academic.

Although Braille suffered from what is now known to be a preventable condition, in the early part of the 19th century, treatment was not a feasible proposition, and Braille's unfortunate accident was to lead to the liberation of other blind people all over the world.

The Educational Career of Louis Braille

As a child, Braille was intelligent and resourceful and soon learned to fend for himself. According to Boulter [see Dobree and Boulter] (1982) his intelligence and persistence were noted by the local school master who allowed him to be admitted to a class in his school. Although unable to read or write, Braille learned quickly by rote and was soon seen to have a thirst for knowledge which was not easily assuaged.

Ironically it was the death of Braille's father in 1819 which led to the decision to send him to the Paris school for the blind as a means of reducing financial strain on the family now that the harness making business was no more. Braille eagerly grasped the chance fate had afforded and enjoyed the broadened academic curriculum he was now able to follow. He became particularly skilled as a cellist and organist, being appointed in his teens as Organist Intern at the Church of St. Nicholas in the Fields and later at the Church of St. Vincent de Paul.

After completing his education, Braille was asked to stay on at the Paris school as an assistant teacher and in 1828, at the age of 19, he became a full professor of the establishment. At the time it was highly unusual for blind people to serve as teachers at the Paris school, but it was apparent that Braille's own personal knowledge of the problems posed by blindness, and his ingenuity in overcoming them added greatly to his value as an instructor during the classes he conducted in history, geometry and algebra.

Piper Sit Thee Down and Write

As a teacher, Braille recognised that, despite his best efforts, the educational attainments of his pupils would always remain proscribed until the blind had full and unlimited access to books and the ability to refer to their own notes. He was therefore greatly intrigued when he became aware of a system of embossed dots and lines on paper which had been evolved some years earlier by Charles Barbier, an army officer, as a silent means of passing messages between military units at night. Over the years as Boulter (1982) recounts, Barbier had evolved a number of modifications

to his original system. It had never however been recognised as being of potential value to the blind. In fact, when it finally reached the Paris school where Braille was employed, the headmaster set it aside as being of little consequence. However, when it came to Braille's attention, he immediately recognised its potential. But the code, as Barbier had designed it, was judged by Braille to be deficient in a number of respects. Firstly, it consisted of a basic grouping of 12 dots, so that the size of each group could not be covered by a single finger-tip. Furthermore, the rules for deciphering the groupings were far too numerous and complicated. Boulter (1982) relates how Braille re-designed the system which was eventually to lead to the emancipation of the blind.

> "Having obtained Barbier's permission to modify the system in any manner that might make it suitable for use by the blind, Louis Braille set to work. His first step was to eliminate all the embossed lines and to reduce the groupings of dots to a maximum number of six set down in two parallel lines of three. Thus emerged the braille 'cell' which was, and still remains, the basis for the braille code. A special slate was devised which simplifies the process of embossing dots on the paper using a stylus whose shape was fatefully similar to that of the awl which had caused Louis Braille's blindness. It remained for the 63 combinations of dots achievable in a six-dot cell, each to be assigned a value as a letter, punctuation mark, numeral, letter grouping or word and the Code developed by Braille proved to be a masterpiece of orderly simplicity.
> This was the achievement for which blind people had been waiting since the beginning of time. The system was now at hand by which any book could be printed in a form that could be read by those without sight. Here was a method which enabled blind people to make their own notes, to correspond with each other even at great distances, to make their own calculations, to keep their own accounts - in short, to remove the obstacles that had barred their way to education and progress".

By 1834 the braille code had been completed, including its utilisation for writing musical notation. However, the authorities at the Paris school were slow to recognise the immense significance of what had been accomplished by Louis Braille and he was forbidden to introduce the system into the classroom. He was however permitted to teach the children in his spare time. This he did, and according to Boulter (1982) his efforts were greeted with gleeful enthusiasm by the pupils fortunate enough to be resident at the time.

In 1839, Braille published a pamphlet describing the system in detail
- giving generous credit to Barbier. Following this, general interest
increased, but as Boulter relates, the sighted administrators of the Paris
school continued to be lukewarm and it was not until 1850 that braille was
officially introduced there as a teaching medium. As Pritchard (1963)
points out, under the circumstances it is not surprising that its
introduction to Britain was delayed and the genius of Louis Braille was
ignored here for over 50 years. Pritchard argues however that prejudice,
stubbornness, and a lack of unity delayed its introduction far longer than
was necessary. And, he continues, not until 1872 did the first English
school teach its pupils by braille, and as long as 20 years later, children
were still being taught by Alston and Lucas types (types of raised Roman
print).

Braille himself however did not live to see the fruits of his labours
liberate blind people through literacy. He died at the age of 43 of "a
lung condition" (possibly tuberculosis) in 1852.

In a Book That All May Read

Pritchard (1963) recounts how in mid 19th century England a number of
different and competing systems of reading were in use. As he argues, "At
a time when unity was the main necessity, those concerned with the welfare
of the blind were divided against each other. There was much bitter
controversy, and progress was inhibited". This lack of uniformity meant
that each institution worked in solitary isolation, their teachers being
unwilling to move elsewhere because of having to learn a new system. There
was also a tremendous wastage of resources, the same few books, mainly
religious, being reproduced in each different type. This duplication meant
there was comparatively little for the literate blind to read. As an
example, according to Hurt (1988), the London Society for Teaching the
Blind to Read admitted that it took 3 months to learn to read a Gospel
moderately well using Lucas's raised script. As one critic of the system
pointed out, they could have learnt it off by heart in the same time.

The man responsible for bringing order to this chaos, and for bringing literacy to the blind in England through the ideas of Louis Braille, was Thomas Rhodes Armitage. Unlike Braille, Armitage was certainly not poor but came of a wealthy Irish family. Born in Sussex in 1824, he spent his childhood in France and Germany. He was educated at the Sorbonne and later read medicine at King's College London. After serving as a surgeon in the Crimean War, he worked in German hospitals and finally became a general practitioner in London.

Armitage's sight had been failing for some years, and in 1860 at the age of 36 he gave up his practice and returned to his country home in Ireland. Although he retired from medicine, Armitage certainly did not retire from life, but began a new career - that of a blind man.

Pritchard (1963) relates how, in 1866 he joined the Committee of the Indigent Blind Visiting Society, and for two years visited the blind of London in their homes. Many, he found, were living in squalor and by begging. Those who had, as children, learnt to read at one institution, could not use the system taught at another. Equally, those who had been taught a trade were unable to follow it when left to fend for themselves without materials or a market for their product.

What was needed, Armitage realised, was not monetary relief, but efficient education and training leading to secure employment. He determined to concentrate first on the improvement of education for the blind. The first necessity, he realized, was for a uniform system of reading in order that a plentiful supply of literature might be produced. Moreover, this system, Armitage decided was to be selected by the blind themselves. For this task Armitage obtained the collaboration of four other well educated blind men with no pecuniary interest in any particular system. These five men became the Executive Council of the British and Foreign Blind Association for Promoting the Education and Employment of the Blind. Armitage and his colleagues carried out what must have been one of the first ever 'consumer surveys', and almost certainly the first to actually involve the blind themselves. After almost two years of research and correspondence with

leading associations and institutions at home and abroad, as Pritchard (1963) relates, they reached their decision:

> "The Council recommend Braille as the educational system for all blind children, and for the every-day wants of all blind persons whose touch has not been seriously impaired by manual labour. For the old and dull of brain and touch (they recommended) a simple line system approaching as near the Roman as is compatible with perfect tangibility".

The simple line system they had in mind was Moon, and they advocated,

> "that steps should be taken to introduce Braille to this country and discourage all others save Moon".
>
> From the Report of the British and Foreign Blind Association, 1871

As always, new ideas met opposition. In England as in France the braille system met with fierce resistance. The sighted managers and teachers at the blind institutions raised objections. For, as Armitage himself pointed out, the adoption of the new alphabet, "involves the teacher ... in taking the trouble to learn it and in the case of the braille character there is this further difficulty that reading it is fatiguing to the eye". Armitage adds shrewdly, "Although the objection to the language of the dots is for obvious reasons scarcely ever stated, it nevertheless consciously or unconsciously influences their views very materially". Also, as Armitage added, "a great many seeing managers and seeing people generally could not shake themselves loose from the idea that because the Roman system is best for the seeing, it must be best for the blind".

There were also as Rose (1970) points out, other objections to braille; jealousy, vested interests, dislike of change. There were also, as she continues, those who sincerely believed that some form of Roman character used for the sighted was the best means of communication for the blind. As an example, Abbé Carton, writing in 1838 (quoted in Jamieson et al (1977) expressed the argument for raised Roman print:

> "The largest number of blind is found amongst the poor, and the greatest misfortune of the blind consists in their isolation. All our efforts should tend towards bringing them near to ourselves, and to make their education as like our own as

possible, and to begin this education as quickly as may be, and not to think that a special institution is needed for teaching them to read. If the characters in their books are those which we teach to other children, ordinary schools will be able to admit from their infancy these unfortunate beings who have been hitherto kept afar off under a false pretext; and their misfortune will lie less heavily upon them, their intellect will be developed and the advantages they will derive from their stay in special establishments will be in harmony with what they will have learnt before entering them".

The philosophy behind this argument has a strikingly 'modern' ring, and in fact the controversy continued well into the 1880s, even today the dilemma is not satisfactorily resolved.

Armitage's argument however was that although the blind pupil might learn to read in a less 'ordinary' way, his eventual performance (in reading) was rendered superior by the 'special' nature of the medium used. Writing in 1886 he explains:

"It has often been urged that the blind ought to employ the same character as the seeing in order to receive assistance when reading. This argument might be of some weight if no simpler character existed: but where the choice lies between a character to read which the blind man requires assistance and one which is so simple that he can read it himself, there ought to be no doubt as to the choice. Another common, but equally fallacious, argument is that by adopting a different character from that used by the seeing there is danger of the isolation of the blind being increased; this is not feared by those who it is intended to benefit. A man is isolated by everything which renders the acquisition of knowledge difficult and tedious and his isolation is diminished by everything which facilitates his power of self-education. The best type for him to use is evidently that which he can read most fluently and most correctly; therefore, in the great majority of cases, it will not be the Roman character".

> Armitage T.R. (1886) The Education and Employment of the Blind. London, British and Foreign Blind Association (2nd Edition)

Even in the late 1880s, although almost all institutions made some use of braille, the battle of the types was not fully resolved. Not until the passage of the 1893 Elementary Education Act, making education compulsory for all blind children aged 6 to 16, did the braille system finally triumph.

Armitage however did not live to see the introduction of this piece of legislation for which he had worked so hard. During a visit to his home in Ireland in 1890 he was severely injured after being thrown from his horse and died from his injuries a few days later.

The question of literacy has been dealt with at some length because the 19th century arguments are so similar to the current segregation versus integration debate. History, it seems has a habit of repeating itself. In the 19th century, work for the blind, Armitage concluded was "too much in the hands of philanthropists possessed of sight, who however well intentioned, had often failed to understand the real wants of the blind". Armitage's words have a ring of truth, even at the end of the 20th century.

The eventual acceptance and publication of braille was by no means Armitage's sole achievement. He displayed, as Boulter (1982) relates, an unshakeable confidence in the ability of blind people to play an important part in the organization of their own affairs and to participate in the development of policies which would have a bearing on their lives. In order to contribute, Armitage realised, the blind had to be both literate and articulate.

And I Wrote my Happy Songs Every Child May Joy to Hear

As Pritchard (1963) recounts, Armitage gave liberally of his time and money in the furtherance of this cause. In the preface to the first edition of The Education and Employment of the Blind (1871) he wrote:

> "The belief that I have been able to take my share in this great work has gone far to reconcile me to the abandonment of a profession, to the scientific prosecution of which I had hoped to devote my life; but the very defect of sight which proved an insuperable obstacle in the career which I had chalked out for myself, has peculiarly fitted me for a new and more extended sphere of usefulness".

Thus the foundations of the modern curriculum for blind children were forged by Louis Braille and Thomas Armitage. Had it not been for the work of these two blind men, in the 19th century, it is doubtful whether, even today, the blind would be literate in the full sense of the word. As

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Boulter (1982) points out, access to books and other published material is important not only for study and work but for recreation also. Without braille, the blind will probably always be, to some extent, reliant on other people to help them read and write. Although the technology to 'read' print or to translate it into tactile symbols now exists, it is extremely expensive and beyond the means of most blind individuals. In any case, the reading of print, out loud, by a machine hardly constitutes true literacy.

When the development of braille is viewed from a historical perspective, Armitage's arguments for the medium appear to be almost watertight. It is possible however, that in the 20th century, some blind children may be denied the chance to learn braille. Ironically one factor in this could be the advent of modern technology in the shape of reading machines, tape recorders and computers. Yet another factor is the move towards integration for all children coupled with the high cost of teaching the medium to individual children in isolated schools.

A high degree of motivation is necessary for a child to master a difficult medium such as braille, and parents and teachers must also be convinced of the benefits in order to be able to help their children. However, it seems that today many parents are not convinced of the benefits afforded by braille and are content to allow their children to rely on modern technology. Indeed it seems that the present day 'well intentioned philanthropists' are sometimes actively discouraging its use because it renders integration that much more difficult.

The two quotations below are from the sample group.

35. <u>Lee Davidson, age 6. Useful Vision but Poor Prognosis. Integrated into Normal School</u>

"There's no way he's going to a blind school. He's coping perfectly well (at normal school) and he's with all his friends and his brothers and sisters so I can't see the point. (Supposing he has to learn braille if his sight gets worse?) Braille? I can't see as he'd need to learn that. I mean, he can use a tape recorder and a typewriter if it comes to that, so what would he want to learn braille for?".

20.   Andrew Cannon, age 15.   Had Useful Vision but Sight Deteriorated.
      Integrated into Normal School.   Previously Educated in Partial Sight
      Unit – Now Closed

>   "Well, I'm hoping I can get by without learning braille really.
>   I think it's old fashioned and out of date now.   I can type and
>   I use a tape recorder and besides I can still see to read if I
>   hold it close enough.   I'd like to get a job in catering, I mean,
>   it's all we ever did in the P/S unit, make cakes.   So I got quite
>   good at it.   And I won't need braille for making cakes, will I?".

In Conclusion

This chapter has been concerned with the special curriculum for blind
children, concentrating particularly on the achievement of literacy.
Curriculum however is closely bound up with issues discussed in earlier
Chapters of the Section on special education, not least the
segregation/integration debate and the assessment process which decides
which children will follow a special curriculum.   Issues of power and
inter-professional conflict also play their part in deciding the content
of the special curriculum.   Attitudes are also important, not only of those
who teach and administer, but also of those who learn.

It seems that in the field of special education, dilemmas are unavoidable.
However, more sociological and consumer type research of the kind carried
out by Armitage and his colleagues over 100 years ago could go some way to
resolving them in a not unsatisfactory manner.

Below, to conclude the chapter, is a quotation from Rose (1970).   An
obviously satisfied consumer of segregated special education remembers his
schooldays:

>   "I remember Worcester",

mused an old boy, at school there in the 1950s.

>   "I remember midnight feasts and meccano and great fires in the
>   common room.   Afternoons on the river, and the smell of it and
>   the sounds of the great cathedral clanging out.   And browsing in
>   the library among musty braille books.   I remember trying to make
>   gunpowder and acetylene, and tramping all over Worcestershire and
>   Shropshire and Hereford with packed sandwiches and bus timetables
>   all worked out.   That was my Worcester".

CONCLUSION TO SECTION III

In Section III I have been concerned to show how the historical development of the special curriculum has influenced, and continues to influence the ways in which children with visual impairment are educated today. History it seems has a habit of continually repeating itself.

Although apparently influence by an ideology of 'benign humanitarianism', special education is also permeated by inter-professional conflict and power struggles between individuals and groups with vested interest.

One of the most interesting findings to emerge from this section is the fact that the 'integrated' children experienced rather more problems in many areas of their education than did those in special schools. This held true throughout their educational careers but problems tended to increase as the children got older and entered secondary education. Although the sample group was far too small for any 'significance' to be attached to this finding, it would appear to indicate that, in Sheffield at any rate, there is a continuing need for the special school environment, with its resources and support in the education of children with severe visual impairment.

Section IV is concerned with healers, and in particular those concerned with restoring sight to the blind and visually impaired. The four chapters deal with the evolution of doctors in general and the eye specialist in particular from four different, but entwined, perspectives.

Chapter 16 examines briefly the development of medicine as a profession from a 'Freidsonian' perspective and touches on the ways in which the prevailing philosphies of health and disease have affected those defined as 'sick' or disabled.

Chapter 17 outlines the evolution of today's eye specialist from the quack, charlatan and empiric of yesterday.

Finally, Chapter 18 is concerned with the education and socialisation of doctors past and doctors present.

Much of this section is devoted to the historical aspects of medicine and ophthalmology, and some readers may prefer to omit these sections. Those sections which can be omitted are presented in a different type face and include the early parts of chapters 17 and 18.

My aim however in presenting these wider issues is to demonstrate that the ophthalmologist has a key role to play in the development of the careers of his patients, (and this applies whether he is able to restore their vision or not). My thesis is however that the ophthalmologist, because of the ways in which he is educated and 'socialized', is ill-prepared to play the role 'expected' of him by society, especially in cases where intervention fails or there is no known treatment or cure for the condition.

In essence the eye specialist is a 'craftsman'. His education and skills, (which are considerable) are directed towards the repair and restoration of the organ of sight. In the majority of instances the ophthalmologist is able to heal or at least to help his patient. It is when intervention fails or blindness is irreversible that both doctor and patient are set

adrift in an uncharted ocean. The doctor is unable to meet the expectations of the patient or society; both doctor and patient are therefore rendered powerless, and by virtue of his history, background and education, the doctor is not equipped to play the 'supporting role' which would fulfil the needs of the patient.

CHAPTER 16

MEDICINE IN SOCIETY

The whole earth is our hospital

Endowed by the ruined millionaire,

Wherein, if we do well, we shall

Die of the absolute paternal care

That will not leave us, but prevents us everywhere.

T S Eliot; Four Quartets, East Coker, IV

SOCIETY IN MEDICINE: A 'FREIDSONIAN' REFLECTION

Although in Western societies medicine has come to be perhaps the dominant and most powerful of the professions, Freidson (1970) points out that this has not always been the case. In the introduction to "Profession of Medicine", he writes:

> "Among the traditional professions established in the European universities of the middle ages, (medicine) alone has developed a systematic connection with science and technology. Unlike law and the ministry, which have no important connection with science and technology, medicine has developed into a very complex division of labour, organizing an increasingly large number of technical and service workers around its central task of diagnosing and managing the ills of mankind. Too, it has surpassed the others in prominence. Since the production of goods and other forms of real property are far less of a problem to post industrial societies than is the welfare of their citizens, since welfare has come to be defined in wholly secular terms, and since the notion of illness has itself been expanded to include many more facets of human welfare than it did in earlier times, medicine has displaced the law and the ministry from their once dominant positions. Indeed, in one way or another, the profession of medicine, not that of law or the ministry or any other, has come to be the prototype upon which occupations seeking a privileged status today are modelling their aspirations. The better we understand medicine, then, the better we will understand the problems that may be posed by the professionalisation of the key service workers of the welfare state".

Freidson writes that, if we consider the profession of medicine today, it is clear that its major characteristic is its preeminence. This

preeminence he argues, is not merely that of prestige but also that of expert authority.

Today, medicine's knowledge about illness and its treatment is unchallenged and considered to be authoritative and definitive. Whilst there are other autonomous professionals, for example dentists and ophthalmic opticians, and other types of healer, as for example osteopaths and homeopathists, Freidson points out that, "there are no representatives of occupations in direct competition with medicine who hold official policy-making positions related to health affairs". According to Freidson, the position of medicine today is very similar to that of state religion yesterday. By this he means that medicine has an officially approved monopoly of the right to define health and illness and to treat that which is defined as illness. However, as Freidson points out, this highly prestigious position in society is not a long established one, in fact it is less than 100 years old. If medicine could have been called a 'profession' in the past, its characteristics were he argues, very different to those of today.

During most of recorded history, there has not been a single occupation identifiable as 'medicine', though there have been many kinds of healer. Following the rise of the university in Europe, medicine became for the first time a 'learned profession'. Freidson points out however that only recently has it become what he terms a "true consulting profession" and only very recently has it attained the strength and stability which now characterize its position in society. Freidson however questions whether the doctor in this elevated position better meets the needs of his patient than the healer in a more primitive society.

In western society, medicine has taken over from state religion, matters concerned with life and death, health and sickness, the treatment of sickness and restoration to health. The medical profession also control access to virtually the whole range of para-medical and rehabilitative services. Because doctors are the only official 'designators' of health and disease, they are the only profession allowed to 'certify' health and illness. In order to obtain aids and appliances (for example low vision aids) the disabled must be 'certified' by a doctor as being in need of these aids. As we have seen in the previous chapter, doctors are active

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in the field of education, particularly special education. Even if we are never defined as 'sick' or 'disabled', the medical professional will still control many aspects of our lives including our entry into and departure from it. Doctors in western society have also taken over from the ministry many of the rituals and rites of passage associated with these life events.

The Consulting Relationship and the Concept of Client Rights

Freidson (1970) points out there is no doubt that in some circumstances the patient is likely to be so ignorant of the nature of his problem and its possible solutions, as not to be trusted to choose what should be done for his own good. By the same token, he may be so immature or so disturbed by his problem as not to be rational about its nature or solution. Thus, Freidson argues, even if he is intellectually capable of understanding the professional's explanation of what is wrong and what should be done, he is emotionally incapable of using his intellectual faculties. When both ignorance and emotional disturbance are present, the patient may simply hurt himself if given the opportunity to participate in his care and treatment. Indeed, as Freidson points out, the customary professional characterization of the client – which in medicine goes back as far as Hippocrates – insists on his ignorance and irrationality. Such characterization, Freidson writes, is the prime justification for the medical profession's inclination to make the patient at best a passive participant in the healing process, "to, in essence, remove from the client his everyday status as an adult citizen, to minimize his essential capacity to reason and his right to dignity. Expertise in general claims its privilege by claiming the client's incapacity". Freidson goes on however to pose the question: just how common is this fearful, ignorant kind of patient? Here, as elsewhere, he claims, "an item of professional ideology is accepted uncritically and applied globally, without analytical scrutiny or justification".

Freidson goes on to consider the historical change which has taken place in the nature of the public itself. As he argues, a hundred years ago, the average patient was no doubt illiterate and superstitious, the difference between the formal education of the man in the street and the average professional being very great. Since that time however, universal

education for everyone has considerably narrowed the gap. Secular and rational modes of thinking have also spread progressively throughout the population. Freidson points out that, whilst the length of professional medical education has increased over the last fifty years, the average length of formal education of the 'man in the street' has increased to an even greater extent and an increasing proportion of the public are now seeking further and higher education. Thus, Freidson argues,

> "Assuming that formal education means something important (and if we do not make that assumption about laymen we cannot do so for professionals), laymen are far more likely today than yesterday to be able to participate intelligently in the active evaluation and pursuit of the solutions which professionals offer to their problems".

AUTONOMY AND ADVANCEMENT IN MEDICINE

No one is nostalgic for the bleeding and purging prescribed as treatment in the 19th century and medicine has obviously advanced since then. But as Freidson points out, advances in knowledge are one thing, and those in practice are quite another. It is in these practical areas - in the designation and management of disease and in the social organization of medical care - where, Freidson argues, medicine has not advanced. As he writes:

> "While the profession's autonomy seems to have facilitated the improvement of scientific knowledge about disease and its treatment, it seems to have impeded the improvement of the social modes of applying that knowledge".

Because it is autonomous, the profession of medicine is immune from regulation or evaluation from other occupations. It is also designated by society as a 'dominant profession'. As Freidson relates, insofar as it regulates itself and is not subject to outside evaluation from others, it also educates itself. He also points out that its educational institutions tend to be self-sufficient and segregated from others, having their own independent resources and facilities. Those educated in such schools, Freidson argues, are largely protected from contact with faculties and students from other schools.

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Freidson argues that the profession, by virtue of having the right to regulate its own work, appears to assume that it has also been granted the right to regulate the clientele instead of having to be responsive to it, as is for example a salesman. Thus, writes Freidson,

> "the characteristics of professional autonomy are such as to give professions a splendid isolation, indeed, the opportunity to develop a protected insularity without peer among occupations lacking the same privileges".

The Flaw in Professional Autonomy

This writes Freidson is the critical flaw in professional autonomy:

> "By allowing and encouraging the development of self-sufficient institutions, it develops and maintains in the profession a self-deceiving view of the objectivity and reliability of its knowledge and of the virtues of its members. Furthermore, it encourages the profession to see itself as the sole possessor of knowledge and virtue, to be somewhat suspicious of the technical and moral capacity of other occupations, and to be at best patronizing and at worst contemptuous of its clientele. Protecting the profession from the demands of interaction on a free and equal basis with those in the world outside, its autonomy leads the profession to so distinguish its own virtues from those outside as to be unable to even perceive the need for let alone undertake, the self-regulation it promises".

Over the past century, Freidson argues, the medical profession has not merely devoted itself to serving the needs which the public has brought to it, it has also devoted itself to discovering and elineating new needs and developing its own moral conceptions of what mankind should ideally be. Protected by its prestige and its autonomy, the profession has also been able to develop its own institutions for serving these needs it has delineated. As Freidson puts it, "... after becoming autonomous, the profession has less and less come to reflect what the public asks of it and more and more come to assert what the public should get from it". He continues:

> "Consulting the profession the state obtains not only expert opinion on how to serve the needs the public perceives but also partisan opinion about what the public's needs actually are

irrespective of lay opinion. Social policy is coming to be formulated on the basis of the profession's conception of need and to be embodied in support for the profession's institutions".

Freidson's argument is that professional concepts of need are not justified if they do not conform to the concepts and ideas of the public they serve and professional "knowledge", he maintains,

> "cannot therefore be a guide for social policy if it is a creation of the profession itself, expressing the commitments and perception of a special occupational class rather than that of the public as a whole".

In western society, every citizen has certain theoretically inalienable rights, sustained by institutional arrangements designed to protect them. However, on entering the professional domain, Freidson argues that the citizen is expected to give up all but the most basic of these rights and to put himself into the hands of the 'expert', trusting implicitly in his knowledge, judgement and good intentions. As Freidson writes: "He is expected to take a role which is akin to that of a house pet, or a child, dependent on the benevolence and knowledgeability of the adult caretaker".

Autonomy and Its Self Sustaining Perspective

Discussing the development of medicine as an autonomous profession, Freidson argues that once given a special status, the profession, quite naturally forms a perspective of its own. A narrow and distorted one claims Freidson, because the profession is answerable to no one but itself. Once such a self-sustaining perspective is formed, protected from the views of outsiders, and insulated from the need to justify itself to others, Freidson argues that the profession,

> "cannot reasonably be expected to see itself and its mission with clear eyes, nor can it be reasonably expected to assume the perspective of its clientele. If it cannot assume the perspective of its clientele, how can it pretend to serve it well".

During his discussion of the limits of professional knowledge, Freidson points out that the established professions (in which he includes medicine,

the law and the ministry) have been granted autonomy in order to help their clientele towards health, truth, justice and virtue. But he poses the question,

> "what, concretely, is health, justice, truth and virtue? Who is to determine it? Is it a matter for determination by a special class of moralists disguised as experts? Or is it a matter of such importance as to be every man's choice for his own life?".

Freidson's questions will be addressed in the following pages.

THE ART OF HEALING AND PREVAILING PHILOSOPHY

The art of healing dates back into pre-history, in fact to the dawn of mankind. Throughout the ages, healers have based their techniques for curing victims on the prevailing philosophies of causality. These philosophies have changed or evolved in the course of time as new knowledge has come to light. Poynter (1971) argues however that there is seldom any clear-cut departure in the history of ideas, but rather a gradual merging of new ideas into old and a gradual separating out and abandonment of old standpoints as new facts are accumulated which require explanation. Poynter also notes that no philosophy or body of ideas is ever completely ousted by another, but strands of the one persist and eventually influence the other. Even today, for example, we often speak of being in a good or a bad humour although 'humoural theory' was discarded many centuries ago.

In medicine, as in the field of education, although over a much larger time scale, certain bodies of ideas have tended to recur, albeit in different guises, throughout the history of healing. Indeed, as Haegar (1988) points out, many of the treatments used in Hippocratic times are considered sensible today: for example, diet, herbal remedies, massage or listening to a song or story. Many of the principles of surgery used by the Ancient Greeks are also still in use – one example being the use of tar in the treatment of wounds. This, as Guthrie (1945) points out, is a surprising forerunner of the antiseptic method. It seems, however, that, as with educationalists, healers have been prone to fall into the same traps as did

their predecessors; periods of dogma have halted and stagnated the progress of medicine throughout its history.

IN CONCLUSION

It has been pointed out that a fairly pervasive criticism of the medical profession runs through the work. This is apparent in many of the quotes of respondents and from Figure 4.2. It was with the aim of trying to redress the balance and to explore some of the reasons why satisfaction ratings for certain types of healer should be so low that some of the history of, and background to, the medical profession has been included.

Many doctors are, it seems, prisoners of their own evolutionary background and are unable to break free from this mould or out of a self-perpetuating system. Some of the reasons why this should continue to be so are explored in the following two chapters.

Some readers may wish to omit the passages presented in alternative typeface.

THE MAKING OF DOCTORS

I swear by Apollo, the physician, by Asclepios and Hygiea and Panacea, and by all the gods and goddesses, calling them as witnesses, that I will carry out, according to my judgement and ability, this Oath and this Indenture.

I will honour him who has taught me this art as I would my parents and will make him a partner in my livelihood, and if he should fall into debt I will assist him. I will hold his sons as my brothers, and shall teach them this art if they should wish to learn it, and I shall do so without fee or indenture. I shall allow my sons and the sons of my teacher to take part in my written and oral instruction and in all other instruction, as well as those pupils indentured with me who have taken the Oath, but no one else.

I shall use treatment for the healing of the sick according to my ability and judgement, but never to their injury or harm.

Neither will I administer to anyone any medicine which is poisonous, even when asked to do so, nor will I suggest such a course.

Also, I will not give to any woman a means of abortion.

I will ever keep my life and my art undefiled and clean.

I will not cut those who are suffering from the stone, but I will leave them to men who practice such operations.

Into whatsoever houses I enter, I shall go to heal the sick, avoiding all intentional wrong-doing and especially every sexual act against the persons of woman or men, whether free or slaves.

Whatever I see or hear in the practice of my profession, as well as those things which I may learn in my intercourse with men, if they be such as should not be imparted to other men, concerning these I shall remain silent, in the conviction that such things must be kept close secrets. Now if I carry out this Oath and break it not, then may I gain for ever reputation among all men for my life and for my art; and if I break it and foreswear myself, may the opposite be my lot.

"The Hippocratic Oath", c. 460 BC

Above is a translation of the Oath which has for over 2,000 years been referred to as the 'Hippocratic Oath', although, as Pollak (1968) points out, it is probably actually slightly older than Hippocrates himself. Pollak argues that although neither Hippocrates' knowledge nor his theories have remained of importance, what is important is his interpretation of the doctor's profession and the eternal principles of medical thought and treatment.

The ophthalmologist as we know him today has emerged only during the last hundred years or so. Throughout ancient history and acros all cultures, certain surgical proedures and operations have been eschewed by the 'learned doctor' and the physician. In all cultures, these procedures have included operations on the eyes, removal of bladder stones and operations to reduce hernia. Until the advent of 'scientific medicine', and the introduction of ihalational anaesthesia and antisepsis, the outcome of such operations was usually unfavourable and often disastrous. Such procedures, therefore, were left to those lower down the hierarchy of healers.

Pollak (1968) informs us that, generally speaking, it was in London that English surgery developed into a scientific profession. This, he says, was because in the metropolis were the ancient hospitals of St Bartholomew and St Thomas. The most successful and ambitious surgeons therefore tended to settle in London. There were however a number of other practitioners who were known as 'itinerant surgeons'. Many of these were quacks or mountebanks but some had been apprenticed to master surgeons in the usual way and had become members of the Barber-Surgeons Company. The quacks who practised surgery specialised particularly in those operations shunned by regular surgeons because of persistently poor results (cataract, hernia and bladder stones).

Perhaps the most colourful of all the itinerant practitioners of the 18th century was John Taylor (1703-1772). He was usually referred to as the Chevalier Taylor or Gentleman John Taylor. Despite his title of 'Chevalier', Taylor was not a member of the nobility. He was an Englishman born in Norwich. Taylor was a braggart and, according to Haeger (1988), his swaggering proved too much even for his contemporaries. O'Shea (1990) quotes Samuel Johnson as writing that the Chevalier's career was "an incidence of how far impudence will carry ignorance". Taylor did however attend some of the most famous and brilliant people of his day. Haegar (1988) informs us that, in his autobiography, Taylor claimed to have cured the kings of England, Poland, Denmark

and Sweden, many princes and countless nobles as well as the Pope. One of his 'feats' was to relieve Johann Sebastian Back of his blindness at the age of 88. This we know to be untrue because, as Haegar points out, Bach died blind at the age of 65. In fact Taylor's aggressive use of mercury to treat post operative ophthalmitis may well have contributed to Bach's rapid decline following the operation. It is also likely that the condition was caused in the first place by the introduction of unsterile needles into the eye to displace (couch) the cataract below the line of vision.

Taylor travelled around Europe performing his eye operations and usually managing to leave town before the consequences and side-effect became apparent. Although O'Shea (1990) declares that "despite a few legitimate discoveries, he did considerably more harm than good", Taylor was not the complete charlatan that many would have us believe. For example, he invented a more efficient type of cataract needle and was the first person to describe the condition of conical cornea. And, according to Arrington (1959) Taylor also treated squint by severing the tendon of the superior oblique muscle.

THE DOCTOR'S PERSONALITY AND THE CLINICAL MENTALITY

The great majority of entrants to medical schools in Britain (around 77%) come from the professional and managerial classes. And according to Bennet (1979) and Allen (1988) this percentage has been virtually static for many decades and shows little if any sign of changing.

Bennet (1979) notes that there seemed to be certain similarities between many of the attitudes of medical students in the 1960s, and what Adorno and colleagues (1950) termed 'The Authoritarian Personality'. The authoritarian tends to identify with the existing social order and establishment organizations. He is resistant to change, and to any outsiders or minority groups who might threaten the status quo. The authoritarian personality tends to adopt a tough-minded approach to human problems and to dislike expressions of emotion. He accepts the dictates of authority, whether they come from parents, teachers or political leaders, (from the right or left as the case may be). He will change - even totally reverse - his stoutly held beliefs when told to do so by a suitable authority figure. Allen (1988) also found these same

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traits manifest in student groups of the 1970s and 1980s. Bennet (1979) writing on the attitudes of doctors, has this to say:

> "These underlying attitudes suspected in many of the students seem to me at the present time to be manifest in the medical profession when viewed collectively. Furthermore, many of the complaints about the arrogance and unapproachability of doctors seem comprehensible in these terms. The authoritarian profile (and it is intended as a profile, not as a precise description) fits the collective image of all the established professions, but it fits doctors peculiarly well. If these authoritarian tendencies which seem to be present in qualified doctors were also present in medical students it would suggest that the profession was attracting those who identified with the traditional (authoritarian) image of the doctor, and so would tend to perpetuate them when qualified".

Hudson (1966) studied the underlying dispositions of young people, identifying two groups which he termed 'convergers' and 'divergers'. Broadly speaking, convergers do better at straightforward intelligence tests rather than those which are open-ended and there is no single correct answer. They prefer exactness, are intolerant of ambiguity and tend to avoid expressions of emotion and opportunities to use their imaginative powers. They are not only ready to accept authority, but will seek out those courses of study where the body of factual information and the weight of accepted authority is greatest. The "diverger" is the opposite in almost all these respects. In the educational system, the diverger is more likely to be found studying the humanities. Hudson (1968) has also shown that convergers tend to display authoritarian tendencies, particularly with regard to the acceptance of the teaching and attitudes of their elders.

Bennet (1979) points out the difficulties faced by teachers trying to introduce the study of the social sciences into the medical curriculum.

> "'We came here to study scientific medicine, and you are trying to teach us about human relationships. What have they got to do with science?' This quite common utterance was sometimes a taunt, but sometimes a question arising out of a quite genuine bewilderment at the ambiguities inherent in the study of human relationships".

As Bennet (1979) points out, the medical student, unlike the student of the humanities acquires an identity along with his education, on account of his connection with the medical profession.

The medical school and the teaching hospital to which it is attached, will, by their implied power, act as a 'socialising' agent on even the most rebellious student. The socialisation process involves not only conforming and delaying gratification, but also, according to Bennet (1979):

> "developing some armour to protect our private selves from the batterings of other people, so that we can proceed on our way through life without daily being wounded intentionally or accidentally".

Even at school, Bennet writes, the medical student may have to suppress his feelings when confronted by formalized bodies during the anatomy class. The greatest need for protection however comes when he first encounters the sufferings and tragedies which are part of the routine on every hospital ward.

Bennet points out that although doctors are now being made more aware of the psychological factors which affect sickness, they are not being given the support they need to carry the emotional burdens thus generated for them.

Perhaps more importantly, the doctor of today is trained to relieve suffering and thinks in terms of removing it rather than in helping people to come to terms with it. Of course, a great deal of the mental and physical suffering a doctor encounters cannot be relieved. Furthermore, as Bennet argues, the training most doctors receive, (and possibly their own psychological make-up as well) leaves them peculiarly ill-prepared to deal with many of the human problems they routinely encounter.

Doctors have evolved various strategies for coping with stressful situations. A robust kind of detachment is often used, particularly by medical students and junior doctors. Distressing or gruesome matters are made the subject of jokes, often regarded as being in very poor taste by the general public.

Another way of coping is to de-humanise the patients, referring to 'the amputation' or 'the cholecystectomy', or even worse, to the clinically uninteresting patient as 'rubbish'. Whilst as Bennet points out, this strategy may only reflect the doctor's need for protection, this is neither understood nor appreciated by the patient.

The Professional Mask

Another form of protection is the wearing of a 'professional mask'. As Bennet (1979) writes:

> "The average doctor has to play so many different roles that it
> is hard to find out which one represents the 'real' person, if
> indeed the idea of there being a real person, or real self, has
> any true meaning. On the surface, however, there is undoubtedly
> a professional self, which almost everyone finds necessary for a
> number of good reasons".

Using the 'mask', the doctor can present to the world a front of the wise and competent physician. However, as Bennet points out, one of the dangers of such a performance is that the doctor comes to believe that he actually possesses great wisdom and competence. He will work tremendously long hours because he believes the service cannot function properly without him. He will believe that he is in enormous personal demand and patients must therefore not be surprised when they are kept waiting for long periods to see him. He will also have generated a lengthy waiting list to consolidate his view of himself. Bennet (1979) writes:

> "His feelings of self-importance can delude him into thinking
> that he has special insights and therefore can express dogmatic
> opinions about everything, including personal morality. He may
> also come to live through his patients. He has probably managed

to establish a style of working where his patients have to accept him uncritically, and finds that their company makes few emotional demands on him. Eventually he cannot tolerate anyone close to him who is not dependent".

The Honoured Scientist

This is the term which Solzhenitzyn (1971) has used to describe the doctor who has been unable to resist the ceremonial trappings of his job; the academic doctor, and all who seek institutional distinction in professional organisations:

> "... if a man was called a Scientist during his lifetime and an Honoured one at that, it was the end of him as a doctor. The honour and glory of it would get in the way of his treatment of his patients, just as elaborate clothing hinders a man's movements. These Honoured Scientists went about with a suite of followers, like some new Christ with his apostles. They completely lost the right to make mistakes or not to know something, they lost the right to be allowed to think things over. The man might be self-satisfied, half-witted, behind the times, and trying to conceal the fact, and yet everyone would expect miracles from him".

Although Solzhenitzyn was writing from his own experiences in Central Asia, he could equally well have been writing about someone in 'Everydoctors' own teaching hospital.

The Virtuoso Role

As Bennet (1979) notes, the opportunity to enjoy the 'virtuoso role' has become possible because of the huge success of medicine since the middle of the 19th century. Prior to the advent of inhalational anaesthesia in 1846 and Lister's introduction of antisepsis ten years later, doctors had a much lower status in the social hierarchy. The surgeon, who as we have seen did all the messy manual work came even further down the scale. As Bennet writes: "Nowadays, with the pre-eminence of technology, technical knowledge and manual dexterity have overtaken human qualities as gatherers of prestige, and so the surgeon has now been elevated to the position of highest regard".

Nokes (1967) pointed out that, just as the prima donna requires an orchestra and supporting cast, so the surgeon needs operating theatre assistants and nurses. The virtuoso is nothing without his backing group and can only achieve his full identity against this background. Nokes however makes the point that, almost as important as his background, is his distance from it. The virtuoso must stand alone.

This kind of power means that the virtuoso doctor has the unchallenged right to work as he likes. As Bennet writes, the greatest single danger of this is that his personal peculiarities, prejudices and blind spots will proliferate unchecked and on-one will be able to point out his foibles to him.

Laying Aside the Mask

As was pointed out earlier, most people, and certainly most professional people, find themselves wearing a mask which, although not usually of their conscious making, provides a form of protection. Sometimes however, as Bennet relates, the mask is shattered by some life-event; perhaps some near-fatal illness or an experience which leads to a fundamental reappraisal of values in life.

On the other hand, a few people, as Bennet points out, seem to go through life without the need for such armour. But what is common to all people who have either shed, or have never had a protective mask, is their vulnerability. By laying down their armour, they are declaring that they are not perfect, nor inviolable. Although not actually indicating their weaknesses, they are accepting the possibility of personal weakness. It is this potential, Bennet argues, which other people can discern and relate to.

> *The wounded surgeon plies the steel*
> *That questions the distempered part;*
> *Beneath the bleeding hands we feel*
> *The sharp compassion of the healer's art*
> *Resolving the enigma of the fever chart.*
>
> T S Eliot; Four Quartets, East Coker, IV

The idea of this weakness or 'the wound' as Bennet calls it, is very old, particularly in relation to healing, and stems from Greek mythology. In some cultures, it is expected that the healer will also be a sufferer. As Bennet relates, this is demonstrated in societies where there are Shamans (see Eliade [1964] and Lewis [1971]). Shamans are people regarded as having a mixture of priestly and healing powers. However, a requirement for the role is that they possess some defect which would, in Western society be regarded as a disability or illness. This could often be of a quite spectacular kind, for example epilepsy. It would however, be expected that the sufferer had mastered the condition or in some other way come to terms with it. Thus as Bennet points out, in these cultures, what might seem to people in the West as a weakness, was seen as evidence of the ability to communicate with the spirit world and with the sufferer. Disability was thus conceptualized in positive rather than negative terms.

In Christian culture, the principle of the wounded healer is exemplified in the person of Jesus himself. Bennet (1979) points out that Christ was a healer who had no power and no status in the community, so that, in temporal terms, he was ineffectual. Although he was important during his lifetime to those who had known him directly, his world-wide influence could only begin after he had been betrayed, publicly humiliated and put to death. St Peter (I Peter, 2.24) expressed this in the words, "By his wounds you have been healed". Bennet also points out that Peter, because he had earlier denied even having known Jesus, had thereafter to carry his own wound – the reminder of his human frailty – throughout his subsequent ministry.

"I am Consumed in the Service of Others"

An idea rather similar to the concept of the wounded healer is contained in the device: "Aliis inserviendo consumor" (I am consumed in the service of others). By this the healer compares his service to his fellow-men with the candle which consumes itself while it gives light to others. Throughout the whole of what Pollak (1968) terms the modern period up until the present time, the burning candle can be found as a symbol of unselfish fulfilment of duty in the portraits of medical men and in their armorial bearings.

THE CLIENT SPEAKS

As a conclusion, two of the mothers from the sample group describe experiences of communicating with healers. The first with a 'virtuoso performer' and the second with a 'wounded healer', who had already laid aside his mask.

35. Mrs Davidson

"Well yes, I did get to see him (consultant) eventually but it was quite a battle. They sat us outside one of the cubicles (waiting to see the doctor) where the underlings work from. I knew it wasn't his (consultant's) queue because he's always in the big room at the end. I thought, well I'm fed up of this. I remembered what you said last time – I could see him if I needed to, and I thought, he's not God, he only thinks he is. So I went back to the desk and I says, 'Look, it's Mr B's name what's on these records and I want to see t'organ-grinder, not 'is ruddy monkey, and I'm going to sit here till I do, 'cos my health visitor says I can. Well it worked anyway and I did get to see him".

1. Mrs Gill

"You know, I do miss him, even now (ophthalmologist died about two years prior to interview). Mr D and the others are all right, nice and that, you know. But Mr A, well he was something special – he was a gentleman (I remember) after Robin had had his operation, I was picking him up out of the cot to cuddle him, and Mr A came up behind me on his ward round; and he said, 'no, don't pick him up yet because he's not properly round (from the anaesthetic) yet and you'll spoil his operation'. Well he could see that I was upset and wanted to cuddle him, and do you know what he did? You won't ever guess. He said, 'You hang on, I'll be back soon'. And a bit later up he comes with his own little boy – he was about the same age as Robin then – and he says,

'Here, you cuddle R for a while, I'll come back for him after I finish my round'. I won't ever forget that you know. I mean, what other consultant would have done anything like that? He was just ... oh, so ... kind".

Conclusion

In his final chapter, Bennet (1979) discusses the weaknesses and 'wounds' of doctors. And he writes: "An alcoholic doctor may be a public menace but he is a credible human because his wounds and weaknesses are plainly apparent, and so he may be approached in preference to the respectable citizen". It is argued however that the doctor should be beyond reproach and not someone who is the victim of human weaknesses.

In modern times, as Bennet points out, professional standards have been tightened and raised by the influence of supervisory bodies. Through them, the public has gained a great deal, but, the question is implied, has something perhaps also been lost?

CHAPTER 18

DOCTORS IN THE MAKING

If I have seen further it is by standing on the shoulders of giants.

Sir Isaac Newton (1642-1727)

THE INSTITUTION OF MEDICINE - ART, CRAFT OR SCIENCE?

According to Poynter (1971), medicine, in its broadest sense, is an important department of knowledge; in its narrowest, it is the practice of an art, one of what used to be called the 'useful arts' or applied sciences. Nowadays it has become more popular to imply that medicine is a science, or rather, as Poynter writes, "a group of sciences, sometimes called the life-sciences, the bio-medical sciences, or the health sciences".

The medical profession as a whole is a conservative one. As Poynter writes:

> "Trained to be cautious and sceptical of innovation, especially in its public utterances, (the medical profession) offers a restraining hand rather than an encouraging push when social reforms that concern it are under urgent discussion".

Poynter adds that although the relief of suffering is a noble vocation, medicine has always been a highly competitive profession, "with the ways of advancement carefully guarded and narrowly routed".

Doctors, as a group, tend to react to change in their status and conditions with shock and protest. And as poynter infers, the more devoted they are to their ancient colleges and institutions, with all their ritual and ceremony, the more strongly as a rule they react to proposed government action which they inevitably regard as 'interference'.

The hospital, as Poynter relates is a special kind of community with its own individual character and traditions which are not easy to change. Teaching hospitals, which have their own special traditions, transmitted

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from teacher to pupil over long periods, are even more resistant to proposals for reorganization which might well destroy their identity.

Many medical schools have famous names which are known all over the world, and their reputation attracts many doctors from other countries. Some however are still housed in obsolete 18th and 19th century buildings with world famous departments often housed in basements and other inadequate premises. The education which medical students receive in these schools also has its roots in the 18th and 19th centuries and as Poynter notes, it is still essentially based on the apprentice system, with clinical teachers attempting to produce doctors in their own image. Poynter (1971) argues:

> "Despite attacks on the curriculum (of medical education) which have hardly abated over the last hundred years, it is never subjected to more than minor modifications and any kind of balanced training appropriate for the needs of the present is made difficult to achieve by the reluctance of teachers in established subjects to give up any of the time already allotted to them".

Poynter argues that most hospitals are inward looking and tend to dismiss any criticism made by outsiders, especially the lay public, as ill-informed. And as in some other public services, there is a tendency to regard the institutions as belonging to those who staff them rather than the population they serve. Poynter's argument is that the end is often lost sight of in the involvement with the means.

The education and socialisation of doctors past and present, forms the subject matter of this chapter. In it, I am concerned to show some of the reasons for the continuing conservatism within the profession and the maintenance of the status quo by self-perpetuating systems of medical education.

The impact of the scientific revolution on medical education and the evolution of medicine as a science, to the detriment of 'the art' is also discussed as is the development of the teaching hospital as we know it today and the rise of specialist hospitals for certain kinds of illness. The chapter is concluded with some quotes from the respondents of the study

sample group. Some readers may wish to omit the early sections of the chapter printed in the alternative type.

REVOLUTIONARY MEDICINE

> "_ the majestic violence of light, which is in itself supreme, brings to an end the bounded, dark kingdom of privileged knowledge and established the unimpeded empire of the gaze".
>
> M Foucault (1973) The Birth of the Clinic

The rise of the hospital as a teaching institution rather than a dumping ground for the outcast poor and destitute, is connected, in the opinion of Foucault (1973) with the clinical examination of bodies.

One of the basic changes in eighteenth century French medicine was brought about, Foucault reveals, by the French revolution. This was the development of the hospital as an apparatus of examination. The focus of this examination, as Turner (1987) explains, was "the body, now rendered into the profane object of a secular science".

Foucault (1973) traced the development of the hospital examination of sick patients over a number of centuries within the French hospital system. He notes that, while in the 17th century, the doctor's visit was casual and irregular, by the end of the 18th century it had become a regular and organized routine. He also points out that the physician had by now become an established member of the hospital staff, replacing the religious staff who had increasingly assumed a subordinate position. Thus the hospital, as the place of what Foucault has termed the 'medical gaze' became the institutional representation of medical disciplines and regimens.

The discipline implied within the clinical examination of sick persons is, as Turner (1987) points out, "an invisible form of power which renders the patient visible". The examination also involved a detailed registration and administration of the patient. This administrative process within the hospital system permitted medical staff, as Foucault (1973) writes, to "follow the evolution of diseases, study the effectiveness of treatments, map similar cases and the beginnings of epidemics". As Turner (1987) points out, these disciplinary methods subordinated the individuality of the patient under the routine of description, administration and control, making possible a new power for the medical profession.

Turner (1987) is concerned to show that the new system provided for better education of doctors and the elimination of quacks by regulation of entrance to the profession by examination covering both theory and practice. More importantly however according to Foucault (1973) the hospital transformed the sick patient into an object of medical training. The sick were to become useful as illustrations of disease. Since

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the sick were typically the poor, they also became useful in the fulfilment of science. As Foucault expressed this idea: through the clinical gaze, the sick now became a spectacle.

The Clinical Gaze and 'The Appliance of Science'

During the late 18th and early 19th centuries, the application of science made available many new techniques and instruments for the examination of previously invisible parts of the body. The clinical gaze was thus enhanced by various "aids to vision" such as the microscope, the stethoscope and more importantly for eye doctors, the ophthalmoscope invented by von Helmholtz (1821-1894).

The dissection of the human body was once more permitted and Foucault (1973) quotes a passage from Bichat (1801) giving some advice to doctors and medical students:

> ".. for twenty years, from morning to night, you have taken notes at patients' bedsides on affections of the heart, the lungs, and the gastric viscera, and all is confusion for you in the symptoms which, refusing to yield up their meaning, offer you a succession of incoherent phenomena. Open up a few corpses: you will dissipate at once the darkness that observation alone could not dissipate".

> X Bichat, Anatomie Generale (1801)

Thus as Foucault writes, "The living night is dissipated in the brightness of death".

The Invasion of Light

A reformation of philosophy was a necessary prelude to scientific discovery. Philosophers like Bacon (1561-1626) began this reform process. In the main however, these philosophers stated their views with caution having no desire to become martyrs in the cause of truth. Truth they argued was not derived from authority but from experience. These early philosophers paved the way for scientists such as William Harvey (1578-1657) who discovered the circulation of blood.

By "standing on the shoulders of these giants", nineteenth century scientists such as Jacob Henle (1809-1885) were able to discover and lay bare the microscopic and macroscopic structure of the entire human body. It is interesting to note also that Henle did not confine his attention to histology. He stated his conviction that infectious and contagious diseases were caused by living organisms, thus as Guthrie (1945) points out, prophesying the dawn of bacteriology.

Contemporary with Henle was Louis Pasteur (1822-1895) who, though not a medical graduate was one of the outstanding figures of medical history. Pasteur's early researches concerned crystallography. He was however a man of many abilities and wide interests. As Guthrie (1945) relates, Pasteur in turn investigated

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and elucidated the diseases of wine, insects, domestic animals and man. He showed that fermentation was not merely a chemical reaction, but that it was due to micro-organisms, and that the souring of wine and milk could be prevented by the application of heat (pasteurisation).

Pasteur set out to ascertain whether the causative organisms were spontaneously generated or were already present in the air. And it was Pasteur's proof of atmospheric germs which led Lister (1827-1912) to apply the principle of antisepsis to surgery thus giving rise to the advent of modern surgical technique.

In 1868 Pasteur suffered a cerebral haemorrhage, and although he eventually recovered from the paralysis, he suffered a long and tedious illness. Following his recovery, Pasteur devoted his life to the study of bacteriology and it was as a 'wounded healer' (although not a doctor) that he made perhaps his greatest contribution to medical science. At great risk to himself, he studied killer diseases such as anthrax and rabies. He was able to isolate the causative organisms and attenuate them for inoculation. He thus considerably reduced the mortality rate from these diseases and set the stage for modern preventive medicine.

"Omnis Cellula E Cellula"

Another famous medical man of the nineteenth century was Rudolf Virchow (1821-1902). Virchow was also a man who encompassed several careers within his lifetime, being eminent as an anthropologist, a pathologist and a politician. His greatest achievement was his conception of the cell as the centre of pathological changes. For him there were no specific cells in diseased tissue; every morbid structure deriving from pre-existent cells. The motto, "Omnis cellula e cellula" (each cell arises from another cell), was the foundation of his work on Cellular Pathology published in 1858. This work destroyed at a blow the whole philosophy of "humeral" pathology. Although Guthrie (1945) points out, the views of Virchow have been considerably modified, nevertheless, at the time, they marked a considerable advance in thinking.

Illuminating Spectacles

Guthrie (1945) notes that the microscope may have been known to the ancients, although the evidence is inconclusive. In its earliest form the microscope consisted of a simple biconvex lens. The first man to apply the microscope to the study of disease was, according to Guthrie, Athanasius Kircher (1602-1680). Kircher was Professor of Physiology at Wurzburg. Whilst examining the blood of plague victims he found, "countless masses of small worms, invisible to the naked eye". It is now generally agreed that what Kircher really saw were red blood cells rather than plague bacilli, which could not have been seen with a lens of

such low power. His inference however was correct - that contagious diseases were conveyed by minute living organisms.

Guthrie (1945) informs us that it was Zacharias Jansen, a spectacle maker of Middelburg in Holland, who, about the year 1609, accidentally discovered the principle of the telescope and microscope by placing two lenses together in a tube. Galileo later turned this invention to practical use, but the instrument remained merely a toy for some years.

The origin of spectacles (or eye-glasses) themselves however, is lost in antiquity. Their invention has been attributed, rightly or wrongly, to Roger Bacon (1214-1294) - along with the microscope, the telescope, the diving bell, and gunpowder.

Spectacles however were not well received by doctors or oculists. As Sorsby (1933) relates, almost down to the middle of the nineteenth century, the fitting of glasses was the prerogative of untrained vendors, mainly itinerant, who usually combined this business with that of general pedlar. It cannot be said therefore that spectacles made any contribution to the armoury of the doctor in connection with the clinical gaze. This had to wait, in the case of ophthalmology, for the advent of the ophthalmoscope, (re)-invented by von Helmholtz in 1851. (According to Arrington [1959], the principle of the ophthalmoscope had been discovered 30 years previously by Johannes Purkinje (1787-1869), although if Helmholtz had knowledge of this, he makes no reference to the fact).

AIDS TO VISION - THE FOUNDATIONS OF MODERN TECHNOLOGY

The new technology which enabled doctors to see, hear or touch previously invisible inaccessible or forbidden parts of the body, was to alter the character of the clinical gaze. Foucault (1973) writes:

> "As soon as one used the ear or the finger to recognise on the living body what was revealed on the corpse by dissection, the description of diseases, and therefore therapeutics took quite a new direction".

The turning point for this new direction may well have been the invention of the stethoscope in 1818 by Rene Laennec (1781-1826). Guthrie (1945) recounts the story:

> "Shortly after his (Laennec's) appointment as physician to the Necker Hospital in 1816, he had occasion to examine a patient whose stoutness made it difficult for the physician to hear the heart sounds. Inspired, it is said, by having noticed two children playing with a log of wood, one tapping or scraping it while the other listened by holding his ear against the sawn end, Laennec rolled a quire of paper into a cylinder, and, placing one end over the patient's chest and the other to his own ear, discovered that he could hear the heart's action, 'in a manner

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more clear and distinct than I had ever been able to do by the immediate application of the ear'".

Ascultation by direct application of the ear to the patient's chest had been known since Hippocratic times. But as Lannec pointed out, "the older method was not only ineffective but inconvenient, indelicate, and, in hospitals, even disgusting".

Here in fact was the crux of the matter. Hospitals in the eighteenth and nineteenth centuries were filled with paupers - material for teaching and research. Many of them had infectious or contagious diseases and ulcers or bed sores. The physicians naturally kept their distance and left any actual physical contact with the patients to wound-dressers or surgeons. There were also moral obstacles to the doctor placing his ear directly against the patient's heart, particularly in the case of women. Foucault however gives a different perspective on this: "The moral obstacle was experienced only when the epistemological need had emerged; scientific necessity revealed the prohibition for what it was: Knowledge invents the Secret". Continuing on the same subject he later writes:

> "It is no longer shame that prevents contact, but dirt and poverty; not the innocence, but the disgrace, of the body. Ascultation is not only direct, but 'inconvenient for both doctor and patient; only disgust makes it more or less impracticable in hospitals; it is scarcely mentionable in the case of most women, the size of the breasts is a physical obstacle to its practice'. The stethoscope is the measure of a prohibition transformed into disgust, and a material obstacle, -".

The Piercing Glance

With the use of the new technology, the character of the clinical gaze was altered. As Foucault writes: Thus armed, the medical gaze embraces more than is said by the word 'gaze' alone.

> "It contains within a single structure different sensorial fields. The sight/touch/hearing trinity defines a perceptual configuration in which the inaccessible illness is tracked down by markers, gauged in depth, drawn to the surface, -".

Foucault (1973) describes how, at this point, the 'gaze', which is distant, all embracing and scans a free field, became transformed into the 'glance'.

> "The glance, on the other hand, does not scan a field: it strikes at one point, which is central or decisive; the gaze is endlessly modulated, the glance goes straight to its object. The glance chooses a line that instantly distinguishes the essential; it therefore goes beyond what it sees; it is not misled by the immediate forms of the sensible, for it knows how to traverse them; it is essentially demystifying. If it strikes in its violent rectitude, it is in order to shatter, to lift, to release appearance. It is not burdened with all the abuses of language. The glance is silent, like a finger pointing, denouncing. There is no statement in this denunciation. The

glance is of the non-verbal order of *contact*, a purely ideal contact perhaps, but in fact a more *striking* contact, since it traverses more easily, and goes further beneath things. The clinical eye discovers a kinship with a new sense that prescribes its norm and epistemological structure; this is no longer the ear straining to catch a language, but the index finger palpating the depths. Hence the metaphor of 'touch' (le tact) by which doctors will ceaselessly define their glance

And by that very fact, clinical experience sees a new space opening up before it: the tangible space of the body, which at the same time is that opaque mass in which secrets, invisible lesions, and the very mystery of origins lie hidden".

Thou Hast Searched Me and Known Me

The passage above from Foucault (1973) is somewhat reminiscent of Psalm 139 which, Hull (1991) reminds us, is a meditation on knowledge: "O Lord, thou has searched me and known me!" (v 1); or,

"My substance was not hid from thee, when I was made in secret, and curiously wrought in the lowest parts of the earth. Thine eyes did see my substance, yet being unperfect; and in thy book all my members were written, which in continuance were fashioned, when as yet there were none of them".

v 15-16 (A V)

Hull (1991) meditates on this psalm, the author of which, he feels certain, was blind. God, he says, has that strange power of knowing at a distance, seeing something which is still far away, ("Thou searchest out my path and my lying down, and art acquainted with all my ways", v 3, RSV) and of knowing what we are thinking, ("thou discernest my thoughts from afar", v 2 RSV). In some ways, Hull points out, God's knowledge of the world is rather like the knowledge which the sighted have of the blind. A sighted person can see a blind person and recognise him at a distance, and a sighted person can sometimes tell what a blind person is thinking from his facial expression. None of this is reciprocal to the blind man. He needs touch in order to see, and therefore can never see at a distance. He needs language in order to translate another's thoughts.

God's knowledge fills the psalmist with wonder: "Such knowledge is too wonderful for me; it is high, I cannot attain it", v 6 (RSV).

The knowledge which God has, continues Hull, is inescapable and darkness cannot prevent him from knowing: "wither shall I flee from thy presence?" v 7, and: "Yea, the darkness hideth not from thee; but the night shineth as the day; the darkness and the light are both alike to thee" v 12 (AV).

Hull likens the Knowledge of God to the knowledge which the sighted have of the blind. Could it not also however, be paralleled with the knowledge which the doctor has of his patient? With the coming of the new science, the doctor attained the 'high knowledge', previously attributed only to God. Was it therefore

here, at this point in time, as the gaze became narrowed and sharpened into the glance; and armed with the new science and new trinity of sight/hearing/touch that the birth of a new doctor-god took place?

The Compassionate Gaze

There is a difference however, between the 'doctor-god' and the God of the psalmist. The God of the psalmist shows compassion and understanding. Hull (1991) considers this, and writes:

> "'If I take the wings of the morning and dwell in the uttermost parts of the sea...' (v 9). I may, perhaps, live beneath the sea, in that world of the unconscious depths. Even there, the One who is the Lord of all worlds will make himself known to me in the manner which suits my condition. He will not show himself to me; he will not appear to me. He will not offer me a vision or be transformed in glory. He will remember my blindness. '... even there thy hand shall lead me and thy right hand shall hold me' (v 10)".

Foucault (1973) on the other hand describes the clinician's gaze as "silent and gestureless". The observing gaze, he says "refrains from intervening". In others words it is cold and 'clinical'.

Although Foucault uses metaphors concerned with touch when describing the glance, they are not gentle metaphors. "The glance *strikes* in order to *shatter* ...". It makes '*striking contact*'; it '*burns* things to their furthest truth'. The glance then is invasive, sometimes violent; care and support are not embraced within the clinical gaze.

MATERIAL FOR TEACHING AND RESEARCH

Whilst Foucault (1973) attributes the 'Birth of the Clinic' to the French Revolution, this does not account for the very similar process occurring in other parts of the Western World at around the same period. Abel-Smith (1964) attributes the evolution of the teaching hospital in England, in part to the Industrial Revolution:

> "As villages expanded into towns and towns into cities in the great drift to urban living generated by the developing industries, there were more and more places where it became practicable to attract staff and patients for a hospital".

Prior to the turn of the eighteenth century, the main care of the sick came from within the family circle. The patient was made as comfortable as the love and care of the family could make him. As Abel-Smith (1964) points out, "Illness was not regarded as a circumstance which required much

positive action. All that could be done was to ask God to remove the affliction in his own mysterious way". Thus only the sick who had no family were driven to seek institutional care, as Abel-Smith writes, "either because sickness had made them destitute or destitution had made them sick". Finally there were those who hoped, after everything else had been tried, that they might find relief or cure away from home.

The growth of the hospital 'movement' was made possible by money given by the public; but the major impetus in channelling these donations in certain directions came increasingly from doctors, who, as Able-Smith points out, wanted hospitals for teaching and research.

Before the founding of hospital medical schools, medical teaching had been a combination of theoretical instruction and somewhat casual apprenticeship to a medical practitioner. In 1800 however, the Royal College of Surgeons was founded, leading to a closer association between medical education and hospitals. The College laid down requirements for medical education, one of these being, "a year's attendance on the surgical practice in a hospital". The Society of Apothecaries Act of 1815 also required of students, six months hospital, infirmary or dispensary practice.

For these reasons, there was a rush of students to hospitals in the second decade of the nineteenth century. It is reported that in the early 1820s, the theatre of St Thomas' hospital:

> "was crowded in every part by upwards of four hundred students of the most respectable description; in fact, we never before witnessed so genteel a surgical class: the sight was most pleasing, for they all appeared gentlemen of cultivated manners and good education".
>
> S Sprigge, The Life and Times of Sir Thomas Wakley London, 1899 (Quoted in Abel-Smith, 1964)

"The sight was most pleasing" not least because all these students had paid three guineas or more for the privilege, and as Abel-Smith (1964) points out, the greater part of this money went into the pocket of the lecturer.

Gradually more and more hospitals acquired associated medical schools, with more and more hospital surgeons taking on teaching responsibilities. And

in order to meet the new demand, more and more hospitals were founded. As Abel-Smith (1964) writes,

> "While in the eighteenth century hospitals had been founded by laymen to meet the needs of the sick poor, in the first half of the nineteenth century many hospitals were founded to serve the needs of medical students and their teachers".

In 1828 University College opened a dispensary (outpatient clinic) and shortly afterwards, an inpatient department to provide teaching material for its medical school. As Abel-Smith relates, the doctors wanted acutely sick patients with interesting diseases for teaching purposes. It was easier to achieve this if a pool of prospective patients was created from which selection could take place. This was one of the main functions of the dispensary or outpatient clinic. From the crowded halls, the junior doctors selected and handed on to their seniors, those cases they would find of interest. The selection of patients would also be influenced by the likelihood of a cure being achieved. Doctors needed to show results in terms of cure. They were therefore naturally reluctant to surround themselves with cases which showed the limitations of their professional skill. As Abel-Smith writes, "Doctors who taught particularly wanted to demonstrate success".

Spectacles for the Gaze

The hospitals offered many advantages for medical education. The many different types of cases made it possible for large classes of students to learn at the same time. Wards in the newer hospitals were built to noble proportions with generous corridors between the rows of beds. Although many historians attribute this to higher standards of hygiene and ventilation, there was, as Abel-Smith points out, another reason: more space had to be created for the bedside teaching of medical students. Some teachers, had as many as 100 students following them round the wards.

The practice of having groups of patients with similar diseases sorted into separate outpatient clinics or wards had advantages for research as well as for teaching. Experiments with different kinds of treatment became

easier. And, as Abel-Smith points out, if an experiment failed, at least there would not be any repercussions on the doctors' private practices. As Foucault (1973) comments, "sickness, which had come to seek a cure, was turned into a spectacle". On the same theme Foucault writes:

> "But to look in order to know, to show in order to teach, is not this a tacit form of violence, all the more abusive for its silence, upon a sick body that demands to be comforted, not displayed? Can pain be a spectacle? Not only can it be, but it must be, by virtue of a subtle right that resides in the fact that no one is alone, the poor man less so than others, since he can obtain assistance only through the mediation of the rich".

Abel-Smith (1964) argues that while the paying patient had a legitimate right to object to being observed and prodded by a group of students, a person in receipt of charity was hardly in a position to complain about such invasions of his privacy. Thus the hospital doctor was able to practice his art and perfect his technique on the poor, to the benefit of his private patients. It gradually became known to private patients, that hospital doctors possessed the most advanced knowledge. Thus as Abel-Smith points out, for the doctor, charitable work became the key to fame and fortune. Thus, although these hospital appointments were honourary, they nevertheless carried a great deal of prestige and power. They were however extremely hard to come by for the average doctor. Abel-Smith reports that in the 1820s appointments to hospitals were obtainable only by family or money influence.

Once a post was achieved, it seems, the duties of a surgeon at a large teaching hospital were not too arduous. Abel-Smith relates that in 1848, when there were 397 surgical beds at St Bartholomew's, only about 400 operations were performed in the year.

Then, as now, there was very little room at the top of the medical profession. Abel-Smith (1964) reports that out of about 15,000 practitioners registered in 1860, fewer than 1,200 were working in 117 of the larger voluntary hospitals. Of these, only 579 were classified as being "physicians and surgeons who have charge of inpatients". The remainder apparently were assistants and junior housemen.

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Promotion to the ranks of honourary physicians and surgeons was very slow. The posts had a high monopoly value and there was little incentive to share the spoils by creating new posts. It seems also that those in post usually lived to a ripe old age and there was no statutory age for retirement.

For promotion to be achieved, the good opinion of the existing staff was essential. And then, as now, candidates were prepared to be blatantly exploited in order to gain this.

During years of anxious waiting, the junior doctors carried out all the routine work of the hospital. They selected suitable cases for their seniors from the many hundreds of outpatients and gave day-to-day supervision to the inpatients in the absence of the senior doctors. In most hospitals the junior doctors carried out all this work without payment, and only gradually were small salaries of £50 to £100 per annum, with full board, introduced for resident medical officers. It was also the rule in many provincial hospitals, that even the most experienced 'registrars' were forbidden to engage in private practice, lest they take away business from their seniors.

Thus it was, as Abel-Smith (1964) explains, that there accumulated in each hospital a group of exploited and frustrated young doctors. The lack of promotion opportunities was not the only reason for discontent. As the frontiers of medicine advanced, the younger generation of doctors developed special interests in particular diseases and techniques.

For further progress however, new clinics needed to be set up, special equipment was required, and a group of beds set aside for the new speciality. And a new speciality could only be accommodated at the expense of an old one. Naturally, the old guard of established doctors fought against this sectionalization of medicine. They clung to their beds and refused to see limited resources diverted to the new departments. So, as Abel-Smith relates, the aspiring specialist found himself blocked and thwarted by the older generation of general physicians and surgeons who controlled the general hospitals.

The Rise of the Special Hospital

The reaction of some of the dissatisfied and ambitious young specialists to the frustration of the general hospitals was, as Abel-Smith relates to go off and found a special hospital. One such doctor was John Cunningham Saunders, a protege of Astley Cooper at St Thomas Hospital. According to Abel-Smith, Saunders had little hope of a hospital appointment, and went off to Gravesend, "anxious about his future prospects". He was however summoned back by Cooper in a letter ending, "I shall endeavour to make your situation comfortable from a pecuniary point of view but I had rather make that the subject of conversation when I see you". (From: E T Collins, The History and Traditions of Moorfields Eye Hospital, London, 1929. Quoted in Abel-Smith 1964). Saunders was made comfortable from a pecuniary point of view by the foundation of Moorfields Eye Hospital.

Of course not all special hospitals were founded in this way. The first special hospitals, as Abel-Smith points out, had been started to make provision for patients who could not safely be accommodated in the general hospitals and for patients whom the Royal Colleges were not interested in treating.

Because of the danger of infection (to other patients and to doctors) obstetric patients, children, those with fevers and venereal diseases were excluded from the majority of general hospitals.

In addition to children frequently being a source of infection, there were other reasons for excluding them completely from most hospitals. During the eighteenth century it appears to have been accepted that the mother should live in the hospital with her child, (an idea only recently revived by psychologists). "If you take away a sick child from its parents or nurse you break its heart immediately ..." (G F Still, The History of Paediatrics, London, 1931). Dr George Armstrong, who founded the first children's dispensary, refused to support a proposal for a children's hospital on the grounds that it would be impossible to run a hospital where "the Mothers and Nurses would be perpetually at variance with one another ... if there must be a nurse to each Child what kind of Hospital must there be to contain any number of them?" (ibid).

Patients with eye diseases fell into most of the categories which would exclude them from general hospitals. Many suffered from infectious conditions, this would include many of the soldiers returning from the Napoleonic Wars, among whom there was a high incidence of trachoma. Almost all the children attending workhouse schools and institutions suffered from infections of the eyes, many becoming blind because of this (See Hurt, 1988, Chapters I and II). Many, perhaps the majority of ophthalmic patients were incurable at the time and any treatment available produced poor results. For many reasons then, as Abel-Smith relates, the treatment of eye diseases in the early nineteenth century had been "tacitly abandoned, even by the hospital surgeons, and turned over to the oculists".

Abel-Smith (1964) points out that the distinctive feature of specialist hospitals was the fact that most of them were founded and controlled by doctors. As he explains, while the general hospitals had been mostly started by charitable laymen who had solicited aid from doctors, the specialist hospitals were mostly started by doctors who solicited aid from laymen. The new specialist hospitals then, met the needs of their founders in a variety of ways. They provided clinical material and resources for the development of skills, unhampered by obstruction or surveillance of the old guard of 'great men'. They could also be used to attract private patients. As Abel-Smith points out, an advertisement extolling the work of a hospital was a legitimate means of raising money to help the sick poor. However, it also had the effect of enhancing the reputation of the doctor who ran it. Thus as Abel-Smith writes, "Some of the specialists were indirect beneficiaries of the charities they created".

THE DOCTOR'S CAREER

As It Was in the Beginning ...

A recent study of doctors and their careers (Allen 1988) suggests that in many ways, the lot of the doctor has changed very little during the last 150 years. Allen's study is a survey of the views and experiences of over 600 doctors, who qualified in 1966, 1976 and 1981. The report shows widespread anxiety among doctors about the future development of their careers and considerable discontent with their conditions of service.

There was also evidence of anxiety and discontent among young doctors about what they saw to be decreasing job opportunities, difficult working conditions and unacceptable demands on their personal lives.

Allen (1988) makes the point that nowadays doctors *qualify* when they graduate at the age of 23 or 24 and are usually fully registered a year after qualification, having completed a pre-registration year working in a hospital. However, as she points out, doctors are not regarded as *trained* until they have completed their postgraduate training after registration. This requires a minimum of three years and can be as long as ten to fifteen years for those wishing to become hospital consultants. Allen argues that there is no other career in which the training period is so long and demanding, involving as it does, years of postgraduate study at the same time as working very long hours. It is this which makes medicine such a uniquely difficult career for anyone who wants to lead a 'normal' life, and particularly difficult for a woman who would like to marry and have a family.

Why then do people want to become doctors? As Allen argues, the attraction of a medical career remains very strong. Applications for medical school are still far in excess of the number of places, and it is generally accepted that only 'the best' scholars will apply. Although qualified doctors do occasionally change career, this is not the rule, as once having embarked on medicine as a career, there is strong pressure to continue with it.

Allen (1988) asked the sample group of doctors what had led them to choose medicine as a career. She found a fairly consistent pattern of a group who had "always wanted to be doctors". With the men, this was often related to the fact that other family members were doctors. The women were more likely to have "wanted to help people" from being very young.

This difference between male and female doctors is interesting when we consider that since ancient times, physicians have come of families of healers. (Legend has it that Hippocrates himself was descended from Asklepios, the archetypal physician). It is only recently however that women have been allowed into the profession, and it seems to be the women

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who have brought to the fore this 'new' concept of caring and wanting to help people, rarely mentioned by men.

Allen found that the main reason given by doctors for wanting to study medicine was because they were good at science subjects. This was most marked among the 1981 qualifiers, who were much less likely than the other groups to say they had always wanted to be a doctor. Both men and women had been attracted by the glamour of medicine. Both these reasons, it seems had led to bitter disillusionment with medicine as a career, and many bitter comments from Allen's respondents.

The doctors in Allen's sample came mainly from middle class backgrounds. Overall, only 8% had fathers in manual work. Among the 1981 qualifiers only 4% had a working class background.

... Is Now ...

As Allen (1988) relates, there is a traditional view that medical students are heavily influenced by eminent doctors with what she terms 'star qualities', to follow a particular speciality or career in medicine. Allen wanted to ascertain whether this was a dying phenomenon and whether 'star performers' were on the wane.

There were many references to patronage and 'sponsorship', and one fifth of the doctors said they had been encouraged or influenced in their choice of career or speciality by a consultant or professor in medical school. Positive influences at medical school were however mentioned less frequently than negative ones. Forty one per cent of the 1981 women graduates said they had been put off a speciality by consultants. This applied most strongly to surgery, obstetrics and gynaecology and psychiatry.

Most of the doctors appeared to have arrived at their career choice almost by accident, there being hardly any career guidance given in medical schools – 80% of the 1981 graduates having had none at all. As Allen writes,

> "Far too much is still left to chance and personal patronage, and far too little attention is paid to a realistic assessment of each student's overall suitability for a variety of specialities as well as the future manpower needs of medicine in all specialities".

It is not only in the field of careers advice that personal counselling for medical students and young doctors is lacking. Research by Firth (1986) confirms that medical students show higher levels of stress than their contemporaries, one of the main reasons for this being their relations with consultants. Many doctors, both men and women used the word 'humiliating' to describe experiences at medical school, and it seems that medical students are often treated in ways which few other young people would tolerate. Allen questions whether such a 'toughening-up process' is the best way to ensure that medical students can cope with all the stresses of the training. The availability of more personal counselling would, she feels be a more appropriate solution to the problem.

One of the reasons why medical students submit without complaint to treatment (including sexual and racial discrimination and harassment) meted out to them by consultants, is that they are dependent, for the best jobs, on a system of personal patronage or sponsorship. Allen reveals that, far from being a relic of the past, patronage appeared to be taking on even greater importance. It was generally recognised that 'high-fliers' needed to have powerful patronage from, 'friends in high places'. Surgery was recognised as a speciality in which career progress without patronage was almost impossible. Therefore, although they felt they were treated appallingly, students dare not risk offending senior doctors, being dependent on them for jobs and references. Typical of the comments given to Allen regarding patronage were those from a Senior House Officer qualified in 1981:

> "You get tipped for the top if you're male, white, Oxbridge or London. Female or coloured – forget it! ... You succeed in

getting sponsors if you are a good toe-the-line sycophant, so the right people don't reach the top. Consultants work together - their own private empire. If you're not among 'the chosen' you can't break in. You're on the outside and that's that".

And Ever Shall Be?

The views of this house officer were echoed by many of the junior doctors of both sexes. They were very critical of the life of a young hospital doctor which demanded long hours of study and constant moves to further their careers. They felt there was considerable pressure for young doctors to cultivate sponsors in a way which many felt amounted to 'toadying' and was not in the best interests of the patients.

Most of the doctors interviewed however, felt there was little impetus for change in a system which seemed to be self perpetuating. Many of the younger doctors were also very bitter about the consultants' attitudes, for example:

> "I'm sorry to say that the average consultant doesn't give a toss about the working conditions of his junior colleagues. They tend to think that as they've been through the mill, why shouldn't the next lot suffer too. You very rapidly forget the deprivations you've been through. They very rapidly forget what it's like to be up all night".

Allen also found a dramatic increase in the reported incidence of regret among the respondents on their decision to become doctors - from 16% of the 1966 qualifiers to 46% of those qualified in 1981. For example, a male, divorced orthopaedic registrar:

> "Hardly a day goes by when I don't regret it. If I'd known, I'd not have done it. The demands on your life are far too high. The hours and the continual exams and studying - year after year. Also the job uncertainty and insecurity at my age. I'm trained for nothing else. I've no 'get-outs' - no adequate alternative but to stay in the system. My training is worth nothing if I don't stay in medicine".

Doctors, Allen found were becoming increasingly aware that the way to get on in medicine was to follow a conventional career. Opportunities for

younger doctors to try out various options were much more limited than they had been for their older counterparts. The system of promotion which favours 'conventional people with conventional careers' was thought to be increasingly important in forcing doctors to make early career choices, and to stick to them without deviating, even if they found they had made a mistake.

THE CLIENT'S VIEW

This chapter has been concerned to show some of the reasons why the medical profession, despite the progress of science and the use of modern technology, remains locked in its own ivory tower with what seems to be a built in system for perpetuating its status-quo. It is apparent that this system benefits neither the doctor nor the patient. Yet, unless drastic changes are introduced into the curriculum for the teaching and socialisation of doctors, the system seems set fair to continue on its course into the foreseeable future.

By way of illustration, some of the respondents of the blind sample group caught up in the system voice their opinions.

On Being a Spectacle

4. Wendy Jenkinson. Functionally Blind. Cataracts

> "It's a good job she doesn't have to go (to hospital) very often.
> (Yearly appointments) I really hate going. I get all worked up
> about it for weeks before the appointment. It's being in that
> big (consulting) room with all the other people waiting to be
> seen and all the doctors and students all standing round and
> having a look. And all the other patients can hear everything
> about you. There's no privacy at all. Then you have to wait for
> hours, and all they say at the end of it is 'Well that's fine,
> come back in a year'. I've never had enough courage to ask them
> anything. It seems it's all for the doctors' benefit. There's
> nothing in it for us".

Can Pain Be a Spectacle?

35. Lee Davidson. Functionally Blind. Cataracts & Neurological Syndrome

> "Sometimes I wonder why I keep taking him back. Usually he has
> to have ointment in to dilate his eyes for a week before he goes.

It's really strong and it hurts him. He really cries and fights when I put it in, and I get all screwed up inside having to do it. I woudn't mind so much if it was going to do any good. But they always try to make him sit still at the machine, and he's just not big enough and the light hurts his eyes. There's always a kicking and screaming match and it usually ends up with two nurses and a doctor holding him down while they examine him. And when it's all over, you're no further on".

Such Knowledge is High, I Cannot Attain It

20. Andrew Cannon. Functionally Blind. Cataracts

"When you go, (to hospital) you don't get to know anything. You're more confused when you come out than before you went in. It's all talking to each other in 'doctors' language' and they never translate it or tell you what they're on about. They never tell you anything, they just treat you as if you wouldn't understand".

Material For Teaching and Research

7. Adam Stacy. Functionally Blind. Retinal Dystrophy (Progressive)

"We only go once a year, and really it's not worth the effort. I'd discharge him, only, well - I keep thinking maybe in the future, he might be cured. You know, you hear of so many marvellous things nowadays, heart transplants, and liver transplants, and I think well, they might be able to do an eye transplant one day. But in the meantime, well, he's just an interesting case, I suppose a sort of 'visual aid' for the students and young doctors. I'm not sure I like it, but I can't see that I've any alternative really except to go private".

Incurables Are Excluded

28. Cynthia Carter. Totally Blind. Congenital Anophthalmos

"No she was discharged the first time we went. They just registered her blind, and that was that. (Child born without eyes) If they can't cure you, and you're not an interesting case, they just don't want to know".

CONCLUSION TO SECTION IV

In Section IV I have dealt at some length with the history and background of those employed in the healing professions.

Although the science and technology of medicine continues to advance at an ever increasing rate, the 'art' of healing seems to have been left behind and has advanced little, if at all since the dawn of modern medicine.

With these advances in technology, patients increasingly expect to be cured and doctors expect and are expected to bring about such a cure. When science, technology and the doctor fail in this respect a breakdown in communication occurs as both doctor and patient are unprepared for such an event. A crisis situation is therefore set in motion.

In the final section of the thesis, the families are studied as they progress through the stages of crisis to emerge with a new identity. Some of the ways in which they can be helped and guided on this journey are considered.

INTRODUCTION TO SECTION V

The six chapters of Section V deal with the families' passage into and through the crisis brought about by the diagnosis of blindness in a child and the rearing of that child.

Chapter 19 explores issues of power and inequality in professional/client relationships, particularly those of doctors and patients.

Chapter 20 presents a theoretical framework within which disaster and crisis situations can be studied. Using this framework in parallel with the patient career, the process of consultation is examined.

Chapter 21 is concerned with the consultation process in clinical settings. The evolution of the GP as we know him today, from the ranks of the tradesman and the craftsman along with the developing 'service relationship' is explored. Readers may however omit this section if desired and following this short diversion we rejoin the families in their career through the consultation process to the point of 'impact'.

Chapter 22 deals with the families' experience of 'impact' or the diagnosis of blindness. Rites of passage are then required to facilitate entry into a new identity. The ways in which the medical profession control this passage by using ritual and 'clinical ceremony' is discussed.

Chapter 23 is concerned with the ways in which the families adapt to and cope with their disabled child. It is part of my thesis that families need first to mourn the lost identity of their seeing child and that, as the bereaved people studied by Parkes (1972), they must pass through despair in order, finally, to reach resolution.

Chapter 24 The final chapter explores some of the ways in which families can be helped and guided on their passage through despair to resolution and finally, where possible to their empowerment.

THE DOCTOR-PATIENT RELATIONSHIP: POWER AND INEQUALITY

"If ever I need to remind myself what a patient feels like coming
to a hospital out-patient department, all I have to do is to take
a five-minute walk down the hill from the Bristol Royal Infirmary
to the Law Courts. I ordinarily inhabit a hospital environment
where I have a distinct role and status, where the organization
is totally familiar, where the uniforms and grades of staff are
readily identifiable, and where no harm is likely to come to me.
In court I have a function, to give evidence say, but I am not
part of the organization, and certainly have no status there. It
is impossible to know the details of what is going on yet there
is always a sense of urgency with small groups talking earnestly
in the corridors, and an outsider is unable to differentiate the
figures in dark suits, black gowns, wigs and the like. The
assembly of unidentifiable figures engaged in urgent but
unintelligible business leaves me with an uncanny feeling that
only trouble can result from the proceedings. At all costs I
must not put a foot wrong or else the incomprehensible machine
will somehow land me in the dock instead of the witness box".

> Glin Bennet (1979), Patients and their Doctors

Thus writes an experienced doctor in an endeavour to help medical students
and young doctors to understand the uncertainties and anxieties of patients
entering the bureaucratic web of the hospital system. Bennet giving
evidence in the courtroom however is not quite the same situation as the
initiate out-patient. He is middle-class, well educated, articulate, and
probably in possession of expert knowledge of value to those dealing with
the case. The prospective hospital patient on the other hand is much more
likely to have a working-class background, to be less well educated than
the doctor and inexperienced in dealing with large bureaucratic
institutions. The patient is likely to be suffering not only uncertainty
but also a high level of anxiety. As Revans (1964) observes, "Hospitals
are institutions cradled in anxiety".

This chapter is concerned with a social process (communication) within a
clinical setting, or settings. According to the dictionary,
"communication" is defined as "the giving, imparting or sharing of
information". Although communication is, of necessity, a two way process,
the dictionary definition implies inequality. By this I mean that the
information is given by an active communicator and received by a largely

passive recipient. In the clinical setting, such research as has been carried out indicates that this is in fact usually the case - the doctor is the active communicator whilst the patient, in almost all situations, is a largely passive recipient.

In previous chapters of this study, the parents' accounts of events and situations were examined within a largely psychological framework. The camera lens will in the coming chapters be changed to a wide-angle one in order to examine events and relationships from a (largely) sociological viewpoint.

Davis (1982) points out that much has been written in medical sociology about the characteristics of doctors, and that even more has been written regarding the characteristics of patients. Surprisingly little however has been written about the doctor-patient relationship, and even less about the ways in which medical work varies from setting to setting. Freidson (1970) notes that most of this work is an attempt to explain doctors' behaviour by reference to abstractions such as 'ethicality' or prior medical training. Instead, Freidson argues, it makes better sense to look for explanations, bearing in mind:

> "That people are constantly responding to the organised pressures of the situations they are in at any particular time, that what they are is not completely but **more** their present than their past, and that what they do is **more** an outcome of the pressures of the situation they are in than of what they have earlier internalised.".

As Davis (1982) points out, what sociologists have in the main done, is to look at the consequences of medical work without examining the nature of, or variations in the content of such work. Instead, Davis writes, "medical work has been regarded as an old battlefield on which David and Goliath are eternally pitched against each other", except it seems David invariably loses. The reasons for David's continual loss are according to Freidson (1970) connected with the general dominance of the professional.

In the face of such a lost cause, it would seem there is little to be gained by studying the battlefield because we know in advance what the outcome will be. As Davis (1982) points out however, old battlefields do

have their interest, particularly when the battle is still going on. Davis also makes the point that medical sociology seems to take as a fundamental premise that the outcome is always in some way to the detriment of the patient.

Freidson (1970) argues however, that, "all that doctors do is not the same and does not require the same type of interaction". Thus Freidson makes it clear that there are several different battlefields, and Davis (1982) adds, "this is not something that one finds getting due acknowledgement in sociological literature on 'the doctors' role'".

Admittedly, as Davis (1982) points out, the sociological literature on the performance of medical work is quite seriously defective, fragmentary and partial. Because of this it is difficult to piece together the ways in which medical work and the various settings for its execution together exert a powerful influence on the nature of the interaction between doctor and patient. In such circumstances, Davis argues, it is easy to fall into the trap of making sweeping generalisations about 'medical work', 'the doctor's role', or 'the doctor-patient relationship'.

One of the first problems confronting sociologists wishing to study doctor-patient relationships, and indeed the whole field of medical practice, is that of access. As Stimson and Webb (1975) point out, because of the medical emphasis on confidentiality and the private nature of the consultation, it is probable that doctors who do allow sociologists access are in some way unusual compared to their colleagues. If this is the case, it would follow that these unusual features might well be reflected in their interactions with patients.

Stimson and Webb (1975) also warn that the entry of a research worker into the normally private two-person consultation may well affect the quality of the interaction.

Even where sociologists are allowed access, this access is certainly not unlimited. Most sociological studies of medical practice have been centred around either general practice (eg.. Stimson and Webb, 1975) or paediatrics, (eg.. Davis, 1982). Sociological studies in the field of

ophthalmology are notable only by their complete absence. This state of affairs is in fact perfectly logical when we consider that GPs and paediatricians are perhaps the two groups of doctors most concerned with patients in their family and social settings. It is also noteworthy that, of all doctors, paediatricians elicited the highest satisfaction ratings amongst the parents of the blind sample. Research in the field of general practice also indicates that, on the whole, patients like their GPs and are generally satisfied with the service he provides.

Thus it would appear that sociologists are only allowed access where 'good practice' is already taking place and where the doctors concerned are not afraid to have their work put under the microscope. These will also be doctors who are ready to admit that there is room for improvement in their practice and who are probably already committed to improving communication and client satisfaction ratings.

Even in these highly selective areas, the sociologist is still usually denied access to certain types of client. Voysey (1975) for example was not allowed to interview parents of the most seriously ill children, nor those known to have problematic backgrounds. It must also be said that there are more subtle ways in which access can be restricted. By this I mean that the doctor can almost always control which patients are seen by him when the researcher is present. Thus the doctor can, if he so wishes, manipulate the situation so that any patients who might have 'problems' are seen by another doctor. Finally of course, the patient or parent may refuse to participate, which might also have an influence on any biasing of the sample group.

Implicit in this introductory chapter are a number of questions which will be addressed in the chapters which follow.

One of the main concerns of sociologists studying medical practice has been that of 'communication'. For as Davis (1982) remarks, "concern with communicating normally arises when relationships are seen as unequal, frustrating, unpleasant, and unjust". However, before becoming too embroiled in this issue, we must first ask ourselves the question: "Is communication in medical settings necessarily always 'bad'?"

Davis (1982) points out that, "It is not clear quite what would count as 'good' information for those reporting dissatisfaction or whether there is any generally satisfactory standard information package that can be identified and translated into ready recipes for doctors to use". For example, Davis continues, "does communicating the findings of 'cancer' in a known caner ward create the same problems for the communicator as communicating 'flu' in a GP surgery?" Once again there is a tendency to ignore situational constraints in the literature.

In fact, if other situations marked by an imbalance of power were to be studied, they might well, as Davis (1982) points out, all be found to be equally defective. And as he argues, doctors are probably no worse at communicating than are say, teachers to pupils or most professionals to clients in a professional consultation. Davis goes on to point a finger at sociologists themselves, who, after all he writes, "seem to have earned a certain notoriety for their own inability to 'communicate'".

If we assume that an imbalance of power is inevitable in the doctor-patient relationship (and even Freidson [1970] has to admit that the role of the 'passive' doctor is empirically unlikely or even impossible), is this state of affairs necessarily 'bad'?

On the face of it, whichever medical battlefield we choose to study, Goliath looks set fair to win. It is as well to bear in mind however that the same is true of the original story. And even if Goliath's victory is inevitable, is this necessarily to the detriment of the patients? Or are there perhaps chinks in Goliath's armour, and does David triumph rather more often than sociologists assume?

If communication is found to be 'bad' or 'faulty'; given the constraints of time, setting and (perhaps most importantly) the workings of bureaucratic machinery), can the situation be improved - and if so, how?

In order to address these questions, it is my intention in the following chapters to return to data presented previously and re-tell the 'story' of events leading to the diagnosis of the handicap, the crisis which this

brought about, the passage of the family into and through this crisis and the ways in which they coped during this period.

APPROACHES TO CRISIS

"Doctors and patients may come together holding somewhat different conceptions of illness. The doctor's views are largely moulded by his professional training and clinical experience. The patient's views are influenced by the need to cope with a particular problem and his cultural and social understanding of the nature of the problem. Thus it is in the doctor-patient relationship that lay and professional cultures most intimately meet and sometimes clash. The definitions of illness or the norms of functioning held by physicians vary in the extent to which they conform to lay conceptions. In some situations the views of particular groups of patients and doctors are closely congruent; in other circumstances they differ and clash not only in respect to whether illness exists but also on a cultural level. The definition of illness thus may take place in a context in which there are competing views of the patient's condition, and resolution of the problem may depend on how these different definitions come to be applied in a specific instance. This is not to imply that the doctor is unable to maintain his unique perspective in the situation. However, whether the patient responds to the doctor's expectations and co-operates in treatment, as well as many other facets of care, is intimately linked to the perspective of the patient and his associates".

D Mechanic, "Medical Sociology", 2nd Ed (1978)

A FRAMEWORK FOR DISASTER

In this chapter, the families of the blind children are followed in their 'Passage through Crisis' within a framework of their 'Patient Career'.

Davis (1963) describes his study of polio victims as a "naturalistic" one:

"It neither focuses on a single aspect of the family's experience with the child's illness and its aftermath nor does it try, as does much present-day sociological research, to test a series of preformulated hypotheses of highly delimited and analytically refined facets of the experience".

Davis's approach is essentially a descriptive one. In his (1963) study, 'Passage Through Crisis', he describes and analyses certain experiences common to the families studied as they move from one set of conditions to the next: the onset of the child's illness, its diagnosis as polio, the

child's hospitalisation, the course of his treatment, his discharge from hospital, and his reincorporation into the family setting.

Using a similar framework to that of Davis (1963), the natural history of the evolving crisis of blindness in the family will be dealt with. The families' conceptions of blindness and the alterations in these conceptions as a result of experience and interactions with treatment professionals will be discussed as will the stresses and strains produced by clashes of perspectives and communication difficulties. Following diagnosis, the problems of identity posed for the child and his family by the newly acquired status of a handicapped person have to be faced and some of the strategies of adjustment employed will be described.

Harrisson (1977) notes that Powell and Raynor (1952) in an analysis of mass-disaster situations, identified a sequence of seven events or phases which may or may not be discrete: warning, threat, impact, inventory, rescue, remedy and recovery. Harrisson points out that it is possible to adapt such an outline of disaster events to a small group or to individuals to show the sequence of events occurring during a personal crisis.

Davis (1963) modifies the mass-disaster framework to structure and aid the analysis of the development of the crisis experience in the families of the polio victims. Here the crisis sequence is used to assess the psycho-social impact on the families and their subsequent adjustments to "altered life circumstances". Davis takes the crisis events as they occur in sequence to analyse the personal adjustments of the members of 14 families using just four of the disaster stages as follows:

Prelude Stage

From the time when the parents were aware that the child was unwell until they reached an awareness that the condition was probably serious.

Warning Stage

From the realisation that the condition was probably serious until a diagnosis was made.

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<u>Impact Stage</u>

The time at which the diagnosis was made and communicated to the parents.

<u>Inventory of Adjustment Stage</u>

The period of assessment and formulation of recovery perspectives.

Other researchers have also found this kind of approach useful when studying how families adapt to illness and handicap. Speedling (1982) for example, studied the victims of heart attacks and the responses of their families at home and in hospital. Harrisson (1977) used a similar approach when studying family stress in response to two long term conditions - Perthes Disease, from which the patient normally makes a full recovery and cystic fibrosis, which is usually terminal.

Davis's (1963) four stage crisis framework has been utilised as follows to study the families' reactions to blindness:

<u>Prelude Stage</u>

From the time the parents became aware of something unusual or abnormal in the child's visual responses, until they realised that the child probably had a visual defect. This stage includes the help-seeking process and 'lay consultation' and referral systems.

<u>Warning Stage</u>

From the decision to seek professional help, through the GP consultation, to the referral to an ophthalmologist.

<u>Impact Stage</u>

The stage at which the diagnosis of blindness is communicated to the parents.

The period in which the families assess the situation and formulate their coping strategies.

For the families in the blind sample, the prelude stage begins with the process of seeking help.

THE PRELUDE TO DISASTER

Mechanic (1978) reminds us that our knowledge about the processes that take people along various paths to helping practitioners is limited.

> "At most (he writes), one can sketch the range of such processes and the length they can go in various cultural contexts and among various social groups. We know very little about the ways people use their friends and acquaintances in attempting to cope with distress, and not much more about the use of a great variety of non medical practitioners such as clergymen and lawyers, semi medical persons such as druggists, and marginal practitioners such as chiropractors and faith healers. Obviously such factors as cultural and group organisation, kinship and friendship patterns, and medical orientations are important, but the help-seeking processes themselves need much illumination".

Freidson (1960) and (1961) has pointed out that patient behaviour may vary widely, involving differing attempts to deal with the condition which troubles him. The person may first try folk remedies, he may discuss his illness with family members, friends, neighbours or work mates in a casual way to explore various alternative explanations for his condition. He may ask the advice of others as to whether he should consult a medical practitioner or he may go to the doctor on a 'trial visit'. In short, professional help seeking often occurs through what Freidson (1960) describes as the "lay referral system". Freidson describes this process in the following way:

> "Indeed, the whole process of seeking help involves a network of potential consultants, from the intimate and informal confines of the nuclear family through successively more select, distant, and authoritative laymen, until the 'professional' is reached. This network of consultants, which is part of the structure of the local lay community and which imposes form on the seeking of help, might be called the 'lay referral structure'. Taken

together with the cultural understandings involved in the process, we may speak of it as the 'lay referral system' ...".

E Freidson (1960) "Client Control and Medical Practice"
American Journal of Sociology: 65: 374-382
Quoted in D Mechanic, "Medical Sociology", 2nd Ed

Mechanic (1978) points out that it would be oversimplification to assume, having isolated a pattern of care seeking and use of "lay referral systems", that a similar pattern will apply in different kinds of illness situations. As he argues, the meanings attributed to illness vary widely, and with changing meanings variations in help-seeking patterns are likely to occur. In some cases for example, relatives and friends may encourage treatment, while in others they may deny the presence of symptoms and be reluctant to define the condition. This as Mechanic points out frequently happens with mental disorders. To illustrate his point Mechanic quotes from a study by Yarrow and colleagues (1955) which describes five trends characterising the process through which wives attempt to cope with their husbands' increasingly difficult behaviour:

"1. The wife's first recognition of a problem depends on the accumulation of behaviour that is not readily understandable or acceptable to her.

2. This forces her to examine the situation and adjust her expectations for herself and her husband in such a way as to account for his deviant response.

3. The wife's interpretation of the problem shifts back and forth from seeing the situation as normal on one occasion to abnormal on another.

4. She tends to make continuous adaptations to the typical behaviour of her spouse, waiting for additional cues that will either confirm her definition or lead to a new one. She mobilises strong defences against her husband's deviant behaviour.

5. Finally a point is reached at which the wife can no longer sustain a definition of normality and cope with her husband's behaviour".

M Yarrow et al (1955) "The Social Meaning of
Mental Illness", Journal of Social Issues
11: 12-24. Quoted in Mechanic (1978) 2nd Ed

Mechanic (1978) argues that there is a stronger inclination to normalise or rationalise the symptoms of emotional disturbance than those of physical

illness. For Mechanic, this tendency is explained by the cultural conceptions held about mental illness and the stigma attached to it.

However, if we return to the five trends observed by Yarrow et al (1955) outlined above, and substitute mother or parent for wife, child for husband or spouse and blindness for mental illness, it becomes apparent that there is a remarkable similarity to the responses of the parents in the blind sample group during what might be termed the 'prelude' and 'warning' stages of the crisis process.

Very similar responses have also been described in other studies. For example, Davis's (1963) polio victims, Harrisson's (1977) sample of children suffering from Perthe's Disease and the heart attack victims studied by Speedling (1982).

The trends in behaviour found by Yarrow et al (1955) constitute some of the reasons for delay in seeking professional advice. However, as Bennet (1979) argues, the issues surrounding this delay are highly complex. Bennet also points out that, whilst defence mechanisms give a person time to adapt, if a pathological process is continuing during this phase, this is not, in the long term, to anyone's advantage. Bennet goes on to discuss some of the reasons for the delay in help-seeking. Some 'delayers', he notes, have an excessive fear of surgery which they may see as punishment or mutilation. Others have a fear of dying, and yet others delay because they are depressed and have suicidal wishes. The self-image of the patient may demand perfect health, so that the possibility of illness cannot be accepted. This may be one of the main reasons why parents delay in seeking advice: they see their child as 'perfect' and are unable to accept any other image of him. Other people may delay because they feel shame about the condition, and as was noted in earlier chapters, blindness is a stigmatising condition, and many of the parents, particularly the mothers, felt shame at producing a blind child.

Discussing patient delay in seeking advice when cancer is suspected, Bennet (1979) remarks:

> "... the way people react to the threat of illness is not
> rational, and can never be expected to be rational. The

attitudes of shame which used to be attached to having tuberculosis persisted for a long time after the disease had been shown to be curable; no doubt something similar applies to cancer. Cancer education and routine screening programmes have not been as successful as on rational grounds they ought to have been. The early appearances are now better known, and are presumably taken in subconsciously by the delayers, but cancer cannot be cured for sure".

Bennet (1979) also points out that while the patient is criticised for not seeking help, it is apparent that even when the patient does disclose symptoms of a suspicious nature, the doctor, for various reasons may fail to register them. Sometimes, as Bennet writes, the reasons will be found in the circumstances of busy clinical practice. There is often however, as he reveals, a tendency to let things slide:

"if the first examination reveals nothing definite then no further action is taken, or else a remark is made such as: 'We'll keep an eye on it'. Better perhaps to make no examinations at all than foster dangerously misleading expectations".

In discussing the problem of 'denial' by the doctor, Bennet (1979) quotes from research from Titchener et al (1956), which although undertaken many years ago is nonetheless still highly relevant:

"Sometimes there was mutual hostility between the physician and his patient, with a resulting interference with the normal process of diagnosis and treatment. In other instances strong, positive sympathetic feeling toward the patient irrationally prevented the physician from making a diagnosis with poor prognosis and caused him to act on the basis of wish fulfilment, treating the patient as though he or she had a less serious condition. In two cases in our series the physicians who were close emotionally to their patients treated them for menopausal symptoms when one was bleeding from advanced uterine cervical carcinoma. It was inferred, though not proved, that in each case the otherwise competent physician was too moved by the suspicion of gloomy prognosis to employ his full diagnostic powers".

> J Titchener et al (1956) "Problems of Delay in Seeking Surgical Care", J. Am. Med. Ass., 160, 1187-1193, Quoted in Bennet (1979)

Bennet (1979) argues that it would seem likely that the factors which hold back certain members of the public from coming forward with their suspected cancers also act upon the medical profession. He notes in this context

that doctors are just as reticent at presenting themselves for treatment of suspected cancer as are the lay public. This collective behaviour seems to be an active denial of reality. It is of course dangerous because, as Bennet points out, "doctors have many ways of operating the denial process, and in holding the distressing realities out of reach of themselves they deny the patients the benefit of prompt treatment".

In this respect, it is interesting to note that in four of the five cases of malignancy in the blind sample, there was a delay between presentation and diagnosis of 6 months, 9 months, approximately 1 year and three years respectively. What is of particular interest here is the fact that in the only case where there was no delay, it was a trainee GP who saw the child, and he had had no prior contact with the family. In all the other cases, the families concerned had been with the same GP for a number of years and knew him well.

It seems feasible that this 'collective denial process' may well also operate in the hospital environment. In the case of a hydrocephalic child, blinded at the age of four following blockage of his shunt, medical staff (according to the mother), refused to admit that the child's vision could have been affected and she apparently had to insist on having an ophthalmic opinion herself.

Although it would seem equally likely for the denial process to operate in a hospital as in the GP's surgery, there may be other factors at work here. Davis (1963) points out that "uncertainty" is often feigned in order to serve social-managerial ends:

> "Instead of openly confronting the parents with the prognosis (that the child would be left with a disability), treatment personnel sought to cushion its impact by hedging, evading questions, and acting as if the outcome were still uncertain".

Thus they tried to spare themselves the emotional scenes that outright utterance of the prognosis would probably have entailed.

As Davis argues, in many illnesses, especially those of a chronic or permanently incapacitating nature, 'uncertainty' is to some extent feigned

by the doctor for the purpose of gradually getting the patient to accept and put up with a state-of-being which is initially intolerable to him.

THE PROCESS OF CONSULTATION

In examining the GP consultation process Stimson and Webb (1975) extend the social activity of the consultation both temporally and spatially to include actions outside the face to face contact of patient and doctor, but with reference to that contact. Analytically, they divide the process into three stages:

> "<u>The stage prior to the consultation</u> which includes the patient's expectations and his 'rehearsal' for the consultation.
>
> <u>The face to face interaction</u> when the consultation actually takes place. This includes the 'performance' of the patient in presenting himself and his problems.
>
> <u>The period after the consultation</u>, during which the patient makes sense of what happened and makes his treatment decisions".

Stimson and Webb (1975) point out that the use of such concepts as anticipation and reappraisal necessarily assume an account from the perspective of the participants in the interaction. And, as in their study, the following account is reviewed from the perspective of the patient, or in this case the parents.

In following the families of the blind sample on their "passage through crisis", I have largely followed the path of Stimson and Webb (1975), using Davis's (1963) modified mass disaster sequence as a framework.

Lay Consultation in the Approach to Crisis

Freidson (1972) suggests that within local communities there are two linked referral systems, the professional and the lay. The lay system is under the control of the client (in this case the parent) for he can seek help and advice from whom he will. Harrisson (1977) points out that movement through the two systems is paralleled by the patient-career. The lay system varies in length and operates until the point at which professional aid is sought. The GP acts as a bridge between the two systems, his

position being at the apex of the lay system and the base of the professional one. Entry into the professional referral system begins with contact between client and GP. At this stage client choice begins to become more restricted and the system separates him to some extent from lay support. As Harrisson (1977) argues, "the further the client penetrates into the professional system the more his choice in the management of his condition is restricted".

The time span of the prelude and lay-consultation periods varied in the blind sample between a few days and many months. As with the children suffering from Perthe's Disease in Harrisson's (1977) study, social class did not seem to have any bearing on the length of time spent in lay-consultation prior to seeking professional advice. In his study of polio victims, Davis (1963) found that:

> "... a commonplace explanatory framework is applied at the onset
> of the child's illness. With the introduction of incongruous
> symptoms, this becomes ambiguous and less tenable, giving rise to
> a course of action that eventuates, sooner or later, in a
> definition of the child's condition as one more serious and
> dangerous than that originally contemplated".

Davis (1963) observes that although warning cues of a symptomological type were perceived by most parents, it was rare for these cues to emanate from just one source. Typically, he writes, "the perception of one cue triggered off others, which then fed into each other to produce pronounced strain on the 'normal outlook' with which the child's illness had been viewed".

Davis found that the first warning cues elicited different reactions, not only from family to family and parent to parent but also even in the same individual as his original definition of the child's condition grew less tenable. Davis reduced these many and varied reactions to three main types: rationalisation, reinterpretation and vacillation.

A strong denial component is often present in the rationalisation response. For example, one of Davis's (1963) respondents, the mother of a seven year old boy reported:

> "Well, I'll tell you the truth. We didn't - we might have thought of polio, but we didn't want to. We just didn't want to think of it I guess, even though he couldn't walk ... But that night I said to my husband when was getting ready to take him to the doctor, I said, 'I can't hardly believe that he could possibly have polio'. I said, 'Look, I can move his legs'. And I went to move one and he yelled out, and that almost knocked me over. I just stood there, almost - just - I just didn't know what to say. So I thought then, 'Well, I bet it is'. But I didn't want to think about it".

The reactions to illness described above, denial, rationalisation, reinterpretation, and vacillation, have been noted by other researchers. Examples include, Speedling (1982) in his study of heart attack victims and Harrisson (1977) studying stress in families with children suffering from long term and terminal illness.

Similar responses also occurred in the blind sample. For example, Mrs Grant quoted in Chapter 5 put Andrew's visual defect down to clumsiness, "... he always was clumsy and used to bang into things all the time. And he's always sat with his nose right on top of the tele".

Nina McDonald's nystagmus (abnormal movement of the eyes) was normalised by her parents, who found her behaviour quite amusing:

46. Nina McDonald. Functionally Blind. Optic Atrophy

> "We used to laugh at her when her eyes flicked. I used to say to her dad, 'Ooh look, she's doing it again'. We used to think it was just to get attention. After a bit I thought, perhaps it's some kind of nervous tick, you know caused by her hair getting in her eyes, so I had it cut".

All three types of response can be found in the quote below as Lucy Baldwin's mother begins to realise that her child's behaviour does not fit the normal pattern:

> "I was in town shopping, outside Marks & Spencer it was actually.
> When suddenly it hit me. Lucy's blind I said to myself, just
> like that, out of the blue. And suddenly all the funny things
> she did, clicked into place. I told my mum, and she said, 'Don't
> be daft, of course she isn't blind. Take her down to the
> doctor's and he'll tell you she isn't'.
>
> (Mrs Baldwin is quoted in Chapter 5 after the consultation with
> the ophthalmologist)
>
> ... I walked out in a daze and wandered round town with her
> for ages. I couldn't cope with their (relatives) reaction. I
> told everybody she was all right after all".

Defining the Problem

Davis (1963) points out that:

> "... a considerable portion of the individual's health and
> illness experience takes place in locales and with persons far
> removed from the guidance and control of institutionalised
> medical authority - in the home, at work, with kin, friends,
> neighbours and others in the person's routine orbit of
> existence".

Stimson and Webb (1975) stress the importance of significant others in
defining the problem as an appropriate one for medical attention:

> "It appears to us that advice-giving has a crucial part in the
> decisions surrounding illness. Advice is given in strong terms.
> The ill person may be told that they 'ought' or 'should' go to
> the doctor or call him out. Reference may be made to other
> people's experience with a similar problem, as a comparison, or
> to what is known to be 'going around at the moment'".

Stimson and Webb also note that there is usually some uncertainty in the
person's mind. People do not always know whether they or their children
are ill or not, or whether they are ill enough to take some action about
the condition. Stimson and Webb suggest that the greater the uncertainty,
the greater the importance of others in the decision to consult.

From their interviews Stimson and Webb noted a high degree of reluctance
to consult a doctor over minor ailments. Comments such as, "I try not to
worry the doctor unnecessarily" or, "I have to have something really wrong

with me before I go to the doctor" were common. Many felt they had to justify being there: "You feel you've got to justify being there, prove that you've got something really wrong". It seems from Stimson and Webb's research that people also feel they should be able to judge for themselves the seriousness of their problems, and that doctors expect them not to waste their time on trivial matters. The importance of others in the decision to consult among the blind sample parents is evident in the following quotes.

21. Marie Williams. Functionally Blind. Leber's Ameurosis

"She always rolled her eyes around right from being tiny. Sometimes they flicked about really fast. Well, when it's your first you don't really know what to expect, do you? I used to think she was just really alert, you know, looking round at everything. It was my neighbour, actually - she's a nursery nurse and had kiddies of her own as well, she said it wasn't right and I ought to go and see the doctor about it".

24. Jill Barnes. Functionally Blind. Retinal Dystrophy

"She was always a mardy baby - never shut up screaming unless you picked her up all the time. I tried gripe water and colic medicine but nothing did any good. I asked my mum what she thought - I was at my wits' end. She said she oughtn't to cry like that all the time and I should take her to the doctor's. Of course, I know now she was crying because she couldn't see me and not from wind or anything".

The introduction of cues suggesting that something might be seriously wrong with the child places a strain on the parent's earlier common-sensical diagnosis ultimately rendering it wholly untenable. And, as in Davis's (1963) study, these cues may also be though of as marking the terminal point of the 'Prelude Stage' of the crisis process.

THE WARNING

"... the ideal consultation. The doctor's attention is devoted exclusively for a short period of time to the life and problems of another human being. He is there to listen and to help. His training will have made him receptive to a wide range of distress signals and given him the means, or knowledge of the means, to answer. The occasion will be unhurried and something will be gained by both participants; a good consultation brings satisfaction to the doctor as well as the patient".

> The Future General Practitioner
> by a Working Party of the Royal
> College of General Practitioners
> 1972, p 3
> (Quoted in Stimson and Webb 1975)

"It never did seem right to me, not from her being a few days old. But she was my first you see, so I didn't really know what was right or wrong. I took her to the doctor's when she was three or four weeks old because the white of her eyes had gone a reddy brown colour. But he just said it was due to pressure from the delivery. I tried to tell him it had only just gone like that, but he wasn't listening. He said first time mothers were all the same, coming to him with every little thing, and to go away and not worry. Well really I was scared to go back after that you know, for fear of wasting his time like".

> Mother of Danielle Ellington
> Child suffering from a malignant
> tumour of both eyes

CONSULTATION IN CLINICAL SETTINGS

The "Warning Phase" follows the families of the blind sample from their decision to seek professional help, through their consultation with their GP, to their referral to an ophthalmologist.

The chapter is concerned with the different pathways taken by the families as they approached the impact of their crisis. As in Stimson and Webb's (1975) study, the consultation process is divided into three stages:

I   The Stage Prior to the Consultation which includes the patient's expectations of the doctor, and his 'rehearsal' and preparation for the consultation.

II The Face to Face Interaction which includes the patient's 'performance' and presentation of himself and his problems.

III The Period Following the Consultation in which the patient recalls and makes sense of what has happened and makes his decisions with regard to his treatment.

Chapter 22 is also concerned with the ways in which people make a decision to seek professional help and the factors which influence this decision. The expectations of the client in relation to his satisfaction with the service are also explored.

The chapter begins with the evolution of the GP from the ranks of tradesman (apothecary) and craftsman (surgeon) to the professional we know today and some of the ways in which "the move to the workshop" has influenced his practice.

The Move to the Workshop

In their separate ways, Foucault (1973) and Goffman (1961) describe the movement of the healer away from pedlar carts and home visits and into the "workshop complex", where, instead of the 'server' bringing himself and his tools to the client, the client comes to the server.

Both Goffman (1961) and Foucault (1973) imply that the "workshop" is a locale in which the resources, technical means and personnel to effect "repairs" can all be brought together in one stable location. In addition, workshops are specialised locations in which different kinds of service are made available.

Goffman (1961) points out that there are also advantages to having a workshop which are social in character, i.e. the server has an increased status leverage when he acquires a workshop. Furthermore as he writes, "Owning or renting one's shop ensures that the client cannot turn the server out of the house and that the police cannot make him 'move on'. It is the client who becomes the guest".

TRADESMAN TO PROFESSIONAL: THE DEVELOPMENT OF THE GENERAL PRACTITIONER

The movement of doctors to a workshop environment is bound up with the rise of the tradesman (apothecary) and the craftsman (surgeon) to professional status. This evolution is discussed by Reader (1966) in his essay on the Rise of the Professional Classes in Nineteenth Century England. Reader notes that medicine was, in the early 19th century (and to some extent still is), "readily susceptible to the taint of magic, folklore and humbug". To this must be added the fact that most of the population could not afford the advice of a qualified physician. Many of the poor were also illiterate, here being the reason for the ancient shop signs such as the barber's pole (red for the blood and white for the bandage) and the flagons of coloured liquid symbolising the apothecary's shop. As Reader points out, here was a situation made for quackery.

Out of this welter of ignorance and exploitation, as the 18th century drew to a close, a few surgeons and apothecaries began to emerge as honest and reliable men (no women were admitted to either trade), to whom the less affluent could turn for medical attention. It was also as Reader (1966) points out, among these men that many advances in knowledge were being made. As he writes, "The surgeons were not hampered by veneration of the classics, and they cut people up to see what really went on inside".

Neither surgeon nor apothecary could as yet be clearly distinguished from the skilled tradesman. Throughout the 18th century they were still organised, so far as they were organised at all, in livery companies of the City of London. As Reader notes, the apothecaries had parted company with the grocers in 1617 and the surgeons with the barbers in 1745. Neither group however had established learned bodies. Nor indeed would it have been generally considered reasonable that they should do so. The surgeon, after all, was a craftsman and the apothecary a shopkeeper. Neither in these circumstances, could be a gentleman - not at any rate until he had become rich and famous, as some of the early 19th century surgeons did.

Surgery without anaesthesia, was a rough and bloody business and was unlikely to attract anyone of refined taste or adequate fortune. So, as Reader (1966) notes, surgeons in the early 19th century were usually, "men of little fortune - younger sons, sons of ruined men, orphans".

Reader (1966) goes on to explain that at the turn of the 18th century, there were three orders of medical practitioner - physicians, surgeons and apothecaries and druggists. The apothecaries came third in this recognised order and were regarded by the physicians with even greater contempt than the surgeons. Reader informs us however that this contempt was tempered with an element of alarm because these shopkeeper apothecaries were presuming to prescribe treatments for people who came into their shops. Reader notes that in 1703 the physicians had tried to crush this presumption by legal action. The House of Lords however held that the apothecaries were within their legal rights, and this, as Reader notes, became thereafter a standing grievance with the physicians. Reader argues however that the apothecaries also had their pride and rated themselves as being above the ranks of chemists and druggists, though as he points out, the drawing of the demarcation lines must have been very difficult. According to Reader, the difference probably rested on the fact that apothecaries went out to visit patients, whereas chemists and druggists remained shop bound.

Shopkeeper to Gatekeeper

Although the druggists fought hard against the drawing of the line which was to separate them from the medical profession, in 1841, Reader informs us, they tacitly admitted defeat by setting up their own professional body - the Pharmaceutical Society.

Thus the apothecaries became peripatetic, converting their shops to surgeries or "workshops", and became doctors. The druggists remained behind their counters and became pharmaceutical chemists. Reader points out however, that the chemist, to this day, retains the right to prescribe for minor ailments. Reader also notes that it was the despised apothecaries, who through their professional body, were the first of the healers to establish a system of qualification and registration on modern lines. And he observes that the passing of the Apothecaries Act in 1815 marked the emergence of the doctor whom we know today as the General Practitioner. As Reader (1966) explains:

> "By the beginning of the nineteenth century the professional pre-eminence of the physicians was being strongly challenged. Most of the new thought on medical matters, including new thought on professional organisation and training, was growing among the despised surgeons and apothecaries. But for the present they were still very much the lower branch of the profession - the 'general practitioners', a term, not of honour, that came into use round about this time. The physicians were fighting a determined defensive action, not at all to their own credit or ultimate advantage".

Thus it becomes apparent from Reader's essay that the GP or the doctor of the ordinary people, arose, not from the ranks of the learned physicians, but from those of the skilled craftsman (surgeons) and the retail salesman, (apothecaries).

THE CONSULTATION AND THE 'SERVICE RELATIONSHIP'

Goffman (1961) uses the term "service relation" to describe the case where the server has a complex physical system to repair, construct or "tinker with". The system he deals with in his essay on the "Tinkering Trades" (doctors), is the client's own personal possession - his body. Goffman describes this relationship as follows:

> "The type of social relationship I will consider in this paper is one where some persons (clients) place themselves in the hands of other persons (servers). Ideally, the client brings to this relationship respect for the server's technical competence and trust that he will use it ethically; he also brings gratitude and a fee. On the other side, the server brings: an esoteric and empirically effective competence, and a willingness to place it at the client's disposal; professional discretion; a voluntary circumspection, leading him to exhibit a disciplined unconcern with the client's other affairs or even ... with why the client should want the service in the first place; and, finally, an unservile civility. This then, is the tinkering service".

Stimson and Webb (1975) see the consultation as a special type of social encounter in which one person seeks information or advice from another, both parties sustaining for a time a single focus of attention. Stimson and Webb note that consultation with a doctor is distinguished from everyday conversational social interaction in that:

> "(1) it is geographically and temporally inflexible: consultation usually takes place at a certain place and at a certain time; (2) there is specificity: the advice will be the reason for the interaction - other topics may be raised but only incidentally; and (3) ... there is a competence gap between advice seeker and advice giver".

In discussing the consultation process, Stimson and Webb (1975) argue that as it is usually enacted on the doctor's territory, this gives him certain strategic advantages over the patient (a "David and Goliath situation" as described by Davis 1982). The patient requests to see the doctor, who makes himself available to see patients only at certain times. The

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doctor's time is seen as being more valuable than that of his patients. As Stimson and Webb note, it is the patients who go into the aptly named waiting room to wait their turn to see the doctor. In the surgery the patient is surrounded by technical equipment in a clinical setting - symbols of the doctor's specialist knowledge. Stimson and Webb also argue that because the doctor is seen as having access to specialist knowledge which is not available to the layman, this gives him the ability to act as the primary decision-maker in the consultation and allows him the greater control in the interaction.

PRIOR TO THE CONSULTATION - THE DECISION TO CONSULT

Using the "Tinkering Trade" service model with regard to the decision to consult, Goffman (1961) writes:

> "There is a threshold point where the possessor himself finally sees that his possession has suffered damage or injury. If the possessor cannot make his own repairs and if he defines his problem as one that a server can help with, he becomes a client in search of a server, or in search of referral to a server through a set of intermediaries.
>   Once a server is found, the client brings him the total possession, or the total of what remains, plus, when possible, the broken parts. The central point here is that the whole complex of the possession, all that the server will need for his work, is voluntarily put at the disposal of the server by the client.
>   Now begins the famous process: observation, diagnosis, prescription, treatment".

Goffman remarks that, at this juncture, it is remarkable how frequently a lab coat of some kind appears, symbolising not only the scientific character of the server's work but also a "spiritual poise of disinterested intent".

As Stimson and Webb (1975) noted, other people (lay consultants) often help the person to define the problem as one requiring medical intervention. This is not always easy, particularly when the patient is a child and symptoms are ambiguous. There is always the fear of, "wasting the doctor's time", or of being labelled a "worrying mother". In terms of the uncertainty of the person about what action to take, Stimson and Webb

suggest that, "the greater the uncertainty, the greater the importance of others in the decision to consult".

Stimson and Webb (1975) also point out that the GP controls access to resources including treatment, certain social services and referral into the hospital system. Thus as they note, "Because these resources are only available through the doctor the patient's freedom to choose whether or not to consult, and thus his control over the doctor is limited".

Expectations of the Consultation

Having made the decision to consult, what does the client expect to be achieved during the process? Are those expectations, in the main, fulfilled and are the patient's expectations similar to those of the doctor?

As Stimson and Webb (1975) point out, "expectation" seems to be a concept which, like many others used in describing social aspects of medicine (eg.. satisfaction) is extremely difficult to examine analytically. And as they also point out, researchers define and analyse these concepts in different ways.

Expectations, Stimson and Webb note, can be used in the sense of how one actor hopes or would like another actor to behave or act; or on the other hand in terms of how he usually does act on the basis of past experience of similar interactions.

Stimson and Webb argue that the medical encounter has features which can be distinguished even by those who have little experience of such encounters. This, they attribute to the doctor's 'routine' pattern of activity aimed at diagnosis and treatment, so that even the infrequent attender to some extent 'knows the agenda'.

Stimson and Webb also found evidence that, in a group practice, patients tend to match their problems to particular doctors, in the hope that he will 'perform' as expected. On many occasions however, as they point out, people may not know what they were expecting, in the sense of knowing what

they wanted, until after the event, and it is only in retrospect that they could begin to understand their expectations. This it seems was true for many of the parents of the blind children. However, 'reassurances' such as "He'll grow out of it" or "don't worry, it's normal", were, in retrospect at any rate, not what the parents had wanted, nor what they had expected. Anticipating a negative reaction from the doctor may prevent the person from consulting him in the first place, and fear of (as the parents saw it) ridicule or rebuff, often added to the delay in diagnosis because it prevented parents from returning for further consultation as the quotes below show.

2. Matthew Tomlinson. Functionally Blind. Retinal Dystrophy

> "Well, I took him back the second time and his (the doctor's) eyes rolled up into his head and he said, 'Look, I've told you already, it's just a squint and he'll grow out of it. They won't operate before he's six anyway, even if he doesn't'. So I thought, well, it's no good going back. I mean, you just get nowhere".

21. Marie Williams. Functionally Blind. Leber's Amaurosis

> "I took her back again (to the GP) when she was about eight months, but he still said it was normal for babies' eyes not to focus until they started to walk. I just knew it wasn't right, but it's like talking to a brick wall".

The Journey to Impact

As previously stated (see chapter 5) many parents said they had found it difficult to convince professionals that something was wrong. As can be seen from the tables in chapter 5, there were indeed long delays between the problem first being noticed (prelude stage) and diagnosis (impact stage). These delays were usually in months, but sometimes amounted to several years. It would appear that this time lag between suspicion and confirmation of the sight problem is not confined to the Sheffield area. As can be seen from the tables referred to, the longest time between suspicion and confirmation in the Sheffield sample was 7½ years. However, the RNIB survey (Walker et al, 1992) quote a time lag of 10 years as being the maximum in the nationwide survey.

Harrisson's (1977) findings in her study of children suffering from Perthe's Disease show a somewhat similar pattern in the delay between the first GP visit and the specialist consultation. That the parents in Harrisson's study also had difficulty in convincing their doctor that something was wrong is evident from the number of visits they had to make to the GP before he referred them to a consultant. Harrisson's results (Tables 5 and 6 on page 50 of her study are reproduced below as Table 21.1).

Table 21.2 overleaf shows the time lag between suspecting and confirmation of the vision problem found by Walker et al (1992) in the recently published RNIB survey.

Table 21.1   Time Lag Between Suspicion and Confirmation of Perthe's Disease

TABLE 5

Number of G.P. visits made before consultant referral

	No.
None	2
1	22
2	30
3	16
4	4
5+	10
Total	84

TABLE 6

Time in months between first G.P. visit and consultation

	No.
Under 1	39
1–2	21
3–5	11
6–8	6
9+	6
Not obtained	1
Total	84

Reproduced from: S P Harrisson (1977) Families in Stress. London, RCN

Table 21.2   Time Lag Between Suspecting and Diagnosis of Visual
             Impairment from the RNIB (1992) Survey

Table 3.5   Time between first suspecting the sight problem and its confirmation

'How old was . . . (child) when it was first suspected that he/she had an eyesight problem?' (S3Q9)

'How old was . . . (child) when it was first definitely confirmed by tests that he/she had an eyesight problem?' (S3Q12)

	Total
	%
Confirmed at the same time	60
Time between suspicion and confirmation:	
1 year after	18
2 years	6
3 to 5 years	9
5 to 10 years	3
All with a time lag between suspicion and confirmation	36
No data	4
Total %	100
Base	285

Reproduced from: Walker et al (1992) "Blind and Partially Sighted Children in Britain: the RNIB Survey Volume 2" (Table 3.5, page 48)

In the case of the Sheffield sample, it has to be taken into account, the study being retrospective, that parents were having to recall events which may have taken place sixteen years ago. Some of the accounts were confused and had obviously become distorted over the years. In some cases, where both parents were present at the interview, their accounts were dissimilar and they could not agree as to the sequence or the timescale of events. However, although it is generally acknowledged that the GP is the 'gatekeeper' to specialist and hospital services, and in British studies at least, this seems to go unquestioned, according to the parents of the Sheffield sample, the majority of the blind children arrived for consultation with the ophthalmologist by a route other than via the GP. The data show that only 11 (20%) of the children were referred directly from the GP, and it appears that only 14 (25%) ever consulted him in the first place. Five of the 11 referred by the GP had already consulted another professional (three an optician, one a clinic doctor and one a

school doctor), and had a letter for the GP to refer the child to an ophthalmologist. Unlike Harrisson's Perthe's Disease sample, only four of the blind sample parents consulted the GP on more than two occasions and none more than four times. All then took an alternative route, most commonly via the Health Authority clinic doctor.

If we exclude the premature babies and those with a family history, who were examined before being discharged from the maternity unit, the most usual routes to the consultant were through the Health Authority clinic (11), the GP (11) and the Paediatric Department (10) where the child had been attending for some other condition - eg.. epilepsy or hydrocephalus.

Table 21.3 overleaf gives a breakdown of the referral sources.

The results shown in Table 21.3 are probably quite unusual and it is unlikely that they would be repeated today because the situation has changed quite dramatically over the past few years.

At the time when many of the families reached the warning and impact stages of their crisis, Sheffield was fortunate in having an ophthalmologist who would accept referrals directly from the then Local Authority clinic doctors, and from health visitors through this system. As can be seen from Table 21.3, clinic doctors referred as many patients as did the GPs. Parents who failed to convince their GP something was wrong simply went along to the local 'Welfare Clinic' for a second opinion. This may have been the reason why no parent in the Sheffield sample consulted the GP more than four times prior to referral. Following the death of this consultant however, the service became fragmented with ophthalmologists no longer accepting direct referrals from the (now) Health Authority Clinics, although children can still be referred through the Orthoptic Clinic. The situation has also altered in that virtually all the Health Authority Clinics have been closed because GPs have now taken over responsibility for child health surveillance, thus effectively closing a major route of referral and eliminating a means of obtaining a second opinion. The Hall Report (1989) also recommends that the routine screening of children under 5 for vision defects should cease. This could well add to an already deteriorating situation.

Table 21.3 Agency Referring to the Ophthalmologist (N=55)

Child Health Clinic Doctor	11
GP (5 had letters from other agencies)	11
Paediatrician	10
Maternity Hospital (Premature Baby Unit)	9
Maternity Hospital (Family History)	6
Self Referral (Other family members already patients)	3
Health Visitor (Through Clinic System)	3
Children's Hospital Casualty Department	1
School Doctor	1

The quotes overleaf illustrate the kinds of use made of the Health Authority Clinic System.

8. Danielle Ellis. Totally Blind. Bilateral Retinoblastoma

"Well, I've got a lot more faith in the clinic doctor than my own really. I mean, I'm pretty sure that Dan wouldn't be here now if it hadn't been for the clinic doctor. I'd been to my own doctor twice and just got called a worrying mother and told it was 'pressure'. But when I went to the Welfare, Dr F just took one look and sent her straight down to the hospital".

5. Michael Kent. Totally Blind. Pseudo-Glioma

"He got referred really quickly actually, but it was probably because we short-circuited the system. I'd asked the GP and the obstetrician when I was pregnant, what the chances were of having a blind baby. (Strong family history, mother's father and uncle both born blind), and they just fobbed me off, saying virtually no chance at all. When he was born I was pretty certain he was blind, although the paediatrician who did the post natal exam said he was OK. It was a fluke actually that his six-week check appointment at the clinic came two weeks early. Anyway I decided to take him down, and we saw Dr P. She 'phoned the hospital and got us an appointment that same week".

"It wasn't our own GP that sent her, it was the Welfare Clinic actually. I'd noticed one of her eyes turning in and the black was a different colour, it sort of shone like a gold colour - like a cat's eye in the dark. (This is a description of 'amaurotic cat's eye, which is a 'classic textbook sign' of retinoblastoma). I thought it might be a lazy eye. I'd took her to the doctor's twice, but he said it was nothing. Then my neighbour said that a paediatrician went to the Welfare Clinic on Thursdays, so I took her down. He said she seemed to have a squint and got us an appointment at the hospital. Well they sent her down to Bart's (St Bartholomews Hospital, London) to have her eyes irradiated (radiotherapy). When I think back, I suppose she might have died or had to have both her eyes out, if it hadn't been for the Welfare".

THE CONSULTATION - FACE TO FACE INTERACTION

Little information regarding the actual GP consultation was collected from the blind sample group. It must be remembered, in any case, that only 25% of the parents consulted him in the first place. On the other hand, Stimson and Webb (1975) directly observed the consultation process and therefore have quite extensive data on the subject.

Stimson and Webb note that during the face to face interaction, both actors (doctor and patient) are essentially concerned with the same problem, that of effective self presentation. As they point out, the conscious and unconscious presentation of the self affects the behaviour of the other and calls forth a reaction from the other. (See also Goffman 1959).

The doctor uses various techniques to maintain his status as an expert. He is the actor controlling the process, in charge of entry and exit cues and also the amount of time the patient is allowed to spend on his 'performance'.

Stimson and Webb argue that the control the doctor exerts can be more overt because, in many respects, he is expected to "act like a doctor", and because he holds the 'trump card', i.e. he controls access to treatment resources. Stimson and Webb noted that there was rarely open conflict with regard to the negotiations taking place during the consultation. In fact,

they make a point of stressing the emotional flatness of the interaction. As they write:

> "Both parties generally recognise and retain some semblance of formality and exercise restraint to prevent the encounter from completely 'breaking down'. A patient seldom makes accusations to a general practitioner's face about what are considered to be inefficiencies and inadequacies; similarly, a doctor rarely loses his temper with a patient. If it appears that this point is being approached, one actor seems to step down and attempts to avoid the issue or heal the breach".

The degree of overt conflict which can be expressed during a consultation is, as Stimson and Webb point out, limited by both doctor and patient in the interests of maintaining a relationship over time. Silence on the part of the patient during the interaction can be a means of exerting self-control in the face of information which is sudden, dramatic or emotionally disturbing. Stimson and Webb argue that both doctor and patient seem to co-operate in this process of containment, almost as if they have an obligation to each other to do so. The "emotional flatness" and lack of drama observed by Stimson and Webb during the consultation, are in marked contrast to the 'stories' related by the patients after the event.

Reassurance and empathy are also common features of the GP consultation, although as has been previously noted, patients sometimes feel, in retrospect, that this 'reassurance' was misplaced and did more harm than good.

Entry and exit cues are as noted above, generally managed by the doctor, and the patient has little control over these. Stimson and Web noted that, once having left the doctor's presence, the exit was generally speedy, in contrast to the often much longer period spent waiting to see him. Once the door has closed on the patient, there is no going back, even if he has forgotten something important to him. The doctor's time is then devoted to the next patient or to the doctor himself.

Stimson and Webb's observation and analysis of the consultation process was continued beyond the face to face contact, to include the patients' thoughts and conversations about the consultation, and the decisions regarding treatments prescribed by the doctor. This retrospective assessment they term "reappraisal", and it is during this period that the patient makes sense of what has happened during the interaction, evaluates the doctor and the consultation and makes decisions regarding the use of any prescribed treatment. Stimson and Webb note that after the consultation, patients may, once again, pass through the 'lay consultant' system as they did on the approach to seeking professional help. Talking to 'lay consultants' helps the patient to evaluate and assess his 'performance' and management of the encounter. During the reappraisal, the patient might also begin to sort out in his mind what his actual expectations of the consultation were.

Story Telling

One means of evaluating the consultation from the patient's point of view is by 'story telling'. According to Stimson and Webb, the 'story' is a form of communication:

> "1. which highlights a process by which people make sense of past events, 2. in which certain standards of behaviour of doctors and patients emerge, are sustained or are changed; and 3. in which some redress is made for the inequalities in the relations between client and professional. The story is thus a means of accounting for or explaining the social world of doctors and patients, is a means for the negotiation of norms, and affirms the integrity of the patient".

In 'stories', the roles of doctor and patient tend to be reversed, the patient usually dominating the encounter and the doctor playing a more passive role. The 'plot' often uncovers major areas of conflict, but the patient is always shown to have acted sensibly and rationally whilst the doctor is made to appear foolish or incompetent.

Stimson and Webb (1975) argue that stories reaffirm for teller and audience the principles of appropriate behaviour for doctors and patients.

Criticisms of how a doctor did behave, show how he should behave. The teller can reconstruct what actually happened in terms of what he would have liked to have happened. Thus incidents which are described in critical stories are often those where the doctor has not acted as the patient would have liked. The doctor therefore loses the respect that his status normally affords him, and, in the 'story', is described in derogatory language which makes him appear foolish or laughable. In the 'stories' related by the respondents in Stimson and Webb's study, we meet for example with, "Two Minute Todd" and "Doctor Undress". Other doctors are described as "pooving round the room like a scared rabbit" or, "standing with his backside against the fire". Thus as Stimson and Webb argue:

> "Those who see themselves as relatively powerless in a situation can redress the balance by stressing their own human and sensible qualities as against the comic qualities or stupidity of the more powerful, in this case the doctor. By laughing at the professional, he is degraded. ... One detracts from the power of the person by making him the subject of laughter or scorn".

Although, the doctor (in real life if not in 'stories'), generally controls the outcome of the consultation, once the patient has left his presence, the doctor's control ceases. After the consultation, any decision making lies with the patient.

The problem for the client is one of accessibility, i.e. the doctor controls access to the resources the client wants or needs. The doctor for his part, maintains control by 'granting' access only according to certain regulations. Stimson and Webb point out that the medical profession's concern to establish and maintain autonomy has grown partly from the contradictory nature of their work. By providing a service in which the altruistic element is stressed, they are vulnerable to exploitation by those they purport to serve. The doctor could revert to being the 'paid servant' of his patient. Stimson and Webb argue that although patients generally see themselves as relatively powerless, in some ways the medical profession perceives the lay world as threatening. Therefore to protect themselves against abuse and exploitation doctors 'grant' access to resources according to a set of rules, and 'bestow' a service to those in a weaker position.

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Doctors control not only access to services and treatment but also to knowledge regarding illness, treatment and resources. Stimson and Webb observe that information given by doctors is selective and given only at a general level. And, as has been noted previously, to be denied knowledge is to be denied power. Thus once again we have a "David and Goliath situation", with, as usual, Goliath set fair to win.

However, as was noted above, the doctor has no control over what the patient does once he has left the surgery. The patient is then at liberty to exploit other sources of information and access to treatment resources. And, as Stimson and Webb point out, the doctor is as unlikely to find this out as is to discover whether his instructions have been followed or ignored.

It would appear from data collected from the blind sample that this type of "exploitation" is rife. (It will be remembered that only 20% of the children were referred through their GP). Alternative routes of access included, the Health Authority Clinic system, other professionals, for example, opticians or health visitors and 'going private'. Access was also granted by the hospital to those having relatives already attending the Ophthalmic Clinic.

In Conclusion

As Stimson and Webb have noted, the activities of the professionals are to some extent controlled by the behaviour of their clients. There are, they argue, three ways in which patients can exert control over doctors and the treatment they receive. First the patient can exert control by choosing which, if any, doctor to consult, and as can be seen from the blind sample, this control can be considerable. Second, from their observation of consultations, Stimson and Webb noted that patients can exert control by influencing the face to face interaction by his 'presentation' of his case. This particular aspect of control however appeared to be very limited in the case of the blind sample. Third; once he has left the surgery, the patient is in control of the decisions he makes regarding the doctor's advice and prescribed treatment. Here again, the blind sample clients were

able to 'exploit' the situation in order to obtain access to the required resources.

Thus, if we return to the "old battlefield" (Davis 1982) where David and Goliath are "eternally pitched against each other", we can see that although the dice is heavily loaded in Goliath's favour, the impact from catapult and pebbles can be considerable, and should not be disregarded.

CHAPTER 22

THE IMPACT

"Above all the out-patient department should offer a true consultation on the lines of private practice ... The consultation must be completely private - just the consultant with the patient and his own doctor - and no nurses, almoners or clerks should be allowed in the room".

> Sir James Spence (1953), 'Function of the hospital out-patient department'. Address to the Royal Society of Medicine reported by the Lancet, i, 257

"Well the problem with seeing the Great White Chief (consultant) is, there's no privacy. You go in this great big room with chairs all round, and he sort of sits in the middle on a chair on wheels. And there's around fifteen to twenty people in there; other patients, nurses, two or three other doctors and sometimes a load of students as well. All the other patients are having drops in and treatment done at once, so you never get his full attention. Everybody can hear what happens to everybody else so there's no way you can discuss anything. I must admit I don't like going in there, I'd rather see one of the other doctors in the little rooms, it depends who you get, but at least you're on your own".

> A consultation from the blind sample taking place in the 1980s

THE SOCIAL ORGANISATION OF THERAPEUTIC CARE

In the West today, illness is viewed within a natural-science framework. This, as Jacobs (1979) points out, contrasts markedly with the philosophy of many pre-literate societies where the approach is much more holistic. Furthermore, as Jacobs notes, the Western view of illness as a natural-science model extends to hospitals and those who work in them. Today much of the emphasis in our health care system tends to be on pathology. The "medical gaze" (Foucault 1973) has become lazer sharp and able to pin point minute areas of the body. As part of this process, an elaborate battery of technological aids has been built up, hospitals forming the main locale for such provision. As Jacobs (1979) puts it, "We have a 'national sickness service' rather than a 'national health service'".

The impact of this increasingly sharp focusing of "the gaze" upon an every decreasing field has led to an increasingly fragmented service for the patient. Indeed, as Jacobs (1979) writes:

> "the growing complexity of the social organisations and institutions involved in therapeutic care increases the likelihood that, with the attendant specialisation, people will come into contact with a separate range of functionaries at different points in the illness process. Associated with this complexity is a tendency to detach symptoms from the person manifesting them".

In Parsonian (Parsons 1951) terms, the Western medical professional role is "functionally specific", that is, those working as specialists in health and disease are expected to apply their knowledge and skills to problems of illness and the promotion of health and to restrict their professional concern to these areas. The narrow specialisation and fragmentation of care which abounds in Western medicine today is somewhat reminiscent of the situation in Ancient Egypt. We might also compare the situation as it is today with that existing in the seventeenth and eighteenth centuries when the specialists were quacks, charlatans and mountebanks. This is not to suggest that the actual practice of ophthalmology has not advanced since the days of Chevalier Taylor. The healing of eye diseases and restoration of sight to the blind are everyday occurrences at every ophthalmic unit in the country. The vast majority of people are cured or helped by the system and most people (including the author) are highly satisfied with the services offered. The problem is that with increasing specialisation (and it is rare now to find even a 'general ophthalmologist') comes increasing fragmentation of services, and holistic care becomes an increasingly distant goal. At the point of impact therefore, the service fragments and the point of greatest social need occurs at the point of greatest clinical detachment.

This chapter follows the families through the impact stage of their crisis. The issues discussed in the chapter include: the ways in which the layout and setting of the out-patient department influence the consultation process, the 'ceremonial order' of the clinic, its rites and rituals and 'backstage culture'. The consultation itself is examined with reference

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to the spoiling of identity and rites of passage into the new identity. The chapter also examines the denial of emotion in clinical situations and contrasts the 'emotional flatness' of the consultation process at the point of impact with the highly emotionally charged 'stories' which are related after the event. Much of the material is examined within a 'Goffmanian' style framework.

THE APPROACH TO IMPACT

"Consultations involve a wide range of technical diagnostic aids and a variety of specialist medical and paramedical personnel. The relevance of these, apart from their general intimidating character, is the ability and obligation they give to the consultant to structure the interaction. Teaching and consultation functions allow the doctors a separate, free discursive area in which discussion can take place in terms partly or entirely opaque to the family".

David Silverman (1987) 'Communication and Medical Practice'

In-depth studies of out-patient departments, particularly recent ones, are rare. As Forsyth and Logan (1968) note, "out-patient departments are more frequently commented on than studied".

Forsyth and Logan (1968) revealed that apart from the proposals in the appendix of the Porritt Report (1962), no published standards to be achieved in out-patient departments existed at the time of their survey (the mid 1960s). This, they note, "is the more surprising at a time when money is being spent on new departments many of which seem to provide for the concern of the patients no better than the departments they have replaced". It is noteworthy that this comment could easily have been written today.

Forsyth and Logan surveyed and rated external facilities such as: car parking, access to the department, signposting, reception and information for patients. They also studied internal facilities including seating accommodation, toilet and cloakroom facilities, arrangements for children, canteen facilities and 'exposure' to casualties. Other areas of study included booking systems, waiting time for an out-patient appointment, systems of communication with GPs and record keeping. In all these areas,

they note from their ratings, that in the opinion of the researchers, very few hospitals reached even the half-way mark.

On the subject of waiting for an appointment, Forsyth and Logan write:

> "There is some evidence that appointments are not always granted without undue delay. A Ministry circular (Ministry of Health Annual Report for 1964, HMSO, London 1965) expressed official concern at the delay between referral and consultation and ... urged that attention should be given to other ways of tackling the problem. The circular ... suggested that two weeks should be the maximum time elapsing for non-urgent cases between referral and consultation. (A study) of thirty Hospital Management Committees found that none could meet the two-week requirement".

Even in the 1960s, patients referred for an ophthalmic opinion waited longer for an appointment than those for most other specialities. According to Forsyth and Logan (1968), in the hospital associated with the longest delay, the waiting time for a routine appointment with an ophthalmologist was sixteen weeks. Today (1992) the average wait for a non-urgent appointment is sixteen to eighteen months and often more than two years. Recent government directives have reduced the waiting time for an operation dramatically. However, the government has not yet issued guidelines regarding how long patients should have to wait for an out-patient appointment. It would appear that in many cases, patients wait just as long for an operation, but on a different waiting list.

Because of the diversity and age range of the sample group, and the changing pattern of waiting times for appointments over the years, it is not possible to ascertain whether the wait for an appointment influenced, to any great extent, the time between noticing the problem and its diagnosis. This delay between suspecting and confirming visual impairment is however not one which is confined to Sheffield. Walker and colleagues (1992) found that in 18% of their (country wide) sample, there was a delay of between two and ten years between suspecting the condition and its diagnosis (3% being between five and ten years). It will be remembered that the maximum delay in Sheffield was 7½ years - probably around the average mark.

"When you go to out-patients you know you're going to be there more or less all day. I remember the first time I went, I just got completely lost, and there's nobody to tell you where to go or what to do. There's notices saying 'no prams allowed', but how are you supposed to get the kids there? There's a notice saying 'Follow the lines for treatment', but they don't lead anywhere. How blind people go on, I just don't know. You've got to be telepathic. The toilets are really scruffy and so's the canteen - orange juice and fag ash all over the tables. You know you're going to be there hours, but there's nowhere for the kids to play. There's no toys, not even a book or magazines. They can't run about or you get told off, and you can't go to the canteen in case you miss your turn. So by the time you get in thee (to see the doctor) nobody can do a thing with them. I mean, loads of kids go, and you'd think, well, surely they could find room for a toy box at least".

> Comment from a mother in the blind
> sample

Silverman (1987) studied doctor/patient relationships in both NHS and private settings. On the NHS setting he writes:

"Both NHS clinics are held in functional rooms, with unadorned white walls, no carpets, simple furniture (a small desk, one substantial chair for the doctor and a number of stacking chairs for patients, families and students). ... any member of staff may enter at any moment, announcing their arrival by merely a formal knock. So the patient may face a shifting population of students, colleagues entering for advice, a nurse arriving to change the paper sheets on the couch or a booking clerk entering to sort out appointments".

Silverman contrasts this setting with that of the private clinic:

"To enter the consulting rooms of the private clinic is to enter a different world. The main room has the air of an elegant study, perhaps not unlike the kind of room in a private house where a wealthy patient might be visited by an eighteenth century doctor. The walls are tastefully painted and adorned with prints and paintings. The floor has a fine carpet. The furniture is reproduction antique and includes, as well as a large leather-topped desk, several comfortable chairs, a sofa, a bookcase which holds ivory figures as well as medical texts, and a low table, covered with coffee-table books and magazines. Plants are placed on several surfaces and the room is lit by an elegant central light fitting and a table lamp. To add an executive touch, there are three 'phones on the desk, as well as a pen in a holder".

Silverman also notes that private patients rarely waited more than fifteen minutes for their appointment and that, if there was a delay, the doctor always apologised. In contrast, as we have seen from the experiences of the blind sample, NHS patients frequently wait several hours for their appointments. Silverman points out that the NHS appointment, "was simply an indication of when they would be available to be seen, not a guarantee of their consultation time - and would be seen by whichever doctor happened to be free".

Regarding NHS clinic accommodation, Forsyth and Logan (1968) write:

> "An insight into the level of clinic accommodation may be gleaned from the twenty per cent of consultants who reported that frequently they have two or more patients in the same room while taking histories or conducting examinations. It was almost the rule among ophthalmologists and very common for orthopaedic surgeons".

It has to be pointed out however that this situation has been perpetuated by the ophthalmologists themselves rather than any lack of money for better accommodation. As an example, in Sheffield, when the ophthalmic department was transferred from nineteenth century accommodation to a newly built hospital, the ophthalmologists actually chose to transfer the nineteenth century layout to the new premises. One difference was that 'the big consulting room', the room in which the consultant himself works, was even larger, to accommodate more patients with plenty of room for students and other doctors.

Although a few of the families 'went private' for one or more consultations at a later stage, for all but two of the families, the impact stage took place in a NHS out-patient clinic or hospital ward in the kind of setting described above.

THE EXPERIENCE OF IMPACT

28. Cynthia Carter. Totally Blind. Congenital Anophthalmos

> "To tell you the truth, even now I can't remember much about it (being told baby born blind). I can remember the doctor taking her away as soon as she was born, he said to examine her. I heard him say something like microcephaly (probably

microphthalmos). It was David (eldest son) who said that she'd got no eyes. I just don't remember what the doctor said at all. It probably sounds daft, but you know, I didn't realise she was blind until the blind people (local voluntary organisation) came round to say she'd been registered (blind)".

32. Bethany Hartley. Functionally Blind. Retinopathy of Prematurity

"When they've been on the Prem Unit, apparently Mr D (ophthalmologist) examines all the babies. When she was discharged they said he'd been round and I'd to take her to the H Hospital for a check up, but they never said what it was for, just 'all babies have to go'. After he'd seen her in the clinic, he said she'd have to go in and be examined under an anaesthetic. It was after that he 'phoned up (see page 111) and said she was blind. But nobody had ever said anything to me about oxygen could make them blind".

44. Sally Patterson. Functionally Blind. Cataracts and Freidrich's Ataxia

"He (the paediatrician) knew what was wrong, there's no two ways about it. And he didn't do nobody any good by not coming out with it. It made things a lot worse because we couldn't get the things she needed like a wheelchair and alterations to the house. All that time he kept us hanging on and never telling us straight. If he hadn't retired we probably wouldn't ever have found out".

39. Winston Whitehead. Totally Blind. Microphthalmos

"Well, nobody's ever said, you know, that he's blind, or anything about what's wrong with his eyes. But they've got to be blind, haven't they, if they go to Tapton (blind school)? It's like ... you have to keep going back to the hospital, and they say, 'yes, fine, everything's OK. He's doing very well, there's no change and all that, and come back in six months. But nobody's ever said like ... this is what's wrong or that his eyes won't get any better. And, ... well, you're not allowed to ask them any questions, it's just for them to examine his eyes".

As can be seen from the quotes above, the actual impact or climax of the crisis was experienced by the families in different ways according to the circumstances. After analysing and reflecting on the replies to questions concerning the ways in which parents were informed that their child was blind, it seemed that impact could be said to have struck in four different ways. The divisions however do not have clear cut boundaries and there is a degree of overlap between the categories. Because the classification

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might be of use to other researchers or those caring for people in crisis, I have outlined the categories below:

1. Immediate Impact - which occurs apparently without warning.

2. Impending Impact - the impact follows a warning period of varying length.

3. Progressive Impact - knowledge of the condition is built up gradually over time.

4. Delayed or Abortive Impact - the patient is not informed of the diagnosis.

Immediate Impact The experience of immediate impact is probably rare. The blow is inevitably severe and often, literally, fatal. Examples might include accident or heart attack victims who wake up in an intensive care unit. We could also include in this category the birth of a severely deformed baby or a 'fresh stillbirth'. Even in these situations however there is usually a period of warning, although it may be measured only in seconds. The screech of brakes, severe chest pain, or the furtive removal of an unprotesting bundle all constitute a warning, although they may not always be recognised as such. Of the blind sample group, only those cases where the child was born with complete absence of, or tiny rudimentary eyes, could be said to have experienced an immediate impact.

Impending Impact Many of the families described situations where the impact seemed immediate. However, when these 'stories' were analysed it was apparent that there had in fact been a period of warning, although this had often been ignored or denied. In some cases, for example the second quote (Bethany Hartley) the child was admitted for 'investigation' or examination under anaesthetic (EUA). In the eyes of the professionals, this should have alerted the parents to the fact that something was probably wrong, and that the child had been taken out of the 'routine check' category and placed in the 'severe doubt' one (see Davis 1982). It appears however that this 'message' is not always communicated to the parents, so that, for them, the impact seems to come 'out of the blue' or

without warning. Many of the 'warnings' were normalized and looked upon by the parents as unusual facets of normal development. For example, "I used to say to his dad, 'Isn't it funny, the way he feels things instead of looking at them?'"

As can be seen from the work of Davis (1963) and the previous chapter (see particularly case 51, Lucy Baldwin, some parents had already realised that something was seriously amiss some time before the 'impact consultation'. This realisation however does not appear to soften the blow, for, although Mrs Baldwin says she had realised that Lucy was blind before the consultation, afterwards she, "walked out in a daze and wandered round town with her for ages". In almost all cases, rationalisation, denial and vacillation continue long after the actual impact. This is well documented in the works of Davis (1963) - polio victims and Speedling (1982) - heart attack victims.

Progressive or Gradual Impact   Davis' (1963) study of polio victims revealed that parents were 'kept in the dark' long after the prognosis was quite clear to the doctors. The doctors justified this secrecy by arguing that it was "better for parents to find out for themselves in a natural sort of way". The real gain however, Davis suggests, was made by the doctors themselves for, by failing to reveal 'bad news' they avoided unpleasant 'scenes' with distraught parents. Although Davis' research was completed in the early 1960s, a similar approach is commonly used by doctors today. Similar accounts can be found in Hall and Stacey, Eds (1979) and Silverman (1987). The 'Progressive' approach seems to be most frequently used in cases where the child has a long-term disability with a poor prognosis. Although unpleasant 'scenes' are avoided, the 'progressive' approach is not always in the best interests of the client because, as can be seen from the work of Turner (1987) and Foucault (1973), knowledge and power are intimately bound together and to be denied knowledge is to be denied power. Access to required services is also blocked, as Sally Patterson's mother pointed out, 'we couldn't get the things she needed'.

Delayed or Abortive Impact   Silverman (1987) notes that when a child is multiply handicapped having a poor prognosis and where there is no extended

period of hospitalisation, the long-term prognosis may never actually be raised at out-patient consultations. As he writes, it would be easy to see this as a form of medical paternalism, giving only as much information as the parent needs at each stage (Progressive Impact). However Silverman found that the doctors on the paediatric heart unit would respond in detail to any questions the parents raised. Silverman argues that, "The position seems closer to a common decision-rule about terminal illness: 'tell if the patient asks'". As we have seen however, many parents, like Mrs Whitehead (Case 39) do not ask and are therefore never 'told'.

RITES OF PASSAGE AND CLINICAL CEREMONY

In chapter 5 it was noted that families rearing a blind child experienced difficulty in negotiating some of the 'transition points' as they progressed through the family life cycle. It was argued (see Barnhill and Longo [1978]), that families who fail to complete these transitions successfully are particularly vulnerable to stress. It was also noted that many of the children experienced delay in being allowed access to the 'rites of passage' associated with these transitions, and that, for some children, certain rites are withheld altogether.

Rites of passage are also associated with the 'labelling' or acceptance of a person as 'sick', 'impaired', 'handicapped' or 'challenged'. These rites usually occur during and following a period of admission to hospital. See for example Davis (1963) - polio victims; Speedling (1982) - heart attack victims; Harrisson (1977) - Perthe's Disease victims and Silverman (1987) - children admitted for heart surgery. As was noted earlier however (see Silverman 1987), unless parents ask, an explanation of the condition may not be forthcoming in the out-patient department. Many of the blind children were never admitted to hospital as in-patients, their condition being either 'obvious' as in the children born without eyes, or 'hopeless' in cases of diseases of the retina or optic nerve for which there is no known treatment. Thus a number of the blind children remained for long periods in a kind of 'identity limbo' where, although obviously not 'normal' they had been denied passage to a new identity as 'handicapped'. As we have seen, unless a person is actually 'labelled' as 'handicapped',

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access to necessary services is either blocked completely or made more difficult.

The Spoiling of Identity

8. Danielle Ellis. Totally Blind. Bilateral Retinoblastoma

"To tell you the truth I can't remember a lot about it (the consultation). I think I blocked a lot off, kind of shut it out of my mind. I can remember being in this big room, it seemed to be full of people, doctors and nurses and other patients sitting round the edge. I can remember being called to sit by his (consultant's) desk and him examining her. I think he said something about it being a kind of cancer and they'd have to have her in to take her eyes out. After that, it seemed ... he was talking ... but I don't know what he said. That's what ... fifteen years ago now, but it's still completely blank ... what he said to me then. Like I said (see chapter 5, page 111) it was the parson (hospital chaplain) who explained it to me. I suppose Mr A must have said that she might die, but I honestly can't remember".

As has been noted previously, the spoiling of identity tends to occur more frequently in in-patient rather than out-patient situations. There are obvious disadvantages to the 'breaking of bad news' in the out-patient clinic. As Silverman (1987) points out, "the implied inability of the medical profession to restore a sick child to health is potentially embarrassing for them". In a large consulting room, with students and other doctors present it is even more embarrassing. As Silverman (1987) (observing the process in children doubly handicapped by Down's Syndrome and heart disease) writes, "(the) clinical discourse has lost its association with a magical power to make the child well". Neither is the patient suitable 'material for teaching or research'. Therefore, "Faced with an irreparably damaged child, the clinic and the State hand back the creature to the family" (Silverman 1987).

The Hospitalisation of Children

Child patients, as Stacey (1979) points out, are to be found in many parts of the hospital system and not always where a paediatrician has oversight. Stacey also notes that children are frequently admitted to adult wards in specialist areas such as ENT, orthopaedics, ophthalmology and general surgery. She reveals also that the Welsh Hospital Board Working Party

(1972) found that two thirds to four fifths of children in hospitals were under the care of specialists other than Paediatricians. The 'Court Report' (1976) revealed that half the children admitted to hospital are admitted for surgery and the major part of this is done by general or specialist surgeons whose main work is with adults. It is also noted in the Court report that one patient in five in departments of ophthalmology is a child. As Stacey (1979) comments:

> "Experience in the Welsh Hospital Board area suggested that greater concern was expressed for the all-round needs of children in paediatric wards rather than in other wards. The large number treated elsewhere is therefore of particular note".

It is noteworthy also that all children in the blind sample who were admitted to hospital for the eye complaint, were admitted to an adult ward in a general hospital.

The Rituals of Hospitalisation

Jacobs (1979) draws our attention to the fact that the process by which a child becomes a patient could be said to constitute a 'rite of passage'. van Gennep (1960) divides the rite of passage into three stages: separation, liminal transition or marginalisation and reintegration or aggregation. Fox (1992) argues that all the theory actually says is that "things have a beginning, a middle and an end". Be that as it may, as Jacobs (1979) notes, the child emerges at the end of the process with a new identity. Jacobs uses the theory to explain the ways in which children are 'depersonalised' and stripped of their former identity as they become patients in an orthopaedic hospital.

Children admitted to ophthalmic wards for examination, investigation or operation can be said to undergo similar rites of passage, entering as 'normals' and emerging with a changed identity – that of 'blind' or 'impaired child'. In this instance, 'rites of separation' involve 'stripping the child' by removing his own clothes and washing and dressing him in theatre garb. He is then separated from his mother as he leaves the ward for theatre and is accompanied on his journey to a new identity by strangers.

For Jacobs (1979) 'liminal transition' or marginal rites represented the period prior to the beginning of (orthopaedic) treatment. Some of the children studied by Jacobs were admitted more than a week before their operations. The waiting period for the children admitted for ophthalmic surgery was much shorter, most being admitted either the day before, or on the actual day of the operation. For the blind sample then, the period of liminal transition is represented by the period of waiting for the actual diagnosis, that is, the period between the child being taken to theatre and the parents being informed of the results of the operation or investigation. This period varied considerably according to individual circumstances. It could be a matter of hours, i.e. the surgeon could inform the parents as soon as he finished his operating session, or, in the case of certain operations, it could be several weeks or months before the results were revealed. For some surgeons, it is not their 'policy' to 'inform' parents of results prior to the child's discharge from hospital, but to do this at a follow-up appointment in the out-patient clinic. Thus many children could remain in this 'marginal state' – a kind of limbo for the parents – for considerable periods of time.

Rites of reintegration or aggregation form the third stage of the process and involve the creation of the 'new identity'. In Jacob's study, this constituted the establishment of the identity of 'patient' on an orthopaedic ward. In the blind sample, rites of aggregation lead to the new identity of 'blind' or 'handicapped child'.

Passage to a New Identity

Strong (1979) describes the spoiling of identity in a neurological clinic thus:

> "... what was at issue was the parents' whole conception of the child: its present, its future and their own future as well. And, whereas normalising a child might be done in a session, as might the revelation of minor illness, stigmatising a child could take many months or even years. Although it is conventional to refer to the telling of bad news as something that occurs at one point in time – 'when they told me' – such a description does not capture the complex nature of the process by which such news was broken here. To some extent this depends on clinical uncertainty. As doctors saw a child over time, so they gained a more accurate version of the child's condition and capacities.

Just as crucially, however, the stages depended on the doctors'
belief that bad news should be broken slowly, that parents had to
prepare themselves for the worst, that they could not take
everything in at once, and that the news staff had to tell should
match parents' expectations".

Below, some of the parents in the blind sample describe their passage to
a new identity.

Preparation and Separation

53. Charlotte Winter. Totally Blind. Bilateral Retinoblastoma

"When we knew that she'd got to have the other eye out, she said
to me one night, 'Will it always be completely dark from now on?'
and I said, 'Yes darling, it will'. She just seemed to accept it
really and just said 'Oh. But I can still go to school though,
can't I?' And I said 'Yes, 'course you can'. She said, 'Well I
won't be any different to a lot of the others at school, will I?
Because they can't see at all either, can they?' I said, 'No,
and besides it's to make you better'. But it didn't did it? And
I feel somehow that I betrayed her, because really it just
prolonged the agony and she lost what vision she had and still
died".

55. Harry Anderson. Useful Vision. Retinoblastoma

"At the Children's (hospital) you can go up to the theatre door
with them, but at the RH hospital you have to leave them at the
ward door. It's like engraved on my mind, how he looked on the
trolley. He was so small and vulnerable, and so *clean* in his
white gown. His face and hands were all shiny and he was fast
asleep ... like a little sacrifice. And I thought, when he comes
back they'll have taken his eye out. And I wondered what he
would look like, and if ... if I would recognise him".

Liminal Transition

18. Marie Masters. Functionally Blind. Retinopathy of Prematurity

"She was admitted just as a day-case for the examination. They
took her to theatre about 2 o'clock and she was back before
three. I thought the doctor would come round and tell me what
they had found after he finished operating. I was all tensed up
waiting for him, but he never came. About 6 o'clock the sister
came and said she could go home. And I said, 'But the doctor's
not been to see her yet'. 'Oh', she says, 'he won't come
tonight, he's gone home now. You get the results when you come
back to out-patients', and gave me an appointment for three
months. Well, I was completely floored. You know, getting all

worked up and then having to wait another three months. I think that was the hardest part of all really".

Aggregation - Towards a New Identity

8. Danielle Ellis. Totally Blind. Bilateral Retinoblastoma

"When they brought her back from the theatre, her eyes were all bandaged up, and the thing I remember most was being terrified of them taking the bandages off. I had nightmares about it. I saw these - just holes in her head where her eyes should have been. I was ever so frightened, but I didn't feel I could ask anybody what she would look like or what would be there when her eyes were out. Well, it was silly really, because I got myself all steeled up, because I knew I'd got to face it and look at her. And well, when they finally did take the bandages off, I nearly cried with relief, because really, she just looked as if her eyes were closed and she was asleep.

You know, it's funny, but when she was little, I preferred her not to have her (artificial) eyes in because she seemed more like my Danielle without them. Somehow she seemed, ... well, kind of doll like with them in".

2. Matthew Tomlinson. Functionally Blind. Retinal Dystrophy

"I think what finally made it sink in, you know, that he really couldn't see, was after he came back from theatre. Before he went up, there was a mobile hung above his cot and the nurse came and took it away. She didn't say anything, just took it down, and I knew then that that was it, they'd found he couldn't see. But up to then, you know, I'd somehow always hoped they were wrong".

The Ceremony of Surgery

Jacobs (1979) noted that the rites of passage undergone by the children to become orthopaedic patients, and the ward rituals surrounding them, had the effect of transforming children into passive receptors rather than responding to them in terms of their own unique experiences and needs. Davis (1982) found a similar process at work in the Special Care Nursery when discussing "Children as Work". In this kind of situation doctors do not have to 'act' to an audience of parents as the area could be described mainly as 'backstage'. In the special care nursery as in the orthopaedic ward, babies and children are 'work' and are therefore treated as passive objects. Fox (1992), studying the rituals of surgery in the operating theatre, also had occasion to note the ways in which patients become

'objects'. He writes, "Once within the boundaries of the OT, no patient may walk, they are always passive objects". The administration of a general anaesthetic then ensures that the transformation is complete.

Fox (1992) summarises the process of the transformation of person to object as follows:

> "1. The patient is brought passively into the OT.
> 2. The patient is rendered unconscious.
> 3. The patient is rendered unable to breath, and dependent upon theatre personnel for life support.
> 4. The patient is stripped of clothes, and all vestiges of identity apart from a hospital bracelet and hospital notes. They constitute the separation of the patient from the outside world, completing the removal of a patient's identity ...".

The proceedings conducted during the actual operation are, as Fox points out, characterised by the patient's dependence upon others for his existence. As he writes:

> "In this dangerous condition, the surgical patient lies naked and unconscious, reduced to so much meat, oblivious to time, physical changes and pain. Her/his identity is defined only by a plastic tab around the wrist, and the name of the operative procedure written on a board in the theatre".

Fox argues that the routines and rituals of the operating theatre serve to move a patient from a dangerous state into a safe one, as someone who is 'healed'. The surgeon is granted authority to be the agent of this change of status. Fox points out that the ritual clothing worn by the surgeon has many characteristics in common with other officiators at rites of passage, for example the clergy and judges. The high status accorded to surgery today, Fox argues, derives from its possession of ritual attributes, which the other healing specialities do not have. As can be seen from the history of medicine however, until the advent of general anaesthesia and antisepsis, the craft of the surgeon was held in relatively low esteem. It is therefore interesting to note the strong opposition from many doctors to the introduction of both these innovations. It seems that suffering on the part of the patient was a necessary part of the process of healing.

Hall and Stacey (1979) point out that in our acceptance of medical practice we have accorded to doctors the right to inflict pain. In so doing we also give our consent to the surgeon to violate and wound the body. It has to be pointed out however, that following recovery from this 'assault' the patient expects to be 'cured' or 'healed', or at the very least, no worse than he was before the operation. Surgery however does not invariably result in a cure. And indeed, for all the children in the blind sample, treatment had either failed or was simply not available. Often the surgical procedure was carried out merely to confirm a diagnosis of severe visual impairment. Within the sample group therefore, the end result of the surgical intervention was not 'healing' but the spoiling of identity.

I propose now to discuss some of the medical and nursing rituals commonly encountered in the hospital setting, and to explore reasons why, if they are as unnecessary as many researchers would have us believe, they are so widespread, so deeply rooted and so resistant to change.

HOSPITAL RITUALS AND THE ESTABLISHMENT OF RIGHTS

Most rites of passage are cloaked in mystique and embedded deeply in ritual. This has been so since the dawn of mankind. Walsh and Ford (1989) in their study of ritual in nursing, suggest that many of the rituals carried out by nurses are not only unnecessary, but actually harmful to the patient. They also note that nurses tend to withdraw from the patient in pain or distress, and instead to focus their attention on ritualistic behaviour which has little to do with the patient. Fagerhaugh and Strauss (1977) found that medical and procedural tasks were given a higher priority by nurses than the psychosocial needs of the patients. Wondrak (1992), a nurse educator, writing of his experiences as a patient commented that many nurses (the 'techno types'), "while always polite, concentrated their skills primarily on the hardware that surrounded me: clearing blocked cannulae and getting intravenous infusions working". Contact with the patient by these 'types', he notes, was via the medium of technology.

Most researchers studying medicine in a hospital setting have included a section on 'The Ward Round'. The following passage is from Walsh and Ford's (1992) study entitled 'Nursing Rituals'.

> "The consultant's ward round is one of the regular rituals of ward life and offers a splendid opportunity to watch what Chapman (1983) describes as the most striking medical ritual of all, the deference ritual. The use of intimidation, mystification and prestige symbols all combine to maintain the status and power of the insiders (consultants) while the outsiders are excluded (everybody else). Berger and Luckman (1975) have written of how the medical profession shrouds itself in the age-old symbols of power and mystery from outlandish costume (the white coat which serves no purpose on the back of a consultant during a ward round) to incomprehensible language (medical jargon). These rituals set the medical profession apart from everybody else and deny entry to all but the chosen few, who in their turn must comply with the ritualistic practices of what at times looks like a cross between the freemasons, a medieval guild and the mafia".

We have seen from the work of Allen (1988), Walsh and Ford (1989) and others, that medical students, junior doctors and nurses are often humiliated, verbally abused and sexually harassed by consultants. Walsh and Ford argue that this is part of a ritualistic behaviour pattern that has been learned and reinforced over the years by the passive participation of those who allow themselves to be treated in this way. They point out that in the field of child abuse, it is often said that an abused child is likely to become an abusing parent. Is this, they ask, also true of the rituals of the medical profession?

Montgomery (1987) offers an interesting analysis of such situations. She considers verbal abuse to be part of a regular behaviour pattern. Verbal abusers, she argues, need victims to restore their own feelings of power and control, but first, they must depersonalise the victim. Thus they see the victim, not as Dr John Smith or Nurse Mary Brown, but as a stereotypical doctor, student or nurse. The victim participates by acquiescing passively to the non-person role. Montgomery argues that this acquiescence leads to repetition of the behaviour on the part of the consultant.

As we have seen, rituals are used in medicine and nursing to dehumanise and de-personalise lower orders of staff and patients. Rituals (and general

anaesthetics) also convert patients into passive objects on which the craftsman in his workshop can work without fear of protest or interference from the 'owner'. It is also noteworthy that, whilst in this helpless state, the patient is denied an advocate. He is separated from relatives and staff with whom he might have built up a rapport, at the ward door. Thus, as in those other ceremonies at which doctors officiate, most notably birth and death, the patient makes his journey towards healing or changed identity alone.

The Protecting Veil

Having noted some of the situations in which rituals take place in the field of medicine, it is necessary now to look at some of the reasons why they might be necessary - if indeed they are. Some authors, including Walsh and ford (1989) and Fox (1992) maintain that many of the rituals performed in nursing and surgery serve no useful purpose and may actually be harmful or counterproductive. As an example Walsh and Ford point out that nurses are so concerned with routines of cleanliness and washing of beds, that, although the plastic cover keeps the mattress dry on the outside, inside, "there is a positive bacterial broth stewing away with great scope for cross infection". Fox (1992), discussing the wearing of masks in the operating theatre notes that staff at all levels are aware of the doubtful value of masks and that doctors, particularly consultants, regularly flout the rules of wearing them. However, he writes:

> "If I suggested that personnel 'liked' to wear the mask, that it 'meant more' than being simply a scientifically valid practice, this met with strong denial or incredulity and threatened the continuity of the research bargain with some informants".

Walsh and Ford (1989) found nursing rituals to be highly resistant to change. They report that it took two years to eradicate an outmoded dressing technique and to introduce a more rational one. But, if rituals are so 'unnecessary', 'harmful' even, why should they be so prevalent, so deep rooted and so resistant to change? To answer these questions it is necessary to look at what actually 'happens' during the ritual, i.e. what is achieved during the process.

Medical and nursing rituals can be divided into three broad categories:

A) Those which confer or confirm position or status.

B) Those which change or alter status or identity.

C) Those which grant the 'right' to doctors and nurses to carry out procedures disallowed to the laity.

Some of the more common situations in which such rituals might be used are outlined below.

The conferring or confirming of status. Examples include graduation ceremonies and the consultant's ward round which has already been discussed.

The alteration or changing of identity. The person enters hospital as a teacher or bank manager. Following the ritual of the admission process his identity is changed to that of 'patient' or 'sick person'. After rituals of healing he is 'cured' and has his former identity restored to him during the ritual of the discharge process.

The granting of rights disallowed to others. We have granted to doctors and nurses the right to 'officiate' at birth and at death. We also 'allow' them to spoil identity and thus to stigmatize by labelling or 'registering' people as 'impaired', 'handicapped', blind or deaf. The 'right' to violate the bodies of others in the interests of 'healing' is also granted to medical practitioners. For example, we allow them to cut open the body during surgical operations, to give injections and to administer poisonous substances in the form of 'medication'. All of these procedures would be punishable offenses outside the field of medicine.

Examination of the above situations reveals that, in order to play their parts effectively, the actors involved require a cool head, a steady hand and to be in a state of emotional calm. The actual situations however militate against this as the atmosphere is tense and fraught with conflict.

It would appear then that the acting out of rituals or the carrying out of 'standard procedures' might help in some way to ease tension and lessen conflict. Rituals also, in various ways, seem to 'protect' the actors from harm. Thus the patient undergoing surgery is rendered unconscious, not only so that the surgeon can operate anonymously and without interference, but also for his own protection against fear, pain and shock.

Incubation and the Temple Sleep

It is interesting to compare the rituals taking place in present day hospital wards and operating theatres with those of the cult of Asklepios performed five centuries before Christ, the inner precincts of the Asklepian Temple were closed to the unclean and the unconsecrated, just as the modern operating theatre is out of bounds to those not wearing special sterile clothing. Those who came to be cured could set foot in the temple only after ritual cleansing and purification. The present day patient for surgery is usually bathed and the area to be 'healed' is shaved. Special 'cleansing' agents are applied to the skin before the incision is made. The Asklepian priests supervised not only the ritual acts of the cult, but also the complementary practices connected with healing. In the same way, the surgeon of today not only performs the operation but supervises the actions of the 'supporting cast' - junior doctors, nurses, technicians and other members of the surgical team.

The culmination of the pilgrimage to the shrine of Asklepios was the 'temple sleep' (incubation). Following the administration of a sleeping drug, the priest, dressed as Asklepios, accompanied by his assistants, also suitably attired, administered treatments and gave instructions. 'Incubation' combines elements of both the surgical operation and the surgeon's ward round. Instead of a sleeping drug, the modern surgeon administers a 'pre-medication' prior to a general anaesthetic. He then carries out the ritual cleansing (scrubbing up) and dresses up in special clothing and headgear to signify his status and to protect him from harm (infection or injury).

The Roots of Ritual

The roots of the rituals of healing are, it seems, embedded deeply in the past, and as researchers (see for example Walsh and Ford 1989 and Fox 1992) have found, are difficult if not impossible to eradicate.

Rituals take place in many areas outside the field of medicine and seem to be particularly prevalent in the 'professions'. Examples of ritualistic behaviour can be witnessed every day in the Law Courts and the Church.

It must be pointed out however that rituals are not only performed by adults in work situations. They frequently crop up in the actions or games of children. As can be seen from previous chapters and the work of the Newsons (1968), bedtime rituals are commonly used by children as a way of coping with separation. The Opies (1959 and 1985) revealed the ways in which folklore is passed from one generation to the next in singing games played by school children in the street or playground.

The Reasons for Rituals

Chapman (1983) described ritualistic nursing practices relating to birth, death, status and power in a study of five London hospitals. She discussed these actions not only in terms of defences against the stresses of the job, but also as social acts which convey meaning to other nurses.

My own thesis is somewhat similar to that of Chapman. Looking at ritualistic actions in nursing and medicine, they appear in the main, to serve two overlapping 'purposes'.

A) They serve in some way to protect the participants from harm.

B) They transmit lore and culture to junior members of the group and to future generations.

As we have seen, during childhood, rituals and 'blessings' serve to protect us from harm during sleep and periods of separation from carers. In the operating theatre, the patient is protected by the rituals of surgery from

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infection, shock and accidents such as the leaving of a swab or instrument
in the wound cavity. Ritual also protects the surgeon. The clothing
protects him from being infected by the patient. It also renders him
anonymous, so that if the operation fails and the patient is not healed,
this will be regarded as failure of medicine as a whole rather than failure
of the individual surgeon.

The Purpose of Ceremony

As patients and surgeons in the operating theatre are protected by the
ritual of the surgical process, so are the participants in consultations
in the out-patient department by the 'ceremonial order' of the clinic
(Strong 1979). Stimson and Webb (1979), noted with regard to the GP
consultation, that the interaction taking place between doctor and patient
was 'emotionally flat'. Research also suggests that during out-patient
consultations with specialists, where 'bad news' is broken or identity
spoiled, the 'action' is nearly always completely devoid of emotion (see
for example Silverman 1987; Davis 1982 and Strong 1979). It seems almost
as if the participants are wearing masks and acting out a pre-scripted
drama. Indeed, in one American out-patient setting studied by Strong
(1979):

> "... consultations took place on a floodlit stage in front of
> workers, interns and residents, who sat in tiered seats in
> semi-darkness. Although one doctor typically controlled the
> occasion, there might be two or three staff on the stage all
> playing a part. Members of the audience might also join in: by
> calling out comments and questions, by being asked their
> opinions, or by coming onto the stage themselves".

In some respects the 'big consulting room' in the ophthalmic out-patient
clinic can be likened to the amphitheatre clinic described by Strong above.
In this situation an 'audience' of patients, doctors, students and others
sits or stands around the periphery, while the consultant and the patient
to be examined take centre stage in the middle of the room. The consultant
sits before a 'console' from which he can also manage stage effects. At
the touch of a switch, for example, the room can be plunged into darkness
and a minute area of the eye 'spotlighted'. It is also interesting to note
the similarities between the situations described above and those in which

healing took place in former times, for example in Ancient Greece with the quacks of the 17th and 18th centuries and the 'virtuoso surgeon' described by Bennet (1979). All these healers are 'showing off' their skills and celebrating success in front of an audience. Post operative patients take centre stage and are pronounced 'healed', thus reinforcing the surgeon's status and advertising his skills. Failure to cure under these circumstances will obviously be acutely embarrassing to all participants in the drama. Here, rituals and the ceremonial order of the clinic are utilised to save the situation.

The Masque – Shield or Barrier[1]

> *On with the motley, the paint and the powder!*
> *The people pay thee, and want their laugh, you know!*
> *If Harlequin thy Columbine has stolen, laugh Punchinello!*
> *The world will cry, "Bravo"!*
>
> *Go hide with laughter thy tears and they sorrows!*
> *Sing and be merry playing thy part*
> *Ah! Laugh, Punchinello! for the love that is ended.*
> *Laugh for the pain that is eating thy heart.*

<div align="right">

R Leoncavallo, "Pagliacci" (1892)
Translation by F L Weatherly

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The use of the 'professional mask' as protection from the 'slings and arrows of everyday medical life' has been discussed in a previous chapter. The doctor uses his professional mask, not only to protect him, but to present a front, i.e. 'the wise and competent physician' or the 'brilliant surgeon'.

It is interesting to note that doctors are not the only people in the field of medicine to make use of the 'mask'. Patients and clients also use them,

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[1] The idea of using the word 'mask' ambiguously was taken from Sir Michael Tippet's oratorio 'The Mask of Time' (1983) where "the word 'Mask' is used in the tradition of the Renaissance Masque, which was a theatrical display or pagent with great diversity of ingredients ... by using the alternative spelling of 'Mask', I have deliberately suggested a contemporary ironic ambiguity".

Sir Michael Tippet (1983)
From the Preface to the recording

although for slightly different reasons. Whereas the doctor uses his mask to deny emotion and present a front, the client uses the mask, not so much to deny emotion as to conceal it so that s/he also presents a front of 'having taken the bad news well' or the 'calm, coping parent'.

Because of their prolonged, close contact with the patient, nurses are less able than doctors to make usee of the mask as a form of protection. They more frequently utilise the 'masque', which takes the form of a kind of theatrical performance of 'busy-ness'. Here the nurse takes refuge behind medical technology, the tasks of nursing or the 'nursing process' (see Wondrak 1992).

Conclusion - The Unanswered Question

In this chapter, I have attempted to show that ritual behaviour and 'masques' are a part of everyday life in the medical world. They are deeply ingrained and highly resistant to change. It would seem also, that they are 'necessary' as a means of coping with stress. Some authors, including Walsh and Ford (1989) suggest that if professionals were counselled and worked in a supportive environment, much ritualistic behaviour would be unnecessary. However, in the present climate, this seems to be an ever receding goal and we are left with the unanswered question, 'Who counsels the counsellor?'

In the following chapter, which is concerned with aggregation and acceptance, the ways in which support networks and coping strategies are utilised by clients will be discussed as will the ways in which organisations and professionals help the families with the rehabilitation process.

AGGREGATION AND ADJUSTMENT

O Night! do I not see my love fluttering out among the breakers?
What is that little black thing I see there in the white?

Loud! Loud! Loud!
Loud I call to you, my love!

High and clear I shoot my voice over the waves,
Surely you must know who is here, is here,
You must know who I am, my love.

Low-hanging moon!
What is that dusky spot in your brown yellow?
O it is the shape, the shape of my mate!
O moon do not keep her from me any longer.

Land! Land! O land!
Whichever way I turn, O I think you could give me my mate back again
*   if only you would,*
For I am almost sure I see her dimly whichever way I look.

O rising stars!
Perhaps the one I want so much will rise, will rise with some of you.

O throat! O trembling throat!
Sound clearer through the atmosphere!
Pierce the woods, the earth,
Somewhere listening to catch you must be the one I want.

But soft! sink low!
Soft! let me just murmur,
And do you wait a moment you husky-nois'd sea,
For somewhere I believe I heard my mate responding to me,
So faint, I must be still, be still to listen,
But not altogether still, for then she might not come immediately to me.

Hither my love!
Here I am! here!
With this just-sustained note I announce myself to you,
This gentle call is for you my love, for you.

O darkness! O in vain!
O I am very sick and sorrowful.
O brown halo in the sky near the moon, drooping upon the sea!
O troubled reflection in the sea!
O throat! O throbbing heart!
And I singing uselessly, uselessly all the night.

O past! O happy life! O songs of joy!
In the air, in the woods, over fields,
Loved! Loved! Loved! loved! loved!
But my mate no more, no more with me!
We two together no more.

From: 'Out of the Cradle Endlessly Rocking'.
THE LEAVES OF GRASS. Walt Whitman, (1859)

This chapter is concerned with the ways in which families become aware of and cope with the spoiled identity of one of their members. It was noted in an early chapter that many of the symptoms displayed by parents following the realisation that their child was blind, were components of what has been termed the 'mourning process' (see Parkes 1972). Bowlby (1980) notes that the mourning process in the case of parents with terminally ill children, "starts at the moment that the diagnosis is conveyed to them". As in the case of widows and widowers, mourning begins with a phase of numbing often punctuated by outbursts of anger. However, as Bowlby points out, because the child is still alive the second phase is modified. Instead of the widow or widower disbelieving that the spouse has died, a parent disbelieves the diagnosis and, more especially, the prognosis and instead of the widow or widower searching for the lost partner, the parent attempts to prove the doctor wrong or to search for a cure in alternative medicine or from another doctor.

The importance of the 'search' for the lost one during grieving has, until recently often been undervalued and has been taken by some authorities as evidence of 'pathology'. Poets and 'storytellers' on the other hand have long been aware of its importance, and of the stages of what is now termed the 'mourning process'. Whitman's (1859) verses quoted above, although pre-dating the work of Freud (1917) by over half a century, graphically illustrate the stages of grieving giving particular emphasis to the search for the lost one. (The 'subject' of the poem is a migrant sea-bird pining for his mate who has failed to return to the nest). We are reminded by Bowlby (1980), that the word 'bereave' stems from the same root as 'rob'.

Parkes (1972) maintains that pining is the subjective and emotional component of the urge to search for a lost object. He argues that an adult human being has the same impulse to search that is shown in many species of social animals (Lorenz 1963). Bowlby (1961) noted that members of lower species protest at the loss of a loved object and do all in their power to seek and recover it. Externally directed hostility is frequently observed and withdrawal, rejection of a potential new object, apathy and restlessness are, Bowlby writes, the rule.

As Parkes (1972) argues, the value of such behaviour for the survival of both the individual and the species is obvious, crying and searching both making it more likely that the lost one will be recovered. In the meantime however, the separated individual is in a state of danger and must be prepared to fight or flee should the need arise. Hence, as Parkes notes, the importance of the 'alarm reaction' at this time.

Parkes (1972) draws our attention to the fact that grieving resembles a physical injury. The loss is often spoken of as 'a blow', and as in the case of physical injury, the 'wound' gradually heals - or at least it usually does.

In some cases however complications arise and healing is delayed or further injury reopens a healing wound. In these cases abnormal forms of mourning may occur which can be further complicated by other kinds of illness. Parkes adds that occasionally the outcome can be fatal and it seems the mourner can literally 'break his heart'.

Thus in many respects grief can be regarded as an illness. However, as Parkes points out, it can also bring strength. Just as broken bones often 'mend stronger' than unbroken ones, so the experience of grieving can strengthen and bring maturity to the person undergoing the process.

Part of the difficulty however of fitting grief into existing descriptive disease categories, as Parkes (1972) writes:

> "derives from the fact that grief is a process and not a state. Grief is not a set of symptoms which start after a loss and then gradually fade away. It involves a succession of clinical pictures which blend into and replace one another".

Parkes is concerned to show how numbness, the first stage, gives place to pining, and pining to depression. And as he writes, "it is only after the stage of depression that recovery occurs".

Mourning then is a process of transition and as such requires 'rite of passage'. As Parkes (1972) writes in the introduction of his work on bereavement:

> "Psychosocial transitions are the times when we reassess our picture of the world and our means of being a part of it. They are experienced as impinging upon us but their effects include major changes in the heartland of the self. At such times we are uniquely open both the help and to harm. We need protection, reassurance, time to recoup, and help in developing blue-prints for the future. Those who are in a position to meet these needs must expect to find the recipient of their help defensive, sensitive, vulnerable, and unreasonable. Even so, a little help given at a time of transition will often be more effective than help given at other times and, in the long run, it will be appreciated more".

This chapter then is concerned essentially with grief and with the process of mourning, which, as has been noted, begins with the diagnosis of the problem, or with the 'impact'. During the chapter, the families continue their passage through crisis and are observed as they work through their grief to its final resolution.

In their search for that which is lost, the families work through the stages of numbness, anger, guilt and depression coming finally to the acceptance that the object is lost for ever, "And I singing uselessly, uselessly all the night ... But my mate no more, no more with me! We two together no more". Only when he reaches this point of acceptance that the object is lost for ever can a mourner seek the help he needs to rebuild his life. It is at this point however, as we shall see, that the mourner, still wounded and vulnerable, encounters not helping hands and kindly words, but the entangling 'web of welfare' or the proverbial 'brick wall'.

Some of the reasons why, in the face of research, government reports, the expansion and improvement of social services and the higher standards of training and education for carers, this continues to be the case will be explored. The main works of reference used in this chapter are: Parkes (1972) and Bowlby (1980).

Soothe! Soothe! Soothe!
Close on its wave soothes the wave behind,
And again another behind embracing and lapping, every one close,
But my love soothes not me, not me.

> From: 'Out of the Cradle Endlessly Rocking'.
> THE LEAVES OF GRASS. Walt Whitman, (1859)

Observations (see Bowlby 1980 and Parkes 1972) of how individuals respond to the loss of a close relative show that over the course of weeks and months their responses usually move through a succession of phases. These phases grouped together have been termed the 'process of mourning'. Admittedly, as Bowlby (1980) points out, these phases are not clear cut, and any individual may oscillate for a period of time back and forth between any two of them. Overall however, Bowlby argues, a sequence can be discerned and he sets out four phases as follows:

"1. Phase of numbing that usually lasts from a few hours to a week and may be interrupted by outbursts of extremely intense distress and/or anger.

2. Phase of yearning and searching for the lost figure lasting some months and sometimes for years.

3. Phase of disorganisation and despair.

4. Phase of greater or lesser degree of reorganisation.".

Bowlby (1980)

Parkes (1972) lists seven features which appear to be major aspects of bereavement:

"1. A process of realisation, i.e. the way in which the bereaved moves from denial or avoidance of recognition of the loss towards acceptance.

2. An alarm reaction - anxiety, restlessness, and the physiological accompaniments of fear.

3. An urge to search for and to find the lost person in some form.

4. Anger and guilt, including outbursts directed against those who press the bereaved person towards premature acceptance of his loss.

5. Feelings of internal loss of self or mutilation.

6. Identification phenomena – the adoption of traits, mannerisms, or symptoms of the lost person, with or without a sense of his presence within the self.

7. Pathological variants of grief, i.e. the reaction may be excessive and prolonged or inhibited and inclined to emerge in distorted form".

(Parkes 1972)

In the final chapter of his study of bereavement, Parkes (1972) considers the extent to which grief for the loss of a loved person resembles the reactions to other types of loss. Here Parkes draws on studies of the reactions to the loss of a limb and the loss of a home.

Those who have studied the psychological reactions to amputation often refer to the 'grief' they encounter. For example, Wittkower (1947) writes, "Mourning is the normal emotional reaction" and Kessler (1951): "The emotion most persons feel when told they must lose a limb has been well compared with the emotion of grief at the death of a loved one".

Parkes' (1972) consideration of the seven aspects of the bereavement process provides us with a framework with which to study types of loss other than bereavement (eg.. amputation) and the reactions of the parents of the blind children.

Realisation

Just as the widow finds it difficult to believe that her husband is dead and often has a strong sense of his presence nearby, so the amputee has difficulty in accepting the loss of his limb and continues to feel its presence. Eighty seven percent of the amputees often forgot the limb was missing and tried to use it. A year later, 46% still found it difficult to believe what had happened (see Parkes 1972).

As we have seen from the previous chapter, realisation was also a problem for the parents of the blind children. Many described the impact as being like a physical blow. Comments such as: "I was shattered, I just went numb". "I was knocked sideways", "I just blanked off", or "I couldn't take in what he was saying", illustrate this.

Hearing bad news, it seems, can be likened to an actual physical impact such as a road traffic accident, a stroke or a heart attack. In many cases the victim in such circumstances is actually rendered unconscious by the blow and it would appear that hearing bad news has a similar effect in that the mind is temporarily put out of action to protect the person from further damage. The comments above also indicate that in such circumstances the victim (parent) feels powerless and impotent, unable to defend herself or to influence the course of the proceedings. We can also see that this protective response, which renders the victim numb and unresponsive can easily be misinterpreted as calm acceptance, "She took it very well". The 'mask' however provides only short lived protection before the second component of the process (alarm) becomes manifest.

Alarm

The reaction to loss and bereavement includes components which can be termed 'non-specific'. That is to say, as Parkes (1972) writes, "bereavement evokes arousal and the responses that characterise the alarm reaction; it may also evoke approach or avoidance behaviour ...". The form these responses tend to take however, as Parkes argues, will be partly 'stressor-specific' (by which he means they will derive from the nature of the situation) and partly 'subject-specific' (they will derive from the personal predispositions of the subject). Alarm is the physiological response to stress or danger and prepares the animal for flight or fight. The symptoms (anxiety, restlessness, irritability, tension, lack of concentration, loss of appetite etc..) are symptoms of strain, and as Parkes points out, they occur in many different types of stress situation and there is nothing about them which is specific to bereavement.

The two kinds of response which have been observed in many research studies are, as Parkes remarks, analogous to Cannon's (1929) "fight/flight"

response insofar as, "fight involves an approach to the problems and difficulties whereas flight involves withdrawal and the avoidance of problem-solving". Parkes goes on to suggest that approach is likely if the unfamiliar or alarming stimulus is not too alarming and if it occurs in a situation in which the animal feels 'safe'. Intruders upon one's territory Parkes argues, are more likely to be approached, and perhaps threatened, than are the same individuals when met on their own territory. This would seem to have implications for the ways in which parents are 'told bad news'.

Parkes reminds us that the techniques which humans adopt when coping with 'emergent' situations may involve approach or withdrawal, or elements of both. The theory of psychic defence, he maintains,

> "rests on the assumption that there is a limit to the amount of anxiety an individual can tolerate and that when this limit is reached the individual will defend himself by withdrawing, psychologically, from the situation that evokes the anxiety".

Is it too large a jump then, Parkes asks,

> "for us to see in this behaviour an echo of the physical withdrawal of an animal in a situation of danger? In neither case does withdrawal necessarily imply failure or defeat, although it may do so. In both cases withdrawal is assumed to reduce the danger of being overwhelmed, and anxiety is the subjective accompaniment of real or imagined danger".

Just how a person responds to a particular form of stress depends, as Parkes notes, on many things. Amongst these are: the characteristics of the stressor; the individual's repertoire of appropriate coping strategies; how he perceives the situation in the light of his previous experience; his capacity to tolerate anxiety and on his need to maintain his own self-esteem.

Yearning and Searching

During this phase the mourner pines for the person who is gone, and is preoccupied with thoughts which can only give pain.

Lorenz (1963) described the effects of separating a greylag goose from its mate:

> "The first response to the disappearance of the partner consists in the anxious attempt to find him again. The goose moves about restlessly by day and night, flying great distances and visiting places where the partner might be found, uttering all the time the penetrating trisyllabic long-distance call ... The searching expeditions are extended farther and farther and quite often the searcher itself gets lost, or succumbs to an accident ... All the objective observable characteristics of the goose's behaviour on losing its mate are roughly identical with human grief".
>
> Lorenz (1963) 'On Aggression', London, Methuen.
> Quoted in Parkes (1972)

It is interesting to note the similarity of the above passage from an ethnological study to Whitman's poem quoted at the beginning of the chapter. But, the reader may ask, what is the relevance of this to the families of blind children? If they pass through this phase of the mourning process (and it is my thesis that they do), what is it that they are searching for? In order to answer this question we must first ask, "what is it that has been lost?"

The urge to search for the lost 'object', as Parkes notes, is less obvious in the reactions of the amputee than in the bereaved person. Obviously, as Parkes points out, the amputee is not going to search the hospital for his missing limb. However, in answer to the question, "Do you miss your limb?" all the amputees replied that they did. When questioned further on the point however, it became clear that what they missed most was the function which had previously been performed by means of the amputated limb. The leg amputees in Parkes' study described how they would lie in bed pining to go swimming or to run through the fields. The more athletic and active they had been in the past the more they appeared to suffer.

Parkes argues that whereas maintenance of contact with loved persons requires the use of scanning, searching and following behaviour from early childhood, there is no need to develop such behaviour with regard to parts of the body. Nevertheless, like the bereaved person, the amputee does tend to be preoccupied with thoughts of loss. He mourns his lost intactness, particularly when this is forced upon his attention. For the new leg

amputee, for example, going up or down stairs, carrying a cup of tea across
a room, or going to the toilet are all difficult and dangerous manoeuvres.
If the arm has been amputated such procedures as getting dressed, cutting
and eating food and buying a bus ticket become very difficult. Parkes
points out that either type of amputee is likely to be self-conscious about
being seen in public in a mutilated state, "Kids look at you" - said one
of his respondents - "it's like the Lord Mayor's Show when I go out".

Can the reactions of amputees who have lost a limb be compared to the
reactions of the parents of children who have lost their sight? Once again
we need to question what it is that has been lost in order to evoke a
searching response. Like the amputees it seems, what is missed is not so
much the actual organs of sight as their function of seeing and
consequently the loss of personal intactness. This is illustrated by the
comments below.

8. Danielle Ellis. Totally Blind. Retinoblastoma

"What I want most in all the world is a pair of eyes that work
instead of these plastic ones. I'd like to know what colour red
is and what blue looks like and whether I look nice wearing it.
I would like to know what I look like and to be able to choose my
own make-up. I'd like to go for a long walk all by myself in the
country. And to know if the boys I meet at parties are good
looking".

44. Mrs Patterson. (Sally Patterson. Functionally Blind & Physically Handicapped

"It really hurts to think she'll never watch her kiddies grow up.
She won't be able to choose clothes for them or see them dressed
up in party frocks. And she'll never see their faces when they
open their Christmas presents and won't be able to read them bed
time stories. It's the little everyday kind of things you know
that I get most worked up about".

33/34. Mr Howard. Robert & Jeffrey Howard. Functionally Blind. Retinal Dystrophy

"Well it doesn't seem right somehow for lads to be indoors all
day playing draughts and feelie dominos. I thought, you know,
when Robert was born, 'great it's a lad' and I thought I'd learn
him to play football and cricket and he'd be good at sport and
that. Then his eyes got worse and worse. But then we had
Jeffrey and I thought, 'this time' ... But it turns out he's got
the same thing. I mean somehow you feel they've been robbed of

what's rightly theirs and ... well, it just doesn't seem right somehow".

Parkes (1972) suggests that the pain of grief, like physical pain, may stem from the experience of damage to the self. If this is so, can the pain of grief be justified in the parents of blind children? The work of Fried (1962) as quoted in Parkes (1972) is of relevance here. Fried studied people who had lost their home through slum clearance. One of his most interesting findings was that many of his respondents expressed feelings of personal mutilation. For example: 'I felt like my heart was taken out of me', 'Something of me went with the West End'. 'It was like a piece being taken from me'. Commenting on the work of Fried and comparing it to his own, Parkes writes:

> "Like the widows (described in his own study) these people seem to have experienced a loss of self, a psychological mutilation which was subjectively just as real as the mutilation experienced by the amputee. Once again we are forced to realise that the skin is not the only boundary around the self and that the home we live in and the people to whom we are attached are, in some sense, ours - they are parts of ourselves".

Thus we can see that searching behaviour can be elicited by many different kinds of loss. What is actually sought however will differ with the circumstances. The amputees sought to restore the functions of a lost limb. Those who had lost their home searched, not only for the building, but also for the lost life style they had experienced when living in that environment. Elements of all of these can be found in the searching behaviour of parents of blind children. Some will seek to prove the doctors wrong by requesting a second opinion. Others will seek a cure, perhaps in some form of alternative medicine or by travelling to another country for more 'advanced' treatment. Where a cure is obviously impossible as in the children born without eyes or children who have had their eyes removed, searching behaviour is directed towards "making amends" (see Voysey 1975), and to restoring 'lost intactness', not only of the child himself but also of the family unit. All are however, in different ways, attempting to retain or restore in some measure, a part of their world which has been lost (see Parkes 1972).

Parkes (1972) noted that feelings of bitterness and anger were frequently expressed by the amputees. Many also felt envy towards healthy, intact people. Intense anger he noted, may also be directed at doctors or others whose actions are seen as being to blame for the loss. Feelings of guilt are also very common and, like the widow or widower, amputees and parents of handicapped children often blame themselves for what has happened. The quotes from the blind sample below illustrate some of these feelings:

42. Louise Brown. Functionally Blind. Retinopathy of Prematurity

"I'm still really bitter about it in a lot of ways. You see I still think, 'why has it happened to me?' I did everything they told me in pregnancy. I didn't smoke or drink or even take a paracetamol. I tried really hard and it doesn't seem right somehow when other people get normal babies and don't do anything right at all".

22. Samuel Bates. Totally Blind. Congenital Anophthalmos

"I'll be angry till the day I die about the way I was told. They could at least have told us together (with spouse). But there was nobody I could turn to. I know now what caused it, it was my neighbour having german measles while I was carrying him. But it's all sort of seething inside me because there's nothing I can do. I can't go up and tell her it's all her fault, can I? So I just have to put a bright face on things and talk to her as normal".

5. Michael Kent. Totally Blind. Pseudo-Glioma

"It's almost an obsession, this anger and hate for all the doctors, but particularly for Mr N (obstetrician). They treat blindness so lightly, as if it's just an extra digit or something. They've point blank refused to terminate if I get pregnant and it's a boy, so I've got to go private or not have any more children. I just couldn't go through all this again, I think I'd rather die".

35. Lee Davidson. Functionally Blind. Cataracts & Hallermann-Streif Syndrome

"I must admit I felt terribly guilty at first - till I knew it was 'a syndrome' that caused it. I thought I'd done it, leaving him out in the sun for too long and it had burnt his eyes. I couldn't bring myself to tell anybody what I'd done. But it was really a relief when they found it was all part of this syndrome".

Feelings of Internal Loss of Self or Mutilation

Feelings of internal loss of self or of mutilation were common amongst the amputees in Parkes' study and are expressed in their comments: "You sometimes feel you've had part of your body taken away and you're no longer part of the world - they've taken part of your life away". "You feel mutilated, you know you'll never be the same again". Another amputee said, "Underneath I feel badly damaged ..." Parkes interprets 'underneath' as reflecting, "the injury to the self which lies within the body whose intactness has been shattered".

There is also evidence from the work of Fried (1962) quoted earlier, that people who have lost a home experience feelings of personal mutilation. Such feelings are also evident in the quotes below from the blind sample:

21. Marie Williams. Functionally Blind. Leber's Amourosis

> "I feel bad and unclean inside myself, particularly in my womb. Something must be missing inside me because I can't make normal babies. You'd think it was easy enough wouldn't you? Everybody else seems to be able to do it. But I made a baby that couldn't see and I suppose it must be because I'm not right myself".

53. Charlotte Winter. Totally Blind. Retinoblastoma - Died age 7 years

> "I think your children are actually part of you, aren't they? When she died, part of me went with her. It's as if my heart had been ripped out".

51. Lucy Baldwin. Totally Blind. Optic Atrophy

> "I know it's irrational, but I feel it's some kind of punishment because I'm bad or wicked. I feel as if I want my womb to be scraped and washed out because I couldn't bear to have another baby inside me, ... it's, ... as if I'm contaminated inside".

Identification Phenomena

Parkes uses this term to describe those features of the reaction to bereavement which seem to indicate identification with the deceased. For example the sense of the spouse being present within themselves or the experiencing of symptoms resembling those of the husband before he died.

In my own study I found no evidence of what Parkes describes as identification phenomena in the parents of the blind children, even in those who had died. Interestingly however, some of the siblings did appear to be demonstrating symptoms which could be described under this heading. For example:

45. Sean Patterson - Brother of Sally No 44. Sean is also visually impaired

> "Sometimes there's no accounting for the things he does. Like the other day I came home and he'd painted his bedroom all over with black paint. Sometimes he sits in her wheel-chair and tries to put her callipers on. It's quite weird really".

38. Matthew Windsor. Useful Vision. Retinoblastoma - Died aged 4 years

> "I think he (younger sibling) does know that he's dead and not coming back but sometimes he acts really strange. He likes to get Matthew's clothes out and put them on. He says he's Matthew and he's not in the sky with Jesus at all".

Whether or not these symptoms are actually 'identification phenomena' is open to doubt. Recent cases of so called ritual child abuse show how dangerous it can be to interpret literally everything children say. Their actions similarly can easily be misinterpreted and the above quotes are included more for the sake of interest than as 'evidence'.

Parkes deals lastly with pathological variants of grief. However, I intend to leave these until later and deal here with Bowlby's (1980) third phase of grief, that of disorganisation and despair.

THROUGH DESPAIR TO RESOLUTION

Bowlby (1980) argues that for grieving to have a favourable outcome it seems to be necessary for the mourner to endure the phase of disorganisation and despair. As he writes of the mourner:

> "Only if he can tolerate the pining, the more or less conscious searching, the seemingly endless examination of how and why the loss occurred, and anger at anyone who might have been responsible, not sparing even the dead person, can he come gradually to recognise and accept that the loss is in truth permanent and that his life must be shaped anew. In this way only does it seem possible for him fully to register that his old

patterns of behaviour have become redundant and have therefore to be dismantled".

Because it is necessary to discard old patterns of thinking, feeling and acting, Bowlby maintains that it is almost inevitable that a bereaved person should at times despair of salvaging anything from his former life and as a result fall into depression or apathy. Nevertheless, Bowlby argues, if all goes well with this phase, the mourner may soon begin to examine his new situation and to consider ways of dealing with it. Bowlby points out that this will entail a redefinition of himself as well as his situation. Thus, no longer is the bereaved person a wife or husband, but a widow or widower and the parent is no longer the proud mother or father of a seeing child but of a blind one. As Bowlby writes:

> "This redefinition of self and situation is as painful as it is crucial, if only because it means relinquishing finally all hope that the lost person can be recovered and the old situation re-established. Yet until redefinition is achieved no plans for the future can be made".

Once this corner has been turned, argues Bowlby, a bereaved person begins to recognise that an attempt must be made to fill unaccustomed roles and to acquire new skills. Poets and storytellers however came to this conclusion long before the psychologists. For example, in Milton's (undated c. 1671) poem, 'Samson Agonistes', Samson reaches the depths of despair before reaching a 'turning point', at which he decides to comply with the Philistines' order to attend the Feast of Dagon. Up until this point, Samson is consumed by anger, grief and self pity:

> *"O loss of sight, of thee I most complain!*
> *Blind among enemies, O worse than chains,*
> *Dungeon or beggary or decrepit age!*
> *Light the prime work of God to me is extinct,*
> *And all her various objects of delight*
> *Anull'd, which might in part my grief have eas'd,*
> *Inferior to the vilest now become*
> *Of man or worm; the vilest here exell me,*
> *They creep, yet see, I dark in light expos'd*
> *To daily fraud, contempt, abuse and wrong,*
> *Within doors or without, still as a fool,*
> *In power of others, never in my own;*

Scarce half I seem to live, dead more than half.
O dark, dark, dark, amid the blaze of noon,
Irrecoverably dark, total Eclipse
Without all hope of day!"

Handel, whose (1741) oratorio, 'Samson', is based on Milton's poem, brings out Samson's 'turning point' even more clearly than Milton himself. At the point where Samson finally obeys an inner voice to comply with the Philistine officer's command to attend the festivities, Samson bids farewell to his friends; and Handel, (together with is librettist Newburgh Hamilton) inserts a verse from a much earlier poem (The Hymn; from The Morning of Christ's Nativity 1629):

"Thus when the sun from's wat'ry bed,
All curtain'd with a cloudy red,
Pillows his chin upon an orient wave;
*   The wand'ring shadows ghastly pale,*
*   All troop to their infernal jail,*
Each fetter'd ghost slips to his sev'ral grave,"

(NB. These words are taken from the vocal score and are slightly different from Milton's original – which see)

With this gently flowing aria, which itself seems aglow with evening sunlight, Samson turns to go with the Philistine, and becomes wholly an instrument of his God.

"Turn You to the Stronghold Ye Prisoners of Hope"

As with Samson, so many of the families in the blind sample reached a turning point in their grief:

5. <u>Michael Kent. Totally Blind. Pseudo-Glioma</u>

"For virtually all the first year I was so bitter and wound up with myself, I couldn't even look at him without wanting to knock hell out of the doctors. But then I started to realise that he was trying his best, in his own way, to reach me and tell me he loved me. It was then that I stopped always looking at his face, because you get no response, and I tried to find other ways of communicating. I went to the library and wrote to Tapton (blind school) to get advice on things to do to help him".

10. <u>Peter Davidson.   Functionally Blind.   Cortical Damage due to Hydrocephalus</u>

"I was so depressed, I couldn't bring myself to do anything. I couldn't watch him trying to do the things that had been so easy before, without breaking down and crying. I thought, you know, 'what a waste', why has God let this happen? Because he was really bright. Why didn't the hospital warn me what to look for (symptoms of a blocked shunt) so I could have taken him sooner.
It was him himself that finally brought me out of it. He was so independent he wouldn't let me help him, particularly feeding himself. So I started to think, 'maybe he will make good, if I can get the right help'. I suppose now that I find him quite rewarding really".

51. <u>Lucy Baldwin. Totally Blind. Optic Atrophy</u>

"For months I just sat around. I didn't take her out, I just didn't want to go outside the house. If she hadn't screamed so much I doubt if I would have fed her. Then one day, I decided I'd got to take a hold of myself, and I thought, 'I've got to get help'. There's got to be other people out there with blind kids, and somebody must know where they are. So I 'phoned the health visitor".

"Weeping May Endure for a Night, But Joy Cometh in the Morning"

Bowlby (1980) notes that although the original relationship continues to fill a central role in a bereaved person's life, as a rule this undergoes a slow change of form during the ensuing months and years. This continuing relationship, Bowlby argues, explains the yearning and searching, and also the anger, the despair and the subsequent acceptance of the loss as irreversible. Bowlby points out that it explains also many and possibly all of the features characteristic of 'pathological mourning'.

From his studies, Bowlby (1980) gained the impression that if recovery was not in progress by the end of the first year, the prognosis was not good. He concluded that a substantial minority of mourners never fully recover their former state of health and well-being and that a majority of those who do, or at least come near to it, are more likely to take two to three years to do so than a mere one. Bowlby also draws attention to the fact that clinicians often have unrealistic expectations of the speed and completeness with which mourners can be expected to recover from a major bereavement.

In the chapter which follows, various facets of disordered mourning as they can be applied to the blind sample will be discussed.

CHAPTER 24

BINDING THE BROKEN HEART

"Sorrow concealed, like an oven stopp'd,
Doth burn the heart to cinders where it is.

Shakespeare, Titus Andronicus

THE BROKEN HEART

"Is grief a cause of death?" asks Parkes (1972). 'Grief' will not be found
as a cause of death on any certificate issued today. The notion that a
person can die of grief has however always been popular with poets and
'storytellers', and as Parkes points out, it was once a recognised cause
of death. He goes on to quote figures from the causes of death in London
in the year 1657:

Flox and Small Pox	835
Found dead in the streets, etc..	9
French Pox	25
Gout	8
<u>Griefe</u>	<u>10</u>
Griping and Plague in the Guts	446
Hang'd and made away 'emselves	24

The origin of the term 'broken heart' is lost in antiquity. Isaiah, for
example bids us 'bind up the broken hearted' (Isaiah 61:1) and the idea
that grief can in some way damage the heart has always been apparent in
mythology and literature. There is however evidence from research which
leads us to suppose that the old physicians were not as foolish as they
might appear. Evidence of a raised mortality rate - particularly from
heart disease - in recently bereaved people can be found in many studies,

see for example, Parkes (1972), Young et al (1963) and Rees and Lutkins (1967). Twelve percent of the widows and widowers in the study by Rees and Lutkin (1967) died within twelve moths of bereavement. There is then, an established statistical relationship between bereavement and increased mortality, but as Parkes (1972) points out, it is still not known why bereaved people tend to die more readily than the non-bereaved.

Many diseases, it would seem, contribute to this higher mortality rate in people who are bereaved, but the most frequent cause of death appears to be heart disease. Parkes and colleagues (1969) carried out a follow-up study of the widowers studied by Young et al (1963). They found that 75% of those who had died had done so from heart disease, most usually coronary thrombosis or arteriosclerotic disease. Parkes (1972) points out however that the fact that bereavement may be followed by death from heart disease does not prove that grief itself is a 'cause' of death. As he argues, we do not even know whether bereavement causes the illness or merely aggravates a condition which would have occurred anyway. As studies have found, bereaved people tend to smoke more, or they may alter their diet in a way that increases the risk of coronary disease. As Parkes (1972) concludes, even if emotional factors are directly implicated, we have yet to explain how they affect the heart.

Only one mother in the blind sample suffered from heart disease (angina), the onset of which occurred shortly after the diagnosis of blindness in the child. It must be remembered however that all the parents in the blind sample were under the age of 50 and the majority under 40, whereas the widowers studied by Young et al were all over the age of 54. Fifteen (30%) of the mothers admitted to extra smoking themselves and reported this in 3 (6%) of their husbands, which may well underestimate the problem. In this context Parkes (1972) observes, it may be that measures aimed at reducing the stress of loss could help to prevent stress related disorders later on. If so, he argues, giving help to the bereaved is a positive contribution to public health and preventive medicine.

Researchers studying newly bereaved people (eg.. Parkes 1970 and Maddison and Viola 1968) have found that the bereaved suffer frequently from symptoms such as nervousness, depression, fears of nervous breakdown, feelings of panic, 'peculiar thoughts', nightmares, insomnia, loss of appetite, weight loss, reduced working capacity and fatigue. As Parkes (1972) points out however, these are all symptoms of 'normal' grief and it is therefore not surprising to find them complained of by newly bereaved people. Other symptoms reported by the bereaved, which are less obviously features of grieving include headache, dizziness, fainting attacks, blurred vision, skin rashes, indigestion, difficulty in swallowing, vomiting, heavy menstrual periods, palpitations, chest pains, shortness of breath, frequent infections and general aching.

More seriously, as Parkes (1972) notes, there are certain potentially fatal conditions such as coronary thrombosis, leukaemia, and other cancers which seem in some cases to be precipitated or aggravated by major loss.

Although Parkes (1970) found that 75% of the widows in his 'London Study' had consulted their GP within six months of bereavement, relatively few of the parents in the blind sample had done so, although virtually all of them complained of several of the above symptoms (see section II, chapter 6, and fig 6.3).

Four of the mothers in the blind sample also suffered from a major physical illness following the diagnosis, (angina, osteo-arthritis, Bell's Palsy and severe migraine). Two of the fathers also suffered from major physical illness, (terminal cancer of the lung and a leg injury due to an accident at work for which he now receives invalidity benefit). Since the study was completed one of the fathers of a multiply handicapped child taking part in the pilot study has died from a rare tumour of the kidney.

Parkes (1972) has noted that, "One way and another women usually come out of bereavement worse than men". In his 1970 American study, it was found that the women showed more overt distress following bereavement than the men, and their psychological and social adjustment a year later was less

good than that of the widowers. Parkes (1972) however found that on follow up two to four years later, it was in fact the men who were found to have taken longer to recover than the women. It is interesting to note in this context that although three of the mothers in the blind sample seriously considered suicide and a further two actually attempted to take their lives, none of the sample mothers actually died, whereas one father in the sample group and another from the pilot study actually did so. These deaths took place sixteen years and six years respectively after the birth of the handicapped child.

THE MOURNER AT RISK

"Who is this that has said: the house of God is a House of Sorrow?"

T S Eliot, Choruses from 'The Rock' IX

Using evidence from his studies of widows and widowers, Parkes (1972) was able to identify a group of bereaved people 'at high risk of getting into difficulties'. Many of these 'at risk factors' also apply to parents (particularly mothers) of handicapped children. The following paragraph from Parkes (1972) has been altered (in brackets) where applicable so that it can be applied to parents in the blind sample.

> "... our high-risk case would be a young widow (mother) with (other) children living at home and no close relatives living nearby. She would be a timid, clinging person who had reacted badly to separation in the past and had a previous history of depressive illness. Closely bound up with her husband (child) in an over-reliant (over-protective) or ambivalent relationship she would not have prepared herself for his unexpected and untimely death (immediate impact of crisis). Cultural and familial tradition would prevent her from expressing the feelings that then threatened to emerge. Other stresses occurring before or after the bereavement - such as loss of income, changes of home, and difficulties with children (siblings) - would increase her burden. Although she may at first appear to be coping well, intense pining would subsequently emerge, together with evidence of pronounced self-reproach and/or anger. These feelings, instead of declining as one might expect, would tend to persist".

Some Determinants of Outcome in Grieving

> *"They all go into the dark, ..."*
>
> T S Eliot, 'East Coker'

The paragraph above from Parkes (1972) can be used to help professionals identify parents of handicapped children who might be at risk of disordered mourning or mental breakdown.

Parkes and others have found that women appear to suffer more frequently than men from 'disordered mourning'. Therefore mothers are likely to be more at risk than fathers (at least as far as mental breakdown is concerned). Parkes pointed out that the 'high risk widow' will be young, and it will be remembered that all the parents in the blind study were under the age of fifty and the great majority under forty. Parkes goes on to describe the woman at risk as being timid and shy, probably having a previous history of depressive illness. Insufficient data were obtained from the blind sample mothers to enable a comparison to be made with Parkes' widows, however such information as was volunteered by the mothers would tend to confirm his findings.

Kinship and Support Networks

> *"... And we all go with them, into the silent funeral, ..."*
>
> T S Eliot, op. cit.

The young woman at risk, Parkes reveals, will have no close relatives living nearby. In this respect the Sheffield mothers were somewhat different from the Young London widows of Parkes' study. In Sheffield, as has been noted in previous chapters, kinship networks are generally extensive. Seventy four percent of the mothers and fathers in the sample group had their own parents living in the same city, many (54%) in the same neighbourhood. There was often also frequent contact with and extensive support from other family members. In the Sheffield sample, the maternal grandparents often formed the backbone of the family support network and as will be revealed later, family support was a crucial factor influencing the final outcome of grieving.

> *"The lights are extinguished, for the scene to be changed ..."*
>
> T S Eliot, op. cit.

The 'at risk widow', Parkes informs us would have been unable to prepare herself for her husband's unexpected and untimely death. The categories of impact previously described in Chapter 25 can be used within the context of being able to prepare oneself for crisis.

Parkes (1972) notes that crisis disrupts the customary modes of behaviour of the people concerned, it alters both their circumstances and their plans and imposes a need for psychological work which takes time and effort. Crisis presents the individual with the opportunity and the obligation to abandon old assumptions about the world and to discover new ones. Crisis situations therefore evoke challenge.

Under mild to moderate stress, Parkes reminds us, most people learn rapidly and are likely to accept the need to change more readily than at other times in their life. People also tend to seek help more willingly than at other times, and other people are more prepared to offer it. Raphael (1986) has observed that the support which society offers to its suffering members during crisis is often considerable even though it may be relatively short term.

However, when the strain exceeds a certain threshold of severity (and as Parkes [1972] points out this varies from one individual to another) the person finds herself unable to cope with the situation and becomes overwhelmed by it. In such circumstances, Parkes observes, old ideas and assumptions may be adhered to rigidly and offers of help, which would involve an acceptance of the need to change are refused. As one of the widows studied by Parkes said to him, "I'll never believe he's dead and you can't make me".

"Human Beings are Seldom Surprised"

Parkes (1972) writes:

> "Human beings are seldom surprised. Their ability to anticipate important changes in their lives enables them to make the necessary changes in their expectations in advance and to experience a part of the emotion appropriate to the disaster before it occurs. When it occurs they are to some extent prepared for it both intellectually and emotionally; their behaviour is correct and emotion adequately controlled".

There are however certain circumstances (for example immediate impact) under which the person has no time to prepare herself for the disaster. There is evidence (eg.. Raphael 1986 and Lonsdale 1979) to show that where disaster strikes suddenly and without warning, the emotional reaction can be very severe particularly in younger people. If the victim dies and the death is felt to be 'untimely' (a child or young adult), the emotional response is often even more severe. In relation to bereavement, Parkes (1972) notes that:

> "... the opportunity to prepare oneself in anticipation of bereavement does affect the subsequent reaction to the event, though it is still uncertain how important a factor this is in determining later adjustment".

The young American widows studied by Parkes (1970) became much more emotionally disturbed following deaths for which they had had little time to prepare. And Parkes also found that this disturbance persisted throughout the first year of bereavement.

"A Movement of Darkness on Darkness"

As has been noted previously, immediate impact is rare and only two families from the blind sample could really be placed in this category, (Case 22, Samuel Bates and Case 28, Cynthia Carter - both children having been born without eyes). I have however added a third - Case 32, Bethany Hartley - whose mother was told over the telephone that her baby was blind. All of these mothers were told the news alone, without their spouse, partner or other family member with them. All suffered symptoms of what

has been termed 'post traumatic shock' (see Raphael 1986). They also suffered from what Bowlby (1980) has termed 'chronic grief', physical ill health and severe and long lasting emotional disturbance.

Mrs Bates "was on librium continuously up until having the nervous breakdown four years ago". (When Samuel was ten years old Mrs Bates was admitted to a psychiatric hospital for almost six months).

Mrs Carter rejected Cynthia, leaving her alone upstairs for long periods of time and 'prop feeding' her in the cot. She did not take the baby out for nearly a year. Mrs Carter now suffers from osteo-arthritis and Mr Carter has since died from lung cancer.

Mrs Hartley "went hysterical" on being told the diagnosis. Bethany's father was in prison at the time of the crisis. He has never been told about Bethany's condition by a professional person. Neither parent accepts that the child will never be able to see and they have "bought her a colour tele' instead of the black and white one, so she'll be able to see it better".

In the blind sample at least then, we can see that immediate impact appeared to set in motion shock waves affecting the mother, the mother/child relationship, the marital relationship and the wider dynamics of family life. With regard to the other kinds of impact described in the previous chapter (impact following a warning, impending impact and delayed or abortive impact) however the parental reactions varied considerably and there was no clear correlation between type of impact, number and type of symptoms suffered, speed of recovery, or family relationship problems. In this context it is interesting to note that the widely accepted notion of the medical profession, that it is better for the patient to find out what is wrong gradually over time, or not to be told at all, would appear to have no foundation in fact. Indeed, in many cases, delaying the impact or withholding information altogether actually led to an increase in anxiety and anger.

> *God bless the Family! - trifle tremendous*
> *One tiny cloud in a colossal sky:*
> *Yet let the Universe touch or offend us,*
> *The Family will fight and win - or die.*

<div align="right">A P Herbert, 'Bless the Bride' (1947)</div>

As was previously noted, no link was found, in the blind sample, between the type of impact suffered and outcome (recovery of function and rehabilitation). It was however obvious that some families made a quicker and 'better' recovery than others. Further examination revealed that, in the main, those families who had relatives - particularly maternal grandparents - living nearby who were supportive appeared to surmount their difficulties, recover their functions and learn new skills more quickly and completely than unsupported families. Parkes (1972) also found that family support was a crucial factor in the recovery of bereaved people. Lonsdale (1979) has shown that parents of handicapped children can also be helped by professionals working in multidisciplinary teams. To be effective however, Lonsdale showed that help must be given as soon as possible after diagnosis - within hours of the child's birth.

IDENTITY IN CRISIS

> "Tradgedy, as it was antiently compos'd, hath been ever held the gravest, moralest, and most profitable of all other Poems: therefore said by Aristotle to be of power by raising pity fear, or terror, to purge the mind of those and such like passions, that is to temper and reduce them to just measure with a kind of delight, stirr'd up by reading or seeing those passions well imitated. Nor is Nature wanting in her own effects to make good his assertion: for so in Physic things of melancholic hue and quality are us'd against melancholy, sour against sour, salt to remove salt humours".

<div align="right">John Milton, Introduction to 'Samson Agonistes'</div>

Parkes (1972) discussing the ways in which bereaved people defend themselves, explores some of the reasons for denial. He argues that in denying the reality of the loss, the bereaved person provides himself with an opportunity to prepare for it. He is, as it were, 'buying time' to rehearse and 'learn his lines'.

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Parkes notes that the widows and widowers found themselves repeatedly reviewing and going over in their minds, the events leading up to the death, as if by doing so they could in some way undo or alter the events that had occurred. Since, as Parkes argues, the suddenly bereaved person can rarely accept in full the reality of what has happened, "it may be that he has the same need to prepare himself for the disaster as the person who has not yet experienced it".

Quite often Parkes notes, the bereaved person may have to use his imagination to fill in the gaps and to provide him with pictures of events which he has forgotten or has never witnessed. As he writes:

> "At such a time there is a conscious need to 'get it right' and getting it right is not just a matter of recalling the traumatic event correctly; it includes the need to 'make sense' of what has happened, to explain it, to classify it along with other comparable events, to make it fit into one's expectations of the world. ... Trying out new solutions, searching for clues to explain 'why did it happen to me?' and repeatedly, monotonously, remembering the sequence of events leading up to the death – these are what make up the process of grief work".

'Grief work', in common with other kinds of work, requires a framework – a kind of 'job description'. Just as a story or play needs a plot and a poem a subject so that they are not just meaningless groupings of words, so the process of mourning requires a framework. And just as a story, poem or play must have a beginning, a middle and an end of which the reader or actor needs to be aware, so the mourner needs a 'pathway' through the process of grieving.

In a play, the actors have roles, they learn their lines from a pre-set script and when they reach the end of this script actors and audience are aware that the end of the play has been reached. Actors are guided through the play by using a pre-rehearsed choreography of movements and actions. Special clothes, sometimes including masks are worn and other 'props' are used as necessary to remind the actors and the audience of their roles. It is noteworthy also that 'the show could not go on' without an extensive backstage support network – the stage manager, choreographer, prompter, scene shifters, tea ladies and many others. All these people help and support the actors in their roles.

But what of the mourner? What of the bereaved person or the parent of a handicapped child? How does she learn her role? Is there in fact a 'role' for those who mourn? If such a role exists in society today, where is the 'script'? Does the 'actor' still need special clothes and 'props' for this role? Perhaps more importantly, where are the backstage helpers? the stage managers, the prompters and the 'tea ladies'? Is there in fact, in our society still a recognised framework for the 'masque of Mourning'? If not, how can the mourner know when she has reached the beginning, the middle and the end of the process? and, equally importantly, how can the 'audience' and 'helpers' know?

"We Must Walk in Black and Go Sadly, with Longdrawn Faces"

Volkart (1957) has pointed out the diverse ways in which societies seem to develop belief systems providing an explanation for death, and a set of rituals which give some support for the expression of the emotions arising from bereavement. Volkart notes that during the period of mourning, social customs determine the roles to be played by members of the dead person's family, impose restrictions on the activities of those most closely related to the dead, and sanction the expression of grief and other emotions.

Clearly, Parkes (1972) argues, guidance such as this should reduce the confusion felt by the newly bereaved and might also be of psychological value in helping them to express their grief. Gorer (1965) however has noted and deplored the decline in the ritual observation of mourning today and believes this to be responsible for much mental ill health among bereaved people. Later work by Parkes (1972) and Bowlby (1980) lends support to this view.

"Only Through Time Time is Conquered"

When there is a prescribed period for mourning, as Parkes points out, a time is prescribed for its ending. (As he notes, the term 'quarantine' comes from quarantina, the Italian for 'forty', which was the number of days of sequestration expected of the widow). Songs and folklore seem to have an accepted period of 'a year and a day'. Thus an accepted mourning period provides social sanction for the beginning and ending of grief and

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perhaps some guidance as to whereabouts the mourner is in the process. Within this framework there is also guidance for the 'supporting cast' – relatives and friends and 'backstage helpers', i.e. those people outside the 'cast' (family and friends) whose job it is to support and assist the actor (doctors, nurses, social workers, ministers of religion and 'tea ladies'). As Parkes (1972) writes:

> "While it is true that social expectations concerning the duration of mourning cannot correspond closely to all individual psychological needs to express grief, which vary considerably, the absence of any social expectations, as is common in Western cultures today, leaves the bereaved person confused and insecure in his grief".

> *"We must go between empty walls, quavering lowly, whispering*
> *faintly,*
> *Among a few flickering scattered lights?"*

> T S Eliot, Choruses From the Rock

2. Matthew Tomlinson. Functionally Blind. Retinal Dystrophy

> "Somehow it was almost as if, because he couldn't see, he didn't exist any more – outside the family I mean. People would either cross the road and pretend they hadn't seen us, or else they'd just talk as if he wasn't there at all".

Thus we can see that in Western culture today, the mourner is often cast adrift, left to play an unrehearsed role without a script and with little or no assistance. Parkes (1972) has also noted that the bereaved person, particularly if she is a widow, often suffers a fall in status and loses her place in the social hierarchy. As Lorenz notes in his description of the greylag goose which has lost its mate:

> "From the moment (the partner is missed) ... it loses all courage and flees from even the weakest geese. Sinking rapidly in the ranking order of the flock, the bereaved goose becomes shy, fearful, and panicky".

Price (1967) providing an explanation in ethnological terms, maintains that similar behaviour takes place in man. Thus bereavement can be expected to

lead to a fall in status and the decline in status produces loss of courage and depression. For example, as Mrs Russell said:

17. Paul Russell. Functionally Blind. Cataracts

"After we found out what was wrong, it was as if it wasn't only that he was blind, but as if we'd done something to cause it. You know, one day everybody was admiring him and saying 'what a lovely baby' and the next, nobody wants to know you".

For the widow or widower then, there is in Western society a 'role', even if it is a somewhat ill defined one. And for parents of 'normal' children there are quite clearly defined roles. As Voysey (1975) writes:

"Any parents, whether or not they have a disabled child, may be held accountable to the official morality for those of their actions which are public or held to have consequences for the public realm".

Voysey also notes that for parents of 'normal' children there is a ready-made stock of knowledge,

"handed down from ancestors or acquired in 'anticipatory socialisation', which provides a guide to the kinds of situations likely to occur and trustworthy 'recipes' for interpreting his behaviour and handling him in such a way as to attain the desired consequences".

Other sources from which information can be readily obtained include friends and relatives and neighbours with children of a similar age. Should they still be perplexed, parents of normal children can turn to the professionals for advice, eg.. health visitors, their GP or the 'clinic doctor'. They also have recourse to a vast literature on the subject. The parents of blind children on the other hand have no such recourse as Mrs Matthews points out:

23. Steven Matthews. Functionally Blind. Retinal Dystrophy

"I just felt at a complete loss about how to cope, like, you know, feeding him and trying to stop him crying at night after we'd gone to bed. When the others were little, they were always round from the welfare, telling you what to do. But after we found out he couldn't see, there was nobody. Even the clinic didn't want to know, they just said to ask at the hospital, but he'd been discharged from there".

The parents of a handicapped child then, are in danger of losing not only their status, but their very identity. How can they adopt a role which has not been defined by society? They have no ready-made stock of knowledge and no 'anticipatory socialisation' or 'trustworthy recipes'. Relatives are stunned and shocked, friends and neighbours turn away, and the literature, sparse enough for professionals, is virtually non existent for parents. It is often at this point in their career that the parents of disabled children encounter and become entangled in the 'Web of Welfare' (see figure 4.1).

In order to obtain the help and benefits they need, the families become subject to the scrutiny of professional helpers. Here, as Voysey (1975) points out, "their good identity as parents, and that of the family may be at stake". The parents protect themselves and their identity in the only way open to them; by presenting a facade of normality and assuming a stance of 'coping splendidly'. An example of this is shown in the quote below:

13. Callum Pickering. Functionally Blind. Retinal Dystrophy

> "I just didn't know what to do really, because they didn't want to see him any more at the hospital. I was scared to ask anybody what to do. I used to spend ages washing his clothes and keeping him clean in case anybody came. You see, I thought if anybody came round and found him dirty and the house not clean, they'd take him off me to go into a Sunshine Home or something. So I just had to be the perfect mother".

Ball (1970) observes that 'respectability' constitutes a 'bridge' between labelling theory's focus on societal definitions and Goffman's (1968) on impression management. Ball also makes reference to two dimensions of truth/falsity and presenting/concealing and discusses strategies that actors might adopt in the constructing of a 'respectable appearance'. These can be: 1. the presentation of virtues; 2. concealing vices; and 3. the creation of the appearance of virtue where other circumstances 'really' pertain. Something of all three of these strategies can be found in the above quote [Callum Pickering]).

> *"He hath sent me to heal the broken hearted,*
> *to preach deliverance to the captives*
> *and recovery of sight to the blind ...*

Should it be the role of the helper or counsellor to break down this facade of 'coping splendidly' which has been erected by the family? Is it their task to 'enable' the client to 'gain insight' into his situation, thus achieving a more 'realistic' viewpoint with a view to 'rehabilitation'? Scott (1969) discusses the ways in which the blind are re-socialised (rehabilitated) by 'Blindness Agencies' in America. Scott writes:

> "... the compliance of one person is the reward a supplier receives for the services he renders. Compliance with the demands of others is the substance of power and, for this reason, willingness to comply with the wishes of others is often a very generous reward. It can be seen, incidentally, that exchange processes give rise to differentiation of power among persons, since there will always be some people who are capable of providing services that others need. Power is attained when the supplier makes the satisfaction of those in need contingent on their compliance with his wishes".

Voysey (1975) examines the coping strategies adopted by parents in relation to the amount of 'power' they have over their situations. She divides them into four 'typical' styles of impression management: 1. coping splendidly; 2. making amends; 3. stoic acceptance and 4. avoidance. According to Voysey's theory, 'coping splendidly' is associated with having power and not being responsible, i.e. the parents have sufficient knowledge to be in control of the situation and can in no way be 'blamed' for the child's condition. 'Making amends' is associated with being 'responsible' but having power. In this situation, the parents feel guilty and 'responsible' for the child's condition whether this is justified or not. They have however sufficient knowledge and the means to 'make amends'. In the case of 'stoic acceptance', although the parents are not 'responsible', they have no power. Voysey claims that 'stoic acceptance' occurs most commonly in cases of 'tragic disability' for example congenital anomalies. According to Voysey's theory, these parents are unable to control the situation and claim to be "taking it from day to day". In Voysey's fourth category, 'avoidance', the parents feel 'responsible' for the child's

condition and in addition have no power to control the situation. According to Voysey, avoidance can occur when no cause can be found for the condition or there are genetic implications and there is no known treatment or cure. The child's condition becomes a 'guilty' secret. (See for example case No 28 Cynthia Carter).

The Power of Enlightenment

> *The soul of man must quicken in creation.*
> *Out of the formless stone, when the artist unites himself with*
>   *stone,*
> *Spring always new forms of life, from the soul of man that is*
>   *joined to the soul of stone;*
> *Out of the meaningless practical shapes of all that is living or*
>   *lifeless*
> *Joined with the artist's eye, new life, new form, new colour.*
> *Out of the sea of sound the life of music,*
> *Out of the slimy mud of words, out of the sleet and hail of*
>   *verbal imprecisions,*
> *Approximate thoughts and feelings, words that have taken the place*
>   *of thoughts and feelings,*
> *There spring the perfect order of speech, and the beauty of*
>   *incantation.*
>
> <div align="right">T S Eliot, Choruses from 'The Rock' IX</div>

It is my thesis that the tasks of the helper, healer or counsellor are not, necessarily to expose the wounded person to his 'pathetic condition', to lay bare his 'guilty secrets', to 'wound in order to heal'; but to restore his disabilities, to build on his abilities, to bind his wounds, and ultimately, to empower him, and then to let go and 'set him free'.

In an article in the Sunday Times Magazine dated 6 December 1992, E Jane Dickson reports on a remarkable prosthetic hand, designed by a French sculptor. "When art and human dignity are in question, you don't scrimp on time or materials", says Jacques Monestier the sculptor. Monestier spent 22 years developing a prototype hand, cast in precious metals and guaranteed to make the wearer feel like a million dollars (it costs £30,000). Monestier was attracted to a painting of the 16th century surgeon Ambroise Paré fixing an artificial hand to an injured horseman:

> "It was an armoured gauntlet, like a golden hand, a
> quasi-mythical object – nothing like those dead, pink, plastic
> hands which pretend to imitate human flesh. This was the hand I

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wanted to create, with the added refinements of modern materials and technology ... Amputees often suffer a loss of self-image. I wanted to transmute what might be considered a disfigurement into something marvellous and exotic. Imagine a disabled person in the tube holding onto a strap with an armoured glove: what an impression of strength! And imagine my golden hand signing a cheque! You cannot restore a lost limb, but you can give people back their power and their pride".

The Tasks of the Healer

These then are the tasks of the healer and helper. They might perhaps be regarded as a sequence or process.

When he is first wounded, the victim needs a period of 'enfolding' as a seed needs to be planted in nourishing soil. Following this period the plant like the wounded person should be allowed gradually to 'unfurl' and grow.

> *For as the earth bringeth forth her bud,*
> *and as the garden causeth the things that*
> *are sown in it to spring forth ...*

In the beginning the mourner needs 'support' but later on this should become 'upholding' as his wounds heal and he gains confidence through knowledge.

> *"To give unto them that mourn a garland for ashes,*
> *the oil of joy for mourning,*
> *the garment of praise for the spirit of heaviness".*

Early in his career, the wounded person will need help to carry out the tasks of daily living – he will need to be 'enabled', but as he progresses this can become 'empowerment' to learn for himself new ways of coping.

> *Thou wilt shew us the path of life;*
> *in Thy light shall we see light.*

The final task of the healer/helper, and sometimes surprisingly difficult,
is to be able to 'let go' and to 'set the captive free'.

> *With wings that I wrested for myself*
> *in the fervent struggle of love*
> *I shall fly away*
> *to the light wither no eye pierced.*
>
> Klopstock, 'Resurrection Ode'
> Trans. William Mann

The Terrible Gift

> *"Lord, shall we not bring these gifts to your service?*
> *Shall we not bring to Your service all our powers*
> *For life, for dignity, grace and order,*
> *And intellectual pleasures of the senses?*
>
> T S Eliot, Choruses From 'The Rock', IX

Hull (1991) explores the idea of blindness as a gift from God – a 'Terrible
Gift'. He resists the idea, because, "if blindness is a gift, I would have
to accept it" and, "I have said to myself that I would learn to live with
blindness but I would never accept it". Yet, he continues:

> "I find the thought keeps coming back to me, and arouses my
> curiosity. Could there be a strange way in which blindness is a
> dark, paradoxical gift? Does it offer a way of life, a
> purification, an economy? Is it really like a kind of painful
> purging through a death? Am I to expect that I shall enter into
> a new, more concentrated phase of life because of this gift?
>   The philosopher Brentando did a lot of his creative work
> after he lost his sight, and attributed this to his blindness.
> Should I begin to think of myself not as a person disabled by a
> defect but empowered by a capacity?".

One or two of the blind sample families had also explored this idea. Some
dismissed it, for example Mrs Bingham:

49. Wayne Bingham. Functionally Blind. Retinopathy of Prematurity

> "Well some say 'he's a gift from God', 'somebody must have
> watched over him and saved him' (from death) they say. But what
> I say is, 'who did it to him in the first place?' That's what I
> want to know".

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Others partially accepted it. For example Mrs Brown:

42. <u>Louise Brown. Functionally Blind. Retinopathy of Prematurity</u>

> "Well people say, 'having a handicapped child is a gift from God' and that He only sends them to people who can cope. Well I don't know about that, looking at some of the ones you see in hospital. But then, thinking about things, (Mrs Brown was exploring her feelings through the 'Minisculpt' models) in a funny kind of way, perhaps they're right, and she is. I mean, she's brought us so much closer together. It's been really hard work, but she's made us a family".

By accepting 'The Terrible Gift', Louis Braille empowered the blind by giving them the gift of literacy. Thomas Armitage built on this system and set the blind free by giving them a 'language' which, like the language of music, is recognised and accepted in every corner of the world.

In Conclusion - To Comfort Always

The tasks of the helper who would assist the wounded have been outlined above. From protection; enfolding and unfurling; through supporting and upholding, to enabling and empowering, and finally, letting go and setting free. The process can apply equally well to a person with a broken leg as one with a broken heart. It matters not whether the victim is physically or mentally wounded, has lost a spouse, a home, a child or a limb. The discipline of the carer is equally unimportant - the model can be used by nurses, doctors, social workers, parents, ministers of religion or 'tea ladies'.

Obviously, not every wounded person will be able, or would want, ultimately to be 'set free', but then, in words attributed to Florence Nightingale, the role of the healer will be:

> "To cure sometimes,
> to relieve often,
> to comfort always".

The role of the healer of the wounded therefore is that of a guide, supporter and facilitator, thus enabling the person to forge his own new identity, and, at last, to empower and set him free.

> *"Now you shall see the Temple completed:*
> *After much striving, after many obstacles;*
> *For the work of creation is never without travail;*
> *The formed stone, the visible crucifix,*
> *The dressed altar, the lifting light,*

> *Light*

> *Light*

> *The visible reminder of Invisible Light.*
>   T S Eliot, Choruses from 'The Rock'

CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

*"God, give us grace to accept with serenity the things
that cannot be changed, courage to change the
things that should be changed, and the wisdom to
distinguish the one from the other".*

Reinhold Niebuhr, 1892-1971

Introduction - "In My Beginning is My End"

Any reader who has turned to these pages for a summary of what has gone
before and a concise list of 'recommendations', will not find here what
s/he is seeking. Such a reader is referred back to the introductory
chapter concerned with the methodology of 'illuminative research'. As was
pointed out in the introduction, although the illuminative approach seeks
to promote change, researchers usually stop short of making policy
decisions. Instead, illuminative research aims to challenge conventional
assumptions, to provoke thought and unsettle established ways of thinking.

If any of these aims have been achieved, the reader who has followed the
argument thus far will already have drawn his or her own conclusions and
may well have formulated some strategies for dealing with some of the
dilemmas presented in the thesis.

From the results of a small scale study of fifty families in a highly
localised area, it would be not only presumptuous but foolhardy to make any
but the most basic recommendations. If, for example, as an uninvited
'outsider' knowing nothing of the constraints or staffing problems
operating in the department, I were to make the recommendation that, "Spilt
orange juice should, in the interests of patient safety be cleaned from the
tables and floors in the out-patient department canteen", I could well make
matters worse by setting alight an already flammable situation.

During the past thirty years several committees of highly distinguished
people have been requested by the government to investigate the needs of
disabled children. Examples include: Platt (1959), Vernon (1972),

Court (1976) and Warnock (1978). On the basis of their research, they have made wide ranging recommendations. Implementation of these recommendations has been patchy and selective, but it is doubtful whether the full package has been put into action by any single authority or institution anywhere in the country. Some of the reasons why this is often the case have already been explored in the preceding pages.

Sometimes research recommendations, as well as being implemented 'selectively' can be taken out of context or imposed upon an unprepared workforce without prior consultation. In some instances recommendations, although made with the best intentions, can have the opposite of the desired impact. As an example of what I mean by this, I cite below the work of the Joint Working Party on Child Health Surveillance (The Hall Report 1989 and 1991). The Working Party was given the following terms of reference:

> "To review and comment upon current practice in child health surveillance in the United Kingdom and to make recommendations for future practice".

In preparing their report, the Hall Committee made a "detailed study of the literature" and were able to "draw on an immense body of knowledge and experience accumulated by doctors, psychologists, therapists, and education specialists over the past 20 years". In Chapter 9 of the report, the Working Party review the policy of screening for vision defects. They write:

> "Conditions causing a disabling vision impairment are individually and collectively uncommon, with a combined incidence between two and four cases per 10,000 births. This figure is however likely to be an underestimate, because there is under reporting of vision defects in children with multiple handicaps".

The Hall Working Party obtained this information from a paper by Shirley Fine contained in Smith and Keen eds (1979). Fine in turn collected the figures from "the notification to the Office of Population Census and Surveys (OPCS) of children with congenital malformations identified within one week of birth". As can be seen from Section II, in the Sheffield sample only 8 of the 55 children were diagnosed prior to leaving the

maternity hospital, and these would be the only ones included in the data collected by Fine. It is also worthy of note that these were figures collected from the 1976 returns - already 15 years out of date by the time Hall (1991) used them to make recommendations for the 1990s. Thus we can now begin to see how major discrepancies arise and are perpetuated.

Although for the second edition of their report the Hall (1991) Working Party had at their disposal the 1989 OPCS survey of 'The Prevalence of Disability Among Children' (Bone and Meltzer [1989]), nowhere in their report is any reference made to this work, but, as we have seen, Bone and Meltzer estimate the prevalence of severe visual impairment at around 1:500 of the population, a very different figure from that obtained by Hall (1991).

With regard to the early detection of severe visual defects, The Hall Working Party write:

> "Many cases are detected by parents or other family members (55% of the Sheffield sample). A *significant number* (my italics) are found at the neonatal examination, by simple inspection of the eyes (3 of the Sheffield sample). Some are found by specialist examination of known high risk groups, including low birth-weight infants at risk of retinopathy of prematurity (9 of the Sheffield sample), and babies with a first degree relative known to have a potentially heritable eye disorder (5 of the Sheffield sample)".
>
> (See Chapter 5 for details)

Regarding the detection of severe visual impairment, the Hall Committee make the following recommendations:

> "1. A careful inspection of the eyes is a mandatory part of the neonatal examination. Fundoscopy is not essential but the ophthalmoscope may be used with a +3 lens from a distance of 8-12 inches, to detect a cataract as a silhouette against the red reflex. If there is any doubt about the adequacy of the neonatal examination, the inspection and the examination should be repeated at six weeks.
>
> 2. The parents should be asked if there is a family history of visual disorders. Children at risk of having a genetically determined disabling visual disorder should be examined with extra care, preferably by an ophthalmologist

3. Parents should be asked soon after the birth and at each subsequent contact whether they have any anxieties about the baby's vision. Specifically, they should be asked if the baby looks at the parents, follows moving objects with the eyes, and fixates on small objects

4. All staff should be familiar with the visual development of the normal baby, and should be alert to the various symptoms and signs which first warn parents that there may be a visual defect: for example, abnormal appearance of the eyes, wandering eye movements, poor fixation and visual following, photophobia, etc".

With regard to the recommendations of the Hall Committee (1991) quoted above, it can be seen from Section II of the Sheffield study that:

Recommendation 1   is not usually carried out and even when the examination is performed, defects are missed.

Recommendation 2   Even when parents actually present this information, it is frequently ignored. In not a single case (according to the parents) was such information requested from the family by the doctors.

Recommendation 3   As can be seen from Section II, many parents repeatedly presented anxieties to doctors, but again were often ignored, reassured, or labelled as a 'worrying mother'.

Recommendation 4   Again we see from Section II of the present study and also from a previous one by the author (Bennett 1981), all grades of staff, from consultant paediatricians to medical students and junior nurses, lacked knowledge of the normal sequence of visual development in babies. Such knowledge belongs to the discipline of psychology rather than medicine and is not usually included in the curriculum followed by general medical or nursing students.

A further factor which must be borne in mind when considering Hall's (1991) recommendations is that, in the Sheffield sample, the category which included the highest number of cases was that of diseases of the retina and

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optic nerve. Such anomalies cannot be detected without detailed fundoscopy, which Hall (1991) considers unnecessary.

A further point at issue is that the Hall report is aimed at an audience of doctors and other staff working in the *community*, yet recommendations 1-4 quoted above are pertinent to those working in a hospital environment over whom Hall and colleagues have no jurisdiction. However, on the assumption that these recommendations are carried out - which, as we have seen they seldom are - the Hall Committee goes on to recommend that:

> "... screening for visual defects in pre-school children should be confined to history and observation. Children with suspected defects, a significant family history or a neurological disorder should be examined by someone competent to give an opinion.
> We do not think there is conclusive evidence to support a more extensive screening programme for pre-school children. ... Staff who wish to carry out screening examinations for squint and other visual defects in pre-school children must first receive adequate instruction from an orthoptist".

Sheffield Health Authority has decided to implement the recommendations of the Hall Committee and abandon the routine vision screening of pre-school children by health visitors. Instead, a part time community based orthoptist will be employed and it is envisaged that she will be able to screen the whole population of children under five in the city. No research has been carried out to ascertain how well this system works in other areas. In fact, Liverpool employ five full time community orthoptists who manage to screen only 50% of Liverpool's 5,000 children born each year. (Sheffield has an annual birth rate of around 7,500 per year).

It is also important that those who plan future services bear in mind that since Local Authority and Health Authority clinics have ceased to exist, and the GP is solely responsible for child health, the health visitor now constitutes the only pathway to a 'second opinion'. It is a sobering thought that the health authority clinics referred as many of the Sheffield children to an ophthalmologist as did the GPs, and furthermore, that at least two of the children probably owe their lives to the 'clinic doctor'.

Having read thus far, it is my hope that the reader will understand (if not condone) my reluctance to conclude the study with a precise set of 'recommendations' to put right all the 'wrongs' which have been done to the families in the study. However, by this, I do not mean to imply that I have serenely accepted the situation because it cannot be changed, but rather, through an illuminative methodology that I have been able to unsettle established ways of thinking and thus may have challenged (or provoked) readers into devising their own solutions to some of the problems.

The study is concluded therefore, not with a list of recommendations, but with a few ideas and some solutions which have been tried in other areas. I begin with the birth of the handicapped child and the impact of this event upon family life.

The Telling of Bad News - An Assault on Normality

It is well documented that the telling of parents that their child is handicapped must be done with great sensitivity and skill (Cunningham and Davis [1985], Lonsdale [1979] and Kew [1975]), and this is reinforced by comments from the Sheffield study. Lonsdale (1979) found that links could be made between the way parents had been handled at this stage and the attitudes they were subsequently to adopt towards their children and their handicaps. Lonsdale (1979) notes that, "The message which came out very clearly was that the telling should be done with honesty as early as possible, with both parents together and with plenty of time available for talking about it". Lonsdale goes on to quote a passage from a leader in a British Medical Journal - unfortunately she does not give the date or the issue number, but quotes as follows:

> "'Telling the mother and the father is a horrid task, and however sympathetically done there is a feeling of incompetence. The essential motivation of medicine is to relieve suffering and here is a denial of that possibility. The response of all is usually to withdraw and not communicate, the well known phenomena of rejection. Often the persons most affected emotionally are unwittingly ignored'".

Implicit in this quotation, as Lonsdale points out, is the need for additional expertise: no one person can have all the skills and knowledge necessary. I have argued elsewhere that the ophthalmologist is a craftsman, and he would surely be a superhuman one if he were also to have the combined skills of counsellor, psychologist, psychiatrist and social worker as well. Lonsdale's research indicated very clearly that the actual 'telling' of parents needed to be improved upon. There was, she argues, "much to suggest that a multi-disciplinary approach might be required".

In telling parents that their child is handicapped, Lonsdale argues that the crisis situation is, "Predictable and its onset controllable. Even if they have some anxieties, parents are not strictly 'in crisis' until they are given this information". However, as she continues, the content of the information is of such enormous significance that they are likely to be thrown into immediate crisis once they are told. Ideally therefore the telling of parents should be carefully planned so that the event is as soon after the diagnosis is known to the doctors as is reasonable, but at a time when both parents can be together. Those concerned should also be able to give as much time as is needed in the situation.

Because parents retain very little of what is initially said to them, Lonsdale found that it was important for the social worker to be present at the interview so that she could hear exactly what information was given and gradually, over time help the parents to absorb this. She argues also that the presence of the social worker at this key interview is of even greater importance, in that it enables work with the parents to be begun, "at the time of their maximum disequilibrium, when they seemed most in need of help and more amenable to influence". Lonsdale was able to show by her research that,

> "a short period of work timed appropriately was infinitely more effective than those situations in which parents were not seen by the team at the crisis point and were subsequently in need of much more time".

The idea of specialist workers combining their knowledge and skills to help handicapped children and their families is not new. The approach was in fact recommended by Vernon (1972), Court (1976) and Warnock (1978). Neither is the idea that parents of handicapped children should be given as much information as is available, as soon as possible after diagnosis, and that this information should be imparted in an honest and sensitive manner. The idea of combining the 'telling' with the teamwork approach is however more unusual.

The team brought together for Lonsdale's study (of 12 months duration) was deliberately kept small, and usually consisted of the paediatric consultant, the social worker and one junior doctor. Sometimes, if prolonged hospitalisation was necessary, the ward sister joined the team as well. The aim was to see the parents as a team and for the consultant to give the medical information, with perhaps a few comments from the junior doctor. The doctors would then leave the parents with the social worker who allowed them to grieve in a protective environment and shared their sadness with them. Lonsdale (1979) writes:

> "It was very much a time of being on hand, being readily available and giving fairly basic tea and sympathy. Some twelve to twenty-four hours later it was anticipated that the parents would be ready for a longer interview in which there would be much more discussion of the implications of the condition, ... As a team we tried to liaise closely and if there was any further important information to be given the consultant would try to do it when I was with him.
> It took some time for the referral procedure to get established and for the consultants and registrars to move to a new pattern of working, which was to call the social worker in at the very beginning and in *every* situation, not just those where parents appeared to be incapacitated by the information and where the social worker was needed to try to help pick up the pieces. It was very much an experiment of giving social work help intensively at the moment of crisis, and when movement forward and continuing progress was seen to be made, the social worker would withdraw".

Lonsdale was able to show from the review of her work that the approach was highly effective as against a group of parents who did not have such input.

The social work input however was intense during the period of the study, and apart from taking 3 weeks holiday during the 12 month period, Lonsdale was 'on call' at all times. This would, as she points out, have implications for hospital social work departments, in that it would mean moving towards rota coverage rather than the usual office hours availability.

Whether Lonsdale's model could work in the long term is however doubtful because of the high degree of commitment required on the part of the social worker. It is probably even less likely to work in the majority of Ophthalmic departments because as Jacobs (1979) noted, ophthalmologists as a group refer on average only 1 in 200 patients to social workers and hardly any of these are children and their families. There is no reason however why the team could not be 'modified' to suit the specific needs of various departments and situations. Does the counsellor for example have to be a hospital social worker? Many nurses (suitably experienced and qualified) undertake counselling as do many community paediatricians. Quite often counsellors seem to 'emerge' from the most unlikely situations. For example, at one hospital, the person who undertook most of the bereavement counselling was, until her retirement, a mortician. Apart from the doctors, is it necessary for the other team members to be hospital based? Could community social workers not equally well fill the role - as 'inreach' rather than outreach workers? I would argue that the discipline of team members is not particularly important. What is important is that there is a gaping void waiting to be filled by someone willing to commit themselves to this kind of approach.

Who Helps the Family?

<u>The Specialist Teacher</u>

Although 70% of the children and their families had at some time had help from a specialist teacher for the visually impaired, the remaining 30% (mainly children with useful vision) had received no such input. On the whole, the families were highly satisfied with the service they received from the teachers. See Chapter 4 for satisfaction ratings for community services.

The Family Health Visitor

All families with young children should receive visits from the health visitor. Four of the families however insisted that they had never been visited at all. Be that as it may, although most of the mothers said they quite liked their health visitor as a person (this in spite of the fact that some families had received visits from as many as eight different Health Visitors) they were unsatisfied with the service she had to offer. Another frequent complaint was that she did not visit handicapped children and that she had no specialist knowledge of visual handicap and was therefore unable to help them with their problems. These same criticisms were also voiced by parents to the RNIB survey team (Walker et al, 1992). Walker and colleagues also confirmed the finding of the Sheffield survey, that health visitors visit families with blind children less frequently than 'normal' families. In the RNIB sample, "Only one-fifth of all the children who had ever been seen by a health visitor had received such a visit in the past six months, and 63% had not been seen for over a year". The RNIB team felt that, "Perhaps what is indicated is a need for an advocate or adviser, drawn from the specialist teacher or the health visitory services". Their findings, as they write, "clearly suggest the need for improved communication of information from the various social, health and education professionals to parents of children with disabilities".

The Social Worker

Fifty percent of the Sheffield families had at some time had social work input, nine of these being community based and 14 hospital based. A further two families had been helped by out of city agencies (The Malcolm Sargent fund for Children with Cancer). On the whole (apart from those receiving help from the Malcolm Sargent Fund), the families did not find the services of the social worker helpful. Because most families had had only one contact with the social worker, they were unable to say whether

they liked the person or not. In 1988 the Social Services Inspectorate examined the organisation of services for the blind and partially sighted (DHSS 1988).

> "Considering the long history of welfare services to blind people, Inspectors expected to find services underpinned by consistent and well-defined policy and practice. However, they found systems that provided services to people with visual handicap based on a variety of custom and practice".

They also found that visual handicap had been largely overlooked in relation to policy and practice issues and that the services failed to fit within the general system. Among the themes which came across most strongly to the SSI team were:

> "- that practice, skill, knowledge and theory have not been integrated sufficiently to provide an acknowledged framework for practice at all levels in social service departments ...
>
> - services specifically required by visually handicapped people were not included in the principle range of services which most social services departments inspected saw themselves as providing. The services were hived off into a separate part of the department's work, and were seen as a distinct entity. As such they were deprived of adequate support and proper communication and, in turn they were not supporting or communicating with other parts of the department".

Considering the findings of the SSI (1988) it seems hardly surprising that the families were dissatisfied with the service they received from social service departments.

Sainsbury and colleagues (1982) were also

> "concerned to explore the organisational and administrative influences upon clients' and social-workers' perceptions of field social-work practice. This was based on two propositions: first, that clients evaluate social work help partly by their expectations and perceptions of the agency from which the worker comes, and not simply by their direct experience of the worker's activities; and second, that social workers act not only in response to clients' needs and feelings, but in ways which reflect processes of socialisation within their agencies".

The clients taking part in the study by Sainsbury et al (1982) were asked about:

> "the relative importance they ascribed, in their relationships with social workers, to friendship (and related emotional support) and to more practical forms of help; and about the frequency with which they needed to seek advice. In all three services (FSU, local authority and probation) friendliness was regarded by clients as the primary 'good': in probation, no clients expressed preference for practical help; and similarly, practical help was preferred by only 10 per cent of local-authority clients and 20 per cent of FSU clients".

There is here a major discrepancy between the Sheffield sample group and that of Sainsbury et al (1988). The blind sample, as can be seen from earlier chapters wanted practical help and information rather than friendship. This may be partly explained by the fact that satisfaction with a service is linked to having one's expectations of it achieved. The blind sample families expected that the social worker would give them information regarding the handicap and how to deal with the associated problems, how to obtain benefits and how to obtain aids and appliances. It seems that none of these expectations were fulfilled. A second reason could be that the blind sample were 'normal' families who had lost status because of having a handicapped child. Their need for knowledge – and hence power – to regain their former status was paramount and while friendliness and emotional support were an added bonus, the need for knowledge took precedence.

It was found, (see introductory chapter) that satisfaction levels were highest where families had had:

An on-going relationship – with the same named person – who was an expert in the field.

All three factors need, it seems to be present, otherwise satisfaction levels remain low.

Some readers may consider that the team approach mentioned previously in regard to the work of Lonsdale (1979) and an on-going relationship with one expert would be a contradiction in terms and therefore incompatible. This

problem could be easily overcome by each family having a 'key worker' as their named expert but with the added support of other team members where appropriate should the need arise. Ideally also in such a situation, the client would have some choice as to the key worker so that, hopefully, each family would receive emotional support from a person with whom they could have a friendly rapport as well as a 'working relationship'.

Developing A Therapeutic Programme

Many large cities now have multidisciplinary teams to help visually handicapped children and their families. No two teams are, it seems, alike, each having a different philosophy and being geared towards different client groups according to the persuasion of the 'key members'. Many deal mainly with multiply handicapped children, others work only with children under five, while yet others are geared towards school age children. Teams are 'led' by many different professionals, for example, orthoptists, paediatricians, specialist teachers and educational psychologists. (None, it seems, are 'headed' by an ophthalmologist).

One of the pioneer teams (established in 1973) is based at the Wolfson Unit in London. Team members include a paediatrician, psychologist, specialist health visitor and an optometrist. The Wolfson Unit team has produced an illustrated booklet, "for parents of babies with severely impaired sight and their professional advisors" (Sonksen, 1991). The guide (illustrated by the specialist health visitor) outlines a development programme for infants and young children to enable them to make use of residual vision, improve this where possible and compensate by using other senses where improvement is not possible.

Sonksen et al (1991) found that such programmes of intervention produced marked improvements in the developmental scores of these children as against those not taking part in such a programme. Intervention programmes used with older children have enabled some of them to utilise their residual vision sufficiently to convert from braille to print.

If the early intervention of a social worker previously outlined (Lonsdale, 1979) were to be added to a developmental programme such as that of Sonksen (1991) the benefits both to the child and the family could be enormous.

Fresh Fields of Research

Multi disciplinary teams could also be fertile breeding grounds for all kinds of research and much valuable work has been contributed by the Wolfson Unit team. It would be interesting to compare such research with studies into the development of seeing children. For example, it was noted in Section II that very little is known about the 'choreography' of the 'pas de deux' of mother and infant (see Stern, 1977) and virtually nothing about the ways in which the blind infant 'dances' with his mother. This area of study might be of particular interest to team members from a psychological discipline.

It would also be interesting to test out the application of the Minisculpt technique in other fields: for example family therapy, marriage guidance and child guidance.

Before abandoning the screening of pre-school children for vision defects, it would be interesting to have a detailed evaluation of the results of a controlled, comprehensive programme carried out by workers specially trained for the project. The development of a teaching and updating package for those who are involved with infants and young children would also be useful in this context.

The early identification of severe visual impairment is of vital importance, not only to the child but to his family. As can be seen from both the national (RNIB) sample and the Sheffield study group, there were often long delays between noticing the defect and the actual diagnosis. Research is needed to ascertain why this is the case and how the situation might be alleviated. Does the answer lie for example in more efficient screening of the infant and young child, the surveillance of 'at risk' groups, in the educating of parents and professionals as to the normal sequence and time scale of visual awareness, in a combination of these, or in some other factor/s?

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Because they had so little professional intervention of any kind, the Sheffield sample form a ready made 'control group' for a study on the effectiveness of individually planned programmes of intervention using a team approach.

Issues Surrounding Education

It would be presumptuous even to begin to make 'recommendations' in the field of education because, as a community nurse, I am a complete 'outsider'. It is usual, however, for "the spectator to see more of the game than the players". Bearing this in mind it is perhaps pertinent to draw the reader's attention to a few points concerning the 'state of play' as it was observed during the research project.

One question which needs to be asked is: "Is the Education Act (1981) working?" There is some evidence (see for example the Audit Commission HMI Department of Education and Science document [1992]) to show that its implementation has been patchy and that each LEA interprets the act differently leading to confusion among both parents and professionals.

A second question which needs to be asked is: "Is integration working for children with severe impairment of vision?" As can be seen from the educational careers of the children presented in Chapter 12, the children in the Sheffield sample who attended special schools experienced rather fewer problems than those integrated into mainstream schools.

At a recent conference in Liverpool, delegates were shown a video of a blind child fully integrated into a normal school. The child had at his disposal the full time assistance of two child care assistants, one who prepared the material for his lessons and the other to guide him through the curriculum, and the help of a visiting specialist teacher to help the CCAs. "Is this integration in the true sense of the word? and what is the cost of this form of integration?" I leave it to the reader to ponder these issues.

Before leaving the subject, one further observation is called to mind. It seemed that some integrated children, in making full use of modern

technology (reading machines, computers etc..), were not actually being taught to read and write for themselves. As pointed out elsewhere, having a document read out loud by a reading machine hardly constitutes literacy. It would seem therefore that some children are back in the same position as those attending the Liverpool School for the blind in the early 19th century, where the object of teaching them to read for themselves was, "the amount of time expended in having various books and newspapers read to the pupils" (see Chapter 14, page 278).

In the field of education as in that of child development, there is wide scope for new research along the lines of the studies carried out by Thomas Rhodes Armitage in the 19th century - research for the blind, by the blind (or at least including them) and about the blind. Even with the advent of the Education Act (1981) parents are seldom consulted as partners in the full sense of the word and children, the true clients of special education, are rarely if ever asked for their opinions. They are for educationalists as for the medical profession often looked upon as 'material for teaching and research'.

The Healing Touch

In Section IV the ways in which doctors' careers developed were discussed. Allen (1988) noted that an increasing number of doctors deeply regret their decision to become doctors in the first place, their disillusionment being heightened by the fact that once the choice has been made, there is no way out of medicine.

Doctors' careers are, it seems, more often than not shaped by others (sometimes 'star performers'), and patronage is still the rule rather than the exception.

When discussing the doctor's personality and the 'clinical mentality' (page 307) it was noted that applicants for medical schools tended to have an 'authoritarian personality', that is, they tended to identify with the existing social order, to be resistant to change and to resent any threat to the status quo. Allen (1988) found these traits still manifest in student groups of the 1980s.

Many students choose medicine as a career because they are good at science subjects. Most scientists tend to be 'convergers' (see Hudson, 1966) in that they prefer exactness, are intolerant of ambiguity and avoid the expression of emotion. This kind of 'clinical mentality' is, it seems, most manifest in surgeons and doctors concerned with the 'craft' of healing rather than the 'art'. The skills of the craftsman are directed towards the repair and restoration of a faulty part of the body. When this intervention fails, the surgeon is rendered powerless as he is ill equipped to play the 'supporting role' which is then required.

As has been pointed out, doctors are channelled into their careers at an early stage and once on the road it seems there is no turning back even if they feel a mistake has been made. Relatively few women make a career of ophthalmology and those who do tend to stay in the less glamorous specialities such as diseases of the retina (mainly incurable).

As we have seen, in the cases of the Sheffield children, treatment had either failed or was not available. The question is therefore implied, "Is the ophthalmologist necessarily the most appropriate person to turn to when a person is incurably blind?" and, "Is medicine the only profession able to help or treat the client?" As has been pointed out, the combining of professionals and resources into multidisciplinary teams such as the one at the London Wolfson Unit can help to alleviate the problems of both professionals and those who are incurably blind or have severe impairment of their vision. The ophthalmologist would then have the resources of the team at his disposal and the team would have an expert to whom they could refer clients as the need arose.

Some Vision Impairment Teams, for example the London Wolfson Unit team, have an optometrist as a member who works in conjunction with the paediatrician and other professionals to ensure that the child has suitable aids to vision including spectacles and low vision aids (LVAs). LVAs are, in the main, available only through the consultant ophthalmologist, but, as with spectacles, needs vary considerably and again, like choosing glasses, the client needs plenty of time in a non clinical atmosphere to decide what best suits her needs. Most LVA clinics however are held on hospital premises and clients are referred only through the

ophthalmologist. If the optician was a member of the vision impairment team, s/he could conduct sessions on other premises, perhaps in school where the child could actually try out different aids in the classroom situation.

Before leaving the subject of aids to vision, I should like to point out that for several centuries following their invention, spectacles were shunned by the medical profession and even considered dangerous. The practice of spectacle making was left to vendors and shopkeepers. Only in the 20th century have doctors concerned themselves with glasses and other aids to vision. It is also noteworthy that, particularly during the Georgian and Victorian eras, spectacles were highly prized as objects of great value costing considerable amounts of money. Frames and cases were fashioned from ivory, tortoishell, precious metals and enamel. Aids to vision were in fact openly flaunted at social gatherings and valued as highly as jewellery. Here I return the reader's attention to the 'golden gauntlet' of Jacques Monestier the sculptor (page 434). As Monestier pointed out, "You cannot restore a lost limb, but you can give people back their power and their pride".

Why should children (or adults) who need LVAs not have these 'designer made' with frames and cases of their own choosing - be these jewel encrusted enamel or with a pop up Mickey Mouse? Most of the children in the survey used their LVAs as infrequently as possible because of the stigma attached to them. This is not surprising in view of the ugly clinical presentation of such aids. A great deal of money is also wasted on aids which are never used and this benefits no one apart from the manufacturer. It seems in fact that money would be well spent in developing a product which the client would want to use and conducting research along the lines of studies by Thomas Rhodes Armitage in the 19th century which included clients in the work would be beneficial to all concerned.

At the Interface

The Outpatient Department can be considered as the interface between the clinical world of the hospital and the everyday world outside. As we have

seen it is often at this interface that the drama of impact takes place and the passage to a new identity begins.

The Welsh Hospital Board Working Party (1972) revealed that, "1 patient in 5 in departments of ophthalmology is a child (para. 18.37), and as has been previously noted, many, perhaps the majority of children are patients in adult general hospitals rather than special paediatric units. It has also been noted that facilities in outpatient departments are not usually geared towards children and specially trained staff are rarely available. We have also seen that ophthalmologists refer very few patients (about 1 in 200) to social work staff and that those who are referred are seldom families with children. None of the Sheffield families had received any kind of counselling help at the point of impact and relatively few had benefited from such a service at any time thereafter.

Since the advent of the Patients' Charter there have been several surveys and studies of outpatient departments. These have on the whole however been mainly concerned with tackling administrative problems and reducing waiting times. One such study was carried out at the Royal Hallamshire Hospital in Sheffield (Hankinson, 1991). A computer simulation was carried out which showed that waiting times could be reduced by up to 50%. An NHS Management Executive document (1992) presents several ideas for giving a better service to patients such as pre consultation test sessions and a more even spread of appointments when most doctors were available.

Many consultants now set aside time for special kinds of clinics, for example retinopathy clinics, where patients can be given longer appointment times and special equipment is available. It might perhaps be worth exploring the idea of special children's clinics along the same lines. Were the ophthalmologist to be a member of a vision impairment team other ideas could also be examined such as an 'inreach' counsellor from the community or a hospital based team member being present at the impact interview and possibly continuing the association with the family as key worker. This could save the consultant time during the interview and in addition, any liaison work, for example with regard to registering the client blind or partially sighted could be carried out during the same clinic session.

There are yet other benefits to those who combine their knowledge and resources in teams. Because there are so few workers in the field of blindness and severe visual impairment, many of them are very isolated. Whilst most enjoy the autonomy, working alone can be very stressful over the long term.

Thus many problems could be solved by the pooling of knowledge and resources of different agencies by the formation of community based on hospital 'Vision Impairment Teams', with workers from education, social services and health authorities joining forces rather than remaining in their own 'ivory towers'. The ivory towers need not be dismantled, but at least they need windows so that other professionals can see what is happening within them and not waste time duplicating work which is already being carried out while missing other areas completely.

Being Allowed Time to Think and Use Knowledge

> "... from my reading of history, the thing you have to have to use knowledge is leisure. Where *everybody* has to work hard just to get a living there is no leisure to think, knowledge stagnates, and people with it. The thinking has to be done largely by people who are not directly productive - by people who appear to be living almost entirely on the work of others, but are, in fact, a long-term investment. Learning grew up in the cities and in great institutions - it was the labour of the countryside that supported them".
>
> John Wyndham, 'The Day of the Triffids' (1951)

In the high speed worlds of medicine, nursing, education and social work it is difficult for managers to justify 'thinking time' for field level grades of staff. And yet, these are the people who are closest to the clients and who can best ascertain their needs and respond to them. As a rule, nurses and other caring professionals who think and write are not highly regarded by their more practically minded colleagues, they are nonetheless, as Wyndham writes a "long-term investment".

Da capo al fine

I now ask that the reader return to the beginning of the work, 'ponder anew' the issues raised, and each in his own way explore new ways to:

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Protect, Uphold, Restore and finally Release (PURR) those in their care who have been hurt or wounded.   Thus:

"With the drawing of this Love and the voice of this Calling

We shall not cease from exploration
And the end of all our exploring
Will be to arrive where we started
And know the place for the first time.
Through the unknown, remembered gate
When the last of earth left to discover
Is that which was the beginning;
At the source of the longest river
The voice of the hidden waterfall
And the children in the apple tree ...
                    T S Eliot, 'Four Quartets', Little Gidding V

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SHEFFIELD HEALTH AUTHORITY/SHEFFIELD CITY POLYTECHNIC: RESEARCH PROJECT

VISUALLY HANDICAPPED CHILDREN AND THEIR FAMILIES.

INTERVIEW SCHEDULE: HEAD SHEET

VISUALLY HANDICAPPED CHILDREN AND THEIR FAMILIES

SECTION I. MEDICAL AND SOCIAL HISTORY

Interview Number [ ]

Date of Interview [ ]

Surname [ ]

Christian Names [ ]   DOB   Place of Birth   Sex

Address:

1

2

3

Diagnosis: 1. Visual Defects [ ]

Diagnosis: 2. Other Defects [ ]

Degree of Visual Handicap [ ]

Family Doctor Name and Address [ ]

Referral Source [ ]

Interview Time (in Minutes) [ ]

No. 2

<u>PREGNANCIES IN BIRTH ORDER.</u>   (Including misscarriages, still births, terminations etc.)

	DOB	Sex M F DK	Delivery N Fps CS Oth N/A	Maturity FT 39-36 35-32 31-28 <28	Alive Dead	* See Below
		1 2 3	1 2 3 4 5	1 2 3 4 5	1 2	
		1 2 3	1 2 3 4 5	1 2 3 4 5	1 2	
		1 2 3	1 2 3 4 5	1 2 3 4 5	1 2	
		1 2 3	1 2 3 4 5	1 2 3 4 5	1 2	
		1 2 3	1 2 3 4 5	1 2 3 4 5	1 2	
		1 2 3	1 2 3 4 5	1 2 3 4 5	1 2	
		1 2 3	1 2 3 4 5	1 2 3 4 5	1 2	
		1 2 3	1 2 3 4 5	1 2 3 4 5	1 2	

and Details where * Marked

(Page 2.)

No. 1

P COMPOSITION

Relationship to Child	Sex M F	Age	Marital Status S M W D/S Oth.	Activity Status FT PT ST U HW Ret Oth	Occupation	Handicap None Vis. Oth.
	1 2		1 2 3 4 5	1 2 3 4 5 6 7		1 2 3
	1 2		1 2 3 4 5	1 2 3 4 5 6 7		1 2 3
	1 2		1 2 3 4 5	1 2 3 4 5 6 7		1 2 3
	1 2		1 2 3 4 5	1 2 3 4 5 6 7		1 2 3
	1 2		1 2 3 4 5	1 2 3 4 5 6 7		1 2 3
	1 2		1 2 3 4 5	1 2 3 4 5 6 7		1 2 3
	1 2		1 2 3 4 5	1 2 3 4 5 6 7		1 2 3
	1 2		1 2 3 4 5	1 2 3 4 5 6 7		1 2 3

and Details where "Other" marked

(9) Age of Child

Ques. No. 7

	Code
Under 3 years	1
3 but less than 5 years	2
5 but less than 7 years	3
7 but less than 12 years	4
12 but less than 17 years	5
Other ___	6

(10) Place of Birth

Ques. No. 8

	Code
JHH	1
NGH	2
NEH	3
Home	4
OOC Hospital	5
Other ___	6

(11) Birth Weight

Ques. No. 9

Actual Weight ___

	Code
Under 1000G	1
Over 1000G to 1500G	2
Over 1500G to 2000G	3
Over 2000G to 2500G	4
Over 2500G to 3500G	5
Over 3500G to 4500G	6
Over 4500G	7
Don't Know/Not Applicable	8

(12) Degree of Handicap

Ques. No. 10

	Code	
Total Blindness	1	
Perception of Light	2	
Perception of Light + Colour or Form	3	Braille
Defect of Central Vision	4	
Progressive Defect	5	
Severe Field Defect	6	Print
Useful Vision with Aids	7	
Other	8	
Don't Know / Not Applicable	9	

(13) Prognosis - Visual

Ques. No. 11

	Code
Very Poor - Total Blindness/Death	1
Poor - Condition Progressive	2
Fair - Condition probably remaining Stable	3
Good - Condition may improve with treatment	4
Unknown	5
N/A	6

Col/Code

Housing

Ques. No. 3

	(3)
Owner/Occupier	1
Tenant: Council	2
" Private Landlord	3
Tied/Rent Free	4
Other ___	5
N/A	6

Ethnic Group

Ques. No. 4

	(4)
Caucasian	1
Asian	2
Negro	3
Oriental	4
Mixed	5
Other ___	6

Mother's Marital History

Ques. No. 5

	(5)	
Single - Never Married	1	Single Parent Family
Widowed	2	
Divorced/separated	3	
Married/Cohabiting with Child's Father	4	
" Other than Child's Father	5	
Other - eg. Single Father ___	6	
Don't Know/Not Asked	7	
N/A	8	

Mobility Pattern

Ques. No. 6A

Have you lived at this address since N was born?

	(6)
Yes	1
No	2
N/A	3

Ques. No. 6B

If No, How many times have you moved since N was born?

	(7)
Once	1
Twice	2
Three Times	3
Four Times	4
Five or more times (Actual Number ___)	5
N/A	6

Ques. No. 6C

If applicable - Were all these addresses in Sheffield?

	(8)
Same Neighbourhood	1
Same City	2
Same County	3
Out of Area	4
Other - eg. Some in, some out ___	5
N/A	6

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12. Prognosis - Mental/Physical (13)

- Very Poor - Complete or Severe Mental/Physical Colapse — 1
- Poor - Mental/physical deterioration in later life — 2
- Fair - Condition probably remaining stable — 3
- Good - May improve with treatment — 4
- Un-known — 5
- N/A — 6

13. Registers (14-20)

	Yes	No	D/K	N/A
	1	2	3	4
A Blind	1	2	3	4
B Partial Sight	1	2	3	4
C Handicap/Observation	1	2	3	4
D High Risk (SID) Factor	1	2	3	4
E Green Star	1	2	3	4
F Central	1	2	3	4
G Other	1	2	3	4

14. Parentage - Both Natural Parents? (21)

- Both Natural Parents — 1
- Natural Mother Only — 2
- Natural Father Only — 3
- Both Foster/Adoptive parents - related to child — 4
- " " - Not related to child — 5
- Other — 6
- N/A — 7

15. Parents Related? (22)

- Not related — 1
- First cousins — 2
- Other relationship — 3
- N/A — 4

16. Family History of Visual Defect? (23)

Yes	No	D/K	N/A
1	2	3	4

Details:

17. Defect (24)

Details:

18. Inheritance Pattern (If known) (25)

- Autosomal Dominant — 1
- Autosomal Recessive — 2
- X Linked — 3
- Chromosomal — 4
- Other — 5
- Unknown — 6
- N/A — 7

(Page 5)

(Page 6)

19. Details Of Affected Persons (26)

20. Family History of Other Major Defect (27)

Yes	No	D/K	N/A
1	2	3	4

Details:

21. Defect (28)

Details:

22. Inheritance Pattern (If known) (29)

- Autosomal Dominant — 1
- Autosomal Recessive — 2
- X Linked — 3
- Chromosomal — 4
- Other — 5
- Unknown — 6
- N/A — 7

23. Details of Affected Persons (30)

24. Pre-Natal Contributing Factors (31-37)

	Yes	No	D/K	N/A
	1	2	3	4
None	1	2	3	4
Rubella in Pregnancy	1	2	3	4
Toxoplasmosis	1	2	3	4
Maternal illness or surgery	1	2	3	4
Threatned miscarriage or bleeding	1	2	3	4
Drugs in pregnancy	1	2	3	4
Other	1	2	3	4

25. Perinatal Contributing Factors (38-47)

	Yes	No	D/K	N/A
	1	2	3	4
None	1	2	3	4
Prolonged or difficult labour	1	2	3	4
Delay in establishment of respiration	1	2	3	4
Convulsions or hyperexitability	1	2	3	4
Cynotic attacks	1	2	3	4
Ventilated or nursed in high concentration oxygen	1	2	3	4
Phototherapy	1	2	3	4
Major congenital abnormality	1	2	3	4
Other	1	2	3	4

(Page 6)

			(61)		(62)
31A	Focusing	Advanced Normal Sighted Normal Blind Delayed Never D/K. N/A	1 2 3 4 5 6	Earlier Same Later Never Don't know N/A	1 2 3 4 5 6
			(63)		(64)
31B	Following	Advanced Normal Sighted Normal Blind Delayed Never D/K. N/A	1 2 3 4 5 6	Earlier Same Later Never Don't know N/A	1 2 3 4 5 6
			(65)		(66)
31C	Smiling	Advanced Normal Sighted Normal Blind Delayed Never D/K. N/A	1 2 3 4 5 6	Earlier Same Later Never Don't Know N/A	1 2 3 4 5 6
			(67)		(68)
31D	Sitting Alone	Advanced Normal Sighted Normal Blind Delayed Never D/K. N/A	1 2 3 4 5 6	Earlier Same Later Never Don't know N/A	1 2 3 4 5 6
			(69)		(70)
31E	Reaching: Vision or Sound cue	Advanced Normal Sighted Normal Blind Delayed Never D/K. N/A	1 2 3 4 5 6	Earlier Same Later Never Don't know N/A	1 2 3 4 5 6

(Page 8)

26 Contributing Factors in Later Childhood

	Yes	No	D/K	N/A
	(48-54)			
None	1	2	3	4
Head Injury	1	2	3	4
Meningitis	1	2	3	4
Drug or Other Poisoning	1	2	3	4
Other	1	2	3	4

27A Parent's Understanding of Handicap

Can you explain to me exactly what is wrong with N?

(55)
Full explanation and complete working knowledge   1
Reasonable working knowledge   2
Incomplete or confused explanation   3
Little or no knowledge   4
Not asked/not applicable   5

27B How did you find out about this? Who was the first person to notice something was wrong? Details:
(56) ☐

27C How old was N at the time?
(57) ☐

28 Genetic Implications Explained?
(58)
Yes   1
No   2
Doctor didn't know or didn't say   3
Yes but explanation unsatisfactory or not understood   4
Can't remember   5
Other   6
N/A   7

29 Genetic Counselling Offered?
(59)
Yes   1
No   2
Yes but didn't accept   3
Awaiting appointment   4
N/A   5

30 Usefulness of Genetic Counselling
(60)
Very Helpful   1
Fairly helpful   2
Not very helpful   3
Unhelpful   4
Don't know   5
Other   6
N/A   7

No.	Dev. Milestone	Age Achieved		Col/Code	Sib. Age Achieved	Col/Code	Comments
	Fine Manipulation	Advanced Normal Sighted Normal Blind Delayed Never D/K. N/A		(71) 1 2 3 4 5 6	Earlier Same Later Never Don't know N/A	(72) 1 2 3 4 5 6	
	Crawling/Early Locomotion	Advanced Normal Sighted Normal Blind Delayed Never D/K. N/A		(73) 1 2 3 4 5 6	Earlier Same Later Never Don't know N/A	(74) 1 2 3 4 5 6	
	Walking Alone	Advanced Normal Sighted Normal Blind Delayed Never D/K. N/A		(75) 1 2 3 4 5 6	Earlier Same Later Never Don't know N/A	(76) 1 2 3 4 5 6	
	Acquisition of Language	Advanced Normal Sighted Normal Blind Delayed Never D/K. N/A		(77) 1 2 3 4 5 6	Earlier Same Later Never Don't know N/A	(78) 1 2 3 4 5 6	

Comments on Development

(79)   (80)   End of Card 3

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MEDICAL SUPERVISION

Interview No. [ ]

Page 10 — Card No. 4

Ques. No.		Col/Code

32A — Ophthalmologist _____ (3) [ ]

32B — Hospital Attended
- RVEH
- SCH
- Rygate
- Other _____
- N/A

(4)
1
2
3
4
5

32C — Frequency of Visits Now
- Monthly or more often — 1
- 4 to 11 times per year — 2
- 2 to 3 times per year — 3
- Once per year or less — 4
- Other _____ — 5
- Discharged - Date _____ — 6
- Don't know — 7
- N/A — 8

(5) 1 2 3 4 5 6 7 8

32D — Helpfulness of Consultant
- Very helpful — 1
- Fairly helpful — 2
- Not very helpful — 3
- Unhelpful — 4
- Don't know — 5
- N/A — 6

(6) 1 2 3 4 5 6

33A — Paediatrician _____

(7) [ ]

33B — Hospital
- RVEH
- SCH
- Rygate
- Other _____
- N/A

(8) 1 2 3 4

33C — Frequency of Visits Now
- Monthly or more often — 1
- 4 to 11 times per year — 2
- 2 to 3 times per year — 3
- Once per year or less — 4
- Other _____ — 5
- Discharged - Date _____ — 6
- N/A — 7

(9) 1 2 3 4 5 6 7

(Page 10)

Page 11

33D — Helpfulness of consultant
- Very helpful — 1
- Fairly helpful — 2
- Not very helpful — 3
- Unhelpful — 4
- Don't know — 5
- N/A — 6

(10) 1 2 3 4 5 6

34 — Other Specialist Involvement
Details:

(11) [ ]

35 — Out-Patient Attendance
Do/did you have any particular problems when attending OPD?
Prompt re: Transport, cost, care of siblings, waiting time.
Details:

(12) [ ]

36 — Admission to Hospital
Did you have any problems when N was admitted to hospital?
Prompt: Being on an adult ward, visiting or staying with him.
Details:

(13) [ ]

37A — Treatment Prescribed
- Drops or ointment — 1
- Spectacles — 2
- Contact lenses — 3
- Shell or artificial eyes — 4
- Occlusion — 5
- Other — 6
- Combination of 2 or more _____ — 7
- None or N/A — 8

(14) 1 2 3 4 5 6 7 8

37B — Instruction in Method
- Demonstration with supervised practice — 1
- Demonstration only — 2
- Written/verbal explanation — 3
- Watched the nurses — 4
- Other _____ — 5
- None — 6
- N/A — 7

(15) 1 2 3 4 5 6 7

37C — Confidence in Carrying out Treatment (A when first given B now)
- Completely Confident — 1
- Fairly Confident — 2
- Not confident — 3
- Failed to carry out procedure — 4
- Home nurse carried out treatment — 5
- Other _____ — 6
- N/A — 7

(16) A 1 2 3 4 5 6 7

(Page 11)

Page 12

38 Help Required

Some people say they would have liked more help at the beginning - do you feel this?

(17) ☐

Details: _____

39A SUPERVISION BY GP - Amount of Support from GP (General)

(18)

Very helpful and supportive	1
Fairly helpful and supportive	2
Not very helpful	3
Unhelpful	4
Other	5
Don't know	6
N/A	7

39B Specific Advice or Help from GP (Regarding Handicap)

(19) ☐

Details: _____

39C Helpfulness of Advice

(20)

Very helpful	1
Fairly helpful	2
Not very helpful	3
Unhelpful	4
Other	5
Don't know	6
N/A	7

40A PARA-MEDICAL SUPERVISION - Other Clinics Attended

(21)

Orthoptic	1
Audiology	2
Speech therapy	3
Physiotherapy	4
Other	5
Combination of 2 or more	6
None	7
N/A	8

40B Helpfulness of Treatment

(22)

Very helpful	1
Fairly helpful	2
Not very helpful	3
Unhelpful	4
Other	5
Don't know	6
N/A	7

41A COMMUNITY HEALTH SUPERVISION

(23) ☐

Clinic Attended

(Page 12)

Page 13

41B Frequency of Attending

How often did you attend, (when K was small)?

(24)

Monthly or more often	1
2 to 6 times per year	2
Yearly or less often	3
Only when sent for	4
Other	5
Don't know	6
N/A	7

41C Reasons for Attending (According to Mother)

(25) ☐

Details: _____

41D Specific Advice or Help from CMO (Regarding Handicap)

(26) ☐

Details: _____

41E Helpfulness of Advice

(27)

Very helpful	1
Fairly helpful	2
Not very helpful	3
Unhelpful	4
Other	5
Don't know	6
N/A	7

41F Specific Advice from Clinic Health Visitor (Re Handicap)

(28) ☐

Details: _____

41G Helpfulness of Advice

(29)

Very helpful	1
Fairly helpful	2
Not very helpful	3
Unhelpful	4
Other	5
Don't know	6
N/A	7

42A HEALTH VISITOR SUPERVISION

(30) ☐

Own health visitor _____

(Page 13)

(Page 14)

43B — Number of Different Health Visitors Since his Birth   (31)

One only	1
Two	2
Three	3
Four	4
Five or more – Number _____	5
None	6
Don't know	7
N/A	8

43C — Approximate Date of Last Visit   (32) [ ]

Date: _____

43D — Frequency of Visits Now   (33)

Weekly or more often	1
Once or twice per month	2
4 to 6 times per year	3
2 to 3 times per year	4
Yearly or less often	5
Other	6
Does not visit	7
Don't know	8
N/A	9

43E — Reasons for Visits – (According to Mother)   (34) [ ]

Details:

43F — Helpfulness of Visits   (35)

Very helpful	1
Fairly helpful	2
Not very helpful	3
Unhelpful	4
Other	5
Don't know	6
N/A	7

43G — Specific Advice or Help from Health Visitor (Re Handicap)   (36) [ ]

Details:

(Page 15)

43H — Helpfulness of Advice   (37)

Very helpful	1
Fairly helpful	2
Not very helpful	3
Unhelpful	4
Other	5
Don't know	6
N/A	7

43I — Referral to Other Agencies   (38) [ ]

Details:

43J — Other Help Given by Health Visitor   (39) [ ]

Details:

44A — SPECIAL ASSESSMENTS   (40)

Rygate	1
Central Clinic	2
Education Authority	3
Other	4
Don't know	5
None	6
N/A	7

44B — Helpfulness of Assessment (To Family)   (41)

Very helpful	1
Fairly helpful	2
Not very helpful	3
Unhelpful	4
Other	5
Don't know	6
N/A	7

45 — PRIVATE TREATMENT   (42) [ ]

Details:

46 — ALTERNATIVE MEDICINE   (43) [ ]

Has N ever had any other kind of treatment outside the NHS? For example, has he ever been to a faith healer?

Details:

VISUALLY HANDICAPPED CHILDREN AND THEIR FAMILIES

SECTION III. DAILY LIVING AND FAMILY LIFE

Card No. 4

Ques. No.		Col/Code
		(44)
47A	**Feeding - Method**	
	When N first came home, did you breast or bottle feed?	
	Breast (fully)	1
	Bottle	2
	Breast and bottle	3
	Other ____	4
	Don't know	5
	N/A	6
47B	**Feeding Difficulties (Later Childhood)**	(45-49)
	Did you have any difficulties regarding his eating habits or table manners at all? (Ask all applicable)	Yes No N/A
	a Teaching him to feed himself	1 2 3
	b Continued use of "baby habits"	1 2 3
	c Finger feeding	1 2 3
	d Touching food/messy table manners	1 2 3
	e Other ____	1 2 3
47C	**Advice on feeding**	(50)
	Has anyone ever given you any special advice on Feeding N? Details:	Yes No N/A 1 2 3
48A	**Toilet Training**	(51) [ ]
	Many blind children are later than average getting Clean and dry. How old was N? Age: ____	
48B	**Norm Comparison**	(52)
	Early (Compared to Illingworth sighted norm)	1
	Normal (Sighted norm)	2
	Delayed	3
	Severe delay	4
	Don't know	5
	Not trained yet	6
	N/A	7
48C	**Comparison with Sighted Siblings**	(53)
	Earlier	1
	Same	2
	Later	3
	Don't know	4
	N/A	5

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52B	**Reasons for Temper Tantrums** What sort of thing caused them? Details:	(62) ☐
52C	**Intervention (Temper Tantrums)** What did you do when he had a temper tantrum? Details:	(63) ☐
53A	**Bed Time and Sleeping Habits** Many handicapped children need extra love and security at bed time, does N have any special comfort habits? Teddy or doll — 1 Dummy or bottle — 2 Musical toy or tape recorder — 3 Security blanket or rag — 4 Stories or songs — 5 Rituals or combination of 2 or more of above — 6 Other — 7 None — 8 N/A — 9	(64)
53B	**Wakefulness or Distress** Does N usually sleep well or is he sometimes wakeful and fretful? Details:	(65) ☐
53C	**Sleeping in Parents Bed** I suppose N/the children come into your bed sometimes (like Christmas) do they? Do they ever sleep in your bed? Details:	(66) ☐
54	**Personal Habits** Almost all blind children develop some annoying habits. Which ones does N have?	(67-75)

Personal Habits

		Yes	No	DK
a	Eye Rubbing	1	2	3
b	Eye poking	1	2	3
c	Head banging	1	2	3
d	Rocking	1	2	3
e	Faulty posture - including head down position	1	2	3
f	Pulling faces	1	2	3
g	Masturbation	1	2	3
h	Other _____	1	2	3
i	None	1	2	3

49A	**Method of Potty Training** Details:	(54) ☐
49B	**Age Potty Training Commenced** Some people think potty training should be started very early and others that it's best to leave it till later. How old was N when you first tried to get him dry? Details:	(55) ☐
49C	**Specific Advice on Potty Training** Details:	(56) ☐
49	**Dressing** Does N have any difficulty dressing himself, eg. finding his clothes, doing up the fastenings and things? Details:	(57) ☐
50A	**Helping at Home** Does N help with the housework; washing up, dusting, running errands and things? Details:	(58) ☐
50B	**Comparison with Siblings** Do the other children help with the housework? Details:	(59) ☐
51	**Stairs and Steps** Does/did N have any difficulty with stairs or steps? Details:	(60) ☐
52A	**Temper Tantrums Frequency** I expect N had temper tantrums, did he? About how often? Details:	(61) ☐

Card No. 5

Ques. No.		Col/Code

55F — Father Participation Rating (3-4)

	N Si
Highly Participant	1 1
Fairly Participant	2 2
Not very participant	3 3
Participant in emergencies only	4 4
Never or hardly ever participant	5 5
Other _____	6 6
N/A	7 7

56 — Effect of Handicap on Siblings (5-11)

Do the other children get jealous of N because of the extra attention he gets? Ask all applicable.

	Oft	Som	Nev	N/A
a Overt jealousy - hitting, verbal abuse, taking toys.	1	2	3	4
b Covert jealousy - biting when Missing, rocking pram.	1	2	3	4
c Regression to baby habits - wetting, soiling, dummy.	1	2	3	4
d Sulking or temper tantrums	1	2	3	4
e Destructiveness	1	2	3	4
f Aggression to toys or pets	1	2	3	4
Other _____	1	2	3	4

57A — Punishment (12)

What kind of things does N get smacked for?

Smacked often for almost anything	1
Sometimes/when necessary (temper tantrums etc.)	2
Rarely (only when very naughty or defiant)	3
In dangerous situations only	4
Never smacks handicapped child	5
Does not believe in smacking at all	6
Don't know (not old enough yet)	7
Other _____	8
N/A	9

57B — Type of Punishment if Does Not Smack (13)

Details: □

58A — Extended Family - Proximity (14-15)

Do Ns grandparents or any other family live nearby?

	G. Pts	Oth
Same dwelling	1	1
Same Neighbourhood	2	2
Same City	3	3
Same County	4	4
Out of area	5	5
Dead	6	6
Other _____	7	7
N/A	8	8

Ques. No.	

55A — Father Participation - General Care (76)

Washing, dressing, putting to bed etc.

Often (Once per week or more frequently)	1
Sometimes	2
In emergency only	3
Never or hardly ever	4
Other _____	5
N/A	6

55B — Personal Care (77)

Changing Nappies or wet or dirty beds etc.

Often (Once per week or whenever necessary)	1
Sometimes	2
In emergency only	3
Never or hardly ever	4
Other _____	5
N/A	6

55C — Supervision (78)

Looking after N whilst you are out, taking him out on his own.

Often (Once per week or more often)	1
Sometimes	2
In emergency only	3
Never or hardly ever	4
Other _____	5
N/A	6

55D — Play and Leisure Activities (79)

Playing with N, reading him stories etc.

Often (Once per week or more often)	1
Sometimes	2
In emergency only	3
Never or hardly ever	4
Other _____	5
N/A	6

55E — Mother's Satisfaction with Father Participation (80)

On the whole, are you fairly happy with the amount of help and support you get from your husband? (regarding N)

Details: □

End of Card No. 4

LEISURE - Holidays and Outings

61A (51) ☐
Are there any problems with holidays or family outings?

Details:

61B Baby-sitting (52) ☐
Do you and your husband **manage** to leave N/the children and go out together sometimes?

Often (Once per week or more frequently)	1
Sometimes	2
Rarely	3
Never or hardly ever	4
N/A	5

61C Reasons (If rarely or never) (53) ☐
Is this mainly because of N, or don't you go out much anyway?

Details:

61D Baby-sitting - Care of Children (54)
Who usually looks after N/the children whilst you are out?

Adult family member	1
Friend or neighbour	2
Paid baby sitter (adult)	3
Older child (family member)	4
Siblings	5
Other child/neighbour listens	6
Left alone	7
Other	8
N/A	9

61E Husband/Wife Separate Outings (55)
Do you and your husband ever go out separately?

Often (Once per week or more frequently)	1
Sometimes	2
Rarely	3
Never or hardly ever	4
N/A	5

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58A Extended Family - Contact

	(16-17) G.Pts	Oth Fam
Often (weekly or more often)	1	1
Fairly often (Once to 3 times per month)	2	2
Not very often (Several times per year)	3	3
Rarely (once per year or less often)	4	4
Other	5	5
N/A	6	6

59A Parental Health
Ask all where possible.

	(18-24) Mother Yes No DK NA	(25-31) Father Yes No DK NA
Weight loss	1 2 3 4	1 2 3 4
Weight gain	1 2 3 4	1 2 3 4
Extra smoking	1 2 3 4	1 2 3 4
Extra drinking	1 2 3 4	1 2 3 4
Psycosomatic disorder (eg. gastric ulcer)	1 2 3 4	1 2 3 4
Other	1 2 3 4	1 2 3 4
None	1 2 3 4	1 2 3 4

59B Parents Mental Health
After having a handicapped child, many parents experience feelings they find hard to cope with. Did you find this? Ask all where possible.

	(32-39) Mother Yes No DK NA	(40-47) Father Yes No DK NA
a Depression	1 2 3 4	1 2 3 4
b Anxiety	1 2 3 4	1 2 3 4
c Resentment	1 2 3 4	1 2 3 4
d Guilt	1 2 3 4	1 2 3 4
e Anger	1 2 3 4	1 2 3 4
f Revulsion	1 2 3 4	1 2 3 4
g Other	1 2 3 4	1 2 3 4
h None	1 2 3 4	1 2 3 4

59C Treatment or Help

(48) Mother ☐	(49) Father ☐

Has anyone ever given you any help with these problems, eg. your GP or a social worker?

Details:

60 Social Attitudes (50)
Has anyone ever been unnecessarily unkind to N because of his handicap?

Adult: Family, friends, neighbours.	1
Adult: Outside neighbourhood	2
Child: Family, friends, neighbours.	3
Child: Outside neighbourhood.	4
Child: School or peer group.	5
Two or more of above categories	6
Other	7
None	8
N/A	9

SECTION 4. EDUCATION, HELP AND GUIDANCE

Card No. 5

Q. No.		Col/Col
52A	**Helping Agencies Involved**	(56)
	Social Worker	
	Area Social Worker	1
	Hospital or Centre Social Worker	2
	Specialist Social Worker	3
	Other _____	4
	Two or more of above	5
	Don't Know	6
	None	7
	N/A	6
62B	Visits Now?	(57) Yes No D/
		1 2 3
	Frequency and Details:	
62C	Helpfulness	(58)
	Very helpful	1
	Fairly helpful	2
	Not very helpful	3
	Unhelpful	4
	Other	5
	N/A	6
63A	Teaching Staff	(59)
	Peripatetic teacher for under 5s	1
	Peripatetic teacher at school	2
	Other _____	3
	Two or more of above	4
	Don't know	5
	None	6
	N/A	7
63B	Visits Now?	(60) Yes No D
		1 2
	Frequency and Details:	
63C	Helpfulness	(61)
	Very helpful	1
	Fairly helpful	2
	Not very helpful	3
	Unhelpful	4
	Other _____	5
	N/A	6

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Q. No.

57   Information For Parents

Did you learn more about H's condition from any of the following sources?

	Yes	no	N/A
a General literature - medical books etc.	1	2	3
b Sheffield Literatur - Dr Powell's book.	1	2	3
c RNIB publications	1	2	3
d Media - magazines and newspapers	1	2	3
e " - Radio or television	1	2	3
f Support services	1	2	3
g Parent workshops	1	2	3
h Parent support groups	1	2	3
i Other _____	1	2	3
j None	1	2	3

68A   Child's Educational Career   (79)

Pre - School Play Group

Yes No D/K
1   2   3

Details:

68B   Normal or Special   (30)

Nor Sp D/K
1   2   3

Details: End of card No 5
                            Interview No. (1-2)

68C   Helpfulness   (3) Card

Very helpful	1
Fairly helpful	2
Not very helpful	3
Unhelpful	4
Other _____	5
N/A	6

69A   Nursery School   (4)

Yes No D/K
1   2   3

Details:

69B   Normal or Special   (5)

Nor Sp D/K
1   2   3

Details:

69C   Day or Board   (6)

Day Pupil	1
Board - Weekdays	2
Full Board	3
Other _____	4
Don't know	5
N/A	6

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54A   Nursing Staff   (62)

Home Nurse	1
Hospital or centre nurse (eg. Rygate)	2
School Nurse	3
Specialist Nurse/Health Visitor	5
Other _____	6
Two or more of above	7
None	8
N/A	9

54B   Visits Now?   (63)

Yes No D/K N/A
1   2   3   4

Frequency and Details:

64C   Helpfulness   (64)

Very helpful	1
Fairly helpful	2
Not very helpful	3
Unhelpful	4
Other _____	5
N/A	6

65A   Voluntary Agencies   (65)

RNIB	1
RSIB	2
Church	3
Parent Group _____	4
Other _____	5
Don't know	6
None	7
N/A	8

65B   Visits Now?   (66)

Yes No D/K N/A
1   2   3   4

Frequency and Details:

65C   Helpfulness   (67)

Very helpful	1
Fairly helpful	2
Not very helpful	3
Unhelpful	4
Other _____	5
N/A	6

66   Own Service   (68)

If you could choose your own kind of service, what would be most useful?

Details:

(Page 24)

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72A Secondary School

Details: _____

72B Day or Board (15)

- Day Pupil ___ 1
- Day Pupil with Resource unit Support ___ 2
- Board - Weekdays ___ 3
- Full Board ___ 4
- Other ___ 5
- N/A ___ 6

72C Helpfulness (16)

- Very helpful ___ 1
- Fairly helpful ___ 2
- Not very helpful ___ 3
- Unhelpful ___ 4
- Other ___ 5
- N/A ___ 6

Nor Sp Unt Oth (17) 1 2 3 4

73A Further Education

Details: _____

73B Day or Board (18)

- Day Student ___ 1
- Day Student with Support ___ 2
- Board- Weekdays ___ 3
- Full Board ___ 4
- Other ___ 5
- N/A ___ 6

73C Helpfulness (19)

- Very Helpful ___ 1
- Fairly Helpful ___ 2
- Not very Helpful ___ 3
- Unhelpful ___ 4
- Other ___ 5
- N/A ___ 6

Nor Sp Unt Oth N (20) 1 2 3 4

74 School to Attend (If not at School)

Details: _____

75 Preferred School (21) [ ]

Is this the school you wanted him to attend?

Details: _____

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69D Helpfulness (7)

- Very helpful ___ 1
- Fairly helpful ___ 2
- Not very helpful ___ 3
- Unhelpful ___ 4
- Other ___ 5
- N/A ___ 6

70A First School (8)

Nor Sp Unt Coh N/A 1 2 3 4 5

Details: _____

70B Day or Board (9)

- Day Pupil ___ 1
- Board Weekdays ___ 2
- Full Board ___ 3
- Other ___ 4
- N/A ___ 5

70C Helpfulness (10)

- Very helpful ___ 1
- Fairly helpful ___ 2
- Not very helpful ___ 3
- Unhelpful ___ 4
- Other ___ 5
- N/A ___ 6

71A Middle School (11)

Nor Sp Unt Oth N/A 1 2 3 4 5

Details: _____

71B Day or Board (12)

- Day Pupil ___ 1
- Board - Weekdays ___ 2
- Full Board ___ 3
- Other ___ 4
- N/A ___ 5

71C Helpfulness (13)

- Very helpful ___ 1
- Fairly helpful ___ 2
- Not very helpful ___ 3
- Unhelpful ___ 4
- Other ___ 5
- N/A ___ 6

Card No. 6

Q. No.		(34)

80

The Future

Thinking about the future, are there any particular problems that worry you?

Details:

81A (35)

Inheritance

If applicable - Does K realise that the condition can be passed on to his children?

Yes	1
No	2
Don't know	3
N/A	4

81B (36)

Intention to Inform

When he is old enough to understand, will you tell K the condition can be passed on?

Yes - Definately	1
Yes- Probably	2
Don't know	3
Leave it to someone else	4
No	5
Other _____	6
N/A	7

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82 (37)

Ideas and Suggestions for other Parents

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83 (38)

Comments regarding Interview etc.

76

Problems With School

		(22-29)		
		Yes	No	N/A
a	Transport	1	2	3
b	Distance	1	2	3
c	Boarding	1	2	3
d	Time away from home	1	2	3
e	Psychological Problems	1	2	3
f	Parent/Teacher Problems	1	2	3
g	Other _____	1	2	3
h	None	1	2	3

---

77 (30)

Further Children

Do you feel having K has changed your feelings about having more children?

Details:

---

78 (31)

Family Planning Counselling

Hospital	1
Health Authority (Clinic)	2
" (Domicilliary)	3
GP	4
Other _____	5
None	6
N/A	7

79A (32)

Family Planning - Method

Oral - Combined	1
Oral - Progesterone only	2
IUD	3
Cap/Sheath	4
Spermicides/Safe Period/withdrawal	5
Male/Female Sterilisation	6
Other _____	7
None	8
N/A	9

79B (33)

Satisfaction with Method

Very Satisfied	1
Fairly Satisfied	2
Not very Satisfied	3
Unhappy	4
Other _____	5
N/A	6

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