Parents as Care Managers: The experiences of those caring for young children with cerebral palsy

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Thesis submitted for the Degree of Doctor of Philosophy

London School of Economics
University of London
January 1997

For Paul, Emma and Louisa

ABSTRACT

Recent legislation has drawn attention to the increasing number of children with disabilities being cared for at home by their parents (the Department of Health estimates 98.5%). These children meet the criteria for 'children in need' in Part III of the Children Act 1989, and for care management introduced under the National Health and Community Care Act 1990. This study undertaken in the early 90's at the cusp of these reforms, seeks to explore the probable gap between the carefully argued and eminently logical proposals of the Department of Health in their policy objectives for children with disabilities and the practice implications for carers.

Existing research in this area has concentrated on the impact of having a disabled child on the family and as a financial liability. Evaluation of community care has been directed towards organisational change and the implications for public spending. The intention here is to examine parents' experiences as care managers of their children's health, education and social care provisions, since consumer experiences are integral to the market philosophy underpinning the reforms. Young children with cerebral palsy have been chosen as an example of a severely disabling condition, and attention has been restricted to children of under 8 in the north London area.

The research methods used are direct, non-participatory child observation, a postal questionnaire and semi-structured interviews. In total, 58 families participated in this study. In addition, facilities in 3 London boroughs and 2 specialist treatment centres were examined in depth.

The findings are discussed in 4 sections (cerebral palsy as a disabling condition, health, education and personal social services) in accordance with the Children Act Guidance Volume 6, which emphasises the contribution of each of these areas and the need to take into account interdisciplinary collaboration. As there is a wide-ranging, relevant

literature crossing many professional disciplines and subject areas, literature reviews are included in each of the sections.

In conclusion, the findings are discussed in relation to improving service provision; future research potential, and the training needs of professionals involved in 'normalising' the lives of children with cerebral palsy and their families.

ACKNOWLEDGEMENTS

I met Sally Sainsbury one evening walking along the Strand in 1991 and was honoured that she was willing to consider supervising this project. Since then the road has been arduous. There have been times of exhilaration and excitement and others of despondency and doubt. Without support from Sally and from numerous colleagues, friends and family, I could not have sustained this task. In particular, Eileen Munro has ben consistently encouraging and balanced in her advice. Mastering computer techniques and establishing competent referencing would not have been possible without Mary-Alice Lowenthal, while the presentation owes much to Michael Bentham and Janice Harrison.

The thesis would not have been possible without the participation of 58 families whose child has cerebral palsy. Jenny Malone has allowed me to check my ideas and has stimulated new avenues to explore. I hope that this study reliably presents the perspectives of parents.

TABLE OF CONTENTS

Page No.

Appendices

LIST OF INITIALS AND ABBREVIATIONS

ADSS	Association of Directors of Social Services
CDT	Child Development Clinic
CHV	Community Health Visitor
CP	Cerebral palsy
DFS	Department for Education and Science
DH	Department of Health
DHA	District Health Authority
DHSS	Department of Health and Social Security
DLA	Disabled Living Adviser
EWO	Education Welfare Officer
FHSA	Family Health Service Authorities
GP	General Practitioner
IPSEA	Independent Panel on Special Education Advice
LEA	Local Education Authority
LMS	Local Management of Schools
NCB	National Childrens' Bureau
NHS	National Health Service
OPCS	Office of Population and Census Studies
OT	Occupational Therapist
SATS	Standard Attainment Tests
SBU	Special Care Baby Unit
SSD	Social Services Department
ST	Speech Therapist
UK	United Kingdom

LIST OF FIGURES

Page No.

Section I

INTRODUCTION

Chapter 1 Aims, Context and Method

1.1 Aims and Context

Caring for disabled children is a subject of current interest. A cascade of change has been initiated by legislation affecting policy and provision for the care of disabled people in the community.[1] The Children Act, 1989[2] includes children with disabilities as children 'in need ', and a detailed analysis of the Department of Health's expectations is presented in Guidance and Regulations.[3] The National Health and Community Care Act 1990 has introduced new systems for caring for people within their families; the Carers (Recognition and Services) Act 1995 sponsored by Mr Malcolm Wicks (Lab. Croydon, N.W.) provides a platform for carers (often parents) to have their own needs taken into consideration alongside those of their disabled children when social services departments undertake community care assessments.

The plight of families with a child born with cerebral palsy continues to receive considerable press coverage. Headlines such as 'Doctors clash on the right to live'[4] recount the dilemmas for the parents of Thomas Creedon, 'fed through a tube in his stomach and kept alive despite his parent's pleas to let him die '. The Sun reports 7.11.95 of a £2.8 million National Lottery win described as a 'lifeline for disabled Nicole, born with cerebral palsy, who will have a chance to learn to walk at the Peto Institute '.[5]

During the post-war years, social policy has been directed towards transferring the minority of children with disabilities who were still cared for in NHS institutions and boarding schools to those with 'parental responsibility' for them at home in the community. This 'normalisation' process was influenced by Bowlby and reinforced by Wolfensberger.[6] The Children Act 1989 endorsed this policy direction stating 'there are unique advantages for children in experiencing normal family life in their own birth family '.[7]

Concern about residential care is expressed by Utting in a Department of Health review of residential child care, which endorses the Children Act Guidance and Regulations on residential care.[8] Both documents question the adequacy of 'corporate, public care' for children including those with disabilities. Utting quotes an SS1 study of community homes in 1985 which revealed that each was 'rated on ten factors to give some indication of the local authorities' ability to act as a good parent...in only 4% of cases were there no elements of failure'.[9] Although it is accepted that 'some children with disabilities or with serious health problems may spend substantial periods of time receiving care or treatment in an NHS facility' and that some children will need to attend residential schools, 'it is against government policy that such children should be placed for long-term residential care in an NHS setting'.[10]

This study concentrates on the increasing number of children with disabilities (the Department of Health estimates 98.5%) being cared for at home. The process designed to meet their needs originates in the National Health and Community Care Act 1990, which requires the social services departments to assess the needs of persons who may require community care services, 'to ensure that people are not fitted into existing services, but that services are adapted to individual needs'.[11]

Children with disabilities meet the criteria for the care management system. It is intended that the two programmes (National Health and Community Care Act and the Children Act), should be 'consistent and complementary and set a fresh agenda and new challenges for social services authorities for the next decade. There is no intention of creating a division between child care and community services and they should form a coherent whole'.[12]

The assumption of primary responsibility for their young child with disabilities implies that main carers (usually the mother) must make choices from treatments, services and educational facilities to enable their children to live 'as normal a life as possible'. The expectation from the Children Act Guidance is that this process of care management should be achieved by 'partnership with parents', so that 'all necessary expertise is marshalled ... within and beyond the SSD '.[13]

Provision is to be the responsibility of the NHS, social services, voluntary and private agencies and education departments, who should co-ordinate 'packages of services from multiple service providers'.[14] It is envisaged that 'a single care manager' may be one way of delivering services, with ultimate responsibility resting with the SSD and parents who should be given options to make preferences 'to avoid conflicts and adversarial debates'.[15]

Moreover, the Department of Health 's policy guidance on the purchaser/provider model requires active participation by professionals to ensure purchasing a package of care, assembled from the public, voluntary and private sectors, and periodic reviews to ensure a 'wider choice of services across the statutory and independent sectors, and better integration of services within and between agencies'. This description does not fit comfortably with the assertion that in some situations 'users and carers might act as their own care managers'.[16]

The Children Act Report 1992 endorses this shifting of responsibility towards users and carers, in the guise of promoting parental responsibility. 'When support within the family fails or is absent, the local authority has a duty to offer aid to the family or directly to the child....The responsible authority must then withdraw when the parents are again able to discharge fully their responsibilities to their children '.[17]

It appears as if subtle adjustments to the extent of public responsibility have been made in the Guidance as planned implementation has revealed the probable costs of offering care management facilities to all children fulfilling the Children Act categories of being disabled. The OPCS[18] estimated in 1989 that at least 3% of children could fit this definition.

The gap between needs and resources has emerged as the major flaw in the promotion of community care planning. Local authorities have, therefore, been forced to promote issues of parental responsibility and choice above care management by public officials for reasons of expediency rather than from strict adherence to the legislation.[19]

1.2 Hypothesis

The consequence for main carers of this policy may be having to assume the mantle of their child's care manager; having to obtain knowledge about matching their child's needs based on the disabling condition to resources; having to develop skills in accessing resources; having to change the focus of their care planning constantly in response to their child's developmental needs and gaining clearer appreciation of the nature of the child's impairments. Sustaining this role as care manager may be the equivalent to full-time employment and in many family situations may be incompatible with the requirements of daily living and in particular their child's dependency needs.

The focus of the present study, therefore, is on the probable gap between the carefully argued and apparently eminently logical proposals for the Department of Health in the policy objectives for children with disabilities and the practice implications for carers. Admittedly the policy includes a right to complain if procedures are not 'accessible, usable and effective'[20] but the procedures are daunting[21]. It will be argued that the complexities of fulfilling the role of care manager do not allow time and energy to engage in this process, and that the less articulate and those for whom English is a second language are disadvantaged. What appears to be a sensitive and well-ordered system for facilitating social policy in partnership with parents to create as normal a life as possible for children and their families, may be experienced as distorting family life in unacceptable ways. The explanation of how this situation has come about should prove useful to both policy-makers and those involved in service provision.

1.3 Research Design

This study is intended to be a piece of qualitative research as defined by Hakin: 'concerned with obtaining people's own accounts of situations and events, with reporting their perspectives and feelings'.[22] It is in the tradition of Glendinning who expressed the need to 'violate the normal hierarchy of credibility' usually led by professionals to allow parents to be heard.[23] Existing research in the area of children with disabilities has concentrated on the impact of a child on the family[24] and as a financial liability.[25]

Preliminary investigations for this study indicated difficulties in defining disabilities as illustrated by the work of the OPCS 1989, which attempted to define by degree of dependence.[26] Enormous variations in need imply many different treatments and appropriate services. To overcome this complexity this study concentrates on cerebral palsy as an example of a severe disabling condition.

The intention in this thesis to take a medical perspective of cerebral palsy might be considered controversial. There has been a firm trend promoted by the Disability Alliance Movement[27] away from a 'medical model,' which locates the source of problems in the individual disabled person to a 'social model, which blames society's oppression and discrimination'.[28] Disability rights campaigners promote with passion their belief that the medical model constituted as it is as a process of diagnosis, treatment and cure demeans disabled people. Their conditions may be incurable, preventing them from being fully participant in society and as a result they may be deemed to be failures. Nevertheless, there is a need to know about a clinical condition and the range of treatments and rehabilitative services which may not cure but may enable an individual to lead a fuller life and maximise potential. Oliver, who champions the social model, values medical research into primary and secondary prevention; reducing the number of handicapped babies being born, and reducing the personal limitations that may be imposed by impairments. His argument that 'without medical knowledge, it may well be impossible to consider the personal, interpersonal and social consequences for the client concerned', supports the approach adopted here.[29]

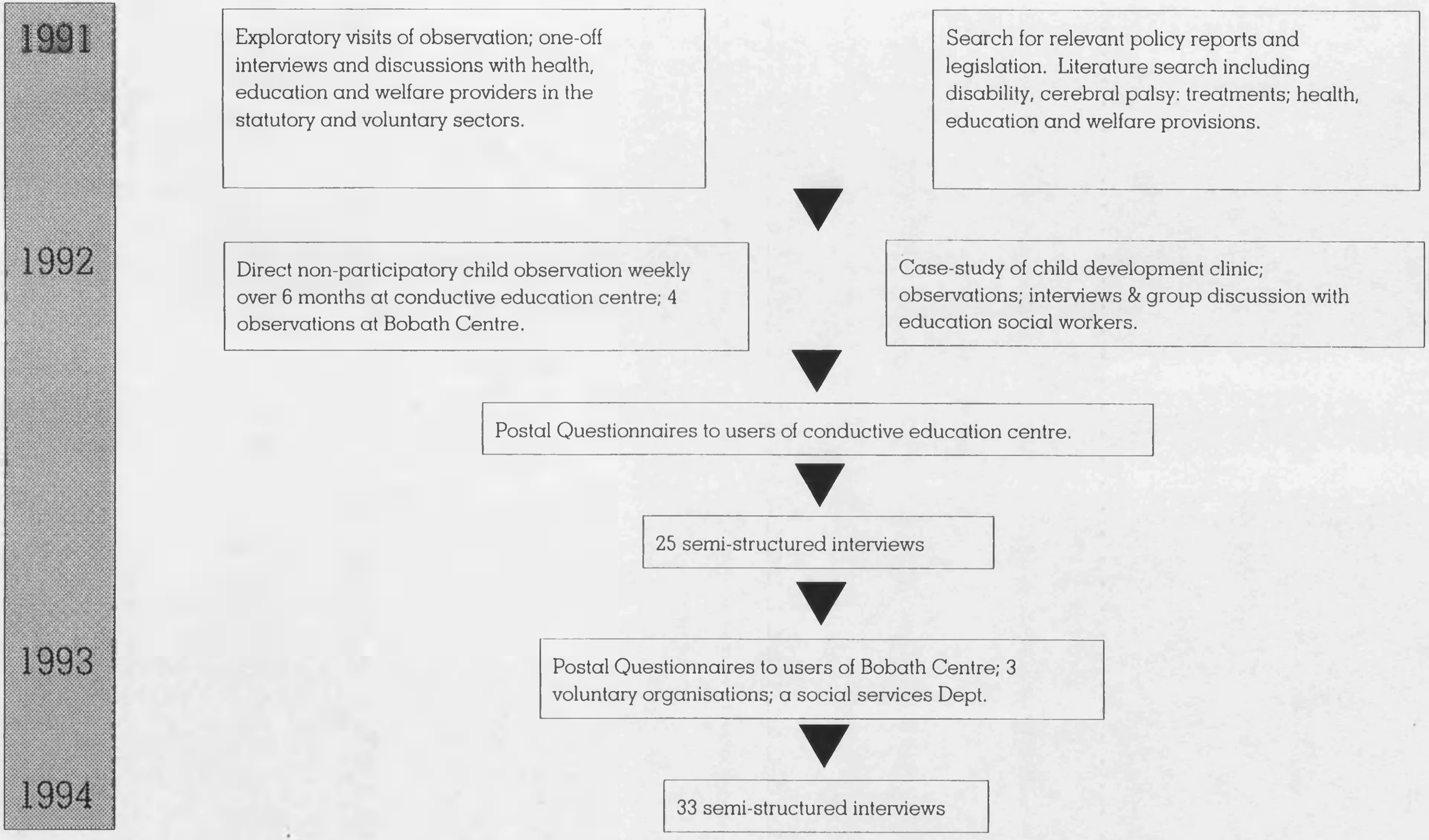
An upper age limit of seven has been adopted in line with the Children Act's designation of 'under 8's and over 8's' and because social policy implications change with a child's chronological development.

The study has been constrained by time and resources. The decision to restrict participation mainly to families and agencies located in London boroughs north of the Thames, made the work manageable and sufficiently rich in material - there are two specialist centres for cerebral palsy children of international reputation in this area. It was also decided to exclude an analysis of the 'costs of caring', as this has been the focus for extensive research. This allows concentration on the trinity of provision, health, education and social services.[30]

1.4 Methods

The methods used were intended to complement each other, producing triangulation, using multiple and different sources and methods of investigation to obtain a rounded perspective against which to test the hypothesis.[31] Figure 1 shows that the fieldwork was undertaken from 1991-4 using a range of research methods.

FIGURE 1


1991
1992
1993
1994
Exploratory visits of observation; one-off interviews and discussions with health, education and welfare providers in the statutory and voluntary sectors.
Search for relevant policy reports and legislation. Literature search including disability, cerebral palsy: treatments; health, education and welfare provisions.
Direct non-participatory child observation weekly over 6 months at conductive education centre; 4 observations at Bobath Centre.
Case-study of child development clinic; observations; interviews & group discussion with education social workers.
Postal Questionnaires to users of conductive education centre.
25 semi-structured interviews
Postal Questionnaires to users of Bobath Centre; 3 voluntary organisations; a social services Dept.
33 semi-structured interviews

The study required choosing and applying those research methods likely to provide knowledge of the following areas as the foundation for understanding and explaining the perspectives of parents:

1) Social policy history and the law.
2) Cerebral palsy as a medical condition and the social consequences of impairments.
3) Provision by the health, education, social services and the voluntary and private sectors.
4) Parents' experiences and attitudes towards provisions in their care packages.

Selection of appropriate research strategies for each of these areas involved having an awareness of problems of negotiating access, confidentiality and invasion of privacy. There was a need also to become familiar with the regular stream of Department of Health publications consolidating community care policy. This process of exploration during the first year and a half produced 'focus-determined boundaries'. It was possible in the next phase of fieldwork to be more certain of strategies suitable to explore the consequences of social policy implementation as experienced by main carers.[32]

The work has some characteristics of a case-study of the world of cerebral palsy. However, the intention was to employ research methods which provided access to aspects of that world which might test the hypothesis presented.

1.4.1 Social Policy History and the Law.

An extensive review of government reports and associated legislation was undertaken to trace policies and practice implications for the care of disabled children at home with their families. Taking health, education and social services as the core areas, the search concentrated primarily on the post-war years and the foundation of the welfare state, following the Beveridge Report, 1942.[33]

A complex picture emerged of separate but overlapping policies, practices and legislation for each of the areas. The needs of disabled children have been examined in detail from the perspective of health, by the Court Report 1976; mental handicap, by the Jay Report 1979; special education services, by Warnock 1981; social services, by the Seebohm Report, 1969, the Barclay Report 1972, and the Griffiths Report on Community Care 1989.[34]

The legislation which ensued from these reports was equally complex, a recurrent theme being the promotion of care at home to avoid the necessity for residential provision and to further 'normalisation' principles. A series of National Health Service Acts from 1946, Education Acts from 1944, social services and disability legislation notably the Chronically Sick and Disabled Persons' Act 1970 identified the statutory duties of central and local governments.

The findings from these reports and legislation have been discussed in Section III, Chapter 4 on health policy, Section IV, Chapter 8 on education policy and Section V, Chapter 12 on Social Services policy. They formed the basis for exploring the hypothesis about probable gaps between social policy, provision and practice, and may be seen as 'building blocks'.[35]

1.4.2. Cerebral Palsy

What it is like to have cerebral palsy and how the impairment influences the choices made by main carers requires an understanding of the condition. The methods used to achieve this were a series of non-participatory child observation sessions (weekly over six months) at a conductive education centre for children under eight years with cerebral palsy. The interested co-operation of the centre's director and the availability of observation facilities through a one-way mirror made the research possible.

Observation of young children is a technique developed initially to train child psychotherapists[36] and has more recently been developed for the training of social workers (see for example, Miller et al, Trowell, Bridge, Fawcett).[37] These writers have emphasised the powerful feelings evoked by observing children, a process which may draw attention to the painful effects of disabilities 'as it were through setting a microscope on the action'.[38] Employed as a research strategy, findings are as painful for researchers as for those undertaking professional training. Despite this emotional impact, observation provided a unique perspective on these children's lives, as discussed in Section II, Chapters 2 and 3.

Additionally, conductive education (a controversial education/treatment provision) was observed; the views of 'conductors' obtained from group discussions and a brief questionnaire, (Appendix 1). These findings helped to fill an important gap, given the dearth of literature in this area (see Section IV, Chapter 11).

However, engaging in direct observation had areas of discomfort. Although the staff at the conductive education centre were regularly observed at work as part of their training, the presence of a researcher who sat writing and failed to provide feed-back, inevitably roused uncertainty. There was also a sense in which the researcher felt under pressure to communicate positive conclusions about the approach in return for being allowed to conduct the research. Participatory research, a method derived from social anthropology may have produced more relaxed relationships with staff, but could not have overcome the ethical problem of concealing genuine reactions to situations. These feelings might have been contained by observing through a one-way mirror system as had been planned. However, it was not always possible to use these facilities and many observations took place sitting in the nursery room.

Negotiating access to observe children elsewhere proved difficult because of child protection/privacy issues. But it was possible to observe the Bobath[39] treatment method on four occasions and to undertake a series of one-off visits to observe children with cerebral palsy in a variety of settings, including those offering hydrotherapy, Portage education, special and mainstream nursery schools.[40] Perspectives on developing countries were obtained from study visits to Kingston, Jamaica in 1992 and to the Spastics Society, Bombay 1994.

Non-participatory observation proved particularly useful in providing understanding of the impact of cerebral palsy and of the group processes within treatment/learning environments. By removing the necessity to concentrate on participation, energy was freed for watching and understanding events, relationships, attitudes and treatment systems. Nevertheless, 'knowing that distortions and biases' are inevitable in this research method, child observation might be described as an 'in-depth exploratory phase' in a study requiring other research methods to provide a more balanced perspective.[41]

1.4.3. Provision by Health, Education, Social Services and the Voluntary and Private Sectors

To obtain information about service provision from the provider perspective, observation visits and semi-structured interviews were conducted using a snowball sampling technique to obtain a broad picture of the nature of provision in the north London area. Three social services departments were examined in more detail, selected for reasons of 'convenience'.[42] It is worth emphasising that at the time of the study, major changes were in process in all provider agencies in response to community care legislation with transience seeming to be characteristic of organisations. There was, therefore, reluctance to participate in research at a time of uncertainty. As will be seen, in Section V, findings from these exploratory visits and interviews provided an adequate backcloth for presenting parental experiences which are at the forefront of this research.

Material for the case study in Section III, Chapter 6, about a child development team is based on a combination of non-participatory and participatory observation, semi-structured interviews and a group discussion. The findings from this multiple research method approach heightened awareness of the intricacy of issues pertaining to the intractable problems of inter-disciplinary work.

1.4.4 Parents' Perspectives

Testing the research hypothesis required access to parents' experiences. However, locating entrées to the families with young cerebral palsy children proved difficult initially. There is no national register for children with cerebral palsy, although Dr. Lesley Willner's report to the Spastics Society Epidemiology Consultative Group reviews six regional C.P. registers within the UK and promotes the idea of expanding registration throughout the country.[43]

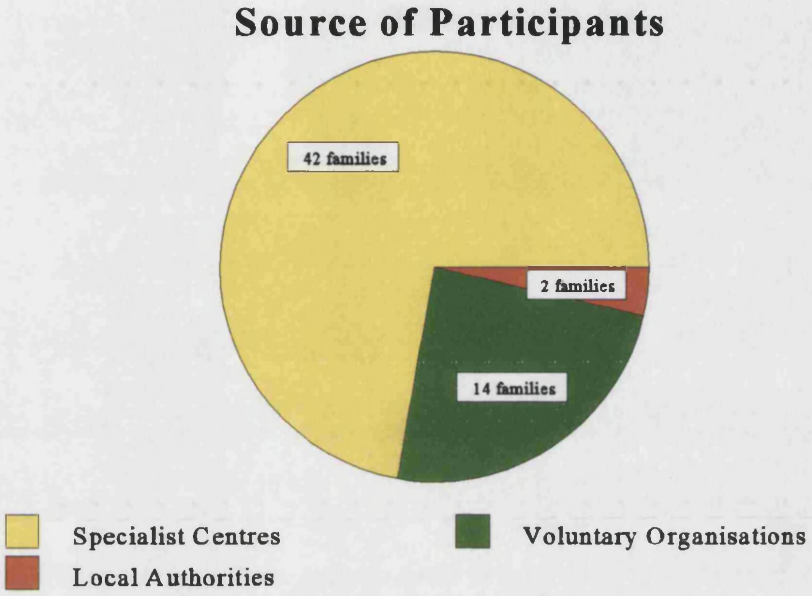
The register of children with disabilities, which local authorities are required to keep in accordance with the Children Act 1989, does not categorise children by disability; it is not compulsory and was in its infancy at the time of research design. Children Act Report 1992 expresses 'disappointment' and 'concern' that by June 1992 one third of local authorities had yet to complete their arrangements for maintaining a register.[44] 'Opportunity' or 'convenience' sampling was therefore inevitable.[45]

There are treatment centres catering specifically for children with cerebral palsy. Negotiating access to parents with the staff by stimulating their interest in the subject and providing assurances of confidentiality, enabled postal questionnaires to be distributed and in-depth semi-structured interviews lasting from one to three hours to be conducted with main carers.

The questionnaire (Appendix 2) was intended to obtain factual information about treatments, services and educational facilities used and about shortfalls in services. The interviews focused on the recollections of the past: the child's history of involvement with social policy provisions; carers' attitudes towards and experience of using the services; carers' opinions, expectations and perceptions of the family adjustment..

Initially 25 questionnaires and interviews were completed by people using one specialist centre. But since these results appeared to reflect a narrow social class, it was decided to repeat the same dual process of questionnaire followed by interviews with carers from a second specialist centre and three voluntary projects. To balance what appeared to be an over-representation of articulate middle class parents, the involvement of social workers from a local authority social services team was enlisted. In total, fifty-eight families participated in the study (figure 2).

FIGURE 2

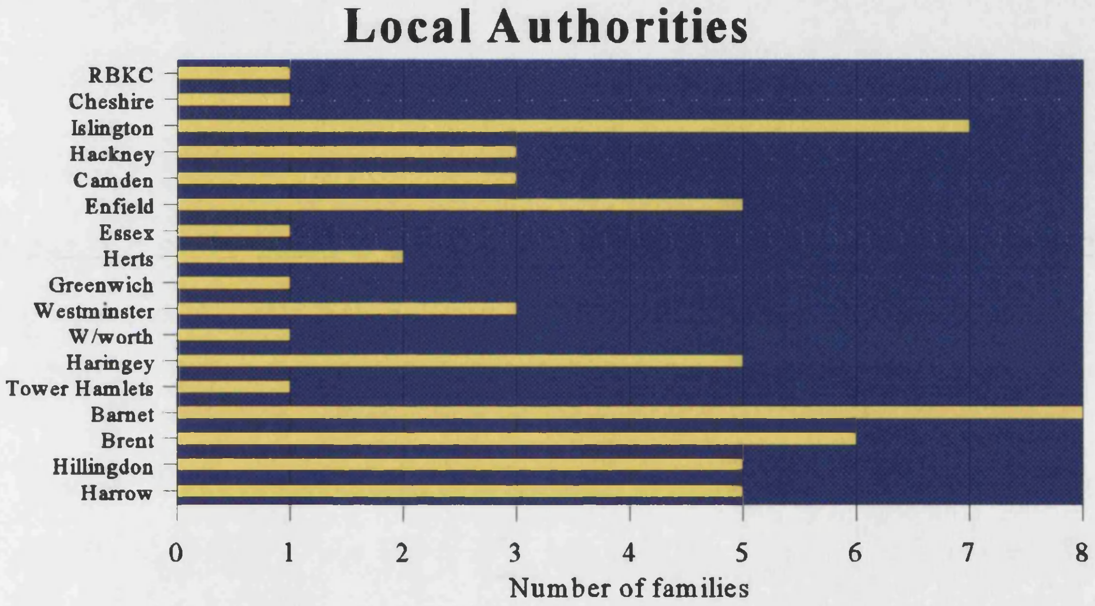


The response rate from the first group (at the conductive education centre) was high (85%), which probably reflected the carers' confidence in the researcher, who had been seen to take a consistent interest in their children during the observation phase. A much lower response rate (25%) was obtained from the postal questionnaires to the voluntary agencies and social services. This probably reflects the personal, sensitive nature of the research questions. Indeed, two parents in the first group declined 'because they could not bear to talk about it!' The questionnaire was designed to focus primarily on factual information but the content was associated with stressful material.

'A good questionnaire is one that works, ... it is a sophisticated craft'.[46] In this study the questionnaire performed the dual function of eliciting factual material and inviting participation in the interview stage of the study. The overall positive response reflected the need to recount a terrible story (an aspect of unresolved grief), the wish to publicise their situation to help others, and an understandable pride in being asked to participate in a study for publication.[47] Interrupted by phone calls as most carers were during interview, a mother said proudly, 'I can't speak to you now, I am being interviewed'.

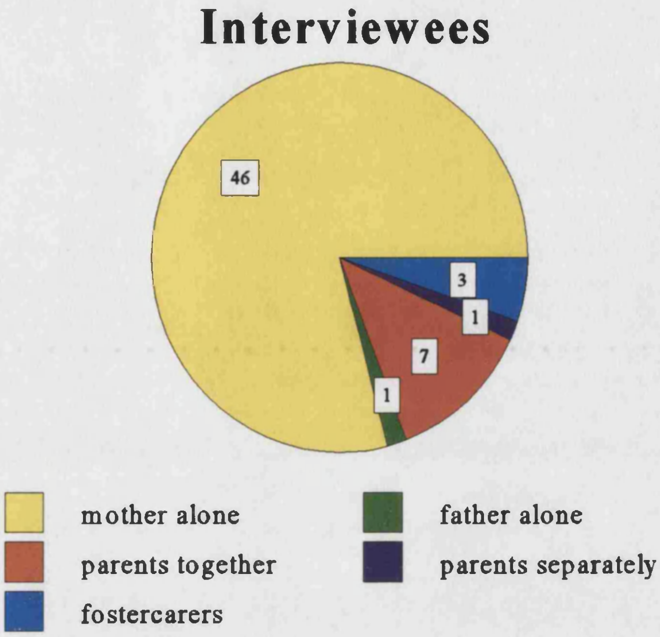
Participants were recruited from seventeen local authorities, the majority being resident in the area of London, north of the Thames (figure 3). All families were interviewed in their homes by appointment, except for a family who had recently moved to Cheshire and agreed to a telephone interview.

FIGURE 3



As anticipated, mothers formed the majority of people interviewed, although seven parents were interviewed together and one couple was interviewed separately. It is likely that more fathers would have been interested to participate but interviews took place in the mornings when husbands were at work and children in day care or at school. This seems to be the least disruptive period of the day for carers.

FIGURE 4



Of participants living with partners, only one father was unemployed. In contrast only one mother was in full-time employment; the majority of mothers (83%) were not able to sustain the caring role and employment. It was inevitable that the majority of participants was from articulate middle class families: this group was keen to be heard and had 'stories to tell'. A similar methodological issue was raised by Tizard and Phoenix in their study of children of mixed parentage.[48] Research into sensitive areas of people's lives is inescapably restricted by the willingness of participants to allow what may appear to be intrusion. The complexity of the lives of these carers which will become apparent in later chapters compounds the problem, since poor resources of time and energy restrict involvement in a project of no immediate personal value.

It is perhaps misleading to discount the value of a study with an over representation of middle class participants. Social policy is designed for all classes, and middle class participants were found to be 'heavy' consumers of the services available. The results also have the potential to show clearly how carers, without having to consider issues of poverty and deprivation, experience acute difficulties directly resulting from policy provisions. Stripped of poverty as a component in their lives, the study may reveal starkly the practice implications of health, education and welfare policy.

Considerable thought was given to the question of when to stop interviewing. Comparable research provides no consistent pattern; Glendinning's study[49] is based on only seventeen families; Beresford[50] on twenty, Sainsbury[51] on 175 interviewed, Herbert and Carpenter[52] on only nine families. Restrictions were established by the problems of locating participants; by recognising clearly emerging patterns of responses consistent with the findings from the earlier research methods and by agreeing with Hakim that 'it is impossible to carry out ad hoc surveys on any scale single-handed'.[53]

Conducting the interviews was usually a painful process dependent as they were on eliciting traumatic episodes in family life. Interviewing skills, particularly empathy, derived from social work training, facilitated the process since most participants seemed to be motivated by a combination of needing to retell their story, and working to publicise their ways of coping for the benefit of others. Having a clear schedule of areas for discussion, (Appendix 3); consistency in application and recognising the difference of focus between interviewing as a helping process in social work and interviewing for research were the requisite ingredients. Sustaining the process was dependent on valuing research in its own right.

This experience is endorsed by Fuller and Petch who argue that social work 'practitioner-researchers' bring considerable advantages to the task, including being 'already expert interviewers and recorders of data', although 'some adjustments in perspectives need quite consciously' to be made.[54] The key adjustment is about belief that 'objective evaluation' may make a worthwhile contribution, although indirect, to the lives of participants through influencing policy provision and practice.

1.5 Data Collection and Analysis

For each of the methods used (observation, visits, interviews) detailed notes were taken manually at the time, analysed and appraised concurrently. This process influenced the choices and timing of further exploration. For example, the observations at the child development centre highlighted the significance of the parent advisor system.[55] This required further investigation by an interview with the organiser, group interview with education social workers and inclusion of a question about the service to relevant participants in the carers' interviews. The research design, therefore, was a dynamic process rather than a fixed architectural plan.

The data from each of the research methods was coded, analysed manually and converted into tables, where appropriate. Overall, the study could be described as qualitative (for words and opinions) and quantitative (for data that could be transformed into numbers). 'Most real world study produces data which call for both qualitative and quantitative analysis'.[56] In a study designed to explore perceptions of service provision, the qualitative results certainly provided human experience of a powerful nature echoing Sharpe's experience, that 'the living nature of feelings, ideas and hopes' of participants may be 'frozen somehow and lost within long computer sheets covered with endless statistics and calculations'.[57]

1.6 Thesis Plan: Presentation of Research Material

The research material presented here has been divided into four sections. Initially, the nature of cerebral palsy is explored both as an example of a disabling condition, and from the perspective of the impact on family life of the birth of a child with this condition. The subsequent sections concentrate on policy, provision and practice in health, education, social services (including statutory, voluntary and private sector). Although ideally these treatments and services should be provided by inter-agency and interprofessional collaboration, the reality is that they are provided and funded separately by different bodies and experienced by parents as separate provisions.

The ordering of the sections has been chosen to reflect the chronological nature of children's involvement: in the early months, health care issues predominate, to be superseded by education after the age of two. Social services are significant throughout and are positioned at the end as the body identified by the Children Act 1989 Schedule 2 to carry responsibility for collaboration.

The views of some professionals and of many parents have been quoted extensively throughout the text. Permission was obtained from all participants and the purpose of the study was explained.

As far as possible, agencies and locations have been disguised and the names of all parents and children have been changed for reasons of confidentiality. Unfortunately, it was not possible to obtain the consent of the children themselves because of their ages and impairments. Although every effort has been made to anonymise the views of participants, it is of interest that they were keen to express them and appreciated the opportunity to be heard.

There is a vast amount of literature relevant to this thesis, some specialist, for example on cerebral palsy treatments, and others embracing broader areas of social policy and disability. A literature review for each section has been integrated into the discussion of policy and findings.

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Section II

CEREBRAL PALSY

Cerebral palsy has been chosen as an example of a disabling condition. A primary reason behind this choice is its complexity, and the findings of research into attitudes towards people who have the condition,[1] that 'the cerebral palsied are seen by the non-handicapped - as a friend, co-worker, play-mate for child, marriage partner - less favourably than those with sensory handicaps or physical handicaps without brain involvement'.[2]

Chapter 2 will discuss cerebral palsy as a clinical condition. Chapter 3 will discuss the implications of this condition for the lives of children and their families.

Chapter 2 Cerebral Palsy : the Clinical Condition

> "We were in this Kafkaesque world of no diagnosis. The consultant wanted us to accept that David was experiencing developmental delay, and he wouldn't come clean about cerebral palsy. All the family wanted to believe he would catch up. Funnily enough, we felt much better when the physiotherapist confirmed our diagnosis that he had cerebral palsy. Now there was something to do."
>
> (David's mother)

This study is about what parents do when their child is diagnosed as having cerebral palsy; what choices they make based on their understanding of the medical assessment; what treatments, social services and educational facilities are available for them to use, through the mixed economy of welfare. The starting point, therefore, is to examine the meaning of cerebral palsy as a clinical condition; the nature of the syndrome; its causes, types and consequent impairments and disabilities; the range of treatments and corrective interventions available. It will become clear that this is a condition riddled with ambiguities. Uncertainty of diagnosis precedes slow realisation of the extent of the impairments. Causation may remain unknown and the effectiveness of interventions hard to assess. In the words of one mother,

> "At first I was frightened by the diagnosis of cerebral palsy. I had to find out about it gradually, only allowing myself to ask about things as I thought I could take it. I used to work myself up into a dreadful state. As you go along you realise the professionals are there for you, not you for them. Now I am much more confident about what is right for my son."

Clinical knowledge should be seen as the foundation, the base-line from which to embark on a study of the implications of the condition for social policy provision. Middleton's concerns about 'half-baked medical knowledge' have some validity, but it will become clear that elementary physiology may be explained to those without medical training.[3] Furthermore, its inclusion is vital to making decisions about the suitability of social and educational provisions over and above those described as medical. Recognition of the importance not only of a clear diagnosis but also of intelligible, clinical explanations was a recurrent theme in many of the interviews with parents.

> "What slowed me down was that I didn't know Emily had cerebral palsy. I thought she had a virus. When I had done a lot of reading and forced the diagnosis out of the doctor, I set about making choices for her and finding out about movements I could join."
>
> (Emily's mother)

This need for parents to have a better understanding of cerebral palsy is endorsed by the Spastics Society (Scope) whose bibliography for parents includes sections on medical aspects and what are called technical books. These cover epidemiology, management and treatments. It is noticeable that voluntary organisations providing services and treatments usually provide pamphlets to communicate the clinical aspects of the condition to carers. Examples of these publications are available from the Bobarth and conductive educations centres. The Spastics Society of India has published a range of medically based pamphlets and promotional videos to increase understanding of this condition as a precursor to discussing rehabilitative interventions. Some of these are written and printed by people who have cerebral palsy.

Perhaps the dilemma of needing a clinical perspective as a starting point for deciding how best to proceed as a parent is best expressed by Marion Stanton.[4] As a parent of Danny, who at four months was diagnosed as having 'severe, spastic, cerebral palsy,' she wrote *Cerebral Palsy: a Practical Guide*. This book begins with a substantial and detailed clinical account of the condition including diagrams of the brain and detailed classification charts from Minear[5] and Levitt.[6] This information is then woven into the ensuing analysis of treatments and services. The intention is 'to produce a publication which is easily accessible to all carers of children with cerebral palsy.......I have been extremely irritated by the text books about cerebral palsy which really can be understood only by professional people.'

This chapter, therefore, acknowledges that a clinical perspective is integral to this study and that it is the area which parents find difficult, partly from ignorance and partly from a combination of fear and shock. For parents in this study disability had been thrust upon them: neither they nor their family and friends had first hand knowledge of disability or of cerebral palsy as a clinical condition. Abbott and Sapsford noted that 'parents are themselves members of the culture which stigmatises them and their children, and share to some extent the attitudes they are forced to combat'.[7] As a framework for this analysis of cerebral palsy as a disabling condition, a profile of cerebral palsy will be presented, which will include a clinical account of its nature, causes and types. A discussion of impairments and disabilities will be followed by an overview of treatments and specialist rehabilitative systems specifically designed to maximise children's potential. The chapter will integrate relevant literature and current research.

2.1 Cerebral Palsy: The Condition

Cerebral palsy is the medical term used to describe 'a group of conditions which have in common the fact that they are severe, congenital, non-progressive neurological disorders, affecting muscle control and movement'.[8] Children with cerebral palsy have sustained irreversible brain damage and their condition is usually diagnosed either at birth or within the first eighteen months of life. Typical of parents' accounts of discovering about their child's condition is the following extract from interviews:

> "The pregnancy was normal and I was able to get up fifteen minutes after the birth. Nicholas looked perfect, apart from a red graze mark on the back of his head. The midwife remarked that he had probably bruised his head on my pelvis. He suckled straight away. Two months later he began

> arching his back and rolling his eyes. By four months we cornered the paediatrician who confirmed our suspicions that it was cerebral palsy."
>
> (Nichola's mother)

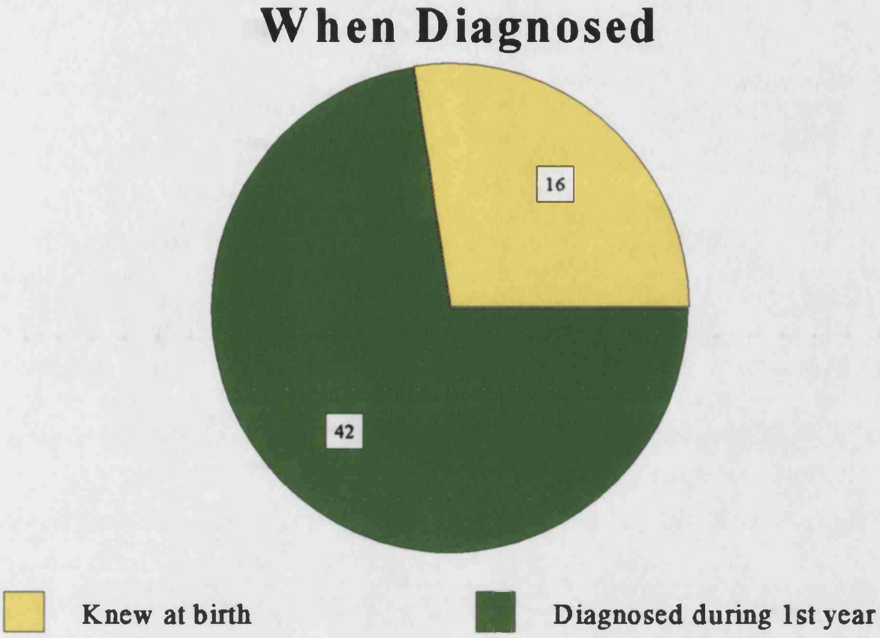
In some situations, the birth experience itself made the diagnosis a certainty.

> "I had a lovely pregnancy, though the summer was hot. I began labour with the twins four weeks early; they were both born using forceps. Sam came first, but Sarah's shoulder got stuck and she was breached. They should have done a caesarian but the consultant was on holiday. It took five minutes to resuscitate her. She was blue and she didn't cry. I was hysterical. It's supposed to be a nice occasion. When I woke up there were five people round my bed. There were no curtains. 'Your daughter's brain-damaged', they said."
>
> (Sarah's mother)

Most common seems to be gradual realisation that a baby is not reaching developmental milestones. Only 16 of parents interviewed admitted to being told the diagnosis soon after birth, while 42 said they learned the diagnosis when their child was between three months and two years. (See figure 5).

> "James was a premature baby but they said he would catch up. At ten months he wasn't sitting up or even waving his arms. My cousin had a boy of the same age and he was doing so much more. I saw a physiotherapist at the child development clinic who told me he had cerebral palsy. It didn't mean a thing to me, but then she said, 'he will walk...well probably'. When I got home I threw things around the room in despair."
>
> (James' mother)

FIGURE 5



Cerebral palsy may be best understood as a disorder caused either by malformation of the cerebral tissues or asphyxia (lack of oxygen at the time of birth) or bleeding in the brain, before, during or after the baby is born. When there has been bleeding, haemorrhage scars the brain, damaging the neurological system which controls muscle function. In the current state of medical knowledge, the damage cannot be repaired, and the outcomes or effects on the body are best described as similar to the effects of a stroke. However, in Bobrow's words 'the complex mechanisms whereby the brain directs muscle activity mean that there are many opportunities for things to go wrong....The sober fact is that we still do not know what causes the vast majority of cases of cerebral palsy'.[9]

Although incurable, this group of conditions is usually not progressive and has in common disorders of movement which seem to be responsive to corrective or rehabilitative interventions. It is thought that early intervention maximises functioning.[10] When considering social policy issues, therefore, these children may be described as physically handicapped since the brain damage appears to interrupt the neurological system controlling muscle use. Clinical analysis of how body movement is controlled by the cerebral neurological system is the focus for research.[11]

This approach is vital to those exploring prevention and cure. For the purposes of parents, carers and social scientists, describing outcomes may be the most intelligible way to gain a workable definition of cerebral palsy. How the condition presents itself; how children with this condition are perceived and therefore how their needs may best be met is a useful starting point. Unfortunately confusion increases when attempting to approach the condition from this angle, because the amount of motor dysfunction varies considerably depending on the extent of the damage, the site in the brain where the accident happened and possibly the amount and type of early therapeutic intervention available. It varies also with the child's inherently unique personality and the social and cultural conditions of the family. There are, however, some common distinguishing features.

2.2 Infancy

Babies with cerebral palsy are not easy to manage; they either fail to reach usual developmental milestones or reach them late.

> "I knew Colin wasn't doing the right things, reaching his milestones because he was my second child. When he was diagnosed as having cerebral palsy at 10 months I needed to find out all about it so I went to the library; Nancy Finnie's book about physiotherapy was reassuring. I learnt more by reading and going on a conductive education course. I have always had to initiate the questions about his condition and find the answers for myself."
>
> (Colin's mother)

Usually babies attain head control by five months; by six months they extend and use their arms for support, getting ready for sitting, standing and balance; crawling develops around seven months and babies walk before the age of two. Brain damage means that the baby has little head control; poor ability to use arms and hands for support, for reaching, grasping and manipulation, and consequently, little balance and control of posture for sitting, standing, and walking. Normal development of sequential motor control from head down to feet over two years may happen late, partially or not at all. Parents may be expecting this developmental delay if they have been told of the cerebral palsy at the time of birth and if they appreciated the significance of what they had been told. For those unaware of their child's condition, or unable to accept it, a painful process of realisation ensues.

> "Paul was taken into special care after he was born. He was having fits and vomiting constantly. At three weeks he was transferred to Great Ormond Street for duodenal stenosis. When he came home at six weeks, he was terrible, screaming all the time, vomiting and staying awake; the longest sleep he had in eighteen months was two hours. At the end of all this my husband and I split up. Strangely I find it more difficult to relate to Paul now as a child with a disability, than when he was so ill. I think I drowned my fears in lots of physical action, cleaning up vomit, nappies and pacifying him."
>
> (Paul's mother)

Having a first child is usually a traumatic event, creating unexpected demands and altering significantly family relationships and role boundaries. Oakley commented on this recurrent theme in women's accounts of childbirth. She describes first-time motherhood as a powerful disturbance to established lifestyles, routines and identities.[12] Caring for babies with cerebral palsy multiplies these factors.

> "I had this fear that James would be a vegetable. He screamed all the time, he was stiff and couldn't bend in the middle to sit on my knee to

> take a bottle. Screaming meant he vomited all the time and I don't think he was getting enough food. The Health Visitor kept coming to ask, 'how's baby ... on the move?' Well, in fact, he can't sit up."
>
> (James' mother)

Holding a child with cerebral palsy comfortably, nursing him, and growing to love and cherish him is a process damaged or inhibited by this young baby's physical problems. Bonding and the subsequent development of attachment between mother and infant is facilitated by holding, feeding and caressing.[13] Babies with cerebral palsy may be alternately stiff and floppy, fail to support their heads, move their limbs in an unco-ordinated way and have difficulty in suckling at the breast or even taking the bottle.

> "Ben looked like a bruised chicken when he was born. I was too scared to touch him and didn't enjoy his babyhood. He was so awkward to hold and I was so intent on doing what was right for him, finding the best therapy. This intense desire to do the right thing was such a strong drive that I forgot about loving. I still feel a different bonding to Ben than to my other children. You spend your time trying to fit in as much therapy as possible so bonding doesn't take place."
>
> (Ben's mother)

Perhaps because these babies are so very needy and their mothers so intent on seeking help, a very strong relationship seems to develop between mother and child. It is rarely one of rejection, although immediate adjustment to their child's disability is a painful process.

> "The problem was, they expected me to love this child, yet for me it could be a life sentence."
>
> (Paul's mother)

A mother described how it helped her with the bonding relationship that her baby was distressed at birth, but not diagnosed until he was thirteen months old.

> "My husband told me Carl was black at birth, because they didn't clear the mucus quickly enough. The midwife was an idiot. I'm glad I didn't notice anything was wrong or pick up the clues as quickly as I should. To me he was a normal baby and it helped me form a relationship with him."
>
> (Carl's mother)

Admittedly, this study is based on families who cared for their children at home, so that failure to bond may be less likely, or may not be openly admitted. Of the carers interviewed, all were natural parents, except one foster mother and two natural grandparents. It is worth noting, however, that the effects of the Children Act principle that 'a child is best cared for within the birth family,'combined with the need to discharge mother and child home from hospital quickly to free the hospital bed, possibly had the effect of forcing the development of a caring relationship.

> "After Ben was diagnosed, we were allowed to walk out of the hospital with him, not knowing what we were letting ourselves in for. I saw the world in dark colours. They said 'don't get attached to him because he may not make it'. I wanted to bring him home, but it took a long time to feel he was mine. I immersed myself in all the practical tasks of looking after him and gradually grew to love him."
>
> (Ben's mother)

Abandonment of children born with disabilities so prevalent in developing countries does not seem to be a major problem in the U.K., although a local authority social worker interviewed for this study, quoted a family where the task was to facilitate discharge home by arranging a package of care for a mother who was unable for financial reasons to give up the job from which she had maternity leave.[14] Her child's nursing needs made it impossible to find a suitable daily minder and the Health Authority needed persuading to accept financial responsibility for home nursing costs.

The family placements social worker,responsible for fostering and respite care in the same local authority, expressed concern about a small number of children, whose physical care may appear to be adequate but whose emotional and social needs may be a cause for concern.It was a striking feature of the families in this study, however, that even where bonding may have been difficult initially, strong infant/mother relationships emerged, in spite of and probably because of the painful beginnings.

Therapists are aware of these handling problems. Finnie writes that the essential purpose of her book is to 'enlist the co-operation of parents, and to suggest ways of handling the child at home.' She writes,'when a normal child is being dressed, washed, fed, carried, he moves with you rather than against you.... the cerebral palsied child can only cry and become stiff and frightened.'[15]

As a respone to this problem, the conductive education centre provides weekly one to one sessions for mother and child with a physiotherapist whose aim is to help mothers to hold and move themselves and their babies to facilitate bonding.

2.3 Pre-school Children

The extent and nature of a child's impairments gradually emerge in the pre-school years. The following profiles of children in this age-range are chosen to demonstrate the range of impairments usually experienced by children with cerebral palsy.

Thomas, aged four and a half, has spastic quadriplegia, which means the muscles in all four limbs vary in tone from floppy to stiff. He is unable to use any of his limbs effectively so that he cannot walk (he uses a wheelchair outside and is carried indoors); he cannot hold anything securely so that he depends on others for all aspects of self-care, including washing, dressing, feeding, and toiletting; he cannot write, but communicates with a computer; although his hearing, sight and cognition are good, he cannot speak, nor can he use signing because of his poor arm control. Eating, particularly chewing are difficult, as is digestion, and to ensure regular nourishment, Thomas is fed by a gastro-nasal drip. The profile, therefore is one of almost total dependence on people, principally his mother, and on a range of equipment and gadgets to ensure survival and achievement of potential. Perhaps as the result of this intense dependency, his mother is his most fierce and loyal advocate. In her words,

> "Overestimation, rather than underestimation is the best way to approach Thomas's potential. The most wonderful day in my life was when the educational psychologist came to test him with the computer for his statement. He scored twelve out of twelve four times. He had scored enough for it to be statistically impossible to be chance. If they'd had their way, he'd have been sent to a special school, but you must assume intelligence."
>
> (Thomas' mother)

In contrast to Thomas, Helen, aged three, has left-sided hemi-plegia. She walks with the aid of a frame or hand rails. She is learning to use her right hand for self-care and writing. She has a squint , which is being corrected with a patch. She hears well but her speech is slurred and slow and with limited vocabulary. Frustration at being unable to move and communicate at the rate of her siblings causes stress at home and school. In her mother's words,

> "Helen wants to be in with the crowd. She attends a small private school; they've put hand rails up on either side of the stairs for her, although there's no wheelchair access. There's a child in Helen's class who has learning difficulties, but Helen isn't very nice to her because Helen has an overwhelming personality. The other child is too slow for Helen."

Poor co-ordination, rather than stiffness is characteristic of children like Paula, aged four. She cannot control the constant movement of all four limbs. She cannot move about unaided, although she can ride an adapted bicycle. For feeding, toiletting and dressing she depends on others, and playing with toys is a haphazard activity, satisfying in making noise and mess but frustrating where manual skills are required. Paula's vocabulary is extensive but her speech is limited by a weak chest, which restricts the voice box. She enjoys books, although reading for herself is difficult to master as her head control is not consistent. Focusing her eyes steadily on the words is interrupted by her constant head movements. For a child like Paula, all the obvious aids like sign language and computer keyboards are problematic. Specially designed seating and imaginative use of equipment are the ways forward, although many parents have reservations.

> "You have to ask yourself: Do our children need all this special equipment? All these chairs with straps....those standing frames ... they're so horrible... it can't be good for a child to be strapped in all the time. In any case it would probably be cheaper for people to hold them rather than to buy that expensive dehumanising equipment. If only he could keep still."
>
> (Thomas' mother)

The severity of impairments depends on the extent of the brain damage. Thomas, Helen and Paula represent those at the severe end of the continuum. Matthew, aged four, is diagnosed as having ataxic cerebral palsy. He can walk, although he is unsteady, easily losing his balance when trying to keep up with others. His arms function well so that he is independent in self-care and he writes and draws well. Speech, hearing and eye-sight are good as are the results of cognitive testing. When undergoing a programme of conductive education, which seemed appropriate because of the concentration on walking skills, Matthew's mother noticed that he was the only child able to speak in the group and that he tended to copy the postures of other children.

> "I got really worried when he kept sitting with his chin on his chest, and waiving his arms around wildly. He can't keep up at the local mainstream nursery school, but I'm not sure whether this is suitable either. To be fair to the conductive education centre, he copies other children wherever he goes. He came back from the mainstream nursery school sucking his thumb: something he has never done before."
>
> (Matthew's mother)

Each child has a unique combination of symptoms, which change as the child grows and responds to therapeutic interventions. This is a condition where the extent of the impairments resulting from the brain damage only emerges slowly. It is not possible for doctors to predict outcomes precisely and this gives rise to frustration and anger on the part of parents. Wyatt provides the perspective of the medical profession. 'Having a diagnosis is both a strength and a weakness. It consolidates a programme of therapy, but may shut down hope of change and improvement which is so important to sustain if a child's potential is to be maximised'.[16]

Parents also experience ambivalence. On the one hand, many would like to know the boundaries on their child's disabilities. When these are not available their anger towards the medical profession, which may have its origins in birth traumas, may be intensified.

> "By eight months I knew something was wrong with David. He didn't sit up. One day I was talking to the physio and asked her whether it could be spina bifida or cerebral palsy. She wouldn't answer. I stormed out and asked the doctors. I had to ask because by then I was five months pregnant with Mark. The doctor said they had suspicions, but with cerebral palsy, it takes time to understand the signs. I think <u>they</u> knew by the time he was six months."
>
> (David's mother)

On the other hand, uncertainty allows for hope. Even if hope may be like chasing rainbows, investment may be made in seeking second opinions on diagnosis, alternative treatments and cures. This process is discussed in detail in Chapter 3 and in Section III, Chapter 5.

2.4 Causes

A duality of themes pervades the above profile of the nature of cerebral palsy; physiology and the clinical responses of medical research on the one hand, and social and emotional considerations on the other. The same themes are apparent in a discussion of causes. Medical research, though in many ways inconclusive, provides material for prevention and management. How parents perceive the causes of their child's condition stems in part from their understanding of how the situation arose. Cognoscere causas rerum is a normal human need!

Although currently there is very active research into the causes of cerebral palsy, and major advances have been made over the last decade in brain imaging techniques, there are still many cases where the underlying cause is 'largely unknown'.[17] Debates are about when the injury to the brain occurred: in utero, at birth or in the early days of life, possibly in intensive care units. They are also about what agent, for example, human error or a virus, caused the brain tissues to bleed and form scar tissue, which manifests itself in neurological damage.

In 1887 Sigmund Freud argued that abnormalities during birth may not be the cause of brain injury but rather the consequence of a pre-existing abnormality in the foetus. This approach was largely ignored until recently. It was the views of a British surgeon William Little, (1862) that birth complications were the most likely causes of cerebral palsy, that have influenced most strongly research and management of this condition. Considerable attention has been paid to improving obstetric care and managing labour so that infant mortality has fallen dramatically since the beginning of this century. In 1901, 149 in every thousand babies died before their first birthday; by 1992 this had fallen to just 7.[18]

Despite this reduction in still births and neonatal deaths, the proportion of children with cerebral palsy has remained steady. Stanley in Australia and Hagberg in Sweden, demonstrated a fall in incidence of cerebral palsy in bigger babies, but an increased survival in low birth-weight babies was accompanied by an increase in cerebral palsy in this group, leaving the overall figures almost unchanged.[19] Electronic foetal monitoring, caesarian sections and the induction of labour are techniques being used more frequently to reduce the risk of birth damage. There is concern about the overuse, possibly abuse of these techniques, in particular caesarian sections. Trowell has studied the effects on the development of bonding between babies delivered by caesarian section and their mothers.[20] Francombe, at the Middlesex University, is currently conducting a survey to gain some understanding of the 'amazing jump' in the caesarian birthrate.[21] He is concerned that fear of accusations of negligence is prompting doctors to perform caesareans to maximise the chance of a successful birth. Only 8 out of 51 hospitals in his survey over 2 years did not have an increase in caesareans. In London teaching hospitals the rate of births by caesarian section was over 20%. The national level in the United States, where there are justified fears of litigation, is 24.7%.

Research into causes of cerebral palsy has paid attention to low birth-weight infants, more of whom are surviving for longer as the result of the availability of special care techniques. It has been suggested that asphyxia at birth or during intensive care may be a cause of cerebral palsy, as may the consequences of their immaturity, such as intra-ventricular haemorrhage. New methods for non-invasive assessment of the brain using phosphorus magnetic resonance spectroscopy (MRS) are being studied at University College Hospital.[22] Results reported so far indicate that for asphyxiated babies, there was often a period of up to 15 hours after delivery when cerebral energy metabolism appears normal. A few hours later, brain cell death occurs.

The development of new imaging techniques for the assessment of the newborn brain since the late 1970s include CT scanning, or computer tomography, which use x-rays to produce images of the brain. With magnetic imaging (MRI) cross sectional pictures are produced, whereas with MRS, information about metabolic processes is obtained quantitatively. Dubowitz asserts in his review of this application of magnetic resonance studies to cerebral palsy, that this 'advanced technology will open up a whole new field of possibilities for the early detection of abnormal brain function'.[23]

This research has crucial significance both for social policy and for parents and their children. Griffin, strikes a note of alarm at 'medical science's increased ability to save premature babies, which should be balanced against the costs and problems it causes'[24]. It is reported that it is now possible to save the life of a baby weighing as little as 1lb (500grams), with consequent lengthy and costly hospital stays, special education needs to be considered and an increasing number of severely handicapped babies to be supported by relatives, friends, health professionals and the community. The issues of euthanasia and abortion are the inescapable consequences of this cost to society approach to disability. This was not a main focus for the interviews but was raised by John's mother who had consented to abdominal surgery for him at the age of five. John had severe spastic quadriplegia, probably caused by placenta interruptus at birth.

> "I told the anaesthetist not to resuscitate him if anything went wrong during the operation. I've never been able to hold him easily. He used to look at me as if he was asking me for help, and it made me feel guilty. He went in and out of hospital and he seemed to be their baby not mine."
>
> (John's mother)

Knowingly proceeding with a pregnancy when there is a probability of the baby being impaired is a dilemma created by the progress of medical research. Amniocentesis can detect early signs of such genetic disorders as Downes Syndrome, and the increasing availability and accuracy of ultrasonic scans showing the development of the foetus in utero, makes prediction more possible. Piontelli in her study of foetal observations using ultrasound, provides vivid descriptions of the rich complexity of movements one could observe right from the early stages.[25] Long before mothers could perceive any of these movements, ultrasound showed that in the womb their babies could suck, stretch, scratch, yawn, rub their hands and feet. Thus there is potential to study foetal development and monitor progress throughout a pregnancy. Early detection removes the joyous mystery of childbirth. That is the price some may be willing to pay for a healthy, able child. As yet invitero surgery, already available to correct some foetal conditions including heart defects, has not been developed for brain damage.

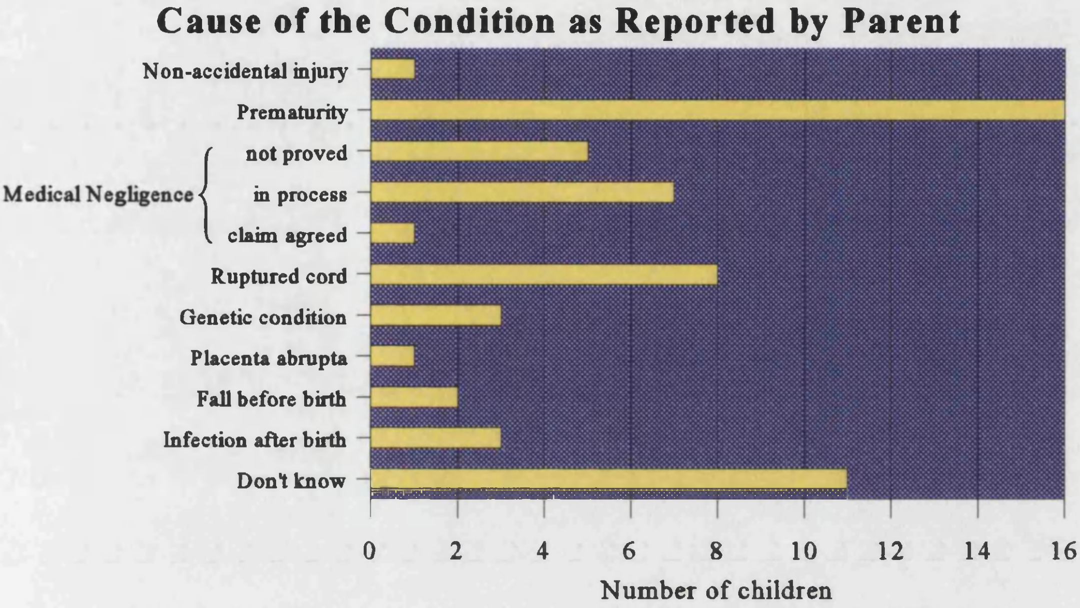
Research into causation has shifted in recent years to studying the likelihood of brain damage having been sustained by the foetus in utero. This reversal to the views of Freud in the nineteenth century has developed from the theory that the causes for premature births, 'small for dates' babies and slow foetal growth may be found in the pre-birth environment. Stanley and Blair quote a study in Papua New Guinea, where severe iodine deficiency has caused spastic diplegia.[26] It is known that 14% of children with congenital rubella have cerebral palsy. Research by Stanley and Blair in Australia suggests a strong relationship between intrauterine growth retardation and cerebral palsy over 34 weeks gestation[27]. Foetuses with damaged or defective motor areas of the brain may grow poorly or be particularly vulnerable to further insult.

The Times reported on 1.3.94 that Dr Martin Bax is hoping to launch an international, ten-centre study of 1,000 children with cerebral palsy to pinpoint the nature and timing of the brain damage, funded by the Little Foundation.[28] He is reported as saying that the main problem with research into causation is lack of co-ordination and underfunding. 'People are willing to put their pennies into a tin to help people with a distressing condition but are not so willing to contribute money to prevent it.'

For parents in this study, while prevention and avoidance of reoccurrence were important, they were most anxious to find an explanation, which might help them to adjust to its consequences, since for them cause and outcomes were inextricably linked. Without prior medical knowledge, or even access to intelligible explanations, distress is heightened by not knowing what happened.

Figure 6 shows explanations provided by parent participants for their child's birth damage. The range of difference is interesting as is the number of premature babies. The group of 'don't knows', may include some whose babies sustained damage in utero.

FIGURE 6



The need to ascribe blame and to undergo a period of grief for loss after the birth crisis is significant for the parents of a 'damaged baby.' These feelings are particularly acute for those who suspect medical negligence.[29]

> "We arranged a very special baptism for Paula. We had gone through such horror and we wanted to acknowledge her presence as our child despite what the hospital had done to her. The medical negligence claim is a necessity to give Paula the quality of life she has lost. It will not make me feel better, but what concerns me is that guy is still out there capable of doing it again. Once I had said Paula's name I had the most positive possible image of my daughter. I don't see disability when I see her."

(Paula's father)

In their active campaign to promote the cause of disabled people, Oliver and Barnes would not find this denial acceptable.[30] However, they themselves operate denial to some degree, by emphasising the irrelevance of theories of grief and mourning. It will be seen in the subsequent chapter how powerful these feelings are for families in this study, and how denial of them by service providers and professionals affects the quality of the services, which Oliver deems should be provided as priorities.

Finnie advised parents 'never to be overawed by the medical profession. Do not hesitate to ask....all you have to do is ask for medical explanations'.[31] It was striking in the interviews that trying to understand cause and to apportion blame consumed time and emotional energy long after babyhood. It always featured in the numerous assessments and second opinions sought by parents discussed in Section III, Chapter 5. Where blame could not be ascribed to medical negligence, parents still harboured grievances.

> "My husband dealt with our possible claim for negligence. He saw a QC who said the case could go on for 8 or 10 years and we would probably lose. I did my best for my unborn baby. I didn't smoke or drink or eat junk food. I personally believe that I should have been monitored. It was Bank Holiday and there was agency staff on the ward. At first they said she was just lazy, but after a bit of a row they referred us to Great Ormond Street hospital. She was diagnosed as having spastic quadriplegia. They said I could have had an infection, or that she could have been distressed in the womb or even had a stroke before she was born."

If no obvious cause presents itself, imagination takes over.

> "When Rachel was born, my mum said, 'look at her, she's absolutely perfect', but by 4 months she wasn't lifting her head. I've no idea why it happened, but it could have been the consultant's fault. None of my other children was under the same consultant. I can't prove he did anything wrong, but I know of other families whose children were born at the same

> clinic and developed problems. On the other hand, I did have an au pair and she may have dropped her, I never did, though I tripped on the stairs with my son."
>
> (Rachel's mother)

It was certainly a feature of this group of participants who were largely middle class and well educated that they expected to receive explanations.

> "My husband and I did science at university, so we're trained to ask facts and to come to our own conclusions. We were told that the medical staff felt stressed by our questions...but we'd lost one baby and had another with brain damage. How could we accommodate the feelings of staff?"
>
> (Helen's mother)

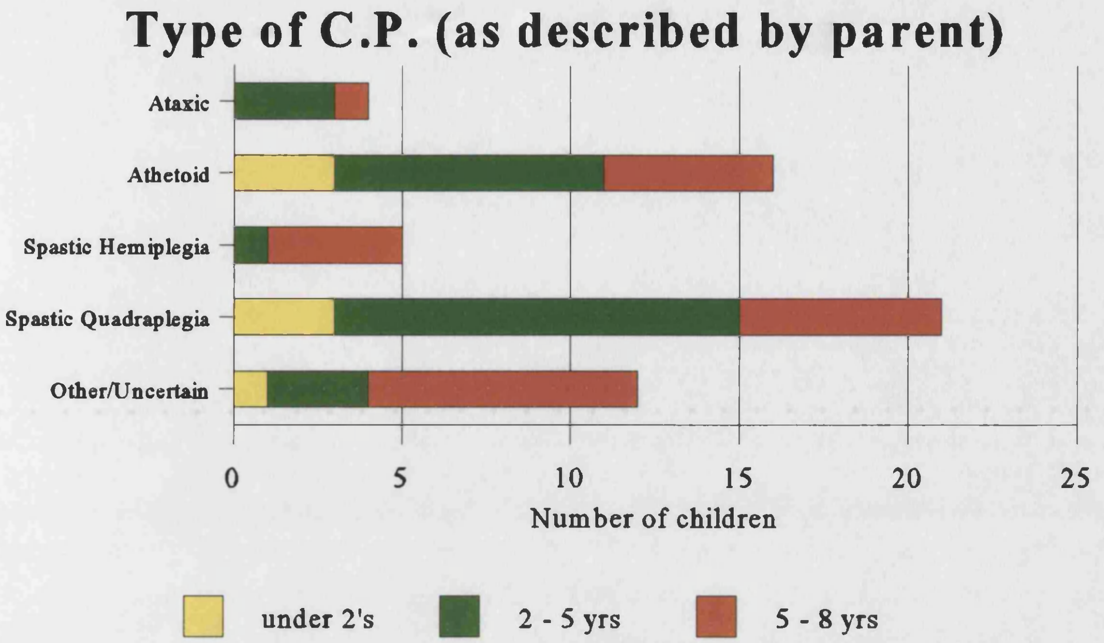
2.5 Types

Classification of their child's condition into types is as important to parents as causes, but this process is equally complex and inconclusive. Cerebral palsy may be classified either by types relating to the site in the brain where the damage occurred, or by the extent and nature of the resulting motor disfunction.

There are three main types of cerebral palsy: spastic cerebral palsy, which is caused by damage to the cortex and presents as muscular stiffness; athetoid cerebral palsy, caused by damage to the basal ganglia and presenting as ill-co-ordinated movements; ataxic cerebral palsy, caused by damage to the cerebellum and presenting as unsteady, random movements.

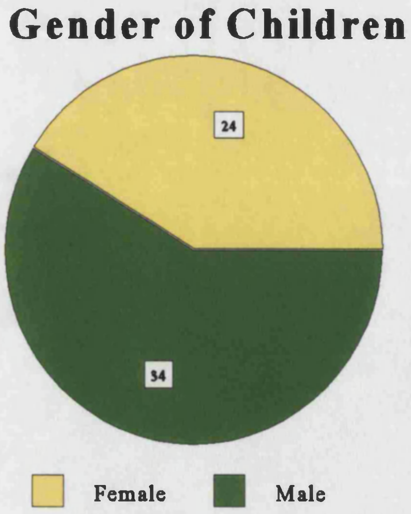
Each of these types may be severe, medium or mild. It is most common for children to appear to have mixtures of more than one type or to present in different ways at different times.

FIGURE 7



Parents were asked in the interviews how they would describe their child's condition. Although this could not be a random sample, the number of children described by their parents as having spastic quadriplegia (42%) is consistent with national figures, (Spastics Society) and the majority (60% of the total participants) were boys, again in line with national averages.

FIGURE 8



It is not usually possible for paediatricians to predict accurately which type will develop even when it is known that brain damage has definitely occurred at birth. Caution is usually exercised in ascribing a definite label to a child's condition.

> "It's not like Downes Syndrome. These babies aren't named when they're born because you can't see it. Eventually they did a full assessment at the Wolfson Centre. I should have been told straight away instead of being allowed to go out of my mind with worry. I had got to the point that I wanted to leave him in the hospital."
>
> (Sam's mother)

The usual way of finding out is for physiotherapy to be started as soon as possible and to adopt a wait and see approach. Inevitably this uncertainty adds to the distress experienced by parents about the initial diagnosis, and confirms for some their lack of confidence in their medical advisors.

> "By Christmas Kate was scissoring her legs and her limbs seemed to alternate between being stiff and floppy. The health visitor kept saying 'she's fine. don't worry' but we wanted the facts. The G.P. was avuncular, saying she had problems. This wasn't enough for us. We couldn't handle it unless we knew what she'd got. We didn't want to hear cerebral palsy but at least when they told us we knew what we had to contend with."
>
> (Kate's mother)

Referral to a multidisciplinary team of physiotherapist, occupational therapist and speech therapist is intended both as an assessment tool and as active treatment. For parents uncertainty breeds searching behaviour. Many in this study, dissatisfied by the diagnoses provided by the NHS, sought second opinions, travelled across the country or even across the world disrupting family life and incurring financial and emotional costs. It is worth speculating whether, if it had been possible for them to be given a definite diagnosis, including causal explanations, typology and specified treatments at the outset fewer of them would have embarked on a series of inconclusive assessments or sought alternative therapies.

Uncertainty about type contributes to the vulnerability of parents, who may make enormous sacrifices to attain uncertain information and questionable treatment advice. An Indian civil servant arranged a transfer to the Indian Embassy in London so that his daughter might be assessed, treated and possibly cured. A Canadian diplomat arranged a posting in London so that his son could be assessed at Great Ormond Street Hospital and attend the conductive education Centre. A Moslem family flew to Canada to consult a relative who was a doctor. She was told that her son, diagnosed as a slow learner in the UK had spastic cerebral palsy and would never walk.

Transfer from the local hospital, where the damage was sustained at birth to a teaching hospital was an ambition achieved by the most articulate and persistent.

> "My GP was happy to deal with specific conditions like asthma where he could prescribe a treatment but when he saw cerebral palsy on the card he said 'What do you do for that!?' Eventually Lucy was referred to GOS for enlarged kidneys but I'm working on getting her complete care transferred there. They've been brilliant about everything including sorting out my Poll Tax. If you get a letter from GOS everyone jumps!"
>
> (Lucy's mother)

The Spastics Society provides a full day assessment by a multidisciplinary team at the cost of £70. This is separate from the society's equally expensive assessment for suitability for conductive education either in the UK or in Budapest. Moving through multiple assessments, some for treatments which may be expensive, disruptive or even bogus is the road along which many parents proceed because they need a clearer definition of the condition and some hope of improvement.The assessments must be as stressful for the child as for the adults.

By the age of about three years the extent of a child's impairments becomes more defined and the longed-for label may be applied, even if this is that the child's condition is a mixture of types. Some parents seemed to take a pride in their child's unusual presentation.

> "He's athetoid in the house but spastic outside!"
>
> (Mark's mother)

> "She's not a classic case, a tendency towards athetosis but with floppy limbs, with joints which go the wrong way."
>
> (Angela's mother)

For a short period, the conductive education centre attempted to divide the children into groups categorised by type for treatment: athetoid children are expected to learn more quickly. The experiment failed because most children had a mixture of impairments and the ataxic children were too few in number. Parents seemed to prefer the diagnosis of athetosis which was reputed to indicate higher intelligence levels. In terms of a hierarchy of disability, being physically handicapped is preferable to being mentally handicapped or both.

The passage of time also allows parents to find some acceptance or accommodation with the condition; the round of assessments comes to an end and some decision is reached about appropriate treatment. The parents decide themselves how to describe their child's condition and the issue of type reduces in importance.

2.6 Outcomes: Impairments and Disabilities

A more useful classification and one favoured by participants is by extent and nature of the effects of the brain damage on the neurological system. Questions in the interviews aimed at discovering how carers perceived their child's disability elicited responses which might be grouped in two ways; either they could be described as severe, medium or mild according to the extent to which they could achieve self-care, and social and educational tasks appropriate to their chronological age; or according to the site of the impairment, for example left or right-sided hemi-plegia, quadraplegia, ataxia (poor balance). Associated with the condition may be epilepsy, squints, sight and hearing impairments, speech and feeding disorders, and mental handicap.

The use of the term 'mild' may be considered to be reassuring by those making the diagnosis, but parents are usually too distressed to recognise attempts to ease their pain.

> "I had high blood pressure before he was born and I think he was short of oxygen. He was slow to feed and he didn't develop, but I didn't want to see it even though I'm a paediatrician myself. My friends, who were doctors didn't say anything although they were really worried. I took him to my boss and she said it was mild. I got cross . He didn't walk until he was 3. I thought 'its not that mild actually'. Now I always listen to mothers."
>
> (Paediatrician/mother)

The range of outcomes varies widely along a continuum from the child who only has "a bent arm which she can usually straighten except when she is tired or unwell; then she goes back to square one despite all the physiotherapy she has had," to the child described as "almost a vegetable, hearing and sight impaired, a bundle of epilepsy unable to understand or do anything independently."

The policy implications for children with such different capacities are considerable as will be seen in subsequent sections. The first child attended mainstream school, did not require a statement of special educational need and no longer needed physiotherapy; the second needed a care package including medical and social provision from a number of professionals.

Children with cerebral palsy have in common disorders of movement. Mobility is prioritised by parents as a means to greater independence. Figure 9 shows that in this study, grouping children by age, none of the under two's could walk; none could walk unaided in the two to fives group, although 6 could walk with equipment; 7 of the over fives could walk unaided (one could run!), but 15 could not walk at all. Of those children in the study unable to walk, only 12 could sit unaided (figure 10).

FIGURE 9

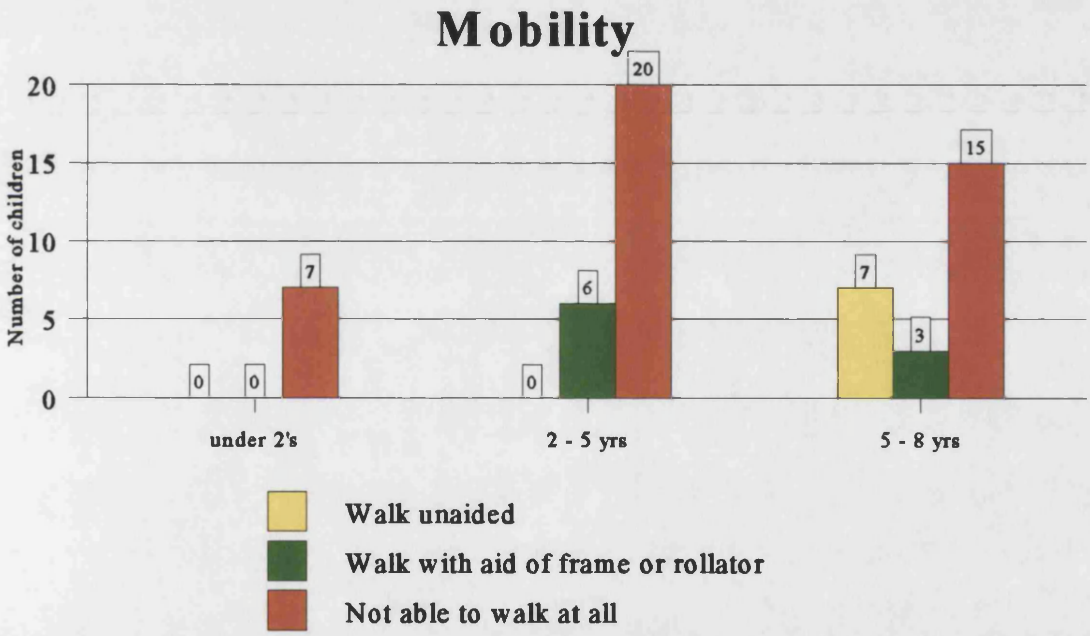
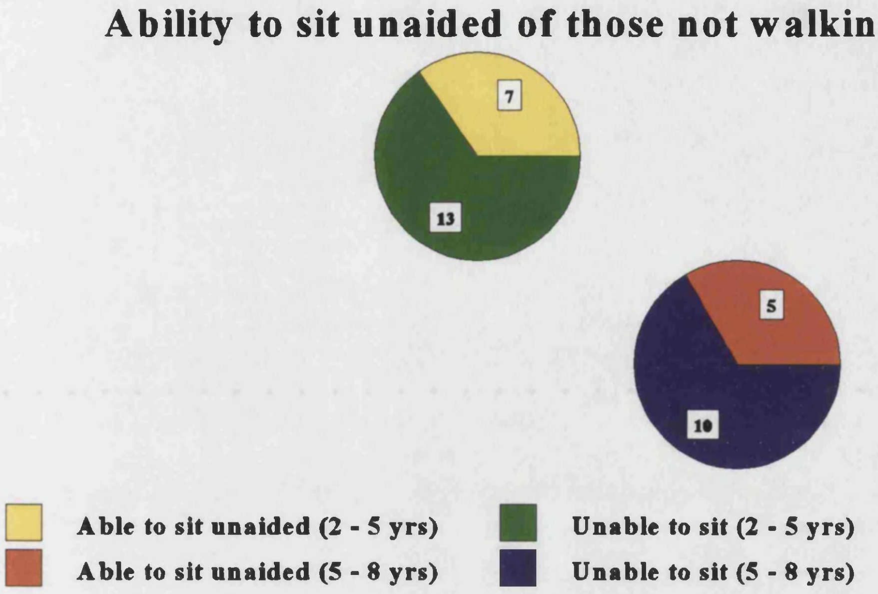
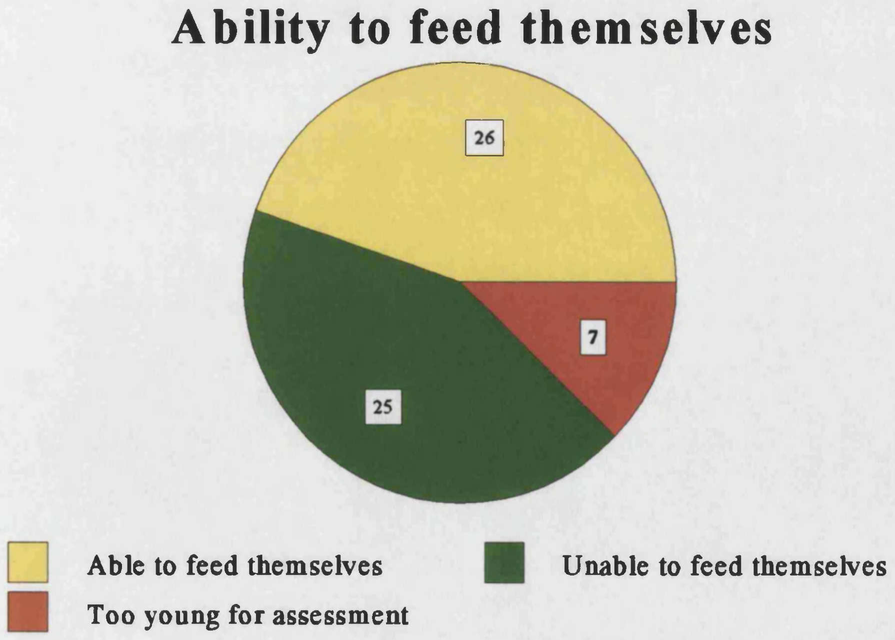


FIGURE 10



This identified a recurrent and important theme, which will recur throughout the text that these are highly dependent children who, despite intensive therapeutic intervention using a range of techniques, are unlikely to be able to achieve independence from people and equipment. Figure 11 illustrates this point further by showing that only 26 children could feed themselves.

FIGURE 11



2.7 Interventions

Acquisition of a knowledge base about the nature of a disease and how it is manifest for each child, should facilitate seeking appropriate treatment. Unfortunately it is characteristic of cerebral palsy that medical treatments, management interventions and systems of care are equally uncertain, riven with professional dissention and inconclusive research. Parents recently traumatised by their child's diagnosis and struggling to manage their lives including caring for their baby with disabilities, begin to find their way through a maze of conflicting professional opinions, inter- agency disputes, and controversial alternative approaches.

From the medical perspective, brain damage cannot be repaired. Medication has limited usefulness in improving muscle tone.[32] The drugs most commonly used to control spasticity and rigidity are diazepam (Valium), baelofen (Lioresal), and dantrolene (Dantrium). Side-effects include drowsiness, nausea and headaches. Dantrium affects peripheral muscles and may result in severe liver dysfunction.

Corrective therapies by the multi-disciplinary team are prescribed, although there is no conclusive evidence of effectiveness. A study by Kanda, et al in 1984 suggested that treatment begun before the children were nine months seemed to help them walk earlier compared to those who started therapy after one year of age.[33] Since it is impossible to locate children with identical manifestations of the disease accurate comparative research is restricted.

It was of interest to observe children with cerebral palsy in residential care in Kingston, Jamaica. The absence of therapeutic intervention meant that children displayed gross motor disfunction and deformities. Their passive lives contrasted painfully with those in the UK with access to therapeutic intervention. This cannot provide the longed-for cure but may be able 'to offer parents help with management, ensure optimal functioning and prevent a lot of things happening that stop a child from walking'.[34]

Simultaneously medical advice is sought about the many conditions like deafness, oesophageal reflux (vomiting), epilepsy and squints which require specialist treatments. In the London area this usually means hospital appointments at different specialist centres.

> "We attend 5 hospitals with Sally. Hillingdon is where she has her therapy, but they referred her to GOS for her kidneys, Harefield for her heart, Stanmore for her spine and the London for gait analysis. The appointments are every 3 months, except if they find something and then you have to go back earlier. You always have to ask them, prompt them into telling you anything. They just ask 'how is she?' and tell you she's doing fine."
>
> (Sally's mother)

A cluster of factors seems to drive parents towards alternative medicines and treatment approaches. Over and above frustration with conventional methods, searching may be seen as an aspect of unresolved grief, guilt, the need to repair. Rationally, it may be possible to acknowledge the absence of cure; emotionally every avenue should be explored. There may also be feelings of being unable to take responsibility for sustaining the treatment programme at home and wanting the experts to take over. The full impact of the alternative treatments pursued by parents will be discussed in Section III, Chapter 7, Section IV, Chapter 11 and Section V Chapter 14.

> "You always hope your child will improve. You get worn out with all the treatment...feeling that you should always be pushing harder. You feel a lot's been taken out of their childhood but you have to go on as you worry for their future."
>
> (Adam's mother)

2.8 Conclusion

There is a sense in which the writer feels entangled in the web of complexities which are the nature of this condition. Therapists may find clear pathways by adhering to professional boundaries; social workers may direct attention to their needs-led services; teachers to special needs in the classroom. It is for parents to take an overview and therefore to have some knowledge about the ambiguities of diagnosis, types, impairments, treatments and services associated with cerebral palsy.

There are no easy routes to improving on many of the issues addressed here. The next chapter attempts to convey the implications for the child and the family of the clinical perspective.

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Chapter 3

Cerebral Palsy: Clinical and Social Aspects of the Condition

> "The nursery children at the conductive education centre lined up behind their assortment of walking aids (sliding ladders) for the last phase of the school day: to walk to meet their mothers at the door. Ester's arms flailed everywhere: she dribbled and protested at attempts to instruct her to hold onto her frame. The door burst open. In ran her younger sister. She darted across the room, scooped up a doll from the floor and brought it over to me before running off chattering happily to herself to find other toys. It was a poignant moment. As I had observed in the corner over several weeks, none of the children with cerebral palsy seemed to notice me. What a contrast to Ester's able sister!"
>
> (extract from observation)

It is not surprising that literature fails to provide detailed accounts of the lives of young children with cerebral palsy. Few can communicate verbally; attention and energy seem to be consumed in controlling involuntary movements; eye contact is rare because of the position and movement of the head. At first, watching is a shocking experience. Gradually the observer becomes absorbed into their world, lulled into their ways of being; the outside is forgotten, until incidents like the one described above provide a rude awakening. For accounts of these children's lives, writers are dependent on what parents say. In order to sustain family lives some sort of denial of the reality of the extent of their children's disabilities is necessary.

> "When I ask my friends how they cope, they all agree that denial is their most effective means of getting by. I don't think of Sam as being disabled, he's just Sam to me with his character and personality. It's only when I go somewhere like the park where there are able children of his age that I get upset. I try to avoid places like that."
>
> (Sam's mother)

This chapter attempts to consider the clinical features of the condition and their social consequences. The accounts of these children's lives are derived from interviews with their parents and from non-participant observations.

3.1 Effects of Neurological Damage

It is misleading to think only in terms of muscle damage being confined to limb movements. Muscles such as those in the mouth which control speech and eating may be impaired, for example, or the eye muscles may not function well causing sight or focusing problems. It was noticeable when observing the children that many had squints.

There emerges therefore a condition with unknown and multiple causes with different outcomes. Every aspect of everyday living may be affected to some extent, requiring time, energy and ingenuity to surmount presenting difficulties. From the child's perspective, to be unable to explore the environment voluntarily, or to control ones own actions may be unattainable. 'In simple acts like climbing up a step and jumping off again, or running up and down a grassy slope, able-bodied children display an effortless spontaneity, but children who have disabilities that restrict mobility may be denied these simple expressive pleasures and the opportunities for growth they engender'.[1]

Take dental care, for example. Children need regular dental check-ups and training in dental care. During the post-war years standards of dental care have risen, but Curzon and Fayle have shown that there has been no improvement in the standards of dental care received by children with cerebral palsy. They explain this finding by reasons caused by the nature of the condition.[2]

Getting into the dental practice is the first problem. They quote a study in Leeds (1989) which showed that only fifteen percent of dental practices were on the ground floor. Having obtained access, children with cerebral palsy usually take more time to treat: positioning in the dental chair and keeping the head and limbs still present problems. Dentists need to consider both the practical aspects of performing treatment, and also communication skills to reduce the normal fears that people experience when going to the dentist. Treating tense and anxious patients requires skill and special care is required for these children, who have probably already had excessive and sometimes painful experiences of numerous, different medical interventions. Unfortunately, as Curzon and Fayle point out, the NHS capitation fee is low and therefore time becomes an economic factor in a small dental practice, which has to be run as a small business. Their recent research has shown that continuous, conscious sedation with a new drug, Propofol, has been very helpful in enabling children with cerebral palsy to accept dental care. In terms of dental care at home, parents may have to participate much more actively.

Within the normal day for a parent, including rehabilitative treatments, chasing social and educational resources and meeting the usually daily living needs of the family, it must be difficult to carve out enough time for dental care, unless it becomes a priority because of tooth-ache!

It is the nature of the parenting task to prioritise their child's daily needs, which change as the child grows and develops. This shift is usually in the direction of greater independence and the need for less direct provision of care. The young child gradually assumes responsibility for self-care, so that by the age of five attendance at school without one to one care is attained. Perhaps the most striking feature of this condition is that it is characterised by failure to reach milestones, which demonstrate growing independence. Parenting, therefore, has to be more participatory and for those children with severe impairments, indefinitely so.

This unavoidable dependency seems to grow into an almost symbiotic duo of parent and child: it is necessary to know so much about each child's unique movement patterns and how to respond to them most effectively, to maximise potential and to ensure a child's comfort. For this reason it is not easy to provide substitute carers (baby-sitters) for example; mothers do not easily trust others like nursery nurses and teachers to be able to replace them in their absence, and conflicts with the many professionals providing treatments and services become strained by what appear to be a mother's 'over-intrusive' attitudes. Conversely, well-meaning helpers need to learn about the child's complex physical needs in order for the child to be safe.

> "Social services sent a helper when Zara had been ill for several days. I hadn't slept, and I think the person who came was unnerved as Zara looks desperate when she is ill. Whoever feeds her has to sit here and be trained by me. As a single parent I manage with the help of a nurse paid for out of my interim compensation. I know there is no miracle cure so I have to aim at a good standard of life for Zara, even if it seems too much for me on my own sometimes. I know of one person who committed suicide under the pressure."
>
> (Zara's mother)

What ideally should be a 'partnership with parents' may turn into a battle. Ester Cotton commented in an interview at the Hornsey Centre for conductive education in north London, that 'parents have changed over the years from being grateful and humble in receiving advice about their children, to being suspicious and questioning': children could not be treated without the active involvement of parents, (principally mothers) in the process.

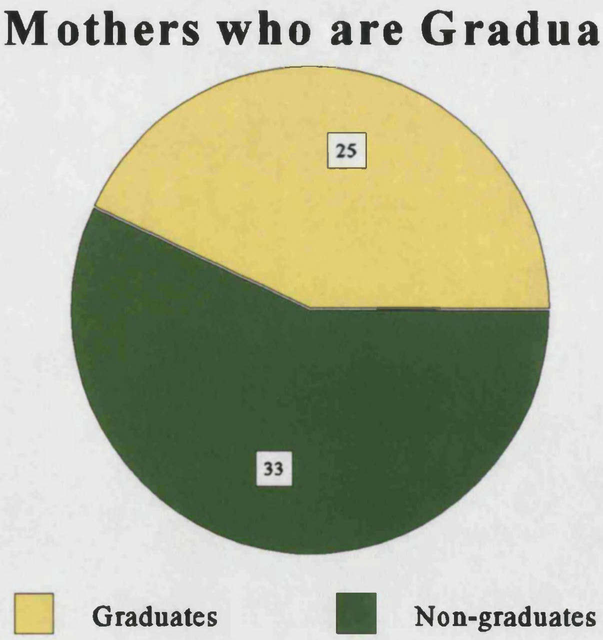
3.2 Intellectual impairment

The intense, dependent relationships between children and their mothers apparent in this study relates directly to the nature of the condition. It will be seen in subsequent chapters, that mothers become therapists, social care planners, teachers and advocates over and above their usual roles as mothers. Their intense love and confidence in their child's abilities is striking. An almost inexhaustible need to leave no stone unturned in search of means to improve the quality of life, seems to be driven by hope and, in many cases, conviction that cognitive functioning remains undamaged. In the painful process of accepting the physical handicap designation, there seems to be a driving force to deny an associated mental handicap. The 'active mind trapped in a damaged body', is described poignantly by Christy Brown.[3] He managed to break out of his condition of 'crooked mouth, twisted hands and useless limbs' to paint and write. In the early years of life, most mothers tend to stress cognitive abilities even when they are not easily identifiable.

> "Nicholas lay prone on the couch during the interview with his mother. She described him as being 'not a classic case, having a tendency towards athetosis, but being too floppy, because all his joints go the wrong way.' Despite total dependence and inability to communicate , her active planning was searching for a suitable school. 'It's education he needs, not nursery care.' For the interviewer, there seemed to be a large discrepancy between these aspirations and what could be seen."
>
> (extract from interview notes)

This dimension to the condition may be heightened in this study involving parents with high educational attainments themselves. Of the mothers interviewed, 25 were university graduates (figure 12).

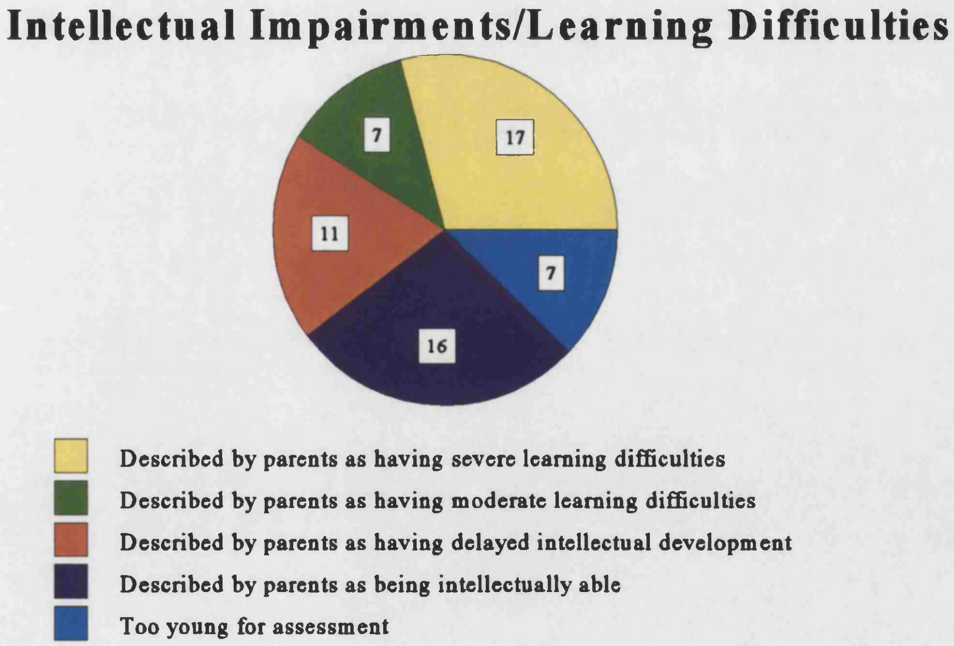
FIGURE 12



> “Paula's never going to be normal physically. At best it's going to be walking round the house. Walking's not vital, but it hits me as I am going to work on the train. Paula will never do that. I have a stubborn view of the future; my expectations for her academically have no boundaries; I see ability, not disability when I see her and I want her to go to university.”
>
> (Paula's father)

In reality, however, cognitive damage may be a feature of cerebral palsy and the extent of this damage varies along a continuum from severe to mild as does the physical damage. Parents’ descriptions of their own child’s intellectual impairments is shown in figure 13. Albeman and Nicholson estimate from their research at the Wolfson Institute, that about thirty five percent of children with cerebral palsy will have severe learning difficulties as well as disorders of movement.[4] They predict that 'the marked rise in the survival of very immature and low-birthweight babies ..... will need increased medical and paramedical care, parental support and appropriate educational provision'.

FIGURE 13



The problem is that controversy surrounds the subject of accurate intelligence testing and these children have the added problem of being unable to use conventional testing methods, which require manual and verbal skills. Under stimulation and age-inappropriate expectations may result from poor physical and delayed emotional development. Intensive concentration on corrective interventions for physical problems in the early years may also cause cognitive development to be relegated to a secondary position. Indeed, the conductive education scheme consciously advocates prioritising attention to motor skills. 'As with the concert pianist and ballet dancer, who practice for many hours daily to perfect their finer movements and skills, the brain-injured child needs hours of repetition and reinforcement to establish a longer attention span and new normal motor patterns'.[5]

Whether or not children with cerebral palsy have sustained cognitive damage, physiological in origin, all of them might be categorised as having learning difficulties because their access to learning opportunities is restricted. For example, children who do not crawl cannot explore for themselves the feel, shapes, size and smells of things in a room. Choice of toys to play with, objects to handle and discover have to be handed to them. The importance of play and range of opportunities for expanding knowledge and skills cannot be overestimated in the pre-school years. Child psychologists have studied the meaning of play for healthy emotional development and to expand knowledge.[6] The sheer fun and pleasure derived from it cannot be overestimated, for in the words of Schiller, it provides for 'the expenditure of exuberant energy'.[7]

This discussion of intelligence levels is the essential basis for understanding parental involvement in the education statementing process, discussed in Chapter 8. It underlies parents' reluctance to use services specifically designed for children with learning difficulties, such as Portage. It is no accident that few parents in the study were associated with Mencap, preferring to refer to the Spastics Society as more appropriate for their children's physical disabilities. Parents' perceptions of their child's needs appeared to be skewed in this way.

> "They used Andrew in a teaching session at the hospital in front of a load of students. They lifted him up like a rag doll saying there's this and that and special schools for the mentally handicapped-this freaked me out. No way was he going to one of those."
>
> (Andrew's mother)

Educational attainment of children with wide-ranging handicapping conditions has progressed rapidly in the post-war years, as emphasis has shifted from concentrating on disabilities and focusing on things a child is able to achieve. The intention is to improve the quality of a child's life by concentrating on abilities that are unimpaired and developing aids and adaptations to compensate for disabilities.

Gone are the pre-Warnock days when children might be deemed 'ineducable' by the local education authority. 'Education as we conceive it, is a good, and a specific human good, to which all human beings are entitled. There exists, therefore, a clear obligation to educate the most severely disabled for no other reason than that they are human.'[8]

3.3 Health Care

Despite the heavy medical emphasis given to cerebral palsy, these are not usually sick children, nor are their lives threatened by the condition, except where motor dysfunction affects feeding and breathing. Although more prone to accidents and more vulnerable to infection, modern pharmaceutical progress has contributed to the longer survival of these children and has ensured for them healthier lives. As children reach the age for full-time schooling, (as will be seen in Section IV) the educational rather than health service providers takes the lead in provision of need.

Nevertheless, hospitalisation as sick children may be more frequent than for able children as the usual childhood illnesses are likely to be more severe and difficult to treat. For example, two year old Cathy had been admitted to hospital four times in the previous year with dehydration. A stomach upset became a life-threatening condition for her, because of a combination of factors: difficulty in chewing and swallowing, her usual intake of small meals and her very active rehabilitation programme.

Rehabilitative programmes are provided on an out-patient basis, but some corrective surgical interventions require hospitalisation. Surgical interventions are controversial, and their success rests on an appraisal of the effects of any intervention on other parts of the body. Achilles tendons and abductors may be altered in length, for example, and surgical techniques may be used to prevent curvature of the spine and hip displacement. From the child's perspective, surgery may be yet another painful and intrusive experience designed to increase potential, but with uncomfortable and long-lasting effects. To be of any value, surgery needs to be followed by prolonged and intensive physiotherapy to which parent and child need to be committed.

Accepting the offer of surgical intervention, or actively pursuing it may mean prolonged periods of illness for an otherwise healthy child. From the perspective of parents, seeking ways forward, however, surgery must be included in the range of choices sought in the total process of maximising potential.

> "I would deem myself as culpable if I did not pursue every avenue to greater normalisation for my daughter. We took it on ourselves to get a second opinion for her at Great Ormond Street Hospital and, when the surgeon told us we would have to wait at least eighteen months for a bed, we paid fourteen hundred pounds for her to have the operation privately. We will be in hospital for a fortnight and she won't be able to go back to school for three months. It will put her back a year."
>
> (Nichola's parents)

Surgery means that the child with disabilities becomes temporarily a sick child. Sometimes this is the result of parental choice, medical advice and the availability of treatment facilities. Sometimes it is the result of deformities that develop as the result of spasticity. Funded by the Spastics Society, Scrutton[9] is currently studying the problem of hip dislocation in the Thames Regional Health Authority Area. His concern is that 'children who are severely delayed in walking, and particularly those with stiff legs, are at risk of having a problem with their hips. Some hips very gradually dislocate causing problems with movement development, posture, and later on pain.'There is always the potential for muscular problems to cause orthopaedic problems. Monitoring is needed and surgical intervention is a possibility, although disagreement between orthopaedic surgeons, paediatricians and physiotherapists persists as research progresses. This, therefore is yet another of the uncertainties characteristic of this condition, which results in parents having to make choices.

There are some children who have medical conditions in addition to cerebral palsy, or in association with it. Peter had a genetic disorder of his metabolism, Propionic Acidemia, which may have caused his brain damage. It was diagnosed too late, but controlled by a high calorie, low protein diet. Gastro-Oesophagal Reflux is another associated condition, which if left untreated means chronic vomiting, painful swelling, inflammation of the oesophagus and recurrent aspiration pneumonia.[10]

Another aspect of cerebral palsy with medical and social implications is epilepsy. Most children suffer convulsions, though the availability of anti-convulsant drugs seemed to make management of fits, for mothers in the study an unremarkable task, compared with the other demands on their attention. It is worth pausing to reflect that parents, whose child has epilepsy alone without the other complexities of cerebral palsy, tend to find this a difficult condition to manage. Reports that parents of chronic epileptic children have a high rate of psychiatric disturbance, related to the stress of managing the condition[11]. For parents of children with cerebral palsy, so many things have to be taken in their stride, that in the interviews management of anti-convulsants was rarely mentioned.

> "Sara used to have 40 petit mal attacks per day, but they've been reduced to fifteen or twenty with her new drugs. Great Ormond Street Hospital had run out of ideas, so we're now under University College."
>
> (Sara's mother)

3.4 Daily Living

For most children with cerebral palsy, feeding presents difficulties. Many cannot chew and swallow easily; they may spill much of their food as the result of involuntary movements; they may be unable to close their mouths voluntarily so large quantities dribble out. Patient feeding and constant cleaning up demand time and an even temper on the part of carers.

> "Nicky is so difficult to feed because she tongue-thrusts. When it was snack time at the conductive education centre I was supposed to sit opposite her, hold her head in the middle, put the spoon in her mouth and hold her on the box all at the same time. She cried all the time because she was hungry and I felt like throwing her through the window."
>
> (Nicky's mother)

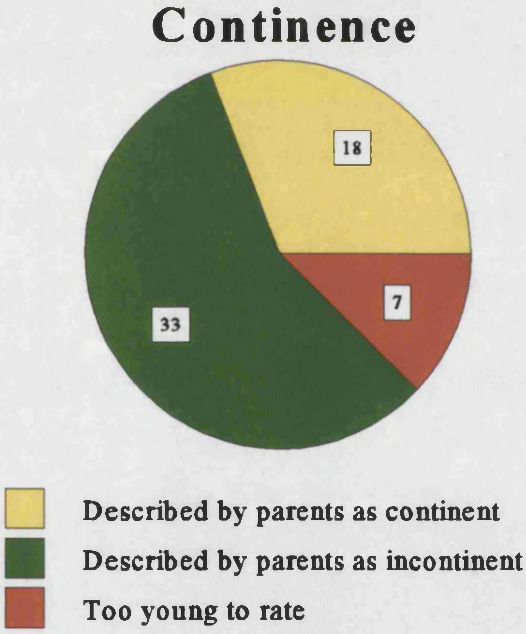
'Undernourishment may not be recognised or worse may be accepted as an inevitable consequence of cerebral palsy'.[12] Sullivan attributes growth failure, weak muscles, possibly worsening of the existing neurological impairment to undernourishment. Weaker muscles in the respiratory system reduces the cough reflex and increases the risk of aspiratory pneumonia, and inhibits speech development.

His proposed solution to the problems of undernourishment, a Percutaneous Endoscope Gastromy, involves a feeding tube being placed into the stomach through the abdominal wall. This method of feeding has many advantages including being unobtrusive and quicker than oral methods. It is, however, an unsocial way to eat and removes the child further away from a normal life-style. His finding that children may end up overweight by feeding in this way suggests that the method may only be used in extreme situations. Balancing the social and emotional needs of children against physiological ones has to be considered.

Mark, who attended the conductive education Centre during the period of observations, was fed in this way. While the other children in his nursery class sat round the table for lunch, assisted by the conductors, Mark aged 3, was laid on the floor in the middle of the room, his stomach exposed, to have white fluid injected. It appeared to be an undignified way to receive food, although the other children paid no attention, partly because eating their own food was such a difficult process for them, and because none of the group could speak.

Continence is an issue which concerns all parents in the second year of a child's life (see figure 14) Those children who are most severely disabled may never be successfully toilet-trained. Free nappies are available for children over two years, although finding out about provisions such as these seemed to be a matter of chance.

FIGURE 14



> "We found out from other parents about free nappies and the orange parking badge. As soon as cerebral palsy was diagnosed, someone should come along from the borough. This is our first encounter with disability.

> I'm not backwards in coming forward now and I've managed to get a washing machine from the Joseph Rowntree Trust as Ben creates so much washing."
>
> (Ben's father)

However, many parents are successful with toilet training, although this requires careful attention to a child's communication system: many learn to communicate by 'eye pointing', for example. This subtle means of indicating needs can only be successful with people who know the child well. Toiletting, like all other self-care tasks, requires the use of special equipment. It may also involve adaptation of the house to provide accessible facilities.

Changes in routine and of personal carers may cause temporary lapses in bowel control. This is true for all children, but may be particularly difficult for children with cerebral palsy, especially if attempts are being made to include them in mainstream schools. Support workers, unfamiliar with the unique needs of the individual child may jump to premature conclusions about a child's suitability, even thinking that mothers have misled them.

> "My input has helped Barry fit into mainstream school. I think also the fact that we were new to the area and I am medically qualified made the staff more responsive. After initial optimism they began to get cross because he wasn't fully toilet-trained and he couldn't do his coat up and sit still like the others. They tried to make him conform, but they found him difficult and awkward. The work of finding the right balance between overprotection and getting him to do things for himself could only be dealt with by my intervention. Barry became stressed out, having accidents at school and hitting his sister at home. A year later he still won't use the school toilet though the bags of dirty washing have stopped coming home."
>
> (Barry's mother)

Radical changes in how the household is organised may be necessary to ensure successful toilet training. This may include building costly house extensions or moving.

3.5 Family Relationships

Many studies have described the effects of the birth of a handicapped child on the family. The recurrent theme seems to be the social, emotional and financial costs of caring[13]. Relationships between parents, siblings, extended family members appear strained and distorted.

Fears for the stability of family life were expressed by Younghusband in the report of a working party on children with special needs, where a mother of a 21 year old spastic girl is quoted as saying: 'truly a handicapped child is a handicapped family'.[14] This potential for family breakdown poses a serious threat to the success of community care policies, based on the principle of care within the family. Part 111 of the Children Act 1989 may be understood as a recognition of the need to provide a range of practical services (respite care, family centres, day nurseries) to bolster vulnerable families.[15]

More recently there has been a subtle shift from fearing breakdown to expressions of surprise and admiration that so many families appeared to survive. Beresford interviewed twenty parents 'to discover the resources and strategies used by parents as they coped with the care of the child'.[16] Martlew echoes this admiration for survival in her study of eleven families each with a child with cerebral palsy.[17] She identifies what she calls 'coping functions to regulate stress and manage the problems, many of which were beyond their control'.

Any discussion of family relationships must take into account the changing nature of all families in the U.K. in the post-war years. Considerable rhetoric has been expressed by politicians about their fears for the survival of the traditional family and the likely consequences of a 'cycle of family disintegration, truancy, drug abuse and crime'.[18]

Social policy is blamed for instituting a 'dependency culture' on the one hand, and for providing insufficient facilities to underpin the family on the other.

Family trends over the past thirty years are summarised by Utting, as lower marriage rates, increased cohabitation rates, childbearing being postponed, fewer large families, a sixfold increase in annual divorce rate, increase in lone-parent families, increased numbers of mothers with young children being in employment and employment patterns being increasingly polarised between 'dual earner' families and homes where nobody has a paid job.

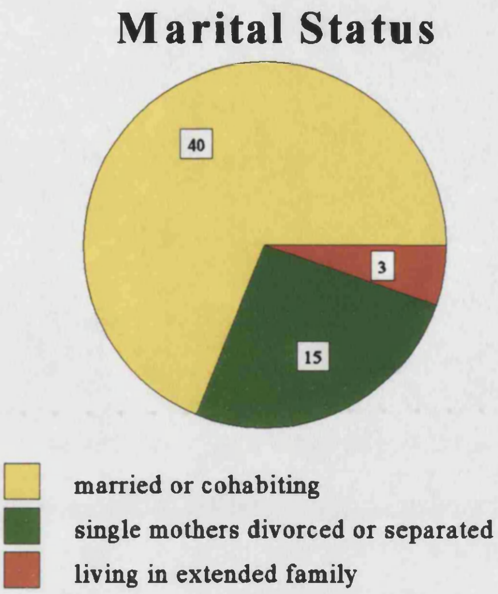
It is beyond the scope of this study to assess the significance of these national trends for families with a handicapped child. It is relevant to emphasise, however, that the panic about the nature of family relationships is relevant; resources may be drawn to the most vulnerable families, but the apparent general disintegration of families combined with the non-interventionist stance of the right wing government may mean that even less resources may be forthcoming. Praise, along the lines of Beresford therefore may be the only way forward.[19]

This study of families who care for a child with cerebral palsy provides evidence of the effects on marriages, family size, siblings, extended families, and employment. Each of these areas will be considered separately.

3.6 Marriage

Family breakdowns had occurred in the lives of 27% of the families interviewed, but 65% were either married or living as a stable family unit at the time of the interview (see figure 15). The national figure for lone parents is 21% but the divorce rate may rise to 40% of new marriages if current trends continue (OPCS).[20]

FIGURE 15



It is impossible to locate accurately the cause of marital disharmony since it usually stems from interrelated factors rather than from a single cause. Undoubtedly the birth of a child with cerebral palsy was a contributory factor in some of the separations in this study but was probably one of many.

> "Our family life took a hell of a battering after Ben was born, but our relationship had always been fiery so its not surprising we separated."
>
> (Ben's mother)

Many couples were making conscious efforts to ensure the stability of their marriages either by seeking help or by making choices which took into account the likely effects on spouses.

> "You can never do enough for your child; there's so much information that it takes over your whole life. That is too high a price to pay. We want to maintain our family life and our marriage at the same time as doing the best for John. That's the compromise we've reached otherwise the choices would do our heads in. We have to discount a lot of choices for him."
>
> (John's mother)

It seemed from this study that survival during the first year presented major challenges to both parents, whose reactions inevitably differed. Comforting each other and finding ways of adjusting their roles within the family competed with the rehabilitative and care needs of the baby with cerebral palsy.

> "The social worker at the hospital offered us help but I pushed my wife forward. I honestly didn't think I needed help then. She had to do all the arrangements and the caring because I had to hold down my job to support us all. Understanding my emotions was not what I was looking for. We knew we were under pressure. We didn't know how we were getting by. We didn't need to. But I cried every week on more than one occasion. I found myself crying at my desk. My wife doesn't know. I don't want it to prey on her mind."

(Paula's father)

Some partners could not stand the pressure.

> "We had been together for four years before the twins were born. The children weren't planned and the relationship fell apart when Sarah screamed all night for the first six months and I had no time for him. My time was taken up with feeding the twins: one of them was hungry all of the time. We had travelled extensively together before so now he took off on his own."

(Sarah's mother)

Others consciously chose to put the interests of their child before those of their husbands. This was demonstrated by an Indian mother who decided to bring her child for treatment and education in the U.K., leaving her husband in India.

> "I could not stand by watching Ravi doing nothing in India. I got so tired cleaning and cooking for my husband's family and trying to do therapy. I got irritated and lost my temper a lot . My husband never realised how difficult it was for me. In the end I made the choice to come here, but I wish my husband would come here and see the difference in Ravi now."

(Ravi's mother)

Although still cohabiting, 5% of participants reported marital disharmony, describing situations where they still lived together because the husband was the breadwinner but that they effectively led separate lives.

> "I think we should get on with separating. We lead separate lives. A lot of husbands leave their wives when they have a handicapped child and I wish mine would just go. He sticks around providing for us financially but doing nothing else. I am really a single parent managing everything. David has developed behaviour problems now resulting from his frustration at not being able to walk. When he's sitting in his wheelchair waiting to go out he'll stick his fingers down his throat to make himself sick."

(David's mother)

Perhaps the most reliable summary is to acknowledge the added stress to marriages of the birth of a child with cerebral palsy, but to consider this alongside the other pressures on marriage in the 90s. Strong relationships and commitment to resolving difference make it possible for many couples whose child has cerebral palsy to be positive about their relationships.

> "Our strength is that Robert and I are very close. We are consistent with the kids and plan our lives together. Although I was very depressed to the

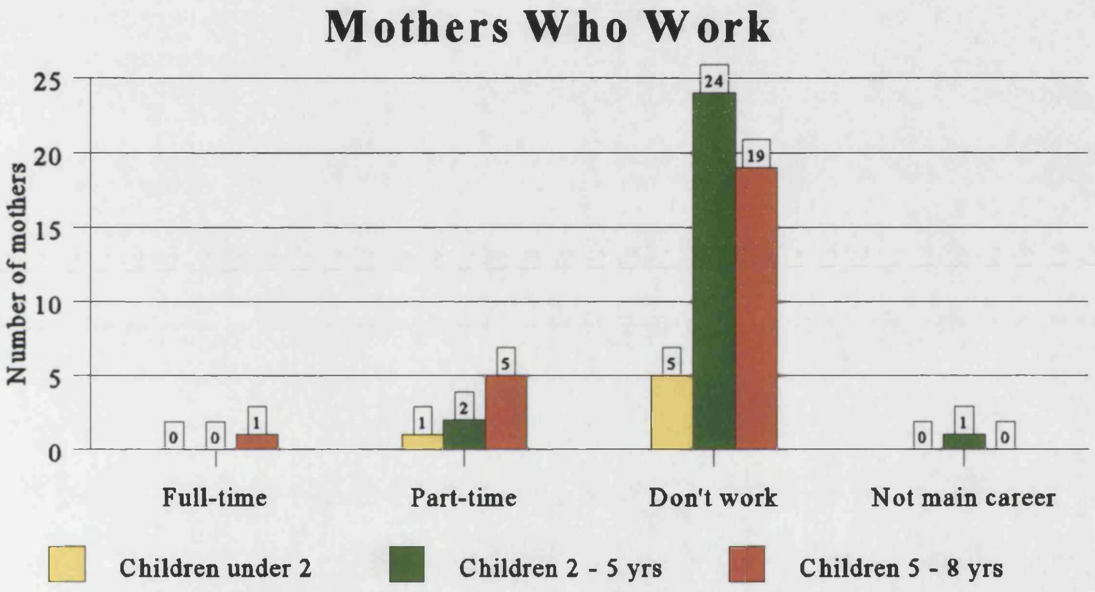
point of being suicidal at first, we got through it together; he is my best friend."

(Clive's mother)

3.7 Employment

Almost half of women with children under five in the U.K. are economically active.[21] This contrasts sharply with the lives of mothers in this study (figure 16).

FIGURE 16



Although 25 mothers were university graduates with professional careers before childbirth, only 8 did some part-time work. Of these, one mother with a child under two years did one day per week; another mother with a child under five did free-lance journalism at home while a third planned to give up part-time lecturing at the end of the academic year. Only one mother who was a teacher, had a full-time job. Her child was over five and her headmaster had agreed a flexible time-table allowing her one day per week to attend hospital appointments. This pattern is to be expected since mothers were the main or sole carers for the majority of children.

It might have been expected that mothers might regret the loss or interruption of their careers. Of those in the study, many had taken maternity leave with the intention of returning to work. What seemed to happen in most households was the acknowledgement that being their child's care manager was a full-time job in itself leaving little time or space to grieve what they had lost by not returning to work. Unlike the mother of an able child, who during the first five years of a child's life progressively finds dependency needs reducing and short spaces in which to resume a career and achieve some economic independence, the mother of a child with cerebral palsy initially becomes her child's therapist. It is advisable to become advocate, teacher and social care manager. Learning the knowledge and skills to function in these capacities, alongside managing appointments and daily living needs may be experienced as a stimulating if exhausting substitute for a career.

Illustrating this point, one mother showed a four drawer filing cabinet full of relevant paper work including an academic paper she had written about special educational needs. Another mother had a study devoted to the paper-work, which had got so out of hand she had had to employ two sixth formers for a fortnight to do her filing.

> "Letters come though the door every day. There's shoals of paper-work, especially school stuff about statementing. It needs to be kept in date order. To do it on your own is mindless and depressing. I spend my time phoning and writing off for the things Adam needs all the time, that's why I don't work . I've raised over five thousand pounds for a motorised wheelchair; I go into school to train his helper; I support other parents .It's a nightmare. I really need to go out to work for a day a week to escape."
>
> (Adam's mother)

Another parent became so skilled and knowledgeable about the law in relation to disability that she began a part-time law degree, (she was managing a claim for medical negligence, asserting her daughter's rights as a child in need under the Children Act 1989 and challenging her daughter's statement through judicial review). One mother admitted that she tried to return to part-time work, but her attempts failed.

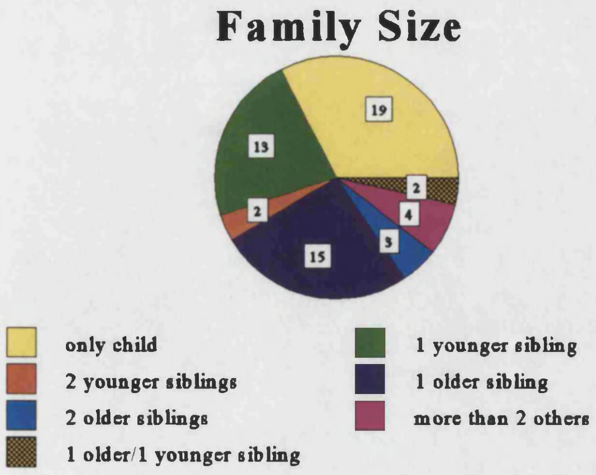
> "We went on holiday and talked it through. Something had to go. I volunteered to stop work on the understanding that it would be for a trial period. Rarely do I get a day when I'm not seeing somebody, and I've got the physio and O.T. to fit in. Paul tried looking after Lisa for a day but she went blue and he panicked so I gave up thinking about work."
>
> (Lisa's mother)

3.8 Family Size

There are fewer large families in the U.K. and fertility rates have declined from a post-war peak of 2.9 children per woman in 1964 to 1.8. Child bearing is being postponed. The average age at which women give birth to their first child has risen from 24.7 years in 1961 to 27.7 years.[22]

Parents of children with cerebral palsy are not immune from these national trends, but information from this study suggests that other processes directly related to having a child with cerebral palsy influenced family size (figure 17).

FIGURE 17



Of participant families, 19 had only one child. Some said they had intended to have other children but they were afraid.

> "We wanted another child but it was like being on the edge of a cliff. Should I jump? I spent hours on the phone to the Institute of Child Health. After I became pregnant again I miscarried at eight weeks. It was a great relief."
>
> (Anne's mother)

Many mothers remembered vividly their experiences of a birth which had been traumatic and vowed not to return to the same hospital if they were to become pregnant again.

> "When they told me Michael had cerebral palsy I felt as if the floor had opened up in front of me and all hell was below. If I become pregnant again I will avoid the hospital and have private care."
>
> (Michael's mother)

One mother who conceived a second time accidentally, decided to have an abortion. The decision was as much related to fear of the outcome as to feeling too exhausted by her son's needs as a child with multiple handicaps.

> "In retrospect, I think I should have gone through with the second pregnancy but I panicked at the time and felt very relieved after the abortion."
>
> (Sam's mother)

Tension created by painful memories may contribute to difficulties in conceiving a second time, but for each couple the discussion about planning another pregnancy raised problems on a number of levels.

> "Can we give Paula everything she needs in her early years if my wife becomes pregnant? She could not lift her up for example. Of course we would like her to have a brother or sister but there are difficulties with being able to conceive when you're under so much pressure. What has happened to Paula has affected every part of our lives and our ability to have future children."
>
> (Paula's father)

A sizeable percentage(23%) of the participants decided to risk having a second child, usually after genetic counselling. This was particularly important for those parents who had not received an explanation for their child's disability.

> "It was fantastically stressful having the second one. I had appalling flashbacks at the beginning of the pregnancy...Oh my God, it was like being in Hell. The birth wasn't so bad, it was the pregnancy and we regularly saw midwives who had cared for Michael."
>
> (Michael's mother)

The motivation of such parents seemed to be wanting to become a family unit, wanting to prove that things could go right, and wanting to provide a sibling for the child with cerebral palsy.

> "A friend helped me to make the decision and so did counselling at Norwood Child Care. We knew it would be good for Ben to have another child around to stimulate him. Our lives are geared too much round Ben and we all needed another focus."
>
> (Ben's mother)

Partners did not always reach the decision easily or amicably.

> "There was terrible tension: rows and arguments. My husband said we could never go through that again. We waited a long time but I needed to replace the twin who had died and also to experience having a normal child. Women tend to forget men's feelings. After the second pregnancy, my husband said he'd been trying to work out what he would say to me if it had gone wrong again. I even thought I didn't want another baby during the pregnancy, but it was too late."
>
> (Helen's mother)

Having overcome fears, the decision to have a second child was seen positively by parents.

> "I think Bobby's improved as the result of his sister's presence. He seems more determined. She has helped us cope with Bobby. I couldn't have devoted my whole life just to him. We've got to have some normality in the family. I hope to have a third child but Sally is such a handful, so mischievous and not an ounce of fear. I've put it off for a bit. Bobby is so passive. I would advise others to do the same."
>
> (Bobby's mother)

Attitudes derived from religion and culture strongly influenced decisions about family size. A Moslem mother described how disability tends to isolate families turning them in on themselves. Having a second child might provide for her child with cerebral palsy the companionship denied him because of his disability.

> "In the mosque there is a section apart reserved for wheel chairs. Families treat disabled children as if they have something wrong with them, a disease that their children might catch. They move away and don't let their children play with Perkil. It's sad to see. We have learnt so much from books to change our attitudes and he really wants to be with

> children. That's why we had another baby. At least he doesn't have to go outside to find a child to learn from."
>
> (Perkil's mother)

Only two families in the study had large families, both being Orthodox Jews. One family had seven children, the youngest of which had sustained brain damage at birth through medical negligence. The other family had nine children, the eighth child being a premature baby who survived intensive care but sustained a right-sided hemi-plegia and mental handicap. This mother was pregnant again at the time of the interview. In both cases, the children with cerebral palsy were twin pregnancies.

In accordance with their religious beliefs, both mothers expected to have more children. Permission to practice birth control might be obtained from the rabbi on health grounds, but even the second mother who had undergone a hip replacement and needed another operation, thought having a child with cerebral palsy insufficient grounds for seeking dispensation. Her survival seemed to depend on the provision of a residential place for her son for four days per week in a local home for Jewish families.

> "I have my fears, but I leave it to God and pray that I have a healthy baby."
>
> (Joshua's mother)

The other mother would have liked to have had more children, but admitted that after the birth of a child with disabilities most mothers find it hard to carry on.

> "I would have loved to have more children. I think there is someone above who decided it shouldn't happen. I think it's for the best. If the child with cerebral palsy is your only child it can consume you so much. They'll drag every ounce of emotional and physical strength out of you. It happened to me and I realised every-one in the family had special needs too. It was a really hard thing to do but you have to resist it."
>
> (Benjamin's mother)

3.9 Siblings

Research by the Family Fund in 1975, found that only 28% of the 268 families with more than one child said that their other children's lives had been unaffected by growing up with a seriously disabled sibling.[23] A conclusion supported by many authors explored this theme which has particular relevance to the Children Act philosophy of locating the care of children with disabilities within their own families.[24] The recent concern expressed by Jones and Bilton that local authorities are concentrating resources too narrowly on child protection issues to the exclusion of implementing Part III requirements for children in need, relates directly to fear of family disintegration under strain.[25] The Department of Health recommends short breaks (respite care) to provide temporary relief for all family members, the provision of which will be discussed in Section V.[26]

A study, such as this which concentrates on very young children reveals the sheer amount of necessary work that mothers have to do to care for their children. Consequently the larger the family the greater the volume of caring needs and the less time available for each child. Grief reactions and intensive implementation of demanding therapeutic programmes compound the problem. It is probable that relationships between siblings may become more obviously difficult as children grow up. Siblings groups providing therapy and space away from home were used by two families in this study. The local Health Authority provided one of these groups and the other was sponsored by a voluntary agency.

Parents gradually confront the very differing needs of their children although the presence of able children in the home sometimes accentuates the developmental delay of their child with cerebral palsy and reactivates the sense of loss.

> "Even at the ages of 4 and 5 children notice that Cathy is different and ask questions. At Mark's birthday party they said, why does she dribble so much?"
>
> (Cathy's mother)

A process of adjustment on the part of parents is accompanied by an equally painful one of assisting their children with cerebral palsy as they become aware of their disabilities.

> "Hannah saw her younger sister Rosey walking. 'Why is she doing good walking already?' she said. I explained that when Hannah was born she was very poorly so for her it is much harder. Moments like that are sad. We're beginning to realise what Hannah should have been doing. As first time parents we didn't know how delayed she was."
>
> (Hannah and Rosey's mother)

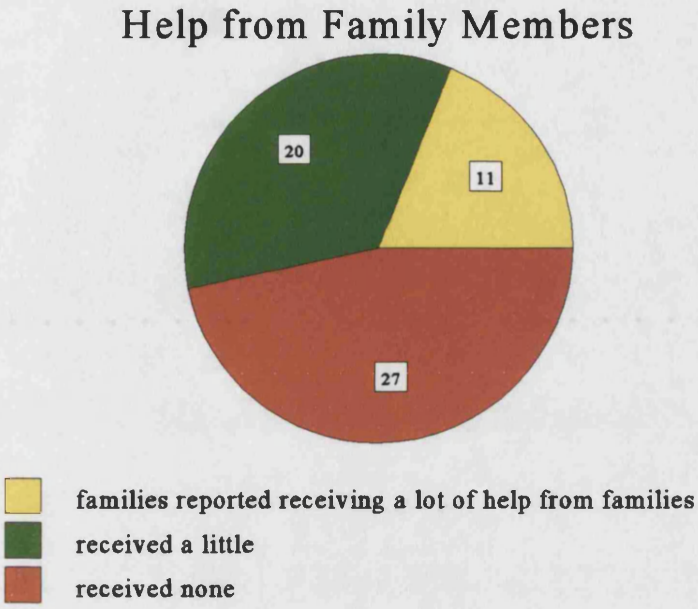
3.10 Relatives and Extended Family

The success of care in the community depends on the availability of family, friends and a notion of community, which is an ill defined concept.[27] Research has examined in detail the contribution of extended family members to the care of children with disabilities in their own homes.[28] Notable from the findings is the dependence on grandparents. This may reflect the trends for people to take early retirement and also the fact that people are living longer.

Nevertheless much depends on cultural expectations of family styles and responsibilities and their changing nature over time. The movement of people around the country and around the world facilitated by ease of travel and improved education may disrupt family patterns and leave nuclear families dependent on public or private welfare services.

Families in this study included many professional middle class couples living away from their places of origin and dependent on the community (figure 18).

FIGURE 18



Of the participants interviewed, 27 reported not living near relatives; 20 said relatives helped 'a little' and only 11 said they received substantial family help. This result is probably consistent with life in a cosmopolitan capital city. The countries of origin of participants were numerous: 44% of mothers and 46% of fathers reported that they were born outside the U.K. It should not be assumed that the proximity of family could be relied upon. Yet some provided a vital lifeline: three grandfathers were observed participating with their grandchildren at the conductive education centre for example. Grandparents were often cited as sources of strength in times of crisis especially at the time of birth.

> "I phoned my mother from the hospital; I couldn't speak; she had to shout at me to help me get the words out; she thought my wife and baby were dead."
>
> (Paula's father)

But grandparents too have to adjust to the sense of loss of the perfect baby. Complex emotions churned up by childbirth are exacerbated by uncertainty and the need to blame.

> "My relationship with my father has been uneasy since Anne was born. At first he was very comforting, taking me backwards and forwards in the car to hospital when she was in intensive care. More recently he seems to criticise us for not doing enough. He has been used to buying everything he wants all his life so he thinks we should buy a private physiotherapist. He doesn't understand that we are getting the best possible help from the Bobath Centre. He's still at the stage where he's looking for a cure."
>
> (Anne's mother)

Ethnic minority families usually experience greater isolation, being far from their countries of origin, torn between staying in the UK for therapeutic facilities and returning to the familiarity and nurturing family relationships in their countries of origin.

Atkins and Rollings have explored the 'myth' of the extended family for Asian and Afro-Caribbean families, emphasising the significance of isolated immigrant families in relation to community care provision.[29]

> "I am a country person. I miss the sun and sea of the Caribbean. I only came here to do a course but now this has happened to me I can't go home. The claim for medical negligence will take years and he needs his treatment."
>
> (Adam's mother)

Participants were asked whether they could name a 'special person' whom they found most supportive in the care of their child (figure 19).

FIGURE 19

Of the 48 responses, only 5 named family members, while 5 identified friends and four identified other parents. Eight mothers stated they were the prime carer without help and 26 others named a range of professionals. Thus this group did not see themselves as supported by family and friends in the community as expected by community care policies. The importance of support from other parents could be a double-edged sword. On the one hand it is a relief to share experiences with those who may be able to empathise. On the other hand segregated friendships may be experienced as restricting and may be as uncomfortable.

> “I've formed some very strong friendships with people with whom I've little in common, and yet I feel bonded to them. What surprises me most is the lack of support I feel from the friends I had before Joe was born. They're not on the same wave-length. They're Jewish as I am, and the Jewish attitude towards handicap means they will make donations and sell raffle tickets, but you can tell by their body language that they have an attitude problem. When they see Jo, they dismiss me either by admiring me for coping and say that they couldn't, or they imply my needs are

> covered by specialist charities like the Spastics Society, so I don't need them."
>
> (Joe's mother)

3.11 Child Protection

Children with cerebral palsy are vulnerable. Detailed knowledge of their uniquely individual needs is required to ensure healthy lives. Observation of rehabilitative treatments revealed sessions when children's bodies were moved, positioned, manipulated sometimes using punitive-looking equipment (like standing frames and prone standers) to inhibit their naturally dysfunctional movements and to encourage those more useful and normal. Seemingly instructed, cajoled and bribed to participate in these physically intrusive sessions these very young children were strictly limited in control over their own bodies. Resistance and tantrums during sessions seemed to be expected by therapists and parents, who devised various diversionary techniques including toys and stories as distractions. Somehow it did not appear as if their bodies were their own!

In child protection terms, therefore, children with cerebral palsy are trained through their therapy in particular physiotherapy and O.T. to allow numerous adults, many of them strangers, to move their limbs and bodies frequently, to co-operate in rehabilitative processes. The large numbers of adults involved with their treatments, care and education is remarkable and is increased because of the frequent staff changes in public services. The problem is compounded by the fact that many of these children have poor or no verbal abilities to inform others and their physical impairments prevent them from moving away from potentially dangerous situations.

To the observer, some treatment techniques appear abusive in the sense that they are enforced, they take so much time that the other needs of childhood appear to be overridden and very occasionally they might be considered to put the child at risk either emotionally or even physically. Conventional physiotherapy sessions may take place weekly for periods up to an hour in length, but carers are expected to use these sessions to learn how to do it and to repeat what has been learnt daily at home.

Alternative therapies put greater emphasis on integrating therapy as a main way of living at home allowing very little space for other childhood experiences. Probably the worst example of this is Patterning, (the Domon Delacato System) which recommends up to eight hours per day on the programme and requires a team of helpers to implement. Activities are carried out in rapid succession and may include, for example, 'masking' (wearing a mask which has a valve at the bottom to control oxygen intake and encourage the child to breath more deeply), or 'cross-patterning' (which involves 3 people, one on each side of the child and the third turning the head: the child is then moved through the action of crawling for a specified number of minutes). From the child's perspective, this must be experienced as a massive assault and grossly intrusive.

> "From 8 months until Ben was 2 we tried the Delacato method. We had 30 volunteers who came on a rota. It seemed to calm him down at first and he began to get moving, but then he began to say 'no'. We had to make a choice and Ben made that choice. I try to listen to him. We changed to conductive and then to Bobath."
>
> (Ben's mother)

Stress should be placed on the fact that parents may choose these treatment process with the intention of improving their child's chances of achieving a fuller life. An 'abnormal' life-style may lead to the attainment of normal functioning. It will be seen in Chapter 7 that parents frequently do not appreciate fully the basis for, or consequences of their choices.

Therapists also may prioritise the potential benefits of treatments over considerations of safety. An exert from interview notes illustrates this point.

> "The mother admitted that she had forgotten the appointment. 'I have been so worried because my daughter was brought home from the conductive education centre with concussion. They said she'd fallen over and banged her head. They hadn't called a doctor and she was drowsy and vomiting after the journey in the school bus. I get so worried. It's not the first time it's happened but she's doing so much better there than at the mainstream nursery.'"

From these examples, the concerns expressed by writers about protecting children with disabilities has justification. It will be seen in the Section V, however, that preoccupation with child abuse issues may divert social workers' attention from the totality of needs exhibited by children with disabilities.[30]

3.12 Conclusion

It can be seen that the ambiguity surrounding cerebral palsy makes it difficult to provide accurate definitions of its nature and presenting features. However, it is a child's early years which provide the directions for future care, treatments and education.

Although life expectancy for children born with cerebral palsy is less than that of the normal population community care policy needs to recognise the consequences of a diagnosis of cerebral palsy throughout the life stages[31]. The characteristics and dilemmas discussed in this chapter form the platform from which to analyse health provision in Section III, education in Section IV and social services in Section V.

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Section III

FAMILIES AND HEALTH CARE SERVICES

Born in a medical environment, often surrounded by the complex technology of the intensive care units, the children in this study went on to experience a range of medically-oriented approaches as their parents searched for means to help them realise their full potential. A series of assessments preceded multi-disciplinary treatment programmes. Despite the absence of firm evidence of effectiveness, the first two years for most children were medically-orientated, and for those whose conditions were very severe, the medical perspective continued to have primacy of importance in care packages throughout their lives.

The most remarkable change in the lives of children with cerebral palsy over the century has been the growing contribution of doctors and health care professionals to what used to be a hopeless, incurable condition. The explosion of medical science and technology has provided improved diagnoses, cures for some of the symptoms, and treatments to enable children to lead fuller and more 'normal' lives.

Chapter 4 will provide an overview of the development of government health policy in the post-war period to explain the situation of parents and their children. Chapter 5 will focus on the contributions of NHS professionals within the current statutory framework from the perspectives of parents users. A case study highlighting the issues involved in assessments is the subject of Chapter 6. Dissatisfaction with orthodox approaches leads parents to explore alternative medicines in the private and voluntary sectors, which is the focus for Chapter 7.

> "My father was born with a condition which must have been cerebral palsy in the 1920s. They lived in the West Country and the local doctor advised 'putting him away'. My grandmother was a remarkable women. After seeing a consultant in London who advised the same, she 'lost' his medical records somewhere between London and Bristol and set about teaching him to walk herself. (Teacher at a Special School)."

The post-war development of rehabilitative services and the establishment of a universal, free and comprehensive National Health Service in 1948 have altered dramatically the range of treatment choices for parents devising care packages for their children. Options exist both in the public sector and privately as alternative medicines extend the range of consumer choice for a minority expressing dissatisfaction with orthodox medicine.[1]

Parents experience confusion about different treatment approaches provided by different authorities and funding sources. Nevertheless separation is characteristic of British social policy. At government level health and social services are organised separately from education and governed by different legislation. Implementation of statutory duties is divided between central and local government with the independent sector as providers.

4.1 Health Social Policy toward Disabled Children

Prior to 1948, British health care was a complex mixture of private and public services; the private sector consisting of voluntary hospitals and private practitioners; the public sector of municipal hospitals and community health services run by local government.[2] The amount of medical care available to children with disabilities therefore depended on their family's financial status and the extent of their impairments. At one end of the continuum, those sufficiently able might attend mainstream schools, while the most severely disabled children particularly those described as 'mentally defective' might be admitted to 'long-stay hospitals, sanatoria, approved public assistance institutions, certified houses, and approved homes, and under individual guardianship.'[3]

Residential care concentrated on sustaining daily living, although educational needs were recognised. The Curtis Committee, while acknowledging that 'few of us would have been competent to judge medical care' recommended that a physically handicapped child 'should not have added to his other hardships and sufferings the feeling that his years are being wasted so far as his mental development is concerned'.[4]

Educational needs, (the focus for Section III) were recognised as early as 1892 when the London School Board opened 'a school for the special instruction of physically and mentally defective children... the emphasis being upon occupational activity rather that formal education'.[5] However, medical treatments, particularly corrective therapies did not develop substantially until the 1940s.

The effects of two world wars focused attention on the needs of disabled ex-servicemen and injured civilians and acted as a catalyst for substantial development in treatments. The report of the Tomlinson Committee 1941, emphasised the necessity for action to study rehabilitation, training and resettlement of the disabled. Younghusband 1959 predicted that the growth of hospital rehabilitation services, 'earlier ascertainment and diagnosis, new methods of medical and surgical treatment of certain diseases and disabilities, and the special rehabilitation services which help to speed recovery, may well change the present picture of adult disability within the next generation or two.'[6] These developments certainly had positive spin-offs for children with cerebral palsy. Specialised paediatric treatments, aids and appliances evolved from this earlier research into adult disabilities. New professions, physiotherapy, occupational therapy and speech therapy emerged as essential components of rehabilitation teams.

The 'bracing character of the Tomlinson Report' also had the positive effect of generating hopes for active, productive lives fulfilling society's needs for active labour during the postwar period.[7] If ex-servicemen could undergo successful rehabilitation, so might children.

4.2 The National Health Service

The National Health Service Act 1946 made no specific provision for the handicapped, but the growth of rehabilitative treatments took place within this new organisational context. In essence, Aneurin Bevan aimed to 'universalise the best; by divorcing the ability to get the best health advice and treatment from the ability to pay'[8]. From 1948, therefore, health and education pursued parallel paths, providing for the treatment and learning needs of disabled children. There was overlap and even duplication, but each development took place within a separate complex co-organisational structure.

The tripartite structure of the NHS, comprised family practitioners services (GP's, dentists, pharmacists and opticians) administered by executive councils; local authority community health services and public health (including midwifery and community nursing), and the nationalised hospital service. It was a compromise between GP's, hospital consultants, local authorities and the Government. Effectively, the medical profession was paramount in the new health service: consultants in hospitals, medical officers of health in local authorities and GP's with responsibility for patients on their own lists.

The NHS, therefore, proved to be an uncoordinated system, universally available, but unwieldy for those with disabilities whose needs spanned the three areas of the service. Support for reorganisation and a unified service was reiterated by a series of reports - The Guillebaud Committee, stressed the need for greater co-operation between the three sectors, drawing attention to its most serious impact on the maternity and child welfare services, as did the Cranbrook Committee. The Gillie Report included proposals for closer integration.[9] The reorganisation of the NHS in 1974 created three tiers of health service management below the Department of Health and Social Security at regional, area and district levels. The family practitioner service remained separate. The NHS became responsible for community health services, transferred from local government but social care and environmental health remained with local authorities. This complex and confusing organisational structure seemed to reflect pre-occupation with attempts to establish effective management systems acceptable to medical professionals and the government. User-friendliness was a lower priority.

4.3 Fit for the Future: The Report of the Committee of Child Health 1976[10]

Although plans for reorganisation did not achieve the hoped-for rationalisation of service delivery, a useful outcome was the review of the child health services commissioned by Sir Keith Joseph who considered the 'planned reorganisation and the transfer of the School Health Service an unrivalled opportunity'. Influenced by belief in the 'cycle of deprivation', the committee chaired by Professor Donald Court, spent '3 years of unremitting enquiry' into health services for children to be a potent investment in the country's future'. Chapter 14 contained comprehensive details of issues confronting disabled children and made significant recommendations, starting from the basis that 'no separate service has ever existed exclusively for their benefit'.[11]

Perhaps the most striking features of this report are how issues identified by parents participating in the fieldwork for this study in the 1990s had been clearly identified twenty years earlier. Some changes have happened, notably the appointment of community paediatrician to child development clinics, but the conclusions that 'services for handicapped children are characterised by overlap and by poor coverage... that there is still a serious lack of communication between the various professional staff who actually provide help to handicapped children' are familiar in the 90s.[12] Similar points are made, but with less passion, in the Children Act Guidance.[13]

The Court Report is also sensitive to 'parental participation' and the stresses experienced by parents particularly if they 'shop their handicapped child around, seeking ... an unattainable cure'. [14] The central contributions of both health visitors and social workers are emphasised.

In relation to physically handicapped children, two aspects of treatment are prioritised. Firstly, support is provided for the concept of 'a unified remedial profession... broadened to include nursing and teaching expertise'.[15] This recommendation quotes the Report of a working Party on the Remedial Professions 1973, and applies their conclusion from studying adult rehabilitation to special needs of children.[16] Secondly criticism is directed at the shortage of 'aids and appliances on which some wholly depend', recommending that the 'DHSS and DES should look into the complaints we have received as a matter of urgency'. Both these issues reverberate in the findings from this study of children with cerebral palsy, and are discussed fully in chapters 5 and 10.[17]

A further critical feature of this report is the major overlap with the Warnock Report, published in 1978.[18] Both reports prioritise handicapped children and their families, making strong and bold recommendations for improvement in interdisciplinary and inter-agency collaboration. It will be seen in Section IV focused on education, that health, education and social services continued to function relatively separately, major explanations being financial constraints and professional attitudes to sustaining role boundaries. Innovative ideas of collaboration and parental participation for example, drowned within the complex, underfunded organisational structures of health service and local authority management. Within this historical context, the Children Act Guidance should be seen less as innovative and more as a revival of things identified as good practice in earlier years, but not yet achieved.[19]

4.4 Report of the Committee of Enquiry into Mental Handicap Nursing and Care 1979[20]

The Jay Committee developed the themes identified by Court and Warnock about the care of children in the community, taking as its focus the mentally handicapped.

The remit of this committee of enquiry was to consider how mental handicap residential care staff should be trained and organised to provide care outside institutions.[21] It is therefore peripheral to this study of children cared for at home, many of whom are not mentally handicapped and would not want to be associated with that label (see Chapter 3). However, the report is of interest. Of the five 'pen pictures' of mentally handicapped children, two of them, Jill Brown and Joseph Evans have neurological brain damage consistent with a diagnosis of cerebral palsy.[22]

The report actively encourages supporting parents caring for their children at home; recognises the problems of distress at 'this sad and fearful time in their lives' and of the 'numerous professionals who should offer help - it would be fruitless to list all the general services from which mentally handicapped people could benefit'. It recommends that 'the problems might be alleviated by the appointment of a <u>specifically named person</u>....responsible for helping the family to articulate their needs, personally representing them where necessary, and, in co-operation with other professionals, for marshalling the required service'.[23]

Thus, the Court, Warnock and Jay Reports were harmonious in their recommended solution, but 10 years on the Children Act Guidance advocates 'marshalling resources' and 'working together' as if these were 'a new approach to working with children with disabilities that the Act requires'.[24]

4.5 Financing the National Health Service

Financial constraints have proved as problematic as organisational issues throughout the history of the NHS. Initially, 'in the wake of straightened circumstances, due to the Second World War and the subsequent 'cold' war which required greatly accelerated military spending' priority was given to the construction of houses and schools rather than to hospitals.[25] Beveridge did not anticipate the potentially limitless demand for medical care; the expansion of technology, organ replacements, for example; the growth in pharmacology; the demographic changes, in particular the rising numbers of elderly dependent people with greater health needs; the escalating costs of labour to provide the growing range of therapeutic interventions.[26]

Although the Guillebaud Committee concluded in 1956 that there was no evidence of extravagance or inefficiency in the NHS, and recommended more resources particularly for capital buildings, the expenditure costs increased steadily.[27] As Leathard concludes, 'politicians had in effect, invented a financial treadmill when they created the NHS... with no in-built curbs on public expenditure'.[28]

It will be seen that financial problems are a constituent of every aspect of service provision for children with disabilities considered in this study. 'Throwing money at a problem' may not provide a complete solution, but service provision, some requiring increasingly sophisticated technology, is not possible within budgetary constraints.

4.6 NHS Re-organisation 1984-1991

The Griffith Report 1984, was partly a response to the quest for greater economy, but its significance was more in its promotion of management techniques from the business world into the NHS.[29] It was a response to a service run, not by managers but by the medical profession. 'The NHS, as created in 1948, was brilliant but particularly flawed: brilliant because it offered real and politically viable solutions to many of the key problems in paid health care delivery; flawed because, faced with the rampant power of the medical profession, it failed, for nearly forty years, to establish a proper management structure and an integrated corporate culture'.[30]

Under the control of the medical profession, rehabilitation held a lowly place within the hierarchy, consultants 'perched high on the apex of the NHS pyramid... below them, stretching out in ever vaster numbers towards the base came the support staff including physiotherapists, occupational therapists, speech therapists and social workers'.[31] Rehabilitation was in its early stages of development at the inception of the NHS and remained on the periphery. In contrast, acute treatment, surgery and the results of the advances in medical science and technology were centres of power and in receipt of the greatest resources.

This process of management change was consolidated by the 1990 NHS and Community Care Act. In company with other welfare providers, social services, education and housing, the NHS became a series of quasi-markets, based on the 'worldwide disenchantment with the perceived inefficiency and unresponsiveness of large-scale, centrally planned organisations and a greater reliance on decentralisation and markets, quasi - or otherwise'.[32] The essential feature of this system was division of services into competitive independent units, non-profit organisations competing for public contacts.

For the NHS, this meant splitting of health authorities into purchasers and provider units; and the formation of hospital trusts. These organisational reforms were introduced in partnership with the 'care in the community' philosophy detailed by the Department of Health in 1990 and in the Children Act 1989.[33] In theory, this legislation represented a major shift in power from the medical profession to users and carers who were expected to make choices as 'quasi-customers'. In effect, it meant a shift in power from consultants to GPs.

These changes were being implemented at the time of the fieldwork for this study. It will be seen in the analysis of the findings in the next section that in the early 90s the changes were slow to show obvious effects. For example, the full impact of GP fundholding was not apparent, and parents were still expecting full, comprehensive services from a universal, free health service.

Academic research into quasi-markets and the NHS Reforms reach the same conclusions: 'Much of the direct research reported here indicated little actual change of any kind, and even less than could be attributed to the reforms in key areas of quality, efficiency, choice, responsiveness and equity'. Future 'systematic evaluation' is required to counteract 'anecdote and prejudice'.[34]

Although for the parents in this study of children with cerebral palsy the NHS changes were of lesser interest than their own child's treatment plans, professional bodies (as providers of rehabilitation services), have expressed concerns about future directions for their management and quality of treatment. The most vocal have been the physiotherapists. Their predictions may be applicable to other para-medical services.

Rosemary Lane delivering the annual founders lecture at the Chartered Society of Physiotherapists' congress in Glasgow in 1992 described how the reforms in the NHS 'had left the physiotherapy profession demoralised and disturbed at the speed of change'.[35] In response to perceived threats, the councils of the Chartered Society of Physiotherapy and the College of Occupational Therapists agreed to set up a working party to look at joint management issues.

Under the new purchaser/provider system, rehabilitation services realised their vulnerability. They had been very small sections of 'a giant state organisation... controlled simultaneously both by Whitehall and by thirty thousand doctors'.[36] They may have been subservient to the medical profession, but consultants were the source of their work and recognised their professionalism. In contrast, the new NHS business managers prioritised value for money and cost cutting.

It is of interest that little effectiveness research has been published by the professions providing rehabilitation. A number of reasons may have contributed to this, among them being the difficulties of establishing feasible studies of patients with unique combinations of symptoms; the practice-base of the professions; their recent entry into training at university level. Inability to prove their worth is an inherent weakness in a market economy.

Within the new hospital trusts, para-medical units become providers, judged on their throughput numbers rather than on improvements in their patients' life skills functioning. Fears about this development are discussed by Philbrook who reported that West Dorset Health Authority has withdrawn a plan to lose three physiotherapy posts and employ private practitioners. Instead, they set up a £30,000 joint scheme with Dorset Health Services Authority to encourage GP's to employ physiotherapists.[37]

It will be seen in the next chapter that children with cerebral palsy need intensive therapeutic help over many years, and that faith in effectiveness has to be sustained when apparent change may only be preventing deterioration, and when the pace of change is incredibly slow. In monetary terms, children with cerebral palsy potentially consume a large share of rehabilitation budgets.

4.7 Implementing Policy

Thus, a range of government reports provides both evidence of the establishment and progress of the NHS from 1948 until the 1990s reforms. For more than 20 years there is evidence of commitment in their approach to the problems of disabled children.
The Children Act Guidance Vol. 6 does little more than reinforce lessons already learnt about the effects of disability on family life, the seemingly intractable problems of multi-agency and multi-professional involvement, and the need for a 'named person' to co-ordinate interventions.[38]

Yet little research has been undertaken which focuses on how to achieve these goals rather confirming what is already known. For example, Burke and Cigno examined the experience of families of children attending a special school, or one of two special needs units within mainstream school.[39] A key finding to emerge was the importance to families of having a 'named person' to co-ordinate services and facilitate informal networks. However, there is little discussion on how this might be achieved.

There is an abundance of literature on inter-agency and inter professional working spanning many client groups. But, again it is inconclusive. In the child protection field a succession of child abuse enquiry reports following the Maria Colwell Report have culminated in the DH Guidance, Working Together; in health and social care, the work of the National Centre for the Advancement of Interprofessional Education (CAIPE) has concentrated primarily on primary health care issues.[40] McGrath used findings from 37 community metal handicap teams in her study of different models in Wales.[41] This work is particularly relevant to the needs of disabled children and will be discussed more fully in Chapter 6.

4.8 Conclusion

It has been seen that, although there were no policies specifically directed towards the needs of disabled children, there is a long history of relevant reports identifying the issues. At each stage, very few improvements were achieved and the Children Act 1989 marks a turning point in that ideas already formulated were included in the legislation. The parents in this study, therefore, must be considered to be on the cusp of change, since the Children Act recommendations will take a long time to implement. Chapters 5 and 6 demonstrate how parents experience the impact of social care policies in the early 90s.

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> "I phoned every single day. The person at the end of the phone was official and not very friendly. It took about 3 weeks to obtain an appointment at the child development clinic, but it seemed like 3 years. It's terrible to keep parents waiting like that. No-one comes to see you. I hated being alone. I hated to get up in the mornings and to be alone."
>
> (Simon's mother)

'The assessment of handicap is a prescription for action - which may be medical, educational or social'.[1] Having considered the historical context in Chapter 4, the aim of this chapter is to concentrate on parents' experiences of health professionals and their medical responses evidenced from fieldwork.

Had the idealism of the Court Report 1976, the Warnock Report 1978 and the Children Act that 'parents should be recognised as participants in a team of health professionals', been translated from policy into practice, findings could have been presented within the context of multi-disciplinary team workings.[2] There are problems associated with presenting material in this way. The uneven achievements of interprofessional collaboration throughout the country suggest that parental experiences are more accurately considered from the perspectives of their reactions to separate professional contributions.

The material in this chapter will be organised chronologically starting from the point of leaving hospital and beginning care at home, covering the first two years of life and leading into the stage when health treatments should become better integrated with the education service in nursery schools. The discussion starts, therefore, with the roles of health visitors and GPs.

5.1 Health Visiting

This universal visiting service designed to monitor and improve maternal and child health in the pre-school years, has its origins in the growing emphasis on public health and the concern of some Victorians for the welfare of children.[3] The service was given additional impetus by concerns about the health of the nation after two world wars. It became firmly medicalised with the restriction of recruitment to registered nurses, and the development of training accreditation by the Council for Education and Training of Health Visitors, absorbed by the UK Central Council for Nursing, Midwifery and Health Visiting in 1980.

The Court Report attached 'particular importance' to the 'early recognition of handicap' and to the 'central part' to be played by the community Health Visitor (CHV).[4] In the recommended staffing of District Handicap Teams, a CHV 'should be a full member', and trained in 'the course and treatment of all kinds of handicap in children'. [5]

Reinforcement for the role of health visitor was provided by the Warnock Report which recommended that 'the health visitor should automatically assume the function of Named Person for the parents of every young child who has a disability.[6] We are not, however, proposing that the health visitor should in every case provide further support themselves, but rather that she should be able to put parents in touch with those who can'.

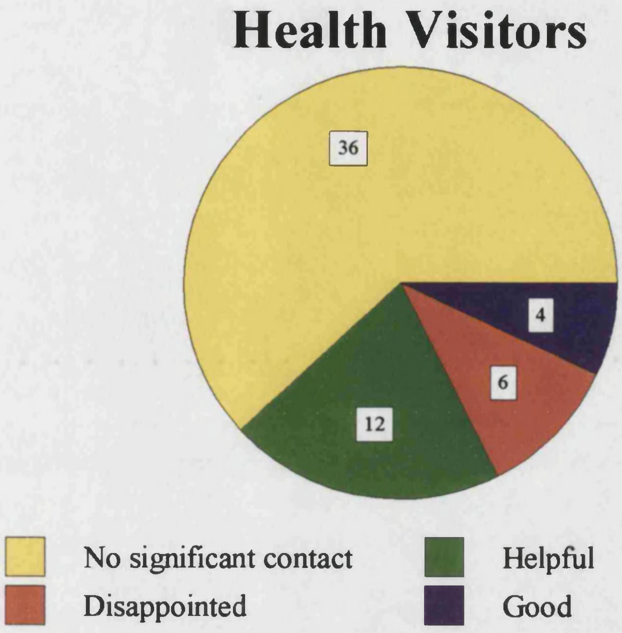
These expectations for health visitors to take a lead role in community health care for children with disabilities was not evidenced in Glendinning's research.[7] She concludes that 'none of the parents indicated that she was in fact a major source of information, advice and support'.

In her study of 20 families caring for a severely disabled child, Beresford reports on the high frequency of contact with health visitors.[8] This might have been expected since many of the children in the study were less that five years old. In terms of quality of help, however, she concludes that 'some parents felt let down because their health visitor failed to visit them after the diagnosis had been made'.

There are difficulties about drawing firm conclusions from questions about frequency of contact because the large numbers of professionals involved in the early months inevitably causes difficulty for parents in identifying precisely which professionals their child had seen. For example, informants may have confused occupational therapists with social workers or community nurses with health visitors'.[9]

In the present study focused on the qualitative aspects of contact with health visitors, the results echoed those of Glendinning and Beresford. Despite the expectation that health visitors might be the main source of advice and support during the months of uncertainty, only 12 families described their health visitor as having been helpful (See figure 20).

FIGURE 20



There were 4 families for whom the health visitor provided a specially good service because she specialised exclusively with disabilities.

> "She gave an excellent service, good at relating both to the baby and to me. She was the first person we met who knew what she was talking about and directed us to the appropriate services in the borough."
>
> (Lisa's mother)

A strongly held view of those who were dissatisfied was that their health visitor lacked training in work with disabled children, in general and cerebral palsy in particular.

> "She didn't know anything about cerebral palsy. I've educated her - it's always been me initiating the questions - they ought to know things like that."
>
> (Cathy's mother)

These experiences reflect the generalist nature of the health visitor role, reiterating Beresford's finding that 'few parents felt that their health visitor had any particular skills or knowledge in relation to disabled children'.[10] She is expected to monitor all young families, but she needs extra training in the complexities of cerebral palsy and the range of disabling conditions likely to be encountered. Training for health visiting has the same dilemmas as for social workers (Chapter 13), but it should be possible for both professionals to learn through practice as was evidenced by Paul's mother.

> "She had the sense to admit she was out of her depth, but she's become a close friend, acting like a social worker. She didn't expect me to take Paul to the clinic and she sorted the nappies out and chased things up for me. She was brilliant."
>
> (Paul's Mother)

Tension between health visitors and mothers was apparent where the diagnosis was uncertain and feelings were raw.

> "At the beginning she was unhelpful, but later...yes I'd got myself together and she found out lots of information for me and did the donkey work. Earlier on I couldn't share my feelings with anybody."
>
> (Nichola's mother)

Hostility to anyone associated with medical services was expressed by those, like Matthew's mother, struggling to come to terms with the diagnosis of cerebral palsy.

> "The health visitor came round and called Matthew 'a naughty baby'. She couldn't help me when I was trying to get the baby to suck. I spent the whole day trying to feed him and he was crying all the time with colic.

> Her comment, 'it's going to take time' was useless. My husband refused her access to the house."
>
> (Matthew's mother)

Frequent visits from a range of professionals was a feature of the lives of many new mothers, although others complained of isolation.

> "The health visitor was one of the battery of therapists who descended on the house, but she soon stopped coming. She said I needed time to come to terms with the disability and would expect us to contact her when we felt we needed help. We lost her telephone number."
>
> (Louisa's mother)

In common with other health professions there was evidence of low staffing levels and inconsistent services. No significant contact with a health visitor was reported by 36 families, and six mothers commented on being disappointed.

> "They told us there would be a full back-up team on discharge. It didn't happen. The health visitor didn't visit until he was 2."
>
> (David's mother)

A feature recurrent in descriptions of other therapeutic services was constant staff changes and shortages in David's case meant he did not appear to have received the statutory visit from the H.V. in the first few weeks. It also mitigated against establishing supportive relationships with families at a time of stress.

> “They're always changing. We've just got a new one. The other one was the best health visitor on earth, but she's left.”
>
> (Charlotte's mother)

Some of these finding express harsh criticism of a service, which clearly could have potential for monitoring, assessment, advice and support. To achieve these ends more investment needs to be made in establishing a cadre of personnel with sufficient knowledge and skill to intervene effectively. It is stressful work contrasting starkly with the positive experiences of working as generalists with babies developing normally. It may be that some health visitors find the situation too painful, which is another argument for a specialist service.

Dingwall et al concluded from their study of the work of 15 health visitors, that 'the main objective of the modern home visit by health visitors is simply to visit' and questioned 'the value of expensively trained and reasonably well-paid professionals going into houses simply for the sake of it'[11]. It is timely to review roles, tasks and training. Twenty years on from Court and Warnock, the health visiting services failed to provide the functions of 'named person' for parents involved in this study.

5.2 General Practitioners

General practitioners have broad-based responsibility for diagnosis, treatment, cure, prevention and referral to specialists for all those, including disabled children, registered with their practice. These duties are allied with those of health visitors although their management and accountability is separate.

GP's are either 'independent contractors' of the Family Health Service Authorities (FHSA) or fundholders, in effect 'small purchasing authorities'.[12] Although by 1993/4 25% of the population of England were in fundholding practices, these different methods of funding general practice did not appear to influence strongly the outcomes undertaken in the initial phase of the change.[13]

Health Visitors, on the other hand, are managed by the District Health Authorities (DHA), although some may be housed in GP practices along with other professional attachments, including social workers responsible to local authority social services departments.

The Gillie Report 1963 encouraged collaboration between primary health care teams, but successful interprofessional working continues to be contentious and the focus for academic debate, Owens, Carrier and Horder 1995, for example.[14] Clearly GP's have more status, authority and powers than health visitors, but their contact with patients may be less frequent and more crisis-focused, since initiative for consultation rests with the patient.

Parents may share uncertain fears about their child's development with their health visitor, but consulting a GP usually means that fears have been consolidated and action is required. 'GP's play a key role in the care of children with disabilities, the nature of their role is as gate-keeper to specialist assessments, treatments and longed-for cures'. [15]

For disabled children living at home, the OPCS research 1989 found that the GP was the health professional most likely to have been seen during the previous year. The consultation rate for children living at home was between 4 and 5 contacts per year, although there was no clear relationship between the number of GP contacts and the severity of the disability.

In terms of quality of contact, Glendinning distinguishes 'considerable variation in the extent to which parents turned to the general practitioner and even greater variation in parents' satisfaction with that care.[16] In particular 'parents questioned the competence of the GP to treat their disabled child', echoing the distrust felt for other generalists, including health visitors and social workers.

Ten years earlier the Court Report identified as problematic that 'at the primary care level general practitioners are not trained to deal adequately with chronic disorders of children'.[17] It is disappointing to find that the results of the present study replicate those of Glendinning: the care of children with disabilities appears to be marginal to general practice and uneven in quality of service. Positive views were expressed by 5 parents.

> "The GP was tremendous, I can't speak too highly of him - he comes round on Saturday mornings if necessary."
>
> (Paula's letter)

Access to specialists and a 'listening ear' when overburdened was appreciated by the mother of twins, one of whom had cerebral palsy.

> "My mum and my nan thought I was cracking up. You have to put on a strong front for the family but I could see Emma's twin was suffering badly - he'd be violent to her, and I found I was shouting at him and telling him off. The GP was very kind and referred him to a psychologist at the surgery. We've both found it helpful."
>
> (Emma's mother)

A child's medical history might influence the quality of service. Emily's mother considered her GP to be overcautious in view of the known medical negligence which had caused cerebral palsy.

> "Whenever we take Emily to the GP he's very paternalistic, but I think he overreacts. For example, when she's got a stomach upset he always refers her to casualty and they put her on a drip to prevent dehydration. I was never quite sure whether it was necessary."
>
> (Emily's mother)

More serious were the experiences of 10 parents who described negative experiences. These seemed to be grouped around lack of specialist knowledge which seemed to originate in their GP's lack of specialist knowledge.

> "Health visitors and GP's don't know anything about disability. They only deal with healthy mothers and babies. If there's a problem the GP sends you to casualty."
>
> (Andrew's parents)

The most vociferous complaints were about failure to diagnose or to refer to specialist services soon enough. These combined feelings about incompetence with frustration at shortage of health care resources.

> "The GP couldn't believe me - you expect answers from the medical profession...I would like to think they would admit they didn't know, instead of fobbing us off as a very difficult family. We were very angry. We'd worked in the health service and expected to be treated differently."
>
> (Angela's mother)

Ambivalence about wanting to accept that something was wrong meant health professionals received projected anger.

> "He was my first child and part of me didn't want to think anything was wrong. My GP said there was no problem but the health visitor saw it at once. We then had to fight to get services. It was outrageous. I didn't know what services I needed or what were available. The health visitor and GP waited for us to ask and we didn't know what to ask for, then when we'd identified it, we had to wait another 3-4 months."
>
> (Adam's mother)

Perhaps the reason for so few families in this study (15) identifying the GP as significant either positively or negatively, is that as soon as suspicions of disability have been raised, referrals are made to the community paediatrician. All participants in the study had been referred to the child development clinic at the time of the study.

The conclusion therefore must be that the development of specialist community facilities advocated by Court has to a large extent siphoned off children with disabilities, from GP practices reducing involvement to episodes of acute illness and as a source of referral.[18]

This study conducted at the initial stages of the NHS reforms cannot provide information about the effects of the purchases/provider split on GP services. However concerns have been expressed about the cost to GP fund-holding practices of purchasing the range of treatments for severely disabled patients. Glennerster et al. quote American evidence of 'cream skimming' where a fixed income per patient would provide practices with an incentive to avoid accepting patients with a high risk of being expensive.[19] This, of course, would be considered unethical by the medical profession.

Continued monitoring is required since parents with children who are undiagnosed or develop disabilities at different stages in childhood need a family practitioner service both as a source of support and as a 'filtering agent' to alternative therapies. It is of interest that although the majority of the participants in this study might be described as middle class, all used the National Health Service provisions as the core of their health care packages. Many purchased extra therapeutic help to supplement the amount of input from the NHS and explored the private sector for alternative medicines, but believed in their rights to receive benefits from the universal NHS as regular tax payers. The GP was their referral agent.

This may be an unexpected attitude from middle class parents in view of the dramatic increase in privately run medical facilities and the growth of private health insurance, which Allsop explains by the trend for subscriptions to be taken out by employers for their employees as fringe benefits, and by a desire to ensure what are perceived as better facilities in private wards and shorter waiting times.[20]

However, since children with cerebral palsy need such a large range of treatments by a diverse range of medical professionals and numerous expensive aids, equipment and appliances, the total cost of individual packages is therefore prohibitive, taking into consideration also the cost of social services and education. Private health schemes are primarily geared in the UK to acute rather than long-term chronic conditions. PPP healthcare, for example, has clear restrictions on the amount of physiotherapy to be paid as a benefit to members.[21]

5.3 The Community Paediatrician and the Child Development Clinic.

Perhaps the most significant outcome of the Court Report 1976 has been the establishment of child development clinics led by community paediatricians.[22] The review by the National Children's Bureau comments positively on the increasing number of paediatricians working either whole time in community paediatrics, or with designated sessions in this speciality.[23]

In practice, all the children involved in the present study had been referred to a community paediatrician. However, only 4 respondents identified the community paediatrician as being a 'special person' in managing their child's treatment. One mother described him being “the most consistent, and better than the GP who knows less than I do”. The most positive comment came from a parent, herself a paediatrician, whose paediatrician had become “like a friend who would fight your corner for you”. However, in general parents made few positive comments. A possible explanation for this may be that after an initial assessment, contact is usually through reviews at 6 monthly intervals. The significance of the community paediatrician therefore is minor compared to that of the therapists, whose contact is frequent, regular and often in the home.

The community paediatrician leads the child development team of professionals, including physiotherapists, occupational therapists, speech therapists, health visitors and social workers. The National Childrens' Bureau found in 1987 that the establishment of child development clinics varied enormously from district to district and in size, membership, parental involvement and referral policy. 'There are many deficiencies in function and gaps in coverage'.[24]

Ten years on, the present study in North London provides evidence of child development clinics varying in policy, organisation and effectiveness. For example, in Borough A, the clinic was housed in the local hospital; treatments were provided on site by appointments with different therapists and little attempt was made to co-ordinate treatment times or content.

> "Whenever we get in the car, I'm on automatic pilot to the hospital. We go everyday for different reasons, physio, hydro, OT, speech, dietician. There are 6 monthly reviews with the paediatrician, infrequent meetings with the social worker and the child psychiatric nurse. Parking is impossible and the schedule is destroyed every time someone is ill."
>
> (Colin's mother)

In contrast, Borough B's treatments were all provided by a peripatetic service from the hospital-based clinic. Home visits often enabled parents to develop confidence in their therapists, and avoided travel problems. For some, however, the system was experienced as intrusive.

> "So many people come to the house. You're not always sure what they can offer, or whether they will come again."
>
> (Lisa's mother)

Borough C had a community-based clinic, separate from the hospital and memories of the birth trauma. Opportunities were available for parents to share experiences and information at the informal Toy Library.

Two levels of involvement with child development clinics seemed to emerge from the interviews. Initially the assessment by the multi-disciplinary team recommends a therapeutic programme. This is reviewed regularly, but the provision of treatments at the second stage, is largely experienced as separate services, variable in quality and quantity.

Academic debates about inter-professional collaboration are prominent in the literature, but the inescapable conclusion seems to be that the notion of team, which owes its origin to 'a group of animals harnessed together to draw a vehicle' may be desirable but difficult to achieve.[25]

The most useful literature has its focus on solutions. McGrath's key points demonstrate how advantages of multi-disciplinary teamwork (efficiency, effectiveness and professional satisfaction) outweigh drawbacks (duality of loyalty and accountability, and the need for support and the development of professional confidence).[26] What seems to be important is understanding group dynamics and processes of conflict, and providing training within professional education so that some professional autonomy is retained, while being able to cross professional boundaries when necessary[27]. As parent participants experienced treatments as separate provisions, they will be discussed in turn.

5.4 Corrective Therapies

It is the natural order of things to seek to heal wounds, repair damage and restore normal functioning. The outcomes of multi-disciplinary assessments by NHS child development teams are usually treatment programmes for physiotherapy, OT and speech therapy, to be reviewed regularly. Prescribed treatments have reassuring effects for medical personnel confronted by intractable disease, and for parents struggling to come to terms with their 'wounded' child. Something can be done.

The emotional impact of cerebral palsy in its powerful distortion of parental attitudes to treatments offered, and to the therapist providers has been discussed in Chapter 3. The driving forces of need to cure and repair, however well-concealed, have profound effects, perhaps the most striking being the willingness to distort family life in pursuit of more, different and sometimes dubious interventions. Parents may appear un-co-operative, greedy and emotionally unstable when medicine fails to provide recognisable solutions.

Early intervention and parental participation are the twin principles for 'adjustment to cerebral damage'. Writing as a physiotherapist Bobath believed 'very early intervention in most cases will give quicker and better results because the child is not, as yet, very abnormal, the treatment is easier, and the mother, if instructed in the proper handling of the baby, can become an active member in the treatment programme with the result that the infant receives more treatments. Once spasticity or athetosis is well-developed, and deformities and contracture have become established, it may take years to achieve - if it can be achieved at all - what might have been done in only months of early treatment'.[28]

The development of speech is also thought to be related to early intervention. Lennenberg proposed that there was a 'critical period' for language development and that delay until after puberty might mean fluency in language could not be achieved because of physical changes in the brain.[29] Lenneberg found a consistent correlation between motor milestones (e.g. crawling, standing, walking) and language milestones (e.g. babbling, one-word sentences, two-word sentences) suggesting that the role of maturation in language development is more like learning to walk than learning to read.

This theory has been disputed; the most convincing evidence being promoted by Curtiss, using the case of Genie who had been deprived of language until she was thirteen years and seven months, but who virtually achieved normal speech through speech therapy sessions.[30] Unfortunately, there is a dearth of systematic research into the results of speech therapy, but the profession holds to the value of learning speech as early as possible and teaching children with physical difficulties (weak breathing, faulty tongue and mouth functioning characteristic of cerebral palsy) to communicate from an early age.

Treatments are usually offered separately by the trinity of therapists (physiotherapy, OT and speech therapy), the expectations being that one parent, usually mother, will participate in regular sessions lasting approximately 45 minutes at weekly intervals to learn how to 'handle' her baby and to become fully participant in treatment aiming to 'counteract the development of abnormal postural reactions and of abnormal postural tone; to give the child functional patterning he will use later on for self help; feeding, dressing, washing for example, to prevent the development of contracture and deformities'.[31]

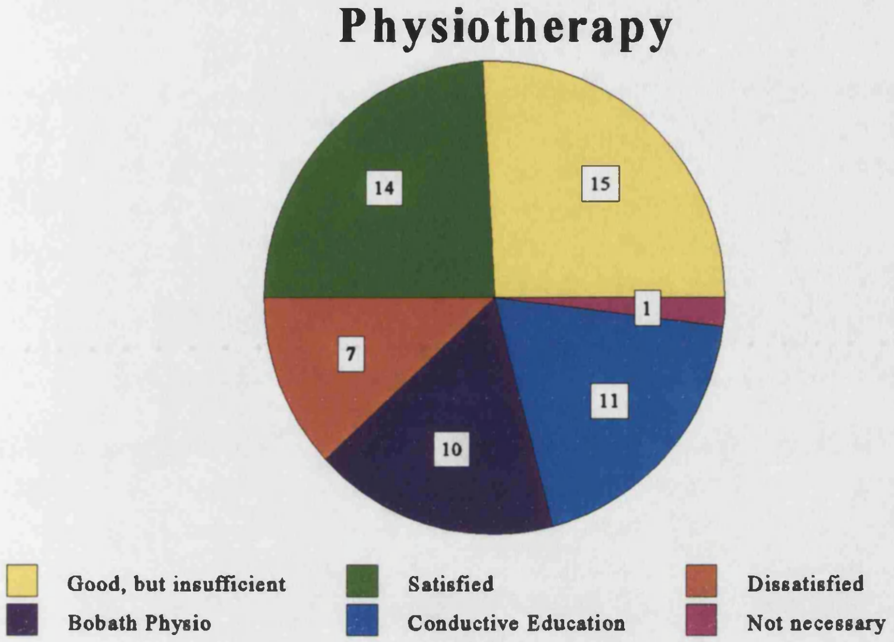
Parents are confronted, therefore, with the harsh realities of the absence of immediate improvement or restoration of normal functioning in the future; the requirement to distort their lives to provide time to participate in the treatments both as a 'student' and as therapist at home; the slow development and change often imperceptible and certainly dashing their hopes that their child might reach developmental milestones. For most of them, acquiring sufficient knowledge of physiology and of the theoretical basis for the prescribed treatment is a perquisite for effective participation, and is not easily acquired.

This study of parents' experiences and attitudes towards NHS treatments paints a picture coloured by both the NHS resourcing problems discussed in Chapter 4, and by the emotional impact of cerebral palsy as a disease.

5.4.1 Physiotherapy

All children in this study had been referred for physiotherapy at the point of diagnosis. As may be seen from figure 21, at the time of the study, 36 were participating in treatment provided by the NHS. Of the remainder, 10 were receiving regular physiotherapy at the Bobath Centre, and 11 were actively participating in conductive education, incompatible with conventional treatment. (see Chapter 11). Of those actively receiving treatment, 14 described themselves as satisfied with the service, 15 considered it to be good but insufficient and the remaining 7 described it as unsatisfactory.

FIGURE 21



Satisfaction seemed to hinge on respect for expertise, knowledge and skill. This was more likely to be established when treatment took place at home, and if the physiotherapist was emotionally supportive.

> "She was the first counselling-type I met. I could pour my heart out to her when she came for an hour each week to my home. She knew Katie had cerebral palsy before we did, and she didn't say anything until we were ready to face it. Katie's three now and she's only just discovered her hands."
>
> (Katie's mother)

Continuity of treatment by the same person provided security, especially when combined with expertise.

> "We were lucky, we had a very talented physio for five years. It was very, very, very good. I didn't know what I was doing half the time."
>
> (Adam's mother)

A recurrent theme for parents was insufficient and inconsistent treatment opportunities offered and this might be explained by rationing of NHS resources.

> "The physios at the hospital were hostile and the sessions were often cancelled. That's why we resorted to the patterning approach."
>
> (Ben's mother)

Some experienced reduced or terminated services when they admitted using alternative approaches (conductive education, for example), and others were advised by their physiotherapists to explore conductive education or the Bobath Centre because of the inadequacies of the NHS.

> "We took him when we were given an appointment but is was too infrequent and we don't have time to follow it up at home. David gets very upset and much of the time is wasted."
>
> (David's mother)

False hopes and expectations certainly contributed to dissatisfaction and were based to some extent on ignorance of treatment aims and potential outcomes.

> "The paediatrician didn't come clean about cerebral palsy, her famous phrase was 'he doesn't look too bad'. I was delighted when he was offered

> twice weekly appointments. I thought it would get him up and walking, but it didn't."
>
> (Carl's mother)

Making effective use of the precious time allocated for their child's treatment created tension especially when the child was unwell, tired, rebellious or simply not in a co-operative mood.

> "It was a wasted effort. The appointment lasted for only 30 minutes. It took ages to park the car and then she fiddled with him a bit and that was it."
>
> (Colin's mother)

Parents expressed anxiety about their child's progress and combined this with feeling protective. Ross and Thomson's evaluation of parents' involvement in the management of cerebral palsy children in two inner cities, concluded that much progress had been made towards involving parents in their child's physiotherapy, but there was much more to be done to reinforce their collaborative role in therapy and to integrate therapy with daily living.[32] Establishing collaborative, useful relationships with parents is both difficult but a priority.

> "It wasn't very helpful. she pushed him to do things he couldn't do. She said he was lazy and that really hurt my feelings. After we changed boroughs, we got a new physio and she's much better."
>
> (Jo's mother)

Entry to school usually meant that treatments were provided on the school premises. Although this relieved mothers of travelling to appointments and feeling responsible for progress, some distrusted the amount of time available for each child. (The issue of including specified treatments within an educational statement is discussed in Chapter 8).

> "It's a relief he has physio at school now, because he won't co-operate with me. He's doing very well there - I've watched him from behind the curtains, but I know that they've reduced the time allowed."
>
> (Bobby's mother)

The key problem with physiotherapy seems to be that it requires considerable time, patience and faith with few obvious signs of improvement. It would be unethical to deprive a child of treatments to establish a comparative study. In any case, no two children are the same. Belief in efficacy has to rest to some extent on faith. The pursuit of greater frequency of treatment sessions either through complaints to the NHS, or by seeking referral to alternative treatments (as discussed in Chapter 7) may be seen as an expression of frustration and the dream that if only there were more help, normality might be attained. A parent's response to the question about the most desirable changes in her experiences of arranging her child's care was the wish to have her own personal physiotherapist available at home.

The likely effects of the NHS changes on the professional service suggest that the resources problem may continue or even worsen. Physiotherapy is perhaps the strongest of the remedial professions and certainly the most vociferous about the likely effects of social policy change. In the words of Potts, 'Each of us is a potential patient, do you want to have a specialist practitioner nurse, a physiotherapist, an OT, a paediatrician, a GP, clinical psychologist, a dietician making regular visits to your home? Thinking about the future, I see a new type of professional, which I will call the health care practitioner who will possess a wide range of expertise. The challenge facing physiotherapy and other health care professionals in the next century will be to justify themselves - rather than seeing this as a threat, we should see it as an opportunity'.[33]

5.4.2 Occupational Therapy

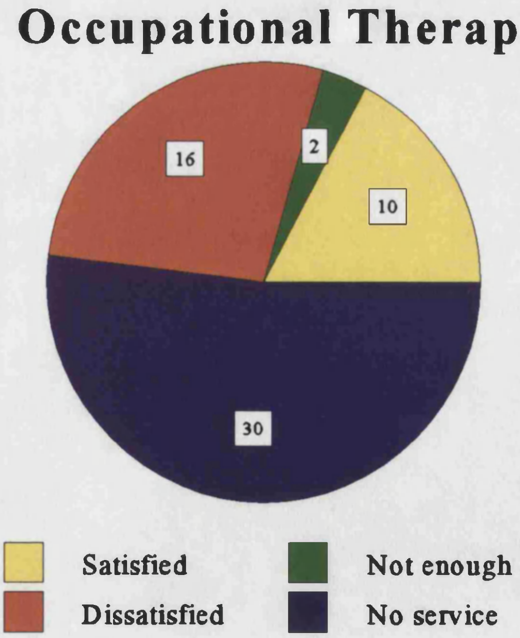
An understanding of the separate, but overlapping contribution of OT to the treatment provided by physiotherapists is necessary for parents. Physiotherapy is perhaps more clinically focused on physiology and anatomy, whereas OT places more emphasis on daily living and psychological attitudes to disability. Nevertheless this distinction is crude, being more a matter of emphasis. To complicate things further, OT's may be employed by the NHS and by local authorities, by whom they are usually known as disabled living advisers (DLA). Children with cerebral palsy may be referred for individual sessions, either at the child development clinic or on home visits. Potentially families may receive a service from both, particularly if their equipment recommended by the NHS needs funding by the local authority as an aid to 'daily living' under the Chronically Sick and Disabled Persons' Act.

The Blom-Cooper Report on Occupational Therapy, challenges popular association of the service with 'basket making' and argues that in accordance with the NH and Community Care Act 1990 the College of Occupational Therapists should 'accelerate the pace of change, already taking place, towards a redeployment of occupational therapists to work in the community, rather than in hospitals'.[34] The Report predicts that ' tomorrow occupational therapists should emerge as major practitioners in community care'. Nevertheless, at the time of this study the overlapping provision caused confusion for parents already uncertain about role boundaries between physiotherapy and OT. It is likely that parental views may have been distorted by uncertainty about the many people who do home visits.

The OT service, as defined by a health services careers document 'is all about helping people to improve their quality of life by enabling them to overcome the effects of their disability as much as possible.[35] Giving support and advice to families is combined with teaching new ways of managing personal care and home skills'. Equipment and aids are provided and collaboration with other therapists is essential to provide consistency. One mother described her OT as "brilliant, she doubles as my social worker, involving herself on a personal level with us and getting to know Ben. She supplied our equipment - two seats, a standing frame and a buggy and she's given us plenty of tips about how to do things. She's on call as well so she's our greatest form of support." (Ben's mother).

As many as 28 families received an occupational therapy service, but there was a low level of satisfaction, as figure 22 shows. Only 10 families reported satisfaction with the service, while two thought it was good but insufficient. The remainder, (16) reported dissatisfaction.

FIGURE 22



Provision of service across the North London area seemed to be patchy and inconsistent so that families living in under-resourced areas were vocal about their grievances.

> "He sees the OT in bursts - lots of input sometimes and then nothing. Sometimes they didn't come for months. One was an American and one German - she was good. I think they're trained differently abroad."
>
> (Peter's mother)

In common with other health care professionals (physiotherapists, speech therapists, conductors) OT's tend to be female and in the early stages of their careers. It was a regular event for a family's favourite therapist to go travelling, changing the location of home and work to accompany a partner, or going on maternity leave. Understaffing often meant gaps in service before replacements were appointed with consequent reduced confidence from mothers who are often uncertain and insecure in their role as their child's therapist. It is ironic that professional publicity literature emphasises 'building confidence, motivation and providing physiological support', when so many parents experienced the borough's provision as "a very weak area".

> "Anthony could be progressing a little more had he had more regular input. Currently he has a Dutch OT who has taught him to undress. He can do it now he's been shown little ways to do it. If there were <u>more</u> input, more children could be more confident. There's so much you can do using commonsense, but you can do it wrongly and it could be dangerous."
>
> (Anthony's mother)

Many mothers reported having few expectations because appointments were "too infrequent to be effective. We learnt more from Portage." As will be seen in the discussion of education (in Chapter 9), those for whom a pre-school experience had been sustained, noticed deterioration when their child entered school.

> “There hasn't been an OT in school now for 7 months. The last one went to Russia - to tell the Russians how to do it - I couldn't believe it!”
>
> (Emily's mother)

These findings are consistent with research findings. Ait-Hoane studied the extent and adequacy of medical and reported para-medical involvement (particularly OT) with disabled children in mainstream education.[36] The results of her study, involving 8 teachers and 3 OT's, indicated that the OT service was considered to be totally inadequate. The national shortage of OTs is particularly acute within social services departments. Mapp concluded that the 'national shortage of occupational therapists has been worsened by spiralling community care referral rates and dwindling resources'.[37] She estimates that 'one in ten social services departments has a waiting list of two years for non-emergency OT services and the College of Occupational Therapists estimates a minimum 231 posts in social services are currently vacant!'

The ADSS Occupational Therapy national workload survey reinforced concerns about the service in social services departments.[38] OT referrals amount to 20.3% of all social services referrals and 17% of referrals are on waiting lists. This high bombardment rate probably reflects the increasing referrals of elderly people being cared for in the community. It would be interesting to know how social services departments share their inadequate staff between the elderly and disabled children.

5.4.3 Speech Therapy

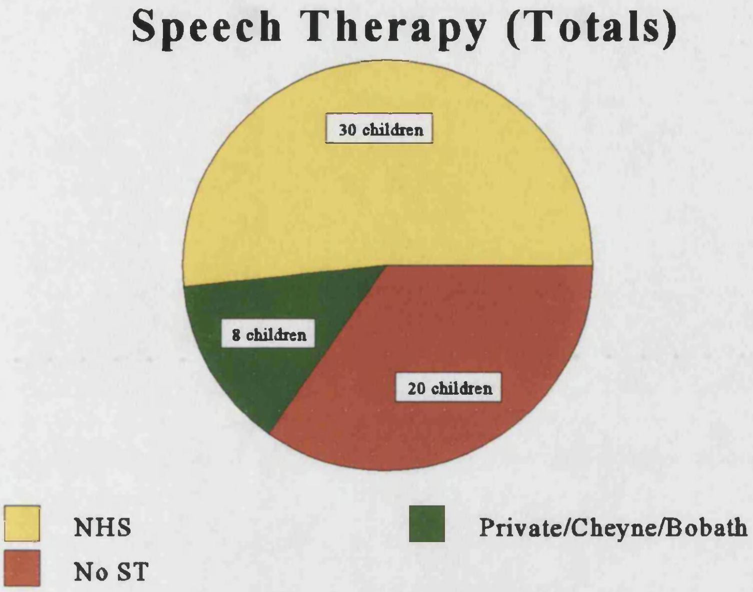
During infancy a combination of maturational processes and learning through interaction with others enables speech and language to develop almost spontaneously. Communication facilitates entry into a social world and is vital to growing independence. Thus, children with cerebral palsy may be considered to be doubly impaired, if they are unable either to move about with others or to communicate.

Brain damage in infancy usually impairs mouth functioning affecting the development of chewing and the acquisition of speech and language. However, both these functions can be improved by early intervention involving collaboration between physiotherapists, OT's and speech therapists. The focus of speech therapy is on improving breathing through strengthening chest muscles. Therapists also advise on appropriate feeding aids, and on encouraging normal tongue action. Throughout, it is necessary for therapists and parents to provide patient and consistent training.

Even children with relatively mild cerebral palsy tend to develop verbal communication slowly. Research has shown the benefits of teaching other forms of communication, Bliss and Makaton for example, as early as possible so that children have positive experiences of communication and therefore social interaction.[39] Some will slowly begin to verbalise while others may learn computer skills and supplement their communication through the use of voice synthesisers. The aims of early intervention, therefore, are consistent with those of physiotherapy, involving experiences of language and movement to stimulate a child's motivation and learning. Both processes are integral to participation in social activity.

In view of this evaluation of the potentially vital contribution of speech therapy to the lives of cerebral palsy children, the finding of this study are disappointing and disturbing.

FIGURE 23

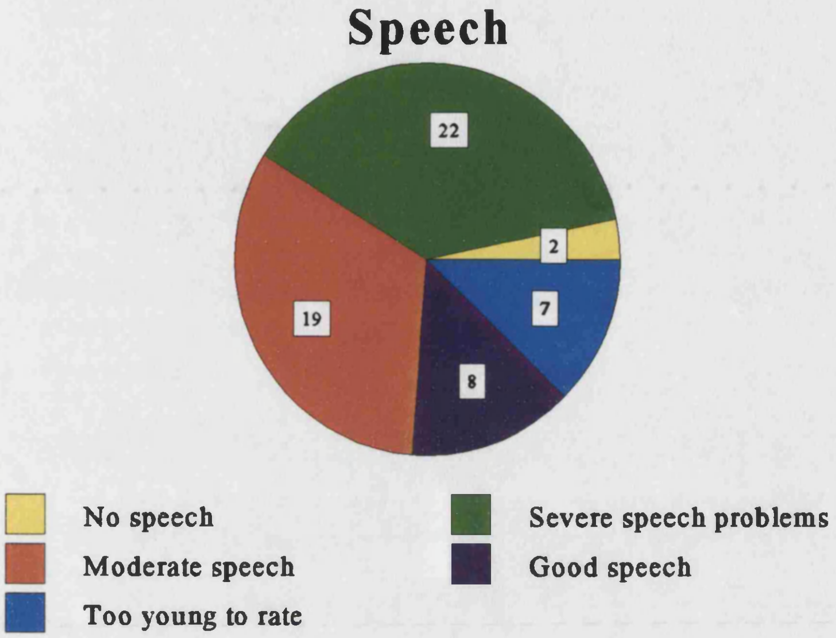


As can be seen from figure 23, only 30 children had any contact with an NHS speech therapist, while 8 others received speech therapy privately; one mother said her child did not need it; only two parents spoke positively.

> "Richard had to be taught how to swallow. I asked to see the speech therapist at the hospital, but she confessed she didn't know anything about babies and she had a caseload of 150. She handed me some photocopied instructions. I went privately, employing someone to help him with eating and drinking. She taught him to ask for things. I paid for about a year and then ran out of money."
>
> (Richard's mother)

The severity of speech problems of children participant in this study may be judged by the finding shown in figure 24 that of the 51 children aged over 2 who might have been expected to have developed speech, only 8 were described by their parents as having 'good' speech. Mothers reported that 19 children had 'moderate' powers of communication, whereas 22 mothers described their children as having severe speech problems, and 2 were described as having no speech.

FIGURE 24



There is a consistent theme from the interviews of irregularity of treatment, cancelled speech therapy appointments, intermittent and ineffective service. It seemed as if the speech therapy service had broken down in many areas.

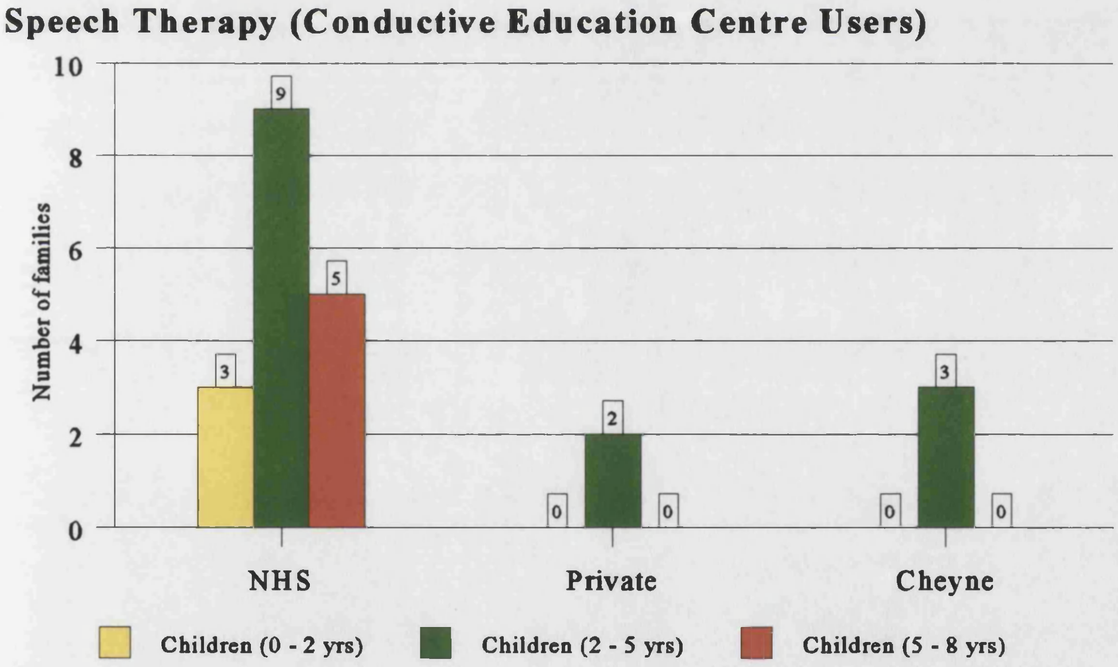
> "The absence of speech therapy is a subject of epic proportions for us. We grew to expect at least 6 months delay on any service provision - with speech therapy there was no sense of continuity or commitment to Matthew."
>
> (Matthew's parents)

While some families seemed resigned to a service from speech therapists, "who all sort of disappear, take holidays in school time, are ineffective, inexperienced and mainly do assessments", others were more assertive: "it took a lot of kicking and screaming to get it started." Speech therapy at the NHS Cheyne Hospital, was accessed by three families, only one of whom had persuaded their local health authority to purchase this treatment. The others paid for it themselves.

Being assertive can be counter productive as Louisa's mother discovered: "I read her notes, 'this parent has trouble with authority' I knew I wouldn't get any further with her."

Although families using conductive education were discouraged by the Centre's director from engaging in alternative treatments (Chapter 11) parents remained unconvinced that the 'rhythmic intention' characteristic of conductive education was adequate for speech and language development. Figure 25 shows that most of the conductive education centre users were also receiving speech therapy elsewhere.

FIGURE 25



> "Drumming in is no substitute for speech therapy. I think Hannah needs a lot more individual help, seeing a specialist weekly. At the conductive education centre she copies the behaviour of children whose conditions are more severe than hers, and she doesn't speak because none of the others are able."
>
> (Hannah's mother)

Evidence from this study is consistent with a skeletal NHS speech therapy service, and private provision beyond the financial means of most families. This defective service reinforces the bitterness of articulate parents committed to assembling packages of treatment to include speech therapy, an essential component for securing lives 'as normal as possible' for their children. It highlights also the empty rhetoric of the Children Act Guidance which prioritises 'consulting children with disabilities' to give them 'the same rights as other children and adults to have access to information... and to give consent or refusal to any action including examination, assessment or treatment'.[40]

5.5 Conclusion

This chapter has shown parents' unsatisfactory experiences of orthodox professional interventions. The predictions of a Health Educational Council's project investigating the contributions of chiropody, dietetics, OT and physiotherapy to health care (1984) were increased staff shortages and budgetary control. They reported 'a more subtle influence as the perceived emphasis within a health service on quantity rather than quality, such that practitioners feel guilty about time spent 'just talking' to patients. Success seems to be measured by numbers of patients pushed through the system'. Nevertheless, there have been experiments within the NHS to try to overcome some of the dilemmas described here. The following chapter will include a case-study illustrating this point.

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Chapter 6 Families and Assessment by a Child Development Team

> "You can spend time trying to fit in as much therapy as possible, when what you want is normal life. What is going on is abnormal. I ask myself 'should I make him do it? does it matter in the long-term in my parental task of making him a balanced human being? There are so many over-therapied children."
>
> (David's mother)

This chapter examines a multidisciplinary assessment system established to decide on appropriate therapeutic intervention for each disabled child. It was designed as a response to exactly the kind of problems described in this study. The child development centre selected for this case study had been funded by the Mental Health Foundation for a research project from 1988 for 3 years. Research funds had been used to develop multidisciplinary assessment procedures, and a parent advisor service initiated in 1985. The rationale for the research has been reported by Cunningham & Davis.[1] Like the Honeylands study in Exeter 1984, it was a local response to the 'needs of parents of young handicapped children living at home'.[2]

The child development team served a deprived Inner London borough with a substantial Bangladeshi population. The team led by a consultant paediatrician consisted of a physiotherapist, OT, speech therapist, social worker, health visitor and parent advisor, working in collaboration with the borough's Portage Service established in 1987, and with the child psychiatric service.[3] The absence of an educational psychologist is worthy of note in the light of the emphasis in the Children Act Guidance on collaboration between education, health and social services.[4] Moreover the social worker commented that the majority of referrals to the clinic came because of the shortage of educational psychologists in the borough. She wondered whether "we would need to see many of our referrals if educational psychologist were able to advise schools on classroom management."

The initial response to referrals to the child development centre was for the HV and social worker to share the work of home visiting to establish the family circumstances and to inform the family of the assessment system. This involved inviting the parents and the child on two mornings to a clinic playgroup with no more than 3 other families.

> "We visit to look at the home environment, so we don't give families impossible tasks in relation to space available at home. Parents aren't going to trust us if we offer 'cloud cuckooland'. The visits also reduce anxiety; as the result we get nearly 100% attendance at the clinic playgroup assessments."
>
> (Social worker)

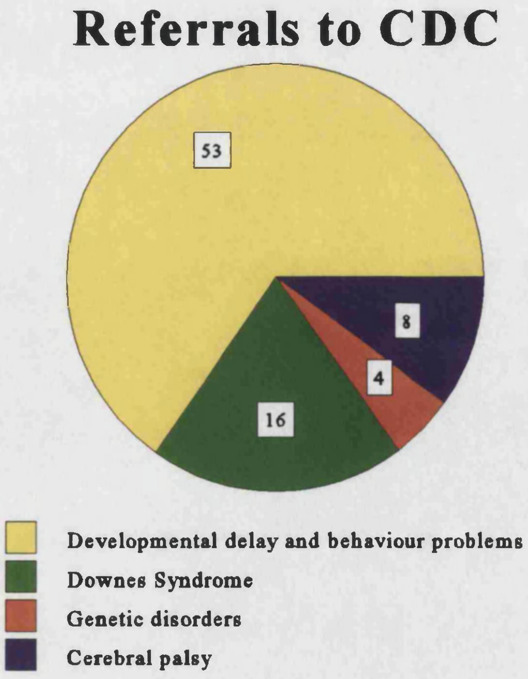
During the play sessions of one and a half hours each, therapists assess the children. More than one attendance allows them to settle in. A meeting of the multi-disciplinary team following the play/assessment session reaches agreement about a recommended treatment plan, which would be discussed at a subsequent meeting between parents and the paediatrician.

Parents are normally expected to participate in the play session with their child in a large room equipped with toys including a slide. There are observation facilities - a one way mirror, which might be used by parents who wanted to observe their child's behaviour in the group. These observation facilities are regularly available for the purposes of training, and interested visitors were invited to attend both the pre-playgroup meeting of professionals, where the findings of the HV and social worker were discussed, and the post-playgroup meeting to consider treatment recommendations.

The philosophy behind providing assessment within a group environment is to provide opportunities to see 'what a child can do, moving away from traditional health service assessments which focus on disabilities and limitations'. The social worker explained that "many of the parents have already been to all sorts of specialists. We try to show them it's not all doom and gloom by asking the question; What can each child do?"

Traditionally within the health service children are assessed individually. This 'group assessment' process might be considered most suitable for assessment of children with behaviour problems than for disabled children, since information about interaction between peers might be an anticipated outcome. Figures obtained from the social worker of referrals to the clinic between January 1987 and March 1991 showed that of the 81 children referred to the service, 53 were for investigation of developmental delay and behaviour problems. A breakdown of the referrals is presented in figure 26 below.

FIGURE 26



Although the social worker thought many children found this "a good experience and wanted to come back", observations of three playgroup sessions revealed little interaction between children. This might be explained by the presence of other family members. On each occasion the majority of families were of Bangladeshi origin and the referred child was accompanied by both parents, siblings and in some instances, grandparents. The strange environment and the presence of a number of professionals might also be considered to have been inhibitive: assessment of four children meant at least 17 people in the room (4 children, 6 professionals and 10 relatives).

During the play sessions each of the professionals fulfilled what appeared to be prescribed tasks: the paediatrician sat with each family in turn taking a written medical history; the OT did puzzles/co-ordination tests at a table in the middle of the room with each child in turn; the speech therapist did her assessments in a nearby room; the physiotherapist tested individual children in an adjoining room where there was more space; the HV and social worker moved from family to family talking with parents and playing with the children; the parent advisor acted as interpreter as required. There was no educational psychologist or Portage worker present.

Using an individual approach within a group environment, each professional collected relevant evidence to pool in the multi-disciplinary team meeting held later. The views of observers were actively sought in this discussion, although parents were excluded even if they had chosen to be observers rather than participants in the playroom.

To the observer the room seemed noisy and crowded.

> "The baby who has cerebral palsy is screaming as she's fed by a gastro-nasal tube held up high by her mother, elder sister and parent advisor. Meanwhile Kirsty who has cerebral palsy lies on the floor, her legs in a

> scissor position. Scott, referred for temper tantrums, poor co-ordination, feeding and sleeping problems, has a tantrum near the slide. I wonder what it must feel like for parents participating in this observed assessment?"
>
> (Extract from observation notes)

Parents were expected to collaborate with the system and usually did so. However, during one observation a mother, described at the pre-playgroup meeting as tired of her child being assessed all the time and wanting to cut down on the number of people seeing her, was persuaded to allow her child to join the playgroup on condition that she could have the history taken in private and observe rather than participate herself.

It was striking that all the professionals were women and, apart from the Bangladeshi interpreter and the Chinese HV, were Caucasian. The Bangladeshi families, many of whom spoke little English, were unlikely to protest about this intrusive assessment method, whereas the mother who did protest was middle-class and articulate. The contrast between the white professionals and the Bangladeshi families being assessed provoked a black social worker student observing the session with the researcher to announce angrily "what do they think they are doing in there? It looks like the white's showing the blacks what to do!"

Another aspect of this group assessment method was its limited value for children with cerebral palsy, particularly those presenting with restricted mobility, and therefore unable to interact with others or use toys and equipment. A contrary argument might be that until observed within the group, the range of ability could not be assessed accurately.

> "Kirsty lies on the floor and begins to roll towards her mother. She smiles, noticing what is going on in the room. She hears her father's voice, responding to his call with a bright smile."
>
> (Extract from observation notes)

Perhaps the absence of choice of assessment procedure, the public nature of parts of the process, and the fact that some professionals, (physiotherapist and speech therapist) work outside the group, raise questions about the method.

The other dimension to the system is the dynamics of the multi-disciplinary team. The aim should be 'the efficient and effective use of resources, ensuring that the best interests of the patient are protected'.[5] In this case study, the fundamental question is whether the multi-disciplinary team provided quality service by effective collaborative working. A truly rounded picture would include both evaluation of treatment outcomes through follow-up after assessment, and seeking opinions of parents. This is beyond the scope of this study centred primarily on examining professionals working together.

6.1 The Multi-disciplinary Team

'Working together' may be deemed successful if a service is delivered through a collaborative partnership between the range of professionals involved. The aim of the child development clinic is to make a comprehensive assessment of treatment needs of disabled children in participation with their families.

During the observed sessions the team appeared to work co-operatively, reaching mutually agreed decisions through fully participatory discussions between professionals and visitors following the playgroup assessments. It is relevant that the system had been operational for 4 years by 1992, the year of this study. Group work theory suggests that in the early stages of team working 'issues of power control and status are paramount, whereas the middle stages are characterised by intimacy and a sense of belonging'.[6]

Nevertheless, interdisciplinary work is notoriously difficult. 'Conflict is a natural and inevitable development of interdisciplinary team life.[7] Conflict may be destructive, or channelled constructively by reaching compromises which enable the task to be accomplished and cohesion sustained for future working.

The most likely barriers to success may be located in the problem of 'crossing occupational barriers'.[8] MacKay et al. identify these as 'ascribed and perceived occupational status;...occupational knowledge and the perceived importance of that knowledge for health care; ...fear, even distrust, of the perspectives of other occupational groups!' They conclude that 'interprofessional working is a question of the redistribution of power in health care'.

Applying the notion of power distribution to this child development team, it was clear that although functioning democratically, the hierarchy of professionals was led by the paediatrician who chaired the meetings and met separately with parents to deliver decisions. Deference to the consultant is usual within the health service, thus providing a familiar structure for participants. It also endowed decisions with the authority usually ascribed to medical consultants, who legally are ultimately accountable.

Because the team functioned publicly, there was a sense in which ways needed to be found to overcome or conceal destructive conflict. In this team, professionals appeared to cross professional boundaries with ease. For example, the social worker and HV shared the initial home visits, and there was an expectation that all professionals played and interacted with families in the playroom. However, each therapist had prescribed functions, which for the physiotherapist and ST meant leaving the room. The OT appeared to be making educational assessments, usually the responsibility of educational psychologists whose absence avoided a potential territorial dispute.

The Royal Commission of the NHS (1979) suggested that the difficulties of a multi-disciplinary approach were 'more attributable to inter-professional jealousies than anything more solid'. By providing opportunities for using separate professional expertise within a team context, what Plunckham called 'professional territoriality' was avoided.[9]

Successful teamwork involves negotiating both professional and personal roles. In this child development team, power and influence appeared to rest with the most experienced member, the OT. In comparison, the physiotherapist and speech therapist were younger, probably newer recruits to the service. They made their independent assessments, which together with the social factors provided by the social worker and HV were pooled with the medical history taken by the paediatrician and the educational dimension from the OT. Each professional suggested the treatment related to their expertise and final decisions were reached by dialogue between OT and paediatrician. The usual distribution of power in the health service places OT's lower on the hierarchy than physiotherapists. (See Chapter 5). This different distribution of influence may be explained by the personal experience of the postholder and also because most of the children needed 'educational' assessments. Had there been an educational psychologist in the team, things may have been different.

According to Greenwell 'interprofessional team-working involves forming horizontally organised teams from vertically managed groups of staff'.[10] The exclusion of representatives from education (caused by understaffing rather than by design) from a team composed primarily of representatives from health apart from the social worker (managed by the local authority social services team) removed a source of potential conflict allowing the medical model to prevail. It meant also that the 'vertical management' (health) was also effectively the 'horizontal' manager because the greatest power appeared to rest with the paediatrician.

Perhaps the apparent effective teamwork should be ascribed to the fact that the team had shifted 'emphasis from a professional to a task-oriented approach'.[11] By this process, the assessment as an end in itself took priority over expertise, heightened commitment to productive interaction and offered intellectual stimulation.

Participation in making developmental assessment of disabled children can be a disheartening and painful process engendering anxiety for therapists working in isolation. Usually support is provided by peer teams of physiotherapists or OT's, for example. The multi-disciplinary team provides a more rounded picture of a child's capacities; a more holistic assessment of potential change. When one profession may feel despondent another may be more positive, thus providing defences against the anxieties and fantasies inevitable in the work.[12]

Under-resourcing of treatments, a recurrent theme in this study, was probably another significant factor influencing the functioning of the team. Although a spirit of optimism seemed to surround the assessment system, likely outcomes were less hopeful. For example, speech therapy could not be provided regularly for all children in need of the service so that the speech therapist largely acted as a consultant to those in day to day contact with the children, and the OT overcame the problems of a long waiting list by referral to Portage. The area social services office was in disarray. There appeared to be management difficulties as work was devolved to neighbourhood teams, and accommodating the new statutory requirements of community care was draining resources. (See Chapter 12). Unfortunately thorough assessments could not be matched by intensive therapeutic involvement, which remained the responsibility of separate underfunded services.

In summary, this part of the case study has highlighted the recurrent problems of interdisciplinary working, thereby reinforcing the view expressed periodically in this study, that aspirations to multi-disciplinary collaboration expressed in social policy and legislation are fraught with difficulty. The team described in this study was able to sustain collaborative functioning over several years. But effective participation by users appeared to be more apparent than real. Medical professionals were more influential than either social services or education. Moreover, even when the system effectively identified many needs of these children, monetary constraints prevented the implementation of effective treatment plans.

6.2 Parent Advisers

The Parent Adviser Scheme was designed to be integral to the child development assessment system described in the previous section. Jointly funded as a research project since 1988, the scheme aimed to provide trained counsellors (parent advisers) to work with families who had a child with special needs, visiting them at home, 'showing respect and working in partnership with them in order to facilitate the development of parental self confidence, and to foster the family resources in order to help them to help themselves and their children'. (Unpublished parent-adviser literature).

Recognising that there were already numerous professionals providing treatment and care for disabled children, counselling training was offered to professionals already involved with families to enable them to enhance the quality of their work. The intention was not to create a new profession but to enhance the skills of those in established professions. Those eligible for training included personnel at the child development clinic (including physiotherapists, OT's, speech therapists, secretaries), HVs, nursery nurses, teachers, social workers, day centre staff, education welfare officers, parents, school governors and interested volunteers.

The counselling training course designed and taught by a counselling co-ordinator consisted of 10 weekly half-day sessions. Course participants endorsed by their managers, committed themselves to course attendance followed by working with one or two families as a parent adviser/counsellor. Regular supervision from the co-ordinator and participation in support group sessions were requisites of the training package. Training was free to employees of the local NHS Trust, and fees were charged on an incremental scale to local people and those from outside the borough.

On completion of the course, parent advisers were 'matched up' with families referred to the scheme from a variety of sources - child development clinic, doctors, Portage workers, education social workers, Barnardos and the adult mental handicapped team, since the scheme was not confined to children. The most effective point of referral was the special care baby unit (SBU) of the hospital at the point of diagnosis. Parent advisers might work with families already on their caseloads in their professional capacities as physiotherapists or OT's, for example. It was more usual, however, for families to be allocated specifically for counselling, and managers were expected to allow their staff to spend time within their regular working week as parent advisers.

> "I find I have to match up families quickly and well, otherwise they'll drop out, or their managers change their minds or change jobs. You have to keep chasing them up because sometimes I don't have a suitable family for them when they finish the course."
>
> (Course co-ordinator)

In essence, therefore, this was devised as a relatively low-cost scheme for training counsellors to be paid through their own employers, who must have endorsed their application for training and accepted the implications for future participation. Apart from the training costs of the employment of a full time co-ordinator, on-going service costs were met by employing bodies. Parents and other non-employed participants were expected to work as volunteers, but to ensure adequate Bengali workers, payment was provided through section II money (Race Relations Act, 1976) for Bengali parent advisors to work with families, set up groups for mothers, and act as interpreters.

The scheme has much to commend it. Being responsive to the emotional impact of disabled children on family life has been a recurrent theme in social policy when debating the shift to 'the handicapped child remaining in his family and in the local community, whenever this is possible'.[13] An NCB sponsored report advocated casework and counselling as integral to interdisciplinary assessment centres comprising 'core' professionals from health, education and social services working 'in participation with parents. A multi-disciplinary problem needs a multi-disciplinary solution', and 'if co-ordination is lacking no-one is accountable'.

These themes were developed in the Court Report and the Warnock Report, both of which advocated a 'named person sensitive to the needs of parents, with particular expertise or interest in the area of the child's disability'.[14] There were also specific recommendations that 'families from ethnic minority groups are likely to face particular difficulty' The chorus of advocates for sensitive counselling for families was joined by academics, and by the Children Act Guidance which stresses the need for 'personal counselling, support and representation'.[15]

More attention seems to have been given to acknowledging the existence of stress for parents than to recommending how this would be reduced, although there seems to be agreement that one among many professionals should be nominated as 'key worker'. The Children Act Guidance emphasises further that the 'care manager' should have overall responsibility for provision and co-ordination of services, but the 'key worker' should be 'directly involved with service delivery'.[16]

Three levels of need seem to emerge: a manager of services functioning across agencies and professions; a key worker, who was also a service provider; a counsellor specifically focusing on the anguish experienced by parents of disabled children, particularly in the early stages of diagnosis. The key worker and counsellor may be the same person. But, while all professionals involved should be sufficiently aware of emotional issues to work collaboratively with parents, some parents may need counselling as a service in its own right, in order to participate fully in their child's treatment programme.

Cunningham and Davies are critical of what they define the 'expert model', where parents expect professionals to be fully in control of decisions[17]. They advocated a 'consumer model' within which the parent-professional relationship decision-making is ultimately in the parents' control and 'the professional respects the parents, acknowledging their competence and expertise in knowing more about their total situation than anyone else'.

The parent advisor service under discussion has the potential both to sensitise professionals to the emotional needs of parents when providing their particular specialist service, and to train skilled counsellors to help the most distressed families. Although this latter function should fall within the roles and functions of social workers, the constant reorganisation of social services, social work training courses, and priority given by social services departments to child protection (discussed in Chapter 14), meant that the area where this research project was located was not unusual in having only a "social work service, largely cut-off from families with disabled children and constantly complaining that they've too much work to do" (Course Co-ordinator, Parent Adviser Scheme).

Comparison of the scheme's valid aims with outcomes in practice, revealed operational difficulties mainly stemming from the intractability of interprofessional working. The training courses have proved well-subscribed and have earned positive assessment from a range of professionals appreciative of the opportunity to concentrate on developing counselling skills. The training co-ordinator regarded the parents of the disabled children as the best trainees, "they're really dedicated and not constrained by their work situations." By parents she meant mothers, as fathers "have expressed interest but are afraid."

Physiotherapists in the borough were required to do the course and proved to be "really keen, usually using their training with their own families to improve their physiotherapy." One of the parent participants in this study of children with cerebral palsy was resident in this area and received help from a parent adviser, also her physiotherapist.

> "From the time Nicola was 5 months, our physio. was our parent adviser. We were great friends, but she went to Romania. After a fight I was allocated a new physio. She wasn't a parent adviser so she devotes all her time to Nicola and not to me!"
>
> (Nichola's mother)

In contrast, OT's and speech therapists were not actively involved; teachers had not taken on families but used their learning from the training course in class; education social workers were good, but organisational difficulties within their service meant that few actively used their training with referred families.

Out of a team of six education social workers in a neighbourhood team participating in an evaluative discussion of the scheme, three reported having done the course. The other three planned to apply for training. Apart from using their learning within their work as educational welfare officers, evidence of provision of a parent advisory service as envisaged by the project was disappointing. One had advised a Bangladeshi family for 3 months (6 visits) until their return to Bangladesh; another was advising a 26 year old mentally handicapped adult as she found advising families with school children conflicted with her role as EWO; another had just completed the course and was liaising with an OT in preparation for starting counselling his first family. The team leader had decided that no team member should take on more than one family, and the service came to an abrupt end when the team was disbanded in response to local authority re-organisation a few months later.

Since the scheme was dependent on effectively 'stealing' professional time from organisations with separate management, it could not succeed if managers later reneged on their commitment. But pressure on staff resources was not the only explanation for difficulty. The scheme seemed also to have been in conflict with the child development centre, which was the ideal focal point for referrals and on-going work.

The course co-ordinator was not a member of the assessment team, although the HV and social worker had done the course and a Bengali-speaking parent advisor usually participated in the group assessment playgroups. The co-ordinator was highly critical of the child development team.

> "I get very annoyed with the CDT. They spend their lives doing assessments but the services aren't available - a child can wait for 2 years for provision. The parents start to get angry because they can't supply what they need and the parent advisers are left helping them to fight for services. The professionals think we incite these parents to demand the treatments they've been promised at the assessment."

This echoes the conclusion of the previous section that the assessment team focused more on collaborative working, paying less attention to parent-users and their children's therapeutic needs. In the co-ordinator's experience too many referrals were made to the Parent-Advisor Service "when parents were very angry or difficult to manage." The expectations of medical professionals that the parent advisor might ensure more co-operation tended not to be met, and parents themselves were suspicious about the service.

> "It depends on how parents are told about the service. Their prime requirements are treatments and cure. They're not interested in parent advisors who might be seen as spies for the medical team responsible for rationing poor resources."
>
> (Parent-Adviser Co-ordinator)

Another problem stemmed from the medical model of the CDT. Combined frustration at poor treatment provision and anguish about their child's disability roused parental hostility to the paediatrician. "There's rivalry between us as the doctors wonder why parents don't treat their advisors as enemies. Parents feel helped and supported by us, if they can overcome their initial suspicions." Rivalry was expressed over the issue of confidentiality: "The medical team may find our feedback useful for their professional assessments, but they don't like our adherence to confidentiality and our unwillingness to spill personal stuff."

Perhaps some lack of clarity about the aims of the scheme contributed to the enmity. The title 'parent adviser' suggests expertise in practical help and advocacy, rather than in counselling and understanding. The co-ordinator admitted that she would like to see the name of the service changed as "it's very misleading. The CDT staff confuse us with social workers and are annoyed that we refuse to accept child protection cases; paediatricians refer for behaviour modification approaches and expect cures, whereas we prioritise listening to parents. Professionals still seem to refer the child for treatment for bed-wetting, for example, rather than referring the parents for understanding."

As Beattie identified, 'boundaries between professional groups are developed and maintained through chains of competence in dealing with specific problems.[18] Where clarity is lacking, or boundaries overlap, conflict is inevitable'.

The scheme was adapted to include the employment of Bangladeshi workers to act as interpreters and advocates instead of as counsellors. Their contribution included collaboration with the predominately white team of professionals at the CDC; with the local Portage Service in establishing parent groups, and encouraging parents to learn English.

Under-resourcing appeared to have constricted this project in a number of ways. Not only were professionals undermined by the limitations imposed by their managers; the project itself could not implement plans for a resources centre in collaboration with the local Barnados respite care scheme, because “social services are being very neglectful, imposing cuts right across the board.”

Without designated accommodation or adequate secretarial backing, the co-ordinator left the project after 4 years (1988-92) fearing that the purchaser-provider ethos in the NHS might weaken the service further, since the future depended on public bodies prioritising counselling over and above other provisions with more distinct, measurable outcomes.

This part of the case study portrays a creative and brave attempt to empathise with parents, and to humanise the medical model of treatment provision for disabled children. Although problematic operationally, the model has been adopted in other areas. Children's Services News reports on a scheme in south-east London funded through the Primary Care Development Fund, Optimum Health Service NHS Trust, and Lewisham and Guy's Mental Health NHS Trust[19]. It is interesting that this scheme employs parent advisers on a part-time basis rather than being dependent on either volunteers or professionals 'borrowing' time.

6.3 Conclusion

Parents living in areas such as this benefitted to some degree from efforts, to improve their lives. The scheme clearly had enormous potential as a means of recognising the counselling needs of parents of disabled children. It will be seen in chapter 13 that local authority social workers are trained to fulfill these functions but for organisational reasons, rarely achieve this. It is heartening that the scheme has been adopted in other areas.

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Chapter 7 Families and Alternative Approaches to Treatment

> "I am a foreigner in this country where my baby was damaged. They should tell me what I need to help him. I am his mother not his physio, O.T. and speech therapist. How can I be all of these things when I have not been trained? Going to Budapest was my way of finding the treatments which were not available here."
>
> (Zola's mother)

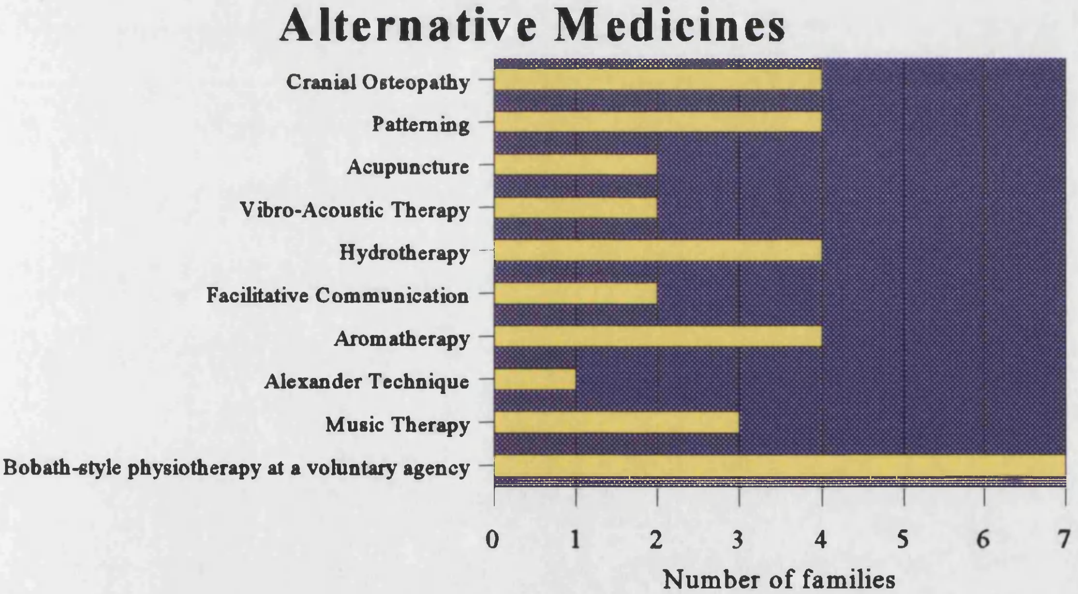
Dual pressures drive parents of children with cerebral palsy to explore alternative treatments outside the National Health Service. Poor and deteriorating publicly provided health care as evidenced in previous sections, combine with emotional needs to ensure that no stone has been left unturned in gaining access to therapeutic help. Parents are driven to experiment in areas often inadequately evaluated and largely unregulated. Other contributory factors seem to be media publicity, which promotes unusual solutions, and the recent changes in social policy in its espousal of a mixed economy of care. Lewis and Glennerster have demonstrated how the government attempted to strengthen the independent provider sector by deciding that local authorities must spend 85% of the social security element of their grants in the independent sector.[1]

Sharma's research into the reasons for using alternative medicines indicates that users are 'generally voicing anxieties, which they share with many who do not use alternative medicines....only a few of the people interviewed gave explicitly ideological reasons for their initial attraction to alternative medicines....Most patients would be seen to be (negatively) dissatisfied with the service offered by orthodox medicine, coming on the whole from its areas of notable failure rather than (positively) attracted by an alternative world view the former may claim to offer'.[2]

This conclusion fits with the consistent frustration expressed by the parents of children with cerebral palsy about the quality, quantity and effectiveness of the orthodox treatments available through the NHS. However, parents of school-age children may regret their usually episodic involvement with alternative approaches when they reflect on their treatment planning during their child's early years.

> "The problem of finding the right treatment can consume you so much, particularly if you only have one child. I gradually realised that everyone in the family had special needs. It was really hard to stop going out looking for alternatives but you have to resist it."
>
> (David's mother)

FIGURE 27



The range of alternatives tried by some parents in this study (see figure 27) was wide, including cranial osteopathy, patterning, acupuncture, herbalism, homeopathy, aromatherapy, vibro-acoustic therapy, facilitative communication, the Alexander Technique, and music therapy. One parent of a four year old reported having used nine of these approaches, because she "hated the patronising attitudes of professionals who treated her son like a baby. I've put together my own programme for him, selecting the best out of the unconventional medicines."

For parents of children in their second and third years, a pattern of progress emerged, starting with NHS treatments, then to the conductive education centre in London; then on to the Peto Institute at Budapest; and finally to the Bobath Centre in London. These options may be explored simultaneously or in a different order, but most parents worked their way round each of these options like a journey of discovery in territory they were unlikely ever to have explored had their child not been born with cerebral palsy.

> "I had to take Emily to the child development clinic for a weekly half hour session, which she screamed her way through. They used to do home visits, but they said it took too long. It was ridiculous... I'm sure I should have felt better but Emily couldn't control her limbs. She must have felt a bit like she was plastered! I was still at the stage where I thought it was just physical - you never think it's the brain. I heard about conductive education on the radio. It helped me a lot but one hour a week just wasn't enough and it's wrong to close in the holidays. What do I do with her for 6 weeks? My NHS physio was reducing our time because we'd chosen conductive. I turned to Bobath where Emily started going three times per week for one and a half hours."
>
> (Emily's mother)

The subsequent sections of this chapter examine in more detail two examples of alternative treatments; conductive education in Budapest and the Bobath physiotherapy treatment at the Bobath Centre in north London.

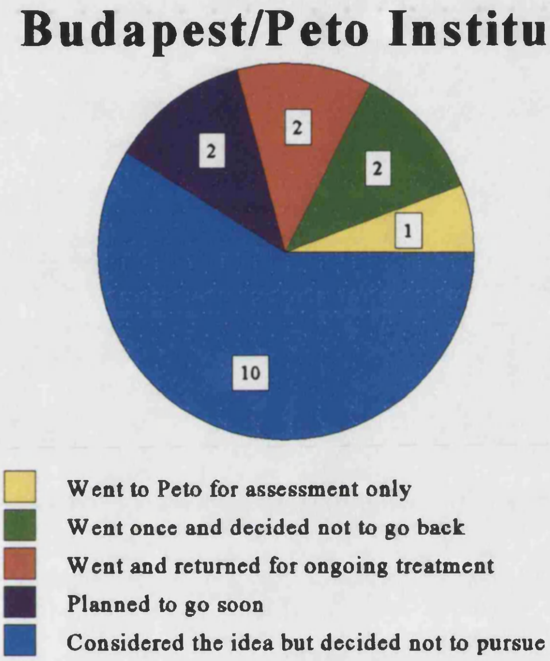
7.1 Going to Budapest, The Peto Institute

Conductive education presented as an educative process available at a centre in north London rather than therapy, will be evaluated in more detail in Chapter 11. But many parents are tempted to explore the Peto method as a treatment alternative by going to Budapest.

> “Conductive education and going to Budapest was a bit like Everest to me: it was there to be scaled. I became worried about how they were treating him because it reminded me of breaking in a horse. We tried Bobath next, but it was so inconvenient to get there when I was pregnant again. On reflection, I don't think it's necessary to go to those lengths - we think he will work out how to manage himself.”
>
> (Ben's mother)

Media publicity for the Peto Institute began with the BBC film 'Stand up for Joe' in 1986. The possibility that this educative process involving strict training under the instruction of Hungarian conductors might enable children to walk was the carrot which drew many parents to consider this expensive and disruptive choice. Even those participants with access to conductive education in London considered this option, the explanation lying in the tendency of parents to feel they ought to leave no avenue unexplored, no stone unturned to restore to their children the abilities so harshly removed. Even those who could not afford this option seemed undeterred, but involved family and friends in fund-raising campaigns, sponsored events, car boot sales, and newspaper publicity for donations. It is remarkable that so much energy was generated in this way by families already leading full lives providing day-to-day care. Figure 28 shows that 17 families actively explored this option. Although the majority did not become involved, they were aware of this alternative approach and discussed their views during interviews, sometimes using the opportunity to clarify their reasons for not pursuing it.

FIGURE 28



In response to UK and European demand, the Budapest Institute set about marketing conductive education in the UK, in conjunction with Scope (the Spastic Society) who were already providing conductive education in their residential boarding schools. As boarding schools faded in popularity, conductive education on a daily basis in collaboration with family life seemed a popular alternative. Scope offered either assessments for suitability for short periods of treatment in Budapest (usually 4 weeks) or conductive education in newly-established 'Schools for Parents', the first of which opened in Essex in 1994. For those children selected to go to Budapest, the commitment was to go on regular short visits after which parents should 'practice' the regime at home before returning for further training. In Budapest, the Hungarian children were kept separate from the UK and European visitors, their programme being like that of a boarding school. Thus, some parents felt immediately cheated on arrival as their children were given a somewhat diluted version of the real thing and secrecy surrounded the approach; they were not allowed to watch.

Undoubtedly the conflicts within the conductive education field have been influential in promoting an interest in going to Hungary. The conflicts may be traced in the journal, *The Conductor,* which promoted the view that only training by Hungarian conductors was the 'real thing': other organisations, including the conductive education centre in London should be avoided as dangerous imitations. 'A plethora of diluted schemes in the name of conductive education could immensely destroy public confidence in the very idea of transforming the lives of the motor-disordered and their families.... Well founded and effective work has no need to borrow the name of conductive education and the less substantial certainly should not'.[3]

This dispute had its origins in the attempt to establish genuine conductive education at the Birmingham Institute in collaboration with The Peto Institute in Budapest from 1986. Large sponsorships were secured from the Department of Education, Birmingham Council, Marks and Spencers, Woolworths and many other private businesses to establish and monitor through a Department of Education four year research programme, 'Conductive Education UK.'

The Birmingham experiment received a bitter blow when the research team concluded in 1993 that 'the claims made on behalf of conductive education ... do not appear to justify the wide-spread introduction of the system into the United Kingdom'.[4] Interestingly, this adverse publicity affected sponsorships particularly from the Government, but has not deterred investment in the enterprise by Scope and those protagonists of a method promising hope to those in despair. It is as if the heightening of emotion caused by the traumatic effects of the condition skews rationality. Faith is sustained by the absence of effective alternatives, and parents have to make difficult decisions on their child's behalf because they are not old enough or able to speak for themselves. Early intervention is advised to heighten chances of success. 'Only during the first three years does the mother have the wonderful ability to promote the child's personality development. After that her influence diminishes. Original brain damage remains the same, but if the Peto system is not started until several years have passed, irreversible features are added to this late start.'[5]

Participants in this study were acutely aware of the controversy surrounding conductive education. Their experiences of the conductive education centre in London left many of them dissatisfied as the longed-for cure did not happen. Many parents sought other treatment approaches, usually Bobath but others looked for 'the real thing', through buying an assessment for suitability for a place at the Peto Institute in Budapest through Scope.

> "We felt we had to take Sally to Hungary. She was making some progress at the conductive education centre in north London, but we wanted her to move on more quickly and to have experienced staff. We were disappointed. We went to the Moira Institute in Budapest because Peto was full. The facilities in London are far better, and we were only allowed to watch her treatment for a few minutes from behind a curtain at Moira. We'd raised the £2,000 from a sponsored dance. We needed to go, but we now feel reassured that we are doing the best we can in this country. You can see why the method was developed in Hungary. The winters are cold

> and the pavements steep. If a child can't walk, there is nowhere to go and school attendance is impossible"
>
> (Sally's parents)

Marketing of conductive education may be motivated by believers in the system, but the obvious commercialism adopted in its promotion made many parents wary.

> "The assessment was very basic. After watching an out- of -focus video accompanied by music like themes from a European ice-skating competition, the conductor barks instructions at your child for ten minutes. Then you are told, 'of course he is suitable for Peto'. We went to Budapest for one week but we couldn't take it and neither could Mark. He was spectacularly sick everywhere. The trouble was Mark couldn't do anything in harmony with others in the group...I suspect that they believe too much in learning by instruction. That's not my idea of education."
>
> (Mark's mother)

Only two of the 58 families in this study committed themselves to the Peto Institute, returning regularly for intensive sessions. Both mothers were single parents, for whom accessing rehabilitation for their children appeared to be central to their lives. Making regular visits to Hungary became a way of life. For them, this private provision largely replaced other alternatives including state funded treatments. One mother paid for her visits from her medical negligence payment. However, for the majority of parents, Budapest, and trying out conductive education, was a passing phase; an expensive, emotionally draining episode in their lives motivated by searching behaviour. Rationality in making the choice appeared to be overcome temporarily by the pressures of compulsive marketing and the fact that reliable information about the system was unavailable. Middle class parents concentrated on finding out as much as they could to make their own evaluation of the system.

> "Our GP's view was that whatever we do, Paul will develop as he was going to. Perhaps he was right, but you're under so much pressure, you can't be rational. Looking back you realise that the choices you made were not rational. You were compelled to go anywhere and everywhere to change things, repair the damage, make things better. We took Paul when he was five. At the Peto Institute we were not allowed to watch, so the mothers spent their days together in coffee shops. Some of them enjoyed the companionship, but I kept wondering why I had left my family in England to sit there. Paul's seven now but he still asks me why I took him to that horrible place where they let him fall on the stone floor. I feel so guilty. If children were treated like that in my London borough, they'd be put on the child protection register."
>
> (Paul's mother)

Reed's study of parents who took their children to Budapest went to press before British families attended the Peto Institute in large numbers.[6] These early visits lasted several months and many parents experienced the period as one of uncertainty. As one mother reported,

> "I can't remember a time when I was really relaxed. I think that I must have been in a state of moderate tension for the whole four months. But, the main worry was, as it always will be, whether Christopher is pulling his weight enough to be given more time. I longed for my husband and my children...I cried regularly and I know other parents who did."

An accurate summary of the dilemmas for these parents is provided by Reed in her conclusion. She asks, "what will be the future? Will families by saying, 'we're sick of fragmented, goal-less, uncoordinated services that won't do what we want them to, no matter how hard we try? We need an effective integrated approach so badly that we're prepared to go abroad for it?'" The findings in this study suggest that parents found the approach attractive initially because 'deep down inside, the life for my spastic son in the UK is a wheelchair', but the majority were quickly disillusioned.

7.2 Bobath Physiotherapy

Bobath Physiotherapy was favoured by more families as the approach seemed to be closer to orthodox treatment methods, and accessing the treatment did not involve travel abroad. The Bobath Centre, founded in 1957 by Bertha and Karel Bobath as a registered charity, moved to new, purpose-designed premises at East Finchley in 1993. Primarily concentrating on post-graduate training courses for physiotherapists, income is generated from course fees and from donations. Until the move, UK parents received treatment free, but in response to the new purchaser-provider system within the NHS, local health authorities are now invoiced for treatment fees. Thus parents may no longer be allowed to sustain local NHS treatments simultaneously.

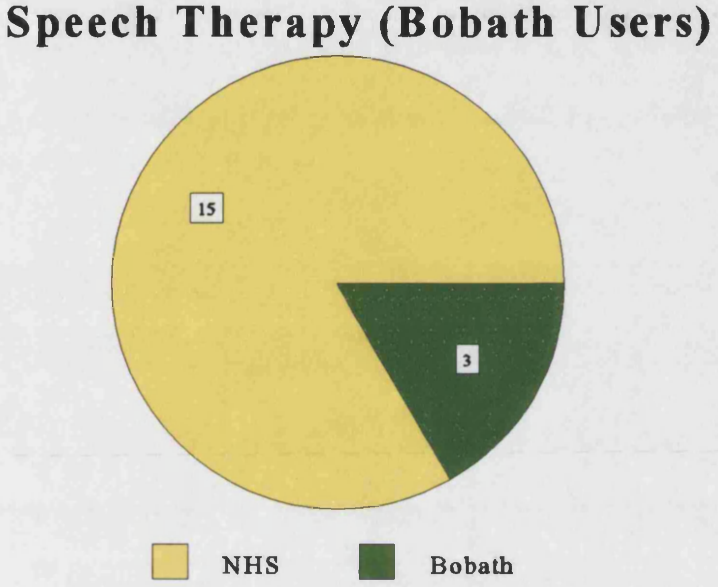
'Bobath treatment aims to inhibit abnormal movements and to stimulate more normal patterns of movement'.[7] Children are treated individually for three quarters of an hour three times weekly; parents are taught how to 'handle' their child's abnormal movements and an interdisciplinary team including OT's and speech therapists is led by physiotherapists, many of whom are seconded from the NHS for training.

Observation of the treatment method revealed intensive individual sessions during which the child was positioned in certain ways to strengthen muscles, reduce contractions, and inhibit abnormal movements. A child may be laid across a sausage-shaped roll or over a large beach ball. In order to encourage a child to sustain these positions, numerous diversionary tactics are employed including toys, reading stories and conversation to engage interest. The sessions usually need joint participation of therapist and parent who is able to learn about the treatment aims and processes. Therapists are noticeably skilled in communicating with children. The child is expected to co-operate and concentrate. One of the children being observed kept saying she did not like her therapist 'because she makes me work too hard!' There are certainly difficulties if children are tired or unwell, and for those over five attending regularly after spending a full day at school.

For the lay person and probably for most parents, physiotherapy is usually equated with exercise and movement. It is therefore disconcerting at first to witness this passivity in positions which appear to cause discomfort, since uncoordinated movement is 'normal' for children with cerebral palsy. The system also contrasts with the Vojlta method of physiotherapy widely used in Germany and in Asia. This treatment elicits patterns of reflex by hard manual pressure on 'trigger' zones to induce reflexes such as creeping and turning. At the Spastics Society in Bombay a variation of this method involved what appeared to be 'tickling' pressure points to stimulate 'normal' movement. All of these methods need reinforcement by parents at home between treatments, and their results are very hard to measure.

Of all the treatments available, the Bobath method is favoured by parents because they are regularly engaged in the process; the centre provides an interdisciplinary team approach, and it is consistent with and complementary to the conventional NHS approach. Observation included watching the physiotherapist, speech therapist and OT discussing chest strengthening in relation to feeding, and trying out a computer system compatible with the child's hand-motor patterns. Unfortunately the Bobath Centre is not immune from the national shortages of therapists: soon after the observations, the speech therapist went on maternity leave and a replacement could not be found! Figure 29 shows that only 3 Bobath users were receiving speech therapy at the Bobath centre at the time of the study - most children continued to receive this treatment from the NHS. Chapter 5, 4.3 has described the frustrations of accessing adequate NHS speech therapy.

FIGURE 29

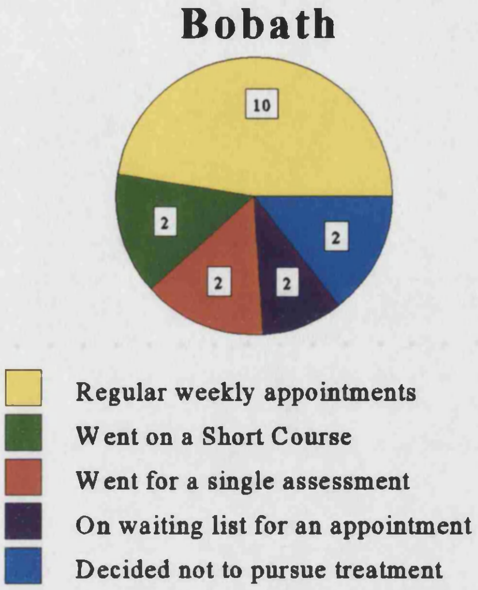


Some participants in this study were recruited by arranging for the questionnaire to be sent to all families registered with the Centre who lived in the area, and were in the specified age group. In total, 100 questionnaires were sent out to families in the north London area. Ultimately, only 18 parents were interviewed. This much lower response rate than that from the conductive education centre may be explained by the fact that families had met the researcher at the conductive education centre, where the director exerted strong influence over the parents. What emerged, however, was that many participants recruited through the conductive education centre said they were in the process of transferring to Bobath or had done so already. Many of those recruited through Bobath had attended the parent and child group at the conductive education centre.

Negotiating the research with the Bobath Centre revealed that the majority of children treated travel from all parts of the UK and abroad. The pattern is for parents to come at six monthly intervals and stay with their child for a two week intensive course. Some may be accompanied by their physiotherapist who might be training simultaneously, but all parents are given advice and videos of their child's treatment to use when returning home. The reason for this was that the Bobath Centre prioritised its training function above treatment provision. Specialist post-graduate Bobath physiotherapy courses were purchased by the NHS physiotherapists, who could then practice their new skills in their hospital departments. This policy meant that more families might have the opportunity to benefit from the approach albeit indirectly. It also ensured a regular income from course fees.

Although not clearly specified, policy seemed to be to discourage the provision of regular weekly treatment to local children on an on-going basis, but to provide an advisory service to parents and their NHS physiotherapists. Only ten participants had been able to establish the status of receiving their main treatment at the Bobath Centre. This seemed to have been achieved by constant pressure, telephone calls, weeping and pleading to achieve the desired effect. It is no surprise that all the successful mothers were graduates and professionals themselves, (an OT, a social worker, an equal opportunities officer for example). This policy caused bitterness among those whose applications failed, or who were offered only one-off assessments, their main treatment remaining the responsibility of the NHS. The eagerness of two families to participate in this study seemed to stem from their mistaken belief that the researcher might speed up the offer of an appointment at Bobath. Figure 30 shows that 8 participants recruited from Bobath had only limited contact with the Centre.

FIGURE 30



An impression is gained of strongly motivated and articulate professionals, dissatisfied with the Health Service being convinced their child's treatment needs can be met at Bobath, if only they could be allowed access. Previous experience taught them that concealing involvement with other treatments meant they were more likely to be successful. Having achieved an assessment, pressure must continue to ensure the continuation of treatment.

> “My grandmother used to say, if you weave a web of deceit you'll get trapped in the end. We went to Bobath three times each week but we needed to try Hungary. My husband speaks Hungarian and we went as a family for 4-5 months. We didn't tell Bobath, though they suspected it. They make parents make choices but we needed to try both methods.”
>
> (Hannah's mother)

The ten regular Bobath users spoke positively about the treatment, and were involved in a parent-led support group which produced a regular newsletter.

> "I'd have gone insane if they had refused to treat her, as I couldn't make sense of the situation. Through twice weekly appointments I learnt to hold her and feed her. They said she would never get off her gastro-nasal tube, but she did. I believe in the Bobath principles: we're not saying they're experts, but we need very specific help, and we need a lot more help than we get."
>
> (Emily's mother)

Only two families decided against continuing to pursue Bobath treatments. One "preferred putting together a programme of unconventional therapies" while another described Bobath as overly didactic. "We found out about it ourselves, but experienced it as chaotic. We have a video, but our son screamed all the time during the one week assessment. We had one therapist after another."

During the period of this study the service offered by the Bobath Centre was disrupted by moving to new premises. The disappointment felt by those waiting for appointments and those only provided with one-off assessments was caused in part by the Centre's need to clarify its treatment policy. Discouraging on-going treatment to allow frequent turn-over of patients had the effect of seeming discriminatory against those with little leverage. In effect, those who chose to attend the Bobath centre as part of their child's 'treatment package' seemed to be those who had fought 'tooth and nail' to obtain it.

In effect, the majority of children in this study who were receiving NHS physiotherapy were being treated according to a Bobath principles, but those children being treated at the centre were seen more frequently. Their therapists might be students in training, but quality was sustained by supervision from permanent staff members. In order to avail themselves of this treatment the ten parents in this study drove their children across north London three times per week and sustained the programme at home. One parent employed a sixth former to provide the diversions (reading and toys) necessary to divert the child's attention while being placed in various postures, for example over the sausage-shaped roll.

7.3 Conclusion

A picture emerges from this analysis of professional treatment provision of parents clamouring for more frequent appointments from orthodox services unable to respond adequately; temporary flirtations with medical alternatives which are found to be ineffective, too demanding on family life and in the case of conductive education, possibly dangerous. The crucial issue about making choices from unorthodox methods is the paucity of reliable research. Sutton admits, for example, that 'so far there has been very little theoretical examination of C.E. and none as yet from the medical profession in the English-speaking world, although some has been published in German.'[8] Nor is it easy to gather information as so much is dependent on single case studies and promotional literature, which feeds the irrationality characteristic of distressed parents.[9] The absence of research is compounded by the limited regulations on unorthodox medical practice. Osteopathy, for example, had been unregulated until the Osteopaths Act 1993 requiring a statutory register of practitioners.[10] It is in this somewhat disillusioned state of mind, that parents proceed to arrange their children's education, which is the subject of the next section.

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Section IV

FAMILIES AND THE EDUCATION SERVICE

During their child's second year the parental care management role extends into the education arena. Painfully parents are acquiring knowledge about cerebral palsy and its application to their own child's condition; they are becoming adept at negotiating treatments from the NHS and private alternatives; they are participating in treatments and care in collaboration with professionals; they are attempting to adjust emotionally to the effects of the birth on themselves, their families and their child's future. Feelings are still raw as plans for education need consideration.

Entry into the complexities of special education needs involves a new knowledge base, contact with a different range of professionals, with LEA's and with schools. The involvement with health care continues and needs to be integrated within a care package, which includes education. Thus inter-agency and interdisciplinary processes are widened and choices need to be made about both a child's educational needs and about where best to direct time and energy. For the researcher, the world of education and in particular of special needs education is as daunting as it is for parents. It is possible to distinguish two main themes underpinning policy and provision in this area.[1]

The first is the recognition of the rights of all children including those with disabilities to educational opportunities. The abolition of the category of 'ineducable children' (Education Act 1987) has stimulated the development of teaching and learning techniques to enable all children to maximise their potential within the state system. This reflects the equal opportunities and disability rights movement and this is reinforced by the Children Act 1989.[2]

The second theme is the major change in educational policy, provision and practice stemming from the Education Reform Act 1988. Political debates continue into the 90s about how educational services should be managed, by whom, what should be taught and how work should be assessed, whether results should be publicised and what the results mean. Concerns about funding and financial management of schools; standards of literacy, numeracy and articulation attained by pupils; the changing nature of the roles, tasks, training and responsibilities of teachers; parental choice and participation are issues jostling for public attention. 'Many of the reforms have been formulated with prime regard for the mainstream majority, yet all have implications for children with special needs'.[3]

This is the uncertain and complicated context in which parents as their child's care managers confront the education system. Chapter 8 reviews the history of special education policy to explain how this situation has arisen. The process of educational statementing is the significant theme which emerges, and this is discussed from the perspectives of parent participants. Chapter 9 examines how parents experience arranging their children's pre-school education in the light of the convoluted system they encounter. Chapter 10 considers the issue of choice between mainstream and special education. In Chapter 11 a case study of conductive education in north London represents an alternative approach to treatment and learning reflecting disillusion with conventional statutory provision.

> "Although I am critical of the education system, I don't know how much the problems were really my own. I couldn't come to terms with the category of 'learning difficulties'. Mark had been misdiagnosed as deaf and there's been no clear medical diagnosis. I went round schools within the borough and outside, not knowing what I was looking for. After coping with all Mark's illnesses, all the hospital appointments, so many professionals from the health service and social services, I had little patience with the educational psychologist."
>
> (Mark's mother)

In order to negotiate appropriate education for their children, parents in this study have had to familiarise themselves with both the mainstream and special needs services and to acquaint themselves with current controversies, many of which are rooted in the history of education. This chapter traces the development of special needs education policy, as the backdrop for understanding the main emergent strand of concern for parents: statementing and decisions about the appropriate school.

The history is chronicled in detail by Warnock.[4] It is an account with clear milestones in the form of legislation concerned both with extending educational opportunities to all children for longer periods of their lives, and increasingly providing for children identified as having special educational needs. From the mid-nineteenth century to the present day there has been considerable legislation formalising what has become a universal educational provision for all children in the UK from age 5 to 16.

Debates have been intense at each stage of implementation and resources problems have restricted the effectiveness of the legal requirements. Nevertheless, Adams concludes that 'the story of special education in the United Kingdom is surely one of which the nation has every right to be proud...and British ideas and examples in this field have commanded-and still do-attention, admiration and imitation in many other countries'.[5]

The origins of the development of state responsibility for the education and training of the country's future workforce may be located in Victorian humanitarian and philanthropic activities. The first separate educational provision for physically handicapped children was made in 1851 when the Cripples Home and Industrial School for Girls was founded in Marylebone. A training Home for Crippled Boys followed at Kensington in 1865. Both institutes aimed to teach a trade and the children, who came mainly from poor homes, and contributed to their own support by making goods for sale.[6]

The Foster Education Act 1870 which established School Boards to provide elementary education in those areas where there were insufficient voluntary schools, did not include disabled children but some of the school boards developed occupational activities for those unable to attend their elementary schools, although not legally obliged to do so. For children with mobility and communication difficulties stimulation, teaching and training depended on the initiative of family and friends as is still the situation in developing countries where the emphasis is on volunteers, community development and self-help. The alternative was boarding schools designed for specific disabilities.[7] Examples were the Heritage Craft Schools and Hospital at Chailey, Sussex, (1903) and the Lord Mayor Treloar Cripples' Hospital and College at Alton (1908).

The pervading belief was that disabled children needed country or sea air for health reasons. Many disabled children probably benefitted, especially those with respiratory conditions and those from urban areas likely to have insanitary living conditions in the late nineteenth and early twentieth century. However, it is probably that this policy of providing residential care in the country may have been strongly influenced by the Eugenics movement. Children with disabilities were considered to be unsightly or even dangerous and should be institutionalised as far away as possible from the public gaze.

Until the 1944 Education Act, 'new provision continued to be made, much of it by voluntary effort and of a pioneering nature. Open air schools, day and boarding schools for physically handicapped children, schools in hospitals and convalescent homes and trade schools all contributed to more varied facilities available to local education authorities and parents'.[8]

8.1 Education Act 1944

1944 was a landmark for all children when compulsory school age was lowered to 5 and extended to 15. This legislation expressed concern for the health and productivity of the nation's children in the post-war years. In the words of Dwark 'War is good for babies and other young children.[9]

For children with special needs, The Handicapped Pupils and School Health Service Regulations 1945 listed 11 categories of disability using medical terminology, giving detailed guidance on the provision to be made for each category by local education authorities. Children whose disabilities could be catered for in ordinary schools should attend, but treatments should be provided in special schools. It is interesting that the process of 'integration' of disabled children into mainstream schools began long before Warnock 1978. Special provision was designed to ensure that the more severely disabled did not fall through the educational net, rather than to promote separatism.

8.2 Warnock and the Education Act 1981

The integration debate peaked in the UK with the Warnock Report 1978 and the consequent Education Act of 1981. Again there was concern for the health of the nation and it was no accident that the Court Committee was simultaneously preparing their report on child health (see Chapter 4).[10] The work of the Warnock committee announced by Margaret Thatcher in 1973 was to 'review the educational provision in England, Scotland and Wales for children and young people handicapped by disabilities of body and mind, taking account of the medical aspects of their needs, together with arrangements to prepare them for entry into employment; to consider the most effective use of resources for these purposes and to make recommendations.'

Delays in completing the report were caused by a change of government, as well as the very wide brief and the detailed attention paid to the task by the large committee. However, 5 years later the Warnock Report provided a unanimous, detailed and challenging account with recommendations that serve as the bedrock for future special needs education. Despite disputes provoked by many of the recommendations, particularly those which clearly required heavy financial investment by LEAs, Warnock's significant contribution is the assertion that 'education is a good to which all human beings are entitled. ..No civilised society can be content just to look after these children; it must all the time seek ways of helping them, however slowly towards the educational goals we have identified'.[11]

In general the Warnock Committee consulted widely, but the focus was on education, representing a move away from medical labelling used by the Committee on Child Health Services, 1976. The Report contains 224 recommendations. Those most pertinent to this study are,

- The abolition of medical categories of disability, replacing them by the broader description of 'children with special educational needs'.[12]

- The promotion of early educational opportunities for children under five.[13]

- Multi-professional assessments facilitated by a Named Person, 'the health visitor, social worker, educationalist or other professional with particular expertise or interest in the area of the child's disability'.[14]

- Parents as Partners.[15]

- Inclusion of more children with disabilities in mainstream schools, with special day and boarding schools remaining for 'relatively rare or particularly complex disabilities'.[16]

The Education Act 1981 incorporating the Warnock philosophy came into force on 1 April 1983. LEA's were to review and change their special educational provision. Introduced in an unfavourable financial climate, many Warnock flag-ships, particularly interdisciplinary collaboration with health services and pre-school education, were lost. This has particular significance for parents in this study for whom separation of provision by health and education had deleterious effects on their child's total care as can be seen in Chapters 9 and 10.

Warnock is mistakenly remembered more for the statementing process, developed by bureaucrats as an implementation tool, than for the ideals promoted for meeting the special educational needs of disabled children. In the hands of civil servants, much of Warnock's idealism dissolved. An education-focused service evolved with educational psychologists replacing paediatricians as the lynch-pins of the service. The opportunity for collaborators promulgated by both the Court and Warnock reports was lost. Parents were consulted, but informed of LEA decisions, frequently based on the cheapest option. The initial move towards inclusion of disabled children in mainstream schools was strongly influenced by the need to reduce the costs of special schools and in particular, of out of borough placements in boarding schools.

Nevertheless, considerable progress was made in the area of special education in the 1980s, and the influence of Warnock principles pervade decisions made by parents as will be seen in Chapters 9 and 10.

8.3 Education Reform Act 1988

This legislation hardly mentions special educational needs, but is having a profound effect on the realisation of Warnock principles, on the ways educational services are delivered to all children throughout the country, and on parents' experiences of making choices for their disabled children.

'The general aim of the reforms has been to introduce a more competitive, quasi-market approach to the allocation of resources in the education system, and to increase the range of parental choice over children's schooling', 1993.[17] The changes represent attempts to improve educational standards in 'a system where high-quality provision is financially rewarded'.

The chief characteristics of the system are,

- The National Curriculum and national testing.
- Open enrolment extending parental choice of schools.
- Local management of schools (LMS) meaning devolved budgets.

The systems is consistent with the purchaser-provider model introduced in both the NHS (see Chapter 4) and the personal social services (see Chapter 12).

Clearly a mixture of motives, financial and educational, vie with each other when evaluating this approach. The legislation reflects both urgency to reduce public spending and to raise standards of achievement. Commitment to changing the deleterious effects for the nation of low levels of achievement among school leavers, combines with enlisting parental support by extending choice.

Scarcely a day goes by without newspaper headlines about educational policy: the outcomes of national testing; political disagreements between and within the Conservative and Labour Parties about 'streaming'; conflicts between teachers and politicians about the changing nature of their jobs. This turmoil affects all childrens' education.

For children with special needs the implications of the 1988 educational reforms are uncertain. However, a concern has been expressed by Galloway, et al,[18] about 'confusion' created by the Act and about the dangers of a 'market economy in which schools compete for children'. This is likely to lead to a system where schools compete for 'desirable children'. If a child needs extra resources, educational statements may secure some income, but statements may be insufficient incentives to make major alterations to accommodate a child with extensive needs.

Special schools are particularly concerned that publications of the SATS (Standard Attainment Tests) required by the National Curriculum, may provide negative publicity for their children. The knock-on effect could be a reduction in the numbers of parents choosing the school, and severe financial problems to be faced at local level through LMS.

However, it would be misleading to conclude from this review of special needs educational policy that little has been achieved in the post-Warnock years. Despite the current funding restraints and turbulent political educational arena, many LEAs have promoted inclusion of a broader spectrum of disabled children within the mainstream system, thus ensuring their human rights 'to develop their potential to the full'.[19]

The picture presented from the fieldwork for this study, is an uneven one varying from borough to borough and from child to child depending on the nature of their condition and their family situation. The degree to which their educational needs were met appeared to depend as much on local interpretation of policy as on the willingness and enthusiasm of teachers and parents to make situations which originally appeared unpromising, work. 'The fact remains that no government can legislate for good practice, nor for goodwill'.[20]

8.4 Educational Statements

Out of this complicated account of the development of special needs education a clear issue emerges, which is both the legacy of this history, and the area which concerns and bewilders parents most.

The origins of the statementing process may be found in the Warnock Report where emphasis is placed on the importance of beginning assessment as early as possible, particularly where 'severe congenital abnormalities' are 'apparent at birth or... discovered in the early years of life'.[21] The multi-disciplinary nature of assessments in advocated firmly, since 'it is impossible to separate assessment from continuing treatment, care and education'.[22]

It is interesting that the seeds for statementing were sown in the report, incorporated in section 5 of the Education Act 1981, and formalised in Circular 1/83 issued by the Department of Education and Science, jointly with the Department of Health and Social Security. From 1983 the previous Special Education forms were replaced by statementing procedures formulated by each LEA in consultation with professionals, often including health and social services.

Under Section 5 of the Education Act 1981, there is an obligation on LEA's to ensure that provision is made for children with special needs and that this should be based on 'what the child actually does in educational terms, rather than on his or her disability'. Parents may initiate this statement themselves, or it may be triggered by one of the professionals involved in this child's care from the age of two years. In the case of children with cerebral palsy the referrer may be a physiotherapist or occupational therapist involved in regular assessments.

Written evidence is collected from all professionals who know the child and from the parents. The authorised officer of the LEA, usually the educational psychologist, has the task of determining the level of extra care provision, and of writing a statement of special educational needs which identifies the nature of educational need and whether these may be met. After drafting, the parents and professionals receive copies and may appeal against plans.

For children with cerebral palsy a crucial issue is not only which nursery or school is identified but whether the necessary therapeutic help will be provided by the local Health Authority. Under the 1988 educational reforms, the advent of the LMS and the purchaser-provider system have prioritised the question of who pays and whether the school can afford the costs.

For parents, the educational statement is significant as it identifies need and clarifies their child's rights. From the perspective of schools, statements bring extra resources so that should a child be enrolled in school without a statement, the school is likely to initiate the procedure as quickly as possible.

As the process may begin from age two it includes pre-school provision in playgroups and nursery classes. It will be seen in Chapter 11 that some parents succeeded in persuading their LEA to pay for conductive education on the basis that the borough had no comparable resources.

As the Warnock principles were converted by civil servants and local authority administrators into a system of practise, dilution of idealism took place, especially about the multi-disciplinary nature of assessments. The statementing process, where final decisions rested with educational psychologists, became primarily a function of education departments. Health, social care professionals and parents were required to provide their written assessments of need, but power and decisions rested with education as the body responsible for provision and funding.

This conversion of policy into practice has parallels in the Health Service discussed in Chapter 4. Both the Court and Warnock Reports provided comprehensive and in-depth understanding of the needs of disabled children and their families, but their idealism was overridden by organisational considerations in the hands of bureaucrats and administrators, as well as by the constraints on revenue.[23]

Ten years on, the Audit Commission confronted these issues with recommendations 'designed to enhance clarity and accountability and to enable LEA's to implement the fundamental principles of the 1981 Education Act in the 1990s'. Their thorough review drew particular attention to serious 'deficiencies in the management of special needs provision including parents' views not being acted upon' and 'the lack of priority given by LEA's to the timely completion of the process of assessment and issuing statements'.[24]

Official recognition of deficiencies in the statementing procedures was endorsed by the Spastics Society in their Make a Statement Campaign, 1993. The Society's Parliamentary lobby was aimed to 'raise awareness of the special educational needs of children with disabilities' and in particular advocated that 'children with special educational needs and their parents must have a real choice about which school the children attend and how they are educated'.[25] Timed to coincide with the Education Bill, which became the Education Act July 1994, the Spastics Society was concerned about the redistribution of power from LEA's to parents, and about 'resources to follow special needs pupils triggered by the statement'.

This campaign was successful. Part III of the Education Act 1993 gives parents rights to state where they would like their child to be educated and a new appeals system has been established for those dissatisfied with their child's statement. Considering the turmoil in mainstream educational policy it is heartening to see that special needs children are still taken into consideration by legislators, although the proposed system will inevitably be costly.

Fieldwork for this study took place on the eve of these changes (1992/3), reflecting both the need for reform and also how far practice and procedures have drifted away from the Warnock principles. Far from being an interprofessional assessment, LEA's have to decide how limited educational resources should be deployed, using written communications from health and social care professionals, whose knowledge of the child is usually far better than that of the educational psychologist who may not even have met the child.

This profile of the LEA statementing service explains why the Children Act Guidance needs to reiterate commitment to 'a collaborative... response to individual children's special needs' through 'linking assessment processes under the Children Act 1989, the Disabled Persons Act 1986, the Education Act 1981 and the NHS and Community Care Act 1990'.[26] In terms of principles, the 1989 Guidance on interprofessional collaboration is a 'revamp' of Warnock with stronger exhortation that 'more effective participation by parents in assessment under the 1981 Act should be a priority for SSDs'. Little is new in the Children Act except section 19, Part III which requires LEA's and SSD's to work together in looking at the pattern of day care services in the area, consulting with DHA's and others and publishing a report every three years.

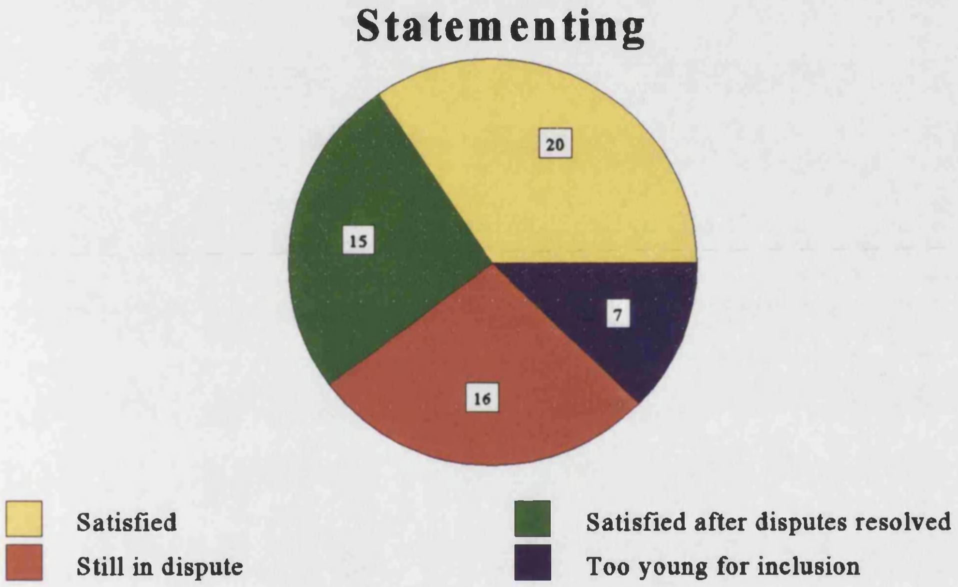
'Telling the Day Care Story' contains conclusions on the first of these day care reviews produced by local authorities 1992/3. This review is about provision for all children and does not attend to the special needs of disabled children. However, some of the findings are relevant as they provide the context in which special day care has to be arranged. While concentrating on how local authorities should produce better reports, this review considers the needs of under 5's emphasising the complexity of provision and service underfunding hampering innovation. The review acknowledges that 'to make provision of full-time day care and/or nursery education for all or the vast majority of 3 and 4 year olds, would require an increase of between 50% and 70% in the current levels of services. This is not a realistic proposition'.[27]

It is worth reflecting on whether rhetoric can be effective, if not accompanied by resources, since underfunding must have been one of the factors inhibiting the implementation of the total Warnock package. 'The 1981 Education Act contained the seeds of its own destruction. It not only linked resources to statements, but also extended the concept of SEN to include up to 20% of children. It thus created a demand which LEA's were unable to meet and which the government had no intention of resourcing'.[28]

8.5 Findings from Fieldwork

Of the 58 families in this study, 48 were involved at some stage in the statementing process at the time of the interview: 28 of the children had reached the age of five and therefore required compulsory school arrangements.

FIGURE 31



It was possible to classify the experiences of parents under 4 headings as can be seen in figure 31. There were those (20) who were satisfied with the process, others (15) who were satisfied after a dispute resolved, and some (16) who were dissatisfied with dispute on-going. The remaining seven children were too young for inclusion. On the one hand, 35 were satisfied eventually, but 24 had experienced the process as one of dispute. This fits with the description of parental participation as being full of 'conflicts and adversarial debates'. Children Act Guidance.[29]

Therefore, a firm conclusion must be that all parents experienced the process as one of participation and involvement, which took up varied amounts of time and energy over and above what they might have expected to do had their child not been disabled. Taking a more positive position, it is heartening to discover that so many were eventually satisfied and that of these 20 were relatively conflict-free. Typical comments from this group were

> "It was an easy ride - I knew what I wanted and I got it."
>
> (Peter's mother)

> "We didn't realise how important the statement was, but the headmistress rushed it through in time."
>
> (Mark's mother)

> "I didn't even have to fight - they agreed without any argument to the special school for Jewish children."
>
> (Ben's mother)

Perhaps those choosing special schools found the process smoothest.

> "I was worried about the stigma attached to Special School, but I talked about it with another mother and the statement process was trouble-free."
>
> (Stacey's mother)

For those wanting mainstream school, difficulties were seen as consequences of a decision-making process which had been handled well.

> "We disputed one or two things but it wasn't really a problem - the dispute was about a helper and who would pay, about lunch-time cover

> when she had a break and how the school would deal with having a child in a wheelchair."
>
> (Emma's mother)

Even some educational psychologists at the hub of the system received praise.

> "He came 4 times, he's wonderful. Danny isn't stupid and the educational psychologist was willing to do a thorough assessment - you have to assume your child is intelligent even when he can't speak."
>
> (Danny's mother)

The stories of those who were eventually satisfied drew attention to the weakness of a system based on decision making by the educational psychologist.

> "I couldn't understand how the educational psychologist had so much say in the decision. She know nothing about Jo. She'd only seen him once at nursery. I wasn't very impressed, so I did enquiries myself."
>
> (Jo's mother)

Some statementing floundered on disputes between personalities, echoing the strained relationships with health professionals. (See chapter 5).

> "We had to change the educational psychologist in the middle. He was so obnoxious. I spent 3 days crying, after seeing the special school he suggested. I was scared because I didn't want to be labelled a 'racist' but I couldn't see Charlotte being happy there."
>
> (Charlotte's mother)

Persistence by parents saved the day.

> "It was an almighty struggle... they hoped I'd give up. Eventually I got the statement based on an assessment by the physiotherapist which was two years out of date."
>
> (Paula's mother)

Help was enlisted from a variety of sources, apart from the information centres advising on legal rights (IPSEA: Independent Panel on Special Education Advice for example), help came from other professionals, parents, friends, charities including Mencap, the Elfrida Rathbone Society and the Hydrocephalus Society. It was heartening to hear that in one situation a social worker had been useful!

> "I get my Social worker to write the letters, and then they listen!"
>
> (Louise's mother)

Those parents still locked in disputes about their child's statement tended to express bitterness and frustration.

> "I trust the professionals, but all the reports they write about Nicholas are passed on to people who have never seen him. I don't think I've been treated fairly."
>
> (Nichola's mother)

Many of the disputes were about funding, either between social services and education or between public and private alternatives.

> "Education will not pay for her place at the conductive education centre, but social services will because she's on the child protection register. But, they won't pay for transport so I have to stay all day with her."
>
> (Stacey's mother)

As will demonstrated in the discussion of conductive education in Chapter 11, paying of fees depended on the attitude of the LEA to the system.

> "These was the question of back-dated fees for conductive education. I can't see the dispute ever being resolved as the local authority school just does not have enough physiotherapy input. We want the best for Hannah and we believe that is conductive education - we want the final word."
>
> (Hannah's mother)

Like the disputes with the NHS, much wrangling was reported about adequate physiotherapy and speech therapy, which needed identification on the statement to ensure funding.

> "After 2 years of drafts, it was done wrong. There were no provisions, nothing. No physiotherapy or speech therapy, yet he can't speak at all."
>
> (Matthew's mother)

'Statements generally identify provision in such vague terms that, contrary to the intention of the 1981 Act, they cannot guarantee a specific level of provision. According to many LEA's , this vagueness is deliberate because statements can lead to open-ended financial commitments, which LEAs, faced with finite budgets, may be unable to meet'.[30]

> "They're only doing a draft statement now, so Paul's in an 'assessment place' at school. The statement's deliberately woolly. There are many other children there without statements. It's frightening."
>
> (Paul's mother)

The most critical comments were about delays, incompetence and poor communication.

> "The psychologist came 9 months ago and I haven't heard anything since."
>
> (Mark's mother)

> "The process started 6 months ago, but I got a call from the education department last week to say that all the papers had been lost, so we've started all over again!"
>
> (Mark's mother)

Statements should be reviewed annually, so that initial agreements are only the start of the long road continuing until the child reaches the age of 16.

> "We're at crisis point now; the statement's being reviewed... she's getting so self-conscious about her problems and we're apprehensive about the mainstream school - we'll give it a go."
>
> (Sarah's mother)

The worst dispute had been in process for 3 years at the time of the interview. The parent had been offered a special school place in a small class.

> "I keep refusing to consider the only offer they've made; a place in a special class with 5 boys all of whom are black. I regard this as double discrimination so I'm teaching her at home myself."
>
> (Charlotte's mother)

Pervading the interviews is the same determination witnessed in the relation to health, to secure suitable professional input for their children, by persistent tenacious argument. Children with cerebral palsy have very specific needs including access to therapists, access to buildings and to the curriculum, communication aids and usually personal helpers. Disputes where these areas have been 'glossed over' in the statement, licence schools to provide a minimum facility which may be little better than day-care. The most articulate and the wealthiest families are likely to take legal action against LEA's. The new appeals procedures established by the Education Act 1993 may be intended to safeguard the rights of children with cerebral palsy and their parents to access to clearly identified therapies. Nevertheless, legal aid is not available and expert witnesses need payment.[31]

> "We've won our case, apart from a clerical error in the reported result which has delayed implementation at school. We had to pay £1,000 for expert witnesses. I handled the case myself to keep the costs down. We were determined that the amounts of physiotherapy and speech therapy would be recorded so the school could not continue to slither out their duties."
>
> (Comment from parent after Review Panel 1996)

8.6 Conclusion

While there is certainly no room for complacency on parental experiences of statementing procedures, middle class parents are inevitably most vociferous and persistent. This study was conducted in London where local authorities are notoriously under resourced, and providing patchy services since the demise of ILEA, which had considerable investment in the quality of special needs education.

These findings suggest there are some grounds for optimism because some families were satisfied and those who complain usually complain loudly! The Audit Commission Report and the 1993 Education Act suggest that complacency is not the problem - it is poor funding in 'the only developed country to attempt special education reform without an allocation of additional funds to carry it out'.[32]

At the same time as parents were handling the administrative process required for their child to obtain an acceptable educational statement, choices had to be made about nursery and schools. The next chapter examines the places chosen and their significance as elements of care packages.

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Chapter 9 Pre-School Education

> "A year after Charlie was born, cerebral palsy was diagnosed. Charlie had been deprived of oxygen for a few crucial moments. There was no doctor present and I felt the midwife had been a bit lazy. I don't think about it now (10 years later). The worst moment was when they told me he would never speak. As a teacher, I feared for his education. It took a long time to get over those memories."
>
> (Extract from interview with Mrs Gillian Howarth)[1]

Commitment to education during the first four years of life is a central tenet of the Warnock Report.[2] Statements of special educational needs may be initiated from a child's second birthday so that parents are only beginning the realise the extent of their children's impairments, and therefore the required educational facilities, when they, according to the law, begin to explore the educational components of package of care. This chapter examines parents' experiences of arranging pre-school education, taking Portage and pre-school playgroups as examples of available choices.

Throughout the history of education policy there has been ambivalence towards making pre-school facilities universal. This is undeniably linked to mixed attitudes towards the role of women in society, the dilemma being about their competing tasks of participating in the workforce and parenting children. Concerns about signs of breakdown of family life and the assumed related increase in crime reverberate. The consequences have been inconsistent provision and reluctance to allocate resources to a comprehensive public pre-school education system.

Lewis quotes post-war circulars from the Minister of Health and Education stating explicitly that the children of working mothers were to be given priority for day care or nursery education and that 50% of wartime nurseries were closed by 1955.[3] The issues are still prominent in 1996 as Parliament debates whether the 'dismal results from the first national tests of 11-year old, showing more than half failing to reach the expected standard in English and Maths' may be improved by 'expanding pre-school provision'.[4]

Unfortunately the proposal to offer parents nursery vouchers to purchase day care and education for their 4 year olds, has to be interpreted as more of a vote-catcher than an expression of genuine intention to expand educational opportunities. The sum of £1,100 on offer could only cover half the costs of a child's place and is unlikely therefore to stimulate the growth of provision, or enable poor families to benefit. The Audit Commission have warned that the scheme would require powerful procedures to prevent fraud. About £750 million worth of vouchers will pass through hundreds of thousands of pairs of hands when they transfer the funds from the Exchequer to the proprietors of 40,000 separate institutions.

There exists, therefore, a patchwork of provision for pre-school education across the UK, varying in quality, quantity and system. All parents have the task of assembling an educational package of care from a range of playgroups, day-nurseries, nursery schools, work-place creches and family centres provided by public bodies (social services and education), voluntary organisations, private businesses, community and self-help groups. The purchaser-provider split introduced by the 1988 Educational Reform Act has shifted 'the shared responsibility of the state and families to use the best knowledge we have in caring for and educating our youngest children'[5] towards those with 'parental responsibility'.[6]

Middle class parents prioritise this responsibility for choosing appropriate education. Their aims are underpinned by belief in the known advantages for later success, but also involve considerations of cost, travel, the kind of system available locally and their own family composition. Parents with only one child may be able to be more creative, even setting up their own playgroup if suitable facilities are not available locally. Children of working parents may be dependent on childminders or nannies to manage their 'education packages' or on workplace nurseries that may vary in quality.

In contrast to European countries, Sweden in particular, British children have very unsettled, patchy and irregular early education.[7] Some children may spend different days of the week in different places, with different children and adults and adjusting to different approaches. Over the period of three years (from ages 2-5) the educational experiences of middle class children may be characterised by change; those of poor families by the absence of early stimulation. Goldsmiel and Jackson believe that 'a society can be judged by its attitudes to its youngest children'. The absence of coherent policies and what is more important, public expenditure provides children with unstable experiences and unequal opportunities.[8]

This uneven profile fits uncomfortably with what is known about the need for consistency of care in the early years. Bowlby's idealism about the primacy of the relationship between natural mother and child may have been adapted by Rutter for example, but research of child psychologists about attachments emphasises the significance of stability.[9] Writing primarily about children presenting severe behavioural problems, Holmes 1995, draws attention to dangers for healthy adult development of 'inconsistent and fragmented care', advocating the necessity 'to appreciate the importance for children of seeing the same person in the same room at the same time every day'.[10] If children feel secure, they feel happier and can learn more.

Considerations both of educational opportunities and quality of care operate when parents are making choices and increasingly considerations of safety and child protection jostle for attention as society becomes aware of risk factors. Children require protection against physical, sexual and emotional abuse, the latter being perhaps the most elusive or the one most likely to be overlooked. Assumptions that having obtained a place for a child in a pre-school educational unit future learning potential and personality development have been safe-guarded should not be made.

The work of Menzies Lyth and of Bain and Barnett, indicate serious problems in staffing day care and consider the emotional implications for children of spending their 'formative' years exposed to malfunctioning staff groups.[11] A major conclusion of their work is that 'exposure to the day nursery was a cause of a high level of aggression in nursery children', which may be connected to a number of factors including inadequate staff ratios, poor staff training, and 'cutting off of feelings' by staff because of undue work expectations.

This is the unpromising scenario in which the parents of children with cerebral palsy attempt to assemble their packages of education for their children. Disabled children receive priority through the statementing system, but local authorities may be slow to reach decisions (one LEA reported to the researcher being 3 years behind on finalising statements); parents may not be aware of their rights (this is particularly relevant for poor and refugee families) or the statement may be in dispute, (see Chapter 8). Warnock's recommendation that 'the provision of nursery education for all children should be substantially increased as soon as possible, since this would have the consequence that opportunities for nursery education for young children with special needs would be correspondingly extended' has not happened.[12]

As we have seen, establishing 'health care packages' involved parents in stressful searches for treatments from a variety of sources, many proving disappointing because of being under- resourced or because parents had false expectations of their potential efficiency. The search for treatments does not go away when education priorities are acknowledged, and they have to be accommodated into the care packages of the child and family's weekly schedule.

Echoes of searching behaviour and the need to make reparation are evident as parents find their way through education resources. Their passions are fired also by instincts to find places and people who will recognise their child's strengths which need to be maximised, to compensate to some degree for the weaknesses which have been a focus for so much health care treatments.

In their parental statement to the LEA, when Paula was 3, her parents wrote

> "We have experienced a pattern of inadequate therapy. Our impression is that what is available is in no way related to what Paula's needs, but is governed by resources and our constant requests."
>
> (Paula's parents)

Their educational aspirations for their daughter, whom they described as 'cognitively well in advance of her age, considering her inability to explore the environment or communicate freely', "were to work in partnership with Paula's education and not to feel the powerless recipients of help".

Children with disabilities may use both mainstream and special provisions in their first five years. Portage, playgroups, nursery classes and conductive education will be considered separately in the ensuing sections. If there is any discernible pattern in choosing, it is one of progression from the earliest form of provision of home-teaching through playgroups, nursery classes to first school entry. But, the progression is neither smooth nor consistent involving different facilities on different days, during different weeks and years. Perhaps there is also a greater difficulty in locating appropriate education and more emotional tension involved in the paths which most parents of disabled children tread.

9.1 Portage

This little-known home-based, peripatetic teaching service has its origins in Wisconsin USA in the early 1970s sponsored by John F Kennedy's Head Start Programme. Using a behaviour modification approach, it was developed for mentally handicapped children in rural communities[13]. It combined a practical solution to parents' travel problems with a conviction that parents are potentially the child's best teachers.

This view is firmly adopted by Warnock. 'We recommend that there should be a comprehensive peripatetic teaching service which would cater, wherever possible, exclusively for children with disabilities or significant difficulties below school age'.[14]

Portage was introduced to the UK in 1976 and has developed numerous independent initiatives, varying in form, funding and personnel. The Warnock dreams have not been realised. A patchwork service may be discovered throughout the country, depending on local initiatives.[15] These local Portage services provide short training for Portage workers who are primarily volunteers from many professions including nursery nursing and teaching. Many Portage workers are parents dependent on their own experiences of educating a handicapped child, and they are usually represented on management committees of services receiving minimal public funds.

Training has been the subject for reservations about the quality of the service. In advocating 'a comprehensive peripatetic teaching service', Warnock criticises the Portage workers 'some of whom are not professionally qualified as teachers' and advises teacher training with special courses which 'should include interprofessional courses'.[16]

Another weakness of Portage is the obvious schism between academics on the one hand, who value the behaviour modification approach which enables measurement of change through using activity sheets and check-lists, and service providers and users on the other, who put more emphasis on the relationship between parents and worker and the flexibility of the model.[17]

The International Portage Conference in Ochio Rios, Jamaica in 1992 provided a battle ground for these differences, heightened by the rift between the academics and Portage providers in developing countries. Community based rehabilitation programmes (CBR) rarely use check-sheets because of literacy problems, and tend to work through forming community groups in villages rather than providing a home-based service.[18]

Tension was heightened by the announcement by the Wisconsin delegates that they had abandoned the Portage check-lists, replacing them by a systemic approach to the whole family in assessing needs. This presentation of Portage with accompanying literature offended both the disciples of behaviourism and the parent providers, who saw this commercial venture to be in conflict with the voluntary, self-help features of the service. Evidence of the same schisms could be detected at the fifth International Portage conference in New Delhi in 1994, but fears about a Black Death epidemic affected representation so that research reports from academics held prominence.

There is a burgeoning literature on Portage evident in the Bibliography of Published Papers and Materials compiled by Shearer for the International Portage Association 1993. Different models from many countries Thorburn from Jamaica, Whelan from Korea, White from UK, Tiilikka and Hautamaki from Finland, are examples.[19] If there is a common theme, it is participation with parents in finding ways of helping and educating their own children. However, even this is controversial. It echoes the question posed about whether parents want to provide therapy, how effective delegation of tasks may be, and how the family is affected by this process.

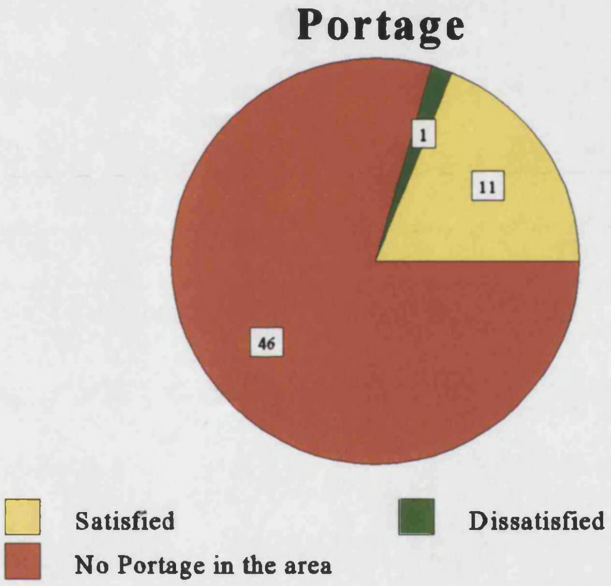
Warnock has no doubts about 'the value of parents as partners'. The report advocates 'a dialogue between parents and helpers working in partnership. In our view the need for special education may begin at birth'. 'We see parents as being the main educators of children wherever possible'.[20] Although not universally adopted, this view has spawned experimental projects which include Portage. The most publicised has been the Honeylands Project in Exeter reported by Brimblecombe. The Honeylands centre was designed to meet 3 needs of parents: information, including opportunities for discussion and understanding; provision to learn specific skills, and chances to feel less isolated. The experiment offered co-ordination between health care and early education.[21]

To be successful health needs cannot be separated from education for children with cerebral palsy. One of the most interesting on-going action research has been reported in Holland.[22] Portage workers were paired with physiotherapists and measurable improvements in the achievements of children have been reported using Portage-style check lists. This action research continues at the University of Groningen and the results may have both international relevance and may be a useful model when considering issues of overlapping functions between different therapists. (See Chapter 5).

9.2 Findings from Fieldwork

Although some of the debates about Portage may appear peripheral for children with cerebral palsy in this study, themes reverberate in the interviews with parents. There were however only 12 families who were or had been Portage users (see figure 32).

FIGURE 32



The reason for this poor take-up of the service probably lies in its focus on mentally handicapped children, poor local availability, and the preference of parents for systems directly providing professional corrective therapy.

Portage literature from developing countries, Loftin (1989) on Latin America and Zaman on Bangladesh for example, include physically and mentally handicapped children.[23] Visits to the Early Stimulation Project in Kingston, Jamaica (1992) and to the Bombay

Spastic Society (1994) provided evidence of Portage systems 'successfully integrating educational and rehabilitative objectives'. In the words of the physiotherapist directing the Kingston project, Jamaica:

> "Here we have no pre-school teachers, occupational or speech therapists, so I have to use my 'hands on' experience and what I have read in books to provide the best I can for children whatever their disabilities."

The UK Portage Early Education Programme concentrates on cognitive tasks, and is directed towards the parents of mentally handicapped children.[24] However, the publication in 1993 of the Portage Guide to Early Motor Skills acknowledges the value of Portage to 'paediatric occupational therapists and physiotherapists'. The pack is also designed to assess older children whose motor development is delayed.[25]

Portage providers in the UK are being encouraged to include children with cerebral palsy but this service may not be available locally and is usually seriously under-resourced. In Borough A, there were two Portage workers employed by the Early Years Team of the LEA. There was a waiting list for the service which excluded children attending playgroups or nursery classes. One mother was distressed to discover the NHS withdrew her O.T. It was a feature of making choices that sometimes parents felt they could not be open and honest but had to be furtive in accessing and evaluating resources appropriate to the needs of their child.

> "At the beginning, I didn't realise OT would stop when Portage started. I was disappointed. I caused a few ripples at the hospital. I didn't realise I was causing problems."
>
> (Clair's mother)

Although absorption in accessing therapies for their children may be a contributory factor in the under-use of Portage, many of the parents who did use it seemed to appreciate the contrasting approach.

> "It met an emotional need in me at the right time. All the other therapists were looking at Susan's weaknesses. Portage was flexible enough to use the strengths, challenge and develop them. It has motivated both of us by seeing success."
>
> (Susan's mother).

In a genuinely free market, customers should be able to make their own private purchases, but where public funds are involved their choices become public concerns. Suspicion of the Portage method seemed to stalk among professionals, particularly where Portage was staffed by volunteers without specialist training. Parents attending parent and child groups at the conductive education centre (discussed in Chapter 11) were discouraged by conductors from continuing with Portage because of conflicting techniques and the intention that the conductive education methods learnt in the groups should become a way of life in the home. Parents varied in their acceptance of these doctrines.

> "It's so appealing when they tell you that you can cut out all the other therapists, and it's only later that you realise you need them."
>
> (Mark's mother)

Boroughs C and B in the study had no Portage service although C used to have one worker 'until they had a row with the National Portage Association'.

> "Our borough doesn't have it, but I would like it as it helps you to aim for something."
>
> (Jo's father)

Borough B had a thriving Toy Library, combining informal support for mothers with toy lending facilities, while many Jewish parents in borough C and B made use of a Portage Programme provided by a voluntary organisation Norwood Child Care. Conflict between Norwood and the local LEA's had developed since the adoption of the purchaser/provider split. Prior to this the LEA's had expected this service to be provided free to eligible residents. The imposition of charges proved problematic for those parents unwilling or unable to fund the service for themselves.

The check-list dilemma evident in the conference proceedings, was given a low priority in evaluating Portage by parents in this study. Some used checklists, but first and foremost, they valued their relationship with the Portage worker.

> "I like the check-lists, my daughter's not so behind as I thought she was. The Portage worker has become a friend, who comes and plays and brings lots of interesting things. Even though she's a professional, she doesn't act like one - I could say anything to her and fleetingly she'd say something about her own life. She was here for 2 hours and I didn't think, 'I would be doing my washing now'."
>
> (Sarah's mother)

For vulnerable parents in the first two years of their child's life, a friendly visit at home contrasts favourably with hospital appointments and little understood therapies.

> "She's very good, but she's very overworked, being the only one in the office. We started by using the charts, but we soon decided to go our own way."
>
> (Peter's mother)

Of the 12 Portage users, only one was dissatisfied. Most mothers considered it to be brilliant, "taking all the thinking out of what you have to do for people like me who are busy."

The dissenting voice commented, "she came once, but I couldn't understand what she was on about." The most frequent responses to questions about Portage were either it was not available in the area or that they had not been referred. Unlike the better-known therapies

(O.T and physiotherapy) parents were unlikely to fight for it. One parent even doubted its usefulness.

> "Portage is a very linear model, behaviour modification - it doesn't allow for children to leave something behind - its going to underestimate children. I wouldn't use it."
>
> (Emma's mother)

Interviews with parents, combined with visits of observation during this study showed their local versions of Portage were far-removed from the ideals of academics quoted earlier. At best, there was a worker who might use check-lists; some areas limited service to lending toys and one LEA appeared to be using Portage as a way of helping Bangladeshi mothers for whom English was a second language with information, advice and an interpreter service.

The conclusion must be that Portage played only a small part in the lives of children in this study. The service was appreciated most for the relationship between mother and worker, a feature of the approach emphasised by Silverman & Stacey.[26] Their description of the Hints Project (Home Intervention) in Haringey based in Social Services not in the LEA, promotes taking into consideration the needs of the whole family. It is consistent with the Wisconsin systemic approach and may be seen as a development from concentrating on the cognitive development of a child to a more holistic approach to the overall needs of the family.

Nevertheless, it seems likely that public spending will continue to be restricted so that parents of children with cerebral palsy may continue to prioritise therapies, or be unable to access little more than a minimal service. This finding contrasts with the policy expectations highlighted by Warnock and reiterated by the Children Act Guidance 1991.[27]

> "I entered the sitting room Andy lay on a mattress on the floor. His baby sister crawled around. There was a Fisher Price toy radio next to Andy's head. The word 'Portage' painted on it in bright yellow told me that this was one of the services the family was receiving."
>
> (Extract from Interview)

9.3 Playgroups

Playgroups are the most important form of provision for the under 5's in terms of number of places and numbers of children attending. They provide places equivalent to about 13% of the under 5s' population[28]. They also provide disproportionally for middle class children, while nursery education is more often used by working class children[29]. It might be anticipated, therefore, that parents of children with cerebral palsy might attempt to access this resource.

The pre-school playgroups movement has its roots in the dearth of public nursery school provision. It is mainly a private or voluntary agency service concentrating on providing part-time places in unstructured environments, with opportunities for children to learn through play with others outside the home. Warnock recommends that 'they should be prepared to accept young children with disabilities or significant difficulties wherever possible'. Consistent with Warnock recommendations on Portage, emphasis is placed on 'suitable training of staff in helping to meet the special needs of young children with disabilities'.[30]

It is a disappointing finding, therefore, that only 7 families in this study reported use of a pre-school playgroup. There seem to be a number of explanations for this which echo those discussed in the Portage section, namely resources, attitudes and suitability. There seemed to be no shortage of playgroups in the north London area, but they differed widely in how they were organised and whether they could accommodate disabled children. As Statham et al, discovered there are at least 16 ways to run a playgroup.[31] What they have to offer depends on accommodation, often in church halls, and on the training background of the staff. The Pre-School Playgroup Association offers part-time short-courses, but many leaders are volunteer mothers or employees receiving subsistence level pay.

In Borough A a playgroup run by a parent/ex-ward sister appeared to concentrate more on standards of care and health, while another led by an ex-teacher provided direct instruction on the 3R's. Opportunity playgroups usually reserve a small number of places for children with disabilities, obtaining subsidies and extra helpers from social services. The availability of places in opportunity playgroups seemed to be low in all their boroughs though Borough A appeared to have a well-functioning system of liaising with social services for carers, and OT's from Health for advice on equipment.

Joining a playgroup is usually a child's first experience of being separated from mother, who usually has mixed motivation for initiating the arrangement. Since playgroups usually function only for 3 hours in the mornings and children usually start attending for one or two mornings per week, they can only be used by non-working mothers or by those who have minders and nannies. They may be seen as a first experience of independence and an opportunity to learn to play with peers, negotiating early relationships. Motivation for parents of children with disabilities has an extra dimension rooted in their struggle to come to terms with their feelings about their child's condition.

> "Playgroup was valuable as it was our first experience of separation and that is important. It also provided social interaction with able-bodied children - as an only child Paula's therapy programmes leave no time for her to socialise."
>
> (Paula's father)

Some mothers resisted comparing their child with able-bodied children of the same age.

> "I've been putting off going to the playgroup - I felt vulnerable and didn't know if I could face it. You have to go through stages of acceptance at

> your own pace, and deal with situations as you meet them. People don't know what to say when they see Hayley. I want a little understanding from them and I know you're always going to get negative people. My biggest fear is that she's not going to have friends. My husband says I worry about lots of things that may never happen."
>
> (Hayley's mother)

How able-bodied and children with disabilities related to each other was of interest.

> "It's only an impression, because I'm not there, but the other children seem to react to her disability by mothering her. This is alright as long as it doesn't become 'smothering'. We worry about her not making friends. She told us that her 'best friend' was her helper."
>
> (Charlotte's mother)

The competing demands of corrective therapy influenced decisions about using playgroups.

> "I moved him from playgroup where he happily stood in his frame, played with water and sand, and handed out the apples in turn. He needed to learn more, in particular how to walk."
>
> (Paul's mother)

Safety issues are heightened for children with cerebral palsy. Hannah's mother was more cautious than Ben's

> "I had a friend who runs a playgroup. It was quite rough: 30 children in a huge hall. It was the best thing I did. You want to wrap them up in cotton wool, but it does no good."
>
> (Ben's mother).

> "I went with her and spent my time picking her up as others trampled on her....she can fight back now, but she couldn't then. The nursery class was too fast and noisy; the classes are too big even for normal children."
>
> (Hannah's mother)

Perhaps one of the biggest difficulties was accessing appropriate equipment. Either arrangements had to be made with OT's, and payment renegotiated through health and social services for the provision of duplicate seating and standing frames, for example, or the mother had to take their equipment backwards and forwards. It also meant that unskilled staff needed training in using equipment and staff energy was likely to be taken up with safety issues.

> "I had to get Paula ready and load up the car; drive her there, unload and ensure her special helper was prepared. The session only lasted 2 hours and I had to do everything in reverse, before taking her home for lunch. We usually had an appointment with a therapist in the afternoon. Social services were so slow in providing the right things that Paula had grown out of them before they arrived."
>
> (Paula's mother)

Use of 'mainstream' playgroups seemed to be problematic for parents in this study. The voluntary sector offered more appropriate alternatives. For example a drop-in playgroup' with paid play leaders offered parents and children an informal meeting place; a therapeutic playgroup, run by a Jewish Voluntary agency provided a time-limited experience (10 weeks). There was a playgroup held simultaneously with a mothers' group aimed to attend to the emotional needs of both mother and child.

> "The therapeutic playgroup probably helped me most with coming to terms with things. I'd like to go now, but I suppose there are others who need it as much as I did. The Health visitor couldn't offer me anything. She just sat drinking cups of coffee but I realised she worried about me:

> I was a parent under stress! Sometimes I can be honest and sometimes I can talk about what has happened to my son, sometimes I end up crying. It seems to come out... it may be the kind of people I'm with, I don't know. It feels safe to share with other parents how I'm feeling. Jo likes the playgroup."
>
> (Jo's mother)

Taking into account these emotions underlying choices of playgroup, it may be concluded that for some parents a therapeutic environment may be beneficial. This observation fits with Warnock's support for 'opportunity groups...where mothers chat and children play' and 'structured sessions devised and supervised by psychologist and therapists'.[32] It is also consistent with the action research reported by Bower on providing play facilities in parallel with a mother' group for depressed women with young children on the White City estate. Her belief that experience in a group may help mothers achieve 'real improvements in their own mothering capacities', may be extended to mother of children with disabilities[33].

9.4 Conclusion

Small numbers of children with cerebral palsy make use of Portage and pre-school playgroups. Their experiences mirror those of able children but are exacerbated by patchy, underfunded provision and what appears to be limited commitment to promoting these facilities for disabled children with communication and mobility impairments. There can be no doubt that from, the evidence presented here, the expectations of Children Act Part III, appear to be more 'rhetorical' than reality-based.[34]

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Chapter 10 Choosing Between Mainstream or Special Education

> "I didn't like what I saw of the special school. They were all strapped to their seats. Outside the classrooms wheelchairs were lined up. I said Jo could sit 'holding on', but they said he needed to concentrate on the lesson, not on his sitting and needed his hands free. I excluded this school from my choices. I didn't need to make a second visit."
>
> (Jo's mother)

A child's educational statement of special needs is the passport to the school where education will be provided. This chapter will examine the issue of choosing between special and mainstream education at pre-school and first school levels.

Passionate campaigns have been conducted for the inclusion of children with disabilities in mainstream education. Although some children with disabilities have always been educated in mainstream classes, the impetus for increasing numbers came from Warnock.[1] Driven by beliefs in normalisation, equality of opportunities, anti-oppressive practice, human rights and the social model of disability, LEA's, schools, teachers and parents have facilitated many more pupils with disabilities to 'share in the lives of ordinary schools and communities'.[2]

Fervent commitment to an ideal sometimes causes participants to adopt extreme positions and to minimise factors which way detract from the validity of their cause. It might be argued that the promoters of mainstream education for all have oversimplified the considered recommendations of Warnock, underestimated the degree of change necessary in mainstream schools to make inclusion work, and overridden the views of parents and children themselves. These factors need separate consideration as the context for the findings in this study.

Warnock advocated the removal of categories of disabilities, replacing them by a broad category of 'special needs' to emphasise positive attitudes towards making educational provision, instead of a deficit model identifying disabling conditions. The report acknowledges the complexity of the process of achieving integration and 'expects an increasing proportion of the children who at present receive separate special education to be educated in ordinary schools'.

But, 'we recommend that a number of special schools should be designated as specialist centres for relatively rare or particularly complex disabilities, and should be developed as such by groups of local education authorities'. This recommendation was based on the belief that positive discrimination will always be required to give some children with special educational needs the benefit of special facilities, teaching methods or expertise...which cannot reasonably be provided in ordinary schools'.

This is applicable to children in this study, many of whom had very high levels of dependency needs. Nevertheless, it would be argued by disability rights campaigners that society ought to be willing to make necessary adjustments to the school environment however difficult and costly. 'One thing is clear.... integration in ordinary schools... is not a cheap alternative to provision in separate schools'.[3]

Considerable progress has been achieved in the 80s in adapting mainstream schools, identifying 'barriers to access to education' and undertaking research into issues and outcomes.[4] Hegarty et al found pupils with the same levels of difficulties successfully coping in different types of schools, both special and mainstream.[5] Gilbert and Hart stressed the need to check beyond issues of access - ramps, handrails and lifts.[6] Attention had to be paid to adapting the curriculum, the attitudes of teachers, pupils and those with disabilities themselves for progress to be made 'towards integration'.

These observations lead into the debate about replacing medical categories of handicap by categories of special educational need. Attempting to reduce the negative effects of labelling children, may have the effect of minimising and possibly neglecting the complexities of special provision required for each child to benefit from the mainstream experience. This is particularly relevant for children with cerebral palsy, many of whom have multiple disabilities. In their case, categorisation may be seen positively as serving their interests. There are obviously problems for single schools in meeting widely different needs effectively on the same site.

Consideration of practicalities, funding and principle sometimes means that the feelings of parents and children themselves may be overlooked. It is worth noting that going to school may be stressful and emotionally taxing for all children. Bullying and racism, for example have been identified as problems for children in inner-city schools. Schools may be experienced as uncomfortable places in which to grow up.

Children with disabilities may seek refuge from large potentially damaging experiences, by choosing small, 'safer' special school environments. 'My initial experience of mainstream education was, to say the least traumatic and could have damaged me more severely than any illness or disability that I have suffered'.[7] These issues have been presented as the backdrop for the fieldwork results from this study.

FINDINGS FROM FIELDWORK

10.1 Nursery Schools

Day nurseries provided by social services are often confused with LEA nursery classes. Whereas nurseries are staffed by nursery nurses and priority for admission has been concentrated on 'children from disturbed backgrounds,... considered by social workers to be 'at risk'.[8] Nursery schools are staffed by trained teachers and ought to be giving priority to children with disabilities.[9] In fact, nursery education provides places for just under 10% of under 5's in the UK, or roughly a quarter of 3 and 4 year olds.[10] Most of the provision of nursery education is part-time, and there are large variations between local authorities.

In this study, 23 children were attending or had attended an LEA nursery class. This total, excludes the 7 children under two years old. Of these, 15 were attending a special school nursery, the remaining 8 were in mainstream classes; 7 children were attending on a part-time basis ranging from 3 days per week to half a day; 6 children were combining enrolment in an LEA nursery class with attendance at the conductive education centre.

The debate about the relative advantages and disadvantages of including children with disabilities in mainstream classes is evident in the responses of participants to questions about education choices. There seemed to be two interlocking concerns about the opportunities offered in special nursery schools; intellectual stimulation combined with encouraging mobility. This concern about their children's intellectual development, discussed in Section II, was expressed frequently.

> "It was for developmentally delayed children. It was quiet and slow and under-stimulating. Nicky was ready for action. In a group of non-mobile children, he was developmentally beyond the others."
>
> (Nicky's mother)

> "She's not got learning difficulties even though she's not mobile and non-verbal. The special school class is institutionalised. All the children are strapped up. I'm trying to keep up her learning which couldn't be possible there."
>
> (Sarah's mother)

Parents of children with cerebral palsy are highly conscious of mobility issues, which explain some of their reservations about special nursery schools. Parents did not want their children "just wheeled about in chairs". They either refused the offer of a place, or attempted to combine attendance with enrolment at the conductive education centre.

In the wake of Warnock many LEA's have recognised 'the crucial importance of early educational opportunities for children with disabilities'.[11] Parents in the survey complained less about resources, than about their experience of reaching agreement about where their child should go, echoing negotiations with the NHS. (Section III).

> "I was on the phone every day. They were evasive for no apparent reason. They said, 'we've had a meeting ...we've discussed Stacey, but we haven't made a decision yet! I said, 'When's the next meeting?' They said, 'we don't know!'. There'd be a three-way conversation going on. I pursued it vigorously for 3 weeks. The delay was unacceptable. You have to fight and it isn't right."
>
> (Stacey's mother)

The same reservations about poor therapeutic facilities witnessed in relation to play groups (Chapter 9), were expressed about special and nursery classes.

> "We decided against the place in the mainstream nursery class. Our reservations were based on the poor resources of the health service. The special needs teacher was impressive, but she was a 'one man band'. What would happen if she left? The nursery school had a good atmosphere, but we were uncertain how Paula would react in that setting."
>
> (Paula's mother)

A range of issues emerged including safety communications, the provision of helpers and the severity of the child's condition. They seemed to be exacerbated by under-funding by some LEA's.

> "I worry about her poor communication. I so want her to have the same opportunities as the other kids and to be part of mainstream if at all possible, but I don't know whether she'll be happy if she can't make herself understood. She has a welfare lady, who looks shattered by the end of the day. Hayley has a helmet and walking frame - they thought she was a liability to others. In her mind, she's like the rest and wants to do everything they do. She's got double knee, hip and ankle joints so she has trouble in keeping her balance as she rushes around."
>
> (Hayley's mother)

These varied responses confirm the Warnock view that choice of special mainstream education should be available to enable parents to participate in decision-making. Some parents avoided or by-passed the issue by turning to conductive education in the pre-school years, as will be seen in Chapter 11. The necessity to revisit the dilemma became unavoidable when schooling became compulsory at the age of 5.

10.2 The Fifth Birthday: Entering full-time school

The 5th birthday is an important milestone in the lives of all children. Compulsory School attendance means separation from mother or main carer for 7 hours daily; association with peers in an institution focused primarily on education, conducted by teachers and regulated by the National Curriculum. It is assumed that children have reached adequate levels of self-care to sustain their lives in the classroom and playground. Independence and self-sufficiency are fostered with 'sink or swim' attitudes to adjusting to the school regime. Welfare assistance is primarily for crises, sickness and accidents. Nurturing may be identified as an aspect of the class teacher's role, but is largely nurturing through learning.

Education policy takes away the element of choice about who has main responsibility for children during the day time. Babyhood is truly over. Parents have to negotiate levels of partnership with their child's school: this may vary from brief meetings with the class teacher to involvement as classroom helpers and fund-raising through the parent/teacher association.

Despite anticipatory planning, this life change requires emotional adjustment by both parents and their children. Decisions have been made influenced by parental aspirations; their recognition of their child's character; local resources, financial constraints and family size. As the result of the Education Act 1985, middle class parents have become more vociferous in stating where they want their child to be educated, lodging appeals with LEA's when disappointed.

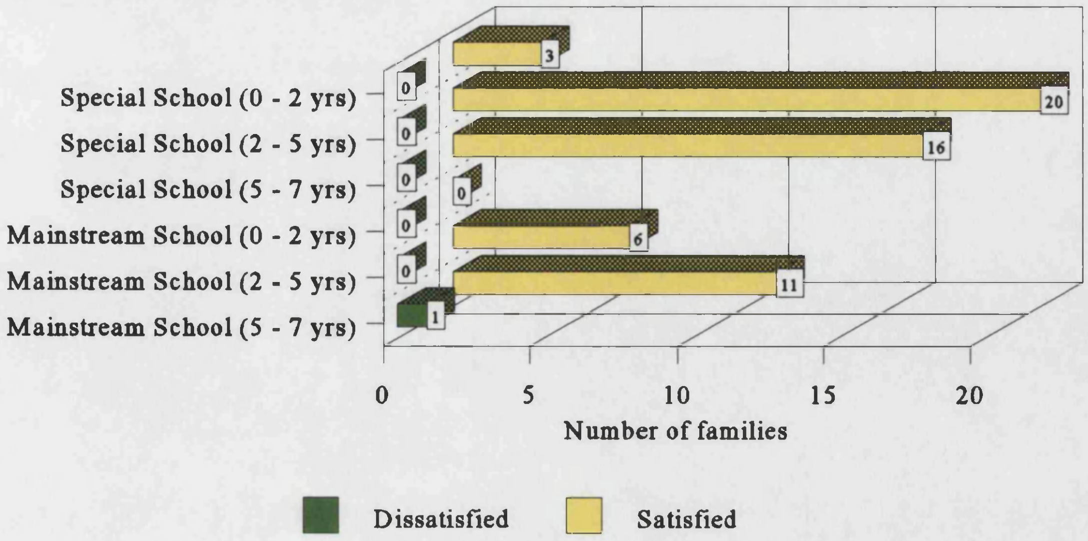
For children with cerebral palsy, starting school is also a milestone, but one of a greater complexity. Although the statementing process may have been initiated from age two, and many children with disabilities may have been given priority for nursery school places, there is more urgency to formalise educational planning. This inevitably confronts parents with the reality of their child's condition.

While many parents may continue to operate on some level of denial combined with an adversarial approach to securing resources, many need to reflect on their child's situation, revisit their child's experiences from birth, reassess their potential. For parents like these the 'tragedy model' of disability may be seen in a most appropriate light. The process of coming to terms with reality may release energy for realistic planning.

There were 28 children over the age of 5 in this study. Sixteen of them were attending LEA special schools and eleven were in mainstream schools. One child was being educated at home by her mother, because of a disputed statement. All other parents reported satisfaction with their choice, although one child had moved from mainstream to special school.

FIGURE 33

Special Education



The number of children in special school is remarkable (see figure 33). .If the number of children over 5, of whom there were 16, is added to the number of children between the ages of 2 and 5 in this study attending special nursery schools (23) the total amounts to 39 out of the total of 58 children. Of the children in mainstream classes, only 7 were in LEA schools. The remainder were in small private schools, where parents had negotiated special provisions.

Although it might have been expected that the Warnock recommendations and the promotion of integration by the Disability Alliance movement should have provided impetus for a radical shift in resources form special schools to mainstream, this has not happened. The figures in this study fit with the conclusions of the Audit Commission and of the work of Swann. He wrote 'overall these is no evidence of a trend towards integration... there is little indication that education authorities at either national or local level take the duty of integration very seriously'. In 1991 he predicted that 'the proportion of primary aged children in special schools in England may be on the increase'.[12]

It has been seen in Section II of this study that cerebral palsy children need considerable assistance (equipment and skilled professional help). An explanation for the large numbers of children with cerebral palsy in special schools may lie in the cost factor.

The research of Lunt and Evans into statementing reported as one of the 'most noticeable and dramatic findings, the increase in numbers of children with statements, or put forward for statementing over the past 3 years'.[13] This identification of a greater proportion of pupils for statements may be interpreted as an attempt to gain access to 'earmarked resources', but the levels of need of children with cerebral palsy, and indeed any physical handicap, is very high.

Croll and Moses report that in general, teachers are more positive about the integration of pupils with physical and sensory difficulties than any other subgroup, if issues of access, mobility, communication, continence and social relations are identified.[14] Halliday's analysis contains creative solutions including guidance to teachers on how to manage in the classroom. The main issue is willingness to allocate adequate resources.[15]

It is interesting that 3 children in this study could be described as being severely disabled: unable to walk, use arms/hands or to speak. They were among the small group in LEA mainstream schools because of the full participation of their parents in fighting for the principle of inclusion.

> "My primary concern is to have Danny's human rights met. To do this I have to offer him a whole range and that is available in the mainstream school. They've never had a child with disabilities in his school before so I have to work with them consistently."
>
> (Danny's mother)

There can be no complacency when a place in mainstream has been secured. Dramatic illustration of this point was provided by a mother whose son could not climb stairs.

> "They wanted Andrew to leave his mainstream school after 2 years as his class was going upstairs. For a year we carried him up and downstairs and the Health and Safety people said it couldn't go on. The school refused to change his classroom to the ground floor and the LEA said the cost of installing a lift would be too high. He couldn't move schools because there's not a single non-church school in the borough without stairs. Andrew wanted his friends to change schools with him. I said he

> would be the first child in Britain to be expelled for being disabled! Eventually the LEA provided the money for a lift from the profits from the sale of some buildings."
>
> (Andrew's mother)

Sustaining inclusion, therefore, demands considerable negotiation skills and persistence. Many parents may be unable or unwilling to participate. so intensely.

> "I've found the staff in the mainstream school very defensive and reluctant to work with other professionals. They are suspicious of the physiotherapists, for example, and have refused my offers to take them to Bobath to show them how to handle Paula. Their agenda is that of the School, but my agenda and that of health professionals is Paula's needs. Obviously there's a conflict."
>
> (Paula's mother)

Pursuit of inclusion requires holding onto principles of human rights and idealism throughout. In principle, individual members of the teaching staff may share these beliefs but putting them into practice may put them into conflict with the organisation.

> "I'll give you an example. The statement says Paula should have access to a colour printer at all times (other children have paper and pens), but the teachers keep moving it into other classrooms 'to share' the resources. When I point this out, I'm seen as difficult so I have to choose my battles all the time; when to do it and how much to put up with. The class teacher will never meet with me unless the head teacher is there which

> makes every meeting a confrontation, and I know they label me as difficult."
>
> (Paula's mother)

Many parents are neither confident enough nor passionate enough to explore in detail what is happening in the classroom Enquiries about everyday life in a mainstream class may reveal that subtle segregation processes take place despite the school's commitment to integration.

> "I couldn't believe how much segregation takes place. For example, all the disabled children are put in the therapy room when it's wet play and on Friday afternoons they are taken out of class to play separately - I think they are seen as children with problems who can't take the pressure of a full week's teaching."
>
> (Andrew's mother)

From interviews with parents of children in mainstream schools, an impression was gained that the system depended to some degree on their steady involvement. This might be in the form of constant monitoring or of providing assistance in class to uphold the provision.

> "I go into school on Tuesdays to help him with swimming - there's a problem I haven't solved yet as they're not going to allow a woman to go swimming with boys in an Orthodox Jewish school. They've asked me to find a male helper, but I'm having difficulties."
>
> (Ben's mother)

LEA's employ helpers for individual children. Funding people with suitable skills to undertake this work for poor renumeration is problematic. Nor is their work easy, involving confident, working relationships with the child, the mother and the class teachers. The lack of a system of national training for this task demonstrates how far the commitment of public funds needs to go to facilitate mainstream schooling for children with dependency needs. 'Ten years is a short time for a radical innovation to have bedded down'.[16]

> "The helper doesn't understand about 'therapeutic handling'. They lift her like a sack of potatoes and leave her during breaks - if Paula needs the toilet she has to ask a child to go and get the helper. By the time she's come, Paula's wet herself."
>
> (Paula's mother)

Perhaps the multiplicity of issues facing parents who sustain the mainstream choice discourages many from embarking on this voyage. Instead they settle for the special school, and in this study report satisfaction. The pace of life in a special school is slower; equipment, therapists and special needs educators are available. It is possible to side-step emotional problems arising from relationships between able-bodied children and children with disabilities. If parents and their children prefer this environment perhaps as Warnock recommended, this choice should always be available.

However, if it is the case that many prefer integration but have to settle for a special school because of under-funding and practical barriers, this study shows there is still a long way to go. On the positive side, considerable progress has been made by a small number.

10.3 Special Schools

In view of the investment required of parents to sustain their disabled children within the mainstream system, perhaps it is not surprising that so many parents in this study decided on special day schools. The consideration of boarding education as an option was usually postponed until middle school age. Most parents in this study appeared to be satisfied by their choice of special day school. The reasons may be found in the considered, realistic assessments made by parents of their own child's needs.

> "I want Stacey to be happy and confident. I know she's got learning difficulties and I remember how children with disabilities were treated when I attended a big comprehensive school in London. I think about her feelings. Children like Stacey were laughed at - I didn't realise it at the time, but I do now. Children are so cruel."
>
> (Stacey's mother)

Thus, for parents protecting their children is seen as a priority alongside the need to find a school where the pace of life is suitable for their child.

> "Clive has developed intellectually but physically he's very slow. The mainstream school is fast and noisy. He needs his routine. He's not ready for the busy environment."
>
> (Clive's mother)

The pace of life in special schools may be an attraction. Another bonus is on-site equipment, therapy staff and people who know how to `handle' children, approaching them with positive attitudes. This was a striking feature of a special school in Borough A visited during the fieldwork.

Expensive equipment including an exciting adapted adventure playground had been provided by sponsorships by local firms and the Rotary Club. The active Parent/Teacher Association had raised funds to build a bungalow in the grounds of the school for older children to practice daily living skills. Full-time therapists were on the premises in contrast to the mainstream schools where therapists visited infrequently, disrupting the daily time-table.

Far from being cut-off from the 'real world' children joined classes with a neighbouring mainstream school for various subjects, including art and music. The borough regularly held music festivals at the civic centre where children from special and mainstream schools participated. Instead of a ghetto approach to special education these was a belief in providing extra resources to facilitate fuller participation in community activities.

> "In mainstream the children with learning difficulties sit at the back - they're not really integrated. In his special school, Michael has everything. It's an ideal place for him - touch screen computers, outings and even horse-riding."
>
> (Michael's mother)

Perhaps the key issue is happiness. Not only do parents have to work hard to sustain their children in mainstream schools; the children themselves may find it too difficult.

> "He had a mean look on his face as he came towards us down the corridor in his wheelchair. We knew he was aiming straight for our shins."
>
> (Comment by a mainstream pupil)

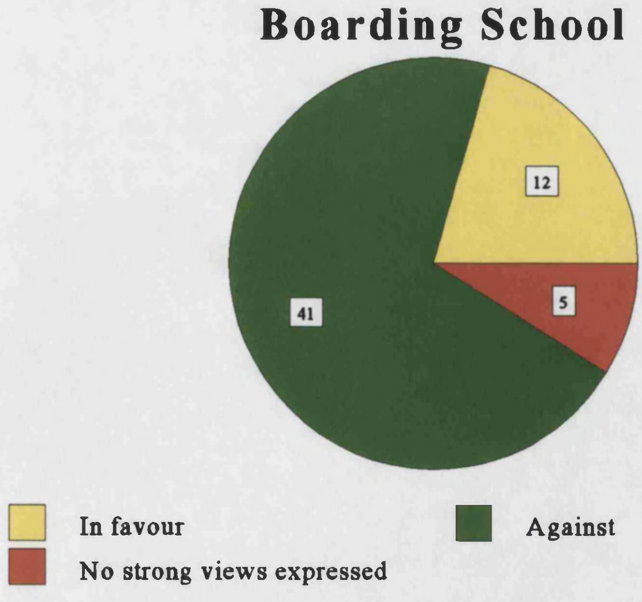
Attitudes like these should not deter the processes of arranging inclusion of children with disabilities in mainstream education, but they are a warning abut the complex nature of the task. It is insufficient to hold a belief in 'inclusion' without considering the possible consequences for children, their parents, the staff and pupils in the school, and devising strategies for combatting them.

10.4 Boarding Schools

Considering special education away from home is a further dimension to the special school's debate. Voluntary organisations, notably the Spastic Society and the Shaftesbury society, have concentrated resources on boarding provision, often sited in inaccessible country areas. Their decline in popularity may be ascribed to a number of factors including the shift in social policy from institutions to care within the family.

Warnock predicted that education 'in residential special schools is likely to continue to be needed 'and recommended that 'a range of different types of boarding special schools should be available'.[17] Although all the children in this study were living within their families, 12 parents were positively considering boarding school as the next stage in their planning for the care and education of their child (see figure 34 below).

FIGURE 34



A strong reason for this was their fears about being unable to lift and care for their child. Many mothers complained of back strain, and coupled this with worries about what would happen "if I fall down the stairs". One mother who described her son as "spastic and autistic", worried that "he is very strong and could be dangerous in adolescence".

Considering the boarding school option was a distressing matter for parents. 41 participants said they had dismissed the idea. Some felt they 'couldn't come to terms with it emotionally', or 'couldn't cope with the idea after visiting a special boarding school'. "I've resisted it so far, but he may need it when he's 10 or 12." Close relationships developed between parents and children through continued dependency needs, made the prospects of separation even on a weekly boarding basis, painfully unacceptable.

> "He's more special to us than a 'normal child'. Whenever he does something it's rewarding. It's nice to have him here and to lead a life as normal as possible. It is with his family he is going to find happiness."
>
> (Sam's mother)

Pressure from the conductive education centre for continuation of the system discussed in more detail in Chapter 11, influenced 4 parents strongly in the direction of considering boarding school as an option.

> "I thought 'no' at first, but then I thought I shouldn't be selfish and should think of Ben's needs, not my own. We can't give him up yet and we've been told there's a long waiting list."
>
> (Ben's mother)

Fulfilment of plans depended on the LEA's willingness to pay, but for one parent this seemed to provide an end in sight to meeting his child's extensive dependency needs, while another took her child's perspective.

> "At the moment he's too much of a baby, but I need to earn a wage. There's no special school in the borough."
>
> (Robert's father)

> "His biggest need is to make friends. If I could find a good school in London I'd consider it. At his present school, parents wouldn't dream of inviting a handicapped child to tea. Maybe he'll be able to establish more longer-term friends at boarding school."
>
> (Anthony's mother)

The majority of parents were committed to caring for their child within their family and were reluctant even to make use of respite care discussed in Chapter 12. In this their views are in harmony with the 'normalisation' features of social policy which are the driving force of the Children Act. As Hannah's mother said, she needs to feel safe with the family. She doesn't even like to be left overnight with family or friends.

10.5 Conclusion

The 1980s witnessed growing recognition of the educational needs of all children including those with disabilities. Statementing of special needs and the availability of more mainstream opportunities are features of the UK system. Participants in the study felt the effects of the nation's dawning response to their children's inclusion, but were frustrated by both the turmoil throughout the education system in the 1990s and by public spending constraints. Their impact was probably most severe for those who regarded intellectual capacity as their child's most positive feature: their bodies may be dysfunctional but hope was sustained that an 'active mind' was trapped in a 'damaged body'.

This theme is eloquently described by Jackson and Marsden. They comment on the 'mesh of hopes and anxieties' from the moment of birth, illustrated graphically by one of the participants in their study[18].

> "When our Richard was born, he had a funny head.....he had the funniest shaped head that you can imagine. It stuck out here like that! And I said, 'Oh, Dr Sykes, look at his head. I've never seen one like that'. And Dr Sykes said, 'I have. It's a long time since I've seen one like that. Don't you worry Mrs Beckworth, those are brains. Those are brains pushing out, and as long as you take care of him until that head's firm, you mark my words, something will come of this'."

Concern for maximising their child's potential seemed to be the driving force behind turning from the public section to private options. Conductive education will be analysed in the next chapter as an example of this process.

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Chapter 11

Families and Conductive Education: a case study of a private resource

> "You have to choose the method which you understand the best. If I understand what they are trying to achieve, I can help my son."
>
> (Andrew's mother)

Dissatisfaction with both the quality and frequency of health care and the patchy nature of educational provision appears to be the impetus behind experimenting with conductive education. The method has been discussed as an alternative to conventional rehabilitative treatment in Section III, Chapter 7, where the focus was on conductive education at the Peto Institute, Budapest. In this chapter, discussion will centre round conductive education provided at a day school centre in north London, and as a radical alternative to LEA provision.

What is conductive education? This question is at the nub of the choosing process for parents, and concerns providers, funders and researchers equally.

The literature is disappointing and unlike Bobath, the centre in north London fails to provide adequate explanatory publications. This reflects the impression of an organisation expecting unquestioning faith in their commodity, and parents who are unquestioning in their gratitude for this opportunity to improve their children's lives.

Research literature is also disappointing. Andras Peto (1893 -1967) the founder of the conductive education movement, published virtually nothing - the system and its methods existed, implicitly in the work of his Institute and its 'conductors'.[1]

The textbook by Hari and Akos translated 1988, contains detailed technical explanations.[2] The photographs are probably the most useful aspects of this work, demonstrating how education is 'conducted'.

The most comprehensible explanatory articles are those of Ester Cotton located in professional journals 1965-1974.[3] The Conductor, a journal published by the Birmingham Institute, provides news about the expansion of the methods in the UK. Neither of these sources is easily accessible to parents, nor is some of their content directly relevant, tending as is does to be promotional and defensive.

Conductive education advocates received a bitter blow in 1993 with the completion by Bairstow, et al of the DFE Evaluation of Conductive Education for children with cerebral palsy.[4] This research compared progress of two groups of children, one at the Birmingham Institute in collaboration with Peto Institute Budapest, and the other from special schools in Lancashire. The report concluded that the latter group's progress was better, and that parents of children with cerebral palsy should regard with caution the promises made on behalf of conductive education, and they should not feel they are failing if they do not secure conductive education for their child.

These research results were not available at the time this fieldwork. Instead, parents in this study heard about possible 'miraculous' improvements from the media, and found out about conductive education by trying it for themselves. Consequently it was a feature of their interviews that parents initiated discussion about their understanding of conductive education, its underlying principles, how these were implemented and how this might be appropriate for their child.

Out of the work of Cotton 1974, Sutton 1978, Hari and Akos 1988, it is possible to derive the major principles. Conductive education aims to teach people with brain damage ('cerebral dysfunctions'), how to be 'orthofunctional', a state where a person has 'normal control' over the body movements.[5] There is emphasis on achieving mobility since the system originated in Budapest where there were no special schools, and admission to mainstream depended on being able to walk.

The theory applies to other aspects of functioning, in particular, feeding, continence and speech. These abilities are vital for full participation in human activities and ensure independent living/survival. Early intervention in the first years of maturation is recommended, although the same principles apply to adult stroke patients.

Achievement of these aims requires an holistic approach, excluding other therapies, continuity throughout waking hours, and minimum use of equipment like standing frames, wheel-chairs and straps.

Conductive education derives its name from the main means of application which is teaching people to control their bodily movements, by instruction or 'pedagogy', constant repetition known as 'rhythmic intention' and reinforcement through group activities using rewards and punishments techniques. This requires a relentless day-time programme, which contrasts sharply with individual, child-centred Western interventions.

It is likened by Sutton 'to teaching of dance, in which non-intuitive movements (all normal motor acts are non-intuitive in the motor-disordered) are taught in a disciplined and orderly fashion with skilled attention to the learners' attitudes, motivation, persistence, morale, rate of learning and skills'.[6]

There is dependence on conditioning, although one parent described it as:"brain-washing, that's what they do to them, isn't it?" The researcher's notes include the following comment on an observation.

> "This comes over as a cross-between revivalism as they chant instructions, and Hitler's Youth as the conductors deliver orders."

The method also involves equipment, 'sparse, but relevant to the learning situation'.[7] This means slatted chairs, stools, tables and plinths (long slatted beds) and sticks for 'holding on' and helping to retain balance in walking.

The programme of instruction is implemented by teams of 'conductors', young women who should have received 4 years' intensive training in Budapest. Their training 'creates a new profession and a new professional outlook to deal with all the problems of a neurologically impaired child'[8]. In-service training combined with teaching in the subject areas of child care, anatomy, physiology and movement theories enables them to take responsibility for the daily 'education' schedule, divided into 'task series'.

'Task series' are practising a number of linked tasks, usually learnt spontaneously by healthy children. They are not 'simply exercises' but 'intentional activities'.[9] Songs and verses are chanted to encourage learning within the group environment. 'Intention' is expressed by including 'I' in each activity.

> "Now, if you're all ready to begin, all sitting up straight, bottoms back; I look at my feet, look, look, look. How should our feet be? I put my feet flat and apart. Say it with me, and knees apart. I hold my ladder with 2 hands, one, two fingers on top, thumbs underneath, so we can get wrinkles on our wrists. After 3 we'll all sing with Leah: Wrinkles, wrinkles on my wrist, I hold on tight and make 2 fists. I sit straight, heads in the middle and hips together so we can say mmmm. Let me hear you."

(Extract from observation of nursery group)

Task series like these go on all through the day at the north London conductive education centre, apart from a half hour rest period after lunch when the children 'rest' lying on slatted benches without covers listening to a story tape. Lunchtime is included, demonstrating CE as integral to daily life, and there is even a regime for toilet-training.

> "I am sitting on my potty, on my potty, on my potty, I am sitting, we'll
> wait and see. Do a wee, do a wee, in the potty, do a wee wee in the pot.
> Has anyone done a wee?
> You have Matthew? Let's see.
> Jo, no wee? Never mind.
> Shoes off everybody."
>
> (Extract from observation of parent and child group)

The nursery group at the north London centre is expected to perform the instructions of the conductor together harmoniously, in keeping with Sutton's description of 'dance'.

> "I look at my feet... look, look, look. Is everybody looking.
> I put my feet flat and apart, knees apart.
> I put my hands forward, push, push, push.
> Who has got lovely straight arms?
> I hold on with two hands, one, two.
> Heads in the middle and lips together."

There task series last about an hour before a break for drinks. In the nursery group of 8 children, 2 conductors help individual children while the main conductor gives directions.

Unfortunately very few children can follow the instructions because of the severity of their disabilities. One child needs individual attention throughout and others sabotage the process regularly, so the routine rarely felt like rhythmic dance. Instead there was an atmosphere of tension; will the conductor be able to complete the planned task series?

> "You must hold on, fingers on top and thumbs underneath.
> Ellie screams and refuses to hold on.
> Jo, if you don't do it, I will take your turtle away.
> Heads in the middle and lips together
> Charlotte, that's enough... or you'll end up going outside again.
> I push my ladder forward, push, push, push
> I move one hand up and hold, I stand tall.
> Charlotte is screaming.
> Conductor tries to override the noise by singing 'we're children standing tall, we're children standing tall, if you're happy and you know it, shout.
> Leah joins in enthusiastically, while Charlotte bellows.
> Are you going to stop crying?"
>
> (Extract from observation)

A possible explanation for the apparent failure of these conductors to establish rhythm may lie in the diverse and serious nature of these children's disabilities. Certainly the method is recommended for children able to follow instructions.

Related to defining CE is the question of whether it is 'education', 'therapy' or a combination of both. Sutton writes 'conductive education is not a 'therapy', but a pedagogy aimed at creating new skills and mental structures out of social interaction in the material world'.[10]

Children with full-time places at the north London centre are expected to relinquish all other therapies, "although we know some of them keep them on secretly. The most helpful and least contradictory alternative is Portage because of its emphasis on learning." (Comment by director).

For some parents it is a great relief to reduce the number of appointments to keep, places to go and instructions to follow. It is also less confusing for their child.

> "It's a wonderful place. It taught us so much. We like the idea of the child being considered as a whole, rather than in bits and pieces like hips and spine. Physio is just looking at one part of the body, whereas the centre completes a whole day's interventions for you."
>
> (Stacey's parents)

Others were more cautions about losing other options and worried about whether they should continue them covertly and whether they were contradictory.

> "The director <u>says</u> she doesn't mind parents arranging extra physio, but she does really!"
>
> (Emily's mother)

Whether the NHS would allow simultaneous use was another consideration discussed in relation to Bobath in Chapter 7 and Portage in Chapter 9.

> "The hospital cut off Danny's physio and I didn't agree. It's important for him to have exercise, not just to use his brain."
>
> (Danny's mother)

For parents a clear choice had to be made between Bobath, a treatment, and CE which claimed not to be, but seemed as if it was. The edict that other therapies were superfluous confirmed parents' impressions that they were choosing a form of treatment.

> "I don't think the conductors knew I was taking Paula to Bobath, but Bobath gave us two weeks to make up our minds which method to adopt. On the whole I don't think I can afford to work in partnership with professionals. I've always had to seek out alternatives very actively, knowing that if I don't press the right button, I won't have any choice. When I've pushed very hard for what I want and even when I succeed, there's always strings - threats, you'll lose something if you try something else."
>
> (Paula's mother)

The problem seems to be caused by the translation of 'pedagogy' with its meaning of didactic teaching style into 'education', which has a broader and different meaning in English. Although CE claims to educate the 'whole child', concentration on learning mobility, daily living skills and speech inevitably displaces literacy, numeracy and inter-personal skills. Cotton argues;

> "If a child has TB spine, we expect her to be in hospital because it is necessary for treatment. So with cerebral palsy, Peto said, 'give me a child until he is 7 and I will give him back his autofunctioning. He will soon catch up with his school work when he can walk'."
>
> (Extract from interview with Ester Cotton)

Following this argument, the best place for CE is in a boarding school environment, although instructing parents to follow CE techniques in the home may compensate. While one parent found the philosophy of “having higher expectations for my child more encouraging than contact with NHS professionals”, attitudes to parents are discouraging. The philosophy that they know best, and should prescribe / advise means that the staff become frustrated by parents who fail to accept the advice. The attitude, 'we know best' raises the question, 'whose child is she?'

There seems to be muddled thinking about the 'therapy' versus 'education' debate which ensues in part from the shortage of therapeutic resources discussion in Chapter 5. On the one hand, physios and OTs disapprove of the conductive approach because of fears of physiological damage, particularly to the hips. On the other, several parents said their therapists had recommended CE as a better resourced facility, and perhaps the clamour from demanding parent might be diverted, if only temporarily.[11] It appears therefore that CE is, in the minds of parents, an alternative therapy, and by virtue of the concentration on physiology and anatomy, might be included within therapeutic options.

Endorsement of this view may be obtained from the Symposium on Cerebral Palsy 1987. Tatlow's paper describes CE as 'combining systematically specialist methods' and carrying them over into daily life, 'making for spirited, happy cerebral palsied children who are motivated to work for long periods to overcome their motor problems'. In Tatlow's view, the Bobaths focused too much on 'clinical symptoms' but both processes had the same intentions.

From the education perspective, defined in Western society to include the 3 R's and socialisation, there is conflict with 'pedagogy', a style of teaching. When pure CE is provided in the UK therefore, conductive education centres are confronted with DFE inspections and the National Curriculum. Failure to adhere to these requirements could mean fewer LEA's willing to purchase places. Thus, risking a conclusion which would be considered heretical by CE promoters, conductive education does not fit classification as either education, or therapy, based on Western medical science.

In summary pure CE embraces a philosophy of engaging with a child to apply intelligence and self-control over motor malfunction with the aim of achieving as soon and as effectively as possible functioning as independent able-bodied people. It is no surprise therefore, that while being attracted by the promises of rapid change and maximising potential, members of the Disability Alliance Movement regard CE as in conflict with their principles of equal opportunities for disabled people and changing the environment rather than expecting disabled people to strive consciously to attain 'normal functioning'.[12]

> "We probably avoided a conflict by taking Jo out of conductive education without discussing our feelings with the director. There was too much concentration on his weaknesses, and I worried about his self-esteem and how the demands of the system distorted the family. We have to think increasingly about how Jo feels and he hated it. We have to accept him as he is and wants to be, rather than as others would like him to be."
>
> (Jo's parents)

CE has been promoted vigorously as an approach to be purchased from Eastern Europe. There the harsh life-style of many families living in small inaccessible apartment blocks, the 'disabling environment', steep pavements and harsh winters for example and inaccessible schools make the approach consistent with the cultural environment for which it was devised. The didactic pedagogy, alien to the freedom allowed in UK homes and schools, appears eminently consistent with child rearing patterns in Eastern Europe. It is also consistent with the formal instructional style of teaching observed in schools in

Kiev, Ukraine on a study visit. Problems arise when a treatment born to fit one culture is transplanted to alien soil.

11.1 Conductive Education in the UK

If extensive choice is considered to be an advantage, parents in north London are fortunate to have a version of conductive education within travelling distance. Apart from those living near the Birmingham Institute, families in the UK opting for conductive education travel to Budapest. Scope has actively encouraged this traffic by agreeing a financial contract with the Peto Institute. It also offers conductive education at Ingfield Manor, a boarding school in Sussex. From 1994, Scope-sponsored 'schools for parents' have been established in some neighbourhoods in the South East but these are small, part-time facilities resembling structured playgroups associated with support for mothers.

Vestiges of conductive education are evident in many provisions for children with motor disorders. The special school in Borough A used 'conductive furniture'; a class teacher found 'rhythmic intention useful sometimes'; a voluntary self-help group provided a conductive education class run by a Hungarian conductor with Bobath training. However, the conductive education movement vigorously promotes the approach as a total package with claims that other interventions may be unnecessary.

The conductive education centre in north London founded by Ester Cotton, a physiotherapist, who had been converted to the work of Andras Peto during a visit to Budapest in the 60's, is a private institution offering mother and child sessions twice weekly for babies; parent and child groups twice weekly from aged 2-3; a nursery group from aged 3-5 an a school group from 5-7 years. While the baby sessions are free, places in the other groups must be purchased by local authorities or by parents themselves, many of whom raised money by sponsored activities. It had been expected that the LEA of the host borough would sponsor children, but in practice, suspicion was directed towards the approach by the educational psychologist and by the LEA for whom providing special school places was cheaper. Funding was therefore a cause of concern for parents, some of whom had taken up places before statements had been decided by LEA's. Parents worried when they received invoices which they knowingly could not pay.

One child was funded by social services because she was on the Child Protection Register, but usually LEA's sponsored children for fees and transport. Those living in Borough A were funded because of the absence of a school for physically handicapped children in the borough. Some children were sponsored up to age 3 as the parent and child group was unique and reasonably inexpensive. In total, children from 22 Greater London local authorities used the centre during the time of the study. Families moved house temporarily to enable their child to attend and visitors from abroad (Canada, Sweden and Israel) came specifically to assess the benefits of the approach for their child.

For parents to be able to exercise real choice, they needed to understand the approach. Unfortunately this is not easy in the case of conductive education. Parents attending the parent and child group felt they were discouraged from discussing these issues. 'Less talking, more working' was an instruction to a mother. Sharing understanding of the process took place in the car park after the sessions!

Some of this lack of communication between staff and parents might be explained by parents anxieties that their children may not be progressing satisfactorily and therefore might fail to be promoted to the nursery group. Overall parents appeared to feel infantilised rather than being engaged as partners in a shared process of improving the lives of children with cerebral palsy.

A complicating factor was that the conductive education centre in north London was considered to be heretical by proponents of 'pure' conductive education at the Birmingham and Peto Institutes. Conductive education was provided by 'conductors' who had undertaken in-service training over 2 years, instead of the intensive 4 year course in Budapest. Sutton promoted the view that 'a plethora of diluted schemes in the name of conductive education, could detrimentally destroy public confidence in the very idea of transforming the lives of the motor-disordered and their families..... Well-founded and effective work has no need to borrow the name of conductive education and the less substantial should most certainly not'.[13]

It is noticeable that the Peto Institute, keen to promote CE as a commercial venture, tended to be less harsh on dissidents. 'There are many roads to Rome, and nobody should be compelled to think that only one method exists. If a method is done by talented and decent people and gives good results then this is just as welcome'.[14]

Schism within the movement lessened with the prospect of negative results from the DFE research. The Conductor became more mellow reporting variations in the UK including the north London centre and round the world in a more positive light. 'In the past 12 months, the Birmingham Institute has followed a policy of developing contact with other centres which employ conductors or which have a strong interest in CE'.[15]

These internal disputes about the nature of provision to be purchased mirrors the discussions about Portage. Although to some extent peripheral to their own decisions, such disputes cloud the issues for those parents attempting to make reasoned informed choices. Parents in this study made their decisions by taking their child for assessments about which they felt anxious and ambivalent. If their child was found unsuitable, did this confirm their worst fears? Was their child 'ineducable', or was the system some kind of confidence trick to extort fees? Some parents quickly concluded the latter, from assessments at Scope.

> "We paid £70 for an assessment. We were crammed into a room with 10 or 20 other parents like slaves under a ship's deck. The room was very stuffy and someone who spoke broken English lectured us 'like the clappers'. Michael had hysterics and refused to join in the group session. I was sorry for the people who'd come all the way from Leeds. We couldn't believe it when we were told Michael was suitable."
>
> (Michael's parents)

Assessments for admission to the centre in north London were less traumatic being done on an individual basis, but still lacking hard information about how CE might benefit the child. Children were enrolled 'on trial' from the point of view of the centre, and that of the parents. Research interviews revealed their suspicions and concerns might have been allayed by more reassuring communication. There seemed to be an underlying suspicion that if they were critical or their child did not make progress it was either because they were not enforcing the system adequately at home, or their child's weaknesses were preventing an infallible system from working.

> "I am willing to talk to you but I have to be careful because Matthew's still at the centre. It's all too repetitive for him now, particularly the language side, but until the LEA confirms his place in the mainstream school, I don't want them to know I'm dissatisfied."
>
> (Matthew's mother)

The centre's director was in constant conflict with LEAs about funding. Parents were probably right to suspect that these issues influenced their judgement when advising the most appropriate education for their child. It was an obvious organisational weakness that the director held responsibility for funding alongside that of assessing developmental needs from her professional stance as a qualified OT. Curiously a parent informed the researcher that the organisation was not in financial difficulties.

> "Hasn't anyone told you about the money? At the time Christine was just starting in the nursery, there was a threat that the centre might have to close for financial reasons. A group of parents led by my husband set about organising a 'Golden Letter', which resulted in a large financial investment. There's no reason why so much emphasis should be put on whether people can or can't pay."
>
> (Christine's mother)

Interviews with the director indicated her need for support and for separation between management and professional decisions. These dilemmas are frequently encountered in growing private organisations with mixed loyalty, in particular belief in promoting CE, commitment to the needs of individual children within the context of an educational system restricted by shortage of funds.

In the same way that the director's judgement became confused, so did that of parents. Their motives were sometimes influenced more strongly by emotion than by reason and hard facts. Practical considerations like travel, family responsibilities and the likely effects on other commitments to alternative therapies swirled around and did not go away when a child enrolled because there was ever-present an atmosphere of testing. Was the system suitable? Could the child benefit? If not, with whom did the faults lie? Was funding for this provision worth fighting for?

Section II presents cerebral palsy as a condition resulting in different disabilities along a continuum of severity, each child being unique. Regular assessments are required in the early years to monitor developmental changes and the consequences of therapeutic interventions. Although C.E. is usually recommended as most appropriate for ataxic and athetoid children, all children under the umbrella of cerebral palsy received education at the north London centre.[16] This broad admissions policy was connected to some extent with the need to recruit those whose LEA's would fund, but there was also a genuine belief that CE could benefit a wide range of motor disorders. From their experiences of testing the system for their child, disparity of need caused concerns for parents.

> "Danny doesn't need to strengthen his arms as only his legs are affected, so only half of the programme involved him. I was confused as the physio was horrified that the centre hadn't x-rayed his hips. I was tired, the children were suffering so I stopped going. I told them that my time was limited because of having a young baby as well as Danny. It was just an excuse."
>
> (Danny's mother)

If a child appeared not to be progressing, unsuitability might be given as the reason.

> "Didn't you notice Polly kept dropping toys and chewing pieces of tissue? We think she might have been autistic. Her mother is very angry with us and has taken her out of the nursery group. We don't know where she's gone."
>
> (Director)

Success is always encouraging, but the most able children tended to leave early because educational psychologists recommended progress to a mainstream school. Funding would therefore be discontinued, and so would the CE way of living.

> "We follow-up children when they have gone to other schools, but feel despondent about them. They use wheel-chairs for mobility round the school and strap them in to do lessons."
>
> (Director)

These follow-up visits proved contentious both for the school staff in the new school, and for parents. The director expressed regret that some school disallowed visits. A parent reported,

> "They visited Michael at his mainstream school last week, but I'd taken him for a hospital appointment so he wasn't there. They should have told me they were coming."
>
> (Michael's mother)

Firm belief in CE seemed to breed conviction that the system is best, thus giving rights over a child's future care despite no continued formal involvement. Echoes of this attitude may be discerned in the arrangements for visiting children at home.

> "During school holidays, conductors are expected to do home visits either in the early morning to see how a child gets up or in the evening for putting to bed."
>
> (Director)

Although intended to be helpful to parents these visits had an aura of inspection around them rather out of step with parental partnership. In fact, interviews with parents revealed that few of these visits actually took place as conductors who were not paid extra for doing them in the holidays and at unsocial hours, found them invasive of their private time!

11.2 Progress Through the System

Children at the conductive education centre were there on trial. Few parents fully understood the aims and practice of CE. They tried it out in the hope that an intensive programme might supplement or build on other treatments. Few children progressed from mother and child sessions through to the school group. Funding problems might be the decisive factor in change, but their parents' assessment of the system and whether it was appropriate was central. Essentially these children were in transit through an unusual regime , while parents struggled to understand what it was all about. Usually they came because they were dissatisfied with NHS provision.

> "We felt we were getting more in terms of input than from anywhere-else. Whether the approach is correct or not is another matter!"
>
> (Stacey's parents)

Many came because they had failed to obtain an appointment at Bobath, and moved on when they were successful.

> "The deceit of it all! I couldn't stand the tremendous pressure CE put on parents. I thought I was failing and my physio was reduced because I was going to the conductive education centre. I wept on the phone to the receptionist at Bobath. It helps to cry doesn't it... that's how I got my

> pushchair. Anyway I got an appointment at Bobath and went there regularly after that."

11.3 Mobility

Mobility and speech are central foci for CE, but parents expressed reservations about both these areas. Concentration on walking seemed inappropriate for some children.

> "He's in so much pain when they try to walk him. He can't put his feet flat on the floor. I don't think they should be trying. His supports aren't right. I've only just been able to leave him. He was screaming last week because they try to keep making him walk. Time will tell if he manages it."

(Paul's mother)

Disciples of CE would argue that for children with very restricted mobility, progress will be slow and require intensive exposure to the method. Indeed during the observations, very few children could walk with assistance and only one in the school group walked unaided.

> "Milly staggers across the room holding a wooden bar. She is exercising fierce control of her body. Any minute it looks as if she will collapse in an unco-ordinated heap. She is so thin - I wonder whether she will be able to sustain this effort when her body shape changes in adolescence."

(Extract from observation notes)

Conductive education was devised in a country where children had no access to wheelchairs and walking aids - being unable to walk meant being unable to go to school.

In London, however, the system is imposed despite the availabiltiy of such equipment. The method puts children under pressure throughout the day, presenting hardships which able children would not encounter.

> "I followed Charlotte and the co-ordinator into the toilet and was surprised to see she had to mount a stone step up to the toilet and another to wash her hands at the sink. Charlotte can only stand by 'holding on'. It looked as if these steps were built deliberately to test/train the children to overcome adversity. She began to scream as she stood grabbing the basin. The conductor who knew she should not communicate with the observer, commented to the air, 'she's screaming because she fell backwards and bumped her head last time. What a stupid place to put a step! I expect this is what it's like in Budapest!'"
>
> (Extract from observation)

Later, the research interview with Charlotte's mother at home confirmed the harsh nature of the regime, raising child protection issues discussed in chapter 3.11. Charlotte was the child whose mother had forgotten the appointment for the research interview.

> "I had forgotten you were coming. We had a bit of a shock yesterday. Charlotte came home and started vomiting. They said she had fallen over. We took her to casualty and they said she had concussion. It's not the first time she's fallen on those hard floors. It really worries me, but she's making so much more progress than in her other nursery."
>
> (Charlotte's mother)

11.4 Protection and Care

With testing conditions come potentially dangerous situations.

> "Nicola refused to walk to the lunch table, she sat and bellowed. The conductor tried to persuade her but she completely refused. She was left sitting on the box, 'holding onto' the ladder in front. Eventually she fell off and banged her head hard. I could see it coming and had to exercise considerable restraint to keep to the observer role and not to intervene. The conductors clearly thought this should have taught her to do what she was told. She continued to bellow, causing a disagreement between conductors, one of whom thought she needed a cuddle!"
>
> (Extract from observations)

In line with this training goes suspicion of attempts to sabotage the programme. There seemed to be no provision for a child who might feel unwell, since this could be an avoidance tactic.

> "Hannah looked miserable and the conductors kept trying to engage her in the task series, muttering to each other that perhaps she wasn't well. Eventually they decided to take her temperature but had no thermometer; when they found one, unbelievably they did not know the normal reading. Having decided perhaps she wasn't well, they let her lie down on one of the wooden slatted beds - there were no covers, no comfort. What sort of training have these conductors had? They appear to know little about caring for children and to be insensitive to their emotional needs."
>
> (Extract from observation)

Parents were encouraged to observe their children, often concluding that the group approach was unsuitable for their child. They too often prioritised therapeutic factors over emotional needs.

> “The class isn't pushing him enough. He likes it and I think the way they 'drum it into him' is good but he can crawl and they won't let him. I think he needs a lot more individual help but he probably gets more there than he would in other schools.”
>
> (Jo's mother)

It is significant that the Centre staff does not include either a child psychotherapist or a social worker to attend to the emotional needs of both the parents and their children. Perhaps this kind of approach might have made it difficult for anyone to enforce conductive education which depends so heavily on controlling feelings, and sacrifices individual needs to group priorities. These speculations were endorsed by discussions with the conductors, who quickly left to obtain more and different training in caring for children. Paradoxically the attraction of the work at the Centre was compassion for disabled children, but the nature of the regime did not fit comfortably with these emotions.

11.5 Speech and Communication

What worried many parents was the absence of speech therapy - 'rhythmic intention' was seen as a poor substitute for professional individual therapy. Several mothers admitted to continuing speech therapy privately, while two mothers, whose children could speak, worried about the absence of peer communication.

> "Emma's very chatty and there's no conversation. She and Matthew run riot because they find it so boring and repetitive. We've watched her each week and try to do the same things with her at home to help her mobility, but we've arranged to transfer her to the mainstream nursery next term."
>
> (Emma's mother)

During the period of observation in the nursery group, only one child could speak sentences. These were uttered in 'Dalek-like' manner. Was this the effect of listening constantly to 'rhythmic intention'?

Conductors spoke 'normally' to each other at break times and when clearing up the lunch. At these times their speed of movement as they 'bustled' around tidying up and their fluent exchanges brought a breath of reality to the otherwise strange atmosphere in the nursery. Everything happens so slowly because of the children's restricted mobility, and the absence of language emphasises the protracted pace of the daily activities. A striking feature of life in the nursery was the absence of communication between children, which might be explained in part by the didactic, structured regime and in part by the children's speech impairments.

It was disconcerting during the observations that none of the children seemed to notice the observer's presence when the sessions took place within the nursery room. This behaviour contrasted so markedly with the usual behaviour of young children in day care settings - children may overwhelm visitors, seeking attention, wanting stories or to be picked up and noticed. Immobility removes this option, but the children rarely made eye contact and appeared very infrequently distracted by the observer's presence. During her short period of employment, the innovative Australian teacher drew attention to the observer's arrival and departure and offered drinks at meal times, telling the children,"you should welcome people who come to see you, that is how people usually behave!"

11.6 Staff: The Conductors

The absence of professional physiotherapy was also a complaint since many parents had been deprived of their NHS provision, or had been driven to try CE as an alternative because NHS physio was inadequate.

> "At the time Charlotte started, the borough was supplying physio fortnightly and that wasn't nearly enough. We are getting more in input than anywhere else, but it feels like the blind leading the blind."
>
> (Charlotte's mother)

Parents were right to suspect the quality and knowledge/skills base of the conductors, who were recruited from a range of professional backgrounds, frequently nursery nursing and teaching. The Director expressed a preference for graduates, perhaps to improve the status of her staff, whose photographs and qualifications were on display in the hall. The in-service 2 year intensive training combined daily early morning meetings and a half day per week training session on physiology, anatomy and the principles of CE.

The majority of conductors were young females in their 20's, who showed enthusiasm for an innovative approach, compassion for disabled children, physical energy and ability to work patiently with very dependent children.

A questionnaire to the conductors (Appendix I) revealed that they arrived eager to learn and implement change but rarely stayed longer than 12 months. This caused lack of continuity and meant that at any on time there were large numbers of novices working with children. During the period of observation there was only one trained physiotherapist among the conductors. The quality of her work was noticed by parents.

There was a consultant medical advisor but he only appeared periodically and none of the other staff were specialists in orthopaedics.

> "I'm waiting for an appointment at Bobath because I'm disappointed with the CE approach. They've got a lot of sorting out to do about their staffing - I hope they do it before it's too late."
>
> (Matthew's mother)

This kind of comment echoes the disciples of the 'pure' CE model who argue that only Hungarian conductors should be involved in the work.

During observations task series were led in different styles by the conductors. The nursery nurses tended to be stricter, keeping to the routine, despite sabotage by recalcitrant children. An enthusiastic Australian teacher introduced so many changes that conductive principles became blurred. For example, it was usual for nursery children to be placed on potties at regular intervals during the day in public view - a group approach to toilet training!

> "You will each be taken to the toilet when you need to go - people don't usually go to the toilet with others watching."
>
> (Australian Conductor)

Conductors were regularly observed at work by the director and her deputy as part of the in-service training programme. Departures from the CE regime were regularly commented on by the director to the observer as they sat together behind the one-way mirror. This was part of the induction process provided to the observer about the true nature of the system, and caused unease. A regular stream of visitors was welcomed to the centre, and given guided tours and instruction. Expressions of scepticism were interpreted as lack of understanding, and were usually withheld as they might seem discourteous in the face of this generosity and openness about what was being done.

The social worker who was training as a Conductor at the time of the study received criticism for being too absorbed in the needs of individuals and too little aware of the group process.

> "Watch her playing the recorder. She's concentrating too much on her performance and not enough on the effect her playing has on the children."
>
> (Director)

The conductors had a usual range of reasons for leaving - getting married, pregnancy, moving house, but many went on to further, different training in direct work with children. For them, conductive education was a temporary and unusual episode in seeking suitable careers.

11.7 Play-times

Perhaps the most central criticism of the centre is the almost obsessive attention give to mobility and the consequent absence of opportunities for play and relaxation for the children. The nursery group was a large, bare room, with toys stacked away on shelves. At break-time a child might point to a toy and be allowed to handle it, but so much time was spent on structured instruction that play was low priority.

Child Psychologists stress the importance of play for healthy child development. Isaacs describes play as 'the child's life and the means by which he comes to understand the world he lives in'.[17] Winnicott stresses that it is 'by playing and only by playing that the individual child is able to be creative and to use the whole personality'.[18] Play also ensures fun and happiness as a rightful childhood experience.

> "I came to England so Nicholas could benefit from CE. It's been the first time in his life that he has had success...he's learning to do things independently - but I do feel they are sacrificing play and clear communication skills for motor skills. I really couldn't care less if he walks, but I do care about him being happy with a well-balanced life."
>
> (Nichola's mother)

CE does not allow for the activities usually expected in day care centres. Although the rooms were brightly painted and decorated with pictures suitable for young children, there were no videos, computers, sandpits, painting tables or water trays. In the summer, children stayed inside doing their task series with the door open. The garden which has no play equipment, contrasted sharply with the playground in the Special School of Borough A, equipped with swings and roundabouts adapted for wheelchair users.

Lots of toys and books were stacked in boxes on shelves and a child was encouraged to choose one at break times. But children with cerebral palsy usually move in an unco-ordinated way. Using anything requiring fine movements or even holding toys is often impossible. Solitary play is therefore rare. If play is not initiated by an adult, children in the nursery tended to sit doing nothing; if they are handed toys, they often drop them and need to be watched both to see if they like their choice or have been unable to hold and play with the toy. Interaction between children was also rarely observed and the strict regime did not encourage this.

> "The children are lying on the slatted beds for their rest period. I wonder why none of them sleep. Perhaps it's too uncomfortable. It's strange the

> way they just lie there. Leah begins to reach out to Sarah lying on the bed next to her. She begins to exercise Sarah's leg up and down. Is this how these children play?"
>
> (Extract from observation)

Outings were not arranged for the children because "they have so much work to do, and their parents can do this" (Director). Thus, they did not experience the excitement of travelling with peers and having fun. Again there is a sharp contrast to the children in the Borough A special school.

> "We teach them how to behave at the blue table in class and then take them to the restaurant in BHS to see if they can transfer their social skills to another setting. You will see our children in town; you will meet them in London and abroad, even up the Alps! We believe in broadening their opportunity and raising public awareness."
>
> (Teacher at special school)

There was some conflict between the expectation that parents would provide entertainment and socialising, and that they would continue CE at home to compensate for not attending a boarding school Most families found adapting their life styles to run along the lines of conductive education both disruptive and unacceptable.

> "We went to a parents' meeting at the conductive education centre last week. A parent had made a video of what they were doing for their daughter at home. It made us all feel like complete failures. It really is unnatural what goes on. They don't care about families at all."
>
> (Nichola's mother)

In the end the majority of families in this study did care about preserving their way of life. Only four children persisted with the Peto method, making regular visits to Budapest. Two of the mothers were single parents of a lone child. They were able to allow the Peto approach to become part of their lives:"it is a way of life.... you don't have to make separate time for therapy."

With these exceptions, from their child's 5th birthday, CE had been left behind as an episode in the progress of these parents and children through public and private alternatives to care, therapy and education. It had been an attractive choice, but a choice conflicting too sharply with the ideas held by UK parents of how childhood should be perceived.

11.8 Conclusion

Although initially attractive, this 'holistic' system was essentially alien to the participants in this study who required explanations, participation and for their children to mix pleasure with learning. Ultimately, with a few exceptions, the longed-for improvements took too long and those who persisted found they could not sustain the costs of private provision if the LEA withdrew funding.

The more positive participants might have been more loyal, had the system at the north London centre inspired confidence. But the constant staff changes and the uncertainties about the DES requirements for the National Curriculum at the time of the study meant that policy changed frequently and changed back again before a system had been tested adequately. This policy 'on the hoof' did little to inspire confidence that participation should be sustained in an uncertain regime.

Parents many have felt more confident in their choice of conductive education if they had been able to understand and trust the method. But they were expected to accept an under-researched and controversial approach. Chosen by parents as an alternative to conventional medical rehabilitation, conductive education is criticised by medical researchers who have expressed concerns about potential skeletal damage and, in particular, hip displacement.[19] There are also on-going debates about the characteristics of children judged suitable and unsuitable for C.E.[20] Since medical expertise casts doubts on C.E. and, in any case, motorised wheelchairs and walking frames are available in the U.K., parents felt increasingly uncertain about its validity.

This study of an unconventional approach, has discussed concerns about how children were treated. However, emphasis should be given to the genuine commitment of the Director and her staff to improving the lives of children. Indeed their faith in the system could not be tested adequately because stability could not be established. So many problems, including the requirements of the National Curriculum impinged on the organisation.

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Section V

FAMILIES AND THE PERSONAL SOCIAL SERVICES

Previous sections have identified the multiplicity of agencies and professionals involved in providing treatments, education and care for young children with cerebral palsy. This section has as its core the personal social services with local authority social services departments, voluntary and private agencies as providers and social workers as key professionals.

Underpinning this section are the two major legislative changes (the Children Act 1989 and the National Health and Community Care Act 1990) which have been designed to establish a care management system involving a purchaser-provider split and a needs-led approach 'to ensure that people are not fitted into existing systems, but that services are adapted to individual needs'.

The Children Act 1989 places the duty on local authorities to provide support services for children and families 'in need', a category which includes disabled children.[1] They should 'marshal expertise' in conducting assessments and managing packages of care, designed both as preventive measures and as 'cures for needy situations.'[2]

The definition of 'disabled children', for the purposes of the Act, is that used in the National Assistance Act 1948. A child who is 'blind, deaf or dumb or suffers from mental disorder of any kind or is substantially and permanently handicapped by illness, injury or congenital deformity or such other disability' is eligible for social services provisions. Section II of this study demonstrates how the disabling features of cerebral palsy fit these criteria.[3]

It is the overall responsibility of the social services departments to co-ordinate 'packages of support' for 'children in need' and this includes education and health, although local authority SSD's may delegate responsibility to the 'agency most relevant to the current needs of the child with a disability, and this agency may change over time.'[4]

Since this study is based on the premise that in reality parents themselves are their childrens' care managers, a study of how participants experienced 'working in partnership with' social services reaches the heart of the argument.

It is useful to begin in by exploring how social services departments as bureaucratic institutions have responded to the requirements of the Act (Chapter 12). Chapter 13 will examine the roles and tasks of social workers in relation to disabled children. In Chapter 14, the shift from statutory provision of welfare to a quasi-market with voluntary and private sector agencies as suppliers will be reviewed.

> "The community paediatrician said we would hear from the social services department. We haven't and we don't know what their role is. We don't know who to turn to for advice-you may be able to help us. We need a playgroup, respite care, a holiday and the house needs converting so we have a toilet on the ground floor."

12.1 Historical Context

The history of social services departments over the twenty- five years of their existence suggests that this may be infertile ground for sowing the seeds of the Children Acts' heady idealism. Established by the Local Authority Social Services Act 1970, following the recommendations of the Seebohm Report 1968[5], the new departments 'gathered together under one roof most of the personal social services previously carried out in children's departments, health and welfare departments.'[6] The new organisational structure covered some two hundred thousand staff in nearly two hundred local authorities. Apart from the problems of staffing and training anticipated in the Seebohm Report Chp XV111, the very size of the enterprise proved to be its Achilles heel.[7]

As early as 1973 the Social Science Research Unit of Brunel University examined the complexities of these bureaucracies adopting a systemic approach. The project funded by the DHSS concluded that there was need for continued exploration of 'the whole network of procedures and systems by which the department decides what needs it has to meet, how they are to be met, and reviews after the event how well they have been met both in individual cases and in its total operation.[8]

The weakness most relevant to this study was the inability of departments to establish a stable system for service delivery. Constant reorganisation to improve performance and to reduce spiralling costs effectively made departments inaccessible to those in need of their services. Instead of providing Seebohm's 'services, universal in scope ....readily accessible and available to all families', informal waiting lists and rationing became the norm.[9]

Those potential clients not inhibited by the Poor Law legacy were angered by this inaccessibility. Threats of violence from dissatisfied clients contributed to the development of a fortress mentality in some social services departments unable to confront unmet need. A social work tutor attempting to visit a student on placement in a social services department in the 1980s failed to gain admission alongside a dissatisfied client who threatened to drive his car through the office windows if he was not allowed in to see his social worker!

Initially work was divided between intake and long-term teams staffed by generic social workers, although few of them were qualified and the system was managed by social workers trained in their professional services to clients but not in management. As early as 1978 Stevenson and Parsloe were concerned about the loss of specialist knowledge and skills in the wake of genericism.[10] The Barclay report demonstrated the concerns at government levels about the roles and tasks of field social workers in local authority social services departments.[11] The failure to reach agreement in this report indicated problems both in the organisational structures of local authorities and in the profession employed to provide the services.

Short flirtations took place with neighbourhood teams, 'patch working' and 'going local', Hackney and Islington for example.[12] By the late 1980s, however, many local authorities had reverted to a limited generic service combined with some specialism in fostering and learning disabilities for example. On the eve of the Children Act the trend was for services to be provided on a pre-Seebohm model of specialising by client group. Services for children with disabilities might be located in learning difficulties, disability services (primarily for adults) under the Chronically Sick and Disabled Persons' Act 1970, hospital paediatric departments, but rarely within children and families divisions.

Throughout the late 1970s and 1980s social services departments experienced public spending cuts, strikes by social workers, accusations of espousing 'loony left' causes and losing direction by providing platforms for anti-racist and anti-discriminatory causes. Dissatisfaction was expressed by the media, politicians, academics and by clients themselves.[13]

The most destructive events in this already tarnished history were the child murders, child abuse scandals and the concentration on child sexual abuse. The conclusion of the Blom Cooper Inquiry[14] into the death of Jasmine Beckford in 1984 that this was 'a predictable and preventable homicide' marked the beginning of a crisis period for social services departments and their social workers as 'with almost sickening regularity the newspapers reported the deaths of children at the hands of their parents.'[15] Social workers and their employers could not get the balance right between failing to protect children by leaving them with their abusing parents and taking them into public care too soon and too frequently on inadequate evidence of risk.[16]

In this context, the Children Act might be seen as a damage- limitation exercise intended to clarify the roles, tasks and responsibilities of local authorities and their social work staff. As will become apparent later, the attitudes of parent/users involved in the present study were such as to suggest that this social services history provides an unpromising location for achieving 'tangible gains from the implementation of the Children Act' demonstrating that the Act contains more than 'empty rhetoric.'[17] In the words of one parent: “social workers are obnoxious and one of the worst aspects of arranging for my child's care is dealing with social services”, quite an indictment on designated implementers of community care legislation in the 90s!

12.2 Relevant Sections of the Children Act

Guidance Volume 6, Children with Disabilities covers children from ages 0 to 18 both at home and in residential care.[18] Relevant to this discussion are the sections on organisation and management of services; the register for children with disabilities; the recommended services for children in need and their families; and the complaints procedures.

The implementation of the Children Act is being monitored annually by the Department of Health. The first report of the Social Services Inspectorate on services to disabled children and their families 1994 in four contrasting local authorities, based their findings on twelve standards for evaluation derived from the Children Act. They consulted with a project group including parent representatives from voluntary organisations, an SSD and the SSI. The inspection took place at about the same time as the fieldwork for this study (1992/3) which involved studying as examples the responses of three local authorities in the North London area and interviews with parents living in seventeen different boroughs.

In the following discussion of fieldwork findings relevant to local authority provision, it will be interesting to compare results with those of the SSI, which reported that no authority had met any of the standards set, concluding that 'lack of progress was significant since the needs of, and services for, disabled children had historically had a general low profile.'[19]

12.3 Organisation and Management of Services

At the time of the introduction of the Children Act in 1991, most local authorities had reverted to some form of specialist service delivery defined by client group. Local authorities were expected to adopt the principles of the new legislation, but were allowed to devise their own organisational systems to achieve these ends. This heralded another round of reorganisation characteristic of the history of social services. The Children Act principles needed accommodation alongside the major operational changes initiated by the NHS and Community Care Act.

The personal social services during the 90s have witnessed what the Department of Health has called a 'cascade of change', the most important characteristics being the shift from a welfare economy to a business culture with devolved budgets, with the associated aim of enhancing user participation and generating services in the voluntary and private sectors.[20] The perpetual requirement for curbs in public spending has also restricted any changes required by the new legislation.

12.4 Borough A

This Outer London Tory authority had recently implemented a new management structure in response to severe spending cuts. The upheaval had included removing a tier of management at the civic centre; redundancies and redeployment of senior staff; and the resignation of the social services director in protest about the dilution of provision. Services were managed by two divisions: children and families concentrating on child protection, and an adult division covering the elderly, disabled and mental health.

Services for children with disabilities were located in both divisions and no single sector of either division appeared to be taking overall responsibility for co-ordinating the various facilities. Finding out about existing services and locating them presented a challenge to the researcher and inevitably for potential service users.

Parents of children born with cerebral palsy at the local hospital might be referred to the part-time hospital-based social worker managed by the children and families division. She saw herself as able to provide advice, information and 'crisis intervention' at critical stages, for example immediately after diagnosis, at age two for education statementing, and when there were problems with treatments and equipment.

> "Recently a mother asked me to intervene to speed up the delivery of a standing frame. It had been in the store for 6 months while social services and health argued about whether it was an aid to daily living or a medical prescription and who should pay for it. If supply was delayed much longer her child would need a larger size."
>
> (Paediatric social worker)

Unless there were concerns about child protection, parents of children with cerebral palsy would usually be referred to the adult division of social services in the community for assessment by the disabled living adviser (DLA) for aids and equipment under the Chronically Sick and Disabled Person's Act 1970. If the child was considered to have learning difficulties, a referral might be made to the social work team for people with learning difficulties. This was unlikely for children with cerebral palsy because of the early uncertainty of the extent of brain damage as discussed in Chapter 2, and because of the distress experienced by parents in acknowledging cognitive damage.

Priority for places in the 2 local authority day nurseries and the 2 opportunity playgroups and inclusion in the family link scheme for respite care was confined to those families "known to us for some reason other than that of disability - there must be concerns about child neglect or child protection." (Paediatric social worker)

The Children Act did not require management changes but expected clarification of local authorities' lead responsibility, emphasising also the rights of parents to be informed and to participate. In Borough A, traditionally slow to change and only recently reorganised, a dispute described by a social worker as a 'war' broke out between the children and families teams who believed that they should have main responsibility for children with disabilities. According to the Act they should be seen as 'children first,'and therefore met the criteria for services from the children and families teams. The social work teams for people with learning difficulties (including children) on the other hand argued to retain services for children with learning difficulties, providing "a seamless service for people with learning difficulties from birth to death." Social worker, learning disabilities team.

Their services should be extended to include children with physical disabilities by improving facilities. For example, the respite care residential provision might be altered by providing a lift and widening doors for wheel-chair access. The facility was restricted to able-bodied young people.

The 'war' ended when the new director decided, largely for economic reasons, to maintain the status quo, but to review existing services to ensure that they complied with the Act. It was decided not to include responsibility for children with disabilities in the children and families division because "the pressures of child protection would mean that their needs would be low priority, and the existing staff lack expertise in disability." (Manager, disability services). Admittedly children with disabilities "tended to get lost in the disabilities division concentrating on the elderly, but assessment and care management is required and it would be a tremendous advantage for children with disabilities to be a assessed under the borough's care management system."

Therefore in Borough A "the location of service would depend on how the parents perceived their child's disability; physical disabilities being the responsibility of adult services and those with recognised intellectual impairments to learning difficulties." Organisational change was minimal being confined to altering categories of children given priority for day nursery places to conform with the requirements of Part III. The respite care link families scheme was expanded by appointing a full-time co-ordinator who aimed to double the number of families available by advertisement and recruitment.

12.5 Borough B

Like neighbouring Borough A, this borough was experiencing public spending cuts and on-going reorganisation in 1991. Service delivery was by client specialism without a clearly identified team for children with disabilities apart from the learning disabilities service. Interviews with staff suggested that the borough was in a state of continuous upheaval and uncertainty, but that there was a positive attitude to improvements in response to the legislative requirements.

There were two hospital paediatric departments within the borough. Social workers from the community-based team regularly attended ward rounds in one hospital so that early referrals might be made for social care if a diagnosis of cerebral palsy had been reached soon after birth. There was no social work service to the other hospital, which straddled boroughs A and B. Referrals for community services from this hospital depended on the part-time social worker from Borough A. This meant that communication with medical personnel was minimal and referrals unlikely. There were no plans to provide a social work service to this hospital even though at interview concern was expressed about the quality of obstetric care provided. The social worker interviewed seemed to believe they should "keep away from a hospital where doctors were known to damage so many babies at birth in favour of positive teamwork with the other hospital."

Constant change and restructuring seemed to be the flavour of this borough's approach. In contrast to the minimalist approach of Borough A, Borough B set about dividing all services into Assessment and Provisions Teams, moving staff and offices and generally creating an ethos of active improvement in response to community care requirements. Clients were addressed as customers, and privatisation was being promoted vigorously by a Tory Council with a slender majority. Budgets were being devolved to divisions of social services which were designated business units.

In response to the Children Act, the children's section of the team for people with learning difficulties was detached and relocated under the management of children and families. This team differed from the other social work teams in the children and families division, which concentrated on child protection and were divided into under 8's and over 8's.

This new children with disabilities section provided services for children with wide ranging disabilities from birth to age 18 and divided its work into assessment and provision teams. Originally it was intended to introduce performance related pay as incentives to speed up the number of assessments completed and ensure that plans were implemented by providers. This seemed a highly inappropriate system for ensuring the suitable provision of welfare since assessment of need is a complex process. For social workers to receive payment according to the quantity rather than quality of their assessments, there must inevitably be some conflict between motives of welfare and of profit. The scheme was found to be impractical.

Although the location of service provision was clearer for potential customers than in Borough A, and publicity material in several languages was distributed widely expressing the borough's commitment to what it called 'Total Quality', the new team was almost immediately forced to concentrate on reducing the number of children in care (mainly black and considered to have challenging behaviour and/or autism) placed out of borough, both to reduce costs amounting to between £700-900 per week, and to comply with the Children Act principles antipathetic to residential care. Active development of fostering schemes for black children in care were to take priority over new referrals of children with disabilities living at home.

It proved impossible to find in- borough placements for the children with autism and challenging behaviour placed at considerable distances out of borough so that staff time continued to be used on regular review visits at great expense. These are a requirement of the Act and consequently limited resources available for children in the care of their parents.

Within two years of this reorganisation further spending cuts necessitated reductions in service: the amalgamation of assessment and provision teams, fewer staff; redundancies of family aids and word-processing clerks. What had been experienced as a co-operative team reacted to uncertainty by staff conflict.

Borough policy was to adopt privatisation policies with enthusiasm. At the time of writing the borough was negotiating the sale of the authority day nurseries to a private consortium in the north of England to avoid closing them on grounds of cost. The likelihood of places being available for children with cerebral palsy seemed to be receding as budgetary constraints took priority over duties to children in need.

12.6 Borough C

In 1991 Borough C was providing a generic social service with additional specialisms including services for people with learning difficulties. More cautious than Borough B but more adventurous than Borough A, a Children Act Implementation Officer was appointed for a year to research and make recommendations about responses to the legislative changes. There was recognition that hitherto children with disabilities were "picked up by social work teams depending on how their disability was presented; there were many duplications and many who missed out on rights altogether." (Children Act Implementation Officer)

There was a strong team of paediatric social workers in the local hospital responsible for directing referrals to various sections of social services depending on the identified need. As in Borough A, relevant provisions needed detective work although the multi-disciplinary team of the child development clinic liaised well with social services. Parent participants from this borough spoke most positively about access to services achieved through the toy library at the clinic.

> "At first I wasn't really 'with it'. The physiotherapist and deaf teacher kept coming to the house and I used to get fed up with having to spend hour after hour with professionals who didn't help me. Going to the toy library was brilliant because at last I could find out information and could talk it over with other parents. We were all at the same stage of shock and ignorance of where to go or what to do."
>
> (Emily's mother)

In response to the Children Act, it was decided to create a separate team for children with disabilities detaching it from the existing team for people with learning difficulties to give a higher profile to the needs of children. Unlike Borough B, the management would remain within special services, primarily responsible for community care. Except where child protection issues were prioritised, children with disabilities and their families would be the responsibility of specialist services.

An imaginative scheme for co-operation and collaboration with health, education and voluntary organisations was floated by making an audit of the existing groups involved with providing services for children with disabilities in the borough; abolishing those groups which duplicated each others functions and establishing procedures for collaboration for those remaining under the lead of social services. The audit revealed that there were 47 different working groups and committees with interests in children with disabilities in the borough, many duplicating each other and being largely ineffective in achieving change. Unfortunately achievements were limited by the redundancy of the development officer as spending cuts began to bite into social services funding.

Borough C, therefore, provided community care assessments and provisions from an identified social work team managed separately from children and families but liaising where child protection issues had been identified. The working rule was to decide whether child protection or the existence of the disability was the primary focus of need. If the former, children and families held the case and if the latter, the team for children with disabilities provided key workers. Since this distinction was not always clear cut and both teams were under-resourced there was potential for conflict and delayed social service involvement.

12.7 Register of Disabled Children

The requirement on local authorities to keep a register of children with disabilities in their areas is designed to facilitate planning and monitoring of need.[21] The process is intended to be achieved through liaison with health and education and through partnership with parents 'from whom professionals may have much to learn.'[22] As with other parts of the Act, this duty seems eminently reasonable. It may seem rather surprising therefore that the SSI found in 1994 a 'lack of effective registers in any of the Authorities.....so that no reliable information was available in those communities. Services were being provided on an historical basis rather than using current information. '[23]

Concern that parents might confuse this register of disabled children with the child protection register, and about confidential material, influenced the decision that the registration process should be voluntary and that service provision should not be dependent on it.[24] This development effectively deprived the process of any teeth it might have had. Parents may have been expected (in the somewhat righteous terms of the Act) to be partners in a process of meeting their needs. In practice,(judging from the participants in this study) few held sufficiently positive views of social services, health or education for an atmosphere of trust to have been established. Nor had inter-agency collaborative processes reached the stage in many areas to make joint registers possible.

The other factor delaying the implementation of this duty seemed to be that various listings of children existed already in social services departments. The learning disabilities teams kept lists of clients as did paediatric social workers. Any family receiving aids and adaptations under the Chronically Sick and Disabled Person's Act 1970, had to be registered. It is also worth querying the value of keeping a general register of disability when disability is so hard to define and covers an enormous continuum of need.[25] Sensitivity to parents' wishes not to have their children registered under certain categories is understandable, but undermines the value of a registration process.

Given these limitations of registration it is of interest to discover that Boroughs A, B and C in this study had made progress in implementing registration systems as required by the Department of Health. The complexities of achieving an effective register were discussed in an interview with the responsible manager in Borough A. A register already existed under the Chronically Sick and Disabled Persons' Act; the Learning Disabilities Team held a planning register; Education had their own system of recording statemented children; voluntary agencies had their own lists of users. At the time of the interview discussions were in progress with Education and Health; consultations were planned with consumer groups. Some agreement had been reached about what constituted 'disability' and it had been decided that the new register should be held by social services at the civic centre on computer with a computer link to Education. "Health is keen for us to hold it because they are preoccupied with developing trust status." Children below the age of 5 should not be registered unless by specific request, or the child has a very definite learning difficulty and parents are in agreement. The list should be reviewed on an annual basis, and any party may 'trigger' the registration process.

> "To get agreement between Social services, Education and Health is an enormous hurdle to overcome, for example we've tried to use the community care format for the questions. These emphasise the functional disability rather than using a medical model. Health would prefer it to be clinically based . If you did this you would have to have a doctor making the decisions. Sometimes confirmations are necessary from medics. We've also tried to cut out children with a minimal level of disability, for example children in mainstream schools who only need aids...in theory only children likely to need services should be registered."
>
> (Manager Disability Services)

The same issues were being faced by Boroughs B and C. Borough C admitted to only having a card index at the time of the interview, being of the opinion that there were more urgent matters to deal with. Borough B appointed a Registration Officer to take responsibility for both the Children Act and the Chronically Sick and Disabled Persons' Register which were kept separately. At the point of a new referral, social workers were expected to complete two forms as a matter of routine.

Among participants involved in this study, higher than expected numbers said they were registered (nearly half, 48% of respondents), while almost a quarter (24%) said they were not registered; 15% did not know and the remainder 'thought they might be'. On reflection, these results probably meant that registration was under the Chronically Sick and Disabled Persons' Act since only two respondents said they were not receiving equipment and aids from Social Services and two others were waiting for their order to be supplied. It is characteristic of young children with cerebral palsy that considerable equipment is needed in the early years supplied by the Social Services DRO.

The complexities of this registration process cause one to reflect on the resource implications of this DH requirement. It seems characteristic of the Children Act Guidance that there seems to be 'preoccupied with form rather than function; the Secretary of State for Health is cast in the role of nationwide Director of Social services, laying down how things should be done and by whom. It is about process and hardly at all about substantive duties directly benefitting families.'[26]

12.8 Services for Children in Need

Permeating the Children Act Guidance Volume 6, is the mission to buttress the family weakened by the stresses of caring for a child with disabilities. 'Adversarial debates and conflicts should be avoided'; 'brothers and sisters should not be overlooked' and it is acknowledged that 'some families caring for children with complex and multiple disabilities may have neither the time or energy to contribute to assessment and planning unless they are given personal counselling, support and representation.' [27]

To counter these problems the Aide Memoir lists 20 services which may be provided by social services departments.[28] Since parents are to be encouraged to feel 'in authority and control' of any choices made from this list and from the facilities offered by Education, Health, voluntary and private sectors (38 more are listed), the task of bringing up a child with disabilities within their families appears very daunting. There is undoubtably a contradiction here. Stress inevitably increases if, over and above day to day caring, parents have to organise their care plans, taking decisions about so many differing options on the basis that this gives them control over their own lives.

In practice, however, the range of options available in different localities is constrained by funding, and although the Children Act advocates advertising services, finding out about existing facilities and entitlements emerged as a theme of complaint in the interviews.

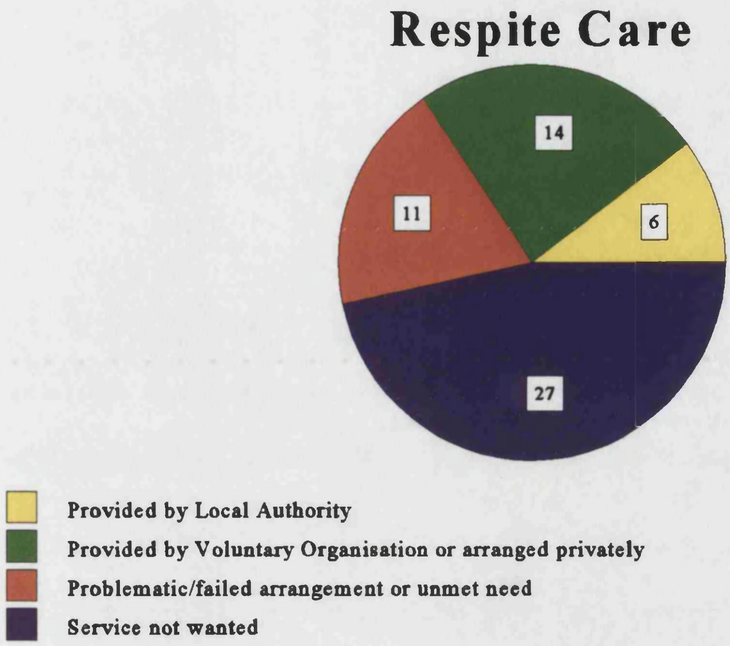
> "As soon as the disability is diagnosed, someone should come along from the borough to give us advice. I could do this for other parents now. I'm not trained in the area and I don't have a great IQ but I've written to all carers' associations in Britain using the Directory for Disabled People. I ask other parents and tell them things, then I put up a fight to get what I want... I've just won a 2 year battle for a disabled parking bay outside the house."
>
> (Jo's father)

Although numerous services are listed in the Guidance, 'packages of family support' should, according to the Department of Health, prioritise respite care, family centres, day care, and home care.[29] In practice, however, the level of use made of these categories by the families involved in this study makes for sober reading.

12.9 Respite Care

Respite care or 'short breaks' is a provision designed to reduce pressure on families by short- term fostering with 'link' families for younger children and residential accommodation for older children. Only 6 families said they were using local authority respite facilities and 1 other replied that the facility 'did not work.' However, a larger number (14) used voluntary or private agencies (see figure 35).

FIGURE 35



This poor response has a number of explanations. The intensity of guilt, responsibility and concern for the quality of care for children with cerebral palsy discussed in Chapter 3 often results in an unwillingness to trust others with their child's care especially overnight, although ambivalence may be detected.

> "My husband's dead against it, but I sometimes wish we could have a break at the week-end. If I had no support from my husband I'd have to take it. When he comes in he gives Emily her tea, takes her out and gives her cuddles. It gives me time with the baby and time to catch up with the housework- you can't live in filth!"
>
> (Emily's mother)

Residential care for children under 5 is unlikely to meet their needs for individual care. Recruitment of suitable foster families is expensive. Training in specialist care is essential. A survey by the Norah Fry research centre reported no growth in the number of family-based respite care services since the implementation of the Children Act in

1991 and a growth in the number of children using the services.[30] Macadam questions whether the Act is hindering the growth of the service it apparently seeks to promote by regulations for foster-care assessments, health and police checks, reviews and registration procedures[31]. She concludes that` the requirements of the Children Act appears to be taking their toll on the amount and quality of service the co-ordinators can provide' and advocates 'adapting the regulations in a way which allow existing good services to flourish while ensuring the child's welfare is safeguarded'.

Despite faith in the value of respite care held by the DH and the Respite Care Association, concerns about the quality and experience of care for the children themselves is evident both in the interviews for this study and in research conducted by Oswin for the King Edward's Hospital fund. 'Short-term care can be a helpful form of support for families but they have numerous dislikes about it; they are not always happy about the way in which their children are looked after and they feel upset about being separated from them.'[32] She concludes that parents continue to use services about which they are not completely happy, and are 'likely to get carried along on a wave of impotence...eventually finding themselves defending a poor service and even recommending it to others'.

Parents in the study seemed to be resistant to residential provision which might be interpreted as failure to cope, tending to request domiciliary help and daycare as acceptable alternatives.

> "Holy Dinah! I only want a break or information about a play-scheme but all the social worker says is 'if you feel you need someone to talk to, make an appointment to see me.'"
>
> (Nichola's mother)

It is probably accurate to conclude that the complex daily living needs of children with cerebral palsy described in Chapter 3, plus the special requirements of each child, the high levels of dependency and the amount of equipment that would have to be transported discourages most families from exploring this facility. Reluctance to be separated from a child possibly harmed by others to be cared for by others is perhaps the unique factor explaining the under use of respite care by parents of children with cerebral palsy. In any event, most parents do not give up the care of their own young, dependent children to others.

12.10 Day Care

Day care may be provided in many forms: minders, au pairs, nannies, nurseries, nursery schools, playgroups and treatment centres. Children Act Guidance encourages purchasing facilities from the voluntary and private sectors. Inclusion in mainstream facilities is advocated and Guidance provides regulations to regulate standards, quality and safety.[33]

Direct provision by social services to participants in this study might potentially be in day nurseries, with individual support workers where necessary and with minders, after special training. Yet, only 7 children had local authority day nursery places, ranging from 4 hours per day to 1 day per week and none had registered minders. This reflects the national shortage of nursery places but also suggests that despite being designated as being 'in need' children with cerebral palsy do not usually obtain day nursery places. As with field social work services (see Chapter 13), priority is given to children at risk of significant harm.

The debate about inclusion of children with disabilities in mainstream facilities (Chapters 9 and 10) is relevant here to consider the effects on day nurseries of restricting places to those meeting the 'in need' criteria. There must be problems in offering shared facilities to the unlikely combination of children who have experienced sexual and/or physical abuse and children with various impairments. Although a nursery matron claimed during an interview that the arrangement was "brilliant, allowing children with mobility problems to use able children as role models and giving the able children experience of handicap" this seemed rather like a rationalisation for an imposed system. A local authority social worker expressed concerns about the behaviour problems of abused children, and the vulnerability of those placed because of their disabilities. This might be an area for future research although local authorities are being encouraged to privatise freeing up allocation criteria, which may rest more on ability to pay.

12.11 Family Centres

As with day nurseries, families in this study were not users of centres, which social services are required to provide as a community resource. The idealism of the Children Act Guidance that centres should work with whole families providing 'friendship support and access to services' has no reality for parents in this study.[34] This is partly the result of poor local resources, and because existing centres specialise in prevention of child abuse and child protection monitoring. Cannan questioned the value of centres with conflicting aims: monitoring of child protection versus training parenting skills.[35] Existing centres would need to rethink their aims and methods before being able to accommodate children with disabilities. Attention would also be necessary to the issue of access to buildings: Borough A had a well functioning family centre but without ramps, lifts, hand-rails or adequate toilet facilities for children with physical disabilities. It seems that a worthy idea flounders by superficial consideration and limited resources. Although no families attended local authority family centres in this study, voluntary agencies, (for example Norwood Childcare for Jewish families), toy libraries at NHS child development centres and self-help groups (like Palace in Islington) met the needs of families to share experiences and information.

12.12 Domiciliary Help

Local authority home care services are expected to be sensitive to the needs of families including a child with disabilities. Domestic help, shopping, and ironing are examples of services to ease the burdens of daily living. In this study a third reported employing private help as would be expected in middle class households, and 4 families employed au pairs financed by interim payments from successful medical negligence claims. Local authority provisions were reported to be minimal. The issue of division of responsibility between social services and health is illustrated by Andrew's mother who felt let down by the local home care services.

> "Welcome to the slum! We all had flu last week and were unable to get out of bed. Eventually they sent a district nurse because Andrew is totally dependent on others for daily living."
>
> (Andrews mother)

Domiciliary services are most necessary for socially isolated families lacking support of relatives, friends or neighbours to provide community care. This study highlights the relative isolation of middle class families in north London and therefore the unreality of a community care policy in areas where caring communities cannot be relied upon. Only about half of the participants reported receiving help from extended family members. The problem for children with cerebral palsy is exacerbated by the medical aspects of the condition.

> "Sara needs 24 hour care: she needs feeding by a gastro-nasal drip. I know if I get it wrong she may die. She sleeps intermittently because of her spasms. I asked for help from social services but they told me they could only help 'at risk' families'. I even took her photograph with me, but all the social worker said was, 'What's the father doing?'"
>
> (Sarah's mother)

The disadvantages of home care provision may be felt keenly by those in small houses and flats. Apart from so many domiciliary visits from peripatetic professionals (health visitors, physios, OTs, speech therapists), the home lacks privacy where regular ancillary help is required.

> "The solicitor attempting to settle the negligence claim does not seem to understand that I need a larger house with an extra room for the au pair: I have to have a room that is mine alone."
>
> (Single parent)

Some of the households in the study felt precarious; so much depended on the health, energy, skills and good will of too few people.

> "My husband says ,it's all very well this community care but what would happen if I fell down the stairs. John would have to stay in hospital then."
>
> (John's mother)

12.13 Complaints Procedures

A characteristic of customer-led services is the right to complain. John Major's Citizens' Charter, the Patients' Charter and the Children Act/ Community Care Complaints Procedures symbolise the shift from welfare to consumer principles, moving the balance of power to consumers: users and carers. Citizens may complain to public bodies in the same ways as they do to British Rail or London Underground. Ultimately it is consistent with Tory principles that public services may be privatised. As has been seen, Borough B in this study had made the most rapid progress towards that goal.

The Department of Health Practice Guidance on Complaints Procedures in Social Services Departments pays meticulous attention to detail, including a complex system of stages for dealing with complaints.[36] If resolution of problems is not possible by discussion with those involved, complaints may be registered formally with the borough's complaints' officer. An independent person should be appointed to investigate and report on the complaint. If the customer is still dissatisfied a review body should be constituted, which should include another independent person.

To ensure the implementation of this organisational structure, Virginia Bottomley promised in the Forward to the Guidance that the "SSI will be monitoring the development of complaints procedures and will continue to disseminate ideas and examples of good practice."[37] This promise has been fulfilled. The results of a questionnaire to all local authorities issued by the SSI were published in 1993. A report of a detailed inspection of four local authorities was published in the same year.

Both these reports contain positive information on the progress of local authorities in establishing a system 'completely new to SSD's'. They convey concern with establishing an organisational system, consistent in style throughout the country, accessible to potential complainants, advertised and set up in consultation with local community groups, able to process complaints efficiently and effectively within twenty-eight days.

The requirements for the establishment of a system appears to have been met by most local authorities by June 1992, but an 'effective complaints procedure inevitably takes time to establish'[38]. These reports concentrate on implementation problems including the appointment of independent persons, the establishment of review panels, consultation and publicity processes.

Although users and carers (customers) are regularly mentioned, the focus is on creating a system and examining its workings. Questions about who complains, why, whether there are clusters of complaints, outcomes of complaints in terms of customer satisfaction, considerations of unmet needs are unattended. There may be plans to undertake this research at a later stage. It is curious that reference to these intentions, if they exist, are omitted from the texts of the monitoring and inspection reports. Consistent with the national picture, Boroughs A, B, and C were setting up complaints procedures at the time of this study. Boroughs A and C decided to appoint a team of independent persons jointly, committing themselves to appointing a group of professionals (retired social workers, free-lance lawyers and university lecturers) capable of independent investigation. Training was provided and attempts were made to recruit representatives from ethnic minority and disabled groups. Borough B established and promoted a system which, in the words of one social worker, "keeps us on the hop, there's always someone complaining about our work and we notice that the same clients keep coming back into the system: they take up a lot of our time."

Although there has been no published national research on this system from a user perspective, it appears from Boroughs A, B and C that there have been fewer formal complaints than might have been anticipated by social services departments used to operating under siege conditions. This may be because potential complaints are dealt with before they are registered formally. It is certainly in the borough's interests to achieve this since appointing an independent person and convening a review board is inevitably costly.

Another significant factor may be the complexity of the system. Despite the distribution of leaflets, in many languages, assuring the public of the user-friendly nature of the system, few people familiar with the workings of local government would believe it. Confidence, time, energy and ability to express and sustain an argument are requirements for setting any complaints system into motion.

It seems clear from the present study that parents of children with cerebral palsy have many causes for complaint, particularly about the limited services available to meet the needs of their families as designated by the Children Act. However, social services comprise only one aspect of a gamut of grievances being pursued in the early years of their child's life. Betrayal by the medical profession is compounded by inadequate rehabilitative treatments, uncertainties about the effectiveness of private provision, encounters with discriminatory attitudes towards disability amongst family, friends and in the wider community.

Essentially there are too many battles to be fought at any one time.

> "You have to accept that you win some battles and loose others. I gave up arguing with social services about the provision of a dressing bench

> which would have meant Paula's dignity could have been respected: she could have been dressed in a sitting up position as children of her age are, instead of having to lie down. Social services said they'd run out of money for this financial year. I'm too occupied with the negligence claim and attempting to take the local education department to judicial review on their unsatisfactory statement to pursue a complaint through social services."
>
> (Paula's mother)

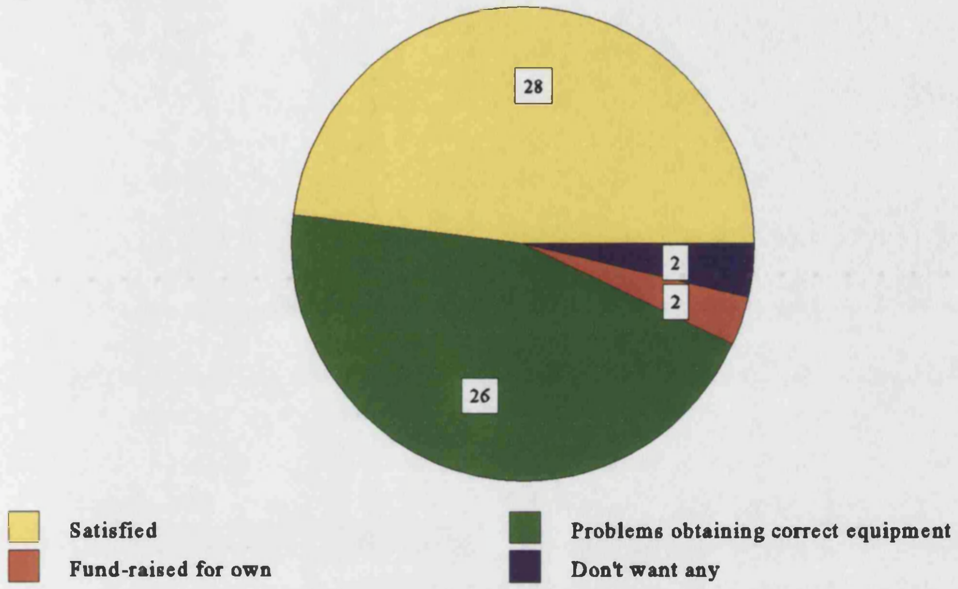
Nevertheless impressions from the interviews suggested that many families experience unmet need and potentially might make considerable demands on the dwindling provisions of local authorities. While feeling frustrated by many of the complaints, especially because investigation takes resources, a social worker in Borough B admitted to encouraging his own clients to complain if he felt their claim was justified: "I tell them about the system and help them fill in the form if they have literacy problems. It's odd that there used to be a section on the community care assessment form for specification of unmet need. It's been taken off on the advice of the DH so the borough may be protected if resources are inadequate".

12.14 Equipment

The evidence so far demonstrates clearly that these parents of young children with cerebral palsy are provided with minimal services by local authorities despite fitting the Children Act category of being 'in need'. Nevertheless they are active customers of aids and adaptations supplied and funded under the Chronically Sick and Disabled Persons' Act, 1970. Only two families said they did not have social services' equipment. This was probably because their disabilities were so mild that equipment was unnecessary (figure 36).

FIGURE 36

Equipment



Suitable equipment may be prescribed as integral to rehabilitative treatment by physiotherapists and O.T.'s, or may be recommended as aids to daily living by either medical staff or the disabled living advisor. In either case, social services order and supply the recommended items. Problems arise when agreement cannot be reached about identification as a medical or a daily living category, important for the allocation of payment.

Standing frames are a good example. Medical opinion may advise the use of a standing frame to strengthen hips and legs; the DRO might value the frame as providing the experience of standing usual for a child above the age of 15 months.

> "You have to laugh. There's no liaison between physiotherapy and education to decide what equipment is needed at home and what is necessary for school use. You can't keep taking frames and chairs backwards and forwards."
>
> (Jo's mother)

Children grow out of equipment quickly and need frequent changes in response to their changing development. Equipment tends to be expensive and there is no guarantee that out-grown pieces may be suitable for other children in the borough. Parents frequently encounter delays in supply because the budget for the financial year had been spent, or because despite medical recommendation, the local authority remained unconvinced that the order was necessary. How claims were prioritised was usually unspecified.

> "You get the feeling when you phone the DLA to argue the case that she thinks you are being greedy. This was a particular problem for us when we were trying to negotiate suitable seating. We needed seats for the bath, for feeding, for relaxing, for the car, and for the playgroup: if Helen's life is to be as normal as possible she needs a range of seating for different situations. We also need a buggy, arm and leg splints, neck supports, feeding, toiletting and bathing equipment. The final straw was when Bobath recommended a prone board. The local authority said we'd had more than any other family."
>
> (Helen's mother)

Many participants complained about delays, unsuitable, ugly equipment, mistakes in ordering and the constant battle to get them to pay for anything.

> "The wheelchair was too small by the time it came. I don't know how they can make such mistakes and the DLA seemed to think she was doing us such a big favour by delivering it."
>
> (Andrew's mother)

> "The DLA changed. We used to have a brilliant one. The new one left an unsuitable bath aid. I told her it was no good but she left it anyway so she could put it in her book and say she had done it!"
>
> (Stacey's mother)

In contrast to these serious complaints, worthy of mobilising the new complaints procedures, 15 participants reported satisfaction. There seems to be little consistency in how local authorities respond to parental requests for help. While a mother in one borough complained about a wheelchair which "was like a big wooden box on a big steel frame, too heavy to push up the hill and too big to put in the car," another reported "we've had all sorts of things, standers, ladderbacks, non-slip mats, stools, bikes, a plinth, all brand new. I've never lacked anything. There's been no hassle. It's been superb."

Supplies from social services are usually supplemented from a variety of sources; toy libraries, loans from other parents, fund- raising,(if you don't mind having your child photographed) charities (Rowntree supplied washing machines), the Social Fund, and interim payments from medical negligence claims.

Initially social services and health are the main providers but toys and educational equipment including computers and communication aids involve collaboration with education and specialist suppliers. Obtaining equipment is only the first step. Establishing suitability, adapting models to individual and developmental needs and finally teaching their child how to use it and to manage frustration are characteristics of caring for the most severely impaired children.

12.15 Conclusion

Taking the different perspectives of social services as providers and parents as recipients, this chapter has catalogued a weary tale of inadequacy and financial stringency proving beyond reasonable doubt that the gap between Children Act expectations in Guidance and the reality for parents of children with cerebral palsy is large. The next chapter concentrates on social workers as professional assessors and providers of personal social services.

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Chapter 13 Families and Local Authority Social Workers

> "I thought we should have a social worker automatically. I did try to make contact at the beginning but she rang at the wrong times and we weren't on the same wave-length. How is it that it took her 14 months to come and then do an assessment in 20 minutes?"
>
> (Ben's mother)

The previous chapter examined social services departments as bureaucracies and providers of personal welfare services. This chapter concentrates on social workers employed as professionals by local authorities and directly involved in implementing both the Children Act and the National Health and Community Care Act, through their practice. The intention is to explore whether social work as a professional service may be useful to families of children with cerebral palsy, known to 'have difficulty in making plans for their lives under the stress of unrelieved emotions' provoked by their child's impairments.[1]

There are, therefore, two dimensions to the discussions. On the one hand, there is the nature of social work from the perspectives of history, literature, research and the statutory and organisational contexts in which the profession operates. On the other, there is the client perspective. The findings from this study are used to assess how parents experience the service and their expectations from it. This approach 'may be threatening to the professional to the extent that it is construed as a challenge to his competence' and may provoke alarm in under-resources local authority departments.[2] It is however, consistent with the principles of care management that it is 'best to involve consumers, parents and children... to ensure that they have ownership of outcomes.[3]

The Nature of Social Work

There is an abundance of literature on social work and no absence of definitions. Some consensus seems to exist that 'social work may be defined ...as a process of helping people to cope better with problem situations' and that 'the purpose of social work is to enable children, adults, families, groups and communities to function, participate and develop in society...employed by a range of statutory, voluntary and private organisations.... as part of a network of welfare, health, housing, education and criminal justice provision.'[4],[5]

The root of the problem of defining social work may be located in the profession's history. The concerns of The Charity Organisation Society were to assist 'those on the verge of destitution....to prevent them becoming a public charge', both by giving financial help and 'by changing habits and attitudes towards work.'[6] Finding a balance between distributing charity and helping people by using interpersonal skills remains an issue for current social workers and for those who employ them.

The history of social work is well documented by Jordan whose Invitation to Social Work guides the reader through a range of roles adopted by social workers beginning with the Charity Organisation Society , which sought under the direction of Octavia Hill to 'introduce scientific principles of almsgiving based on thorough investigation on the habits and modes of life of applicants.'[7] He examines social work under the headings of 'the perfect friend, the social servant and the political animal', and concludes that 'the moral, social and political dilemmas of social work are either somehow resolved, or else fudged, evaded or suppressed.' Rather than 'fudging' issues, some writers have highlighted the conflict in social work between welfare provision and therapeutic help.

Oliver, for example, is highly critical of social workers' appreciation of the impact of disability, urging social workers to move from an 'individual, medical perspective' to a 'social model', which involves social workers paying less attention to crisis theory and more attention to mobilising resources to further normalisation principles and enhance the quality of life.[8] Middleton is equally censorious of the performance of social workers.[9] Her prescriptions of how social workers should do their jobs is based on her 'grave concerns about how some departments relegate social work with disabled children to their lowest priority, and allocate the work to inexperienced, unqualified and least-competent staff'. Much of her advice is both sensitive and sensible. Unfortunately her didactic approach may undermine the confidence of inexperienced workers, thus perpetuating the marginalisation of the client group whose rights she seeks to promote.

This uncertainty provokes criticism, particularly from an organisational perspective. For example, Rowbottom et al found perplexing 'the nature and scope of social work' in their organisational study of social services departments:`there is doubt even as to the proper phrase to describe the field concerned -should it be called social services, social work, social welfare , or just welfare? Is it to do with helping people materially... is it to do with changing people's attitudes and behaviour? Or is it to do with improving the general environment in which they grow up and live?'[10]

Undoubtedly, this lack of clarity of aims and functions has contributed to social works' vulnerability in the face of public concern about child protection issues. The growing awareness of the failure of social work intervention to prevent child abuse and child murder has been fuelled by the media following the spate of child abuse enquiries[11]. Although responsibility ought to be attributed to a number of different professions and to the problems of interdisciplinary and interagency collaboration, social workers have been scape-goated by the media. Media attacks have had the unfortunate effect of prioritising child protection issues within social services departments and within social work training. It is symptomatic of social work education's limited knowledge of the needs of children with disabilities and their families that, in response to the inclusion of children with disabilities in the Children Act, CCETSW called a conference in Leicester in 1992 focussing solely on child protection issues in relation to disability.[12] Without denying the importance of this subject, it might have been better to begin with issues affecting the majority of disabled children, collaboration with professionals, for example.

Another unresolved conflict for the social work profession is, the lobby for community activity and for political activism on behalf of 'oppressed minorities.'[13],[14] This direction in social work education was endorsed by the first edition of CCETSW Paper 30, the blue-print for training social workers on the newly constituted DipSW courses 1989. CCETSW 'will require programme providers and expect agencies to take effective action to combat racism at institutional and individual levels'[15].

Criticism of this 'politically correct' dogma has been fierce. Pinker described 'the council's endorsement of politically correct dogmas associated with ant-racism' and the obligation 'to teach social work students how to challenge all forms of structural oppression' as 'disastrous policies which have ripped the professional credibility out of British social work.'[16]

The consequence for the social work profession of its own internal 'battle of definitions' and poor public relations has been vulnerability to outside influence.[17] If social work is unable to define itself adequately, and the public is dissatisfied, statute is a way of providing strict boundaries. It is significant that the National Health and Community Care Act 1990, consistently identifies 'care managers' as principle implementers leaving it to local authorities to decide whether to employ social workers to perform these tasks. The Children Act is more concerned with 'support services' to be provided as a duty by local authorities 'to offer aid to the family or directly to the child to promote his welfare.'[18] While Department of Health Guidance emphasises the need for 'a single care manager', a 'key worker' and 'an input from the S.S.D. representative' the decision about the professional training of their personnel is left to the employer.[19]

From the new right, non-interventionist standpoint of the 1990s, involvement in family life should be confined to those is society who are having difficulty in functioning. Involvement should be time-limited, cost-effective and performed by a range of people trained appropriately, not necessarily by highly trained social workers. The care-management system with its purchaser-provider split has encouraged local authorities to concentrate on assessment of need by care-managers who <u>may</u> have been social work trained, and to purchase services which may require skilled social workers for emotional and interpersonal issues from voluntary and private bodies. Thus, the trend is for the marginalisation of public provision of professional social work.

This shift in public policy would seem to be detrimental to the needs of families of children with cerebral policy since it is clear from Chapter 3 that clinical, emotional and social aspects of the condition need to be taken into account when making appropriate service provision. It is relevant to this argument to quote Kozier's findings, that although 'the endurance of inescapable sorrow is something which has to be learned alone...we recognize the partial soothing of suffering that comes from the sympathy and understanding of family and friends...and from a relationship with a professionally trained person.'[20]

Social work may have unresolved dilemmas about its role and tasks and about how to achieve them. Nevertheless, the essence of social work is skilled, interpersonal help, which is both empathetic and altruistic for those experiencing intense suffering. Professional training was pioneered by the COS, 'denying that voluntarism had to mean amateurism'[21]. Members of other professions (physiotherapists or playgroup leaders for example) may work in an empathetic manner which is appreciated by their clients, but for them, their own expertise is central. The manner in which they provide their service is a subsidiary factor, rather than being a service in its own right. Social work has a unique contribution distinct from that of other professions in that it may provide skilled help to those families whose child has cerebral palsy, who straddle 'the subtle dividing line...between the rational search for help and aimless wandering...in search of advice.'[22]

13.1 The Organisational Context of Local Authority Social Work

Initially, attention was paid to how local authorities translated these dilemmas about the social work role into service provision as the basis for appreciating the experiences of families as users.

Social workers from Boroughs B and C and a social worker employed by a voluntary organisation working in a school for physically handicapped children were interviewed. The most significant findings were about the categories of families prioritised by social services and about the social workers' experiences of professional practice within the local authority context.

There was remarkable congruence between priorities for social work intervention in the two boroughs, although both made decisions about allocation by "a rule of thumb method, where the child's disability is the main problem for the family." (Social worker, Borough C). A reluctance to be restricted by rules and regulations for determining priorities was seen as offering flexibility.

> "Perhaps we're not very rational, but working in this way we can take action if we see a crisis. Things may change now we've got a new manager. We're still a fairly new team and still thinking about the best ways to allocate our scarce resources."
>
> (Social worker, Borough C)

Bombarded by referrals, (Borough B's Assessment Team had a waiting list of 85 at the time of the study), situations of risk usually involving neglect, were prioritised, as were problems with medical treatment. For example, a Pakistani mother frightened to take her baby home from hospital was referred by the HV. Families needing a full child protection assessment would be referred to the child protection teams.

> "Squealing and shouting parents also get a service and I have no hesitation in advising dissatisfied parents to use the Complaints Procedure. It's a sad fact that if you don't squeal you don't get anything."
>
> (Social worker, Borough B)

Local authorities are expected to undertake comprehensive assessments, but both boroughs seemed to regard making respite care arrangements as the most effective provision to offer. Both boroughs had long waiting lists, problems with responding to emergencies, and concerns that Children Act regulations about reviews meant cases could not be closed.

> "This division of work between assessment and provisions teams has only been in existence for about 18 months but we can't close any cases to make room for the new work being assigned to us by the assessment social workers. The more routine cases, benefits, housing and respite are left aside as we concentrate on the families in crisis."
>
> (Social worker, Borough B)

In the absence of rules about rationing services ,both local authority social workers thought priority should be given to those in crisis; those where there was need for co-ordinating a range of services and treatments; where there was a child suffering from chronic illness; refugees and poor families among whom many were Asian, suffering from isolation.

> "We run a support group every second Saturday for Asian families who are sometimes rejected by their own communities and feel blamed for their child's disability. It's a bee in my bonnet, but I think this group is not well served. We should be producing literature in their language to extend our service."

Concern for ethnic minority families and refugees coincides with the requirement of the Children Act to consider the 'race, language, religion and culture' of children. It also demonstrates that the campaigning of the social work anti-racist model has some credibility in practice.

> "One of my cases is an Eritrean single parent with 2 children one of whom has cerebral palsy. They were referred by the HV who was concerned that the child's legs were being tied together to keep her still.

> They were refugees, who had been housed and given Income Support and then seemingly left high and dry. The flat was damp. The main issue is that they don't know the system so massive rent arrears built up and there was no money to feed the children. When a day nursery place was arranged, they were so deferential and grateful."
>
> (Social worker, Borough B)

Social workers have been maligned by the media for many failings in their service. It is worth pausing to consider the stressful nature of providing a professional service in a local authority context. Bradley & Sutherland investigating occupational stress among professionals in social services departments, emphasised the degree of stress resulting from the organisational structure and advised the conduct of 'stress audits' as the basis for planning stress management.[23] It is only the failures that reach the headlines. To be effective, social workers need a wide knowledge base: they are responsible for a range of different disabilities requiring interventions from numerous sources, statutory, voluntary and the private sector. Skills are required to locate resources, negotiate payment and change them in response to a child's developmental needs and family circumstances.

> "This work is as stressful as child protection work but different. We receive personalised anger from parents about the poor level of service. This is vehement because of the parents' unresolved grief about their child's disability. Child protection investigations come to an end, but here there's a feeling that you can never give enough. You feel the parents' pain and feel you can't give enough, particularly because many resources are controlled by health and education. You have to fight with the parents to get them to trust professionals; you have to fight with your manager to keep the case open."
>
> (Social worker, Borough C)

Some social workers felt frustration in being unable to use the therapeutic and organisational skills they had developed in their professional careers on their clients' behalf. The problem for them, therefore was not whether social work had a contribution to make, but that it was impossible for them to make it.

A useful perspective on this subject was provided by a social worker employed by a voluntary agency and housed in a special school for 50 children with severe physical handicaps.

> "I was surprised when I began to work here how few families had on-going social work intervention. The social worker at the child development clinic is on maternity leave and only usually acts as a trouble-shooter and assessor. The social services teams don't take cases on unless there is a huge crisis."
>
> (Social worker, Special School)

This part-time social worker saw it as one of her primary functions to facilitate access to social workers in social services since all had recognised needs by virtue of the severity of the disability. At the time of interview, only 4 families with children in the school had an allocated social worker from social services. She herself was working directly with about 20 families focussing on serious situations, where a mother was mentally ill for example. She also provided a counselling service to children. Direct work with children is a recognised social work skill which is rarely utilised in area offices where chasing resources takes precedence.

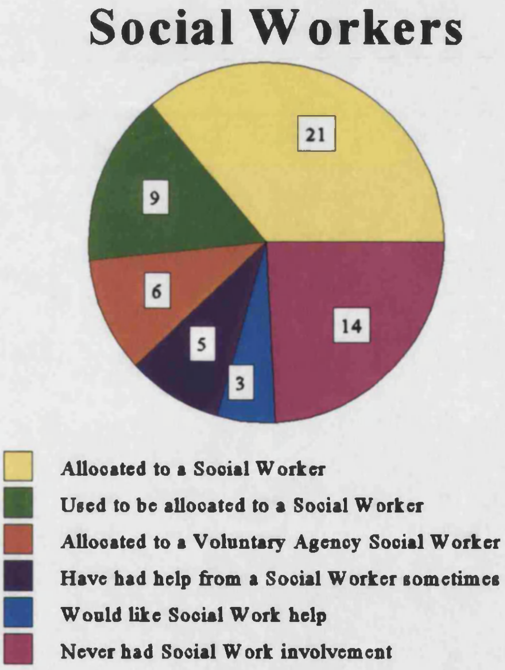
> "It is a hard thing for parents to recognise that their children could have more: only a few of them are able to be politically active. I find it hard as do the physios not to be able to give what a child needs. There is a full-time physio but there's been no OT for 18 months and the ST comes only one day per week yet all the children need it."
>
> (Social worker, Special School)

Perhaps an accurate conclusion might be that social workers appeared to serve as the 'whipping boys' for the failings in provision stemming directly from restricted public spending. Although individual social workers recognised their clients needs for skilled interpersonal work, the local authority context in which they were employed restricted direct practice. Social services managers appeared to prioritise short-term work and most departments appeared to be under resourced.

13.2 Families and Social Workers

Figure 37 represents the involvement of families participants in this study with social workers.

FIGURE 37



It was unlikely that, until the birth of their child, these families would have had any reason for referral to a social worker. Two mothers held the view that they should not expect to receive help from public services.

> "I think the likes of me calling on social services is wrong. I have recruited volunteers through the church to help me with patterning and they help me in other ways. It really is very degrading to have to ask for help at all. I had a very good job and now I have to ask others for help."
>
> (Paul's mother)

However, some mothers were children of the 1960s and 1970s when the ethos of universal welfare was stronger. They had used the free NHS, been educated in state schools and universities and made National Insurance contributions when in employment: they, therefore, believed in the state's responsibility to provide for all citizens in need. It came as a rude shock that accessing proved problematic and their perceived rights were denied. The full force of their negotiating facilities, acquired through their state education was concentrated on making claims for entitlements.

> "We thought we would be allocated a social worker automatically. The whole experience has forced us to rethink our views. I suppose we are 'ageing wet socialists' who resist using the private sector which is why we found the private conductive education centre difficult. We had to try balancing what we believed in with what Tim needed, what was available and what was convenient for us as a family."
>
> (Tim's parents)

There was a close fit between the categories of need prioritised by social workers and those families interviewed who said they had an allocated social worker. A single parent in homeless family accommodation with two children, the elder receiving help at the child guidance clinic for behaviour problems and the younger with severe cerebral palsy, was an example.

> "I had to fight for my social worker. They have lots of part-timers and heavy case-loads. My social worker is new and is only learning the job. She's someone to talk to but I expect she'll leave soon. Sometimes I feel so down. When I've got the children to bed I just sit here in the mess and smoke 17 cigarettes."
>
> (Tom's mother)

Yet other participants seemed equally in need of help. An East African single parent living in a two bedroom flat with steep stone steps up to the front door, looked after John with severe cerebral palsy, his baby brother and two nephews aged 7 and 9. Their mother had disappeared and their father had left them with her indefinitely promising to send money but failing to do so. She had no Family Allowance for them and needed to sort out their status with social services.

> "I phone up but the social worker is never in the office, he's either unobtainable, off sick or on leave. He doesn't cancel his appointments either... he's useless."
>
> (John's mother)

Some reported indefensible, bad practice, for example the parent who felt confidentiality had been breached.

> "She was very unprofessional, contacting several people without informing me. Her Children Act assessment of our needs was 'unreal' showing how little she understood of the effects of having a child with cerebral palsy on our lives."
>
> (Charlotte's mother)

To balance these negative reports there were some satisfied clients, and it seemed as if this resulted from the personalities involved. While one mother said "we had contact at the beginning but she rang at the wrong times and we weren't on the same wave-length", another described the social worker as "brilliant, she doubles up as the OT and involves herself at a personal level....getting to know Ben and she's always on my side. When she moved areas she held onto our case. She's on call. Its great!"

Establishing a helping relationship takes time, commitment and trust. In the public eye social workers are people who are interested mainly in child abuse and may take your children away.

> "I got a letter at the time of the child abuse scandals. When the social worker came I asked her for her I.D. They look at you as if you're not 'at risk' and leave."
>
> (Louisa's mother)

However, being categorised as a potential child abuser could be an advantage in terms of offers of help and support.

> "We had a big to-do last Autumn. We'd never received any help and paid our own au pair. They never offered us any help even though I'd told them he was difficult to manage because he's autistic as well as having cerebral palsy. Then they discovered a wacking great bruise on his bum caused by falling in the bath. Suddenly they decided I'm not suitable to choose who should look after him and we're showered with offers of help."
>
> (Colin's mother)

This experience fits the stereotype of social workers being overzealous about child protection. John Bowis, Junior Health Minister is reported to be aiming for 'a lighter touch' in investigations, recognising a need to 'strike the balance between support and investigation.'[24]

Taking an overview of families in this study, few had allocated social workers because the service is under-resourced and children with disabilities are only prioritised in extreme circumstances. There are accounts of poor professional practice which appear to be associated with the same problems. Only three families said they wanted a social worker and nine families reported that they used to have a service but it failed to meet their needs.

13.3 Conclusion

It was apparent that social work knowledge and skills might have been beneficial in most of these family situations. The obvious need was for professional co-ordination of services and treatments. Even where parents preferred to manage the process themselves, advice, support and collaborative networking might have been beneficial. Many of these parents, traumatised by their child's diagnosis could have used social work interventive techniques, counselling, crisis intervention and task centred practice for example. At least four families had sought this kind of help privately.

Social workers' knowledge of family and social policy systems; their knowledge of psychology and how people react under stress; their repertoire of interventive skills and their value systems might assist in attaining some emotional equilibrium which might enable parents to take better control of their lives and manage their childrens' packages of care more effectively.

But, the care management system appears to be squeezing out professionalism when social work is defined as providing a skilled interpersonal social work service. The findings reported here fit a practitioner's graphic description of social work being like 'mining coal with teaspoons.'[25]

The next chapter turns to the voluntary and private sectors as alternative contexts for purchasing welfare and professional social work.

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Chapter 14 Families and the Voluntary and Private Sectors

> "When the diagnosis became clearer the paediatrician suggested that we should take the supermarket trolley approach and go and see some of the facilities which might be suitable for Emily. We looked at nurseries, schools and treatment centres. It was hard to digest what we saw and to accept Emily would need so much."
>
> (Emily's parents)

Previous chapters have shown that the public sector fails to provide adequately for families with children who have cerebral palsy. In particular, Chapter 13 confirms that social services departments, identified by the Children Act as having a duty towards children with disabilities prioritise those in crisis or in extreme poverty. The majority of parents in this study sought the advice of health professionals and donned the mantle of being their own childs' care managers, seeking appropriate packages of care, treatments and education, from the public, voluntary and private sectors.

The Department of Health Guidance describes a mixed economy of welfare system with voluntary and private organisations and volunteers supplementing, replacing or providing alternatives to public services. Expecting parents themselves to mobilise these resources receives some justification in the Guidance as intending to 'enhance, not undermine, the parent's authority and control.'[1]

This chapter begins by examining voluntary and private sector organisations within their historical and social policy contexts. After seeking definitions of the voluntary and private sectors and the distinctions between them, the experiences of parents accessing, mobilising and using these resources will be explored. 'Social services departments have been obliged to reconcile the tensions inherent in the new community care policy as best they can.' Findings from the fieldwork in this study show how parents of children with cerebral palsy experience these compromises.[2]

Whether the Department of Health's faith in the voluntary sector as a 'rich and creative resource' is justified for children with cerebral palsy is the overriding issue.[3]

14.1 Voluntary and Private Sector Organisations

Establishing definitions of the voluntary and private sector organisations and distinguishing between them goes to the heart of the debate. 'That there is a powerful need to group, classify, define things and facts is a contention found in most areas of social science.'[4] Unfortunately, in relation to the voluntary and private sectors, useful definitions prove to be as elusive as the task of defining cerebral palsy.

Brenton described her task of writing a study of the voluntary sector as 'impossible - although the term 'voluntary sector' is one that is popularly understood in British society, it does not lend itself to clear definition.'[5]

Kendall and Knapp, refer to the voluntary sector as 'a loose and baggy monster', which defies definitions and categorisation. 'There are no single correct definitions in this inherently messy topic.'[6]

Parents caring for their children with cerebral palsy at home have always used voluntary and private organisations. The problem is the diversity and multiplicity of organisations ranging from 'small, unstructured and informally constituted groups and activities which lie beyond efforts to quantify or describe them' to large national charities like Scope, formerly the Spastics Society, with an income of £19.1 million (Charity Commission 1994).[7] Associated with these are private organisations, for example the Bobath Centre offering alternative treatments, and volunteers participating in treatment systems, the Doman-Delacato system for example, as well as contributing to day to day caring.

14.2 The Influence of History

Prominent among the many explanations for this problem of seeking definitions, is the changing nature of state involvement in welfare provision since the nineteenth century. Organisations within the sectors have changed and evolved constantly in response to political and philosophical attitudes to welfare funding arrangements and, therefore, to the state of the economy. Taking an overview, from the mid-nineteenth century to the present the welfare state has 'advanced and retreated.'[8]

Voluntary services (philanthropy, self-help and welfare) and private alternatives have existed throughout, but their character has shifted and adjusted in response both to public provision and recognition of new or neglected causes. The most striking characteristics of the sector are vitality, creativity and the sheer number of alternatives. They come in all shapes and sizes, constantly adapting to change and rising and falling in response to changing societal need; duplicating and overlapping; vying with each other for funds from government, local authorities and the public.

From the nineteenth century state welfare provision increased. The Charity Organisation Society, founded in 1869, attempted to rationalise the relationship between charity and public provision in recognition that philanthropy was haphazard and random. Rough and ready definitions of voluntary provision were adopted, 'the deserving poor going to charity and the undeserving to the poor law authorities.'[9] Those who could pay bought private help, and families and neighbours participated as far as they were able. However, the distinctions proved unworkable as 'the shiftless, able-bodied idler always seemed on closer investigation to fade into a mass of orphans, widows, sick and aged, unemployed or exploited workers.'[10]

Beginning with Beveridge's report on voluntary action in 1948, which distinguished between 'philanthropy' and 'mutual aid', the history of the voluntary sector is punctuated by a series of largely ineffective reports attempting to clarify the changing and uncertain relationship between the state, voluntary agencies, philanthropic bodies, volunteers and private organisations. The inconclusive debates were around recognition that the welfare state could not meet all societal needs, and how to restrain the costs of public spending by harnessing the voluntary sector.

The Seebohm Report 1968 advocated collaboration between professionals and volunteers, and the involvement of voluntary organisations within the new social services departments.[11] A year later the Aves Committee reported on the role of volunteers, but uncertainty remained among professionals about their relationship with unpaid staff.[12]

The Wolfendon Report 1978 was described by the National Council of Social Service as 'a milestone in the history of voluntary organisations since the war', but probably achieved little other than to 'underline the mutual importance and interrelatedness of the four main systems of meeting social need, the statutory, voluntary, informal and commercial. [13],[14]

Focussing specifically on the contribution of the voluntary sector to provision of services for children with disabilities, the Seebohm Report on social services 1968, the Court Report on child health in 1976 and the Warnock Report on education 1978, echo each other in their promotion of ideas for partnerships between the state and the voluntary sector.

As the systematic restructuring of the welfare state began in the Thatcher years, voluntary and private initiatives were encouraged, although financial constraints and the absence of systematic planning led Ellert The Guardian 10.5.95, to comment: 'there are simply too many of them; there always have been, but the promotion of self reliance and business cultures in the 90s acts as a stimulant'. More than 11,000 charities and voluntary organisations had applied for National lottery cash by 7.8.95 More than 175,000 charities are registered with the Charity commission, many more are not registered and one in four people does voluntary work. As will be seen in later sections, this numerous and varying provision makes choice problematic.[15]

14.3 The Social Policy Context of the 90s

The community care legislation, the Citizens' Charter 1991 and the White Paper, The Individual and the Community 1992 are more definitive and prescriptive in designating the voluntary sector as 'a third force operating dynamically and effectively between those areas that are properly the responsibility of government and those that are properly the responsibility of the individual.'[16]

The Conservative Government operating in favour of reduced state provision and public spending, has initiated a privatisation programme, which is likely to affect profoundly both the voluntary and private sectors. By promoting a business culture in areas of health, social services and education, voluntary organisations are being encouraged to tender for contracts and to be providers of what used to be public services. As direct government and local authority grants are replaced by the requirement to sell their services, the boundaries between voluntary and private bodies becomes blurred.

14.4 Towards a Working Definition

Voluntary organisations have in common a 'not for profit' philosophy which distinguishes them from the private sector working ultimately for the benefit of share-holders. However, many organisations fall between definitions of voluntary and private. The Centre for conductive education, in north London, (discussed in Chapter 11) is a good example. Fees are charged at market prices for their professional services to users or local authorities sponsoring them, and the organisation appears to be on a sound financial basis as the result of investments from fund-raising by parents. Since the provisions available have some characteristics of welfare for children in need, parents, particularly those sponsored by local authorities, feel uneasy about the focus on payment. They wonder whether decisions about their child's future depend too heavily on the wish of the organisation to maintain the funding rather than on an accurate assessment of their child's treatment needs.

> "The fact that the conductive education centre was a private facility for us was a big issue as we see ourselves as socialists and we think treatment should be provided by the state. Our local authority disputed the funding and although the director told us to continue to bring him and not to pay while the dispute was going on, they kept sending us the bills. We felt guilty and these feelings got mixed up with our concerns that the treatment concentrated too much on Andy's weaknesses rather than his strengths. We don't want him to be an object of charity but to be valued in his own right so we stopped going."
>
> (Andy's mother)

It is possible that as the purchaser/provider split becomes more established the distinctions between voluntary and private organisations may become more hazy. Already the larger charities, employing staff and incurring overheads resulting from the development of bureaucratic structures are so actively engaged in fund raising as to appear remote from the welfare causes they espouse. 'The dividing line between primarily member-serving or mutual aid and primarily public benefit or altruistic organisations is an extremely controversial one and is likely to remain so.'[17]

> "We felt the Spastics Society did us a gross disservice. They charged us £70 for an assessment. They didn't even take Mark's socks off and billed us in detail for a very basic report. We thought they were supposed to be a charity set up to help parents."
>
> (Mark's mother)

Similarly it is possible to distinguish between volunteers and professionals by payment, but again the boundaries become unclear as volunteers receive expenses and may undertake tasks requiring professional expertise. As one parent pointed out,

> "I advertised for volunteers to help me with David through the church. I've got a card index of about 30 people, but you have to train them and

> some of them can't or don't want to do his physio properly and you don't know how to handle it because they are coming in their own time. I sometimes think it would be better if they were paid to do what I told them."
>
> (David's mother)

An effective way to categorise these organisations is by function, although acknowledging that many organisations are multi- functional and that their character evolves and changes over time. What may start as a small self-help group of parents primarily meeting to support each other may develop, for example, an information service by a newsletter, requiring paid staff, equipment and professional input.

Many writers have taken a functional approach to classifying voluntary organisations. For the purposes of this discussion the following groupings used by Kendall and Knapp are relevant. They identify six categories: service-providing, mutual-aid, pressure group, individual advocacy, and co-ordination.[18],[19]

Applying these categories to the facilities for children with cerebral palsy in the north London area provides some order to a number of organisations whose functions overlap, change quickly over short spaces of time. During the year of the fieldwork, Bobath changed from offering free treatment to billing the local health authority, for example. The process of choosing appropriate components for a child's package of care is a daunting task which exhausts the most staunch campaigners for their children's needs and rights.

14.5 Service Providing

Voluntary and private agencies may provide *alternatives* to, *replacements* for, or *supplements* to state provision. The numerous alternative treatment approaches to cerebral palsy fit this category. Parents in this study tended to look for other rehabilitative approaches during their child's second year, partly responding to the influence of other parents: “I suffered the immense peer pressure...was I a poor mother?” The inadequacies of the NHS service discussed in Chapter 5 and the limited range of educational alternatives discussed in Chapter 11, combined with the search for a cure or at least the possibility of maximising potential were strong motivating factors.

14.6 Mutual Aid

In contrast to the commercially oriented and systematised bureaucratic structures providing treatments, self-help groups may have no formal organisational structure. A parent group in north London met regularly in each others' houses for mutual support, information exchange and to socialise in a sympathetic atmosphere. They had met at the child development centre and decided to prepare a newsletter providing the telephone numbers of parents willing to share experiences through a 'Chat-Line.'

Informal organisations like these either die out as the participants find other places, people and means to meet their needs, or they become more formalised , moving from what Billis has called the 'unorganised middle-ground' to employing staff, fund-raising, hiring premises and even ultimately to selling services.[20] From 'easing the pinching shoe' by self-help, bureaucratic structures may develop.

The Spastics Society (Scope) founded in 1952 by a small group of parents led by Ian Dawson-Smith whose daughter had cerebral palsy, typifies this process. The Palace Centre in Islington, founded by Marion Stanton and a group of parents whose children had cerebral palsy and who believed that their special needs were inadequately catered for by their local branch of Mencap, is an example of a welfare bureaucracy part-way in transition from informal to formal in structure.

What is interesting is that there always seems to be the need for grass-roots activities, so that as organisations become sophisticated and possibly more remote from users, new ones develop in their place. Their aims and focus may be slightly different, but they may be responding to the same identified social problems.

Parents' attitudes towards self-help varied as might be anticipated, depending on personalities and their child's condition. Some saw the drop-in facility at the Palace Centre as a haven away from toddler groups where children are 'developing normally'.

> "I would like Paula to go to Tumble-Tots at the leisure centre, but I can't bear to see children of her age doing what she ought to be doing. It hits home so hard that the doctors were responsible for damaging her."
>
> (Paula's mother)

There is comfort in seeking the company of others who empathise.

> "We went to a social event run by Link Hands-everyone's child there had a disability. All the men were outside drinking beer in high spirits. It was such a contrast to all the previous husbands I'd met who'd been subdued....never any laughter. You've got to get away from being like that. After all, if you feel your situation is bad, there's always someone much worse."
>
> (Paula's father)

Parent initiatives are an expression of having control over one's lives and may be a means of expressing hostility to professional provisions.

> "I use fringe medicines, aromatherapy, music therapy, acupuncture, osteopathy, and feel comfortable at the Palace Centre because it is parent initiated and run. Professionals are patronising. I have to make the choices for my own child."
>
> (David's mother)

Friendships change and evolve over time in response to changing life styles and events. They develop between families of children with disabilities often through self-help groups.

> "The support group of Jewish parents has helped me the most. I've formed some very strong relationships with people with whom I have little in common. Although I'm still friendly with people I knew before, I don't think I could sit down and cry my eyes out with them. They're not on the same wave-length."
>
> (Ben's mother)

It is dangerous to assume that all parents want to associate with others in similar circumstances and that they want their disabled child to be separated from others.

> "We feel isolated, because even my parents don't understand and are waiting for a miracle cure. Hanna can't go to other children to initiate friendships. They have to go to her so she is in effect 'ghettoised' with other disabled children. That isn't the real world."
>
> (Hanna's mother)

Indeed some parents reacted strongly against the assumption that having a disabled child should mean that they should involve themselves with others.

> "We stopped going to the social events when they kept asking us to give lifts to others. My husband has had a really hard time coming to terms with Alison's condition. He can't cope with others. Somehow you have to be allowed to adjust at your own pace. I still can't deal with disability in adults and try not to think about what Alison will be like when she's grown up."
>
> (Alison's mother)

Constantly associating with children with disabling conditions may reinforce depression and fail to eliminate the natural competitive tendencies of parents. Most parents, particularly those who are middle class, are ambitious for their children so that even joining a mutual aid group is part of the painful process of accepting their child's developmental impairment.

> "I was very depressed though I didn't realise it at the time. I found the Palace useful for information but I couldn't stand it. I sat on the floor with Danny singing 'the wheels on the bus go round and round'.He didn't seem to respond like the others and I felt as if I would be sitting there singing the same song for the rest of my life while others improved. I sought individual counselling privately after that."
>
> (Danny's mother)

Moreover, informal organisations are subject to internal quarrels between personalities and rivalry between parents.

> "I got very upset by one mother who was very active in the disability movement. I respected her for that, but she didn't seem to be able to touch her child; you never saw her holding Susan. She was smelly and dirty in contrast to her sister who was always clean. I shouldn't criticise. That's her way of coping. Everybody's different. You really do have to present a handicapped child nicely, otherwise people feel pity."
>
> (David's mother)

Changing aims and objectives also cause conflict as informal structures mature and formalise.

> "I wanted the centre that we set up to provide excellent facilities, better than anything else available, not just play facilities with a play leader. I didn't like the way money was spent. I wanted special toys and above all I wanted to see change in the children's abilities. In the end I walked out. I suppose some children are so damaged witnessing improvement isn't

> possible, but with intensive conductive education Christopher is improving so I don't fit in there anymore."
>
> (Christopher's mother)

Pervading these reactions are the powerful emotions rooted in birth trauma and irreparable damage. From this perspective, offering group support may have as much to do with the impotence of able people and their uncertainty about ways to help as with genuine belief in the value of group processes.

14.7 Pressure Groups

Some self-help groups engage in campaigning as one of many functions; other organisations prioritise campaigning to change attitudes, raise public awareness, advocate change and stimulate financial support. Campaigning tactics include what might be described as on-going strategies: research and dissemination of literature; public meetings; some bodies are more active in lobbying and civil disobedience.

The Disability Alliance movement, which includes people with cerebral palsy, has obtained national publicity for the civil rights campaign mounted outside the House of commons in 1994/5. Pavements were blocked by wheelchairs and undignified scenes of disabled people being carried from the scene made newspaper headlines.

Scope devotes resources to national campaigns on specific issues, for example the 'Make a Statement' campaign of 1994. (See Chapter 8). Hemi-Help is an example of a smaller organisation actively involved in research, information dissemination and publicising the social needs of hemi-plegics (including stroke victims and people with cerebral palsy).

Few parents in this study appeared to be actively involved in public activities, probably because their lives are filled by daily caring and by individual campaigns on behalf of their own child for treatments, services and education.

Another strong influential factor on deciding to involved in campaigns is the rate at which parents come to terms with their child's disability identity. A parent described how they had extended their house in their child's second year, while actively engaged in a rehabilitation programme. Three years later they had to design further alterations.

> "They could have been done earlier, but we didn't accept at that stage that Sally would never be able to walk or climb stairs Even the new shower room is too narrow for a wheelchair."
>
> (Sally's mother)

There is also concern for protecting a child's privacy. While some parents are willing to publicise their child's situation to raise funds others feel that they have a duty to preserve this human right since the children with disabilities are not in a position to do it for themselves.

14.8 Individual Advocacy

It is clear from the present study, that parents primarily advocate on behalf of their own child. However, some voluntary organisations include this facility. Norwood Childcare is a voluntary organisation running parallel with social services in providing a range of social services (social workers, Portage, playgroups, respite care, a family centre with toy library and a therapeutic parent group for mothers whose child has a disability) for Jewish families.

Having a social worker from Norwood enabled many Jewish families in the study to experience 'a single door' and to receive skilled counselling if required.[21] With the problems being experienced by professional social work as described in Chapter 13, it is interesting that apart from the few families in crisis or where there are considered to be child protection issues, only Jewish families in the study had access to a social work service which included advocacy. Ten of the families in the study were Jewish and benefitted from excellent, well-funded and sensitive services. Nevertheless, these families did not restrict their involvement to Norwood, but were as active as other non-Jewish families in mobilising resources from a range of public, voluntary and private sector provisions.

> “Looking back I realise how distressed I was so I found it hard to accept help. The social worker from Norwood came to discuss respite care. She said "it must be very hard for you". I reacted by telling her that if that was all she could say, I didn't need her help. I didn't need her to tell me how hard it was. Now I feel honoured to have her help, as an advocate, a source of strength and support.”
>
> (Ben's mother)

Many specialist organisations exist to advocate on particular aspects of a child's needs. ACE is an organisation specialising in compiling computer equipment appropriate for education and daily living. They advocate directly with schools for the implementation of recommendations. Small specialist resources like ACE have long waiting lists and it is the articulate middle-class parents, who are usually most able to negotiate most effectively for these scarce specialist resources.

> “I met Mark's mother at the school fete. I ended up feeling very uncomfortable. She told me that Mark will probably have to move to a special school as he cannot cope with numeracy. I thought about John's specially designed computer programme and realised how fortunate we had been to obtain an assessment at ACE.”
>
> (John's mother)

It appeared to be a source of disappointment for parents that the voluntary organisation specifically for people with cerebral palsy, Scope, appears to concentrate on national issues failing to provide an advocacy service. With the disbanding of the formerly nationwide social work service on the grounds of cost and duplication of local authority social work services, all that remains is a telephone help-line at Milton Keynes and an information service and disorganised library service in London, staffed largely by administrators. This is characteristic of highly developed organisational bureaucracies, although Billis 1984 has argued that it is possible for large welfare bureaucracies to 'evidence qualities of flexibility, innovation, and care for clients.'[22]

14.9 Co-ordinating Functions

Co-ordination of voluntary sector activities for people with disabilities is undertaken by many large national organisations, some focussing on specific conditions. Of particular relevance to parents in this study are Scope, Mencap, Barnados, the Shaftsbury Society and Ican. These large well-endowed charities are engaged in the processes of adapting their work to the changing needs of society and to policy issues resulting from the implementation of community care.

Barnardos, for example, has shifted resources from orphanages to respite-care and daycare for children with disabilities. The Shaftsbury Society and ICAN still concentrate on boarding school provision, but are changing their schools to accommodate day pupils and encouraging weekly boarding arrangements.

The expectation that Scope would provide the co-ordinating functions for families in this study proved largely illusory, judging from parents' accounts in interviews and from interviews with Scope professional staff. From the parents' point of view they felt let down by the society's espousal of conductive education. The social work service had been withdrawn and there were no local spastics society groups in the area at the time of the study, although plans were being made to set up 'schools for parents' in north London (mini-conductive education day centres).

Scope is not unusual among large voluntary sector organisations in experiencing conflict between management and welfare tasks. 'The overall function of any voluntary organisation is to secure inputs from one group of people and institutions in order to produce outputs for another group.'[23] While the 'real work' of an organisation is concerned with clients, considerable attention needs to be paid to management issues in particular as revisions are required in response to social policy changes.[24]

14.10 Volunteers

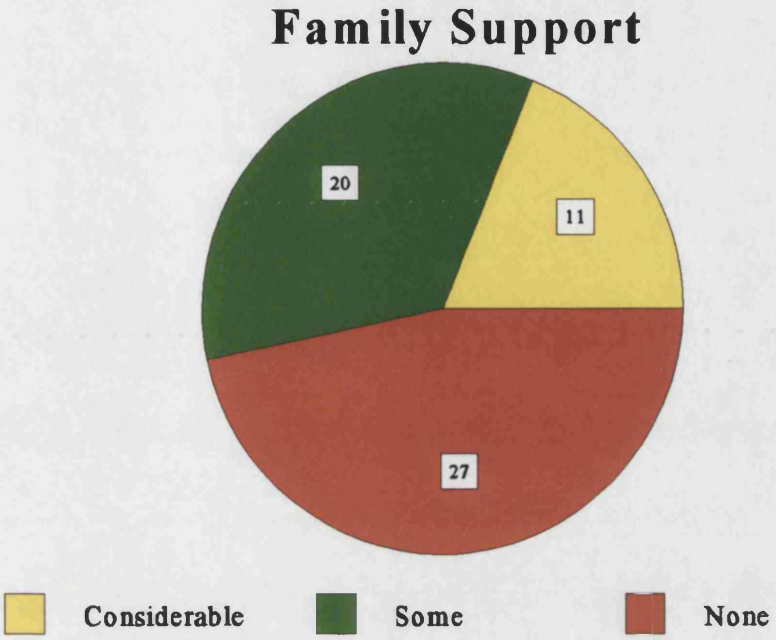
Associated with promoting the voluntary sector is the Department of Health's faith in participation by volunteers[25]. But volunteers are not synonymous with the voluntary sector, being active also in public institutions like social services and schools; in private bodies and by private arrangements. 'Volunteering clearly taps into a natural urge which people have to help their fellow citizens.'[26]

Of the people involved in the present study, only 6 families were using volunteers while 2 others said they had received help from volunteers in the past. Department of Health Guidance Vol. 2 & 6 particularly commends Homestart and Newpin. This fits with the commitment of the DH to care in the home - both organisations offer a range of home care including, cooking, childminding, and advice on parenting skills. Only one respondent listed Newpin as a source of help and 2 others listed Homestart. Explanations for this minimal use of volunteers may be partly explained in the words of one respondent:

> "You only get help if the family accepts intrusive questions and endless forms to fill in."
>
> (Andrew's mother)

Resistance to intrusion combined with feelings that unskilled volunteers could not be trusted meant families in this study did not receive help from a source promoted as a useful component of community care, despite the fact that many were not receiving help from extended families either. Only 11 families reported receiving a lot of help from their families; 20 were receiving a little; 27 were receiving none (figure 38).

FIGURE 38



If there is something uniquely valuable about 'the Gift Relationship', then families with children with cerebral palsy are not benefitting from it[27].

14.11 Conclusion

Since participants in this study were recruited primarily from voluntary and private sector agencies, they might be expected to be particularly informative and positive about those sectors. In fact, the picture that emerges is one of patchy variety.

Despite the problems of distinguishing between different organisations the following conclusions may be drawn.

The private sector is of crucial importance as a provider of treatment and educational alternatives. The voluntary sector is diverse, patchy and used spasmodically by many as a source of information. Restrictions of time and resistance to adopting a 'disability identity' influence participation.

Volunteers, who might have been expected to be a valuable resource, are very marginal in participating in community care despite the relative isolation of many families. Apart from the alternative social work service provided by Jewish Care, the voluntary sector appeared to be as poorly equipped as social services departments to provide therapeutic wok with suffering parents. Nor did there seem to exist a co-ordinating service within the voluntary sector to assist in managing a child's core plan.

Poor families, many from ethnic minorities may have an allocated social worker from social services, but tend to remain uninvolved with the 'rich creative resources' of the voluntary sector. This finding is consistent with recent research findings on community care.[28] However, there is another side to this issue. Searching behaviour appeared to leave families dissatisfied, exhausted and disillusioned. In many cases it appeared as if their children might be described in the words of a parent as 'overtherapied'. A local authority social worker remarked on finding the poor families on his case-load more accepting of their situations, less tense and appreciative of the services they were receiving. It is ironic that an excess of choice may fail to bring solutions but postpone emotional acceptance of long-term disability.

'At times when parents are overwhelmed by the medical changes of their child's condition, they may continue to search for help beyond what appears to be reasonable.'[29]

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CONCLUSION

> "If I had killed her when she was a baby, I would have served my sentence by now. Instead, 15 years later, Rosey is still totally dependent, my back is damaged from years of lifting her. I cannot go into hospital for treatment because there is no-one to care for her."
>
> (Rosey's mother)

Throughout the world there are children with cerebral palsy. Their quality of life and that of their parents and carers depends on cultural and religious attitudes, medical, educational and social resources, and on the legal framework which underpins national social policies. Stark contrasts in quality of care may be discerned between developing countries and the Western world. For example, in Jamaica, many abandoned children live in the under-stimulating environment of residential institutions, whereas in the UK a complex network of health, education and social services provisions is available to sustain the care of children in their own homes, with parents acting as care managers.

It has been shown in Section II that cerebral palsy is a condition riddled with ambiguities. Associated with it are inconclusive research studies, under-resourced treatments and services, ambivalent attitudes derived from prejudice, guilt and grief for this damage to human lives and the consequent family suffering.

This study has concentrated on a small group of children, from a predominantly middle class area of a cosmopolitan city in the UK, at a time of major change in social policy. Recent legislation has promoted the philosophy of 'normalisation' - that the best place for caring for disabled children is with their birth families, and that users and carers should have greater control over their own lives by participating in choices and by having available complaints procedures.

The aim has been to explore the probable gap between the carefully argued and apparently eminently logical proposal of the Department of Health in the policy objectives for disabled children, and the practice implications for carers. Employing a range of research methods described in Section I, this qualitative study primarily adopts a user and carer approach. In contrast to the Department of Health, which presents what might be described as a perspective from top to bottom, this is a bottom-up view of how service users experience policy devised by government and provided by the statutory, voluntary and private sectors.

It is also based on the hypothesis that, although superficially the provisions for children with cerebral palsy in the area selected for the study may appear to be almost utopian, the complexities of the condition, combined with patchy and under-resourced treatment and service provision, have serious consequences for the quality of family life. It is still possible to experience acute difficulties in relation to policy provision without taking into consideration issues of poverty and deprivation.

The study has been divided into four major sections, each examining in detail relevant research literature, social policy history, legislation, service provision and practice implications. The views of parents at the receiving end of care have been quoted extensively. It has been necessary to examine some aspects of care in detail, for example, the parent adviser service in Chapter 6 and conductive education in Chapter 11. Unravelling these approaches through conducting research seems to mirror the tasks undertaken by parents exploring suitability as part of their child's package of care.

Conclusions have been discussed at the end of each section in this study. There remains, therefore, the task of drawing them together in order to identify implications for social policy makers, service providers and the professionals employed by them, and for parents and their children. Out of the myriad of detail considered in this study, three major themes emerge. They are concerned with the nature of the care management tasks undertaken by parents; the consequences of this for the education and training of professionals, particularly social workers, and finally future social policy research directions. Each of these areas will be considered separately.

Parents as Care Managers

There can be no doubt that a gap exists between the eminently reasonable expectations of the Department of Health, and the parents' experience of choosing community care packages. Examples abound throughout the study. In Section III, essential treatments (physiotherapy, O.T. and speech therapy) were experienced as uneven in quality and supply, so that parents appeared to be driven as much by the inadequacies of conventional medicine as by their searches for cures to explore under-researched and potentially dangerous alternatives. Similarly, in Section IV, many parents experienced the activities of the LEA's as "like dealing with jelly". Negotiation for the recognition of their children's special educational needs involved advocacy with officials who seemed to 'slither around' to education policy change and inadequate resources.

The social services departments with responsibility for co-ordination of community care were experienced in Section V as operating a siege mentality, with their professional social workers either prioritising child protection issues or seemingly demoted to being assessors of need to be purchased from the independent sector. In their turn, many private and voluntary agencies were apparently traumatised by the changes required by the new purchaser/provider culture and seemed to be in danger of losing touch with user and carer opinions.

How profoundly the birth trauma had affected parents, the severity of their child's condition and the amount of support they received from family and friends influenced their capacities to be care managers. Their tolerance of poor service provision was usually low, and a vicious circle of blame and distress ensued. Distrust of medical care influenced attitudes to NHS professionals. Having been disillusioned by one public service, attitudes towards others (education and the personal social services) were soured. Disappointment was reinforced.

The gap between policy and provision was felt especially acutely by middle class, educated parents, who expected full participation in their children's treatment, education and care (as the legislation advocates) and were able to argue proficiently for their rights. It is interesting that among satisfied parents were refugees ignorant of their rights and grateful for their damp council flat and nursery place with transport provided.

Throughout, the parents appeared driven to explore alternatives, and the consequences for the children with cerebral palsy, and for the whole family, appeared to be characterised by frequent change in treatment directives and in association with people providing treatments, education and care services. Concern was expressed by parents about 'over-therapy' - too many appointments , too many journeys, too many people to see and too much inconclusive information on which to base judgements. Questions were raised about the restrictions for children with cerebral palsy on being able to play and enjoy their early years; for families of establishing a stable way of living or normality, whatever that might mean.

In essence, therefore, being their child's own care manager appeared to aggravate pain and suffering. Instead of feeling empowered by community care, parents felt abandoned, isolated and ignored by society. Many parents would identify with one father who described waking up in the morning thinking he was in hell.

Education and Training of Professionals

The paradox in this study is that parents wanted to care for their own children and to have powers to choose treatments, education and services for them. But they found the community care system under-resourced, inhibitive and unduly restrictive despite the Department of Health's aims to give service users a greater say in how they lead their lives.

Parents of disabled children still needed a clearly identified person and a 'single door' for two main reasons.[1] Firstly, they needed information, advice and advocacy in order to act as care managers, and secondly, they needed an empathetic service which recognised the long-lasting effects of trauma and stress, and provided sensitive counselling to enable parents to use facilities available for them.

Kozier described how parents could be helped to make beneficial choices in the 1950s.[2] However, in the 1990s there seems to be too much emphasis on providing services and on the process of supply, neglecting the psychological and emotional factors which ultimately govern whether people can use help.

Linked to this is the dependence on family, friends and the 'community' of effective implementation of community care policy. An interesting finding of this study was the relative isolation of families in a cosmopolitan city. Although fewer marriages failed than might have been anticipated (see chapter 3), the nuclear family often seemed to be inward-looking. Part of the explanation for this may be located in the full lives led by parents of disabled children. There can be no doubt, however, that many parents found that extended family members had emotional difficulties in coming to terms with the child's handicap, and this was particularly acute where cultural and religious attitudes were being challenged.

This study holds a message for professionals, particularly social workers, that concerns for management and service provision systems may appear efficient and cost effective and may facilitate monitoring, but having a disabled child may be a lonely experience and human feelings and individual reactions cannot be ignored.

Social work education and training has always prioritised the practice component, where students are assessed on their capacities to engage in relationships, to be sensitive to problematic situations, and to help people, using social work methods of interaction, helping people to find solutions for themselves. The real dilemma for the profession is that care management prioritises organisational functions at the expense of these skills.

Local authority social workers, therefore, are trained to do more than just 'care manage', but are frustrated by policy directives and management of their agencies from practising. Parents, on the other hand, need an empathetic service but their experience of social workers is disappointing.

Hadley and Clough's research indicates that professionals are further frustrated by the way community care was introduced.[3] Instead of being implemented after discussion with professionals, and therefore 'by consent', reforms were 'imposed', usually changing radically expectations from the workforce and challenging the professionalism of social services' employees, the implementers. For social workers the challenge appears to be keeping alive their therapeutic skills while developing care management techniques. Nostalgia for the days of psycho-dynamic casework inhibits many experienced social workers from feeling comfortable within the social services environment.

However, it would appear from this study that both aspects of the social work role are required for effective work with families. Sensitive assessments and help within the caring relationship are needed. But, as Preston-Shoot concludes from his study of judicial review decisions about community care, 'the vague legislative drafting and the unclear concept of need' in the N.H. and Community Care Act and the Children Act, combined with 'the fragile resource base on which service provision rests' mean that 'skills of enquiry, exploration and advocacy' will be required by 'users, carers, and social workers in partnership.'[4]

These dilemmas exist also for the host of professionals involved in service provision for disabled children employed in health, education and the independent sectors. Although no clear recommendations about the vexed question of inter-professional collaboration has emerged from this study, there is common ground in appreciating the consequences of community care for families and joining forces in shared education and training. Restoring the significance of individual experience of service-use as a factor in evaluating community care requires sustained education of provider professionals at pre and post qualification levels to enable them to be heard when advocating for their clients.

Future Research Directions

This study has highlighted many areas where more research could be valuable to parents as care managers. On-going medical research, discussed in Section II, has potential to contribute knowledge about prevention of birth damage, diagnosis and the effectiveness of treatments.

Chapters 7 and 11 have demonstrated clearly the necessity for evaluating unconventional approaches to rehabilitation. It has been seen that parents of children with cerebral palsy appear frequently to be driven to explore unusual methods of intervention at some cost to their families and to their disabled child. Despite the methodological problems of quanitative measurement resulting from the wide differences between each child's symptoms and degrees of impairment, qualitative methods such as case studies and child observation may further understanding. Parents frequently adopted a 'trial by results' attitude to treatments, although they would have preferred to have been able to make more informed choices.

Qualitative research methods have value also in education, to complement quantitative findings of educational psychologists. Section IV sought to unravel the major factors influencing parental choice of schools. As the 1993 Education Act has strengthened parental participation in decisions about where statemented children may be educated, on-going monitoring of outcomes may provide guidance for parents and all those engaged in the educational system. The findings that a higher proportion of children in the study were attending special schools, but that their parents were satisfied (chapter 10) suggests that the campaign for inclusion of disabled children in mainstream schools has many dimensions, requiring further evaluation. Currently research in this area, promoted by those campaigning for expanding educational opportunities for disabled children within mainstream schools, may be in danger of overlooking the opinions of parents who prefer the more protected environment of special schools and are actively participant in contributing to the quality of learning available within them.

There has been a profusion of publications from the Department of Health providing guidance to social services departments on both community care practice and the Children Act. Similarly there has been a steady stream of academic publications concentrating on evaluating this area.[5] If there is a message for research in this study, it is that social policy, provision and practice are aspects of a whole, and that conclusions from each part are only truly valuable when considered as part of that whole. It is disappointing, therefore, that Lewis and Glennerster admit 'we were not able to look at outcomes for users' and that so much current research concentrates on economic, rather than human, costs of caring.[6] The quality of life cannot be measured by cost-effective criteria alone.

Perhaps a major outcome of this study is to demonstrate the enormous research potential on this subject, and the need for wide dissemination of findings. Beresford et al argue that 'one major problem confronting the field of social welfare provision to families of disabled children is the lack of implementation of research findings,' and Barnes expressed concern that 'the university system, implicitly if not explicitly, compels academics and researchers to write primarily for other academics and researchers rather than for the general public and for disabled people.'[7] If parents are to continue as care managers, research results must be available to enable them to make informed choices about effectiveness. Where effectiveness of a particular intervention has been established they may need to lobby for resources in their own areas.

This study has been completed. It has, inevitably, been an anguished account of the lives of parents of children with cerebral palsy. Nor may a magic wand be waved to provide a happy ending. Nevertheless, acknowledgement must be given to the real progress achieved in the UK during the post-war years in rehabilitation, in medical research and in equipment to improve the quality of the lives of the 58 children in this study. Paula, now aged 7, happily participates in her mainstream class with the aid of her computers and can go for 'country walks' in her motorised wheelchair with her grandfather. Her life contrasts starkly with some children in Jamaica, who are still lying on stone floors in children homes, sedated to make their management easier, or with children begging on the streets of Indian cities, or with children confined to bed in Kiev hospitals because there are no wheelchairs, or hidden at home by their families.

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APPENDICES

Appendix I Questionnaire to conductors

Age	20-30	30-40	40 and over

Education Background

Training Background

Are you a parent?

Previous experience of working with children

How long have you been working at Hornsey?

Try to identify 2 positive features of C.E.

1.

2.

Try to identify 2 problems you have encountered with the method

1.

2.

Have you any long-term career plans?

Thank you for completing this questionnaire.

Appendix II

STRICTLY CONFIDENTIAL

Child's age:

CHILD'S AGE	
Under 3 years	
3-5 years	
5-7 years	

Number of siblings in household: ......

Local Authority: ......

HEALTH SERVICES

Does your child receive any of the following treatments?

	NHS	PRIVATE	AT HOSPITAL/ CDC CLINIC	AT HOME
Physiotherapy				
Occupational Therapy				
Speech Therapy				
Hydrotherapy				
Other				

Do you receive adequate services? YES/NO

If No, what service would you like increased?

....

Does your child receive advice from a dietician?

NHS	PRIVATE

1

Is your child's care monitored by a Paediatrician? YES/NO

LOCAL AUTHORITY SOCIAL SERVICES PROVISION

Does your family have an allocated social worker from the local authority? YES/NO

Does your family use a local authority provided respite care scheme? YES/NO

Does your child attend a local authority day nursery? YES/NO

If so, how often: ....

Does your family attend a local authority family centre? YES/NO

Does your child have aids/equipment provided by the Social Services Department? YES/NO
(e.g. standing frame, chair)

If yes, please state what: ....

Is your child registered as disabled by the Social Services Department? YES/NO
(Registration has only been possible since the 1989 Children Act)

Do you consider your services adequate? YES/NO

If not, how could they be improved?

....
....
....

LOCAL AUTHORITY EDUCATION PROVISION

Has your child been statemented by the local authority? YES/NO

If so, were you satisfied with the result? YES/NO

Does your child receive Portage? YES/NO

Does your child attend nursery school? YES/NO

If so, how often: ....

Can you identify any major problems?

....

....

VOLUNTARY/PRIVATE/FAMILY ASSISTANCE

Does your family receive help from any voluntary organisation? YES/NO
(e.g. Spastics Society, Mencap Homestart, Norwood Child Care)

If yes, please specify: ....

Does your family receive help from any volunteers? YES/NO

Does yur family make use of private domestic help? YES/NO

Does your child attend a local playgroup? YES/NO

Do members of yur extended family help you? YES/NO

If so, please specify:
(e.g. grandparents, older sister, aunt, uncle)

SPECIALIST PROVISION

Does your child attend any specialist centre? YES/NO
(e.g. Bobath, Cheyne, Hornsey, Tadworth)

If so:

Who referred your child? ....

Who runs this provision? SELF/LOCAL AUTHORITY/FUND RAISING/OTHER

What treatments does your child receive there?

....

And how often?

....

Who do you think manages your child's overall case?

GP	
Paediatrician	
Centre Director	
Yourselves	
Others (Please specify)	

Thank you for completing this questionnaire, the results of which will be confidential.

Appendix III

Outline for semi-structured interviews with parents/mother/father/main carer

1. Information about child, birth, disabilities: telling the story.
2. Information re. family.
3. Information about specialist treatment centre, positives and negatives about the service.
4. Experience of NHS.
5. Experience of Social Services.
6. Experience of education, statementing and education plans.
7. What have you needed that you haven't received?
8. Special person?
9. A.O.B.