

Disabled Children, Disabling Practices

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DISABLED CHILDREN, DISABLING PRACTICES

by

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A study of the relationship between
parents, professionals and policies
concerned with the family care of
disabled children.

by

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and

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FORWARD

One major thematic focus in the Social Welfare Research Centre has been family care of dependent relatives. To date empirical work has centered on family care of disabled elderly relatives (SWRC Reports and Proceedings Nos. 23 and 35) and this monograph was prepared to see if the caring issues, identified among families with elderly relatives, were similarly prevalent among families with handicapped young children. This research does this and more.

Stuart Rees and Anneke Emerson from the Social Work Department at the University of Sydney prepared this monograph as part of a research contract issued by the SWRC. On three occasions over a twelve month period they interviewed 51 families to examine their use of health and welfare services for their severely handicapped young children. In addition they noted factors relating to the financial and non-financial costs involved in the caring situation.

They found, not surprisingly, that parents (but especially mothers) have enormous and almost unbearable stresses on them if they attempt to care adequately for their severely handicapped young children. Such stress is compounded by the poorly structured and poorly co-ordinated service systems in health and welfare. The research shows, in addition to internal family pressures that the 'helping professionals' were not always very helping because they were too much tied up in their own professional worlds and that they operated in bureaucratic settings which did not facilitate co-ordinated activity. Rees and Emerson further found that the extra financial cost of caring at home for a severely handicapped child was almost triple the amount of the Handicapped Child's Allowance paid by the Department of Social Security, and in addition that this allowance was made available and administered with very little rationality or consistency.

Two points stand out. First, co-operation between medical and non-medical services is inadequate to handle need and second, parents' ability to provide care in the home depends on the usefulness of non-medical services, yet these services take a shabby second place behind medical services, which themselves are not always appropriate in the circumstances. The authors conclude with a number of policy options relating to service organisation and co-ordination, and family support.

This is a pioneering piece in an area in which there is virtually no Australian research. As such anyone hoping for a definitive report on issues relating to the care of handicapped children will not have their expectations met here. They will not, however, be disappointed for this study traces the background and provides valuable data on a small sample. In doing so it adds to our store of knowledge, and in the best of research traditions raises questions about directions for future research in this important area.

Adam Graycar
Director
Social Welfare Research Centre.

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ABBREVIATIONS

AAMD	American Association of Mental Deficiency
AAT	Administrative Appeals Tribunal
ABS	Australian Bureau of Statistics
ACOSS	Australian Council of Social Services
ACROD	Australian Council for the Rehabilitation of the Disabled
ADB	Anti-Discrimination Board (of New South Wales)
AGPS	Australian Government Publishing Service
CMH	Council for the Mentally Handicapped
CMO	Commonwealth Medical Officer
DCA	Domiciliary Care Allowance
DS	Down's Syndrome
DSS	Department of Social Security
HCA	Handicapped Child's Allowance
HMSO	Her Majesty's Stationery Office
MR	Mental Retardation
NCB	National Children's Bureau (United Kingdom)
NGWOs	Non-government welfare organisations
NSW	New South Wales
POWH	Prince of Wales Hospital
RAHC	Royal Alexandra Hospital for Children
SCWA	Subnormal Children's Welfare Association
UK	United Kingdom
WHO	World Health Organisation
YACS	Department of Youth and Community Services

CHAPTER 1

PARENTS AND POLICIES

Introduction

A mother who lives in Sydney's western suburbs has described some consequences of caring at home for a severely physically and mentally disabled two year old child.

'I'm totally housebound. My child doesn't sleep during the day and I'm always tired ... I can't even get sick, I have to keep coping. I have no choice. Why me? Why did God do this? I haven't done a crime, it is a trial'.

Not all parents of disabled young children have had such negative experiences or feel so pessimistic about the future. Some might describe their experiences in positive terms as a gift from God, and would regard the future with unbridled optimism.

However, in the first five years of a disabled child's life, the parents accumulate experience with a variety of relatives, professionals and officials. In these encounters, the objectives and achievements of certain social policies are evident, policies which idealise the family and assume that parents can manage their responsibilities if they obtain certain professionally provided support services. This study tests this assumption by examining the interaction between a small number of mothers and fathers of young disabled children and between those parents and a variety of doctors, Social Security officials, social workers, occupational therapists, physiotherapists and other professional staff.

Theoretical Perspectives

This focus on parents' encounters, told mostly in their own words, provides an important perspective, i.e. from the consumers' viewpoints, on social policies at work. Our analysis uses those theoretical approaches concerned with symbolic interaction and with the sociology of the professions. We document the detail and meaning of family care and professional help. We are less concerned with generalisations about the proportion of families who

judged a service effective or ineffective, in particular because the sample of families was living in an area of metropolitan New South Wales where health and welfare services were regarded, somewhat euphemistically, as under-developed. Nevertheless, we do identify practices, such as the lack of co-operation between different professionals, and experiences, such as the enormous stress placed on mothers and the difficulties for fathers in developing a caring role, which apply throughout Australia and elsewhere (Bayley 1973, Voysey 1975, Rees, R. 1978).

The families' accounts of their experiences took place against a background of official attempts to improve the standard and organisation of services for disabled children. These initiatives are reflected in the recommendations of inquiries such as the Richmond Report in New South Wales (1983) and the South Australian Report on Services for the Intellectually Handicapped (1982). We make use of these social policy proposals by comparing their ideas with the actual experiences of the parents and we stress the importance of politicians, pressure groups and relevant professionals using this information to influence future recommendations for change. Before we reach that kind of detail, it should be helpful to outline some Australian and world-wide dimensions of disability in general and disabled children in particular.

Some Official Figures

The year 1981 was designated the International Year of Disabled Persons. For a time, the media and professional people gave publicity to the world-wide extent of disability and its enormous social, psychological, and economic consequences. According to a UNICEF estimate, there were 450 million disabled people in the world and 140 million of them were children (Medical Journal of Australia 1981). The Director General of the World Health Organisation (WHO) said that 50 per cent of disabilities were preventable, but he also stressed that 80 per cent of the disabled lived in developing countries which had 10 per cent of the world's resources (Medical Journal of Australia 1981).

At the end of 1982, the Australian Bureau of Statistics (ABS) published a detailed survey on the nature and extent of various disabilities and handicaps suffered by children and adults in Australia. The survey estimated that 1,264,600 Australians (8.6% of the population) were handicapped and a further 677,400 were disabled but with no subsequent handicap, giving a total of 1,942,000 Australians or 13.2 per cent of the population (ABS 1982). The ABS

survey relied on WHO classifications of disability and handicap. Disability referred to the loss or reduction of functional ability and activity resulting from disturbances of or interference with the normal structure and functioning of the body, including the systems of mental function. Handicap referred to the social and environmental consequences stemming from the presence of impairments and disability.

The merits of these definitions from the point of view of parents of disabled children will be discussed in detail later. The point to be made here is that neither researchers' fascination with international definitions, nor the events associated with the International Year of Disabled People, nor the publicity given to the ABS survey, help to make the difficulties of disabled people visible to wide sections of the public including politicians. The daily difficulties associated with disability are mostly invisible, even to those professionals responsible for improving the quality of life of disabled children and adults.

Although most parents may pride themselves on their children's 'normality', some statistics suggest that eventually disability may directly or indirectly affect most people. For example, the ABS indicates that 'whereas the proportion of the total population in each age group generally declines with increasing age, the reverse tends to occur with the handicapped population', in other words, the likelihood of encountering a handicapped person in an older age group is greater than that in a younger age group (ABS 1981, p.4). Although, in Australia, disabled young children represent only approximately 3 per cent of all handicapped persons, 8 per cent of the population generally are in the under 5 age bracket.

In the ABS survey, information is available giving the social implications of disability affecting the over fives in the population. For example, estimates are given of the number per 1,000 of disabled people whose area of limitation refers to either self care, mobility, communication, schooling and employment, or a combination of those criteria. But with reference to the under fives, the ABS merely reported that in December 1981, 39,642 children were classified as disabled but that the specific areas of life in which they experienced handicap were not examined (ABS 1982, p.3). Such 'non-examination' occurs because of the difficulty in isolating the handicapping effects of a disability in the under fives. For example, many under fives cannot walk but this is not a handicap for all, rather a developmental stage.

Methodology

This study focuses on the meaning of family care of disabled children under five, paying particular attention to parents' experiences with various kinds of health and welfare services and their representatives. These services are usually regarded as having two objectives:

1. to enhance the development of the child.
2. to support families in their care of their children.

(Wilton, 1981)

It is mostly this second objective which is assessed by parents and examined by us.

Ideas for this research derived from Professor Rees' surprise on discovering the New South Wales Health Commission's long waiting lists of parents who said they would want residential care for their young disabled children. Such surprise prompted questions about the kind of community support services which would enable parents to care at home for their children. However, after only a few interviews with parents whose names were on these waiting lists, the research interviewers discovered that putting the child's name down for residential care was only a serious interest at a particular time. It represented parents' attempts to quickly take out some form of insurance to protect themselves against the prospect of being unable to cope at some point in the future. In most cases, the business of seeking permanent residential care for their child did not prove subsequently to be a major concern of the parents. Nevertheless, it was this idea, that residential care might ultimately be the only way to care for a disabled child, which influenced the selection of the sample.

Thirty nine cases were chosen at random from the waiting lists of the Health Commission in the western Sydney metropolitan area. In an effort to obtain a heterogeneous sample, we also asked other agencies to refer cases to us where parents who were caring at home for young disabled children had expressed interest in residential care. Seven cases were referred to the project from the voluntary agency, the Subnormal Children's Welfare Association and five from social workers in the local District Offices of the State Department of Youth and Community Services. This process produced a sample in which all the children being studied were mentally handicapped and a little over half

of them also had physical handicaps (see Table 2.3). This balance between mental and physical handicap was a result of the way the sample was generated. It was not intentional.

The research began in early 1980 and the last interviews were completed in mid 1982. In each case three interviews were conducted within a period of one year. Each family was interviewed by the same researcher on each of the three occasions. The authors shared responsibility for interviewing the parents and in a few cases, where an issue of particular interest had arisen, or where we considered that some comparison of our perceptions would be useful, both interviewers were present.

In each case we attempted to interview both parents but in a total of 160 'family interviews' in the research overall, only 39 of these were with fathers. We also interviewed a variety of professionals whose information and whose influence on the course of events seemed crucial. For example, interviews with doctors and social security officials enabled us to discover the obstacles to obtaining the Handicapped Child's Allowance (see Chapter 7).

The first interviews followed a semi-structured questionnaire. Second and third interviews were usually concerned with the follow-up of the questions and ideas which had been raised in previous meetings. The parents' answers were recorded either during the interviews or were written up immediately afterwards. Where the respondents made comments which the interviewer considered of particular pertinence, these were recorded verbatim at the time. Our technique was to say to interviewees, 'I would like to write this down', or 'that's very interesting, would you mind repeating what you have just said'.

The families and the professionals associated with them were assured that their information would be treated in confidence. In consequence, the names of families in the text are fictitious but the events being described were derived from real families' interpretations of what was happening to them. In spite of our respect for confidentiality in the text, both interviewers were open and explicit in their relationship with parents. For example, although we emphasised our roles as researchers, we established friendships with some parents and, as a matter of practice, wrote letters to the families acknowledging what they had said in interviews and their contribution generally to the research.

Other comments about the selection and composition of the sample and about the way we gained the co-operation of families and professionals in order to conduct the research are contained in our Chapter 2 description of the 51 families.

Contents of this Study

Chapter 2 begins with a discussion of the meanings of disability and handicap and includes an account of the characteristics of 51 disabled children who live in the Western suburbs of Sydney. Our analysis is intended to have some application to social policies in Australia generally, and the pithy, life-like pictures which have come from these parents' accounts of their lives with their children and their encounters with doctors, social workers and other people in positions of authority, have provided the basis for this analysis. Chapter 3 documents how the parents were given the bad news about their child's disability and how they evaluated the behaviour of the doctors and other staff concerned. Chapter 4 provides an account of the extra financial costs of caring at home for a severely disabled child.

Chapters 3 and 4 set the stage for a consideration of the difficulties which the parents experienced in caring for their children, what they meant by 'coping', and whether a personal network of friends and relatives or professional staff, or a combination of both, helped them to manage any sense of undue stress. In this account of stress and coping, the prime importance of the mothers' child care achievements emerged very clearly.

Chapter 6 illustrates how the parents navigated their way through a mixture of sometimes complicated and often sparse services. Some reference is made to services provided on an Australia-wide basis, but we concentrate on the accounts of the 51 parents which, in the main, refer to services of a more localised nature. The title of Chapter 6, 'Hotch Potch of Services', is intended to provide some flavour of the parents' experiences and evaluations.

Although most of the parents' experiences illustrate how the implementation of social policies, such as the availability of support services, affected the quality of their lives, some incidents are clearer illustrations of social policies at work than others. Chapter 7 examines how parents obtained the Handicapped Child's Allowance and it highlights the undue influence of doctors.

Chapter 8 maps out how many services parents used, for how long and how they evaluated them. In the latter respect we pay particular attention to an examination of what the parents meant when they said they were satisfied or dissatisfied. In the light of such judgements and the parents' accounts of their numerous other experiences, the final chapter develops some major recommendations in relation to changes in policy and improvements in professionals' standards of practice.

CHAPTER 2

FIFTY-ONE FAMILIES

Interpreting 'Disability'

What does family care of young disabled children mean and how can welfare and medical personnel affect the quality of care provided by parents who care at home for young disabled children?

We have already referred to the WHO definitions of disability and handicap as used by the ABS. But official definitions are only part of the story. Often painful controversy surrounds an assessment of a child because doctors and others postpone making a diagnosis. The parents, in particular the mother, may feel that they are being penalised by official underestimates of a child's condition and the consequences for their family. One of our parents, Mrs Martin, explained that doctors and social workers would say only that, at the age of two, her son Andrew was 'developmentally delayed'. She argued that her son's normal appearance made it difficult to obtain either sympathy or services.

'For years I've just become increasingly guilty and anxious about Andrew. I've neglected everything else for him and my husband has become fiercely jealous of him ... If anything Andrew has got worse not better, I still have to change him three times a day and now he's four. He damages what furniture we have, he damages other people's things. It's impossible to take him shopping because he shouts and screams or lies on the ground and refuses to get up. And he's developed asthma'.

In Mrs Martin's case, Dr Albert Kushlick's definition of disability as the incapacity to do things normally expected, could include almost all of this mother's observations of her son's behaviour. Kushlick refers to normal expectations as walking with or without help, feeding oneself, talking in sentences. He refers to departures from the normal as 'inappropriate behaviours such as over activity, physically aggressive behaviour, behaviour which is destructive of furniture, fittings, clothing, which may be attention seeking or self-injury behaviour' (Kushlick 1975). Some clinical conditions which are associated with 'inappropriate behaviours' include epilepsy, autism, spasticity, congenital abnormality such as Mongolism, hydrocephalis, heart or other abnormalities (Kushlick 1975).

Regarding children whose disability is a form of mental retardation, the extent of any handicap varies according to the expected performance of the child in relation to age. For example, many families report difficulties in caring for children precisely at the point at which some normal expectations cannot be met, that is, when, according to the child's stage of development, they would normally expect the child to walk, to begin self-care, to learn to use language appropriately and to learn other skills. In this respect, the American Association for Mental Deficiency (AAMD) (1977) states that

'Intellectually handicapped people are those who mature at a below average rate and experience unusual difficulty in learning, social adjustment and economic productivity'.

The most generally used technical definition, accepted for classification purposes by WHO, describes intellectual handicap as being 'significantly sub-average general intellectual functioning existing concurrently with difficulty in adaptive behaviour and manifested during the developmental period' (AAMD 1977). With reference to such a definition, Hayes and other commentators argue that mentally retarded persons may not feel handicapped by the condition and may experience no problems of social or emotional adjustment (Hayes 1982).

Tizard would go further. The interpretation surrounding a child's physical and mental condition in relation to adaptation to his or her environment provides the basis for arguing that mental retardation is not in itself a scientific category, but rather a social-administrative concept (1974). Actually Tizard qualifies this by stating that severe mental retardation can be classified on the basis of psychological and medical criteria. Mild retardation, however, is an administrative term, it 'lacks clear social and biological definition ... and resembles terms like poverty and social deprivation'.

Judgements about a child's progress in 'adapting to his or her environment' vary according to the expectations associated with that child's age. This relationship of age to assessments of disability and handicap is apparent in the list of 'major life activities' in which the New South Wales Anti-Discrimination Board considers intellectually handicapped children will not be able to participate (1980). These activities include self-care, use of language, learning and self-sufficiency. Children's progress at school, and later in the workforce, determines their degree of social handicap. Family members' experience of being disabled by the presence of one retarded child

may well increase with the age of that child. In this respect it is not surprising that most mentally handicapped children live at home but a large proportion of mentally handicapped adults live in institutions. Other factors which affect the likelihood of a mentally handicapped person eventually living in an institution include increased management problems and the increasing age of the carer(s).

Disabled Young People and Children in Australia

The ABS data about children were derived from interviews with parents who in the first place were asked about impairment and disabilities such as problems with sight, hearing, speech, less than full use of arms, fingers, feet and legs and the presence of mental disability. In the second step of the survey, questions were asked to determine whether the disabled persons, including children and young people, were handicapped in any of three areas —self care, mobility and communication. Levels of severity of disability were graded along a continuum from 'none' to 'severe' depending on the person's estimated ability to perform such tasks as dressing, bathing, eating, moving around familiar and unfamiliar places, using public transport, understanding and being understood by other persons and the amount of assistance required to perform these tasks (Gardner, 1981).

In accounting for the nature of children's disabilities several trends emerge. Firstly, the incidence of physical handicap is approximately five times greater than that of mental handicap. For example, the ratio of children under the age of five years with a physically handicapping condition is 32.5 per cent per one thousand. Physical disabilities include sight loss, hearing loss, nervous system disease, circulatory disease, respiratory disease, musculoskeletal disease and other physical conditions. For the over five group, the ABS provides profiles of the severity of handicap by state (ABS 1982, Table 1.4, p.9) but, as noted above, it is difficult to assess the degree of a young person's handicap merely from knowing something about their disability. Some physical and mental disabilities do not manifest themselves or are undiagnosed prior to entry into school.

A second trend is that in the under five age group, most of the mentally retarded children will also be recorded as having physical handicaps. The degree of overlap is obvious even in the figures which show that of the 39,500+ disabled young children, approximately 6,500 will be mentally retarded and 36,600

will suffer some form of physical handicap.

No specific information is available on the cases and resulting specific conditions of under fives with mental disorders, but in the under 15 age group, some distinctions are made under the general heading of mental disorder.

TABLE 2.1 HANDICAPPED PERSONS UNDER 15 WITH MENTAL
DISORDERS X TYPE OF CONDITION

Numbers	Type of Condition
12,900	Mental Retardation
17,400	Slow at learning or having specific delays in development
6,700	Neurotic diseases, personality disorders and other non-psychotic mental disorders

Source: ABS, Handicapped Persons in Australia, Table 2.10, p.25.

Among the mentally retarded in the population as a whole, that is, including very young children, 13 per cent are thought to have chromosomal abnormalities such as Down's Syndrome, 8.5 per cent have birth injuries, 8.7 per cent have cerebral palsy and 55.2 per cent have other congenital or perinatal conditions. Most of the children in our sample of 51 Sydney families suffered from these conditions, many of which also have physical characteristics and consequences.

A third trend is that most disabled young people live at home with other children. In the population as a whole, most disabled children have brothers and sisters, with only a very small minority being cared for as single children. The household size for handicapped children is reported by the ABS as being similar to the general population. Table 2.2 provides a picture of the household size for handicapped persons under 15 in Australia.

TABLE 2.2 HANDICAPPED PERSONS UNDER 15 WITH MENTAL DISORDERS IN HOUSEHOLD X HOUSEHOLD SIZE

Household size (No. of Persons)	Less than 5 years	5-15
1	-	
2	-	
3	14.5%	9.2%
4	43.4%	34.6%
5	28.4%	29.4%
6	8.3%	15.9%
7	-	5.8%
8 or more	-	4.2%
Total	100.0%	100.0%

Source: ABS, Handicapped Persons in Australia, 1982.

The available ABS figures do not say what proportion of families with young disabled children have both parents, or one parent, present. At first sight one might assume that the proportion of single parents with handicapped children is the same as for the population as a whole — 7 per cent of households with children. But the strain on marriages of caring for a disabled child seems likely to make this incidence higher and at least poses an important question for future research. Certainly among the 51 families in this study, the number of single parent homes increased by two during the period of research: by the time of our final interviews, two fathers, who had been present in interviews at the beginning of a year, had deserted their wives.

Two other important items of background information concern the income of families with young disabled children. The ABS survey reports that income units where the 'breadwinner' is handicapped have, on average, lower incomes than those where the handicapped person is not the breadwinner. However, the costs of caring for a disabled child make considerable demands on family income and the presence of a disabled young child makes it very difficult for the mother to be able to take paid employment.

51 Disabled Children

The 51 families who took part in this study were selected at random from the NSW Health Commission's waiting lists of parents who had indicated their child's need for residential care and diagnostic services, and 12 were referred to us directly by the Subnormal Children's Welfare Association (SCWA) and the State Government's Department of Youth and Community Services (YACS).

When families decide very early in the child's life to seek not only special treatment but also to examine the possibility of permanent residential care, that gives some indication of the child's disability or of the child's behavioural problems and the parents' difficulties in adjusting to having a disabled child. In this sample, all of the children were mentally retarded and in addition many had severe physical disabilities. Although none of these children was old enough to have had IQs assessed and although we would be extremely cautious about regarding IQ scores as a measure of social competence, nevertheless on the parents' and their doctors' admissions, these children mostly had severe disabilities. The extent to which these disabilities would become severe social handicaps, or could be managed so that social handicaps did not develop, was the challenge before the parents and their supporters, including various professional personnel.

The families lived in Sydney's western suburbs. With the agreement of the selected families and any doctors and social workers who regarded such families as 'their cases', we interviewed the mother or father or both on at least three occasions over a 12 month period. In 4 cases, the families were headed by a single mother. In 39 of the cases each father was interviewed at least once, but we acknowledge that in referring to parents' accounts of services most of the points of view came from mothers and most of the caring for the disabled children was carried out by the mothers.

Although we selected the cases 'at random', this is in no way a representative sample. The business of selecting representative samples would raise questions about the comparability of children's disabilities and whether all such disabled children were known or registered. Our objectives in interviewing the particular sample were to document these parents accounts of life at home with their children and their appraisal of the health and welfare services with which they had had contact. We wanted to discover the parents' interpretation of the usefulness of these services, and whether their assessments varied

according to their own personal resources, and over time (that is, from one part of the year or from one time of the week to another).

The 51 children were all under five. The disabilities which had been seen by the parents as obstacles to the child's physical and mental development had been diagnosed by a doctor, usually a paediatrician.

Nineteen of the children were diagnosed as having Down's Syndrome. Of these, eleven had complications such as a heart condition or problems with eye sight and hearing. Of the remaining 32 children, twenty were profoundly or severely mentally and physically disabled in the sense that they had severe difficulties in terms of self-care, mobility and communication. For example, in Case No.1 the child suffered cerebral palsy and though one year old, was unable to sit or lift her head. In Case No.6, the child suffered from Jada Hassan syndrome, was partially sighted and epileptic. In Case No.50, the little boy aged two had ear, heart and kidney problems and was microcephalic, in addition to being regarded as very mentally retarded.

In 12 cases we could argue that the children suffered from mental disabilities and that their physical disabilities were only minor in nature. However, 'only minor in nature' is a comparative judgement based on the severity of the other cases. For example, in Case No.3, a child of normal appearance was regarded by his parents as mentally retarded and described by the mother as having 'chronic behaviour problems'. In Case No.44, the child was epileptic and regarded by his parents as 'moderately mentally handicapped'. In Case No.39, the child was regarded by the parents as mentally retarded because at the age of three and a half he had developed no speech and also suffered from epilepsy.

We have made these distinctions in order to give some idea of the range of the children's mental and physical disabilities and to stress the importance of the parents', particularly the mothers' assessments. We have identified the Down's Syndrome cases because of the certainty of diagnosis. However, the apparent uniform diagnosis of Down's Syndrome obscures the range of disabilities experienced by those 19 children. The recognition of these children's difficulties was likely to increase as the parents came into contact with a greater number of professionals and as their expectations of what the child should attain increased with the child's age, in particular during the school years of 5-16.

In relation to the nature of disabled children's disabilities, a first question for staff involved in social policy and social work is, who do these children live with? Do they have parents, brothers and sisters? Family composition is an important indication of the potential resources which parents may use.

In common with disabled children in the Australian population as a whole, very few of the children were single children living with parents. Four out of the 51 were only children. Twenty four children had either a brother or sister and in 13 cases there were three children in the families including the disabled child. The number of children in the families ranged from 1 to 8, the average number of children was 2.9 and the most frequent was two. There were four single parent families. The following table gives details of family composition in relation to the various disabling conditions.

TABLE 2.3 CHILDREN'S CONDITION X FAMILY COMPOSITION

<u>Disabling Conditions</u>	Number of Children	<u>Family Composition</u> Number of Children in Family*		
		Range	Mode	Av.No.
<u>Down's Syndrome</u>				
(a) with complications e.g. heart conditions	11	2-6	2	3.4
(b) without complications	8	2-8	3(3)+	3.4 *1
<u>Mental and Physical Disability</u> e.g. severe problems with self- care, mobility and communication, typical examples include cerebral palsy, hydrocephaly	20	1-6	2(2)+	2.6 *1
<u>Mental handicap and mild or</u> no problems of physical disability	12	1-4	2(8)+	2.3 *2
TOTALS	51	1-8	2(24)	2.9 *4

* Denotes numbers of single parent families in that group.

+ Mode figures in brackets refer to the number of occurrences of the mode.

Nationality/Income/Housing

Elsewhere we have described this sample as homogeneous (Rees and Emerson 1982), at least in terms of their housing and nationality. In the latter respect they have much in common with all handicapped persons in Australia living in households (ABS 1982, Table 1.6), 79 per cent of whom were Australian born and 9.4 per cent of whom were from the U.K. or Ireland. The figures giving nationality of the parents of these 51 disabled children are shown in Table 2.4.

TABLE 2.4 PARENTS' COUNTRY OF BIRTH

Both parents Australian born	One parent Australian born	Both parents from U.K. and Ireland	Yugoslavia, Holland, Iran, Mauritius
39	5	3	4

With the exception of 2 families of Yugoslav and Iranian origin, all the families spoke English fluently. In other respects too, most of these families had resources which appear at first sight to have facilitated their care of their children, including the disabled ones. Thirty-five were paying for their own homes, 6 lived in low rental Housing Commission accommodation, the remainder rented privately.

Forty-three of the families described themselves as happy with their housing and its location. With 2 exceptions all the families had lived in their present accommodation for more than 2 years.

Income

We cannot make precise comments about these families' incomes in comparison to all families in the population with disabled young children. With the exception of the 10 families dependent on pension (4 lone parents, 4 on unemployment benefit, one on workers' compensation and one on an invalid pension),

the other families' incomes appeared to be above the poverty line, recorded in early 1981 as \$66.70 per week for a married couple and 2 children in rented accommodation (Smith 1982, Appendix 2, p.160).

Not all the families gave information about their incomes. Of the 31 who provided information, their average weekly incomes are listed in Table 2.5. Many of the mothers had various employment skills, but only one was in employment during the period of our interviews.

TABLE 2.5 MAIN BREADWINNER'S OCCUPATION X
AVERAGE WEEKLY INCOME

Occupation	Nos.	Average Weekly Income (Gross*)
Professional e.g. Teacher, Draughtsman	6	\$375.00 to \$480.00
Managerial-Executive e.g. Bank Manager, Sales Manager	8	\$375.00 to \$545.00
Clerical-Sales	8	\$150.00 to \$365.00
Manual (a) skilled e.g. Upholsterer, Carpenter	6	\$250.00 to \$320.00
(b) unskilled e.g. Factory Worker	4	No figures, estimates only
Self employed	9	\$180.00 to \$375.00
Unemployed/sick (4 single mothers)	10	\$145.00 to \$202.90+ (Social Security)
Total	51	

* Excludes family allowances and Handicapped Child's Allowance.

+ Refers to lone parent and two to four children with housing costs, (Smith 1982, p.161 and D.S.S. 1982, pp.31-4).

Of those in employment, incomes ranged from \$250.00 per week for a French polisher (but this depended on overtime), to \$23,000 p.a. in the case of a trained nurse, to incomes between \$23,000 and \$30,000 p.a. in the case of 6 of the 8 families where the husbands were in the Managerial/Executive occupational group.

Summary

All the 51 families had children under the age of 5 who suffered mental handicap and approximately half of these children also had severe physical disabilities. Four of the children were only children and 4 were from single parent families headed by a mother. All the families had been living in this particular urban region for several years and although their housing arrangements appeared to be secure, in other respects their material resources varied considerably. However, no great stress should be placed on the figures for gross incomes. The important point about this sample's material resources is that the majority in employment felt that their jobs were likely to be permanent and so too were their expectations about the arrangements for living in that particular area. At a time of 10 per cent unemployment and increasing costs in housing, it is at least plausible to claim that most of those families, if not above average in their material resources, were not handicapped by the constraints associated with long-term poverty, unemployment, homelessness or not being able to speak fluent English.

The relationship between material resources, including the meagre ones of those 10 families on subsistence level income, and the families' abilities to cope with the responsibilities for their children is discussed in Chapter 5. Before the parents discovered the tasks associated with caring for a disabled child and whether their resources were sufficient, they had to come to terms with the first bad news about their child's condition. That is the subject in the next chapter.

CHAPTER 3

THE MANAGEMENT OF 'BAD NEWS'

Most human beings have to receive traumatic news at some stage of their lives. Professionals of various kinds are employed to enable the recipients of bad news to 'adapt to their failure' (in education) (Clarke 1960), to 'adjust to their loss' (news of death or terminal illness) (Sudnow 1967) or, generally to be 'cooled out' (the case of people who've been robbed) (Goffman 1952). However, it is seldom that the recipients of bad news can say what they think of the professionals' techniques and their general conduct in these trying circumstances. Indeed, studies of clients' and patients' evaluations of professional services have only recently begun to fill this serious gap in the sociology of the professions. Consequently, we asked these 51 sets of parents how they received the distressing news about their child's condition and, in particular, who told them the bad news, whether they perceived this person or persons as helpful and their general feelings about the whole process.

Who gave the bad news?

Of the 50 families able to answer our questions on this topic*, the person to give the diagnosis to the parent(s) was:

- Paediatrician in 39 instances
- Gynaecologist and Paediatrician in 4 instances
- Team approach (Paediatrician, Social Worker, Psychologist) in 3 instances
- General Practitioner in 2 instances
- Social Worker in 1 instance
- Gynaecologist in 1 instance

* The diagnosis of one child had taken place in Iran and that family is not included in this part of the analysis.

The manner in which the news was given was divided into 3 main categories, such division depending on our (researchers') appraisal of the parents' perceptions of the attitude of the person who passed on the bad news.

- (1) Whether the person to give the news was sympathetic, i.e. receptive and responsive to the parents' feelings.
- (2) Whether the person was helpful, i.e. in answering the parents' questions, giving information freely regarding the child's condition.
- (3) Whether the person made referrals to other services which could help the parents further with sorting out their feelings, and how to cope with their child.

The results were as follows:

(1) Sympathetic	19/50
(2) Helpful	19/50
(3) Referrals	24/50 (5/50 of which were 'sideways' referrals for another medical assessment).

In only 8 out of 50 instances was the giver of the diagnosis seen as possessing all three qualities, 7 out of 8 being the paediatrician (the other, a social worker). In 3 of these 8 cases, the respective paediatricians were described as

- 'marvellous, he affected my attitudes positively'.
- 'caring and helpful. He put me straight into hospital so I could learn to care for my child. He introduced me to another mother'.
- 'very good, he arranged for some other parents to visit straight away, which was a terrific assistance'.

In these cases, the paediatricians were in a position to immediately steer these parents towards other helpful people and services. Most of this group of parents was surprised to hear from the researchers that other parents often struggled to find appropriate help. 'I thought that the paediatrician arranged for all new parents of a handicapped child to meet experienced parents straight away', said one mother who was in fact the only one to have this experience.

Some reactions of parents whose dismay at the birth of a disabled child was dealt with sensitively by a paediatrician include the following couple. The

mother said:

'I told the paediatrician not to let the baby live, I didn't want it at first, but he gave me lots of information and made me more aware ... he made me want him'.

In a separate interview her husband confirmed a similar reaction.

'We didn't accept him for the first 2 days, we just hoped he'd die, we knew little about it. It was the paediatrician who first convinced us that the baby was ours ... The hospital staff was also fantastic ...'.

The team approach of telling parents (i.e. paediatrician, social worker, psychologist, ward sister etc. sharing the responsibility) was used in 3 instances. This practice was seen as being helpful in giving information regarding the child's condition, and in making referrals to other services. In the cases where the paediatrician combined with the gynaecologist, or where a gynaecologist acted alone, or where the general practitioner gave the news, the handling of this delicate matter was seen as being carried out indifferently and clumsily, with little or no regard for the parents' feelings or need for more knowledge.

Insensitive Attitudes

Most parents mentioned a total disregard of their feelings, and saw the informant as being distant, non-caring, unable to relate to them, and insensitive to the stresses which parents were facing. Mothers' comments included the following:

- 'Doctors aren't interested in feelings, he told me to let her go into an institution to let her die. They wouldn't let me touch her for 4½ months ...'.
- 'The doctor said my child is a "mongoloid", and I should send her to an institution, he just kept looking above me, as if I wasn't there'.
- 'The paediatrician didn't know how to relate to us. He spoke so softly that I couldn't hear him ... I didn't understand him and blamed myself for giving my child the virus'.

- (One woman who spoke little English) 'the doctor kept talking about 'mongol' and I thought he said that my baby was a mongrel, you know, a dog. I wasn't allowed to see her for 24 hours, and I wasn't allowed to breast-feed her. I cried for many months, I couldn't talk to her until she was 9 months old. God is punishing me ... life is now a great sadness'.
- 'The doctor kept talking - big words, which I didn't understand. I said "Doctor, I'm only a carpenter, I can't understand what you're saying", so he said it again, but I still didn't understand ...'.
- 'The paediatrician said I couldn't expect much from him, just to let him sleep, which he did ... 18 hours a day'.
- 'They just took my baby away for 8 hours, and no one said anything, everyone stayed away from me. I was terribly worried. I wasn't allowed to breastfeed. Finally, I made them tell me'.
- 'I was confused, I didn't understand, I can only remember the words "mongol" and "institution" '.

These are only a few, but typical examples of the negative manner in which a majority of parents were informed about their child's condition. Furthermore, in many cases this negative experience was heightened by hospital nursing staff who were seen as avoiding them. Parents reported to us that 'they didn't know how to talk to me', 'they couldn't handle it', 'they told me to put her into a home'.

In only 3 instances were parents visited by a hospital social worker. In one of these cases the social worker was seen to be helpful in terms of her knowledgeable discussion with the parents about the pros and cons of institutionalisation. In the other 2 cases, the social worker was seen as 'young and wishy-washy, didn't know anything about it herself'. 'I asked her for some books, but she said she wasn't allowed to take them out of the hospital library', as one of our parents explained.

In several cases, mothers left the hospital with guilt feelings, misconceptions, sadness and anxiety as to how they were going to cope with their retarded children. No effort had been made to help the parents resolve the crisis state that they were in, nor to follow them up in the community.

In 19 (60%) of the 32 families whom we were able to interview on this topic, the husband and wife were together when the news was given, while in 13

(40%) of the 32 instances, the mother was on her own. Where the parents had been informed together, they reported that they had been able to share this news, comfort one another and discuss the situation. Where mothers were on their own, they usually said that they wished their husbands had been there. Some had not understood the bad news, and they expressed anxiety at having to tell their husbands. One mother contended that the doctor told her in the afternoon, but she wasn't permitted to ring her husband until 5.00 p.m. as 'hospital rules do not permit patients to ring out before then'.

We have insufficient information as to how parents did finally resolve the crisis which was precipitated by the news, and whether the manner in which the news was given had any bearing on this. It could be speculated that if the bearer of the news could show empathy, be helpful, and make immediate appropriate referrals, that would enable the crisis to be resolved more quickly, and there may be less likelihood of an unwanted child going home with a confused parent. On the other hand, some researchers argue that the 'crisis' can only ever be partially overcome. The parents, or at least the mother, will spend a large part of the rest of their lives accommodating the extra pressures which are part of the responsibility of caring for a disabled child.

The manner in which both mothers and fathers responded to the 'bad news' can be illustrated in terms of these parents' most dominant reactions. We recorded such 'reactions' following answers to our questions on the subject in our first interviews (Table 3.1).

TABLE 3.1 PARENTS' REACTIONS TO THE BAD NEWS

Shock and Dis-belief	Rejection	Guilt	Grief and Depression	Relief and/or Acceptance	Non-Acceptance Non-Comprehen-sion
14	9	2	5	16	4

Where husband and wife were interviewed together, their stated reactions were surprisingly similar. However, when mothers were interviewed alone they reported that, at the time of diagnosis, their husbands took longer to accept their feelings and had postponed any expression of their sense of loss because they did not wish to display openly their emotions. The wives explained, 'he kept his feelings inside more', 'he acted bravely for my sake'. Several women looked forward to the interview at which their husbands would be present so that they could hear how the husband felt at the time of diagnosis, as 'he never really told me'.

Almost without exception, the parental response was affected by the stage at which they were given the news. Where the parents were told at birth, or in several cases where the child had been thought to be normal until it came in contact with a virus, i.e. in cases where the parents were expecting a normal child, the reaction was invariably described as 'shock', 'depression', 'guilt', 'rejection', 'disbelief'. This reaction is apparently typical, irrespective of the actual diagnosis, i.e. whether Down's Syndrome, or mental retardation through some virus, or chromosomal aberration other than Down's Syndrome (Hewitt 1970; Price-Bonham and Addison 1978).

Confirming Suspicions

At the time of our research interviews, a minority of parents still had not accepted the diagnosis, either because they denied it, or because they did not understand it or its implications. In one of these cases, the mother was herself retarded and chronically dependent on State welfare services. It could be argued that she will perhaps never understand fully that her son is mentally retarded, or what the social implications of such a condition are.

For 16 out of the 50 families, however, the term 'bad news' is a misnomer. In these cases the diagnosis came as a relief, either because the parents had expected something to be wrong (and therefore the diagnosis was associated with a sense of acceptance), or because it implied that the parents had not been responsible for the months (or years) of incessant crying and behaviour difficulties, and that they had not been incompetent parents. Rather, the cause of their child's behaviour was due to something outside their control, i.e. something was wrong with their child. Some parents explained:

- 'They (the doctors and psychologist) kept saying there was nothing wrong, and they blamed it on us. They called it "environmental retardation". When he was 4½ years, they finally diagnosed him as functioning at a 2 year level and being overactive. It was a great relief that it wasn't me'.
- 'I took him to a G.P. and a local health centre for 2 years, and told them about his problems. They diagnosed him as normal, although I knew there was something wrong. I paid \$100.00 to have him diagnosed by this organisation. I read about it in a magazine. They prescribed a program of "nervous system stimulation", but I couldn't keep it up, it was too much, I dreaded having to do it. I would have taken my child to other places, but I didn't know where'.

Another couple were relieved when their 3½ year old child was diagnosed as severely mentally retarded as both parents had become depressed about the lack of recognition of the problems they were having.

'Now he's been diagnosed as retarded, we can do something positive. My wife used to cry all the time, and ring me at work every day because she couldn't cope with the situation. I couldn't concentrate on my work through worry'.

Another mother who had herself diagnosed cerebral palsy in her baby, at 10 weeks, went from doctor to doctor to have her diagnosis confirmed, only to be told each time that the child was normal.

'If only they (the doctors) would sit down and listen to the mother, who after all, knows her baby the best. They give you five minutes in and out. My baby screamed the whole time, I didn't know how to comfort him. I was beginning to think I was imagining things, and I wasn't being a good mother. Finally at 5 months, I found a paediatrician who recognised the symptoms straight away and understood what I had been going through. He put the baby and me straight into hospital so I could learn how to manage him'. (Child is severely physically and mentally disabled).

In other words, then, a reaction of relief or acceptance of diagnosis occurs with parents who had suspected that something was wrong over a period of time, who may have been experiencing behaviour difficulties with their child, or who had a suspicion that their child was developing too slowly. Diagnosis meant, firstly, that they were not responsible for their child's behaviour or lack of development and, secondly, that help might now be available to rectify the problem.

It also needs to be said that almost all the 50 parents had no prior knowledge of mental handicap. Before the arrival of their child, they had no face-to-face contact with anyone who had a disabled child or disabled adult member in their family. In the only instance where parents knew of a next-door neighbour with a severely disabled child, it helped them to 'accept' the diagnosis of their own child. They said later, in these circumstances, they were aware of many of the problems that would be involved.

Summary

Most parents were informed about their child's disability by a medical practitioner and, in a majority of cases, this news precipitated some form of crisis. Yet the bearers of the news did not recognise the emotional traumas that parents experienced, and they were generally not seen to be empathic or helpful in giving information nor helpful in putting parents in touch with appropriate services.

A glaring omission from the battery of professionals with whom these parents were involved were social workers, who should be skilled in helping parents to cope with the impact of bad news about a disabled child, who should know a great deal about disability in children and about appropriate services. We argue this point because the task of enabling parents and others to come to terms with a sense of loss and grief through, among other things, learning about support services is one of the central roles of social workers working in medical settings. They should not only have the skills and commitment in undertaking this work, but should also plan to provide the time to do it (Rees and Wallace 1982). Yet in this sample, although 21 out of 50 mothers knew about their child's disabling condition before leaving the hospital, they received no such professional guidance in the hospital nor were any follow-up visits made by social workers.

Effective teamwork between paediatricians, general practitioners and social workers is an area of 'treatment' which is ripe for improvement.

Another important finding is the struggle that many parents have to go through to find help for their child when they suspect that something is wrong. It appears that few professionals give parents credit for recognising symptoms themselves, and rarely do they make home-visits to investigate fully parents' suspicions. The emotional traumas that parents go through for years before

any conclusive diagnosis is made must not be underestimated. Understandably in some cases, diagnosis comes as a relief.

CHAPTER 4

THE EXTRA FINANCIAL COSTS

The style of analysis now changes from the phenomenological approach used to analyse the management of bad news to the inevitably more pedestrian consideration of information obtained from a survey. Such a change of style is not intended to jar with the reader but rather reflects the business of accounting for information about financial costs. Our purpose was to discover the extent to which the care of a young disabled child imposed extra financial burdens on families.

The extra financial costs of caring for disabled children are a burden for families because those costs are often heavy, unpredictable, and more than they can manage. Despite some stereotyped view that the Welfare State foots the bill for such disabilities, the disabled themselves, including families with disabled children, know that the Welfare State is mostly an inadequate provider (Rock 1982).

In order to document the extra monthly costs incurred by the 51 families, we interviewed them about their expenditure in the previous 6 months, at a time when all the children were aged between 1 and 4 years. There were various methodological difficulties in getting parents to provide an accurate record of extra expenditure and in the following discussion about the inventory of costs we have been deliberately cautious and produced only conservative estimates. Ideally, estimates of the costs of caring for a disabled young child should be derived from a comparison of expenditure incurred by families of the same composition, class, status and income, half of whom have disabled children, the other having non-disabled children. Our data did not enable us to make these sorts of comparisons nor to investigate what proportion of family income was spent on the disabled children.

The mothers' estimates confirmed those principles affecting the direct and indirect costs of child-rearing, referred to by Cass, Keens and Wyndham (1983) as (i) the mother's dependence on intra-family transfers (from husband or pension) and (ii) the mother's removal from or subsequent non-participation in the work force and consequent drop in family income at a time when household expenditure needs increase. This latter point was

invariably the first matter raised by mothers when we discussed with them their expenditure, their income and their opportunities for earning.

Income Opportunities

Although many of the 51 mothers said that they would like to work, only one had been able to do so, part-time. In this case, it was possible because her husband was self-employed, and his flexible hours meant that in her absence he could be responsible for child care.

In the first few years, the task of obtaining appropriate professional services and carrying out therapy programs at home was the mother's, and in several cases the conscientious pursuit of services had become virtually a full time occupation.

The mothers' difficulties in obtaining child care also lessened the possibility of their seeking employment opportunities. Full time, high standard day care for a child requiring constant attention, such as toileting or changing of nappies, lifting and feeding, or supervising a child who may have convulsions, or is hyperactive, or who may present behaviour problems, was difficult to obtain. Half a dozen families experienced rejection of their child by one or several pre-schools because their child was not toilet-trained.

Not only will mothers of severely handicapped children find it impossible to obtain any extra income but their husbands may have to turn down chances of working overtime because they are wanted at home. Many fathers stated that in order to accompany their wives to appointments or to be available in times of added stress, such as when the child was hospitalised, they had to take time off work. For white collar salaried employees this did not result in loss of income, but for wage earners it often did. One father told us that for a few months his employers turned a blind eye to his taking time off, but then his pay was docked whenever he had to return home unexpectedly.

Several fathers spoke about lost opportunities for promotion directly owing to their handicapped child. One father was offered a management position in his company in the South-Western region of the State but he thought that facilities for their child would be scarce there, and the family decided to stay in Sydney. A father who was a salesman said that the flexible hours in

this job suited his family commitments and he could not 'afford' to take a more highly paid job which had fixed hours. His physically and mentally handicapped child was too heavy for his wife to lift, wash, dress and feed, so that the emotional burden of his son's problem and wife's depression made it impossible for him to continue in his public relations job, and he requested a transfer to a lower-status clerical position. Another father was unable to accept the position of caravan park manager because the job was located too far away from facilities for his son.

Expenditure

It is difficult to assess the social costs, including domestic rearrangements, which families had to make to care for their children because such items are a matter of interpretation - a burden to one family is a blessing to another. An inventory of the financial costs of caring for a handicapped child is at first sight a slightly more straightforward exercise, yet others who have documented the extra costs of disability have noted that even the financial costs are often hidden and therefore difficult to record (Rock 1982).

The subsequent list of extra expenditure provides an account of costs incurred by all the parents whose children were both physically and mentally handicapped. However, with the exception of the items 'special equipment and aids' and 'items purchased for the child's comfort', the other costs were also incurred by parents whose disabled children were not physically handicapped, i.e. they were costs commonly incurred by all the 51 families.

1. Regular Medication

Most children were required to take several different drugs which, if available on National Health, cost \$4 per prescription. A number of drugs, such as those used to control convulsions, were not available on National Health, and therefore were more expensive.

We did not have any control group of families with children of a similar age, whose medication costs we could compare. In these circumstances we can only document what the parents said about the estimated extra expenses involved in controlling additional complications arising from their child's disability, for example, all the parents stated that they frequently use antibiotics, special skin creams, analgesics, etc. In 1981, pharmaceutical bills were

estimated by parents to range from \$10 to \$30 per month.

2. Special Equipment and Aids

The cost of wheelchairs ranges from \$500 (manual) to several thousand dollars for an electric chair (according to information given by the Spastic Centre). Calipers range from \$50 for a short pair, to several hundred dollars for a pair that bend at the knees. Surgical boots, walking frames, special car seats, hearing aids, bath supports and vaporizers are all costly, and with a growing child may need regular replacement.

Some organisations, such as the Crippled Children's Society in New South Wales, and some hospitals lend equipment to children who are considered eligible. According to a social worker at the Society for Crippled Children, many parents whose child may be eligible are unaware of the possible help available from such an agency.

The Commonwealth sponsored Provision of Aids for the Disabled, which is operated through State Health Departments, was intended to provide universal coverage for the supply of such aids. Shortage of funds, however, has made it necessary to limit provision of aids to those with limited means only and none of the 51 parents had obtained equipment through that scheme. None of their children were in wheelchairs, but many whose children had physical disabilities seemed likely to need such items in the near future.

3. Medical Insurance

Most parents paid the highest scale for full cover and said that they would drop to a lower scale if their child was not disabled, a difference of as much as \$35 per month. One mother who received the deserted wife's pension paid \$35 extra per month for full cover so that, she argued, her child could continue to see her own doctor. None of the parents in the research were aware that their handicapped child could be treated at no cost at their local hospital.*

* On payment of \$20 per out-patient as from September 1981, then towards the end of 1982, under State Government arrangements. The State then waived the charge and introduced a levy on health funds to pay for it. (The High Court confirmed that States could impose a levy on Health Funds.)

4. Transport

To obtain the services of therapists or other forms of professional attention, families travelled regularly from such places as Campbelltown, Picton, Londonderry and Springwood to services located in Penrith, Parramatta, Camperdown (Royal Alexandra Hospital for Children) or Randwick (Prince of Wales Hospital), distances of approximately 80 kilometres or more, return journey. At the time of interviews with the families about extra costs*, they were having regular contact with 4.2 services (See Chapter 8 for detailed discussion), so that it was not uncommon for the mother to drive these distances 2, 3 or 4 times per week.

Parents said that petrol costs were at least \$10 per week, but no-one stated the hidden costs of wear and tear on the car, for which recompense for employees who use their cars would be at the rate of 13¢ to 19¢ per kilometre.

Twenty two mothers stated that they had to purchase a second car, as travelling by public transport with a handicapped child was difficult and time consuming. This involved the extra costs of registration, insurance and the purchase price of the car. In almost all cases where there was only one family car, the husband left it at home for his wife's use and travelled to work by public transport, (or in one instance, by pushbike) entailing extra costs. (A weekly train journey from Mt.Druitt to Sydney at that time cost \$8.90 or \$35 per month.) The 4 mothers receiving Social Security all said they needed a car, but could not afford one.

5. Day Care and Special School

The 15 mothers whose children were attending pre-school indicated that they paid from \$6 to \$20 per week for 3 days of child care. They considered this care necessary not only to help their child develop as normally as possible, but also to maintain or regain their own sanity. Many mothers said that if their child had not been handicapped they might not have used child care.

Most non-government special schools require payment of fees from parents, ranging from approximately \$15 to \$30 per month. As if to add insult to

* This occurred in mid 1982 when most of the children were between three and five years of age.

injury, some parents reported that the special schools asked them to offer their services to help with fund-raising, implying that a condition of having their child attend the school was not only the payment of a deposit, but also willingness to work in their spare time on the school's behalf. One such mother said:

'... he goes there two days per week. I have to carry out a Home Programme with him for them. On top of that, I have to do speech therapy and occupational therapy. I have another child who needs my time too. And then they tell me I've got to help them raise funds. I haven't the time to do it all ...'

6. Private Specialist Services

If community services were unavailable or unsatisfactory or where there were long waiting lists, many parents had used private services. The cost of these services can sometimes be partially claimed from medical benefit funds, but parents were still paying \$12 to \$40 per week for private speech therapy and one parent paid \$50 for an assessment. The cost of the Down's Syndrome programme at Macquarie University was \$10 per week (\$40 per month). One mother paid \$100 for a one-morning diagnosis by an organisation which claimed that their continuous stimulation program could cure her son. It cost \$20 to have a child assessed by the Association for Children with Learning Disabilities (ACLD), and a further \$145 per term for 2 mornings of remedial teaching.

7. Education Aids

Most parents had bought extra educational toys in the hope that it would capture their handicapped child's interest, and/or to compensate for their child's lack of skills and slow development. One mother said:

'First I bought him Lego which was around \$50, but he couldn't put it together. Then I tried some other building sets, they were all expensive. We bought him a special bike two years ago, but he still can't use it. I buy puzzles, special crayons and books, anything that might interest him, and will encourage him to use his hands more. I would easily spend \$20 per month on such things.'

8. Domestic Help

All families with handicapped children are eligible to apply for Domestic Help. The contribution, depending on a means test, varies from \$1.50 to \$6.00 per week. Six of our families received Home Help. (The cost for this was means tested.) One mother was paying only \$2 per hour, but even this low rate for 3 hours per week came to a monthly outlay of \$24.

9. Babysitting

A commonly accepted rate was \$2.50 per hour (\$4 at a professional agency), an expense most parents were unable to meet and in consequence, although these parents needed the relief that comes from going out occasionally, they tended to stay at home. There seemed to be little alternative. Babysitting was a service which most parents found difficult to obtain because few neighbours or relatives were willing or able to take on any permanent responsibility to babysit for the parents of a severely disabled child.

10. Temporary Care

Once or twice a year, to give themselves respite, some parents placed their child in hostel accommodation. In New South Wales such care costs \$5 per day, and \$2.50 per day was deducted from their Handicapped Child's Allowance, another example of adding insult to injury.

11. Special Foods

These can be very expensive but are often necessary for severely or profoundly retarded children with digestive problems. In addition, mothers of children in this group (12) said a blender was purchased to prepare such food.

12. Items Purchased for Child's Comfort

The parents of those 20 children in our sample who had severe problems with self-care and mobility (see Chapter 2) stated that they had bought certain items in the hope that they would help their child to be more comfortable, for example, a waterbed, hammock, sheepskin, bean bag, vaporiser to help with breathing and, in one instance, a swimming pool. The parents of the children who were severely physically disabled were most likely to make such purchases.

13. Extra Clothing

Extra clothing was required for children who soiled themselves frequently, or for those who crawled for years and therefore quickly wore out the knees and elbows of their garments. Several mothers stated that the school or pre-school requested provision of disposable nappies, which could amount to at least \$10 per week (\$40 per month). One child angled his feet when walking and wore out new shoes at the rate of a pair per month.

TOTAL COSTS

Families with a disabled child incur high costs in caring for their child at home. Yet these costs are relatively small by comparison with the costs of keeping the child in an institution. If their child was placed in an institution such as Marsden Hospital, the rate (March 1982) was \$70 per day or \$2,100 per month (\$25,550 per year).

As indicated earlier, all the parents whose children were both severely and physically disabled incurred all the costs listed in Table 4.1. With the exception of a few items amounting to approximately \$30 per month, all the costs were incurred by the other 51 families. This gives us an 'on average' figure of \$200 extra per month and an actual cost of \$230 per month in the case of the apparently more disabled children.

In producing these estimates, in March 1982, only the minimum essential costs were used and some parents certainly spent more on some of the items. There are other grounds for arguing that this list is not an overestimate. Baby-sitting costs are not included, partly because parents said they could not afford them and educational items have been omitted because of the difficulties of obtaining an accurate figure of how much had been spent. We have not recorded other extra costs such as housing adaptations or those incurred when a family has to move house. Apart from the reference to the costs of extra clothing, there is no reference to the extra costs of incontinence, such as those involved in maintaining a washing machine and drier or in buying good quality disposable nappies. Hidden costs such as extra treats for siblings to balance out the attention given to the disabled child or for outings to stimulate the disabled child are not recorded.

In spite of these omissions, the following 11 items add up to a significant

figure of \$230 per month.

TABLE 4.1 : EXTRA MONTHLY COSTS

Items of Extra Expenditure	Average Monthly Cost in Dollars
1. Regular medication	10
2. Special equipment and aids (calculated at 1 item/year at \$100)	8
3. Medical insurance (extra for full cover)	35
4. Transport (gross underestimate, as previously explained), plus father's monthly rail pass or registration, insurance etc. for a second car	40
	36
5. Day care or school fees (\$6 per week, if subsidised)	24
6. Private services (e.g. the cost of Macquarie University's Down's Syndrome Programme)	10
7. Domestic Help (3 hours per week at a subsidised \$2 per hour)	24
8. Temporary care - approximately 12 days per year at \$5 per day	5
9. Special food, formulas	10
10. Extra items (calculated at 1 item/year at \$100)	8
11. Extra clothing	20
	\$230

Adequacy of Handicapped Child's Allowance

Since 1974, the Department of Social Security provides a Handicapped Child's Allowance under the terms of the Commonwealth Social Security Act of 1974. At the time of compiling the above expenses, most of the parents received a non-means tested \$73 per month, and parents of less handicapped children, officially referred to as 'substantially handicapped' could receive between \$20 and \$73 per month, the actual amount depending on a means test. In January 1983, these amounts were increased to \$85 per month for severely handicapped children and a range of \$20 to \$85 for those who could prove substantial handicap. The difficult procedures which parents encounter in

obtaining this extra financial help and the undue influence of doctors in the whole process is described in Chapter 7. In the remainder of this chapter, it is the apparent inadequacy of the current rates which needs to be highlighted.

On the question of the financial adequacy of the Handicapped Child's Allowance (HCA), the Australian Council for Rehabilitation of the Disabled (ACROD), have recently argued that, 'to maintain its value relative to the average minimum weekly wage (AMWW), at introduction in 1974, the HCA would have to be increased by \$15 per month to \$100' (ACROD 1983). ACROD also argue that 'the Handicapped Child's Allowance now would be \$368 per month if relativity with the Family Allowance had been maintained'.

The same ACROD paper refers to the view of the New South Wales Anti-Discrimination Board (ADB) 'that the Handicapped Child's Allowance should be fully indexed to keep up with the cost of living and in addition the size of the payment should be reviewed in relation to the extra costs incurred by a family with a handicapped child'. In 1980 the ADB estimated that that figure would be \$170 per month.

In respect of these arguments and the costs of caring for the most severely handicapped children, as listed above, it is apparent that the Handicapped Child's Allowance is an inadequate supplement to the Family Allowance. In spite of this, parents who may admit their children to care temporarily lose the HCA during that period when the child is away from home. Yet the institution receiving the child would be entitled to receive the Handicapped Children's Benefit, currently worth almost twice as much as families receive for looking after their child at home. It is difficult to identify a plausible government policy in favour of family care and against institutionalisation. In fact the reverse appears to be the case.

Parents' Views on Adequacy

It is an interesting anomaly of consumer research (McKinley 1972, McCaughey and Chew 1977, Rees 1978) that families whom outside observers judge to have received little or no help often expressed satisfaction with services. The consumers' low expectations resulted in high rates of approval of services. In this respect it is not surprising that 13 of the 27 mothers who were receiving the Handicapped Child's Allowance said that it was adequate. But

their judgement seemed related not only to their low expectation of help, but also to their lack of a detailed record of the extra costs which caring for a disabled child imposed on their financial situation. Half of the sample said that the allowance was never enough to cover expenses and several families had incurred debts running into thousands of dollars.

When the child's condition has stabilised and he or she starts attending school, expenses may not be as high. The school tends to cater for many of the child's needs and it was the parents of children who were attending pre-school who contended that for the time being the Handicapped Child's Allowance was adequate.

Most mothers said that the costs were greatest in the beginning, when they were constantly visiting specialists and various non-medical services and were accumulating resources to care for their child. Some parents suggested that the allowance should therefore be higher during the several years following diagnosis.

On the other hand, these parents had little knowledge of what future costs would be as their children grew older. A study by Baldwin suggests that hidden costs such as those involved in constraints on parental employment will be increased with the age of the child (1981).

Another cost, which has not so far been mentioned, is a need to provide for the future. Many parents feared that when they died, their disabled child would be institutionalised and they were anxious to keep him/her financially independent from his/her siblings. Several parents spoke about purchasing a home with other parents, and making investments to pay for its running costs. One parent spoke about buying a farm for their Down's Syndrome child. Another wanted to build an extra room on to the family home where their child could live independently when an adult.

Summary

An appalling picture of economic burden has emerged from our survey of the extra financial costs of caring for a disabled child. In March 1982, the average cost of caring at home for a severely physically and mentally handicapped child was estimated to be \$230 per month at a time when the maximum Handicapped Child's Allowance rate was \$73 per month. For all parents in

this sample, even for the parents whose children did not have physical handicaps, the average cost was estimated to be \$200 per month, but parents acknowledged that some of their expenses were greatest in the first year following diagnosis.

The current practice of deducting the Handicapped Child's Allowance if the child is temporarily admitted to institutional care amounts to adding insult to injury. The practice of paying institutions almost twice as much* as families who care for their children at home is another glaring inconsistency at a time when the rhetoric of policy for the disabled emphasises community care, a euphemistic reference to mothers caring for their children at home.

* At the time of writing, July 1983, institutions would receive \$5 per day as Handicapped Children's Benefit. Parents receive approximately \$2.79 per day Handicapped Child's Allowance, if they have been granted the full amount.

CHAPTER 5

STRESS AND THE SENSE OF COPING

If the policy objectives of Federal, State and voluntary agencies are to enable families to look after their disabled children at home, it is important for the employees of those agencies to know about the factors which make child care difficult and which place excessive responsibilities on one or more family members. With a view to exploring these questions the following discussion focuses on 3 interrelated topics.

- (1) The meaning of stress, expressed in the parents' own words.
- (2) The factors which affected the mothers' experience and management of stress.
- (3) The extent to which health and welfare services and/or support from a personal network affected parents' sense of being able to cope.

(1) The Meaning of Stress

Stress usually refers to a disturbing physiological or psychological influence which produces a state of severe tension in an individual. Social scientists refine the term further, describing a sense of stress as occurring when tensions become unmanageable. For example, McCubbin and others (1980) define stress as a response of the distressed family to the residue of tensions generated by those unmanaged life events which are great enough to bring about change to a family system. For the families with young disabled children, stressful events were chronic, long term and included the physical burden of caring, emotional reactions to the child and the extra social and financial costs.

Although all of the 51 parents could give several examples of stress, there was no uniformity in their reactions to apparently similar events. In these respects the families explained the meaning of stress by making 2 separate points. Firstly, all sorts of life events, when they became unmanageable, were seen as stressful. Secondly, parents described different reactions to and apparently different levels of stress in relation to the same events.

For example, the severity of each child's disability did not produce similar experiences of stress.

Similar observations were made in Bradshaw and Lawton's study of 303 mothers of severely disabled children who formed a random sample of families living in 5 different areas of Britain and who had applied for help from the Rowntree Trust's Family Fund (Bradshaw and Lawton 1981). The mothers were asked questions about some common emotional and physical states associated with stress, and their responses showed that stress was not related to a particular condition or disability.

'It was thought for instance, that mothers of children dying from cystic fibrosis or muscular dystrophy might have higher scores (measuring stress) than children with stable conditions like deafness or blindness. Conditions like spina bifida which present substantial physical burdens might result in higher scores than mongolism, which it is sometimes argued, presents relatively few demands ... In no case was the difference in scores observed larger than could be expected to occur by chance ' (Bradshaw and Lawton 1981).

These authors also found that stress was not related to the mother's age, the child's age, the family size or the difference between one and two parent families. The only qualification to add to these conclusions was that mothers whose only child was disabled experienced less stress than mothers with more than one child. What emerges then, is a picture of enormously variable response to stressful events and even to what is perceived as stressful.

(a) Mothers' Roles

In analysing the Sydney parents' accounts of how they managed child care in general and the disabled child in particular, mothers experienced one or more of the following kinds of stress.

- (i) Physical tiredness amounting often to exhaustion.
- (ii) Anxiety prompted by the sense of stigma associated with the child's handicap, not being a 'good mother', or 'good wife' and, in some cases, to a sense of being 'punished by God'.

- (iii) Increasing sense of isolation contributing to feelings of depression.
- (iv) The burden of extra financial costs.

Sometimes parents' comments referred to all these points. The mother of a 2 year old profoundly physically disabled and mentally retarded child had to ask for her son to be put in residential care. She explained why in her local parish newsletter.

'Oh yes, I got lots of sympathetic remarks and well-meaning messages of consolation. But sympathy didn't calm my screaming child, nor ease the physical exhaustion of myself and my husband. It didn't explain to my toddler why I spent all my time with her baby brother and never had time for her. It didn't lessen the numerous visits to the doctors, assessment centres, nor carry out the numerous household chores that seemed to be reaching insurmountable heights. In fact, it did nothing but increase my great bitterness.'

Usually parents who at the time of our interviews said they felt unable to cope or were only just coping, found it easiest to describe their sense of stress in terms of physical tiredness. Yet, the tiredness seems to have referred often to a sense of failing to meet expectations of family responsibilities and relationships as much as it was an account of physical exhaustion.

The mother of a 2 year old severely physically and mentally disabled child, who has 2 other children (aged 3 and 4) told us,

'I'm always tired and irritable. An early night for me is midnight. I'm often up ironing at 2.00 am. I suppose I get five hours sleep a night on average ... I don't give my husband and the other kids enough of my time ...'

The mother added,

'I'd like him to die ... for his sake ... he's often in pain and nothing can be done ... that really upsets me.'

Two other mothers admitted that when they felt tired and rundown they felt like killing their children. One, who said she had been persuaded by her husband and older children to take her Down's Syndrome baby home, still felt ambivalent about the child even though he was now almost 5 years old.

'When I give him a bath, I sometimes feel like letting him slip into the water and drown. I feel I'm the only one who has such negative feelings ... I get very depressed ... but it's all in my head.'

Physical tiredness leading to a sense of depression is one of the high costs of the incessant demands of caring for a severely disabled child. These costs do not appear to be fully understood by the various professionals - paediatricians, general practitioners, community nurses, social workers and therapists of one kind or another, whose treatment-type meetings with the mother and child may last at most an hour or two hours per week. Within the family, the sense of an increasing barrage of demands, made worse by others' lessening interest and support, is explained by the mother of a one and a half year old severely physically and mentally disabled boy.

'I've been overtired, getting depressed, feel I can't face another day. T. cries all day and night, I have to swing him in a net in the garage at 4.30 a.m. It's the only thing that stops him crying ... the others need some sleep. I can't give my attention to Peter (another child), he's misbehaving terribly ... both our parents are staying away, my mother especially can't handle T. not smiling ... we have no friends left ...'

In this example, as in others, the mother implies that others need more sleep than she does and she blamed herself for the misbehaviour of another child. Even though the majority of family tasks are already undertaken by the mother, many of them still seem to have superhuman expectations of what they could and should achieve.

The mother of Peter explained that the sense of pressure was not always on her because she and her husband took turns in the early hours of each morning to swing the child in the garage. The various references to the roles of the fathers indicate that a mother's sense of coping is affected if the child care responsibilities are shared.

(b) Fathers' Roles

Little is known about the father's role in the family of the disabled child; presumably because fathers are at work at the time when professionals, including researchers, visit, and because it is assumed that mothers do most of the caring. Thirty nine of the 47 fathers were interviewed, mainly in the evenings, about their response to their handicapped child and about how they

contributed to family functioning. The observations that follow include wives' perceptions of their husbands' roles.

The following excerpts from a conversation with the father of an 18 month old, profoundly physically and mentally retarded boy indicate that many fathers do care but that it is difficult for them to play caring roles similar to those of their wives.

'I'm aware of how K. feels, because I love her. I know that she's tied to the house, and life's routine. She needs a break. I try to give her as much opportunity as possible to go out, or have a sleep in the afternoon when I'm here ... Life was so easy before R., but now I couldn't live without him. I have to get up at 5.00 a.m. in the morning to study, and he knows I'm awake, so I hold him in my arms while I study. When I get home, I help to feed and bathe him. We have spoken about temporary care but we find it hard to part with him, although we know we need a break. K. is not a strong person physically, and emotionally this has been a big drain on her. She's reminded of it every minute of the day. She is always worried that he's going to die. These last 9 months have been terrible, always new hurdles to get over, now his epilepsy, then his refusing to eat. Going to doctors is a terrible strain. There's always the worry of how to get there, as K. doesn't drive ... I love R. in a very special way, he's so helpless, his future frightens me, I'm still hoping he'll be O.K., although I know he won't be. Our latest problem is that K. is not going to sleep for the constant worry about R. ... I couldn't cope as well as I do, if I couldn't forget about it while at work.'

This father has described frankly how his child's disabilities affected him, his wife and his marriage. He gave the impression of having accepted his child's handicap, and its future implications. He was sensitive to his wife's plight in caring for their son, and he contributed as much as he was able to relieve her of some of the pressures. This father's role demonstrated 3 particular characteristics:

- (i) acceptance of the disability at the time of interview.
- (ii) ability to talk about feelings related to the disability.
- (iii) helping with child care/housekeeping so as to relieve some of his wife's burdens.

When we had sufficient information, and for the purpose of producing some rough classification of all the fathers' roles, the evidence about these 3 characteristics produces the following table representing a continuum of responses to child care and other family tasks (Table 5.1). Response A we

refer to as 'Continuous Involvement', Response B as 'Occasional Involvement', and Response C as 'Relative Indifference'. Such variety of responses and attitudes gives some idea of the resources available to the wives in their efforts to manage their children and ward off any sense of undue stress.

TABLE 5.1 FATHERS' RESPONSES TO CHILD AND FAMILY

Types of Responses	Acceptance	Express Feelings	Help	Total
A Continuous Involvement	Yes	Yes	Yes	20
B Occasional Involvement	Yes	No	No	4
	Yes	No	Yes	5
C Relative Indifference	No	No	No	10
				39

There was some indication that the responses of the fathers were class related. For example, most of the 'A' fathers had salaried employment which gave them a degree of flexibility in terms of working hours and time to support their wives. By contrast, the 'C' fathers were all blue collar wage earners, whose incomes were not only low, but whose employment conditions made it difficult for them to take time off without losing pay.

However, the responses to caring for handicapped children are not simply explained in terms of fathers' employment and levels of income. The evidence about class affected responses is inconclusive. Among the 'continuously involved' fathers were two who were unemployed and who said that while unemployment created financial difficulties, it also enabled them to take an interest in the children and relieve their wives.

We have recorded the different range of responses not in any way to imply moral judgements but as a means of reminding professional workers that some consideration of the father's role is part of any assessment of the resources available to care for a disabled child at home.

Only half of the fathers, 20 out of 39 in this sample, expressed feelings related to having a disabled child, including affection, anger, guilt and a sense of isolation. Almost two thirds, 25 out of 39, helped with housework and/or children but, as indicated above, we think that from the mothers' point of view, the claims about helping with housework should not be over-rated. For our purposes, an interesting picture of family relationships emerges, ranging from Response A, 'Continuous Involvement' to Response C, 'Relative Indifference'.

Continuous Involvement: The responses and attitudes of these fathers might be considered an ideal, at least from the three points of view. This group contains the fathers who were accepting of their child's handicap, able to express their feelings about it, as well as being helpful with housework and/or child care. In these respects the father of a 2 year old Down's Syndrome boy was described by his wife in these terms.

'My husband helps out, although he's a busy man. This year I've been in hospital three times. He managed the family very well, from nappies to formulas. He's versatile. Since having L. the children are not just my responsibility anymore ...'

The father of a 5 year old mentally retarded boy explained,

'I have to work hard to keep the family happy. I've got to help my wife ... I don't go to the pub, they need me at home. And I've learned to enjoy it. I wasn't so involved with the kids before (i.e. before the discovery 3 years previously, that this little boy who looked normal was mentally retarded and developed behaviour difficulties associated with the mental retardation).'

This father of a 5 year old profoundly physically and mentally retarded boy described the adjustments he made to some daily routine.

'I start work one hour later in the morning so that I can help dress F. and feed him. He's too heavy for D. (wife), and she can't handle him by herself. I don't take lunch to make up for lost time ... I suggested to D. that she go to work and I stay home to look after G., because I'm stronger, and better able to do the therapy with him ... if it would mean he won't go to an institution, I'd stay home if the Government paid me ... all I can do is give him love, and accept him to be handicapped. D. gets very depressed, she has no-one but me to turn to. I don't know how she copes.'

In Category A, the marriages were reported by one or both partners to be 'strong' and some parents reported that they had become closer. When depressed or anxious, these couples reported that they could and did turn to each other.

'K. and I have a good understanding, we turn to each other.'

'I ring my wife once a day from work and we talk about things.'

With one exception, these parents claimed that their priority was the whole family, rather than their retarded child. Regarding family priorities, some parents said that they had changed from initial preoccupation and devotion to the handicapped child, to a realisation that their energy had to be divided among all the family members.

'Our priority is the whole family - we've got to keep the marriage going, and keep the family together. We could have participated in a Doman Delacarto programme, and A's dad offered us \$7,000 to set up a special room for it. But we decided that it wasn't worth making the whole family suffer for an unguaranteed amount of success.'

'C's life is fairly defined, and the others in the family shouldn't be deprived of their future, or opportunities because of him. If we hadn't been able to cope with C. we would have placed him elsewhere.'

Other than knowing that these fathers enjoyed relatively stable marriages in which they carried out their share of housework and child care, we remain relatively ignorant of the personal consequences of stress for such men. On this issue, Cummings found that fathering a disabled child created more stress than fathering a normal child, leaving them with 'a sense of relative inferiority as fathers, which may carry over into their overall general self esteem as men'. In accounting for this stress, Cummings (1976) considered the following factors,

'... fathers' parental roles only infrequently include such rehabilitative or health tasks such as trips to the doctor, therapist, special school ... Fathers, relative to mothers, thus characteristically have fewer opportunities to do something directly helpful for their handicapped child; something that provides concrete evidence of their loving, caring and benevolent concern. Relatively few opportunities for counterbalancing the sense of loss, frustration and attendant anger are provided for in the father's role.'

Cummings observed that services rarely paid much attention to fathers' roles and that there were few opportunities for fathers to unburden themselves, through talking and examining their roles. These observations applied to many of the Category A fathers. Some of them stated that at times they had felt depressed, and had experienced a sense of guilt for having to work and not being able to help more. In addition, some referred to their feelings

of isolation, to wondering how other parents coped, and to worries about the constant financial burden and the future.

These fathers had accompanied their wives to health and welfare agencies and some were members of parent support groups, or were involved in helping to develop local services. In these respects, as Cummings has suggested and our observations support, when fathers became involved in the helping process, this lessened their sense of stress (Cummings 1976). The issue of whether such 'involvement' reflects class differences in lifestyles has been referred to above in our references to those fathers whose occupations enabled them to take time off work. We merely highlight the issue which merits further research.

Occasional Interest and Involvement: This group included fathers who expressed acceptance of their child's disability but felt unable to express feelings and, on their own admission, did not do much to help their wives. In this respect one mother explained,

'I've got the kids all day, 7 days per week, without a break, while his job is only 40 hours. I can't talk to him about the kids because he says he has his own problems.'

Such fathers' alleged difficulties in expressing feelings about their roles in caring for their children were expressed by one mother,

'My husband has always been a good father. He's a soft man, but doesn't talk about it. He has a perforated eardrum, which plays up when he gets upset. When we were told about the handicap he was in bed for three weeks, and felt like shooting himself because of the pain. For the first six weeks we were living under false pretences. He said nothing to me and I said nothing to him. At six weeks he took a fit, and the doctor explained everything again. That night I laid in my husband's arms and we cried all night and talked about it. But it's the only time he's let go. It takes a special kind of man to cope with a handicapped child, because he has to help more with the kids, and he gets less affection from me because I'm always tired.'

The father of a 2 year old physically and mentally handicapped child confirmed that he knew his wife was frequently tired, but said he could seldom do much to help out.

'It's emotionally draining, I know my wife cops it most, but I get depressed too. Everything gets on top of you. We're stuck in a rut and can't get out.'

Relative Disinterest: This group, 10 out of 39, represents those fathers who said they had still not accepted their child's handicap, felt unable to express their feelings and, on their own admissions, seldom helped with housework or child care. The mother of a 3 year old boy with chromosomal abnormality resulting in mental retardation explained her husband's attitudes and family activities in these terms.

'He won't accept B. as handicapped, which makes it hard on me, he could be more helpful even in giving encouragement about the places I take B. His parents were Italian and he has a very definite opinion that a woman's place is in the home. He never gives me a break from the kids. He goes to the pub two, three nights per week. He sees this as an opportunity to relax, a release after work he calls it. He says he doesn't like being bugged by kids when he's tired from work. He thinks that what I do at home is easier than his work, and doesn't see that I have a need to relax too. I have no opportunity.'

The mother of a 2 year old Down's Syndrome boy described her husband's reaction.

'He took it more deeply, and wouldn't ring any friends. He won't pick up D. I have to force him, by "plonking" D. into his arms ... He's a contained person and won't talk about his problems. We have arguments about his discipline - he doesn't support the ideas suggested at the clinic, which puts me under pressure ... He doesn't help in the house, he doesn't see it as his job. I've met other mothers with handicapped kids, their husbands seem to help, while mine sits ...'

Some fathers acknowledged that a sense of pressure or dissatisfaction with life at home had prompted them to seek some form of escape, as in seeking employment away, by being rarely at home in the evenings, by constant arguments if they were at home. In 3 cases, mothers reported that their husbands had deserted them. In these latter cases the wives said that their husbands' departures produced a sense of relief and that subsequently they coped better.

Two of them explained,

'R. never being at home or never being interested when he was at home, all got to me.'

'He was always hitting them, he had unreal expectations. We're all relaxed now that he's gone.'

When the wives of 'relatively disinterested' fathers felt depressed or anxious, they did not expect to look for support from their husbands. Perhaps in consequence, 4 wives in this group said that they had become relatively preoccupied with the care and development of their disabled child, as though other family matters had been relegated in importance.

The roles of fathers are important in two specific respects:

- (i) as a resource to their wives.
- (ii) because the extent to which they shared responsibilities with their wives affected mothers' interpretations of stress and hence their sense of coping.

We return to this second point later in this chapter.

(2) Mothers' Resources to Cope with Stress

Several commentators conclude that the level of stress experienced by individuals is determined by internal factors including, in Pearlin and Schooler's terms, 'psychological characteristics': those positive and negative self-attitudes and the extent to which an individual perceives that he or she has control over life's chances (1982). McCubbin and others refer to 'personal resources' including the range of people and information available to the individual in times of need (1980). These definitions are somewhat broad and unexceptional but what they say is important, if only because it needs questioning.

The theory is that events become stressful in varying degrees, in relation to a family's or individual member's lack of appropriate psychological or personal resources. We question such an explanation. In our terms, resources are represented by a combination of internal and external considerations brought into play in the circumstances of one point in time and in events over time. For example, material considerations such as adequate income, adequate housing and appropriate support from others affect each individual mother's sense of personal 'psychological resources' (Pearlin and Schooler 1978). These points should become clearer if we

compare 2 families' reactions to their respective Down's Syndrome children. Family A enjoyed a high, secure income, a large well furnished home and close support from their respective parents. Family B were migrants who spoke poor English, lived in a small rented house and the father was only occasionally employed.

Family A

Both parents' initial reactions were shock, and wanting their baby to die. The mother said she cried for several days and then realised, 'my attitude affected the attitude of those around me'. She explained, 'I asked God to give me strength, and found that any change in attitude had a good effect on my family'.

The father stated that in talking to the paediatrician and close friends, he also became positive towards the baby. The parents are now involved in a parents' support group and an early education programme, and are hoping that, with this help, their child will eventually attend a normal school.

This family felt that they could and should plan for the future, that they could have some control over the quality of their disabled child's life. They were making specific plans for the future in terms of financial investments and provision of accommodation. In dealing with officials with a view to solving personal problems, they demonstrated what has been referred to elsewhere as a 'circumspect orientation' (Rees 1978), i.e. they had the sense of control over their circumstances which enabled them to seek out a variety of sources of help and experience a sense of equality in their exchanges with professionals.

Family B

The mother stated that the arrival of their Down's Syndrome child was

'An absolute shock ... a great sadness. I cried for many months, and couldn't talk to her until she was 9 months old. Before M. was born, we were a very happy family, now we will never be happy any more ... the sadness will always be with us. What's the use of her going to school, her life will be short.'

The father had become depressed and would not talk about the consequences

following the birth of his child. He had obtained employment which took him away to Newcastle, a 3 hour drive north. The mother had not informed her family overseas, though the child was now 5 years old. She preferred to stay at home, rather than make contact with friends or neighbours. Despite regular contact with a social worker, the family seemed unable to move out of its sense of powerlessness amounting often to depression.

In terms of how personal resources affect responses to stress, Family A showed evidence of striving to make their child have normal opportunities irrespective of his disability. But their apparently comfortable material resources and confidence in encounters with representatives of authority facilitated such 'strivings'. By contrast, Family B thought that God was punishing them for a past wrong-doing and that consequently they would continue to suffer, regardless of any action taken. The mother in Family A discovered that feeling good about herself and her child influenced positively the attitude of others. The mother in Family B felt damned, not worthy of the regard of God, her family or humanity generally. She and her husband were fatalistic and their orientation to dealing with officials and solving problems was essentially 'passive' (Rees 1978), i.e. they did not seek out help and in exchanges with professionals they felt relatively powerless, unable to influence the direction or outcome of the meetings.

Each mother's response to stress is apparently affected by a combination of internal and external resources. The internal resources, as in these 2 families, refer to items such as the mother's interpretation of her role, the attitude of her husband, her own adaptation to any sense of guilt or other strong feelings about the causes of the child's condition and a certain spirituality providing inner strength. Possible external resources include

- (a) mother's opportunities to seek paid employment.
- (b) standard of housing.
- (c) use of outside services such as babysitting.
- (d) a sense of confidence, derived from experience, in using resources.

Families' approaches to the twin tasks of housekeeping and child care represent, as it were, the harnessing of internal and external resources. It is in these respects that we will identify families' own definitions of coping.

The following brief comments about these separate topics are made against the background of assumptions about the extra financial costs of caring for handicapped children. Elsewhere in this report, we have shown how the burden of extra financial costs is made up, how the Handicapped Child's Allowance is an inadequate compensation for these costs and is in any case only obtainable by a small proportion of families.

(a) Employment Opportunities

Most of the 51 mothers said they were unable to seek work because of the full-time responsibilities of caring for their disabled child. Only 2 mothers in this sample were working and one of these was able to work only part-time.

Bradshaw and Lawton (1981) found that mothers who stayed at home, but who wanted to work, suffered significantly more stress than those who were at home and who did not want paid work. In this English study, mothers who were working suffered significantly less stress, but the number of mothers working was considerably less than among mothers in the general population. The U.K. National Children's Bureau (NCB) has also concluded, recently, that the incomes of families with handicapped children suffer 'because mothers are less often able to work and the father's earning capacity is sometimes also affected' (NCB Highlight No.42, 1982).

(b) Housing

Only 4 of the 51 Sydney families said they were unhappy with their accommodation because of insufficient space (such as no yard), or insufficient number of bedrooms, or because of poor standards of housing - 'cold, damp and miserable', as one mother put it. Forty (80%) of the families were paying for their own houses and many said they planned to make alterations or additions to make caring for their children easier. At the time of interviewing, 3 families were making such changes.

Bradshaw and Lawton (1981) concluded that those mothers who perceived their houses to be unsuitable because of the child, suffered significantly more stress than those who thought that their houses were suitable. The NCB also concluded that unsuitable housing would exacerbate the problems of caring for a handicapped child (NCB 1982).

(c) Babysitting

In our previous discussion of the adequacy of services, we referred to parents' comments about the need for some relief to enable them to go out occasionally. In almost all the examples of the consequences of lack of babysitting facilities, including family day care, it was the mother who was regarded as restricted and, in many circumstances, marooned at home. One mother of a Down's Syndrome child who had physical complications said,

'I often feel terrible about not going out. My husband goes to the club, talks to his friends, it helps him. I can never go out with him. I don't know anyone who could look after M.'

The majority of parents confirmed that they seldom went out together because of the difficulty of finding persons capable and willing to handle a child who may be incontinent, may need lifting or feeding, or whose behaviour may be difficult to handle in other ways. In only 4 families were parents able to use older children to undertake babysitting responsibilities.

Bradshaw and Lawton (1981) found that stress did not vary according to the number of times that mothers were able to get out, but rather, mothers who wanted to go out experienced more stress than those who did not. The perception of being restricted created stress. Similarly, mothers who had not had a holiday in the past 3 years experienced more stress than those who had a holiday during the last year.

Clearly, social policies and social welfare practices that do not plan some temporary care and babysitting arrangements are overlooking an important family need.

Coping in Relation to Child Care and Housework

Such interdependence of definitions of stress and sense of coping were inherent in families' expectations that certain objectives in relation to housework and child care were not being met. Although possible resources such as opportunity to work, standard of housing and availability of babysitting have been listed separately from the parents' account of stress, they did affect parents' attitudes to their child and expectations of their roles. Although our exploration of the meaning of coping only follows the verbatim comments about stress, the two notions or experiences are

inseparable. For example, the expectations which parents derived from a particular milieu or culture affected whether they regarded as stressful either lack of sleep or anxiety about a child's lack of progress or the need to do things when other children of the same age had developed responsibilities for self care.

This inseparability of definitions of stress and adaptations to it has been summarised neatly by Reiss and Olivieri: 'First the magnitude of a stressful event is determined by the interaction of hardship and cultural definition. Second, cultural definition shapes the magnitude of the stress, family definition shapes the style of the response' (1980).

With regard to mothers' expectations of their roles and consequent perceptions of stress, Oakley has argued that notions of being a 'good mother' did not call for the same qualities as being a 'good housewife' and the pressure to be both may prove unbearable (Oakley 1974). In enquiring into the impact of housework on child care, Olsen showed that the time a mother spent with her child varied according to the importance she attached to housework and child care (Olsen 1981).

Sometimes parents set very high child care and housework standards for themselves irrespective of whether they had the resources to meet them. If mothers valued spending time with their children, they did so irrespective of tiredness, lack of housework help or progress with household chores (Olsen 1981). These points also emerged in our discussions with each of the families about what they meant when they said they could or could not cope.

From these discussions, three notions of coping emerged, representing a continuum of different expectations and resources.

- (1) A majority of parents suggested that 'coping' implied an ability to accept the child's handicap, perform all the extra chores associated with that child, and at the same time feel that other aspects of life, particularly housekeeping, are under control. In addition most felt they should manage to remain 'relaxed', 'patient', 'very level', 'free from stress', 'sane', 'comfortable'. However, this definition places the mother under considerable stress and leaves her little time for herself.

- (2) A smaller number of parents had a definition similar to the first one, with an important difference in relation to housekeeping. They felt that coping implied 'an ability to do the most important things and not worry about things left undone', or 'getting your priorities straight, that is, an ability to let unimportant things go (such as making beds), and just enjoy the kids'. Such a definition permits the mother not to be the 'perfect housekeeper', leaving her more time for the children and herself.
- (3) Some parents broadened the housekeeping responsibility away from the mother to the whole family, and stated that coping implied a sense of co-operation between all family members, particularly between husband and wife, with everyone accepting the handicap and sharing chores associated with the child and general housekeeping. This interpretation of coping emphasises the responsibilities of the whole family and thereby diminishes the emphasis on the mother's role, enabling her to have time to herself.

One could speculate that, if for some reason the mother is sick or absent for a period of time, then a family which 'copes' according to the third definition, is more likely to be able to manage than would a family which 'copes' according to the first definition. In definition (1), the 'coping' rests almost entirely on the shoulders of the mother, while in definition (3), 'coping' rests with the whole family, so that everyone is responsible, and the mother is able to pursue activities outside the home. In definition (2), although 'coping' is still largely dependent on the mother, it seems that she is expected and expects herself to perform only those chores for which she has time.

In addition to the points about families' expectations of child care and housework, there are two further points to be made. Firstly, that the sense of being able to cope varies over time. Secondly, the task of carrying out specific therapies at home is difficult to achieve.

(i) Variations over time

That the ability to cope can vary from one point in time to another was illustrated by Mrs. G., the mother of a 5 year old, severely physically and mentally handicapped boy.

'I have lots of ups and downs during the week, which are related to how G. is feeling; whether he's sick ... and is eating ... G. won't eat, he vomits his food ... I feel terrible when he's like this. I don't know what to do when he cries ...'

Mrs. G. explained that her level of coping decreased towards the end of each day.

'Between 4.30 and 6.00 p.m. every day is the hard rush. I'm tired from picking up A. from school, and the youngest is pulling at my dress ... It's difficult to cook dinner, and I have to cook two meals, because G. can't eat what we have ...'

This mother's ability to cope was the lowest at weekends:

'My husband has two jobs and comes home late. But the weekends are the hardest to cope, because my husband is often out helping others, and he works on Saturday night as well, and G. isn't at school so I've got to lift and feed him by myself all day, as well as look after the other two ...'

'I've put G. into temporary care for a while, until I pick up a bit. This is the first time I've had to do this ... I hope he'll be alright ... I'm only a small person, and I find it exhausting to lift him, to change his nappy or clothes, etc. ...'

Other mothers confirmed that their ability to cope decreased at the end of the day, when domestic duties of cooking, tidying and preparing children for bed all piled up. As one mother stated,

'I'm a different person at the end of the day. I find myself yelling all the time. I hate myself like that.'

Another mother said that her retarded son's behaviour deteriorated so much by each evening that she often found herself slapping him, and had feelings that she could easily kill him.

Some mothers found it more difficult to cope during school holidays, in particular during the six week summer vacation, even if they could rely on help from their husband, older children or other relatives. It was more difficult to do the shopping with all the children at home, and a few families said that the pressure of a disabled child made outings impossible. A holiday for the children became a period of undue stress for some mothers.

The mother of a 4 year old moderately retarded child explained that her increasing sense of helplessness was sharpest during school holidays. In terms of lack of 'internal/external' resources, her predicament was admittedly one of the worst we observed, yet some of the events which affected her life and that of her child, such as little relief from a constant sense of pressure, were not unusual.

'I'm not coping well during the school holidays. It's too much having them home 24 hours a day for 6, 7 weeks. They run around and scream if I take them to the library. I can't go shopping. No-one offers to look after them because they can't handle B's behaviour. ... My husband is not helpful, I never get a break ... my health is failing, I've been in hospital with a chest infection, then I've got a urinary infection and a vaginal infection and I've had surgical extractions of teeth - I think I'm run down.'

(ii) Therapies at home

Mothers had varying perceptions as to how much time to spend doing therapy with their child, or even how many therapists to visit. Some thought their child would improve miraculously if they worked almost non-stop, while others felt that therapy was the responsibility of trained professionals, albeit with the support and interest of parents.

One mother who claimed to have achieved a balance between housework and child care, including physiotherapy, nevertheless said that no matter how much work she did with her daughter, she always felt guilty about not spending more time carrying out specific therapies.

'At first her needs were no different to any other baby. Then when it became obvious that she was slow, I spent the whole day, every day, taking her places and doing exercises with her. I was so totally involved with C. that I forgot K. (husband) and myself. Now I realise she will not improve very much and I am not working so hard at it any more. I am taking some time for myself, like going to tennis. But it still makes me feel guilty, like I am lazy. My husband helps with the housework and he does the cooking. But he doesn't do physiotherapy - he get frustrated.'

In families where the responsibility for coping was regarded as almost entirely the mother's (see definition (1) above), the time and the stamina required to carry out home therapies would be difficult to find. However, with regard to requests to carry out therapy at home, the following comments were typical of all the mothers who were trying to meet such requests. The

combined expectations of family and therapists could be unrealistic, despite some researchers' careful attention to parents' attitudes to home based therapies (Rees, R. 1978).

'I have to do physio exercises with him and this means that the others miss out ... My husband frequently misses out on breakfast because I'm busy with S., and the other two kids (aged 6 and 8) have to get themselves off to school.'

'If you don't do it at home, they (the therapists) tell you off. This with all the other everyday things, like cleaning nappies, gets to you.'

'The biggest bugbear is doing things at home, because you're out all the time at services and don't always feel in the mood. We have to be in the mood. I feel guilty if I am not doing work.'

'The physio said I had to do all these exercises everyday. They were just too much along with housework, shopping, etc.'

Professional people, such as educators and therapists of various descriptions who recommend home therapy programs to be carried out by the parents, should consider carefully how feasible these roles are in relation to other demanding tasks. Mothers seemed to find the extra tasks of carrying out therapies impossible to sustain because they were experiencing stress due to the conflicts of other demands such as those of housework and child care. It is difficult not to see, straight away, that the responsibility for home therapy is one role that husbands could be more involved in.

Where mothers say they are having difficulty in achieving some kind of balance between these roles, then professional staff who think that home therapy is desirable should discuss the question of stress with a view to either

- (a) helping the parents achieve a balance from themselves, or
- (b) providing domestic help until (a) is achieved, or
- (c) providing help with therapy until (a) is achieved.
- (d) encouraging the husband to take responsibility for some home therapy.

Parents' comments about their carrying out therapies at home indicate that professional services do not always add to families' resources. If one listens to the claims of some professionals who specialise in the area of children's handicaps, then one would think they were a key factor in enabling parents to cope. But are they?

(3) Coping : Professionals' Services and Personal Networks

A key social policy/practice question remains concerning the inter-relationships between families' own resources and those available from professional services such as physio, occupational and speech therapists, play groups, pre-schools, community nurses, social workers, and doctors. One way to explore this interrelationship is to ask how the family's ability to cope was affected by personal social networks compared with professional services. The question is crude because it assumes some direct relationship between coping and the presence or absence of certain support or services, when in fact we know that a mother's sense of coping varies over time and according to her expectations of her role and that the pressure to carry out certain professionals' instructions may prove more debilitating than helpful. However, pursuing this question may show something about the relative merits of personal networks compared to professional services.

During our second interviews we asked all the mothers (and some fathers, too, if they were present) whether they were coping or only just coping. We pursued this question even though we knew that the mothers' expectations of their child care/housekeeping roles varied and, in consequence, so did their interpretations of coping. A majority, 38 out of 51, said they were managing at that time even though some said that this didn't imply that some extra help would not be beneficial or that, if the question had been posed under different circumstances, their answers would have been different. A minority, 13 out of 51, said that at that time they were not coping and most of those insisted that such non-coping was a relatively permanent state of affairs.

In relation to these 'coping questions', we asked what professional services they were in contact with at that time and whether they considered that any of the services provided genuine interest and support, including understanding, encouragement and useful information. These aspects of helpful services represented some of the criteria which mothers referred to in their evaluation of services and which are referred to in detail in the chapter 'Parents' Use and Judgement of Services'. Because this part of the analysis was completed after the second interview, the average number of services which families were in contact with at the time, 3.5, was lower than the average number, 4.2, as calculated after the third interview (see Chapter 8). The relationship between the existence of professionals who provided useful understanding and support and parents' sense of coping was

crudely tested statistically (Table 5.2). This test showed that out of the 38 families who said they were coping, under half (0.46) said they were receiving at least one service which demonstrated real care for the family. Of the non-coping families, a little over one third (0.38) said they had had contact with at least one professional who had shown care in terms of useful understanding and support.

There was no statistically significant relationship between an ability to cope, the availability of useful professional services or the total number of services provided. Differences between abilities to cope will have to be explained in other ways, for example, by the availability of a supportive personal network and the effect of such networks on definitions of stress.

TABLE 5.2 PROFESSIONAL SUPPORT AND FAMILIES' ABILITY TO COPE

Coping Families	Coping Families	Non-coping Families	All
Receiving useful services	17	5	22
Not receiving useful services	21	8	29
All	38	13	51
$\chi^2 = 0.13$		$p = 0.5$	

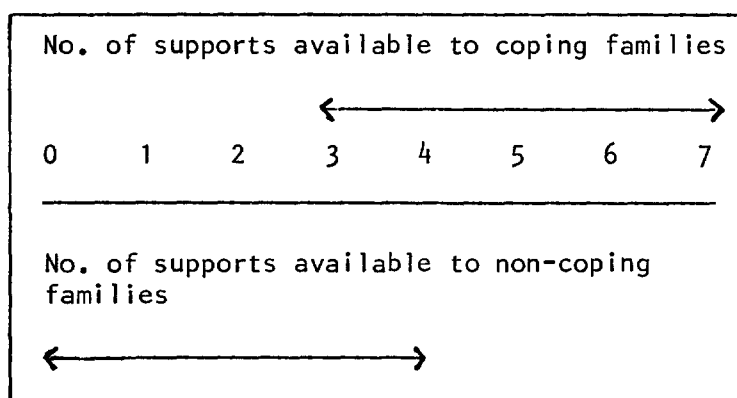
The Importance of Networks

Research literature suggests that informal social networks provide a considerable amount of support to families experiencing stress (Unger and Power 1980; Litwak and Szelenyi 1969). The strong positive relationship between social networks and a family's adaptation to societal crisis, life transitions and family conflicts has been confirmed in such literature and we did not explore this question in any depth. However, we did ask parents about the reactions of their extended family (such as grandparents, mother's sister, friends and neighbours) to their disabled child, and whether they were in any way supportive. On the assumption that the mother did most of the caring for the child and made most of the visits to services, we also asked mothers about the support available from husbands. The categories of support referred to were:

- (1) maternal grandparents
- (2) paternal grandparents
- (3) any other family members, e.g. mother's sister
- (4) neighbours
- (5) friends
- (6) husband
- (7) non-professional contact with the child, e.g. local children who play with the child, volunteer from a neighbourhood centre.

Mothers were asked which of these possible seven sources of support were supportive in terms previously described. In this we were able to give each family a score in terms of the number of supports available from their personal network. Thus, a family with no supports scored 0, while a family who could count on all of those relatives or friends scored seven.* Out of the 13 families who were not coping, 4 had no support at all, 7 scored for 2 supports and the remaining 2 families scored 3 and 4 supports each. All the coping families scored between 3 and 7.

TABLE 5.3 COPING AND THE PERSONAL NETWORK



These results indicate that the number of supports available to mothers from their social networks is important in enabling them to feel that they are able to cope. Indeed, this conclusion has been documented with reference to other population groups and other helping services (McKinlay 1972; Rees 1978)

* These figures were intended to indicate the range of supports available in the family, not the depth of that support. For example, if a mother had three supportive sisters, she would still score only one.

and has important implications for intervention by the helping professions. However, this emphasis on the importance of personal networks should not obscure the earlier point that stress is a matter of interpretation, that what is stressful for one mother is routine for another and that any sense of coping is tied up with these interpretations. Personal or social networks can apparently be important in influencing mothers' definitions of unmanageable tension by being available to help them with some of the tasks which they consider commensurate with being a good wife or mother. This indicates that an important way for professionals to be and to appear relevant to mothers under stress is to reinforce such networks or to build them up where they are fragile or non-existent. Some professionals, paediatricians, community health nurses and social workers can facilitate better communications where networks are breaking down; they can clear up misunderstandings and enable others to comprehend the implications of the child's disability. Parents can also be helped to explain their anxieties regarding contacts with others. In this regard, one mother wrote in her local church newspaper,

'To have quality of life we need successful personal relationships ... but the feeling of embarrassment can be crippling ... they don't know how to handle the situation, whether to look at us or not, whether to offer help, or to honour our sense of independence. The uneasiness makes them act in all sorts of unpleasant ways and some of them may be misinterpreted by us. We get the wrong message. It's taken over two years of agonising bitterness to realise that perhaps I, as the mother of a handicapped child got the wrong message ...'

In tracing the events associated with the management of bad news it was apparent that many parents did not understand exactly what was wrong with their own child, thus making it almost impossible to explain matters to others. The chances of mothers 'getting the wrong message' were high if they were not given effective counselling and follow-up at the time of diagnosis. For example, many mothers came home from hospital in an unresolved state of crisis. They often felt depressed, angry, rejected, and were left to face their family and social networks totally unprepared. No-one helped them to cope with their own feelings, thus making even more difficult the parents' problems of trying to understand the reactions of other people.

It is important to note how hard it can be for mothers coming home from

hospital with 'normal' babies and just how the problems of such 'adjustment' are exacerbated by having a disabled child. For 'normal mothers' the reality does not correspond with the mythology; how much less does it correspond for these mothers?

Several parents thought that people avoided them until they themselves became more positive about their disabled child. One such mother said 'I couldn't expect others to accept my baby, until I fully accepted him myself'. After initial withdrawal of friends and family she found that by a change in her manner of interacting, people began to react more positively. She said that 'I can now put people at rest straight away, by simply referring to the handicap straight away, which then gets it out of the way, so you can enjoy yourself'. She felt that experienced parents might have helped her realise this instead of her reaching this conclusion by painful trial and error.

Experienced parents can assist new parents by discussing the tasks of coping with the child, with housekeeping and with the general public. A majority of parents said that at the time of diagnosis they would have liked contact with experienced parents, but only one family had had such a contact. Most respondents also said that they would be prepared to help new parents by talking about some of their experiences. But no-one had asked them, and an important source of help remained untapped. Other examinations of the influence of social networks on the resolution of personal problems have shown how important peer support can be (McKinlay 1972; McCaughey and Chew 1977).

Summary

If support for families who care at home for severely disabled children is to be a main priority in professional agencies' policies, more attention must be paid to the undue tensions and consequent stress experienced by mothers. It is the mothers who do most of the caring, make most of the contacts with professional services and in most families appeared to carry out the extra physical tasks of washing, lifting and feeding. Perhaps in consequence, mothers often described stress in terms of physical tiredness. The tiredness was associated with their sense of failure to meet ideal notions of being a good wife and mother, to meet societal expectations of having a normal child.

Fathers' ability to share the tasks of housework and child care was a real asset to their wives where there was genuine sharing. On the other hand, the organisation of services at a time when fathers were at work and in the present cultural climate of assumptions about men being 'masculine', not having much to do with child care, made it difficult for some fathers to develop a caring role.

Resources, such as availability of babysitting, size and quality of housing, opportunities for employment and extra income and the ability to make use of a potential range of outside services, were important in affecting mothers' sense of being able to care effectively for their children. This sense of caring or coping affected definitions of stress and whether it was manageable.

The availability of a personal network of relatives and friends who could provide important forms of interest and support had a more direct effect on mothers' sense of coping than did professional services. The latter were not unimportant in affecting mothers' sense of coping, but if their aims were to provide support for mothers, this could be done not only by providing specialised services, but also by reinforcing the mother's personal network. This task could be carried out effectively by staff such as social workers in association with general practitioners and community health nurses, but their effectiveness would depend on such 'named person's' co-ordination of the activities of several professional agencies.

In some families, professional services unwittingly increased the mothers' sense of stress and made more difficult their management of child care. For example, recommendations to carry out therapy programs at home unaided were seen by some mothers as an added burden, particularly if they felt that their child was not making progress. In addition to being offered, and in some cases being inundated with badly co-ordinated professional services whose activities were difficult to comprehend, some families observed that those services which they probably could have understood, such as support from other parents, or planned day-care, were not available to them.

CHAPTER 6

A HOTCH-POTCH OF SERVICES

The Family Ideal

An ideal, based on conceptions of normal family life in which child-rearing is the central activity, is at the hub of assumptions that families with disabled young children should be able to manage their responsibilities (Voysey 1975; Bayley 1973). This ideal expects parents to subjugate their own interests to those of their children and, moreover, to enjoy any sacrifices thus incurred. The ideal refers to parents' joint tasks, yet implicitly it supports the role of the mother as the full-time 'unpaid' carer.

From such untested assumptions and ideals, a chequered arrangement of services has grown in the different Australian States. Each of these services is aimed in some way at supporting or complementing the responsibilities of families, except where the young disabled are institutionalised and the State or voluntary agency takes over the responsibility of caring.

At the Federal government level, financial assistance to families is provided through the Department of Social Security in the form of direct payment, such as the Handicapped Child's Allowance, or subsidies as in the part payment of the costs of residential care. State governments provide a range of health, welfare, education and recreation services, but the ways in which they organise these services vary from a centralised statutory responsibility in South Australia through its Intellectually Disabled Services Council, to an untidy ill-thought-out set of arrangements in New South Wales where responsibility is shared between Departments of Health, Education and Youth and Community Services.

The responsibilities of local government also vary from State to State, but such local governments, through their Councils, can be expected to provide some educational services, as in pre-schools, and some recreation facilities, as in holiday play centres for disabled children. Voluntary agencies, subsidised heavily by State or Commonwealth government, provide welfare services (for example, in New South Wales the Subnormal Children's Welfare

Association or the Association for Children with Learning Difficulties); health services (such as in the therapies available from special clinics); and educational programs, in special schools or sponsored projects.

Private enterprise increases the number of apparent choices available to families. General medical practitioners are likely to provide many families with a first source of advice, assessment, or a first step in what could become an increasingly complex referral system. A second step in such a referral system may be from general practitioners to other private medical specialists and therapists. In addition, private enterprise is likely to provide at least some accommodation services, as in private foster homes.

Implicitly at least, these different services are based on the value that, as far as possible, the child should be cared for at home or in the 'community', not in institutions. These values have been expressed in recent years in a policy of normalisation, which in Wolfensberger's terms means living under conditions which enable each individual to achieve 'behaviours and characteristics which are as culturally normative as possible' (1972). These principles of normalisation have been defined in the recent NSW Richmond Report as 'living a normal life in a normal environment' and living 'with least restraint, i.e. being able to take the risks associated with a normal life'.

At least at the level of statements of policy objectives and community ideals, no reference need be made to the roles of mothers and fathers in caring at home for their children. But in attempting to meet parents' needs and achieve the ideal (of normal family life as far as possible), governments and voluntary agencies have developed other values and goals.

Ideals of Government/Non Government Organisations

Almost every government report on the organisation or re-organisation of services for the developmentally disabled refers to the importance of co-operation between the professions and the families, and between the various professionals themselves, i.e. doctors, social workers, community nurses. Such reports also emphasise the desirability of co-ordination between agencies, which in turn means avoiding unnecessary overlapping and duplication.

Another powerful principle refers to the importance of dealing with all aspects of an individual's and a family's needs, both at one point in time and over time. Such principles are usually represented by references to the comprehensive or holistic nature of services and to the desirability of continuity of care. Regarding this latter principle, Richmond presents the important policy objective, 'the care of the developmentally disabled (unlike mental health services) is distinctly different from mainstream acute health services in that the focus is life-long and educational' (Richmond 1983).

For most professionals the priorities in policies of normalisation for the care of young children with disabilities are early assessment and intervention. Who intervenes at an early stage and whether they do so in a co-operative, co-ordinated and continuously supportive way so as to facilitate each family's chances of leading a normal life with their child, remains to be seen.

Whether professional services make it easier for families to care for their young disabled child at home depends mostly on whether services are comprehensive in their coverage of needs, and easily accessible. Questions about comprehensiveness and accessibility will in turn depend on the degree of co-operation between various professionals and the degree of co-ordination between agencies. By discussing these issues of comprehensiveness, co-operation and co-ordination, we will give some idea of the network of services which confronted these 51 families and some indication of parents' perceptions of the organisation of services.

Comprehensiveness

In arguing the desirability of having one department or organisation responsible for the overview of services for the intellectually handicapped, the New South Wales Council for the Mentally Handicapped (CMH), has identified three levels of need (CMH Today 1982).

- (1) Primary needs, where behaviour 'can be improved and remedied by developmental and educational programmes' and where the appropriate educational and welfare services will promote the individual's independence and integration in community life.

- (2) Secondary needs, where physical conditions associated with mental handicaps may be remedied by non-medical therapies such as physiotherapy, speech therapy and occupational therapy.
- (3) Tertiary needs are those which emerge when additional difficulties are added to existing handicaps, as when a disabled child suffers an illness, develops complications arising from the original condition, or has an accident that requires treatment from general community health services or hospitals.

Confronted with such needs, it is the responsibility of 'community services', so the Health Commission of New South Wales argues in a policy statement in 1981 (NSW Health Commission 1981), to develop and maintain a healthy and happy life for handicapped children and adults. With regard to the services which are likely to be immediately required by families with young disabled children, the New South Wales Anti-Discrimination Board (NSW ADB) lists

- counselling for parents at the time the disability is diagnosed.
- referral to the appropriate health, welfare and educational services.
- early intervention to stimulate development of the child, which includes physio and speech therapy.
- domiciliary nursing care.
- day care and play groups.
- assistance in arranging suitable residential care (NSW ADB 1980).

Whether such services exist in the appropriate quantity and location to match population numbers and needs will be affected by the existence of one authority with the responsibility to plan such services and be accountable for their funding, their distribution and their quality. In the State of Victoria, that responsibility is carried out by the Mental Retardation Division of that State's Health Commission and in Queensland by an Intellectual Services Branch within the Division of Psychiatric Services, Department of Health. In Western Australia, claims have been made that the State 'has been one of the leaders in the field of services for the intellectually handicapped ever since formation of the Slow Learning Children's Group some 18 years ago'. That group, along with other voluntary organisations, is now represented on the recently established Western Australian Council on Intellectual Handicap.

The existence of central authorities at least provides a potential for

comprehensive planning but it cannot guarantee that there will not be gaps in services or that available services will be accessible. In New South Wales, despite the recommendations of the recent Richmond Report, no claim can be made about one authority having planning responsibility for services. Perhaps in consequence, more than half of our families reported that their needs for specialist services had not been met. Their examples of lack of services usually referred to specific services. Six mothers give examples of gaps in services.

'He needs speech therapy, but it's not available here.'

'When the therapist left, she was not replaced so he doesn't get it anymore.'

'He's never had physiotherapy' (mother of a 5 year old severely handicapped boy).

'My husband had to drive to the Prince of Wales Hospital (80 km return trip) every fortnight to get his medicine.'

'I take my child to my friend's house every week for therapy, as my home is outside the team's area.'

'There is a 2½ year waiting list for speech therapy, so I have to travel to North Rocks (46 km return trip) once per week, to get it.'

In an attempt to obtain some overall picture of gaps in services we asked all the families at the end of our second interviews 'what other help do you want for your child?'. The following table shows the major items referred to. Given that any expression of need is influenced by people's knowledge and that many of the families at this stage of their caring were relatively ignorant of available services and of the prognoses regarding their children, this table almost certainly represents an underestimate. We list only the items which two or more families mentioned (see Table 6.1).

If we add to this list the items mentioned once by different families - dental and eye specialists, transport, early intervention, 'more understanding doctors' - we have a total of 75 services which parents felt they needed, but which were not available. Even this conservative estimate produces an average of 1.5 services lacking per family. We took these figures a step further by recording the number of families who were on waiting lists (Table 6.2).

TABLE 6.1 EXTRA HELP WANTED

Services Referred to	No. of Families
More information on services	14
Contact with other parents	10
Therapies in central organisations	10
Practical help - with housework and babysitting	7
Speech therapy	6
Professional counselling	6
Home based therapy	3
Help to cope with behaviour problems	3
Parent education groups	2
Therapists other than speech therapists	2

TABLE 6.2 WAITING LISTS FOR SERVICES

Services Required	No. of Families Waiting
Speech therapy	5
Pre-school	6
Special schools	12
Early education clinics	2

The importance of services which parents had wanted but which were not available, at least not all the time, is captured in some parents' own words. For example, on the value of contact with other parents, the young mother of a Down's Syndrome child said

'The thing I would have liked most was contact with another mother right at the beginning, just so I could see whether or not they were normal, and to see whether their child was like a monster or not, or with terrible behaviour problems. I just needed to know what it would be like, and whether I could cope. The professionals weren't much help, you got the feeling it was all text book stuff'.

In fact, only one of our families had contact with another family around the time of diagnosis and they significantly found this helpful.

'They told us what it is like, and about parent support groups and early intervention. They gave us confidence in dealing with doctors ...'

With 2 exceptions, 15 of the 51 who had contact with a parent support group were parents of Down's Syndrome children, for whose benefit a large, well advertised association already exists. Parents of children with less well known disabilities found it far more difficult to identify appropriate support groups. Yet, 10 such families said they would like to have contact with other parents.

The argument for providing most services under one roof had powerful appeal to families who did not own a car and who did not live near public transport. One mother explained,

'It became very difficult to keep travelling to Parramatta by train. I had to struggle up the railway steps with M., who was then 2. When I was 8 months pregnant, I decided I'd had enough'.

Another mother described the sort of time-consuming and expensive travel experiences which had been endured at some time or another by almost all of the 51 families.

'Once a week I have to drive to Parramatta (104 km, both ways) for the early education program; to Penrith (42 kms) for playgroup and to Lidcombe (112 kms) for speech therapy. Sometimes I go to Westmead (100 kms) for physiotherapy. I don't think parents should have to drive around like that, it's virtually a whole day gone when I go somewhere. Everything should be together, in the same place, then I only have to drive once.'

The value of babysitting and other forms of domestic help has been discussed with reference to the temporary relief which such services provide to parents experiencing undue stress. However, the powerful norm that parents should shoulder family responsibilities as best they can without outside help meant, from our observations, that the number of parents who might have benefited from such a service was much greater than the seven who said they needed it.

If certain specialist services are not available within a 'free' national health service, parents are obviously obliged to seek out private practitioners. Speech therapy was difficult to obtain and, in the case of 3 families, costs for private therapists ranged from \$15 to \$40 per week. To obtain this service, one of the families made a weekly return journey of 50 kilometres.

As if to echo these parents' views about gaps in services, a paediatrician responsible for services for handicapped children in Sydney's western suburbs, referred hopefully to the Richmond Report recommendation that a priority for funding in developmental disability would be 'the provision of additional community services staff to provide diagnostic assessment, early intervention and home support services'. The Richmond Report recommends 6 developmental disability teams (1 per 150,000 population) for the western metropolitan region. In response to this ideal, the same paediatrician expressed her own long term frustration over lack of funds.

'All we've got is one very poorly staffed assessment centre for 1½ million people. I've been asked to write a pamphlet drawing attention to our services. There's no way I could risk doing that because we could not meet the response which would be generated by such publicity.'

Clearly, keeping the public in a state of ignorance is an effective way of rationing scarce resources.

Co-operation

Co-operation refers in this instance to exchange of information and some sharing of other resources between different professionals. From the point of view of parents it is quite apparent that they not only need medical, educational and welfare services, but their easy access to such services is affected by appropriate referrals. Even the goal of providing integrated services (in the rhetoric of service delivery for the developmentally disabled, integration is a popular notion) depends on some semblance of timely referrals, if not teamwork, by doctors, social workers and others, including the representatives of self-help groups.

In some instances parents are sufficiently resourceful to be able to establish their own referral system, with or without the co-operation of

professional people. Over a 6 month period, 1 family with considerable entrepreneurial skills made contact with 23 services, apparently without the representatives of these services knowing about their common interest. The 23-service family expressed appreciation for such a range of choices, but 'range of choices' also implies unnecessary competition and non co-operation. The mother of an 18 month old profoundly physically and mentally retarded girl complained,

'There is not enough communication between doctors and other welfare people, like physios and social workers. They just won't seem to admit that each other exists, which is bad for the parents of handicapped children'.

The mother of a one year old Down's Syndrome girl said,

'... At this time both X and Y (both Health Department assessment centres in different regions) were sending out community nurses for home visits, neither realising that the other was coming ...'.

While this 'free market' system may provide parents with second opinions and checks on the effectiveness of a particular service, the shopping around which precedes obtaining a service is time consuming and represents inefficient use of resources. It is a system which operates in the interests of those people with the skills and resources to compete effectively on behalf of their children. It is a system which is cluttered with obstacles for those families who do not speak English, who do not have a car, telephone, social contacts, education, time or other personal resources. Into this category falls a family who migrated to Australia 2 years previously, and who apparently believed that one of the advantages of coming to this country was that their 4 year old retarded son would have a better future. The family suffered social isolation, depression and worry about the future. In a small second floor flat they had difficulty coping with their son's alleged overactivity, yet they were also anxious because the boy was still not speaking. The mother was pregnant, and both parents were worried about a second child being born with the same disability as the first. Neither spoke fluent English and although the father had been an engineer in his native country, he was unemployed.

This family's contact with services was limited to a meeting with a surgeon 'who operated on his mouth a year ago to make him speak'; two contacts, one year before, with a social worker from a local hospital; a visit from a

speech therapist from whom they have never heard again; and the special school which the child attends daily, but about whose activities the parents say they know nothing. Given this lack of co-operation between professionals, a family which was already handicapped by language and culture had enormous difficulty in making sense of an array of services, each of which appeared to exist independently of the other.

In a previous piece of research we estimated that in New South Wales at least 150 services existed allegedly for the benefit of disabled children and a recent journal article estimates that there exist 'approximately 400 different services for intellectually handicapped people' (CMH 1982). Whatever the accuracy of the estimates, the potential for professional co-operation is considerable. An apparent proliferation of services may have the paradoxical effect of obscuring gaps in services by giving the impression that enough help exists for everyone. On the other hand, not everybody may find out about them.

Our documentation of the management of bad news showed that the diagnosing paediatrician was in the best position to direct parents to services. He or she was the key 'gatekeeper', the person who, as in other health and welfare settings, could control access to personnel and information (Hall 1974; McKinley 1974). In our examination of parents' experiences in obtaining services, it emerged that if they were not referred explicitly for help at the time of diagnosis, it took an average of 10 months before they 'accidentally' came across a service that was needed. However, being in contact with a service did not imply that the family would automatically learn about other forms of help. As in the examples (in Chapter 7) of professionals' ignorance of parents' possible entitlements to the Handicapped Child's Allowance or of the procedures by which such an allowance could be obtained, it was apparent that many professionals were not only ignorant but also reluctant to pass on the information, as though such action was not a priority in their scheme of things.

It is a clear implication of this study that employees such as social workers in association with doctors should regard it as part of their professional competence to know about parents' entitlements under various Federal and State social policies. However, the non co-operation between professionals makes it difficult, if not impossible, to share and so keep up to date on information about support services for families with disabled

children. For example, in examining the extent of co-operation between hospital staff, it was apparent from parents' points of view that doctors dominated the organisation of services for young disabled children and most doctors' referrals were within medical networks and seldom to non-medical personnel (Rees and Emerson 1983). This process occurred even though much of the care, at least of intellectually handicapped children, is not a medical problem and the services which parents need lie somewhere in between medical, educational and welfare services.

Co-ordination

Opportunities for close co-operation between professionals exist in multi-disciplinary assessment centres, where the potential for close co-ordination of resources seems likely to facilitate sharing of information and productive working relationships. By contrast, in most States medical, welfare, educational, recreational and accommodation services have been accountable to separate authorities and this separate organisation hinders professional co-operation, even though almost every government enquiry recommends that co-ordination be improved.

The July 1980 Report of the Tasmanian Board of Enquiry into the Needs of the Handicapped documented evidence of lack of co-ordination of services, as in duplication, overlap and the arbitrary and badly controlled awarding of government grants to voluntary agencies. The Report recommended the establishment of regional advice bureaux to co-ordinate the activities of various agencies and departments within each region. It also produced the formula for the establishment of a Handicapped Persons Secretariat to co-ordinate the structure of State and voluntary organisations with similar interests (Webster 1980).

In his detailed analysis of planning services for the mentally retarded in South Australia, Anstey (1981) concluded

'Diagnostic and assessment services, special education, vocational training and accommodation for retarded people involve many different agencies, each with limited responsibility ... There is a tendency to say that all service agencies are responsible, but in a situation where policy goals and service programmes are unco-ordinated, there is a general blurring of responsibilities. Nor is anyone responsible for communication between agencies'.

This 'blurring of responsibilities' characterises the organisation of services for young disabled children in New South Wales. The jigsaw puzzle arrangements in that State reflect a lack of co-ordination which, in terms of numbers of services and overlapping terms of reference, seems more complicated than elsewhere in Australia. The Richmond Report of 1983 recognises this and recommends the creation of community based multi-disciplinary teams. But at the time of writing, we are a long way from the implementation of the Richmond Report and the 51 western suburbs families were coping with their children several years prior to the Richmond Report.

What effects does lack of co-ordination between agencies have on parents' efforts to obtain services? Sometimes the lack of co-ordination of services results in duplication which parents find surprising. The father of an 18 month old Down's Syndrome boy explained,

'He's to have an assessment done at X (Health Commission Assessment Centre) in 3 weeks time. They just sent us a letter with an appointment. But he's only just had one done at Y (Early Education Programme) and a few months before that at Z (Paediatric Unit at the local Health Commission Hospital). I'm surprised actually, because I thought that X wanted nothing to do with you once you're involved with Y. But we'll go anyway, it doesn't hurt us to have as many opinions as possible'.

Sometimes the lack of co-ordination between agencies providing similar services is the product partly of agencies' ignorance of their competitors' practices and is partly engineered, perhaps unwittingly, by active, motivated parents. One mother explained her grateful surprise at such overlapping.

'Well, the social worker from D (area mental retardation team) visits every now and then, as does the social worker from E (State government welfare agency). My husband is involved with a local government Council, and he met another social worker there on a committee, and she's also been helpful to us.'

In Australia at least, the lack of co-ordination between agencies is compounded by the different responsibilities of Federal, State and Local government, already referred to at the beginning of this section. At this point it is instructive to identify the points of view of the employees who are caught up in these processes and feel powerless to affect them. Illustrations from Federal, State and the voluntary sector show that some employees feel that they are victims of the system.

(a) Federal Level

The Department of Social Security may be a large bureaucracy but that doesn't make non-communication within the organisation inevitable, except perhaps under conditions of staff shortages. This consideration may have contributed to a not atypical piece of non co-ordination between Social Security staff in head office and a regional office over the administration of the Handicapped Child's Allowance. A Social Security officer explained,

'A mother may ring up the regional office to say that she did not receive her allowance. She is then advised to ring head office. Well, we are so understaffed, that we don't always ring everyone back, for lack of time. By this time, she's getting pretty mad, and probably desperately needs that money. When she does get on, we have to request her file from the regional office, and this takes a long time. Often, we're not even sure where it is, it could be in numerous places because often there is some action current on the file, which delays it all, it could be two months. All that time she might be desperate for that money. It puts pressure on the workers here too, trying to explain what's happened, when it's all so crazy'.

(b) State Level

In New South Wales, the separate departments of Education, Youth and Community Services and the Health Commission have given the impression to parents that they compete for clients and for resources, even at a time of severe cutbacks producing staff shortages and other limits to resources. Some staff confirm the impression gained by parents. A Health Commission social worker from a regional assessment team put it this way,

'We may have been seeing a particular family for some time, giving counselling and suggestions about say, early education, and then all of a sudden, someone from YACS may be on their doorstep. They may have had a referral from a playgroup, or somewhere else, but they don't check with us first to see if we're already visiting. From the client's point of view, it is hard to understand why this new person is coming out. This happens regularly'.

In the absence of any central source of information and no one person or group of people being responsible for communication between departments, it is perhaps inevitable that parents receive conflicting advice. The same social worker says,

'Take the case of a family with a child with developmental delay. Agency A might advise that the child ought to stay in a normal pre-school and that he might benefit from interacting with normal children. Then Agency B comes along with a different philosophical approach, and tells the parents that they ought to accept the child's handicap, and that he would progress better in a special school. Parents don't know who to listen to'.

A major obstacle to effective co-ordination between departments is the division of health, welfare and education departments into regions which do not have the same geographical boundaries. Some consequences of such arrangements are explained by the same Health Commission social worker,

'The fact that none of these government regions coincide certainly adds to the chaos and makes working in this place difficult. For example, if we have a case in Fairfield, I might have to contact YACS either in Fairfield or in Blacktown, depending on which part of Fairfield they live in. Also, I might have to contact the Department of Education in Liverpool or Parramatta. It is also hard for other agencies to find out who in the Health Commission to contact, because they don't know how we categorise our areas. We (assessment agency) have operational areas within our region which were worked out without reference to whether they would coincide with YACS or Education Department boundaries. I personally cover five local government areas, which incidentally, won't coincide with the sub-regions recommended by the regional board (Health Commission). Have I confused you? - the whole thing's a mess'.

(c) Voluntary Agencies

Voluntary agencies, often referred to as NGWOs (Graycar and Silver 1982), provide a variety of services to families with disabled children but are dependent on government grants for their survival. This funding must be renewed annually, and there is always a degree of uncertainty whether an agency, or some of its cherished projects, will survive into the next year. In such an atmosphere of uncertainty about funding, any planning of long-term policies is made difficult and, in a time of economic recession, almost impossible. But if agencies cannot plan with families' immediate and long-term needs in mind, families have to plan with their children in mind.

The frustration experienced by some voluntary agencies in securing funding was clearly illustrated by a Catholic nun who had established a pre-school service at St. Anthony's, Croydon:

'There is now such a demand for this service, which is only for severely and profoundly handicapped children. We have one more child than we are officially permitted, and a long waiting list, even though we won't have a vacancy until the end of next year. We have three nuns and one student working here full-time for no pay, and we receive charity for the running of the school bus. I've been trying to get funding for some professional staff year after year, and not getting it'.

In her attempts to understand the grounds on which money was allocated, this respondent felt baffled.

'At first they wouldn't give funding, because we were "too new". I asked YACS for \$22,000 then they replied that that couldn't be enough and that we must need more. Then they sent a letter saying that they didn't have any money to give us. I'm waiting for a reply to our recent submission, but I've heard it down the grapevine that they only have money for one new thing, and we're no longer new.'

Sister M has tried to 'crack the code' for obtaining money. At first she thought it might be 'who you know', so she invited the local Member for Parliament to have a look at their service. 'He said we're doing "great work", but we've not heard from him since.' She had wondered whether it was 'how' the submission was written which attracted support, and engaged the help of someone who was allegedly skilled in submission writing.

'We have written submissions to Social Security, YACS and the Schools Commission, but so far we've only had responses to say there's no money available.'

Her next initiative was to attach a handwritten note to the submission, a plea for someone to observe personally the service in operation and assess its usefulness.

'No-one has ever come to have a look, to see in person whether this service is any good. I wrote on the note "I realise you are busy, and that I am one in a thousand, but if you have the time, come and see what we're doing". I'm keeping it simple, and they might pay attention if the message is simple ...'

She added,

'I don't know how long we can keep going without funding. They rely on our charity ... You can quote me in your research when I say that the system stinks'.

The funding mechanisms of Federal and State governments are not based on a systematic overview of the needs of the disabled population. In 1975, the Australian Council of Social Services stated,

'There has been no effective way of planning the allocations of resources so that grants were made by any kinds of priorities. The best that has been achieved has been to ensure that areas were not overserved. This has meant that "appealing" programs (in public service terms) were more likely to receive subsidy than services for more "unattractive" recipients, buildings have been more likely to attract funds than community based programs ...'.

Summary

References to lack of planning are not intended to obscure entirely the effective initiatives taken by professionals and volunteers in their own localities. However, even an aggregate of local initiatives seems unlikely to produce a range of services to meet the needs of families with young disabled children and enable staff to feel that their skills and those of colleagues in related disciplines will be used to best effect.

The ideal of contributing to normal, integrated family life through a comprehensive range of services in which professionals have high standards of co-operation and agencies are at pains to pool and co-ordinate their resources seems a long way from being realised.

In the next chapter we examine how families found out about a certain social policy provision, namely the Handicapped Child's Allowance, and how doctors of various kinds influenced parents' chances of receiving such financial help. In Chapter 8 we shall look at all the services which these 51 families used and we shall report on the parents' evaluation of the usefulness of such services.

CHAPTER 7

DOCTORS AS GATEKEEPERS : THE HANDICAPPED CHILD'S ALLOWANCE

The analysis of a specific item of social policy requires careful documentation of the statutes affecting that policy and a subsequent identification of the key people whose job it is to interpret legal and administrative rules and guidelines. In this respect the analyst has to move away from the more colourful concerns of consumers' opinions to the prosaic account of what doctors and other officials are obliged to do. In addition, in this chapter we say what changes ought to be made in professionals' practices if the implementation of policy is to reflect the spirit as well as the letter of the law.

However, in comparison with our documentation of other issues affecting parents' care of their children, the change in style in this chapter is not total. We do make some use of parents' views and we do examine the importance of doctors' subjective estimates in making decisions about families' entitlements to the Handicapped Child's Allowance. The administration of this piece of Social Security legislation was affected by the activities of Social Security officials, doctors and social workers who influenced whether parents would make claims and what decisions would be made about their entitlements. In this process, the influence of doctors such as paediatricians, general practitioners and Commonwealth Medical officers was very significant. As the gatekeepers, they controlled information and influenced others' decisions.

Criteria of Eligibility

The Handicapped Child's Allowance (HCA) is available under the Social Services Act 1947 and was introduced by the Whitlam Government in 1974.

For the purposes of determining what a family may be entitled to, there are two categories of handicapped child listed under Section 105H of the Social Services Act 1947:

- (i) 'Severely handicapped child' means a child who

- (a) has a physical or mental disability;
 - (b) by reason of that disability, needs constant care and attention;
and
 - (c) is likely to need such care and attention permanently or for an
extended period.
- (ii) 'Handicapped child' means a child who is not a severely handicapped child but who
- (a) has a physical or mental disability;
 - (b) by reason of their disability, needs care and attention only
marginally less than the care and attention that he would need
if he were a severely handicapped child;
 - (c) is likely to need such care and attention permanently or for
an extended period.

Apart from the specific difficulties of interpreting and implementing such legislation, there are 2 general problems which are virtually inherent in the design and administration of income benefits such as the Handicapped Child's Allowance. The first concerns the problem of finding an appropriate form of words to reflect accurately the physical conditions of a child in relation to the circumstances of their own homes and which oblige the parents to provide various forms of care and attention. The second issue concerns the ways in which parents hear about their possible entitlement to the allowance and so interpret the relevance of the legislation to themselves. Although we have quoted the exact words of the Social Services Act, it is probable that most parents (doctors and social workers as well?) will at best have read about the distinction only in a brochure from the Department of Social Security (1981).

For the families with disabled children, the diagnosis by a doctor that a child is handicapped, but not severely so, can be of considerable significance. If the child were classified severely handicapped, the parent automatically received the allowance at a non-means tested rate of \$73 per month (in addition to Family Allowance). If the child were classified substantially handicapped, the entitlement to the allowance depended on a means test. This included an assessment of the family's income and a calculation of the extra costs incurred in caring for the child.

For a substantially handicapped child, payment was at the rate of \$20 to \$73 per month, but only a small proportion of families with these children received any allowance. For example, Carney has estimated that only 20 per cent of families with a substantially handicapped child meet the low income criteria (1979). According to a Social Security officer, 'one virtually has to be on a pension in order to qualify'.

Under the rules of the Social Services Act 1947, the difference between severely and substantially handicapped should be seen in terms of '... the child ... who requires marginally less care and attention than a severely handicapped child'. Some understanding of the roles of paediatricians in interpreting 'marginally' helps to explain how a decision is made which guarantees a full allowance for some but nothing for others.

Role of the Child's Paediatrician

The paediatrician who diagnoses the handicap can tell parents about the HCA. Yet even in this small sample, only one third of parents obtained such information from their paediatrician. The remaining parents heard about the allowance through friendship networks and, in several cases, 2 or 3 years after they would have been eligible to apply. Parents' difficulties in discovering their entitlements to the HCA have been discussed by the Social Security Administrative Appeals Tribunal and have been recognised in a specific case in which the appellant referred to criticism that doctors and social workers failed to pass on helpful information to parents of handicapped children (AAT 1981).

In applying for that allowance, the parent completes Part A of the claim form. The child's doctor fills out Part B and then sends it to the Social Security Department. The parents do not view what the doctor has written. Such secrecy is apparently maintained on the grounds that parents might tamper with the report. Some commentators oppose such practices even though the Freedom of Information Act (Commonwealth) would probably operate to exempt Social Security information (Section 38) from access procedures and would exempt doctors' reports as 'material obtained in confidence' (Section 45). Nevertheless, Hayes and Hayes argue (1982, p.193)

'In the interest of openness of communication between doctor and parent and fairness of presentation of evidence to the Department,

it would be desirable for parents to read the doctor's report before it is sent off and to countersign it'.

By contrast, a leading paediatrician in the field of developmental disabilities says

'No parent sees what I write in the report, because that way I can say what I think. There are some units where it is believed that parents should see the reports which are therefore woolley; they say nothing'.

Whether or not parents view their paediatrician's report, there is no doubt that its contents influence the Departmental decision as to how a child is to be classified. Confirmation of either general practitioners' or paediatricians' recommendations is made for the Department by a Commonwealth Medical Officer (CMO). A CMO commented on how others' decisions are merely confirmed by him.

'We are not requested to make a diagnosis, we are given a full medical report from the child's paediatrician. We accept the diagnosis made by the specialist. Our role is purely to assess the degree of dependency for extra care (i.e. whether severely/substantially handicapped). We often consult the doctor.'

A doctor's power to help or obstruct parents' efforts to obtain the allowance is illustrated in the following statement by a leading specialist who submits 400 reports per year to the Department of Social Security. He maintained that he had only been 'consulted' twice by a CMO and merely on the grounds that 'he forgot to put the date of the diagnosis'.

'When I have no doubt that the child should have the severely handicapped allowance, I say so, and it is never turned down. If I have some doubt, I suggest a review in two years. If, however, I feel that the child should not get it, I write down what the handicaps are, and leave the decision to the CMO.

Some of my colleagues disagree with the way I state my opinion (in the form). They say it is not my business who gets it or not.

I know some of my colleagues get the allowance for those who do not deserve it. Some doctors overstate the case and get it unjustly. I have seen kids who are receiving it and who do not deserve it. I could get the HCA for my own children if I filled out the form in a certain way.'

These contentions have been confirmed by Hayes and Hayes (1982, p.192).

'Paediatricians who are experts in the area of handicap and who frequently complete the forms can be heard to state that they "know what the Department looks for" and therefore choose their words accordingly.'

That doctors 'choose their words' according to 'what the Department looks for' is confirmed by the mother of a moderately retarded child.

'It is up to them to write a convincing letter. I saw this letter that he wrote to Social Security. It said that N. is severely retarded. I broke into tears and ran to my neighbour. I was so shocked. Then I heard that if he hadn't said this, I might not have obtained the allowance

Another mother said,

'Our doctor has made her out to be far worse than she is. He did this so we could get the HCA and obtain a Housing Commission house'.

On the other hand, some doctors show indifference or at least lack of support for parents. An officer from the Department of Social Security's HCA section voiced his opinion.

'It is not uncommon for the doctor just to put down a scribble which doesn't mean much. Often we can't even decipher his handwriting. This is what a doctor wrote in a report before me, "the only handicap is that the child can only drink goat's milk".'

Subjective Estimates

There are some conditions, such as Down's Syndrome, which are easily identified. There are others, such as some cases of mental retardation, where it is difficult to make a diagnosis. According to one specialist, 'in many cases there is no real evidence, it is a subjective estimation'.

No one should be apologising about subjective estimates. Rather, the responsibility of medical and other personnel is to acknowledge how such an estimation is constructed. The resulting diagnosis and medical report represents little more than what sociologists would call the social 'construction of reality' (Berger and Luckman 1967). More specifically, it has been shown that the outcome of many professional/client encounters depends on the success of people such as doctors and social workers in discovering in the patient or client evidence of moral worthiness (Rees 1978;

Schwartz 1970). In this respect, and with reference to the HCA, the non-medical or moral considerations can be identified in doctors' estimations of

- (1) how the parent presents him or herself.
- (2) the information the parent gives.
- (3) the parents' knowledge of 'what the system is looking for'.
- (4) the relationship between parents and doctors.
- (5) the decisiveness of any medical colleagues in making a diagnosis.
- (6) the doctor's feelings about the case.

We are not arguing that these factors are unimportant. On the contrary, their importance should be acknowledged, thus challenging the narrowly defined conventional wisdom that assessment of entitlement to the HCA depends almost entirely on clinical/scientific (i.e. medical) considerations.

Role of the Commonwealth Medical Officer

In order to decide whether a child is to be classified as severely handicapped, substantially handicapped or not handicapped, the CMO depends on the information furnished in the application form by the child's doctors and the parents. Instructions issued to Social Security staff provide guidance on what conditions correspond to which category.

'Generally speaking, children who have such handicaps as cerebral palsy, Down's Syndrome, hydrocephalus, spina bifida, mental retardation and leukaemia, are classed as severely handicapped children ... Conditions normally regarded as substantially handicapped are: Perthes disease, deafness, mild mental retardation which involves learning and behavioural problems, epilepsy, muscular dystrophy and diabetes ' (Social Security 1974/5).

It is uncertain how the CMO decides whether to see a child for further examination in his office. If Part B is favourably completed by a known specialist paediatrician, the child is rarely required to be examined further. According to a senior Social Security officer in the HCA section, 'Down's Syndrome always automatically gets it, and those applicants where the doctor states that the child is mentally retarded, and the prognosis is poor'. This Social Security officer also pointed out that the decisions vary with the CMO concerned. Some CMOs were 'known' to be sympathetic to some conditions, others were described as having 'dreadful' attitudes.

'There was a dreadful doctor last year, who rejected just about every claim made, including Down's Syndrome and cerebral palsy. As a result, at the moment we are trying to process a lot of appeals.'

This responsibility of the CMO to interpret the difference between substantial and severe appears at first sight to be similar to the same CMO's power, in the case of controversies over invalid pensions, to determine whether an adult is 85 per cent incapacitated for work (Webster 1981). However, it might be even more instructive to examine the Domiciliary Care Allowance (DCA) which is awarded to an adult at the rate of \$21 per week (August 1982) if a medical practitioner certifies that a patient has 'a continuing need for nursing care' and if a registered nurse certifies that 'the patient is receiving adequate nursing care' (NHS Act 1953). This DCA under the terms of the National Health Services (NHS) Act of 1953 is to all intents and purposes an HCA for adults. However, the procedures for assessing entitlement to the DCA are simple, the test that a person is kept out of an institution (S.58E(3), (2)), and less controversial in that there is only one benefit with no means test.

Procedures for administering the HCA have probably contributed to the aura of secrecy surrounding the CMO's decision, and it takes persistence to get through barriers of secretaries, long waits on the telephone, and the eventual responses such as 'there's no CMO here for you to talk to'. A CMO told us that he had medical guidelines which were 'not available to the general public'. In our view, information only becomes available when such 'confidentiality' is challenged by someone perceived as influential. For example, the researchers with the aid of telephones, official titles and headed notepaper, obtained what they wanted.

Estimates of 'Time' Taken to Provide Care

The following information was obtained in an interview with a CMO who indicated that classifications about children's entitlement to the HCA depended on his interpretation of the time which the mother had to spend with the child. This is another example of the similarity between a doctor's interpretation of 'continuing need for nursing care' in the case of adults, and his/her judgements about the care required for handicapped children.

'The crucial element in this assessment is the amount of time that the mother needs to spend in caring for the child and for this reason, mother and child have to be seen together in the medical interview. Cost doesn't really come into the decision, it is determined on a care basis. The cost in caring for a cerebral palsy child may be no greater than that for a normal child - we are concerned with the way the family is tied down ...

There is no set amount of time, like 6 hours per day, spent with the child, therefore the child is severely handicapped. Four hours and he is substantially handicapped.

It has to be determined by seeing the mother and child. Children with epilepsy or diabetes are not necessarily eligible, it depends on the amount of time that the mother has to spend. On the other hand, a deaf child may need a lot of care and attention at first, and later when 10 or 12 years, the time is no longer needed, and the case is reviewed.'

The information the mother gives during the interview, and how she presents herself, clearly influence whether she is considered to be giving constant care, or something less than constant. In this respect the Social Security staff guidelines state

'In his (CMO) consideration of the degree of constant care and attention, the following indications are relevant -

1. Whether the child requires from another person frequent attention with his/her bodily functions.
2. Whether the child requires attention and supervision substantially in excess of that normally required by a child of the same age.
3. Whether the child requires regular supervision from another person in order to avoid substantial danger to himself or others'

(Social Security 1974/5 p.2).

The power of a child's paediatrician and the CMO to come to different decisions in apparently similar cases can be illustrated from a comparison of 2 boys, aged 6 years, of normal appearance and functioning in the moderately retarded range. Both attended a special school for retarded children and were regarded by their parents as overactive. At various times the mothers had been on the verge of nervous breakdown as a result of the pressures experienced in trying to cope with their sons. Despite these similarities, one family whose child had been classified as 'severely handicapped' received a non-taxed allowance of \$73 per month, while the other family received nothing. The mother of the first family explained,

'They diagnosed him at RAHC when he was 3½ years old. He was seen by a team of professionals who were all helpful and interested. They gave us the claim form, and sent it off for us. We never saw what the doctors put down, but it must have been alright, because they (Social Security) just started sending us the money'.

The mother of the second family said,

'I found out about the HCA when he started going to school, just over a year ago. All these years I have been trying to make ends meet going to services, replacing things he ruined. He damages furniture at home and when we go out. He rips upholstery and wallpaper. His clothes need changing at least three times per day because he still dirties himself. He's asthmatic and needs Ventolin and other prescriptions'.

This mother applied for the allowance but did not know what her doctor wrote in Part B of the application form. She was requested to take her child to the Commonwealth doctor. She recalled her experiences:

'I travelled by public transport to see this man. It was over in 5 minutes, it might have been 10 at the most. I was angry and upset. It was just a physical examination yet he is mentally retarded. The doctor did the usual things, listened to his chest, looked into his eyes and ears. He was a gruff abrupt man. He did ask me whether S. could dress himself. Luckily S. got into a mess trying to put his jacket on and I felt like saying "there I told you so". That was the end of the examination, then we got a letter a few weeks later'.

The Contribution of Social Workers

Irrespective of the idiosyncracies which may have affected the outcome of these 2 cases, the question which has been overlooked is whether medical personnel conducting interviews in hospitals, or in central city offices, are best equipped to assess the time and other demands on a family with a substantially handicapped child. We think the answer is no. Under certain circumstances this aspect of the assessment of a family's needs could be better carried out by social workers.

A trained and skilful social worker who visited parents in their home should be sensitive to a range of issues which would enable him or her to determine what resources the family used to cope with the child and what social, psychological and financial costs were incurred in the process. The social

worker should document information about the interaction between mother and child; the extent to which the responsibility in caring for the disabled child and other siblings is shared by both parents (if there are 2 parents); and the availability of support from grandparents or other relatives. The social worker should be able to determine how the family's domestic circumstances affect their ability to manage. Such contextual information can be obtained from a profile of the family's income, occupation, ethnic background, housing costs, and current network of friends and relatives. A clear idea of the need for help in providing care, and hence the justification for some allowance, should then be apparent.

There is not much evidence that such a change in practice, involving an improvement in the co-operation between doctors and social workers, is occurring. On the contrary, social workers were seldom used in the initial tasks of helping families to come to terms with the bad news about their child, let alone in facilitating the assessment of a family's entitlement to the HCA (see Chapter 3). Because such social investigations do not occur, or are not considered important by comparison with alleged clinical decisions, anomalies persist. For example, Down's Syndrome children are automatically classified as 'severely handicapped', and are rarely reviewed. Yet, many parents contend not only that the behaviour of Down's Syndrome children improves, but also that when they reach school age, and if there are no medical complications, they require no more attention than a normal child. Of course, the worry about their future care remains.

The automatic assumptions made about the level of mental functioning and prognosis of Down's Syndrome children do not apply to children functioning in the mildly, or moderately retarded range, especially when of normal appearance. In these cases, there are no automatic assumptions. These are the children who fall into the range where severe and substantial merge, and where it is difficult to make a decision. Here the clinical decision depends on the cues and clues given by the mother to various professionals, but usually to doctors of one kind or another. Ultimately, it seems that parents of these children are rewarded not for the degree of the child's handicap, but according to doctors' interpretations of the parents' persistence and other characteristics - yet another example of what Ball (1970), Balint (1968), Rees (1976), Sudnow (1967) and others have referred to as professionals' use of moral calculations.

Summary

Four particular issues indicate the need for improvement in medical practitioners' services and for reform in Social Security legislation.

1. Doctors and social workers do not always inform parents about their possible entitlement to the HCA, probably because such professionals are as ignorant of the procedures affecting the award of the HCA as parents.
2. The distinction between severely handicapped and substantially handicapped is blurred. From parents' points of view it is not immediately apparent that a child diagnosed as severely handicapped necessarily requires more care and attention than the child dubbed substantially handicapped, or a child who is handicapped but is not entitled to any allowance.
3. CMOs are not the most suitable judges of a child's disability and its consequences for a family's life style. Such an assessment requires an evaluation of the circumstances of the child at home, and suggests that doctors make better use of other staff such as social workers. Apt assessment depends on appropriate teamwork, not necessarily on the alleged medical expertise of one person who often acts alone and in secret.
4. Regarding reform of the Social Services Act, we recommend the abolition of the distinction between severely and substantially handicapped. The HCA should be redesigned so that it has more in common with the DCA which is paid at one rate and without a means test, to those relatives who care at home for a sick relative who is judged to need constant care and attention.

CHAPTER 8

PARENTS' VERDICTS ON SERVICES

The previous discussion of paediatricians' and other professionals' management of bad news showed that some parents - almost all of those with Down's Syndrome children - learned of their child's condition at birth. For others the bad news came later and for some not in the course of one meeting at a specific point in time, but as the slow confirmation of suspicions over several years.

For these reasons our calculations about the number of professional services used by parents date from the time the diagnosis was made about a child's disability up until the completion of the final interviews with the families in early 1982. For some parents the duration of services was the same as their child's age, for others it was less. In the following discussion, the average time for all families from the date of diagnosis to 31 March 1982, was 3 years and 7 months.

Over 3.7 years, the 51 families had contact with at least 655 services, ranging from exchanges of information with paediatricians and social workers, to specific surgery, to educational programs in special schools or specific therapies carried out in their homes. For the purposes of some classification, we have listed 23 different types of services and in the subsequent discussion we will distinguish between medical and non-medical ones (Table 8.1).

These families were in contact with an average of 12.8 services each over this time period, the most frequent number used was 13 and the families' contacts ranged from 5 to 23.

In tracing patterns in families' use of services, key questions for policy makers in health and welfare concern whether services are limited to one meeting or are part of a regular ongoing program lasting months. In following the 'service careers' of these 51 families, we also wanted to know whether the services with which parents were in contact at the end of that 3 year 7 month period had changed in nature and number since the child was diagnosed.

Services Used

Not only were many families simultaneously in contact with an average of 12.8 services stretched over that 3½ year period, a proportion of them had occasion to be in contact with more than 1 person of the same profession. For example, at least 13 families saw more than 1 paediatrician, 19 families used more than 1 physiotherapist, 11 families saw more than 1 social worker and at least 11 families recalled that they had made use of more than 1 assessment centre (Table 8.1, Column B).

These figures, showing some doubling-up of services, are not surprising given that many parents were motivated to obtain the best they could for their children. In these respects one might have expected the figures in Column B to be greater. On the other hand, the services of many of the people listed were not dissimilar and the separate figures for services may have the effect of obscuring the various degrees of overlap and duplication already referred to in Chapter 5. For example, the 'Handicapped Persons Bureau Advisor' is to all intents and purposes a social worker, yet the families also had contact with 31 other social workers from other agencies.

Column C shows the total number of families who had contact with particular kinds of services. For example, at least 47 were in contact with paediatricians, 43 had been seen at assessment centres, 39 had received services from a physiotherapist and the families had made use of 54 playgroups of one description or another. Little use seems to be made of psychologists although this figure is probably disguised by the fact that assessment centres usually employ such professionals. Perhaps more surprising is the small number of families, 6, who made use of Home Help services despite the considerable pressure that almost all the mothers were under and the difficulty that many of them had in combining housework and child care.

The figures which depict services that families had made use of on a regular basis over the 3½ year period are shown in Column D, while Column E refers to services which families said they were not currently in contact with but they thought they would use at some point in the future. If we refer again to the example of the paediatricians, Column D shows that although only 9 families were still in regular contact with a paediatrician, 21 (Column E) expected that they would call on the professional's services again.

TABLE 8.1 CONTACT WITH SERVICES

	A	B	C	D	E
	Families who had one only contact this type of service	More than one contact implying possible duplication and lack of continuity	Total no. of families who had contact with this service	In regular contact on 31.12.81	Services still 'needed'
Paediatrician	34	13	47	9	21
General Practitioner medical	20		20	5	10
Other Medical Practitioners (e.g. Eye Specialist Orthopaedic Surgeon)	20	9	29	8	12
TOTAL MEDICAL CONTACTS			96	22	43
Assessment Service	32	11	43		
Psychologist	8	1	9	1	4
Social Worker	20	11	31	10	4
Physiotherapist	20	19	39	20	1
Occupational Therapist	20	3	23	10	-
Speech Therapist	22	3	25	15	1
Playgroup - normal	15	1	16	8	-
- special	35	3	38	17	-
Baby Health Sister	16		16	4	-
Community Health Nurse	14	1	15	4	3
Handicapped Persons Bureau Advisor	25		25	12	9
Temporary Care	14		14	7	6
Pre-School	15	3	18	15	-
Special School	11		11	11	-
Home Help	6		6	6	
Early Education Clinic	16	2	18	13	6
Parent Support Group	10	5	15	5	
Toy Library	5		5	5	
Vacation Play Centre (for Disabled Children)	4		4	2	
Other Specialist Organisations which were too diverse to classify e.g. associations for crippled, autistic or blind; language course; local generic service; nursing help.			79	27	29
TOTAL OF NON-MEDICAL SERVICES			450	192	63

TABLE 8.2 DURATION AND USE OF SERVICES

Patterns in Use of Services				Disabilities			
No. Services Used Regularly	No. of Families	Av. Chrono- logical Age Yrs. Mths.	Time Since Diagnosis Yrs. Mths.	D.S. No Compli- cations	D.S. with Compli- cations	M.R. Only	M.R. and Severe Physical Delay
1	6	4 - 11	4 - 2	2	1	2	1
2	7	4 - 5	3 - 11			4	3
3	6	4 - 5	2 - 11		2	1	1
4	8	4 - 5	4 - 0	1	1	2	4
5	9	3 - 5	3 - 3	5	2		2
6	8	4 - 0	4 - 1	4	2		2
7	3	4 - 5	3 - 6				1
8							
9	1	3 - 6	3 - 6				1
10	1	3 - 1	3 - 1				1
11							
12	1	1 - 6	1 - 6				1
13							
14	1	4 - 3	3 - 9				1
				11	8	12	20

At least 2 trends are discernible in these figures. One concerns the use of medical and non-medical services, the other concerns the children who appeared to need services on a regular as opposed to an ad hoc basis. 'Non-medical' services could also be regarded as 'para-medical' in classification, because some of the services were provided in a medical setting, albeit not by doctors.

(i) Medical/Non-medical Services

Examination of the figures in Table 8.1 shows the greater usage of non-medical as opposed to medical services. From the total number of contacts we can see that less than 1 in 5 (96 out of 546) were with medical services and out of the current regular contacts (Column D), less than 1 in 10 (22 out of 214) were with medical services. Such figures confirm the observation of the NSW Richmond Report that 'It has been stressed consistently to the Inquiry that developmental disability (in all its forms) is not primarily a medical problem but an educational and developmental problem'.

The reliance on non-medical services appears to increase over time, with a corresponding decrease in reliance on medical services. For example, at the end of the 3 years 7 months period, contact with medical services had halved from being one fifth of all services to one tenth. Conversely, as the child matured, the families made greater use of non-medical services such as the various para-medical therapies and early education*. This is not surprising when one considers that most medical complications, or neurological investigations, occur when the nature and extent of the disabilities are first diagnosed.

We are not arguing that the number of services which parents perceived that they needed was related directly to the severity of a child's disability. (The meaning of 'severity' is in any case a difficult notion to specify.) A severely disabled child may actually require less services than a mildly or moderately disabled child. It is the specific elements of the disability and their individual prognosis in terms of development which will, increasingly with advancing age, influence the need for services. Such need and its variation among the sample has not been examined.

* Although the number of different non-medical services is listed as 20 (Table 8.1), it was not always easy for parents to distinguish between them. Thus, the extent of overlap between services is obscured by the practice of staff with different labels, community health nurse and 'social worker' carrying out similar facilities.

(ii) Regular Use of Services

In the following brief discussion, 'regular' means from weekly to quarterly meetings with the frequency varying according to the professional and the agency, from daily at a special school, to weekly treatment from a physiotherapist, fortnightly meetings with a social worker, quarterly or even 6 monthly check-ups with a paediatrician. During that period of 3 years 7 months, the services which were most commonly used on a regular basis were physiotherapy (20/51), followed by playgroups (17/51), speech therapists (15/51 but with at least 5 other families on waiting lists), pre-school (15/51) and early education (13/51).

The average number of services used on a regular basis after 3 years 7 months was 4.2, with a mode of 5 (Table 8.2). The number of services used regularly was apparently affected by the child's age, the period of time that had elapsed since diagnosis and, in a small number of cases, the severity of the handicap.

Table 8.2 indicates that those families using only 1 service had slightly older children than average (4 years 11 months) and, by comparison with other families, a slightly longer time period had elapsed since diagnosis. In 4 of these families the 'service' being used was a special school which the parents claimed fulfilled all their child's needs.

There is some suggestion in Table 8.2 that continued regular use of services will depend on the severity of the disability. For example, the 4 families who made most constant use of services (from 9 to 14) had children with severe mental and physical disabilities. By contrast, even the Down's Syndrome children with complications did not make regular use of such a large number of services.

This pattern of numbers of users doesn't say anything about parents' experiences in seeking and obtaining help or concerning their overall judgements of services. Some impression of their experiences and judgements has emerged from accounts of the network of services. These 2 topics remain to be explored in some detail.

Experiences in Seeking Help*

The business of seeking assistance from outside agencies was carried out mostly by the mothers, albeit with some support from and occasionally the

* Much of the material in this section is derived directly from Rees, S. and Emerson, A., 'Confused and Confusing : Services for the Mentally Handicapped', Australian Journal of Social Issues, V.18, No.1, 1983.

presence of their husbands. A minority of mothers felt that their pathways to services had satisfying outcomes, but most regarded their experiences as almost entirely negative. Whether the outcomes were seen as satisfactory or unsatisfactory, the tortuous route to services was similar. It involved a sense of powerlessness and frustration which was compounded by the way in which many professionals gave or withheld information, forms of conduct which have already been documented several times in Australia and elsewhere (Green 1981; Steinberg 1981; Waisbren 1980).

Two examples, from either end of the satisfactory/unsatisfactory range of experiences, illustrate the need for improved co-operation between professionals and better co-ordination between agencies. These examples highlight the importance of political initiatives to make better use of existing resources. We will postpone any elaboration of this latter point until the conclusions of this report.

(i) Sharing Information

A small minority, approximately 20 per cent of the mothers, said they were treated patiently and were taken seriously in any discussion with doctors and others about the diagnosis and prognosis of their children. These mothers felt that they had been regarded as worthy people because they sensed being treated as equals and because they were referred quickly from one possible source of help to another. Partly as a result of such referrals, some mothers finished up with services which overlapped, providing them with an opportunity to compare one service with another. A 27 year old mother, Mrs. B., had such experiences.

There were few suspicions on the birth of Mrs. B's little girl, but at 4 months the baby started having convulsions. At this point, the mother said she met with a pleasant paediatrician who observed that the child 'would probably be slow'. These parents made joint efforts to cope with the dismay associated with this news about their child. For these energetic, concerned people, the uncertainty of diagnosis motivated them to leave no stone unturned. In spite of a sense of inequality in association with doctors and others, they nevertheless only came across services in a haphazard way. In Mrs. B's crusade, she and her husband accumulated considerable information and by chance and persistence moved from one resource to another, making contact with 23 agencies over 3 years and 7 months.

When her daughter was 7 months old, Mrs. B. heard from a woman at her church about a playgroup run by the Subnormal Children's Welfare Association. At the same time she heard from a relative with a backward child about the importance of physiotherapy and the possibilities of occupational therapy. At a public hospital, the mother of another handicapped child told Mrs. B. about physiotherapy at a private hospital. Mrs. B. persisted with treatment at a private hospital in order to test whether physiotherapy at the public hospital was as thorough, consistent and effective. Reassured that she was getting the best possible help from the public system, the mother dropped the private hospital after 18 months of comparing both.

(ii) Controlling Information

On several grounds, and in contrast to Mrs. B., most of the other parents judged their experiences as unsatisfactory. Not only was information not available to them, they also felt that professionals controlled the access to services, thus keeping parents ignorant for a longer time than was necessary. At worst these professionals were seen as insensitive and non-caring. At best they were seen as less than frank, often communicating by euphemism and cliché, leaving parents uncertain and angry. One mother said,

'They don't give you information, you've got to be cunning to find out what's going on, like steam open letters you're supposed to take from one to the other'.

In the early stages of diagnosis, parents are almost always in some state of shock and disbelief (Peuschel and Murphy 1976; Wikler 1981). They feel further immobilised when they are without information and other kinds of resources. The experiences of Mrs. X illustrate these points.

Mrs X said that at birth her child had several conditions requiring medical attention and she acknowledged that in the first few months doctors kept her daughter alive. In the first 9 months the mother was referred to 9 agencies, but 2 years after the birth she argued that most of the useful information was obtained in hospital waiting rooms from other parents. She interpreted her experiences as follows.

'The doctors are not interested in your feelings. The doctors see her as different, a specimen. They have no respect for her as an individual. There were always 15 students poking at her, everyone saying how strange she is. They did hundreds of tests on her, but

no one ever told us what there were for or what is really wrong with her.'

This mother's pathway through services began when she was sent to a public hospital by a paediatrician for specialist surgical attention. At the hospital a social worker referred the mother to a private hospital and to a physiotherapist at a public hospital, which specialised in the assessment and treatment of the mentally handicapped. In that hospital, referrals were made to the physiotherapist, an eye specialist and for hearing tests. The physiotherapist referred the mother to a special playgroup. Since that time, in Mrs. X's words, referrals followed to other 'more normal playgroups'.

In spite of a useful experience with a social worker who '... discussed with me the possibility of a home. She did everything and was really good', and in spite of a recent meeting with a paediatrician whom she regarded as interested in her feelings, Mrs. X's evaluations were negative.

'I've got no confidence in the services. You're generally pushed off and it's a hassle to get there. Parents of handicapped children are given the run around. Professional people keep making appointments and changing them. The staff change too often. Just as you might get to know someone they leave.'

Irrespective of their orientations to seeking help and their skills in dealing with officials, both the mothers, Mrs. B. and Mrs. X., felt confused. Some might suggest that the confusion was not only inevitable, but would be greater in instances where the diagnosis and prognosis were uncertain. It could be argued that families with Down's Syndrome children would be treated differently and would report experiences in which different professionals co-operated and made timely referrals (Lucas 1978; Stone 1973). In an attempt to test this ideal, we examined how the news of a child's condition was handled in the hospital. This 'management of bad news' was considered in depth in Chapter 3 and provides supporting evidence of the ad hoc arrangements of services and of many parents' examples of indifferent, unhelpful forms of communication. In such events, members of the medical profession exercised a dominant influence and were seldom challenged by other non-medical staff.

Orientations to Solving Problems

Parents who had the experience of information being shared between themselves

and doctors, social workers and others were also saying that an element of equality existed in such relationships. Parents whose contact with services was characterised by a sense of information being controlled commented on their sense of powerlessness and the inequality of such relationships.

Equality and inequality are characteristics of relationships, not individuals' traits. Yet, the motivated mother who has a facility with language, the material resources to make plans for the future and the support of her husband or their relatives in relationships with people in authority seems more likely to be able to achieve a sense of power-sharing with professional people. The seekers of services, usually among the most motivated of parents, have much in common with those client groups described by Rees (1978) as 'circumspect', by McCaughey and Chew (1977) as the 'copers' and by Perlman (1975) as the 'problem solvers'. Typical of those demonstrating such an orientation to solving problems was a mother who described herself as having left hospital 'confused and ignorant' about her Down's Syndrome baby. Subsequently, she accumulated as much knowledge as possible about her child's condition whether from magazines, from friends, or from the direct experience of meetings with various specialists, of whom she said 'you have to push to get something if you really want it'. Such creative 'pushing' involved this woman in setting up a toy library, participating in a mother's support group and phone-help service.

A similar orientation to solving problems was demonstrated by another mother who explained,

'I'm not leaving a stone unturned, I'll do anything to find out what's available. It's very time consuming, I spend lots of time on the phone, and every time I see someone, I've got to tell the same story again. Actually, I think the professionals like parents like me, because I'm the sort of person who'll be consistent with whatever program they'll prescribe, and that gives them the feeling they're getting somewhere. So they've been very helpful, and also given me referrals. At the moment though, I feel that perhaps I've got too much, it might be time to stocktake ...'.

These were among the parents who recommended that all services should be housed under one roof and who commented on the need to organise their own use of services as efficiently as possible.

As one mother put it,

'... it became confusing to be involved in the same type of service but with different approaches and programs, so we had to decide on which one to take ...'.

Another characteristic of the orientation of these parents was their tendency to evaluate services by comparing one with another, even if it meant duplication and time-consuming effort. Two mothers explained their activities in this respect.

'I kept visiting the private physiotherapist to check on the other one ...'

'I had her assessed at Melbourne Children's Hospital when we were there, to make sure that what she's getting in Sydney is alright.'

In contrast to parents who showed this 'problem-solving orientation' were those whose experiences with people in positions of authority had seldom been positive, and who, in the case of the mothers, were seldom able to count on much support from their husbands or from other relatives. These mothers appeared to have much in common with other client groups, described by McCaughey and Chew (1977) and by Rees (1978) as 'passive' in their orientation to solving problems, by Perlman (1975) as the 'buffeted', by Silverman (1969) as the 'defeated'. They expected little, they seldom pursued successfully their own interests and they didn't receive much. In Australia, Benjamin and Morton analysed the conclusions of several surveys and concluded that the use of community services was related to social competence, knowledge of English, knowledge of available resources, resourcefulness, mobility and physical access to services (1975).

A mother of 2 overactive children, one of whom was mentally retarded, was not only physically and socially isolated in her home, but could not count on her husband for any support. As if to compound such lack of personal resources, she said that she didn't consider asking for help because she perceived the professionals as being 'too busy' and 'not caring anyway'. She contended that she had had numerous experiences where promised services did not materialise, where professionals had expressed interest but nothing more than that, or where she felt that professional people had not understood her situation. Given these circumstances, what was the point of looking for help?

A mother of a Down's Syndrome child with heart defects was one of 3 mothers who admitted that they felt like killing their children. In other respects Mrs. M. felt almost entirely passive in her approach to solving problems and dealing with authority. She explained about her son's 'progress' at a special school,

'At the moment he's not getting anywhere at school; we just have to wait and see what happens. I don't know what to expect (of the school). No one has really explained what is going to happen. I was only told that "this place and (the school) will help you"'.

Given the passive group's style of problem solving, it seemed likely that they would be neither in contact with many services nor would they be among the regular users. Such an hypothesised pattern of use was unlikely to be realised so faithfully. It does not take account of some professional people's determination to help, whatever the responses of the parents, and it overlooks the possibility that the successful problem solver might sometimes confine their regular usage to a small number of services because they had found what they wanted.

Which Aspects of Services were Highly Valued?

Answers to this question come mostly from the mother, except in those instances where couples had had joint contact with a service and we could also obtain the father's opinion. For example, in analysing the management of bad news, we asked both parents their appraisal of the attitude of the person who passed on the bad news.

The parents' responses to the givers of bad news were analysed in terms of whether they saw that person as sympathetic in attitude, helpful in giving extra information and useful in making appropriate referrals. Seven paediatricians and one social worker were judged as possessing all 3 qualities. In these respects, some evaluative comments about people and services are already located elsewhere in this report, albeit with reference only to one event. In that account, parents expressed satisfaction or dissatisfaction mostly in terms of the personal attributes or style of the professional person rather than the tangible outcome of any meetings. In answering the question 'which aspects of services were valued highly?' we adopt the same distinction, beginning with those mothers who said they were satisfied.

Expression of Satisfaction

Only a small minority, 18 of the mothers, said that overall they were satisfied with their encounters with various professionals. The reasons for this expression of satisfaction are not as clear cut as in studies of social work services, which have claimed that people whose expectations of material help were met were satisfied and so too were people who expected the social worker to give explicit directions as to what to do regarding the management of interpersonal problems and whose hopes in this regard were realised (Mayer and Timms 1969). Few of the families with disabled children knew even about the terms of reference of services following their child's diagnosis, but many developed more concrete expectations as they accumulated experience in dealing with professionals. Another caveat to be placed on the following discussion is that there seems to be no direct relationship between the degree of the child's disability and parents' expression of satisfaction or dissatisfaction.

Approximately 5 of the satisfied mothers lumped together indiscriminately their evaluation of all the professionals whom they had encountered.

Typical comments were,

'All the services have been caring. Most of the professional people have known R. since the beginning. I'm very happy with everything.'

'They've all been wonderful and really interested in M. I couldn't have done without them.'

'They've given us no cause to complain.'

The mother of a 3 year old Down's Syndrome girl took these general comments a few steps further by identifying the qualities which she appreciated in a particular social worker,

'I get on really well with her. Even though she's unmarried, with no children, she's not an "us" and "them" social worker, she doesn't pretend to know all the answers. She cares. Although she hasn't got any children, I know that she understands. She takes a personal interest. We went to an auction together once, and we've met for lunch. She's told me some things about her personal life, I feel that I know her as a friend.

Another thing I like about her is the fact that she doesn't tell you about meetings. And what's more all the other professionals are always "at meetings" when you ring up.'

The social worker's demonstration of warmth, spontaneity and ability to do things in the way that a good friend might, gave the mother a sense of equality in the relationship. She said that this conveyed to her that this particular person understood her needs.

Five other families who had been in contact with the same social worker also expressed satisfaction because they saw that person as 'caring', 'a good listener', 'friendly' - all qualities which have been identified in numerous studies of social work as providing the basis of helpful services (Rees and Wallace 1982).

One mother of a 2½ year old profoundly disabled boy had contact with 18 different types of services, including 2 paediatricians, 3 other medical specialists, 3 physiotherapists, a general practitioner, a social worker and the staff of temporary care facilities. She had some negative comments to make but overall described herself as satisfied. The service which she had found the most helpful was that provided by a baby health sister. She explained why -

'She was the only one who understood what I was going through with his continual crying and not wanting to eat ... The paediatrician said there was nothing wrong with him. He said "he's just hungry" but the baby health sister kept visiting, she was a real friend. She referred me to another paediatrician, and then to a physiotherapist ... At that time I was really depressed, it was horrifying. Not one friend stuck by us. I had no family around. Only my husband's mother, but she couldn't cope with it, and stayed away. But the baby health sister came regularly, and she used to babysit for me, sometimes out of work hours, just so that I could go shopping. Those breaks were more important to me than any other thing. She was a real friend to me, and she visits to this day ...'.

'Visits to this day' describes the sense of coherence and continuity which this baby health sister gave to the mother in her attempt to comprehend the network of services and avoid feeling isolated and powerless in her child care responsibilities. Most of the other 18 satisfied families could also give examples of the value of a continuing relationship provided by at least 1 person. The following 2 comments refer to a social worker and a community health nurse.

'I don't expect her to visit all the time; I know they're so darn busy. But she rings now and then, and it's nice to have a talk, and know someone is interested to see how I'm going. If I'm

having some problems, we'll talk about it ...'

'She tried all sorts of things, she wanted to do something ... she was always making efforts on behalf of D. She would ring me up in the week ... She was a real friend, almost the same as pouring your heart out to your mother.'

Apart from the specific personal qualities perceived by the mothers, what seems to have been most important was the mother's impression that at least one person was prepared to maintain interest and responsibility for their case. This notion of one person, or 'a named person' was referred to by the Warnock Committee Report, as having tasks which, among other things, were to provide a sense of coherence and continuity for families with handicapped children (Warnock 1978). The absence of any continuity in relationships and of anyone who could be vaguely regarded as 'a named person' prompted all sorts of expressions of dissatisfaction from the majority of the 51 mothers.

Expressions of Dissatisfaction

Dissatisfaction was expressed mostly with reference to the absence of a set of human relationship qualities, which should be regarded as the rudimentary requirements in a service or individual claiming to be 'professional'. The absence of 'human relationship qualities' was referred to in some mothers' general dissatisfactions:

'They're not interested';

'The services have not done much';

'I'm tired of running around, and having to tell them all the same story';

'They don't really care, government workers take it easy'

The mothers' specific expressions of dissatisfaction were of 3 kinds:

- (i) The lack of any sense of warmth and understanding.
- (ii) Inaccessibility and unavailability, including staff turnover.
- (iii) Serious underestimates of the child's and the family's difficulties.

(i) Lack of Warmth and Understanding

When professionals seem keen to maintain social distance between themselves and the mothers, or when they convey this impression because they are unable to communicate with interest and spontaneity, some mothers regarded such behaviour as pretentious. In this respect one mother referred to an occupational therapist whom she knew was recently trained.

'I feel like telling the occupational therapist to go and get some experience in raising children. The problem is that most professionals haven't had any children. They don't have any idea what it is like in reality. They only know text book stuff.'

It's important to note that the mothers were not saying that to demonstrate warmth and understanding you have to be married, you have to have children, or you have to have direct experience of disabled children. Paradoxically, some professionals were able to demonstrate their warmth and understanding by admitting that there were many things they didn't know, but were prepared to find out. In this respect we'll return momentarily to the observations of some mothers who said they were satisfied. The first refers to a social worker, the second to an occupational therapist.

'She tried all sorts of things. She wanted to do something. She got me into a playgroup. She was always making efforts on behalf of D.'

'She admits she's only just started in this field. She said she wasn't certain about some things, and asked whether I minded if another OT came along. I didn't mind, I was glad to have a second opinion, and for her not to pretend she knows everything. She's only just married, and she has photos of her husband in her office, and other kids she's seen. She sort of shares herself a little. I like that, it makes me feel a bit personal towards her. A couple of times she rang up, and I was feeling really down. I cried on the phone, and the way she responded to me, was with real caring. Not something that was learnt from a text book.'

Comments on the lack of warmth and understanding were often directed at the behaviour of doctors. Before listing some examples, the context in which such criticisms were made merits some description. For example, we can hypothesise that if an individual's sense of self esteem is low, they would be more likely to interpret any display of disinterest, abruptness, coldness or formality as implying criticism of them. This is not to say that on occasions the doctors did not do the things attributed to them.

Rather, a more general point emerges that when people are in a state of crisis, or feel generally powerless or unworthy, then professionals' coldness is seen as indifference, formality is regarded as disinterest, and a doctor's attempt to maintain an aura of expertise is experienced as putting down, if not humiliating, the parent or patient.

Even bearing in mind the conditions under which many mothers made their interpretations, some of the parents' comments about doctors' attitudes and other responses, were very critical.

'The minute you have something wrong with your child, they think there must be something wrong with the parent. They're always making judgements about how well you're looking after the child.'

Another mother commented,

'When you have a handicapped child they think you need a psychiatrist, they have an aura of Godliness'.

A father said about a paediatrician,

'When we asked about the allowance, he said "you mean the ten-buck-a-week-job?" ... He behaved as though we were bludging'.

Another, migrant mother commented on her encounters with doctors,

'They don't listen. I told them she'd get diarrhoea from this kind of antibiotic, but they wouldn't listen and gave it to her anyway, and she got sick. I had to be rough to make them understand. I had to swear at them'.

Although this mother claimed that she voiced her dissatisfaction directly to the doctors, such an open response was unusual. It was more common for parents who felt powerless to collude with the professionals by reluctantly carrying on with contact because the alternative might be worse. Some parents appeared to have been deferential towards doctors, yet critical of them because they couldn't respond to them on personal terms and weren't sure how else to manage such encounters. Two mothers explained their perceptions of hospital paediatricians.

'I'd like to change paediatricians, but I've been told that paediatricians don't like retarded kids. I'm lucky to have this one. They reckon that doctors are upset by Down's Syndrome and don't like taking them on.'

'You have to go along with them though I know they put normal children first and I suppose they know what K wants more than I do.'

If mothers in particular feel that they never receive any encouragement, that becomes another illustration of lack of understanding. Doctors', social workers' and other medical/welfare/educational staff's comments about a child's progress, or even reasons for the lack of it, coupled with careful statements or opinions about treatment, have the effect of giving parents a baseline from which to work and some sense of the interest and identity of the 'helping person'.

Many of the dissatisfied mothers commented on the lack of encouragement, as in the following judgements of a social worker and a physiotherapist.

'If they watched him develop and then pass a comment, I'd be more likely to accept what they say. I'd rather not have them call. They don't help you, they don't encourage you to work the best. They make you disheartened.'

It's hard to know if you're doing the right thing. They only tell you when you're not, professionals never say "you do a good job!"'

(ii) Unavailable, Inaccessible

Many expressions of dissatisfaction were prompted by parents feeling powerless to influence the interest and attitudes of professional people. In several instances such feelings were expressed with reference to professional people not answering the telephone, not returning calls, controlling the times of appointments, or terminating a contact without giving notice. No group of professionals are exempt from such criticism.

'The occupational therapists are never there; (hospital) messages are never returned.'

'They're always at meetings, meetings and more meetings. What the hell do they talk about? You feel there's no time left to help us parents. When you ring up, they're either at a meeting, or having lunch, or out.'

'The community health nurse said she'd be back to visit in a fortnight. We're still waiting, and that was a year ago.'

'The social worker didn't keep her appointment and we never saw her again. She was wishy-washy anyway. There was another one from somewhere else, she was just as bad - making all sorts of promises, and not keeping them.'

These failures to even tell parents about intentions not to visit again were often associated with rapid turnover of staff. Such turnover could have unpleasant, counter-productive effects on parents and children. A mother who blamed herself for her 4 year old's lack of progress in walking explained,

'Between November and April, she had 6 different physiotherapists and N. wouldn't work for them. They said she wasn't getting any better, and accused me of not doing work with her. They said I was giving her drugs that made her dozey. It didn't occur to them that N. wouldn't work for them because they kept changing'.

The turnover of professionals left parents cynical about services generally and unwilling to invest energy in a successor if there was one. These parents seemed to be saying that some professional people gave the impression of playing a game in which a major goal was the least inconvenience to themselves not the greatest convenience for the families. The simple art and courtesy of writing letters, introducing people personally or confirming arrangements by telephone was apparently not part of some professionals' repertoire of values and skills. The business of transferring the responsibility for a case from one worker to another was often not done, or was done poorly. The mother of a 5 year old Down's Syndrome boy admitted that she still needed advice and guidance about her son, but her experiences of people who made only gestures of interest deterred her from trying to discover what they and others could offer.

'We've had 2 social workers call. They came only once each. Then a chap came. I was feeding B., I didn't know he was coming. I didn't know they'd changed. It wasn't convenient for me, I was breast-feeding. I didn't want to let a strange man in the house. He had no identification and the house was untidy. He had a look at B. at the door. He said 'he seems alright' and I haven't seen him since. There's probably another change since him. When I was at X (assessment clinic), I saw another social worker who wanted to come. I told them I don't need help.'

Another mother of a 5 year old profoundly physically and mentally disabled boy spoke about her bouts of depression and having no one to turn to.

'A social worker used to visit several years ago. I liked her. She came often and was good to talk to. She left, and for a long time I didn't see anyone. Then about 6 months ago, a man social worker visited. He didn't visit again, anyway I wasn't sure where he came from ...'

(iii) Underestimating Families' Difficulties

Underestimates of families' difficulties are perhaps inevitable if regular contact is not maintained, if parents feel they can't attract the attentions of the appropriate services or if contacts are ad hoc, promising no sense of continuity. It's easy for professional people to underestimate a mother's sense of stress or to overestimate her ability to cope because, as we've seen, the development of pressures and resources varies over time, even within one day. A mother succinctly describes the potential for misunderstanding and the likelihood of underestimates of difficulties.

'The services generally tend to leave you alone if they think you're coping ... they miss a lot. For instance, they might visit once to see how you're going. But if you don't feel like opening up to a stranger, which usually you don't, you say everything's fine, and they go away thinking 'Oh, Mrs. Smith's fine. No need to see her again'... and that's that. I've been in that situation, and I've been disappointed. I know that other parents are copping the same thing.'

Although there were few examples of parents being dissatisfied because they thought they'd been given the wrong medical treatment, some parents of mentally retarded children commented that those children's ill health could easily be attributed to the mental handicap. The migrant mother referred to earlier is one such example. A second is given by a mother who visited the outpatient department of a general hospital.

'He was screaming when we got to the hospital. Later it appeared he had an inner ear infection and stomach reflux problems. But they didn't take me seriously because he's retarded. The doctor gave me some Serapax and said I needed a rest.'

The Warnock recommendations of having a 'named person' provides one means of families knowing who best to turn to on a regular basis or in times of crisis, thus avoiding the kinds of long term unnecessary stress and suffering which were observed in at least 7 of these 51 families. Specifically, the Warnock Report (1978, p.76) says

'We believe that there is a clear need for one person to whom the parents of children with disabilities or incipient special needs can turn for advice on the different services available to meet their child's needs ... one person should be designated as a named person to provide a point of contact for the parents of every child who has been discovered to have a disability or who is showing signs of special needs or problems. Where a handicapped condition has been discovered, this person should be available to advise the child's parents on which services to contact and introduce them to these services'.

Perhaps if the Warnock policy had been in operation, some parents' sense of stress suffered in isolation could have been investigated and alleviated* (Glendinning 1980). For example, during the course of research, the social worker/researcher was confronted several times with what Cicourel has called the dilemmas of being a researcher or human being (1970). The researcher made referrals for help even though in each of the 7 cases the mothers were in contact with at least one service, such as a special school, physiotherapist, or paediatrician. However, the parents saw these services as having very specific functions and they did not consider using them for everyday life problems associated with not being able to manage. The research interviewer, who was also a trained and experienced social worker, reported underestimates of difficulties occurring in 7 cases.

1. Mother stating she was depressed, not coping and unable to deal with child's behaviour.
2. Parents stating that they could no longer physically care for their profoundly physically and mentally disabled child. They were under enormous pressure, with the mother chronically depressed.
3. Migrant family with moderately retarded boy with behaviour problems, and many associated difficulties, desperately needed some respite and counselling.
4. Mother stated she felt like drowning child.
5. Mother stated she was not coping and feared she might kill her child.

* In this major project undertaken by the Social Policy Research Unit at the University of York, the 'named person' notion was tried out using social workers.

6. Family had debts amounting to thousands of dollars, which caused additional stresses. They could see no way out.
7. Mother desperate, and physically exhausted because her profoundly physically and mentally retarded child had not eaten for 7 days - she feared he was dying. She wasn't coping with her other children. Husband denied the situation. She didn't want to go to the hospital, because 'they'd just stick tubes in him'.

These examples represent some serious cases. There were other instances in which the mother, or both parents, needed support or guidance as to what action would be appropriate and who might be the best person to turn to. They needed someone to negotiate with them and on their behalf, not merely because of the unanticipated problems associated with the children but also because of the lack of comprehensive services, the small degree of co-operation between professionals and the absence of much co-ordination between agencies.

Summary

Many parents' expressions of dissatisfaction implied that they felt they were not taken seriously, they were not understood, they did not feel that services were easily accessible and their sense of stress or their child's lack of progress was underestimated or overlooked. All those points emphasise again the desirability of having at least one professional person responsible to plan with the family the best way to meet their own and their child's needs. This recommendation applied even to families who appeared to have considerable skills and resources of their own. It is a recommendation which is not overtaken even by the Richmond Report's commendable suggestion that health services in the area of developmental disability should provide 'comprehensive diagnostic/assessment and associated counselling'. Even with 'associated counselling' it's so easy for families to fall through the system's wide mesh network.

These parents' judgements of services, whether of satisfaction or dissatisfaction, bring us full circle back to the policy objectives of providing support to enable parents to keep children at home if at all possible. The relationship or interdependence of policy proposals and professionals' skills and other resources is apparent. Policies remain

pointless unless people are able to interpret them to the proposed beneficiaries i.e. unless people know of their rights. Interpretations of policy remain an academic exercise unless professionals implement or enable others to implement the objectives of that policy in the spirit and letter of the law. But 'implementation' could remain as an ad hoc event unless its relevance is checked at carefully planned intervals in terms of its continued desirable effects on families and their children.

A specific illustration of the obstacles hindering the implementation of a policy concerned the administration of the Handicapped Child's Allowance, as discussed in Chapter 7.

CHAPTER 9

HIGHER STANDARDS, GREATER COHERENCE : IMPLICATIONS FOR SOCIAL POLICY

Introduction

The major difficulties experienced by these 51 families have implications for improvements in social policy. They lead to recommendations for change which are proposals for reform and do not address fundamental inequalities in families' resources or in the distribution of services.

We are unapologetic about this reformist stance. It is a necessary strategy which will contribute to political struggles for more substantial change. Our point is that until services are organised to identify in specific areas the numbers of disabled young children living at home and the types of services which they require, it's a little unrealistic to talk at length about longer term goals. A short term objective such as the establishment of some regional responsibility for assessing the need for services must precede the longer term strategy of ensuring that all services are distributed equitably.

In the absence of any coherent Federal, State or regional policy and the trained, committed personnel to back it up, most families were left to struggle as best they could to discover what services might either help their child's development or facilitate their caring at home for their children. In this struggle, some parents met doctors and social workers whom they regarded as knowledgeable, skilful and always supportive. Others found it difficult to meet staff in whom they felt confidence, or (and this might be the same thing) they met various professionals only once and thus gained an impression that the people concerned were indifferent and pre-occupied with the pursuit of their own interests. Although members of the medical profession were often singled out for special criticism, our evidence about unnecessary competition between agencies, lack of co-operation between professionals, and the witting and unwitting maintenance of public ignorance applies to social workers, nurses, occupational therapists and doctors alike. No group is exempt from this criticism. Each of these factors will be discussed briefly. In addition, we highlight the undue pressures placed on mothers and the need to develop a policy

which acknowledges the mothers' role and provides each with appropriate support.

1. Unnecessary Competition

In New South Wales, given the separate yet common interests of the Health Commission, the Education Department, the Department of Youth and Community Services, the Federal Department of Social Security and the range of voluntary agencies, it is inevitable that even well-intentioned professionals often compete rather than always co-operate. The current arrangements have become a breeding ground for some organisations to embark on periodic crusades to evangelise their cherished cause, thus providing them with a sense of identity and distinguishing them from others' often allegedly inferior causes. From the point of view of parents who may enjoy the status of chosen beneficiaries, the system has much to commend it. By contrast, many parents feel left out, their points of view neither considered nor heeded. Agencies may provide one set of services but not those which families require. The mothers in this study referred to the importance of help with ironing, day care and the constructive support of other parents and they complained about the difficulties and the costs of obtaining specialist services such as speech and occupational therapy. The same points were made in submissions to the Richmond Inquiry. For example, the Catholic Archdiocese Advisory Committee on Handicapped Persons said, 'It is claimed that only one third of the children requiring therapy services are currently receiving them. This lack of services is said to be even worse in country regions' (Richmond 1983, Part 2, p.37).

In an atmosphere of limited co-operation, the only common agency theme refers to demands that there are too few resources. In several respects our findings support such claims. Mothers could not always obtain speech therapists, occupational therapists or physiotherapists. The ideal objectives referred to by Richmond - early intervention, home support, access to assessment and counselling - were realised in only a handful of cases. However, even regional assessments of the resources available and the resources required are impossible to carry out if there is no coherent policy, no universally acknowledged lines of accountability and voluntary agencies feel that if they are to survive, they must concentrate on dramatising their virtues.

2. Medical Domination

In the absence of coherent policies, traditional practices continue in which members of the medical profession dominate. In making this criticism we are not overlooking the complaints about non-medical professionals referred to earlier, nor can it be denied that examples can be given of doctors providing high standards of service. In certain acute cases, and from mothers' points of view, doctors have achieved miracles, as in successful surgery when the child is very young.

The undue influence of members of the medical profession was apparent in at least 3 ways.

(i) Although family needs for medical treatment and supervision of their children declined from a high point in the first year of life to little use of such services in the year before schooling began, nevertheless, the organisation of services was headed mostly by doctors or by staff whose roles depended on their paying due deference to medical hierarchies. For example, even the recent Richmond recommendations on improving services for the developmentally disabled are tied in the knot of an organisational double-bind: developmental disability is not a health problem yet health care is regarded as the hub of future services.

The influence of medical models of explanation of behaviour and organisational models which are reluctant to relegate doctors' roles, makes it difficult for parents, volunteers and other professionals to develop other ways of thinking and organising. In this respect the growth of inter-disciplinary teamwork faces considerable obstacles.

(ii) There is very little tradition of doctors co-operating with non-medical agencies and personnel. In hospitals, medical social workers were seldom used to sharing the responsibility of giving bad news to parents and subsequently supporting them. Such non-use of hospital social workers is part of a pattern of doctors' referrals being mostly within medical networks and seldom outside them. This reluctance to work effectively with other staff means that the doctors, acting as gatekeepers, prevent parents from obtaining timely access to important services. In this respect the Richmond Report (1983, Part 2, p.34) proposed that

'The Health Department develop a policy to be implemented in all public hospitals to ensure that parents of all handicapped children identified at or soon after birth are automatically given access to counselling and assessment and early intervention services.'

(iii) The gatekeeper function of hospital paediatricians and general practitioners was evident in their control over information in key areas of social policy. Sometimes this 'control' may have been due to ignorance. In specific areas, such as the administration of the Handicapped Child's Allowance, doctors influenced the provision of important financial resources by withholding information from parents even about the existence of this allowance and by being asked to make unrealistic distinctions between severely and substantially handicapped children. In future, social assessments should be required, not merely medical ones, but to support such a change, many doctors will have to revise their ideas about their importance in relation to the needs of children and parents for a variety of non-medical services.

3. Maintenance of Ignorance

The maintenance of ignorance is both cause and consequence of the lack of any coherent policy. Parents live in ignorance of what services are available, unless they energetically pursue every possible lead. Professionals remain ignorant not only of parents' needs, but also of colleagues whose interests and activities are similar. Many professionals' unawareness of matters of social policy, caused perhaps by their disinterest, compounds parents' difficulties in finding out about such matters.

In an atmosphere of relative ignorance, the disparity between policy and practice is maintained and official rhetoric grows without challenge. Faced with confusion in the arrangements of services, parents sensed that the now familiar notions of 'normalisation', 'integration', 'co-ordination' or, more specifically, 'named person' and 'early intervention' were rhetorical devices. In our view such notions represent value statements which may have reached some level of achievement in some parts of Australia or even in some pockets of New South Wales, but their significance is symbolic, representing goals to be aimed at rather than standards which services have achieved.

4. Family or Mothers' Policy?

Health, welfare and educational services are supposed to help families achieve two separate objectives:

- (i) The fullest possible development of their disabled child.
- (ii) The maintenance of a certain quality of life such that the responsible adults are not disabled by the presence of the disabled child.

Regarding the second objective, the major burden of responsibility falls on mothers and in a large number of cases they experience undue stress and some feel that they cannot cope. Husbands are often resources to their wives, but in the case of interested and disinterested husbands alike, it is difficult for fathers to develop a caring role. The organisation of services colludes with the assumption that the prime carers and managers are the mothers. The way that this assumption is worked out varies according to families' levels of income and other social class differences, but it remains the centrepiece in ideologies about caring for young disabled children at home.

Even to raise the notion 'family policy' is to collude with the ideology of private family responsibility in which the mother is the major carer and in which mothers and sometimes other family members are expected to be disabled by their responsibilities, at least until the child goes to school. In future it seems more useful always to ask what resources does this family need and what overall living arrangements are the most helpful for the child, its parents, brothers and sisters.

The answer to that question could produce a series of commitments for professional employees and volunteers, careful reviews of the extra financial costs of caring for a disabled child and regular appraisal, not only of the child's progress, but also of the stress experienced by the mother, and of the resources available to the families. The answer to such a question should not produce merely a cluttered set of arrangements in which mothers feel they are left to survive. Effective intervention which does not take for granted traditional roles for mothers would aim at mobilising a wider network, at creating opportunities for those who are potentially the most powerful in the child's life, both parents, other key

relatives and friends, to realise their potential as carers.

Until men are able to share equally the responsibilities of caring at home for young disabled children, any future increase in resources must be aimed at supporting the tasks of mothers. For a few years at least it would be more apt to describe such changes as mother policy not family policy!

Recommendations for Change

Each of the following four points relates to parents' accounts of their experiences and to other theses concerning the planning of services and the lack of effective co-operation between professionals. In making the following proposals, we assume that the major responsibilities of professionals in this field are to ensure that their practices become part of a coherent policy designed to meet family and children's needs. This means examining the resources of families with young disabled children, or checking on the information, programs, personnel and other forms of influence available to them. It means that in each State there has to be some statutory responsibility for the organisation, delivery and monitoring of services. A statutory responsibility is significant in providing rewards for doing some things and sanctions for not doing them. It is likely to be more effective than the technique of merely expressing exhortations to interested parties as in the Richmond Report's suggestion that the Minister of Health, in consultation with the Minister of Youth and Community Services, should negotiate with the Minister of Social Security ... 'to establish a mechanism to improve co-ordination of planning and service delivery and to develop proposals for joint Commonwealth State funding of those services' (Richmond 1983, Part 2, p.51).

1. Parents' Charter

A parents' charter, incorporating the main grievances and priorities of parents should provide a baseline for all future State and Federal policies regarding the needs of disabled children and their parents. Such a charter would make distinctions between the needs of pre-school, primary and teenage children and would show the regional variations in the distribution of services. Such a document should be regularly updated.

The beginnings of ideas for a parents' charter exist in the statements of the Parents' Conference in Brisbane (Steinberg 1981), in the various recommendations of the NSW Anti-Discrimination Board Report and in the Parents' Conference recommendations in South Australia (SA Health Commission, Vol.3, Part C). The responsibility for drawing up this charter would be in the hands of the named agency and named person to which we now refer.

2. Named Agency

In each State, a named agency should be given the statutory responsibility for keeping an inventory of the numbers and needs of disabled young children, the resources available in the State, and the terms of reference of the different agencies engaged in providing services for disabled children. This proposal to have a 'named agency' responsible for the parents' charter, for record keeping, for research and formulation of policies is preferable to saying that there should be a Ministry for the Disabled. There are special social, medical and educational needs which should remain the priorities and interests of specialised staff in government departments. But parents with disabled children need to be assured that services are organised to meet their needs and energies are not channelled into absurd forms of competition and overlap. Policies need to be promoted which overcome the obstacles identified by Wilton when she wrote of the problems of mental retardation, 'while community resources can offset the problem, they are rarely, if ever, fully employed to do so' (1981).

The advantage of having a named agency is that at least parents and professionals would know where to obtain information, and which organisation was ultimately accountable. The important 'Community Developmental Multi-Disciplinary Teams', discussed by Richmond, would depend on the information available from the named agency and should become accountable to it if not located within it.

3. Named Person

We take for granted the importance of each named agency nominating one professional person for each newly allocated case, an ideal developed in the Warnock Report in Britain and discussed in Chapter 8. However, the 'named person' position to which our recommendations refer has research and social policy tasks.

The responsibilities of the named social policy planner and analyst would include developing personnel policies - identifying those specialist staff required per head of population and the special numbers of staff needed in relation to the incidence of developmental disability in a particular location.

This policy analyst position would be located in the named agency and would be accountable for the regional funding of services and the planning of resources such as multi-disciplinary assessment centres. Other responsibilities of this position would include the development of coherent policies to provide comprehensive assessment and support for families and their children. In the implementation of such policies, the major issues to be confronted are professional competition and sloppy standards of services, medical domination and uncritical reliance on mothers.

4. Teamwork

The services which parents require often lie in between the interests which derive from medical, educational or social expertise and incentives should therefore be provided to develop experiments in teamwork. The members of teams include psychologists, social workers, program officers, medical practitioners, occupational therapists, physiotherapists and speech pathologists (Richmond Report 1983, Part 2, p.69).

Teamwork would have several objectives:

- (i) The comprehensive assessment of children and their families.
- (ii) The development of individual plans of treatment and evaluation through case review systems (Goldberg and Warburton 1979).
- (iii) Pooling information on decisions about assessment and service provision.
- (iv) Liaison with government and non-government departments.

In achieving these objectives there would be several means at the disposal of the team leader and other members. These means can also be itemised.

- (i) Making the best use of staff skills and interests. This process would include promoting the career interests of staff with a view to facilitating high staff morale. At the very least, measures should be taken to avoid that process whereby staff who specialise in work with the disabled feel that they can make no further progress after a first appointment.
- (ii) Avoiding any uncritical reliance on one profession rather than another.
- (iii) Making the best use of other parents. This is one of the most important points to develop by way of conclusion.

Summary

The basis for planning relevant and appropriate services for families with disabled young children must derive from knowledge of consumers' points of view. Almost all of our arguments about mothers' roles, staff attitudes and policies in teamwork flow from the priorities which have been identified by parents. One of the most valuable experiences named by parents was the support gained from other parents. Yet, this important source of help was under-utilised.

A task of multi-disciplinary teams would be to identify those experienced parents who could be a resource to families who are just starting their responsibilities to care for a disabled child. Experienced parents usually know about the 'unremitting nature of the attention that the disabled child needs and the indefinite period for which they need it' (Bayley 1973) and they can provide acceptable and therefore accessible forms of support for other parents.

The task of professionals is to complement and develop that social network which is recognised (d'Abbs 1983) as providing families with acceptable and continuous forms of support. However, this recognition of the value of social networks in no way diminishes the importance of high standards of professional knowledge, skill, commitment and co-operation. Accountability to parents can only be attained through evaluation by the named agency and named person to ensure that such standards are attained.

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