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University of Kent at Canterbury

Stress and Coping in Families Caring for Children with Severe Mental Handicap

Lyn Quine

1989

Thesis submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the Faculty of Social Sciences, University of Kent at Canterbury.

Dedication

This thesis is dedicated to my children, Ben, David and Calista with thanks for their love and encouragement.

THE EXTENT OF COLLABORATION

This thesis is based upon work I completed whilst working as a Research Fellow in the Institute of Social and Applied Psychology at the University of Kent at Canterbury between 1982 and 1989. The two empirical investigations reported here were funded by the South East Thames Regional Health Authority, Medway and South East Kent District Health Authorities and the Department of Health.

The regulations of the University of Kent at Canterbury require the extent of collaboration with colleagues to be clearly indicated. This statement, endorsed by my colleague and co-grant holder, Jan Pahl, sets out the extent of collaboration between us.

Papers 1-4 follow closely the Report of the first investigation entitled "Families with Mentally Handicapped Children: a study of Stress and of Service Response" on which I collaborated with Jan Pahl. I was appointed Research Fellow, with responsibility for the design and day-to-day work of the project, including the assessment of the subjects in schools, the design of the questionnaire for parents, the organization of the parents' interviews, and the preparation and analysis of the data. Writing up the results for the first report was a joint venture. Papers 1-4 contain findings from the first report-together with new literature reviews and further analysis of the data which was my work alone. Papers 5 and 6 represent new analyses of the data and the ideas expressed in them are mine only.

The second investigation was carried out from 1984-1989. The 1989 Report is my original work with the exception of Chapter 7 which was written jointly with Jan Pahl from analyses I carried out. I am indebted also to Jan for her continued support and comments throughout the progress of the study.

Jan Pahl has read this statement and agrees that it represents a fair description of our relative contributions.

Lyn Quine
October 1989

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ABSTRACT

Stress and coping in families caring for children with mental handicap

The thesis presents a longitudinal study of a representative sample from two health districts of 200 children with severe mental handicap and their families. The broad aim of the study was to investigate the impact on family functioning of caring at home for a child with mental handicap. We adopt a life-span perspective. First, the skills, behaviour and abilities of the children were assessed at school or social education centre by trained interviewers who questioned the teacher or care assistant who knew each child best. Secondly, the person responsible for the day-to-day care of the child (usually the mother) was interviewed using a structured questionnaire. Three years later, 178 children were reassessed and their carers reinterviewed. The study examines key points in the child's and family's life cycle. We discuss parents' reactions to and satisfaction with the way the news of the handicapping condition was first given; the child, family and social factors associated with caring for a young handicapped child which make mothers vulnerable to stress; the effects on family functioning; and the impact on the parents' marriage. We investigate the child, environmental and social correlates of child behaviour problems and present a longitudinal analysis showing the antecedent risk factors for poor outcome. We examine sleep disturbance, a particularly stressful aspect of child behaviour, and show that poor communication skills play a critical role in the development of disturbed sleeping patterns. We present a longitudinal analysis of maternal stress and coping, identifying the child variables and coping resources which predict change in maternal stress over time. Finally, we focus on the transition to adult life of the teenagers in our sample, examining the differences between them and the younger children, the particular concerns of their mothers, and the preparation given at schools and social education centres in the development of skills for independent living. Throughout the thesis we draw attention to both theoretical and practical issues.

ACKNOWLEDGEMENTS

The project described in this thesis was funded by the Department of Health. I am grateful for their support. Many people in South East Kent & Medway District Health Authorities have given generously of their time and expertise: I thank them all, especially Dr. Helen Mair and Dr. Tom Trace. I should also like to thank the teachers in the schools we visited while carrying out the assessments of the children, and the care assistants and social workers who gave us their help. The study could not have been carried out without the people who helped us with the assessments, the interviews and the coding: my warm thanks go to them all.

Thanks also go to my colleagues at the University of Kent for their help and encouragement, and especially to Jan Pahl, co-grant holder on the project, for her support, Derek Rutter for reading and commenting on earlier versions of the manuscripts and Nova Coombs for word processing. Finally, I should like to thank the parents whom we interviewed: I hope that the results of the study will justify the time they spent with us and the trust they placed in us.

September 1989 Lyn Quine

COMMENTARY: THE RESEARCH IN CONTEXT

INTRODUCTION

The articles and reports which appear here represent some of the published work from an eight year study of families caring for a child with severe mental handicap at home. The study was carried out in two health districts in the south east of England and funded by the South East Thames Regional Health Authority, the Department of Health, Medway District Health Authority, South East Kent District Health Authority and the Joseph Rowntree Memorial Trust. The broad aim of the study was to examine the impact on the family of caring for a child with severe mental handicap.

A large number of studies have examined the effects on family functioning of caring for a child with severe mental handicap. Early studies based their approach on a pathological model of family functioning (Holt 1958; Kanner 1953; Schonell & Watts 1957; Thorne and Andrews 1946) in which it was assumed that psychological distress was inevitable among family members, particularly mothers. The birth of a handicapped child clearly has important long-term implications for the family. However, the particular model adopted as a framework for research on a problem has important consequences for the questions which are asked about it and the answers which are obtained. In a critique of the early literature, Wolfensberger (1967) noted that an almost infinite variety of reactions of parents to their handicapped child had been described. Wolfensberger produced a list of some 60 adjectives which he had gleaned from the literature which had been used by writers to describe neurotic parental reactions to the birth of a handicapped child. The most common were guilt, over-protection, rejection and non-acceptance. There was a tendency for reactions observed at a child's diagnosis to be applied to parents thereafter. Additionally, all such emotional reactions were assumed to be persistent and dysfunctional and to cause harm to the family. Wolfensberger noted that most studies were impressionistic, rarely using random samples, systematic methods or control groups. He concluded that parents have been "grossly misjudged, misunderstood and mishandled by professionals as a group" (p404).

There were other dissenting voices in this period too. For example, in a paper entitled "The Myth of Parental Attitudes", Roith, a consultant psychiatrist, commented

> "It is hardly surprising that right at the outset one gets a completely biased and prejudiced impression of these parents and can hardly help being put on the defensive with regard to them and I must confess that this was the idea I had when I first began working in the field of subnormality and commenced interviewing relatives. I sat back and waited for the hoard of guilty and aggressive parents to descend upon me but now after eight long years I am still waiting for them". (Roith 1963 p51).

Other writers, such as Gallagher (1956) and Matheny and Vernick (1969) suggested that parents were informationally deprived rather than emotionally disturbed. These writers suggested that much family stress resulted from the fact that parents did not know where to turn for help and advice about their child, and little help with the practical difficulties in day to day living was available to them.

More recent approaches to studying the effects on family functioning of caring for a child with mental handicap are based on a 'normal' family model. Although it is recognised that such families are subject to stresses and strains, they are not conceptualized as 'problem families' but as families who meet the day to day problems created by a child with handicap, with patterns of behaviour which are similar to those in families with non-handicapped children. These approaches include investigating which families or family members are vulnerable to the stress engendered by the presence of the mentally handicapped child, what aspects of caring are particularly stressful, which socio-economic variables contribute to stress, what are the unmet service needs of families, which families cope with and adapt to the stresses, and how they do so (Beckman 1983; Quine and Pahl 1985; Burden 1980; Crnic, Friedrich and Greenberg 1983; Turnbull, Brotherson and Sumners

1984; Kazak and Marvin 1984; Chetwynd 1985; Kirkham et al 1986). Our own research is in this tradition.

A LIFE-SPAN PERSPECTIVE

It is well documented in the literature that mothers of children with physical and mental handicaps are vulnerable to stress (see for example Dorner 1975; Bradshaw and Lawton 1978; Glendinning 1983). Various aspects of caring for a severely handicapped child have been defined as stressful, from the physical burden of care to the emotional disturbance created by the child, and from the disruption of family life to the burden on family finances. Maternal stress is an important issue because it affects both the well being of the mothers themselves and the outcome for the children. The experience of stress symptoms may influence the ability of individuals to perform the tasks of caring, increasing the likelihood of requests for long term care (Wilkin 1979; Sherman and Cacozza 1984). Stress may also affect the willingness of carers to perform the caring role and may lead to neglect and abuse of children with physical and mental handicaps (Sandgrund, Gaines and Green 1974; Embry 1980; Schilling and Schinke 1984). The aims of the research reported here were to examine the impact on family functioning of caring for a child with severe mental handicap, to determine which child and family characteristics are associated with maternal stress, and to examine the family and social characteristics which may buffer or mediate the effects of stress. We also wanted to trace patterns of stress and coping over time using a longitudinal design.

Coping with and adapting to a child with severe mental handicap is a continuous process. Stress may occur at various stages of the child's or parents' life. Caring for a young child is known to be stressful whether the child has a handicap or not. Many writers have argued that caring for a young adult with mental handicap is particularly stressful, because there is always, in the background, the anxiety about what will happen when the parents die or become too old to care. In the following description of our work we have adopted a life-span perspective. We have organised the work into sections which deal with stages in the family life cycle, from parental reactions and satisfaction with communication at the birth of the handicapped child (papers 1 and 2), to the stresses involved in caring for a young child with severe handicap (papers 3 and 4), including the effects on the parents' marriage (paper 5), to behaviour problems exhibited by the child (paper 6). This group of papers, published in academic journals and as chapters in books, represents analyses from our first report to the South East Thames Regional Health Authority entitled "Families with Mentally Handicapped Children: A Study of Stress and of Service Response" (Pahl & Quine 1984).

Our second report, to the Department of Health, which is entitled "Stress and Coping in Families Caring for a Child with Severe Mental Handicap: A Longitudinal Study" (Quine & Pahl 1989), is produced here in its entirity. Our Time 1 analyses had been cross-sectional, examining variables at a single point in time. Now, we wanted to explore some of the questions and issues which had arisen from the Time 1 study using a more sophisticated longitudinal design and analyses which would allow us to examine changes in child and family characteristics over time. We were particularly interested in two issues: child behaviour, because it can be extremely disruptive of family life and can affect and be affected by family functioning; and maternal stress because it may affect the ability of the mother to care for the child. The report deals with continuities and discontinuities in the children's behaviour from Time 1 to Time 2, and the factors which best discriminate between children with behaviour problems and those without. We attempt to investigate the roots of behaviour disorder to determine whether they are similar to those suggested in the literature on non-handicapped children. We present a longitudinal analysis of stress and coping using the transactional model of stress of Lazarus and his colleagues (Lazarus 1981) in order to examine the risk factors for maternal stress. We report also on sleep problems, a particularly stressful aspect of child behaviour. Finally we consider the transition to adult life of some of the young people in our sample.

DESIGN, METHODOLOGY AND SAMPLE

The study had a prospective longitudinal design. The first phase (Papers 1-6) was carried out in Kent in 1982 - 1984 (Pahl & Quine 1984). The total population of children with severe mental handicap (399) in two health districts were assessed using the Disability Assessment Schedule developed by Holmes et al (1982). The DAS was completed by interviewing the teacher or care assistant who knew each child best. The assessments were concerned with the child's mobility, continence, self-help skills, vision, hearing, academic skills, communication skills, behaviour and medical conditions. A stratified random sample of 200 children with proportional allocation for age and sex was drawn from the population. Interviews were carried out with the person who was responsible for the day-to-day care of the child. This was usually the mother. The interviews included measures of demographic and socio-economic factors, child functioning, behaviour, family environment and relationships, social support, ways of coping, maternal and paternal health, adjustment to and acceptance of the child, life events, maternal stress, the impact of the child on the family, marital satisfaction, felt needs and the families' use of and satisfaction with services. The choice of information was informed by the aims of the study and a review of the literature.

In the second phase of the study (Quine and Pahl 1989 report), three years later, 178 children were reassessed and their carers were reinterviewed. Of the original 200, 6 children had died, 10 families had moved out of the districts, and six families could not be traced. The assessments were conducted as before in schools and social education centres. The interviews were carried out with the children's mothers using a structured questionnaire. Full details about the methodology of the study, the selection of the sample, the design of the questionnaire, the training of interviewers, the coding of responses, and the reliability and validity checks on the data can be found in Chapter 2 of the 1989 report which is reproduced here.

TIME 1 ANALYSES (PAPERS 1 TO 6)

First Diagnosis of Mental Handicap: Parental Reactions and Satisfaction (Paper 1)

Most pregnant women await the birth of their child with anticipation and joy, and expect a normal healthy baby (Solnit & Stark 1961; Kennedy 1970; Bristor 1984). However, about four in every thousand children are severely mentally handicapped. For parents of such children their responsibilities may extend far beyond their initial expectations. Sometimes, parents do not learn of their child's impairment at birth (Carr & Oppe 1971). Evidence of mental handicap may be discovered at various stages of the child's life. Sometimes mental handicap is not detected until the child fails to meet developmental milestones; sometimes the child may become mentally handicapped as a result of cerebral illness or accident. Evidence suggests that the way in which parents are first told of a child's impairment may affect both the way in which they adjust to the situation and their early treatment of the child (Svarstad & Lipton 1977; Brinkworth 1975; Pugh & Russell 1977). Papers 1 and 2 are concerned with the first diagnosis of severe mental handicap.

Paper 1 is a study of parents' reactions to the first news that their child was likely to be mentally handicapped. The main aim of the analysis in this paper was to consider parents' feelings about the way information was given to them and to suggest ways in which communication between parents and professionals might be improved when mental handicap is diagnosed. Questions were asked about the time the news was first broken and mothers' satisfaction with the way they were first informed of the child's impairment.

Most mothers were told by a hospital doctor. In some cases the doctor involved was summoned soon after the birth by the midwifery staff who had delivered the baby; in others it was the paediatrician to whom the child had been referred once developmental delay or other problems had been noted at the clinic. Most mothers said that their initial reaction was overwhelming shock. Only 4% spoke of feelings of rejection and most of these stressed the temporary nature of the feeling.

Where the news came at birth, mothers were often critical of the blunt way in which the information was given by the hospital doctor, and of the delay, denial and evasion they had faced at the hospital. The problem was often compounded by changes in the hospital routine or the reactions of the staff which alerted their suspicions. Parents of children with an impairment which was not obvious at birth, or with emergent handicapping conditions, often had a long period of anxiety and uncertainty before a firm diagnosis was made. Many mothers in this group felt that they had received inadequate and confusing information about the child's condition.

Nearly two thirds of mothers were dissatisfied with the way the news was broken. Satisfaction was related to the time at which the mothers were told about the child's handicap, in that those who found out early were the more satisfied. When satisfaction with the first information about the handicap was broken down by diagnostic category, it was found that in conditions for which a definite cause could be identified, such as chromosomal or metabolic disorders or recessive genes, a significantly higher proportion of mothers was satisfied. Mothers of children with non-specific mental handicap tended to be dissatisfied. Paper 1 suggests that satisfaction may be linked both to early telling and to the existence of a possible cause for the impairment. Dissatisfaction may have its roots in the waiting and worrying which parents have gone through and their heartsearching about the cause of the handicap. The paper concludes with a discussion of doctor-patient communication and makes recommendations for how telling parents can be improved. The conclusions are essentially similar to those of Paper 2 and we shall discuss them together there.

First Diagnosis of Mental Handicap: Characteristics of Unsatisfactory Encounters (Paper 2)

The second paper in this series investigates the characteristics of unsatisfactory encounters between doctors and parents. We reported in Paper 1, that mothers of children with chromosomal abnormalities such as Down's Syndrome were more likely to be satisfied with the disclosure of mental handicap than were mothers of children with non-specific handicap. In Paper 2, we investigate the accounts given by these two groups in an attempt to find out why. We hoped that an analysis of the differences would help us to understand the structural factors which contribute to misunderstanding between parents and professionals.

Of the sample of 190 cases, 62 children were suffering from Down's Syndrome, and in 45% of cases mothers were satisfied with the way the news had first been given to them. Almost all of these had been told at birth or within the first week. Questioned about the source of their satisfaction, mothers mentioned caring, sympathetic attitudes of medical staff, and receiving full and adequate information and follow-up. However, 55% of mothers whose children had Down's Syndrome were <u>not</u> satisfied. The dissatisfied parents were divided according to whether they had received an early diagnosis (at birth or within a week of birth) or a late diagnosis (after a week and up to 10 months). All the mothers in the late diagnosis group were dissatisfied with the first information they received about the impairment: some considered that they had not received adequate information, some mentioned the unsympathetic attitudes of medical staff, while some described the behaviour of medical staff as evasive or secretive. Of the mothers in the early diagnosis group, a number felt that, though they had been told relatively early, they had been faced with unnecessary delay, denial and evasion on the part of medical staff, unsympathetic attitudes, or inadequate information.

As we reported in Paper 1, when the cause of a child's impairment is unknown, mothers are more likely to be dissatisfied with how they are told about the impairment. Of the 66 mothers in this group, over two thirds were indeed dissatisfied and partly this was because identification of nonspecific handicap commonly occurs rather late. By the end of the first year only a third of mothers had learned of the serious nature of their child's impairment, and by the end of the second year the figure was still only a half. Many mothers in this group had been seriously concerned about their child's development for months before the diagnosis was made. Many criticised the process by which impairment was identified and the lapse of time which occurred between their expressing anxiety and their receiving a diagnosis. Over half felt that the diagnosis could have been made earlier, almost a third thought that they had not been given sufficient information, and a fifth mentioned that the doctors appeared cold or unsympathetic.

Both Papers 1 and 2 attempt to put research studies on breaking the news of mental or physical impairment into the theoretical context of the psychological literature on doctor-patient communication. The papers argue that at one level dissatisfaction seems to stem from straightforward difficulties of communication in terms of what is said by professionals to parents. At another level, problems arise from the divergent goals of professionals and parents. At another level again, problems can be attributed to the different models held by parents and professionals about what is wrong with the child, particularly with regard to the relationship between aetiology and cure. These can all be seen as failures of communication (Stacey 1980). The papers discuss two theoretical approaches from social psychology which are helpful in understanding such communication failures. These are the interactive approach of Korsch and her colleagues (Korsch 1968) and the cognitive approach of Ley (1977).

Both papers conclude by discussing how telling parents can be improved:

1) Parents want to be told as early as possible that there is cause for concern about their child even though doctors may be unsure of the exact nature of the impairment. Parents of children with nonspecific handicap are particularly vulnerable in this respect. Parents who are told late tend to be dissatisfied.
2) Parents value a sympathetic and caring approach by doctors and other medical staff.
3) Parents want to be given full information about the child's condition.

Families with Mentally Handicapped Children: The Causes of Stress (Paper 3)

In Papers 1 and 2 we have examined the way in which parents were told that their child had a mental handicap. Now we move on, in Papers 3 and 4, to the stress which the day-to-day caring for the child may have on the parents. Paper 3 examines the child, family and social characteristics associated with maternal stress. Caring for young children can be seen as a major stressor in the sense that it makes numerous adaptive demands on the mother, often requiring a restructuring of her role priorities and lifestyle. It has been argued that the constant pressure of a child's needs, and the maternal commitment to meet these needs, weakens the mother's physical and mental state and increases her vulnerability to psychological distress (Holmes and Masuda 1974; Richman 1976). There is a large body of evidence which suggests that mothers caring for a child with severe handicap are particularly vulnerable to stress (Tew and Lawrence 1975; Bradshaw and Lawton 1978; Pomeroy *et al* 1978; Cooke *et al* 1982; Glendinning 1983). However, until recently, there has been little research on the particular <u>components</u> of caring for a handicapped child which cause stress.

In order to measure maternal stress we used the Malaise Inventory. This was adapted from the Cornell Medical Index by Rutter and Graham for their study in the Isle of Wight (Rutter *et al* 1970). The scale has been used in a number of studies of handicapped children to measure the stress of carers (eg Tew & Lawrence 1975; Gath 1978; Bradshaw & Lawton 1978). The Malaise Inventory appears to meet reasonable criteria of validity and reliability (see Appendix 1 of our 1989 report). Rutter argues that scores of 5 or more are outside the normal range and indicate psychological distress.

The results in Paper 3 showed that the mean Malaise score for respondents in the study was 5.8, a figure which is outside the normal range; 59% of mothers had Malaise scores of 5 or over. The level of stress in the carer did not vary with the diagnostic category of the child's handicap or with the nature of the child's impairment. Children who were incontinent or immobile were not more likely to cause their parents stress, nor were children who were unable to feed, wash or dress themselves or had poor communication skills. However, combining impairments into a composite score produced a significant association between the number of impairments and maternal stress. There was also a significant relationship between maternal stress and the total burden of work involved in the physical care of the children. Mothers whose children needed a lot of help with various everyday activities, including dressing, and undressing, and who disturbed their parents at night, had higher Malaise scores. Additionally, mothers who had more cleaning and tidying, cooking, washing clothes, shopping and other tasks were found to have very significantly higher Malaise scores.

Difficult behaviour was particularly stressful: the more severe the behaviour problems in the child, the more stressed the mother was likely to be. This was an important link, but behaviour disorder is a broad category and it was necessary to find out which aspects of the child's behaviour contributed most to the carer's stress. In all the areas of everyday life we examined, children with greater problems of management were significantly more stressful than those with lesser or no management problems. Thus, children who were difficult to keep occupied, children who were difficult to manage, children who had an unusual appearance, and children who disturbed their parents at night so that they did not get enough sleep were significantly more stressful for mothers.

Some families experienced other stressful sources of hardship not necessarily connected with the handicapped child. Some were single parent families; some mothers and fathers had themselves suffered from ill health in the preceding year; some respondents said their home was not suitable for the family's needs, usually because it was too small; some families had a low income. Many families might have found life hard even if they had not had handicapped children, because of lack of money, poor housing, bad health, or because one or both parents was out of work. For example, our findings showed that mothers in one parent families had much higher stress scores than mothers in two parent families. Also, in families where the husband was in a manual occupation as measured by the Registrar General's Classification, mothers had higher stress scores than where husbands were in non-manual occupations. This finding was reflected in an inverse correlation between income and maternal stress: mothers with lower incomes had higher stress scores.

In order to assess the cumulative effects of economic and social disadvantage, we devised an adversity score, which drew together a number of different aspects of hardship, such as being a lone parent or having a low income. The sample was divided into a high adversity group of 40 who had four or more of the characteristics which we had used in defining adversity, and a low adversity group numbering 160, who had three or fewer. Mothers with high adversity had significantly higher Malaise scores than mothers with low adversity. Moreover, the combination of behaviour problems and/or multiple impairment and high adversity produced even higher Malaise scores.

Finally we assessed the relative importance of all the factors which affect the stress experienced by carers. The variables which best predicted maternal stress were behaviour problems in the child, night time disturbance, social isolation of the mother, adversity in the family, multiplicity of impairments, difficulty in settling the child at night, problems with the child's health, problems with the child's appearance, and the parents having money worries.

In summary, our analysis showed that it is possible to identify factors associated with stress in mothers caring for a severely mentally handicapped child at home and to analyse the relative importance of different sources of stress. The study showed that two aspects of mental handicap were particularly stressful: multiplicity of impairments, and behaviour disorders. In addition, it demonstrated that the plight of the mothers was exacerbated by adverse social and economic conditions.

Families with Mentally Handicapped Children: Impact on Family Functioning (Paper 4)

Paper 4 appears in a book entitled "Coping With Disorder In The Family", edited by Jim Orford (1987). It provides an account of the sorts of problems which affect families in which there is a mentally handicapped child. In Paper 3 we had shown what it was about caring for a child with mental handicap that caused stress. Now in Paper 4, we examined the impact of the child on some aspects of family functioning. The presence of a child with severe mental handicap affected families in a variety of ways. The employment patterns in these households differed from those which might have been expected in a sample of families with growing children. These differences mainly affected the mothers, of whom only 5% were in full time employment, and only a fifth were in part time employment. This was at a time when in Britain as a whole about a fifth of women with children under 16 were in full time employment and a third were in part time employment (Martin and Roberts 1984 p.13). About half of our mothers who were not in employment would have liked paid work but felt that they were prevented from taking a job because of their responsibility for the handicapped child.

Our data on housing, on consumer goods and on income all support the findings of other research, that having a handicapped child penalises families financially in a number of ways. Firstly the responsibility of caring for the child tends to reduce family income, particularly by making it difficult for mothers to earn but also by limiting fathers' ability to do overtime. Secondly, the needs of the handicapped child mean extra expenditure on items such as clothing, bedding and footwear, and on washing and drying. Thirdly, as a consequence of their lower incomes and greater financial responsibilities, families have to cut back in other areas. For example, the proportions who owned cars or who had central heating were lower than in comparable national figures.

The work of caring for a young child with severe mental handicap has been described as the "daily grind" of care (Bayley 1973). A number of studies have shown that it is normally the mother who shoulders this burden (Bailey 1973; Parker 1985; Wilkin 1979). We found that the pattern still continued. The number of husbands who helped every day was very small. The tasks which husbands were most likely to perform were lifting and carrying the child, but only a third whose child required lifting and carrying did this every day. For all the other tasks involved in the care of a handicapped child, the numbers helping every day were much smaller. There were no significant differences between the social classes, but unemployed fathers were more likely to help than were employed fathers.

Alternative sources of help might be the siblings of the handicapped child and the friends, neighbours and relations of the family. However, our results showed that siblings provide even less support to carers than do husbands. The only significant type of help given by friends, neighbours and relations was moral support. By comparison, little practical help was received with child care and household tasks.

One effect of lack of support from friends and neighbours was that parents felt themselves to be socially isolated. Many parents found difficulties in finding a babysitter if they wanted to go out and some never went out in the evening unless they took the handicapped child with them. Over half of the mothers said that having a handicapped child prevented them from going out as frequently as they would have liked, and a half said that having a handicapped child made them very lonely. Mothers who said the child prevented them from going out or who felt lonely because of the presence of the child were significantly more likely to be stressed. Social isolation often extended to the mentally handicapped child and to other members of the family. Many of the children themselves had no relationships with children outside the family apart from those they met at school.

Previous studies have suggested that having a handicapped child may present serious problems of adjustment to other members of the family (Tizard and Grad 1961). Some have suggested that the mental health of siblings may be affected (Gath 1978). In our study, parents were ambivalent about the effects on brothers and sisters. Asked whether the other children had benefitted, three quarters agreed that there had been gains; however, about half the parents saw the difficulties surrounding the handicapped child as a disadvantage to the family. When the child was not only handicapped but also had severe behaviour problems, the parents were more likely to see the effects on their other children as harmful.

The paper concludes by discussing the contribution of the child's and family's social characteristics to maternal stress. Research suggests that families who care for a child with severe mental handicap may need help in a number of areas. Our study found that parents' priorities for additional help were advice/information, financial help, baby/child sitting, short-term care, equipment or aids, help with household tasks, and full-time residential care.

Marriage and the Stress of Caring (Paper 5)

From the impact on the family as a whole of caring for a child with mental handicap, we moved on in Paper 5 to the parents themselves and in particular their marriage. We consider whether a good marriage can act as a buffer against the stress of caring for the child. We also investigate how the care of the child is shared between the spouses and whether the quality of the marital relationship suffers because of the strain.

It has been suggested in many studies that the risk of psychiatric illness is considerably reduced for women who have appropriate coping resources and supportive social networks (Mueller 1980; Andrews *et al* 1981). Recent empirical research has suggested that high levels of social support from primary group members such as the spouse, relatives and other members of personal social networks, and from community based sources, are particularly important for the mental health of individuals under stress (Lin *et al* 1979; Syrotuik and D'Arcy 1984). Specifically it is hypothesised that good social support, such as that found in a harmonious marriage, will act as a protective device, buffering the individual faced with severe life events or difficulties from the effects of stress. Giving birth to and caring for a mentally handicapped child can be seen as severe life events, and we were concerned to investigate whether emotional support within marriage acted as a buffer for the mothers in our sample.

The question we used to assess the presence of emotional support was the one employed by Brown & Harris (1976), which asks whether a woman feels she has a close, intimate and confiding relationship with her husband or partner. Firstly, we examined whether women who felt they had a close confiding relationship suffered less stress. Secondly, we examined whether women who faced particularly severe difficulties, such as caring for a behaviourally disordered or multiply impaired child, were less stressed if they had a close confiding relationship. We found that in both these cases, women who had a close, intimate and confiding relationship with their husbands had lower mean Malaise scores than women who did not have close relationships. However, when we looked at the 66 least impaired children - those who where neither behaviourly disordered nor multiply impaired - there was no relationship between marriage and Malaise. Thus, while confiding relationships protect women under stressful circumstances, they do not appear to act independently of stress.

Next we considered joint and segregated conjugal roles and their impact on the stress experienced by the mothers. The terms "joint" and "segregated" conjugal roles were first used by Elizabeth Bott in a study of the domestic division of labour in 20 London families (Bott 1971). Bott identified two types of conjugal role relationships: joint relationships, where husband and wife shared tasks equally, and segregated relationships with a strict division of labour between working husbands and dependent, homemaking wives. In 1974, Ann Oakley interviewed 40 London housewives. She concluded that only a minority of fathers participated in household tasks, that when they did participate, it was more likely to be in child care tasks than housework, and that patterns of participation were class based, with "joint" marriages being more common among middle class than working class families. We investigated whether having a handicapped child produced a tendency toward joint rather than segregated roles. We found that joint conjugal roles are no more likely to be found in families with severely handicapped children, although joint patterns may be better adapted to meeting the demands of a handicapped child.

It is sometimes suggested that the stress of bringing up a mentally handicapped child causes marital disharmony and increases the likelihood of marital breakdown (Gath 1977; Gath and Gumley 1984). Weale and Bradshaw (1980), for example, in an analysis of handicapped children in the 1974 General Household Survey, found that families with disabled children were more likely to be one-parent families if the child was severely or moderately handicapped, and that lone mothers with such children were more likely to be divorced or separated than lone mothers in the general population. Other studies have found that the presence of a handicapped child can strengthen and enrich a marriage. We found that there were no more single parents in our sample than are found in the general population. Nor were there more children who were not living with both their natural parents (General Household Survey 1985). Thus there was no indication from our data that mothers were more likely to experience marital breakdown if they had a handicapped child. However, there was a good deal of evidence that the quality of a marriage was often affected by the stress of caring for the handicapped child. More mothers in our sample said that they were unhappily married than in other samples where the identical question was asked.

Behaviour Problems in Severely Mentally Handicapped Children (Paper 6)

From the effects of stress on the marriage, we turned finally in the Time 1 analyses, to a more detailed analysis of one of the important components of maternal stress, namely, behaviour problems in the child. The analysis is reported in Paper 6. Serious behavioural problems are quite common in school age children. A number of studies provide evidence for rates of significant disorders of this kind ranging from 6% to 20% (Miller *et al* 1974; Richman *et al* 1982). Estimates from samples of mentally handicapped children suggest that here the incidence is higher (DHSS 1979; Wilkin 1979; Gath & Gumley 1986). We were interested in child behaviour because it had been shown to be an important source of stress, both in our own and in other studies (Cooke *et al* 1982; Chetwynd 1985; Pahl & Quine 1984). It has also been cited as one of the reasons for requests for long term care (Wilkin 1979).

The particular questions which concerned us were these: how prevalent are behaviour problems in children with severe mental handicap? what are the social correlates of behaviour problems? what is the nature of the link between child behaviour disorder and the child's social environment?

It will be recalled that the behaviour, skills and abilities of all 399 children with severe mental handicap in two health districts were assessed at the beginning of the study. From the population survey we were able to assess the prevalence of severe mental handicap in Medway and South East District Health Authorities. We compared our figures with a study of Camberwell by Wing (1971). Overall prevalence figures for our sample were rather lower than those in Camberwell. Rates for nonambulant children were very similar to Wing's figures. So too were rates for children who were severely disordered in behaviour whether or not they were continent. But rates for children who were incontinent were somewhat lower, as were rates for children who were neither incontinent nor disordered in behaviour.

The sample of 200 children proved to be entirely representive of the total population: the proportion of children assessed as having each behaviour problem differed by only 1 or 2 percentage points. In order to investigate the questions we had posed, the sample of 200 children was divided into two groups: the first contained children with severe or mild behaviour problems; the second contained children with no behaviour problems. This enabled us to examine the correlates of behaviour problems. We found that there was a significant association between behaviour problems and incontinence, lack of self-help skills, poor reading, writing and counting skills, and poor communication skills.

Environmental correlates were few. There were no differences between groups in family size, birth order, age of parents, social class or income. There were, however, significant differences between groups in family composition, in that significantly more children in single parent families had behaviour problems. There were no differences between groups in the type of housing or the length of time parents had lived in their present home, but there was a significant difference in the nature of the tenancy, in that a lower proportion of parents of children with behaviour disorder owned their own homes. Richman *et al* (1982) report similar findings in a general population survey.

There were no differences between the groups in the mother's perception of the availability of emotional support in her marriage, the happiness of her marriage, or her reported contact with friends and relatives. This is interesting in view of the findings from a number of studies that there are strong correlations between child behaviour disorder and marital discord (Richman *et al* 1982; Rutter & Quinton 1984). There was, however, an association between maternal stress and problem behaviour. Mothers with behaviourally disordered children were more stressed.

Children with behaviour problems cause mothers more work: mothers of disordered children had significantly more cleaning and tidying; they had extra laundry because of incontinence and heavy use of clothes; they had more difficulties when shopping because of the child's impulsive behaviour and the likelihood that he or she might wander off. More parents of children with behaviour problems reported that their children needed help with dressing, undressing, washing, bathing and using the toilet. This should not be unexpected since we have shown that children with behaviour problems were more likely to be unable to carry out these basic tasks alone. Significantly more parents of children with behaviour problems reported difficulties in managing the child, keeping her or him occupied and safe, and shopping.

Studies of behaviour disorder in children have often found an association between behaviour disturbance in the child and marital discord and/or maternal stress. Our univariate analyses found that there was no tendency for mothers of children with behaviour problems to report that their marriage lacked closeness or that it was, unhappy, though their mean stress score was significantly higher than the mean score for mothers of children without problems. The paper concludes with a discussion of the possible mechanisms underlying the associations between child behaviour, maternal stress and marital satisfaction.

TIME TWO ANALYSES (QUINE & PAHL 1989 REPORT)

Analysis of the Longitudinal Data

Our 1989 report extends our previous work with the 200 families (Pahl & Quine 1984), and so forms the second phase of a longitudinal study. In this second phase, we wanted to investigate a number of issues which grew out of findings in the first phase published in Papers 1 - 6. Firstly, we wanted to gain a better understanding of the impact on family functioning of caring for a child with severe mental handicap, by considering changes in child, parent and family characteristics over time. Secondly, we wanted to examine the continuities and discontinuities in the behaviour problems exhibited by the children over time, to explore the antecedent risk factors for behaviour disorder. As an example of difficult child behaviour, we chose to examine sleep disturbance in detail because our Time 1 analyses had shown that it was particularly stressful for parents. Thirdly, we wanted to study the process of stress and coping in families over time. Finally, we wanted to focus on the transition to adult life of the adolescents in our sample.

Description of the Sample at Time 2

At Time 2 many of the children had acquired new skills. Significantly more children could walk, feed, wash and dress themselves and were continent. Significantly more had good use and understanding of communication. However, over half the children were reported by their mothers as difficult to manage and three quarters of mothers thought the child required more attention to keep occupied than did non-handicapped children.

As reported at Time 1, mothers still carried the main burden of responsibility for care tasks. Women caring for a child with severe mental handicap were more likely to report that their health was not good or only fairly good than were women of comparable age in the general population. Additionally a higher proportion of mothers in the sample were suffering from symptoms of psychological distress than were mothers of non-handicapped children. The stressed women in the sample had consulted their doctors significantly more over the previous year than those who were not stressed. Nearly a third of women in the sample reported consulting their doctor in the 14 days before interview, a figure almost double that found in women of similar age in the General Household Survey. The second phase of the study also confirmed the considerable financial costs arising from caring for a child with mental handicap which we documented in Papers 1 - 6.

Behaviour Problems in the Sample of Children at Time 2

As we have suggested earlier, our reasons for carrying out longitudinal analyses of behaviour were twofold: to examine the course of the problem behaviour we had identified at Time 1; and to try to understand the roots of behaviour disorder, to determine whether they were similar to those suggested by the literature on non-handicapped children. As we have indicated, we considered the likely important factors to be of two types: those aspects or characteristics of the child's own functioning, such as communication skills, which might influence behaviour; and those factors which exerted an external influence on the child, such as maternal stress or poor housing conditions. Trying to establish causal links from patterns of associations is, of course, difficult. However, we wanted to know whether some behaviours might disappear with age while some remained relatively stable. We had found that maternal stress was associated with difficult behaviour but were so far unable to determine the direction of causality. In contrast to studies of non-handicapped children, we had found no association between the quality of the parents' marriage and behaviour disorder. The main purpose of our new analyses was to examine causality.

The analyses reported here appear in Chapter 4 of our report. As a first step, we examined continuities and discontinuities in behaviour. Behaviour problems showed remarkable similarity in prevalence between Time 1 and Time 2. The only exception was overactivity, which decreased in prevalence between Time 1 and Time 2. Our analysis showed that there was also continuity in the persistence of behaviour problems. We used the McNemar Test to examine differences in the changes in proportions of children presenting each behaviour between Time 1 and Time 2. In all the 14 behaviours listed in the Disability Assessment Schedule there was only one item which showed a significant difference in the proportions of children presenting the behaviour. This was overactivity.

As will be remembered, children were identified as having behavioural difficulties if they had one or more severe behaviour problems or two or more mild ones. Of the 100 children who satisfied the criteria for the behaviour problem group at Time 1, 76% still did so at Time 2. Of the 100 children in the behaviour problem group at Time 2, 76% had been in it at Time 1. There were no significant changes in the proportions in each group at Time 1 and Time 2.

We next examined the factors at Time 1 which predicted child behaviour at Time 2. We used discriminant analysis to discriminate between children with and without behaviour problems by means of child, family and social characteristics. Ten variables predicted group membership, correctly classifying 80% of the cases. The variables fell into two groups: child characteristics, such as the child's ability to read, write and count (academic skills), the severity of his or her physical impairment, continence, mobility, communication skills and age; and family characteristics such as the mother's irritability score, maternal stress score, household income and marital discord. These variables together accounted for 33% of the variance in group scores. It is interesting to note that when all the factors were controlled, marital discord then emerged as a significant predictor of behaviour problems, alongside maternal stress, maternal irritability and household income. This is in accord with studies of non-handicapped children, although the causal ordering of the variables has not always been clear. Longitudinal analysis of factors predicting change in behaviour over time produced similar results. Child characteristics were academic skills, self-help skills, communication skills, mobility and age. Family characteristics were maternal stress, marital discord and household income. It is likely these factors are causally related to the risk of poor outcome. Note in particular the role of deficiencies in communication skills as a risk factor for the emergence of behaviour problems.

Sleep Problems in Young People with Mental Handicap

Next, we move on to sleep disturbance which is a widespread form of challenging behaviour, affecting families bringing up both handicapped and non-handicapped children. This analysis is reported in Chapter 5 of our 1989 report. Many children have sleeping patterns which are seen as problems by their parents (Richman 1981a). Young people with severe mental handicap seem to be particularly likely to present sleep problems. Night time difficulties are known to be associated with maternal stress, and with daytime behavioural difficulties.

First, we examined the prevalence of sleep problems. Assessment of settling and waking problems was carried out using the items in the Behaviour Screening Questionnaire (Richman & Graham 1971), and we provide randomly selected illustrations of our ratings in order to indicate the threshold for disturbance.

At Time 1, we found that over half of mothers reported difficulties in settling their children at night, two thirds reported that their child woke during the night at least once or twice a week disturbing their parents, and a third of mothers said they rarely got enough sleep. There was a significant association between maternal stress and mothers' lack of sleep, night waking problems and night settling problems. Reported lack of sleep and night waking problems were significantly related to the age of the child, but settling problems were not. At Time 2, large numbers of children still presented problems. Night settling and night waking had decreased between Time 1 and Time 2 and this was due to age: older children present fewer sleeping problems. The pattern of associations between maternal stress problems and sleep problems which was found at Time 1 was also present at Time 2. The mean stress score of mothers whose children exhibited night settling or waking problems was significantly higher than for those whose children had no problems. Parents reporting severe lack of sleep had significantly higher scores than parents who got enough sleep.

We next divided the sample into two groups, those children who had sleep problems (96) and those who had no sleep problems (70). The criteria for inclusion in the problem group were that the child had severe or mild settling or waking problems, or both, as assessed by the Behaviour Screening Questionnaire. This allowed us to examine the correlates of sleep problems.

A major difference between the groups was in the area of communication and academic skills: children with sleep problems had significantly poorer communication and academic skills than children with no sleep problems. The sleep problem group also contained a significantly higher number of children who were unable to wash, feed and dress themselves, and who were incontinent. As we saw in the Time 1 data, sleep problems were significantly associated with age, which may have been an explanation for some of the differences found between the two groups: increasing age was associated with decreasing problems. A further finding was that children with sleep problems were more likely to have a diagnosis of cerebral palsy or named conditions excluding Down's Syndrome. They were also significantly more likely to suffer from epilepsy. Given that epilepsy is a sign of neurological impairment, this finding, in combination with the association with diagnosis, suggests that there may be a neurological component in sleep disorder.

The children with sleep problems were significantly more likely to have daytime behaviour problems too. They had a higher score on both the Behaviour Screening Questionnaire (Richman *et al* 1982) and the Behaviour Problem Index (Cunningham *et al*

1986). Parents of children with sleep problems were significantly more likely to report that their child was difficult to manage, could not be left unsupervised for long, and was difficult to keep occupied and safe.

There were relatively few associations between socio-demographic variables and sleep problems. However there were significant differences between the two groups of children in mothers' Problem Inventory scores, maternal stress scores, and a measure of maternal irritability (Richman *et al* 1982). A path model, constructed by means of multiple regression analysis, showed that communication skills were a key factor in sleep disturbance and this may reflect the difficulty parents experience in trying to train children with limited communication skills to present more socially appropriate behaviour. We have seen from the section on child behaviour that deficiencies in communication skills are implicated as a risk ractor for the appearance of problem behaviour in general. The path model also draws attention to the fact that families containing children with irregular sleeping patterns are often families with many other problems of family functioning, possibly, though not necessarily, causally associated with the sleep difficulties. This highlights the complex problems for intervention work in families. Chapter 5 concludes with a discussion of ways that children can be helped to establish and maintain more regular sleep patterns.

Stress and Coping in Mothers of Children with Mental Handicap

From a discussion of some of the sources of maternal stress, we move on in Chapter 6 to attempt to assess the outcome of caring for a child with severe mental handicap and to test a transactional model of coping. The transactional model sees stress as the outcome of a lack of fit between the person and his/her environment. Three measures were used to tap coping: the Malaise Inventory, to measure symptoms of psychological distress; the Problem Inventory (Tavormina *et al* 1981), to measure the impact on the family of child related problems; and the Judson Scale (Judson & Burden 1980), to measure the mother's adjustment to and acceptance of her child. There was considerable overlap between the scales, with mothers who had high Malaise scores tending to have high scores on the PINV and low scores on the Judson Scale. However, correlation between the scales was only moderate, indicating that each was identifying mothers with a specific range of problems.

We used multiple regression analysis to examine the child and family characteristics associated with each of our outcome measures. Results from the Malaise Inventory scores suggested that the most important child variables affecting maternal stress were behaviour problems and the child's age. Coping resource variables predicting Malaise were lower social class, financial worries, negative assessment of coping skills, poor acceptance of and adjustment to the child, and recent maternal ill-health. There was evidence that coping resources were able to mediate or "buffer" the effects of stressful child behaviour on maternal Malaise scores. An investigation of factors predicting change in Malaise scores between Time 1 and Time 2 showed that recent maternal illness, social class, feelings of loneliness, and the child's age were the most important variables.

Analysis of the Problem Inventory scores showed that here a rather different set of child variables came into play. High scores on the PINV were predicted by the presence of children with severe caretaking demands - those who had greater supervisory needs, created extra work for their carers, or were difficult to keep safe. Behaviour problems were again among the child-related predictor variables. The unremitting care demands of such children led to perceived unmet service needs appearing as a further important predictor variable. Coping resource variables which were important were those concerning ability to share the costs of caring - social support, marital satisfaction and reported coping by use of social support networks. Feelings of loneliness were associated with higher scores on the PINV and these seemed to be related to perceived inadequacy of social support. Whether such feelings are related to actual amount of social support is not clear, however.

Analysis of Judson scores showed that a number of child variables emerged as significant predictors: taking off clothes in inappropriate circumstances, poor understanding of communication, rocking, severe nail biting, worrying about plans or changes, and night waking. In addition, two care tasks were significant predictors: having difficulties doing the shopping because of the child's behaviour, and not getting enough sleep. Coping variables which emerged as significant predictors when the other variables had been partialled out were perceived ability to help the child's development, maternal Malaise scores and household income. The chapter concludes with a discussion of a variety of ways in which families might be helped.

The Transition to Adult Life

Finally, in Chapter 8, we focus on the young adults in our sample. The problems of adolescence and the transition to adult life can be a source of anxiety and difficulty for any parent and are well documented in the literature (Rogers 1972). When a young person has a physical or mental handicap, the development of independence and the achievement of personal responsibility which are the hallmarks of adolescence may pose particular problems, occurring much more slowly than in non-handicapped young people. In addition, parents are growing older and may have less energy to cope with the difficulties of adolescence, such as the awakening of sexuality and their child's growing need for independence. A recent study has estimated that about a third of mentally handicapped people living at home have parents who are aged 65 or over (Richardson & Ritchie 1986). A particular anxiety for parents is what will happen to their son or daughter when they are no longer able to provide for them (Card 1983; Sanctuary 1984).

How did the young people in our sample fare as they reached adulthood? What skills and abilities did they have? How did they compare with other young people of the same age? What preparation did they have for leaving school? What plans did they and their parents have for leaving home and securing employment? These and other questions were investigated in Chapter 8.

At Time 2 there were 71 young people aged between 15 and 21 in the sample, and the first finding to emerge was that their skills showed considerable improvement between Time 1 and Time 2. They were less stressful for their parents than the younger children, requiring less help with basic tasks; their mothers reported fewer demands on their time and energy than did mothers of the younger children; they were easier to keep safe and occupied and could be left unsupervised for longer; their mothers were more likely to report that they were easier to manage than were the mothers of the younger children; and they were significantly less likely to have behaviour problems. In comparison with non-handicapped young adults, however, they were still much more dependent on help with personal care and mobility, and many still required supervision because of behaviour problems.

Parents' felt needs for additional service provision fell into three categories: information needs, help with the development of communication and other skills, and practical help. As our earlier work showed, the greatest need was for information. Parents wanted advice and information about a range of issues, from advice about the child's progress and specific impairments, to information about the services and help available. Help with teaching communication and other basic skills was an important priority, for parents pinpointed lack of communication skills as one of the young adults' greatest handicaps, both from their own and the parents' point of view.

At Time 1 parents had been asked what they perceived as their greatest worry or problem with their son or daughter. By far the greatest concern was lack of communication skills, followed by concern about the future. While parents were generally satisfied with the preparation for leaving which schools had given to their children, only a third felt that they had been given enough information and choice about opportunities available for their son or daughter. Most young adults who had left school attended a Social Education Centre. None were in open employment, although about half had been given work experience while attending the SEC. Over half the parents would have liked their son or daughter to find a job, but there was a substantial lack of advice on careers or educational courses. The majority of parents were realistic about their childrens' chances of independent living. Living at home was seen to be the best option, followed by living in sheltered accommodation. Over 50% of parents reported that they might have to ask for longer term care at some time in the future.

SUMMARY OF THESIS

To study the impact on the family of caring for a child with severe mental handicap, we have adopted a life-span perspective. We have shown that difficulties can begin at the child's birth, when the diagnosis is first given to the parents, if the doctor's approach is unsympathetic, insensitive or badly timed. We have discussed the stresses on the family, particularly the mother, of caring for a growing child at home, and we have drawn attention to the impact on the parents' marriage and the problems which difficult child behaviour creates. We have presented a longitudinal analysis of behaviour and family characteristics to try to clarify some of the causal pathways. We have identified maternal stress, marital discord and deficiencies in child communication skills as key variables. We have investigated sleep disorders in detail, showing again that child communication skills are important. We have considered the coping resources available to families and we have presented an analysis of how lack of coping resources and certain child characteristics place mothers at risk of poor outcome in terms of maternal stress, low acceptance of and adjustment to the child, and high Problem Inventory scores. Finally, we have considered the transition to adult life. In each paper and chapter we have suggested ways of helping families. In particular, we have emphasised the importance of providing a variety of flexible services to meet the families' needs.

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First Diagnosis of Severe Mental Handicap : A Study of Parental Reactions

Lyn Quine and Jan Pahl

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FIRST DIAGNOSIS OF SEVERE HANDICAP: A STUDY OF PARENTAL REACTIONS

Lyn Quine
Jan Pahl

There is an extensive literature concerned with informing parents of their child's diagnosis of severe mental or physical impairment. Several studies have viewed it as a crisis producing grief, followed by stages of shock and disbelief, denial, anger, adaptation and adjustment, similar to the phases identified in the bereavement literature (Kennedy 1970, Drotar *et al.* 1975, Emde and Brown 1978, Cunningham 1979). Reference is also made to 'chronic sorrow' (Olshansky 1962). A large number of studies report on the identification of Down's syndrome (Drillien and Wilkinson 1964, Berg *et al.* 1969, Carr 1970, Pueschel and Murphy 1976, Cunningham and Sloper 1977*b*, Lucas and Lucas 1980), while others are concerned with congenital malformation such as spina bifida (Hare 1966, D'Arcy 1968, Fost 1981) or severe mental handicap (Hewett 1972, Smith and Phillips 1978, Pahl and Quine 1984, Quine and Pahl 1986).

Three working parties have suggested guidelines for professionals involved in giving parents first information of their child's impairment (National Association for Mental Health 1971; Association of Professions for the Mentally Handicapped 1981*a*; Independent Development Council 1982). Evidence suggests that the way parents are told affects both the way in which they adjust to the situation and their early treatment of the child (Brinkworth 1975, Pugh and Russell 1977, Svarstad and Lipton 1977, Springer and Steele 1980). It is disquieting, therefore, to find that most studies concerned with how parents were first informed of a diagnosis of severe mental handicap report high levels of dissatisfaction. The data presented here are part of a larger study of families with severely mentally handicapped children, which was carried out in Kent between 1982 and 1984. The general results of that study are presented elsewhere (Pahl and Quine 1984). The main aim of the current analysis was to consider whether there are common patterns in encounters which parents find satisfactory as opposed to those experienced as unsatisfactory, and to suggest ways in which communication between parents and professionals might be improved when mental handicap is diagnosed.

Design and method

The study described in this paper was concerned with families with severely mentally handicapped children in two health districts in the south-east of England. The study had two stages. In the first stage all 399 children up to 16 years of age in the two districts who had been or

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were likely to be assessed as suitable for ESN(S)* education were seen by the research team. The children were assessed using the Disability Assessment Schedule developed by Holmes *et al.* (1982). In the second stage interviews were carried out with a sample of 200 families. This was a stratified random sample with proportional allocation for age and sex, so that it matched the total population from which it was drawn. We asked mothers a number of questions about when the child's impairment was first diagnosed, their responses at the time, their satisfaction with the way they were told, and ways in which telling could be improved. One parent of a 13-year-old boy would not accept that her child was impaired. Nine other children were fostered or in a home and the relevant information could not be obtained. This paper therefore is based on the 190 cases where the parent had known the child from birth, and includes one father. It has to be recognised, of course, that parents were reporting retrospectively about highly emotional events, and that their accounts may have been coloured by subsequent experiences. However, parents did seem to recall vividly the circumstances surrounding the diagnosis of the child's impairment. Full details of our design and methods are given in Pahl and Quine (1984).

Findings

When parents were first told

Table I gives the age of the child when the parents were first told of the impairment, compared with a similar study of severely mentally handicapped children carried out by the Centre for Child Study at the University of Birmingham (Phillips and Smith 1976). In our study, 29 per cent of parents were told at birth or in the first seven days. This figure is higher than that given by Eden (1976), who suggests that a firm diagnosis at birth is possible in about 25 per cent of cases, and it is also higher than the figure in the Phillips and Smith study. In our study, 22 per cent of parents (and in the Phillips and Smith study 35 per cent of parents) were not told until during or after the child's third year of life; 9 per cent were told during the child's third year, 7 per cent during the fourth year, 2 per cent in the fifth year and 4 per cent during subsequent years.

TABLE I
Child's age when parents first told of impairment

Parents told	*Present study (N = 190)*	*Phillips and Smith (1976) (N = 210)*
	%	%
At birth	29	21
First year	33	27
Second year	15	17
Later	22	35

TABLE II
Person who first informed parents about impairment

	Present study (N = 190)	*Phillips and Smith (1976) (N = 212)*
	%	%
Hospital doctor	72	66
Family doctor	6	8·5
Nurse	2	2·4
Midwife	3	—
Health visitor	2	—
Child-health doctor	4	9·9
Psychologist	1	—
Lay person	1	9·0
School clinic/teacher	8	4·2

Table II shows that almost three-quarters of the parents were told by a hospital doctor. In some cases the doctor involved was summoned soon after the birth by the midwifery staff who had delivered the baby. In others it was the paediatrician to whom the child had been referred once developmental delay or other problems had been noted at the clinic.

Emotional response of parents

We asked parents about their emotional response when they were first informed of the diagnosis. Most said that their initial reaction was overwhelming shock: 122 (64 per cent) spoke of being stunned, confused or numb. Only eight (4 per cent) spoke of feelings of rejection, and most of these stressed the temporary nature of the

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*'Educationally subnormal (severe)'.

feeling. 37 parents (19 per cent) spoke of accepting the news fairly calmly because they had known that there was something wrong, although no firm diagnosis had been made. For eight parents (4 per cent), final diagnosis made after a lengthy series of tests was a relief from anxiety: 'The health visitor told me she thought he might be brain-damaged. Then there was a dreadful three months wait for this to be confirmed. Not knowing how to help him was the worst thing. When the diagnosis was made finally, it was almost a relief'.

Feelings of anger were mentioned by 15 parents (8 per cent) because they felt that mistakes had been made at the time of birth, that their child's illness had been badly managed, or they had had a difficult job to convince medical staff that the child's development was a cause for concern: 'We kept phoning the doctor because his temperature was so high, and he was screaming, just screaming with pain. The doctor said I was over-anxious, and refused to come. He eventually came on Sunday, angry about being called out. He said I'd better put him in the car and take him to the hospital because I obviously couldn't cope. The hospital later phoned to say he had meningitis'.

How news was broken

Parents were asked exactly what they had been told. Many commented on the difficulty of the task for doctors. 64 per cent of parents had been given a (sometimes brief) explanation of the impairment. 21 per cent had been given only a diagnosis. In only 27 per cent of cases had opinions as to future development or advice on how to help and manage the child been given. (These figures do not add up to 100 because more than one response was possible.)

Parents were often critical of the blunt way in which the news of the handicapping condition was given by the hospital doctor. A parent said: 'I didn't notice anything about her features—she had tremendous feeding problems. Eventually I complained and was immediately transferred to X hospital. Nothing had been said. The houseman asked me 'Do you know why you are here?'. I said that the baby had feeding problems. An hour later the paediatrician and his entourage came in. He asked if I'd noticed anything different about her. I said 'No'. The houseman then told me that she was a mongol. Later he came in with a book with a picture of a woman with Down's syndrome which he tossed onto the bed. He said, 'That's what she'll look like'. It was an old-fashioned picture of an institutionalised person—I was terribly upset'.

The mother of a girl with microcephaly commented: 'The doctor said 'Your daughter has a very small head and brain. She will only ever be a vegetable. She will never do anything. Never walk or talk or feed herself'. Then she said in a matter-of-fact way, 'Take her down to X-ray. She has a heart murmur'.

Parents were sometimes faced with delay, denial and evasion at the hospital. Sometimes newborn babies were taken away to special care nurseries without explanation. Some mothers did not see their babies again for three or four days. One mother of a child with cerebral palsy said: 'They wouldn't let me see her until the following day. By that time my fears of what she would be like were far worse than if I'd seen her straight away'. The problem was often compounded by changes in the hospital routine or the reactions of the staff which alerted parents' suspicions: 'I knew immediately that something was wrong, the minute she was born. They all gathered round to look at her. Then they wrapped her up and took her away. I kept asking 'Is she allright?' and they would say 'Yes, she's fine, don't worry'. But they must have realised I knew, so why didn't they tell me the truth straight away?'.

Parents of children whose impairment was not so obvious at birth, or with emergent handicapping conditions, often had a long period of anxiety and uncertainty before a firm diagnosis was made. Many parents in this group felt that they had received inadequate and confusing information about the child's condition. Three children had actually started at normal school, and later been transferred to special schools. The mothers of two of these children had believed that their child was developing normally in every way.

A number of these parents had been the

first to recognise that their child was not developing normally. Often they believed that their anxieties about their child's development had been disregarded by professionals: 'The doctor said he just had a feeding problem. We found an article which seemed to describe his condition. We took this to the hospital and insisted on further blood tests. After this a firm diagnosis was made'. (This child was found to be suffering from infantile hypercalcaemia.)

Another mother suspected that her child was not developing normally after a bad reaction to the whooping cough vaccination. She felt that the medical profession did not take her evidence seriously. Eventually, when the child was eight, her case came to a tribunal and an award was made.

Reasons for parents' dissatisfaction

Parents were asked how satisfied they were with the way they were first told about the child's impairment. Nearly two-thirds were dissatisfied with the way they were told (Table III). One explanation for this might be that satisfaction is determined by internal factors, by the psychology and personality of the mother, which might lead to a general attitude of dissatisfaction with services. However, there was no correlation between general satisfaction with services and satisfaction with learning about the handicap. Nor was there a significant association between the mother's stress rating on the Malaise Inventory (Rutter *et al.* 1970) and satisfaction with learning about the handicap. A χ^2 test was used, therefore, to investigate whether parental satisfaction was related to the time at which they were told about the child's handicap. Table IV shows clearly that parents who found out early in the child's life were more satisfied with the way they were told.

Next, satisfaction with the first information about the handicap was broken down by diagnostic category. In conditions for which a definite cause could be identified, such as chromosomal or metabolic disorders or recessive genes, a significantly higher proportion of mothers were satisfied (Table V). The 'uncertain aetiology' group in Table V includes cerebral palsy for which often a cause cannot be ascribed (Kirman and Bicknell 1975). Significantly more mothers of children in this group were dissatisfied with the way they were told. It has been suggested that it is much more difficult to come to terms with mental handicap of unknown origin (Hunter 1980, Sleigh 1981). Additionally, perhaps parents of children with Down's syndrome

TABLE III

Parents' satisfaction with way first information about impairment was given

	N = 190	*%*
Satisfied	66	35
Not satisfied	115	60
Couldn't say/other	9	5

TABLE IV

Satisfaction with way first information was given by children's age when impairment was diagnosed

	Parents told		
	At birth (N = 55)	*First year (N = 57)*	*Second year or later (N = 69)*
	%	%	%
Parents satisified	51	33	27·5
Parents not satisfied	49	67	72·5

$\chi^2 = 7 \cdot 57$, df = 2, $p < 0 \cdot 05$.
N.B. In this Table, and in Tables V and VIII, the nine parents who were unsure whether they were satisfied are omitted.

TABLE V

Satisfaction with way first information was given by diagnostic category

	Known condition (Down's syndrome or other) (N = 94)		*Uncertain aetiology (no known pathology, cerebral palsy) (N = 87)*	
	N	%	N	%
Parents satisfied	42	55	26	30
Parents not satisfied	52	45	61	71

$\chi^2 = 4 \cdot 22$, df = 1, $p < 0 \cdot 05$.

TABLE VI

When parents were first told of impairment by diagnostic category

Parents told	Diagnosis Down's syndrome (N=62)	Other known conditions (N=35)	Cerebral palsy (N=27)	Cause unknown (N=66)
	%	%	%	%
At birth	63	26	19	5
First year	37	23	52	27
Second year or later	—	51	30	68

$\chi^2 = 85 \cdot 86$, df = 6, $p < 0 \cdot 001$.

TABLE VII

Parental satisfaction with way they were told of child's impairment in five studies

	Satisfied %	N
Present study 1984 (severe mental handicap)	35	190
Berg *et al.* 1969 (Down's syndrome)	54	95
Cowie 1966 (Down's syndrome)	53	46
Drillien and Wilkinson 1964 (Down's syndrome)	60	71
Hare *et al.* 1966 (spina bifida)	80	120

TABLE VIII

Age of child at time of interview by parents' satisfaction with way information about impairment was given

	Age of child (yrs) 0-5 (N=44)	6-10 (N=58)	11-18 (N=79)
	%	%	%
Parents satisfied	50	33	32
Parents not satisfied	50	67	68

$\chi^2 = 4 \cdot 92$, df = 2, $p = 0 \cdot 0852$.

or other specific conditions, for which a cause can be attributed, were likely to be told about the impairment earlier than other parents. Table VI shows that only 5 per cent of parents with children suffering from mental impairment of unknown cause were told at birth, compared with 63 per cent of Down's syndrome children. Taken together, the findings from Tables V and VI show that satisfaction may be linked to both early telling and the existence of a possible cause for the impairment. Dissatisfaction may have its roots in the waiting and worrying parents have gone through, and their heart-searching about the cause of the handicap.

Another way of investigating this point is to compare parental satisfaction with telling in a number of studies of children with different diagnoses. Table VII shows that parental satisfaction with telling is lowest in our study. It is likely that a higher proportion of parents of children with more obvious congenital defects, such a spina bifida or Down's syndrome, would be told earlier about their child's impairment, whereas our study includes a large proportion of children with non-specific handicap and other conditions not immediately apparent at birth.

Professionals seem to be getting better at telling parents. Berg *et al.* (1969) and Carr (1976) report a steady increase in early telling, and our study confirms this trend. For children born between 1965 and 1972, 28 per cent of parents were told at birth, compared with 38 per cent whose child was born between 1978 and 1982. Table VIII shows that parents of younger children were correspondingly more satisfied.

Discussion

Satisfaction and process of telling

Breaking the news to parents that their child will be mentally handicapped is an unenviable task. The doctor who suspects mental impairment in a child who is not reaching developmental milestones is in a particularly difficult position. He or she does not wish to destroy parents' hope, nor to foster false optimism. Usually, if a doctor suspects mental impairment, the child must be observed over a period of time before a definite diagnosis can be made. However, there is evidence that some impairments could be detected earlier. Chazan *et al.* (1980), for example, estimated that 30 per cent of cases in their sample could have been detected earlier.

How much information should be given? There are great differences between parents in their emotional and intellectual ability to grasp details and to accept the implications of the diagnosis, prognosis and treatment. Shocked parents may not assimilate information immediately, which often results in parents feeling that they have been told abruptly, clumsily and insensitively, or not told at all. Jacobs (1977) reports that doctors in his study were unwilling to accept that they had told parents badly, claiming that they had given full and adequate information, that parents either did not want to be told the truth or were often angry and resentful and therefore likely to be dissatisifed with the information given. However, the Harada and Pye study of midwives (1981) suggests that parents' claims that they were incompetently informed were justified.

These divergent views can be seen as failures of communication. Stacey (1980) discusses such failures at some length: 'At one level these seemed to be straightforward difficulties of communication in terms of what is said by professionals to parents. At another level the problems arise from the divergent goals of professionals and parents. At another level again, problems can be attributed to the divergent models held by parents and professionals about what is wrong with the child, particularly with regard to the relationship of aetiology and cure' (p. 73). Stacey suggests that there may be reluctance on the part of professionals to admit to parents the limitations of their knowledge and ability to cure. Waitzkin and Stoeckle (1972), for example, propose that: 'A physician's ability to preserve his power over the doctor-patient relationship • depends largely on his ability to control the patient's uncertainty'. This may be accomplished by withholding information at the patient's expense. Our study found evidence of withholding of information, careless comments and lack of compassion when the news was broken to parents.

It has been argued that dissatisfaction with disclosure is inevitable; most parents will always react with anger to the 'bringer of bad news' (Spain and Wigley 1975). However, this is not borne out by the evidence. In the Gayton and Walker (1974) study, 77 per cent of parents were satisfied. Cunningham was able to achieve 100 per cent satisfaction, compared with 20 per cent in a control group, when he set up a 'model' procedure in one area health authority (Cunningham 1984, Cunningham *et al.* 1984). Despite this, research into doctor-patient communication by Ley and colleagues (Ley 1977) shows that patients may be dissatisfied even when doctors have made special efforts to inform them. A number of studies suggest that the degree of patient satisfaction may be related to the doctor-patient interaction. Korsch *et al.* (1968), for example, report that satisfaction with visits to a clinic at a children's hospital was positively related to three parental ratings of doctors' behaviour: being friendly rather than business-like; seeming to understand the mother's concern; and being a good communicator. Communication is, of course, an interactive process: sometimes parents are diffident in voicing their conerns, and social distance between doctor and parent can contribute to this diffidence (Cartwright 1964). Parents also may regard the doctor as unapproachable. This deference and diffidence may conceal a desire for information, so clinicians are unaware of it. Traditional medical and nursing training has stressed the denial of emotions and the maintenance of affective neutrality (Jacobs 1979), so doctors are encouraged not to show concern and sympathy. As Jacobs says: 'By depersonalizing situations individuals may attempt to isolate themselves from the hurt they themselves may be caused by inflicting suffering on others. Thus the clinical detachment apparent in the attitude of some hospital staff may be considered a defence mechanism' (p. 91).

These explanations for the persistence of patient dissatisfaction, even when doctors have made special efforts to inform them, are interactive. An alternative set of explanations are cognitive. Ley and Spelman (1967) argue that for communication to be effective, the message it contains must be understood and remembered. Detailed research on memory and comprehension show that two factors are involved, failures of comprehension and failures of memory (Ley *et al.* 1972). Ley and Spelman argued that material presented to patients is sometimes too difficult to understand, and that patients often lack elementary medical knowledge. The importance of these failures to understand is that such patients are unlikely to be satisfied. Failures of memory, too, are common: Ley *et al.* (1976) found that patients recalled significantly more when their doctors had read and put into practice a brief manual of advice on improving patient recall.

How can telling parents be improved?

WHEN TO TELL

In the last two decades more attention has been given to the effect of the way in which parents are told the news, and how and when it is best to do so (D'Arcy 1968, Berg *et al.* 1969, Lucas and Lucas 1980). Our study provides evidence that most parents want to know as soon as possible that something is wrong, even though doctors may be unsure of the exact nature of the impairment. Most studies lead to the conclusion that delay and uncertainty are likely to cause additional distress for the parents, and have a lasting effect on the relationship between doctors and parents (Hewett *et al.* 1970; Gayton and Walker 1974; Carr 1975, 1976; Pueschel and Murphy 1976; Cunningham and Sloper 1977*b*).

We found no evidence of neurotic patterns of responses, such as guilt, rejection, over-protection or non-acceptance, which many earlier writers have reported (Grebler 1952, Schonell 1957, Forrer 1959, Roos 1963, Schaffer 1964). The majority of parents' responses appeared to be adaptive rather than dysfunctional. At first they were deeply shocked, but these feelings were followed by a process of reorganisation and adaptation as they began to think how best they could help their child and integrate him or her into family life. These stages were similar to those following bereavement (Schapiro 1983).

Both the National Association for Mental Health (1971) and the Association of Professions for the Mentally Handicapped (APMH) (1981*b*) have drawn up guidelines for telling parents. APMH recommends that the person to break the news should be the paediatrician, and that both parents should be informed together. In our study, often one parent was told alone and left to inform the other, and parents found this unsatisfactory. APMH suggests that a written report be given to parents after the initial interview, which summarizes what the paediatrician has said and gives details of future sources of help, including the name and telephone number of the parents' key worker.

The Independent Development Council for People with Mental Handicap (1982) suggests that every maternity unit and primary-care team should have guidelines on procedures to be followed in the event of the birth of a handicapped baby. These should include guidance on principles to follow, and practices to be avoided, in informing parents about handicap or suspicion of handicap, and ways in which immediate and short-term support should be provided for the family, including access to advice from appropriate community and voluntary agencies. The primary-care team, social services and education departments should be informed and contact made between the parents and a named social worker. The health visitor should be invited to meet mother and infant in hospital. Some of these guidelines are already being put into practice (Ward 1982). In St. Thomas' health district in London, a written report is given to parents and a copy is sent to the health visitor so that she is informed about the child's condition from the outset (APMH 1981*a*). In Southend, Essex, telling parents has become a duty designated to one person, and other parents of handicapped children become involved with the new parents to offer support and advice (Crowe 1975). In Medway, a community nurse and a social worker now visit families with a handicapped child soon after the diagnosis is made. When regular support is available, it has been shown that parents have a more positive attitude to professionals and a more optimistic attitude toward their child's development (Pugh and Russell 1977).

WHAT TO TELL?

Parents want to be told the truth. There is evidence from our study, and others, that parents are often bitter when they feel information was withheld or they were wrongly reassured (Walker *et al.* 1971, Carr 1975). Parents spoke with appreciation of the way they were told in cases in which a sympathetic and caring attitude was evident and questions were answered fully but simply, in language they could understand. The period of assessment prior to diagnosis is very important, since it is during this time that many communication problems occur (Stacey 1980). The findings of Ley and colleagues show that careful attention to the form and content of the information to be given might be a fruitful approach (Ley 1977). Parents want to know about the prognosis and implications for the future. In our study, 74 per cent of parents had found it hard to get information about their child's condition. Sometimes they were reduced to reading medical notes illicitly in their search for information.

IMPORTANCE OF FOLLOW-UP

Our study suggests that parents' main needs are for clear information and support over a period of weeks after the initial diagnosis. Frequently initial information is not understood or remembered, so follow-up is vitally important (Matheny and Vernick 1969, Lloyd-Bostock 1975, Cunningham and Sloper 1977*b*, Gath 1979, Firth 1982).

The guidelines of the National Association for Mental Health (1971) suggest that breaking the news 'must be only the first step in the continuing management of the child'. After the initial interview there is a need for counselling, which could be conducted in the parents' home. Cunningham (1979) provides a model of parental reactions and needs for particular kinds of help through phases of the crisis. He offers thoughtful advice to counsellors, based on insights derived from a longitudinal study in which families were visited as soon after the birth of the handicapped child as possible, and regularly thereafter.

As they gradually adjust, parents have many questions to ask. How was the handicap caused? What will the child be able to do and not do? What can the parents do to help? Information about services and benefits could also be given at this time. Parents should be treated as participants: they have expert knowledge of their own child (Newson 1976). Burden (1978) has reported the success of early intervention techniques which teach parents how to help their child. The 'named person', as envisaged in the Warnock Report (Great Britain: DHSS 1978), might also be a suitable person to be involved in follow-up (see also Pearce 1979, for discussion). Although desperate for information, parents sometimes find it difficult to absorb and assimilate. Information booklets can be of great help; they need to be brought up-to-date regularly and to be made readily available. Many parents in our study found contact with families of other handicapped children a great comfort and source of advice.

A constructive approach might be to set up locally-based working groups which would draw together all those concerned with this issue: the groups should include parents of handicapped children, as well as professionals. The aim would be to draw up guidelines for better practice and bring these to the attention of all the relevant professionals. The working group could also consider arrangements for genetic counselling, the pattern of antenatal investigation for mothers at risk, early intervention and the introduction of home-teaching services, such as Portage. However, we cannot emphasise too strongly that we believe that all these measures should be part of a continuous health programme for all children, which starts during the mother's pregnancy and aims at the prevention of impairment, where possible, early detection of defects, and the achievement of the maximum potential of each child.

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SUMMARY

This paper reports the results of interviews with 190 parents of severely mentally handicapped children. Questions were asked about parents' satisfaction with the way they were first informed of the child's impairment. Most parents were informed by a doctor, and almost two-thirds were dissatisfied with the first information given. Satisfaction was associated with being told early in the child's life. There was a significant association between the time of telling and the diagnostic condition of the child: parents of children with handicap of no known pathology were more likely to be told during or after the second year of the child's life, while parents of children with Down's syndrome were most likely to be told at birth. The authors discuss ways in which parents can be helped through this difficult time and suggest procedures for breaking the news to parents in a sensitive way.

RÉSUMÉ

Premier diagnostic de handicap sévère: une étude des réactions parentales

L'article rapporte le résultat d'entrevues avec 190 parents d'enfants gravement handicapés mentaux. Des questions ont été posées sur l'appréciation des parents concernant la façon dont ils avaient été informés pour la première fois de l'infirmité de leur enfant. La plupart des parents avaient été informés par un médecin et deux tiers étaient critiques sur la première information donnée. La satisfaction était associée à une information précoce par rapport à la vie de l'enfant. Il y avait une association significative entre le moment de l'information et la condition clinique de l'enfant: les parents d'enfants avec un handicap d'origine inconnue avaient toute chance d'être informés durant ou après la seconde année de la vie de l'enfant tandis que les parents de mongoliens avaient plus de chances d'être informés à la naissance. Les auteurs discutent la façon dont les parents pourraient être aidés à un moment difficile et suggèrent des moyens d'informer les parents d'une façon bien adaptée.

ZUSAMMENFASSUNG

Erste Diagnose einer schweren Behinderung: eine Untersuchung über die Reaktionen von Eltern

Diese Arbeit berichtet über die Ergebnisse der Interviews mit 190 Eltern von geistig schwer behinderten Kindern. Die Eltern wurden befragt, ob sie mit der Art, in der sie zuerst über die Behinderung ihres Kindes informiert wurden, zufrieden waren. Die meisten Eltern wurden von einem Arzt informiert und zwei Drittel waren mit dieser ersten Information unzufrieden. Zufrieden waren die Eltern, die frühzeitig informiert worden waren. Es bestand eine signifikante Beziehung zwischen dem Zeitpunkt der Information und dem diagnostischen Stand des Kindes: Eltern von Kindern mit einer Behinderung unbekannter Genese wurden häufig erst während des oder nach dem zweiten Lebensjahr des Kindes unterrichtet, während Eltern von Kindern mit Down Syndrom meistens schon bei der Geburt informiert wurden. Die Autoren diskutieren die Möglichkeiten, wie den Eltern während dieser schwierigen Zeit geholfen werden kann und machen Vorschläge, wie man die Eltern mit Feingefühl über den Zustand ihres Kindes unterrichtet.

RESUMEN

Estudio de las reacciones de los padres al recibir por primera vez un diagnóstico de minusvalía grave

La comunicación aporta los resultados de las entrevistas con 190 padres de niños con grave subnormalidad mental. Se hicieron preguntas sobre la satisfacción de los padres acerca de la forma cómo se les informó por primera vez del problema del niño. La mayoria de los padres fueron informados por el médico y los dos tercios no estaban satisfechos con la primera información recibida. La satisfacción estaba asociada con haber recibido la noticia precozmente en la vida del niño. Había una asociación significativa entre el momento de la noticia y la situación diagnóstica del niño: los padres de niños con minusvalencia debida a una causa desconocida solian recibir la noticia más bien durante o después del segundo año de la vida del niño, mientras que los padres de niños con un sindrome de Down solían recibir la noticia al nacer el niño. Los autors discuten qué padres pueden ser ayudados durante este tiempo dificil y sugieren métodos para dar la noticia a los padres de un modo adecuado.

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FIRST DIAGNOSIS OF SEVERE MENTAL HANDICAP: CHARACTERISTICS OF UNSATISFACTORY ENCOUNTERS BETWEEN DOCTORS AND PARENTS

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Abstract—This paper presents data from a study of 190 parents and discusses their reactions to being told that their child was likely to be severely mentally handicapped. Dissatisfaction was related to the child's age when the parents were first told about the impairment, which was itself related to the diagnosis of the child's condition. Parents of children with non-specific handicap were often not informed about the impairment until the second or third year of the child's life, while parents of children with Down's Syndrome were usually informed within a week of birth. The paper compares these two groups of parents and discusses the reasons for their dissatisfaction. The study showed that parents valued early acknowledgement of the problem, a sympathetic approach on the part of medical professionals, and the sharing of information and uncertainty. The reasons why parents of mentally handicapped children may continue to feel dissatisfied are discussed in the light of the theoretical literature on doctor–patient communication.

Key words—diagnosis, mental handicap, doctors, parents

When parents are informed that their child is likely to be mentally handicapped, two rather different sets of people come face to face. On the one hand, there is the professional whose responsibility it is to break the news. Whether this is a hospital doctor, a general practitioner or a nurse, he or she is likely to find the responsibility both worrying and difficult. On the other hand, there are the parents themselves. They may be the parents of a new born baby, or they may have suspected for a long time that something is wrong with their child: whichever is the case, the moment when mental handicap is finally confirmed is likely to be a bleak one.

There are many ways in which the encounter can go wrong. A professional may feel that he or she has been both sympathetic and informative and may be dismayed when, at their next meeting, parents seem to remember little of what they have been told. On the other hand, parents may experience shock and anger, and their feelings about how the news was broken may colour their feelings about their child and make them suspicious of professionals in general for a long time to come. It is important to recognize that, while at one level we are concerned with an encounter between individuals, at another level we need to understand the broader structural context within which the encounter takes place. This article discusses some of the structural factors which seem to be associated with parents feeling dissatisfied with how they were first told about their child's impairment.

There is an extensive literature concerned with informing parents of their child's diagnosis of severe mental or physical impairment. Several studies have viewed it as a crisis, producing grief, followed by stages of shock and disbelief, denial, anger, adaptation and adjustment similar to the phases identified in the bereavement literature [1–4]. Reference is also made to 'chronic sorrow' [5]. A large number of studies report on the identification of Down's Syndrome [6–11], while others are concerned with congenital malformation such as spina bifida [12–14] or severe mental handicap [15]. It has been suggested that the way in which parents are told of a child's impairment has a profound effect on them. Evidence suggests that this affects both the way in which they adjust to the situation, and their early treatment of the child [16–18].

Though much is known about parents' reactions to being told that their child is impaired, we know less about the factors which seem to be associated with dissatisfaction. Why are some parents so dissatisfied with the way in which they were told about their child's impairment, while others speak appreciatively of the understanding way in which the news was broken? Are there common patterns which characterize encounters which parents found satisfactory as opposed to those experienced as unsatisfactory? What is good practice in this field and what can be done to improve communication between parents and professionals when mental handicap is diagnosed? Ideally, finding answers to questions such as these would involve taking into accout not only the parents' experience of being told, but also the experience of the professional who broke the news about the child's impairment. Research into interactions between social workers and their clients, involving putting together both participants' accounts of a particular meeting, has shown that there were enormous discrepancies between what the social worker and the client thought had happened when they met [19]. Had a third person been present, he or she might have given yet another account of the event.

In the pages which follow we shall be concerned only with the parents' point of view. This means that we shall not be investigating what 'really' happened, but rather what the parents considered to have happened. We would defend this approach on the grounds that, where people define situations as real, those situations have real consequences. Subjective reality can have as powerful an impact on behaviour as objective reality. The discussion draws its evidence from a study of 200 families with severely mentally handicapped children.

THE STUDY OF FAMILIES WITH MENTALLY HANDICAPPED CHILDREN

The study was carried out in two health districts in the South East of England. Its aim was to assess the difficulties experienced by families caring for children with mental handicaps, to evaluate the effectiveness of services provided for these families in terms of relieving the stresses experienced by those who were responsible for the day-to-day care of the children, and to make recommendations about future developments in service provision for families with handicapped children.

The study had two stages, which we called the 'population survey' and the 'sample survey'. The first stage concerned the total population of children who had been or were likely to be assessed as suitable for ESN (S) education. At the first stage 399 children in the two health districts were assessed using the Disability Assessment Schedule developed by Holmes *et al.* [20]. Information was collected from the teacher or care assistant who knew each child best, about the child's mobility, continence, self-help skills, vision, hearing, communication skills, behaviour problems and medical conditions. At the second stage, a stratified random sample of 100 children was drawn from the total population of 238 children in one Health District and these children were then matched with 100 drawn from the total population of 161 children in the other health district to enable comparisons between health districts to be made. The sample was chosen with proportional allocation for age and sex so that it matched the population from which it was drawn. For the purpose of this analysis, the 200 children have been considered together. An interview was carried out with the person responsible for the day-to-day care of each of the sample children, using a structured questionnaire.

The great majority of the children were living with their natural mother and father and with other children. Single parent families made up 13% of the total and most of these were mothers living with their children. In 59% of families the handicapped child was the youngest in the family, while in 35% of families he or she was the eldest; 18% of the sample were the only child in the family. In 190 instances the chief carer was the child's mother; 6 chief carers were foster mothers, one was the child's father, one was the grandmother, and in two instances we defined the matron of the children's home where the child lived as the chief carer.

The diagnoses of the children are shown in Table 1. For more than one-third of the children in our sample, the cause of their disability was unknown: in some of these cases parents attributed their child's problems to a pre-natal injury, to a difficult birth, to vaccine damage or an infection, but for many the lack of clear diagnosis contributed to their distress. About one-third of the children suffered from Down's Syndrome; this is slightly higher than the figure given for the general population by the Office of Health Economics, which is 25–30%. Fourteen per cent of the children suffered from cerebral palsy. Among the other conditions of aetiological significance were primary genetic or chromosomal abnormalities, metabolic disorders, developmental defects such as spina bifida, brain damage caused by accident or illness and foetal environmental syndromes such as foetal rubella syndrome. Twelve per cent of the sample had siblings who were also mentally handicapped, though in some cases they were mildly as opposed to severely handicapped.

Table 2 presents the major impairments or disabilities affecting the children. A sizeable proportion of the children were quite seriously impaired. About one-third of the children were unable to walk by themselves, over one-third were unable to feed themselves, one-fifth were blind or partially sighted, one-third suffered from epileptic fits and almost one-half had one or more serious behaviour problems.

One parent of a 13-year-old boy did not accept that her child was impaired. In nine other cases where the child was fostered or in a home, the relevant information could not be given. This paper is based on the 190 cases where the chief carer had known the child from birth and includes one father. Parents were asked a number of questions about the time when they first learned about the child's impairment. First, we hypothesized that there would be an association between the nature of the child's clinical condition and the extent to which parents were satisfied with how they were told of it. It seemed likely that where the cause of the impairment was unknown, for example, identification would be delayed, the task of the professional would be more difficult and the parents would be less likely to feel that they had received adequate information. The children were divided into three clinical groups. The first group contained the 62 children who had been diagnosed as suffering from Down's Syndrome. The second group consisted of 62

Table 1. Diagnoses of the 190 children in this study

	%
Cause unknown	35
Down's Syndrome	33
Cerebral palsy	14
Other conditions of aetiological importance	18
Base for percentages	190

Table 2. Impairments of children in the sample

	%
Unable to walk without help	35
Unable to feed themselves without help	44
Singly or doubly incontinent at least twice a week during day	43
Blind or partially sighted	19
Deaf	12
Epileptic	28
Severe behaviour problems	42
Base for percentages	200

Table 3. Surveys of parental satisfaction with first diagnosis of severe impairment

	Parents dissatisfied %	N
Pahl and Quine, 1984		
(Severe mental handicap)	60	190
Laing and Jones, 1979		
(Severe mental handicap) [71]	42	59
Phillips and Smith, 1976		
(Severe mental handicap) [15, 72]		
Down's Syndrome	39	54
Specific medical diagnosis	56	60
No specific pathology	71	71
Berg *et al.*, 1969 (Down's Syndrome)	46	95
Drillen and Wilkinson, 1964		
(Down's Syndrome) [6]	40	71
Lucas and Lucas, 1980		
(Down's Syndrome) [11]	48	79
Cowie *et al.* 1966 (Down's Syndrome)	47	46

children for whom a specific medical diagnosis had been made. The most frequent diagnosis was that of severe cerebral palsy, which carries a strong possibility of impaired mental functioning, but for all of this group there was medical evidence pointing to intellectual impairment of congenital origin or to a pathological condition in addition to intellectual impairment. The third group of 66 children contained those where no specific pathology could be identified and the cause of the impairment was unknown.

Previous studies have documented high levels of parent dissatisfaction with the first news of the handicap, as Table 3 shows. This table, together with Table 4, also provides evidence for an association between diagnostic category and parental satisfaction. As Table 3 shows, the study carried out by Smith and Philips [15] confirmed that parents of children with Down's Syndrome tended to be more satisfied with the explanation given to them than parents of children in other diagnostic categories, who were themselves more satisfied than parents whose children had no specific pathology. Our results, shown in Table 4, do not reach statistical significance, but there is a higher proportion of satisfied parents among the parents of Down's Syndrome children than among the parents of children with non-specific handicap.

Parental satisfaction is also associated with the age of the child when mental handicap was first confirmed [8, 21]. Our results confirm this association. As Table 5 shows, parents who were told early in the child's life were more satisfied than those who were told later. As one might expect, there was also an association between the nature of the diagnosis and the age of the child when parents were first told that the child was mentally handicapped. Nowadays, Down's Syndrome is usually recognized at birth and can be confirmed by blood test a few days later. Children suffering from non-specific handicap are usually identified much later and parents have often been anxious about the development of their child for a considerable time [15]. Table 6 shows that parents of Down's Syndrome children were more likely to be told of the impairment at birth than were parents of children in other diagnostic groups. Of the Down's Syndrome children, 63% were identified at birth or within the first 7 days, and 100% had been identified by one year. By contrast, only 32% of the children with non-specific handicap had been identified by the end of the first year, and only 52% by the end of the second year.

Two other factors which may have been associated with parental satisfaction were the age of the child at the time of the interview, and parental age. It is possible that parents of older children may have had more time for unpleasant memories to fade, or even that older parents are generally more satisfied. There was no association between satisfaction and parental age. However, an association was found between the child's age and parental satisfaction, as Table 7 shows. Parents of younger children were more likely to be satisfied than parents of older children. This finding is open to at least two interpretations. Firstly, it may be that doctors are getting more skilled at breaking the news of severe handicap to parents. Medical and nursing training now includes sociological and psychological components and there is some evidence that there is a growing awareness of the importance of this first interview with parents [21].

Table 5. Satisfaction with the way the first information was given by age of the children when impairment was diagnosed

	Parents were told		
	At birth (%)	First year (%)	Second year or later (%)
Parents were			
Satisfied	51	33	27.5
Not satisfied	49	67	72.5
Total	100	100	100
Number	55	57	69

$\chi^2 = 7.57$; d.f. = 2; significant $P < 0.05$.

Table 4. Satisfaction with the way the first information was given by diagnostic category*

	Diagnosis			
	Down's Syndrome (%)	Other known conditions (%)	Cerebral palsy (%)	Cause unknown (%)
Parents were				
Satisfied	45	41	21	32
Not satisfied	55	59	79	68
Total	100	100	100	100
Number	60	34	24	63

$\chi^2 = 5.35$; d.f. = 3; not significant.

*In this table and in Table 5, the 9 parents who were unsure whether they were satisfied were omitted from the calculations.

Table 6. When parents were first told of impairment by diagnostic category

	Diagnosis			
	Down's Syndrome (%)	Other known conditions (%)	Cerebral palsy (%)	Cause unknown (%)
Parents were told				
At birth	63	26	19	5
First year	37	23	52	27
Second year or later	—	51	30	68
Total	100	100	100	100
Number	62	35	27	66

$\chi^2 = 85.86$; d.f. = 6; highly significant $P < 0.0001$.

Table 7. Age of child at the time of the interview, by parents' satisfaction with the way information about the impairment was given

	Age of child		
	0–5 (%)	6–10 (%)	11–18 (%)
Parents were			
Satisfied	50	33	32
Not satisfied	50	67	68
Total	100	100	100
Number	44	58	79

$\chi^2 = 4.62$; d.f. = 2; marginally significant $P = 0.0993$.

Secondly, it may be that a higher proportion of parents of the youngest age group of children (0–5) *appeared* to be more satisfied because the group did not yet contain the parents of those children who will be diagnosed as intellectually impaired in the first few years of childhood. These would be parents who would be more likely to be dissatisfied. It can be seen that there is little difference in the proportions of satisfied parents in the 6–10 and 11–18 age groups. It would be interesting to identify children in this age group who are newly diagnosed and to compare these figures again in two or three years' time when the age group contains its full complement of mentally handicapped children.

It seemed, then, that there were important differences between, at the one extreme, parents whose children had Down's Syndrome and, at the other extreme, parents of children whose mental retardation had no known cause. Accordingly, we decided to investigate the accounts given by these two groups of their experiences of being told that their child was mentally handicapped. We hoped that an analysis of the differences between the two groups would help us to understand the structural factors which contribute to misunderstanding between parents and professionals.

PARENTS OF CHILDREN WITH DOWN'S SYNDROME

Out of the total sample of 200 families, 62 children were suffering from Down's Syndrome. Of these, 45% (27 parents) were satisfied with the way the news of the child's disorder had been first given to them. Almost all of these had been told at birth or within the first week. Only two parents had been told later, both at 8 days. Questioned about the source of their satisfaction, 52% (14) mentioned caring, sympathetic attitudes of medical staff and 26% (7) mentioned receiving full and adequate information and follow-up. On the other hand, 55% of parents with Down's Syndrome children (33) were dissatisfied*. What were the reasons for their dissatisfaction? In order to explore this question the dissatisfied parents were divided according to whether they had received on early diagnosis (at birth or within a week of birth) or a late diagnosis (after a week and up to 10 months).

Among the 33 dissatisfied parents of Down's Syndrome children nearly half (48%) had received a relatively late diagnosis; on average the 16 parents in this group had been informed of the diagnosis when the child was 9 weeks old. This group consisted mainly of older parents, since nowadays Down's Syndrome is usually confirmed earlier. All the parents in the late diagnosis group were dissatisfied with the first information they received about the impairment. In addition, 4 of the 16 considered that they had not received adequate information, 11 mentioned the unsympathetic attitudes of medical staff, while 12 described the behaviour of medical staff as evasive or secretive. One mother said:

> "I don't think it should have taken them so long to tell me. At least they could have told me they suspected Down's Syndrome. They did a blood test but I didn't know why. I suspected something was wrong because she wouldn't feed properly. But I had no idea she was a mongol. I kept asking questions but no-one would answer them properly. They kept saying 'She'll be all right'. They let me go home with her, when if I had known what was wrong I might have decided not to keep her. After three weeks they called me back to the hospital and told me".

Just over half (51%) of the dissatisfied parents of Down's Syndrome children had been given an early diagnosis of their child's impairment, either at birth or within the first 7 days. Why were these early-diagnosis parents dissatisfied? Of the 17 parents in this group, 8 felt that, though they had been told relatively early, they had been faced with unnecessary delay, denial and evasion on the part of medical staff. One parent said:

> "I suspected as soon as she was born. She had feeding difficulties and she was all floppy. I kept asking the nurses but they wouldn't say anything until the doctor came. He didn't come until the next day. I don't see why they had to wait for the doctor to tell me".

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*These figures do not add up to 62 because two parents were unsure whether or not they were satisfied.

The problem was sometimes compounded by changes in the hospital routine, or by the reactions of the staff, which alerted the parents' suspicions:

"I knew immediately that something was wrong, the minute she was born. They all gathered round to look at her. Then they wrapped her up and took her away. I kept asking 'Is she all right?' and they would say 'Yes, she's fine, don't worry'. But they must have realised I knew, so why didn't they tell me the truth straight away?"

In addition, the unsympathetic way in which parents were told was cited by about half of this group as a source of dissatisfaction, while 40% mentioned inadequate information. One parent said:

"I didn't notice anything about her features—she had tremendous feeding problems. Eventually I complained and was immediately transferred to X hospital. Nothing had been said. The houseman asked me 'Do you know why you are here?' I said that the baby had feeding problems. An hour later the paediatrician and his entourage came in. He asked if I'd noticed anything different about her. I said 'No'. The houseman then told me that she was a mongol. Later he came in with a book with a picture of a woman with Down's Syndrome which he tossed onto the bed. He said, 'That's what she'll look like'. It was an old-fashioned picture of an institutionalized person—I was terribly upset".

PARENTS OF CHILDREN WITH NON-SPECIFIC HANDICAP

As Table 4 shows, when the cause of a child's retardation is unknown, parents are more likely to be dissatisfied with how they were told about the impairment. Of the 66 parents in this group, 45 (68%) were dissatisfied with how the news had been broken to them. Partly this was because identification of non-specific handicap commonly occurs much later. By the end of the first year, only 32%, and by the end of the second year only 52% of the parents had learned of the serious nature of their child's impairment. About half of the parents in this group had been seriously concerned about their child's development for many months before the diagnosis of severe mental handicap was made. Most noticed developmental delay. Sleeping, feeding and behavioural problems and screaming bouts were also a cause for concern. Some parents were worried when children began to have fits. Many parents in this group were critical of the process by which impairment was identified in their child, and by the lapse of time which occurred between them expressing their anxiety and receiving a diagnosis. Parents spoke of long battles with the authorities to get recognition of their child's impairment, and of their frustration when their anxieties about their child's development appeared to be disregarded by their general practitioner. Some parents were told they were over-anxious and that the child would probably 'grow out of it'. Others felt that facts were being suppressed. One parent said:

"I was so worried about him. He couldn't crawl or sit up. My doctor told me he was just slow and would grow out of it. He wouldn't take the problem seriously or refer me to a paediatrician. Eventually I went privately, and was told he was severely mentally handicapped".

Another said:

"It was obvious at the clinic that they were suspicious about something. They kept asking me questions about my medical history. But when I asked they just said 'Don't worry, he's just a bit slow'. I had no idea of the seriousness of his handicap".

Over half (34) of this group of parents felt that the diagnosis could have been made earlier. Twenty-seven per cent (18) thought that they had not been given sufficient information and explanation about this form of impairment. Twenty-one per cent (14) mentioned that the doctors appeared cold or unsympathetic. A parent said:

"They give you this dreadful news. Then you have to go away and live with it. You have to deal with it as best you can. No-one helps. No-one comes to see how you are coping. You are completely alone".

Parents of children in this non-specific handicap group were sometimes unaware of abnormal development. Four children were not identified as severely mentally handicapped until after they had started school at the age of 5. One child had been identified as mentally handicapped at 4 years of age, whilst in hospital undergoing treatment for an eye infection. The news of one child's mental handicap was broken to the parent by a speech therapist. The parent believed that he was just a 'late developer'. Three parents believed that their child had been damaged during routine operations for hernia or adenoids. Seven parents believed whooping cough vaccine to be the cause of the damage to their child, but this had not been confirmed. One parent said of her child:

"She went into hospital to have her adenoids out. When she came home I couldn't believe she was so changed. They [the hospital] said later that she was already backward. But she had stopped doing a lot of the things she could do before the operation".

Another parent said:

"He was normal until 10 months old. He started to have fits within hours of having a second vaccination. Later they said that fits caused the brain damage. But what caused the fits? I am sure in my own mind that it was vaccine damage".

DISCUSSION

Several themes recur when parents are asked about their satisfaction with the first information concerning their handicapped child.

(1) Parents want to be told as early as possible that there is cause for concern about their child even though doctors may be unsure of the exact nature of the child's impairment. Parents of children with non-specific handicap are particularly vulnerable in this respect. Parents who are told late tend to be dissatisfied.

(2) Parents value a sympathetic and caring approach by doctors and other medical staff.

(3) Parents want to be given full information about the child's condition.

On the face of it, these needs seem to be reasonably unproblematic. Why, then, are they so seldom met? We shall discuss each need in turn, using the extensive literature on doctor–patient communication to offer insights into the problems. Achieving patient satisfaction with the transmission of information about illness is an issue which is of relevance to many branches of medical care [22, 23].

EARLY ACKNOWLEDGEMENT OF THE PROBLEM

Much of parent dissatisfaction in this study stemmed from the timing of the first identification and diagnosis of mental handicap. In the Down's Syndrome group the parents who were dissatisfied had often faced delay, denial and evasion before the diagnosis was made. Babies were taken away immediately after birth, with no explanation, and put in special care nurseries. Nursing staff behaved oddly toward the mother. The mother's questions were evaded or ignored. Even though the time between the mother's suspicions being aroused and diagnosis was of comparatively short duration, it was sufficient to raise parental anxiety and anger. Although many of these problems stemmed from a lack of clear guidelines about what nursing staff should do in the event of the birth of a handicapped child, a part of it also seemed the result of what Matthews [24] has called "the question of who is authorized to give what kinds of information to patients" (p. 1374). Traditionally, the doctor–patient relationship has been seen as primary and exclusive. To strengthen this, nurses are trained to preserve physicians' exclusive rights to transmit medical information [25, 26]. The nurse's role in communication has been limited to re-explanation of information imparted by the physician [27]. In our study, we found that the task of breaking the news to parents that their newly-born child was suffering from a chromosomal abnormality was almost always carried out by doctors. Even when a doctor was not present at the birth and had to be summoned from a distant part of the hospital, nursing staff would parry parents' questions about the baby until he arrived. Sometimes the doctor did not talk to parents until after the results of a blood test had become available. Some mothers took the baby home and were not appraised of the diagnosis of Down's Syndrome for several months. It is likely, as Gath observes, that this may have been to allow 'bonding' to take place so that the mother would not reject the child [28]. However, for a mother who believed that she had a normal child, it made the discovery that her child was impaired even more devastating. From the mother's point of view, medical staff had given tacit confirmation to the child's normality by discharging mother and baby without communicating their suspicions.

The mothers of children identified as suffering from mental impairment of no known cause were generally told even later about the impairment. In addition, there was often a lapse of time between parents becoming seriously concerned about their child's development, and diagnosis of impairment. Two questions arise: firstly, could some of these impairments have been detected earlier and secondly, can treatment of parents going through this difficult period be more sensitive? Other studies have suggested that some impairments *could* have been detected earlier [29]. Chazan *et al.* estimated that 30% of cases in one child study sample could have been identified earlier. Newson [30] recommended that parents should take an active part in the diagnosis and assessment of their child: "we start from the basic assumption then that parents in fact have information to impart: that parents are experts on their own children" (p. 105). Newson advocated the use of video "to retain a living record of a child's progress". Some parents who were worried about their child's progress waited agonizingly for months before diagnosis was made. Often parents were given very little information at this time. One parent described this period as 'a conspiracy of silence'. Ingram [31] suggested that the paediatrician should make his diagnosis 'by increasing suspicion' during the child's early life rather than wait until he is older, when the full clinical manifestations of the condition are apparent.

It was apparent from the comments of mothers in this study that they would have preferred to have been told that something was wrong as soon as possible, even though doctors might have been uncertain of the exact nature of the impairment. Delay and uncertainty simply led to additional distress for parents, and may have had a lasting effect on the relationship between doctors and parents [4, 10, 21, 32].

THE IMPORTANCE OF A SYMPATHETIC APPROACH

The findings of this study showed that there was a strong relationship between parental satisfaction with information at first identification and the parents' feelings that the person who communicated the information had a sympathetic approach. Korsch *et al.* [33] reported some similar findings, showing that satisfaction with information at a walk-in Emergency Clinic at a Children's Hospital in Los Angeles was positively related to three parental ratings of doctor's behaviour: being friendly rather than business-like, seeming to understand the mother's concern, rather than not understanding, and being a good rather than a poor communicator. Korsch *et al.* believed that if these essential ingredients are missing from doctor–patient interaction, patients will be dissatisfied.

Other studies of doctor–patient interaction have confirmed that the doctor's affective behaviour is an important ingredient [34–36]. But are doctors really unsympathetic toward parents, or do they only *appear* to be so?

A number of writers have considered this issue. Jacobs [37] observed that medical and nursing training has traditionally stressed the denial of emotions and the maintenance of affective neutrality. Thus doctors are encouraged to show 'clinical detachment' and not to voice concern and sympathy. This may be part of a complex ideology characterized by denial of feeling, the purpose of which is to protect the clinician from the anxieties of his or her job, which arise from encounters with dying and damged children and distressed parents. As Jacobs said, "by depersonalizing situations, individuals may attempt to isolate themselves from the hurt they themselves may be caused by inflicting suffering on others. Thus the clinical detachment apparent in the attitude of some hospital staff may be considered a defence mechanism" (p. 91).

Stacey [38] and Friedson [39] considered the problem to be a failure of *communication* which has its roots in the separate worlds of experience and reference of the layman and the professional worker. Friedson considered these to be always in potential conflict, because of the divergent goals of the actors involved and their different models of normality.

Communication is, of course, an interactive process. Sometimes parents are diffident in voicing their concerns. Perceived social distance between doctor and parent can contribute to this diffidence [40, 41]. The parents may regard the doctor as unapproachable because of his high status. Deference and diffidence may conceal a desire for information so that clinicians are unaware of it. Cartwright [40], for example, showed that hospitalized patients in the professional class are more likely to ask questions about their condition, while those in the unskilled manual group more often waited to be told.

SHARING INFORMATION AND UNCERTAINTY

A large number of parents in our study said that they had not received enough information about their child's condition. Overall, 74% of parents said that it had been hard to get information about their child's condition, and, at another point in the interview, 74% said they wanted more information. Parents were asked what their main sources of information were. While doctors were the most common source of information, being mentioned by 64% of parents, the second most common source was literature (36% of parents), and the third, 'other parents' was 24%. A number of studies confirm that patients/parents do want information [40, 42]. Even if the illness is cancer or the patient is dying, the majority of patients want to be told.

Surveys of patient satisfaction show high levels of dissatisfaction with information. This is in sharp contrast to the generally high levels of satisfaction with other aspects of health care. In an interesting article, Jacobs [43] reported that doctors in his study of mentally handicapped children were unwilling to accept that parents had been told unsympathetically, claiming that parents did not want to be told the truth, or that parents were often angry and resentful and therefore likely to be dissatisfied with information given. However, Harada's [44] study of midwives showed that they believed parents were often inadequately and unsympathetically informed. Certainly parents in our study often felt that doctors were reluctant to give them information or actually actively withheld it. Stacey [38] suggests that professionals may be reluctant to admit to parents the limitations of their knowledge and of their ability to cure sick children.

Waitzkin and Stoeckle [45], on the other hand, argue that the maintenance of uncertainty is used as a *strategy* by doctors to preserve power over the doctor–patient relationship. This is done by withholding information at the patient's expense. Methods of preserving power which have been documented in other studies include elaborate routines which minimize patient involvement and maximize professional autonomy [46]. In consultations, the doctor has a 'hidden agenda' comprising rules, information and procedures such as diagnosis and prognosis, which is not communicated to the patient [47]. The doctor's control over the hidden agenda ensures that s/he controls the doctor–patient encounter. Parents in our study, particularly in the non-specific pathology group, often seemed to be victims of the 'hidden agenda', where for months on end they were given little or no information from medical staff, while having to make a series of apparently pointless visits to the clinic or paediatrician with their child.

Parsons [48] believed that the less uncertain the patient becomes about the nature of his illness and the effects of treatment, the less willing he will be to allow the doctor to make decisions for him. Patients are generally typified as having low status, passive-dependent roles so that they do not demand information from doctors [25]. For example, Lorber [49] found that both professionals and patients view the ideal patient as a co-operative and acquiescent person who plays a deferential role.

West [50], in a study of doctor–patient interaction in out-patient clinics where the child had epilepsy, argued that doctors maintain authority in situations where there is clinical uncertainty about diagnosis and treatment by not disclosing the incompleteness of medical knowledge. However, this strategy may not be effective in preserving power, since continual uncertainty may put the doctor's professional credibility at risk. West presented instances during the period of consultation where the 'hidden agenda' is breached: parents become more knowledgeable about the condition, discovering new sources of information, and becoming more critical of the doctor's treatment and assessment. Our study presented many instances of breaches of the 'hidden agenda'. In one case the parent of a child with infantile hypercalcaemia told us:

> "The doctor told us he just had a feeding problem. But after a lot of searching, we found an article which seemed to describe his condition. We took this to the hospital and insisted on further tests. After this a firm diagnosis was made".

Another parent heard a speaker describing the characteristics of autistic children at a luncheon club. The description fitted her child so well that she spoke afterwards to the speaker, who was headmistress of a school for autistic children. This led to the assessment and diagnosis of her daughter.

Quint [51] and Cicourel [52] have noted that patients receive a variety of contextual clues which inform them that any inquiries they might make are not welcomed by staff. Physicians may continue talking without paying attention to the patient's viewpoint; topics are shifted to avoid dealing with sensitive issues. Non-verbal clues involve simply walking away from the patient without responding to his or her questions, limiting the time available for a consultation, and maintaining a spatial distance to inhibit conversation.

Ley [53] in a review of theory and experiment in the field of doctor–patient communications showed that sometimes patients are dissatisfied even when doctors *have* made special efforts to give them adequate information. He advanced a cognitive explanation for this: that for communication to be effective the message it contains must be understood and remembered. Patients' failures to understand stem from three inter-related facts.

(1) The material presented to patients is often too difficult to understand [42];

(2) Patients often lack elementary technical medical knowledge [54];

(3) Patients often have active misconceptions which militate against proper understanding [55].

We would add a fourth, as far as parents being given news of severe impairment in their child is concerned:

(4) That parents are often too shocked at the initial interview to take in what the paediatrician tells them.

The significance of these failures to understand is that if patients do not understand what they are told, they are likely to be dissatisfied.

Ley *et al.* [56] were able to increase patient satisfaction with communication by increasing understanding. Ley also reports on patients' failure to remember. In a study of patient recall of information given to them by general practitioners, he found most patients had forgotten 50% of the statements made to them within five minutes of leaving the consulting room [57]. He and his colleagues went on to do a number of experiments aimed at improving recall and so increasing patient satisfaction [53, 56, 58]. These investigations led to the production of a manual for doctors containing specific suggestions for increasing the amount and content of patients' recall. Ley *et al.* [58] investigated recall of information by patients of four practitioners before and after the general practitioner had read the manual and put it into practice, and found that patients recalled significantly more when the general practitioner used the suggested methods.

CONCLUSIONS

Research

Parents of mentally handicapped children are not the only group who are dissatisfied with the way in which doctors communicate information. Many studies show high levels of patient dissatisfaction with the information they are given. Research on doctor–patient communication in other settings is able to offer some useful explanations of the failures of communication and some indications as to how the difficulties can be overcome.

Maguire and Rutter [59] have shown that it is possible to train medical students in communication skills. Ley [22] has shown that it is possible to improve patients' understanding and recall of information. More radical experiments have involved giving patients open access to their case records [60, 61], providing access to taped information about the illness and its treatment [62], and providing written information in addition to orally-presented information [63]. Fischbach *et al.* [64] have even suggested that patients should be made co-authors of their medical records.

A further method for improving communication which has received some consideration is patient activation. This covers a number of techniques for encouraging the patient to be more demanding in the doctor–patient interaction. Roter [65], for example, arranged for patients to be interviewed by health educators before seeing the doctor. The health educator discovered what the patient wished to find out and made sure by teaching and rehearsal that the patient knew how to ask for the desired information. This led to an increase in patient questioning.

There are a number of ways in which research in this area might move forward. Follow-up studies to assess the effects of different types of communication would be useful. Model procedures for informing those parents whose children suffer from non-specific mental handicap might be set up and monitored. Studies of the outcome for those children who are identified as suffering from developmental delay in the first year of childhood would be of interest. Finally, in the area of cognitive psychology, further research on the ideal form and content of the information which is given to patients is required.

Practice

This study has shown that the parents of children suffering from handicap of no known pathology are a particularly vulnerable group since there is often a lapse of time between the parent becoming aware that something is seriously wrong with their child, and diagnosis of severe mental impairment. The way this period of time is handled by doctors is extremely important. Four practical recommendations can be made from considering the evidence from our study.

(1) Parents wish to be told of the doctor's concern even if it is not possible for an exact diagnosis to be made. Parents are experts in their own child. Their observations and information are of paramount importance in reaching a diagnosis.

(2) Parents appreciate a sympathetic approach. Some do not find it easy to ask questions although they want full information.

(3) Parents like to be told in private, together, and with the child present if possible.

(4) Parents are often too stressed at the initial interview to assimilate all the paediatrician has said to them. This makes regular follow-up visits vitally important. These visits should be carried out in the parents' home, perhaps by a key-worker or specialist health visitor who has been appointed to advise the family and help them to negotiate encounters with other professionals. The key-worker or health visitor should be knowledgeable about both local and national services and benefits available to familiies with handicapped children.

In the field of mental handicap three working parties have suggested guidelines for professionals involved in giving parents first information of their child's impairment [66–68]. A 'model procedure' has been shown to be extremely successful in improving the way in which parents are told that their child is suffering from Down's Syndrome [69]. This 'model procedure' involved the following routines: the parents were to be told by a consultant paediatrician, as soon as possible after the birth of the child, together and in a private place; the baby was present at the time, so long as he or she was well enough; the parents were to be told as straightforwardly and positively as possible; they were encouraged to ask questions and were told that they could see the paediatrician, and a specialist health visitor whenever they wished in the following weeks. The research showed that parents who experienced the 'model procedure' reported 100% satisfaction, compared with 20% satisfaction reported by a control group. This study was, of course, carried out with parents of children with Down's Syndrome: in the more difficult situation when the cause of the child's impairment is unknown a 'model procedure' could be even more important.

However, work on doctor–patient communication shows that there may be sound sociological reasons for poor communication between professionals and those who consult them [70]. The existence of model procedures does not necessarily mean that all will be well: the best of intentions may still produce imperfect results. This is particularly the case when the diagnosis is uncertain and professionals may feel threatened and may use delay and evasion as a way of maintaining some control over the situation. The results of our study indicate both a need for the training of health professionals in informing parents about their children's handicap and the importance of recognizing why it is that health professionals do not always comply with recommendations for better practice.

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Examining the Causes of Stress in Families with Severely Mentally Handicapped Children

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Examining the Causes of Stress in Families with Severely Mentally Handicapped Children

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SUMMARY

Though it is recognized that the presence of a mentally handicapped child may be a source of stress for a family, less is known about precisely which impairments are particularly stressful. This question was investigated in a study of 200 families with severely mentally handicapped children living in two health districts in South East England. Interviews were carried out with the people responsible for the day-to-day care of the children and stress was measured by means of the Malaise Inventory. The results suggested that the highest levels of stress were associated with the presence of a child with behaviour disorders or with multiple impairments: the stressfulness of these conditions was exacerbated by adversity. A regression analysis showed that the factors causing most stress in carers were, in order of importance: behaviour problems in the child, night-time disturbance, social isolation, adversity in the family, multiplicity of impairments, difficulty in settling the child at night, problems with the child's health, problems with the child's appearance, and money worries. The article ends with recommendations for the development of services aimed at reducing stress in families with mentally handicapped children.

There is a large body of literature which claims that mothers caring for severely handicapped children at home are vulnerable to stress. A number of different aspects have been defined as stressful, from the physical burden of care to the emotional disturbance created by the child, and from the disruption of normal patterns of family life to the impact on family finances (Tew and Lawrence, 1975; Pomeroy *et al.*, 1978; Baldwin, 1981; Cooke *et al.*, 1982; Glendinning, 1983; Buckle, 1984). However, so far this debate has not substantially affected the patterns of service provision. Though there has been increased concern about providing help for families with severely mentally handicapped children, the development of services for this group has, in general, reflected a mixture of expediency, idealism and consumer demand. Rarely, if ever, has detailed research about the problems faced by parents been translated into services. Yet this sort of information is important, both in terms of deciding what services should be provided, and

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in terms of suggesting which families should be given priority if services are limited.

One difficulty facing service planners is that the label 'severely mentally handicapped' does not tell us very much about the child so labelled. Some severely mentally handicapped children are completely immobile, while others are so active that they exhaust those around them; some have to be watched all the time in case they injure themselves or those around them, while others can safely be asked to run errands to the local shop. Faced with this degree of diversity, service planners tend to fall back on their own assumptions about which families are most in need of help: for example, it often seems to be assumed that families with children who are immobile and incontinent will need more help, and will need help more, than families with mobile, continent, mentally handicapped children. But is this true? Is a very dependent child necessarily a greater burden than a less dependent child? Are children with Down's Syndrome really easier to manage, as is often claimed? How stressful is difficult behaviour compared with such problems as incontinence or lack of mobility?

Service provision should, ideally, reflect the answers to questions such as these. Thus, for example, if children with Down's Syndrome really are easier, then children with other impairments could be given priority; if incontinence is a major source of stress, then appropriate help might take the form of a nappy service, or subsidized laundry facilities; if broken nights are more stressful than disrupted days, then night relief could be considered a priority; and if shortage of money is an important cause of stress, then increases in social security payments would be the best form of help for families with mentally handicapped children.

The research described here was part of a larger study of families with severely mentally handicapped children, which was carried out in Kent in 1982–84 (Pahl and Quine, 1984).* The aim of the study was to investigate the stresses involved in caring for a mentally handicapped child at home, and to evaluate the effectiveness of services in terms of the extent to which they relieved the stress experienced by those who were responsible for the day-to-day care of the children. In a study designed to be of use to service planners, it seemed important to examine the sources of stress in some detail in order that recommendations for service provision could be as precise as possible.

THE MALAISE INVENTORY

The scale which was used to measure stress was the Malaise Inventory. This

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*The study of families with mentally handicapped children was funded by the South East Thames Regional Health Authority, the Medway Health Authority, the South East Kent Health Authority, and Pfizers Ltd. The full report of the study is available from the researchers.

was adapted from the Cornell Medical Index by Rutter and Graham for their study in the Isle of Wight (Rutter *et al.*, 1970a). The scale has been used in a number of studies of handicapped children to measure the stress of carers (Dorner, 1975; Gath, 1978; Burden, 1980). In the Malaise Inventory the respondent is asked if he or she has had any of 24 emotional and physical/psychosomatic symptoms in recent weeks. The number of affirmative answers is taken as the total score. Rutter considered that scores of five or six were outside the normal range and indicative of stress.

Rutter checked the reliability of the scale by asking 35 mothers to complete the inventory on two occasions. He concluded that mothers tend to acknowledge fewer symptoms on the second occasion. However, there was a high correlation between the scores (0·91). In the present study, 20 mothers were asked to complete the inventory a second time. There was a correlation of 0·94 between their scores, confirming that the pattern of results was reliable. The inventory was investigated by Cooke *et al.* (1982), who calculated malaise scores in three different ways, comparing each with the others and also with the scores derived from the Symptom Scale: there was very little difference whichever scale was used, all scales correlating closely. In the second of a pair of papers, Bradshaw *et al.* cast come doubts about the validity of the Malaise Inventory, but these are due to a change in the threshold of the measure used to assess association in the first paper (Bradshaw, 1982; Hirst and Bradshaw, 1983). In our study there was a highly significant association between maternal malaise scores and mental health rating, as measured by the Symptom Scale. Hirst (1983) in an assessment of the internal consistency of the Malaise Inventory offered a more fundamental criticism. He argued that there was no evidence of a single dimension of emotional disturbance underlying the set of items. His conclusion was that malaise scores are untrustworthy for testing empirical hypotheses about degrees of stress. However, recent work by Bebbington and Quine (in preparation) using a more appropriate method, suggests that the scale *is* unidimensional. We would argue, therefore, that the Malaise Inventory provides a valid measure of stress in our sample of mothers with severely mentally handicapped children.

THE STUDY

The study described in this article was concerned with families with severely mentally handicapped children in two health districts in the south east of England. At an early stage in the study all severely mentally handicapped children in each health district were assessed, using the Disabilities Assessment Schedule developed by Holmes *et al.* (1982). This information was collected from the teacher or care assistant who knew the child best; the assessments were concerned with the child's mobility, continence, self-help skills, vision, hearing, communication skills, behaviour and medical conditions. At a later stage, interviews were carried out with a sample of 200 families. This was a stratified, random sample, with proportional allocation for age and sex, so that it matched the total population from which it was drawn. Interviews were carried out with the people who were responsible for the day-to-day care of the children, who were usually their mothers. The interviews collected data about all members of the families, about the nature of the children's handicaps, about the problems these presented and about the families' use of and satisfaction with statutory and voluntary services.

RESULTS

The mean malaise score for respondents in this study was 5·83, a figure which is outside the normal range and which indicates that carers were experiencing a degree of stress; 59% of mothers had malaise scores of five or over. However, variations around this mean were very great. Comparisons between this study and others in which the Malaise Inventory has been used are shown in Table 1.

TABLE 1. *Comparison of malaise scores*

	Mean score	*Standard deviation*	*N*
This study	5·8	4·1	200
Bradshaw and Lawton (1978) Parents of severely disabled children who had applied to the Family Fund	9·0	5·2	303
Cooke (1982) Parents of ESN(S) children from the 1970 Cohort study	5·7	5·1	78
Burden (1980) Parents of severely disabled infants	6·1	5·1	25
Rutter (1970b) Parents of normal children	3·2		

Table 1 shows that parents of all types of disabled children tend to have higher malaise scores than do parents of normal children, whose score in one large study was 3·22 (Rutter, 1970b). At 5·83, the mothers in our study showed a similar level of malaise to other parents of disabled children, with the exception of those assessed in the study by Bradshaw and Lawton. The explanation for this may lie in the fact that Bradshaw and Lawton's sample was drawn from applicants to the Family Fund and may therefore have been composed of particularly stressed families. In order to throw light on this issue, we computed the mean malaise scores for the 84 parents who had received help from the Family Fund. We found that their malaise score was indeed higher. At 6·5 their mean score was significantly more than the score of 5·2 for those who had not received help ($P<0{\cdot}01$).

Though we used some quite complicated statistical techniques in the course of this study, we have attempted to present the results as simply as possible. Accordingly, where tables demonstrate statistically significant findings, we have given the level of significance and have noted whether this is highly significant ($P<0{\cdot}001$), very significant ($P<0{\cdot}01$) or significant ($P<0{\cdot}05$). By convention, significance begins at the 0·05 level of probability, that is to say, the relationship would occur by chance only one time out of twenty, and extends to the 0·001 level, where the relationship would occur by chance only one time in a thousand.

Having established that caring for a handicapped child produces measurable stress in the carer, we turn now to the question of which particular problems are most stressful. We compared the impact of different impairments using analysis of variance, which involved comparing the mean malaise scores of mothers with children with particular impairments.

ARE SOME CONDITIONS MORE STRESSFUL THAN OTHERS?

First, it was hypothesized that levels of stress in the carer might vary with the diagnostic category of the child's handicap. Thus children with Down's Syndrome, who are usually communicating and mobile, might be expected to be less stressful for their parents than children with cerebral palsy, who are often immobile and multiply impaired, presenting additional physical burdens. However, when the mean malaise scores of the main diagnostic categories were compared, the differences did not reach significance, and such differences as existed were in the opposite direction to that which one might have expected. Thus the mean malaise score of parents of children with Down's Syndrome was the same as the mean score of the whole sample, at 5·8, while the mean score for parents of children suffering from cerebral palsy was slightly lower, at 5·1.

THE NATURE AND MULTIPLICITY OF THE IMPAIRMENTS

Secondly, it was hypothesized that it might be the nature of the child's impairment which determined the level of stress in the carer. For example, were children who were incontinent or immobile more likely to cause their parents stress? Analysis showed that neither continence, nor lack of

TABLE 2. *Diagnoses of the children's handicaps by the malaise scores of the carers*

	Mean malaise scores of carers	*Numbers of children*	*Analysis of variance*
Down's Syndrome	5·86	66	
Cerebral palsy	5·10	28	not significant
Other conditions	6·48	35	
Condition unknown	5·76	71	
Mean malaise Score:	5·83	200	

mobility, were associated with higher malaise scores in carers. Were children who could not talk, or who could not care for themselves, more stressful? As Table 3 shows, we found no significant associations between higher malaise scores and either lack of communication skills, or lack of self help skills.

TABLE 3. *Nature of the children's impairments by the malaise scores of the carers*

	Mean malaise scores of carers	*Numbers of children*	*Analysis of variance*
Child is mobile	5·75	129	
Child is not mobile	5·95	71	not significant
Child is continent	5·78	115	
Child is not continent	5·89	85	not significant
Child has good communication skills	5·3	46	
Child has some communication skills	5·8	72	not significant
Child has no communication skills	6·1	82	
Child has good self-help skills	5·2	69	
Child has some self-help skills	6·4	62	not significant
Child has no self-help skills	5·8	69	

However, combining impairments into a *composite score* produced a significant association between the number of impairments and malaise. The impairment score was calculated on the basis of data collected from teachers and care assistants in the first stage of the study, using the Disabilities Assessment Schedule, and was therefore quite independent of the 'stress' variable. The dimensions which were used were those which assessed each child's mobility, continence, self-help skills, sensory impairments, speech, behaviour, quality of social interaction, tendency to have epileptic fits, physical disorders and psychiatric disorders. The impairment score was a rather crude measure, combining as it did both physical and mental impairments and some of their handicapping consequences. However, it did give a rough measure of the multiplicity of a child's impairments. Each child scored one point on the scale for each dimension in which she or he was assessed as being severely impaired. Eleven different types of impairment were combined to produce an impairment scale which ran from 0 to a possible maximum of 11; the actual maximum score was 10. The 64 mothers whose children scored 0 or 1 on the impairment scale had a mean malaise score of 5·04; the 113 mothers whose children scored between 2 and 6 had a mean malaise score of 6·03; finally, the 23 mothers whose children were so impaired that they scored 7 and above had a mean malaise score of 7. So children who have more impairments do produce significantly more stress in those who care for them, as Table 4 shows.

TABLE 4. *Multiplicity of the children's impairments by malaise scores of carers*

	Mean malaise scores of carers	*Numbers of children*	*Analysis of variance*
Impairments			
(in addition to retardation)			
0–1 impairments	5·04	64	
2–6 impairments	6·03	113	significant
7–10 impairments	7·00	23	$P < 0{\cdot}05$
Mean malaise score	5·83	200	

THE BURDEN OF CARE

Thirdly, we investigated the relationship between malaise scores and the total burden of work involved in the physical care of the children. Each respondent was asked whether the child required 'no help', 'a little help', or 'a lot of help' with various everyday activities, ranging from dressing and undressing, to eating, washing and using the toilet. The results are shown in Table 5, which also includes data on the association between night-time disturbance and malaise. In all cases, the malaise scores of mothers whose children needed a lot of help were higher than those neding little or no help. The difference reached significant levels when we considered dressing and undressing and night-time disturbance.

TABLE 5. *Burden of care by malaise scores*

Child needs help with	*Mean malaise scores*	*N*	*Test of linearity*
(a) Washing: no help needed	5·11	27	not significant
a little	5·43	53	
a lot	6·16	120	
(b) Meal times: no help needed	5·17	78	not significant
a little	6·05	52	
a lot	6·27	69	
(c) Undressing: no help needed	5·00	70	significant $P < 0.05$
a little	5·94	34	
a lot	5·31	95	
(d) Dressing: no help needed	4·39	23	significant $P < 0.05$
a little	5·45	53	
a lot	6·25	95	
(e) Night-time disturbance: none	4·90	66	very significant $P < 0.001$
some nights	5·33	59	
most nights	7·09	74	

A burden score was created by combining the items covered in Table 5 and this total burden score was also correlated with the malaise score. Again, we found a significant association between the two: the greater the burden presented by the child the higher the mother's level of stress was likely to be ($P < 0.05$). This finding is similar to that reported by Cooke *et al.* (1982).

In an effort to analyse exactly what it was about the child's handicap which produced stress for the carer, an 'extra work' scale was created. This scale was based on a series of questions which asked whether the child's impairment caused extra work for his or her chief carer. The questions covered cleaning and tidying, cooking, washing clothes, shopping, and other tasks. No extra work was scored as 0, a little extra work as 1, and a lot of extra work as 2, to give a maximum possible score of 10. The results of this analysis are presented in Table 6. As this shows, mothers who had a greater burden of extra work because of their handicapped child had very significantly higher malaise scores. These findings, too, are similar to those of Cooke *et al.* (1982).

TABLE 6. *Extra work score by malaise scores*

Extra work score	*Mean malaise scores*	*N*
0–1	4·59	59
2–3	5·01	63
4–10	7·43	76

$P < 0{\cdot}001$, highly significant.

THE IMPORTANCE OF BEHAVIOUR AS A SOURCE OF STRESS

We turn now to behaviour problems, a term which contains within it a variety of characteristics including temper tantrums, destructiveness, night-time disturbance, spitting, biting, screaming, wandering, and sexual delinquency. We have seen that physical impairments, such as immobility or incontinence, were not necessarily related to high malaise scores. However, when we considered behaviour disorders the picture was very different. There was a significant association between the degree to which a child's behaviour was disordered and the level of stress in the carer, as Table 7 shows. The more severe the behaviour problems in the child, the more stressed the mother was likely to be: the 82 mothers with children with severe behaviour disorders had a mean malaise score of 7·03, indicating a high level of stress. It is important to remember that the assessment of the child's behaviour was made by the teacher or care assistant in the course of the population study; the malaise score was calculated on the basis of material collected in the course of the interview with the child's mother. The two measures are thus independent.

TABLE 7. *Behaviour problems by malaise scores*

	Mean score	*Standard deviation*	*N*
Severe behaviour problems	7·03	4·34	82
Mild behaviour problems	5·62	4·40	40
No problems	4·66	3·32	78

$P < 0{\cdot}001$, highly significant.

The link between behaviour disorder and stress is an important finding. However, behaviour disorder is a broad category and it seemed important to find out exactly which aspects of the child's behaviour contributed most to stress in the person doing the work of caring. Each carer was asked about a number of different aspects of the management of the child to determine their association with the malaise scores.

TABLE 8. *Management problems by malaise scores*

	Mean malaise scores	*N*	*Analysis of variance*
Child is easy to keep occupied	4·47	36	very significant
Not easy to keep occupied	6·12	164	$P < 0{\cdot}01$
No behaviour problems	4·66	78	very significant
Behaviour problems	6·57	122	$P < 0{\cdot}01$
Child's appearance is normal	5·53	161	significant
Child's appearance is unusual	7·05	39	$P < 0{\cdot}05$
Child is easy to manage	4·78	74	very significant $P < 0{\cdot}01$
Difficult to manage	5·78	88	
Very difficult to manage	7·76	38	
Parents get enough sleep	4·84	135	highly significant
Parents do not get enough sleep	8·09	42	$P < 0{\cdot}001$

Table 8 gives us some measure of the relative impact of different aspects of the child's behaviour on the carer. In all the areas of everyday life at which we looked, children with greater problems of management were significantly more stressful than those with lesser or no management problems. The carers' mean malaise scores varied from 6·12 where children were hard to keep occupied, through 6·57 where children had behaviour problems, 7·05 where children had an unusual appearance, 7·76 where children were particularly difficult to manage, to a massive 8·09 for those carers whose handicapped children prevented them from getting enough sleep. Here, again, we see the very damaging effects of night-time disturbance.

In all, 21% of the mothers said that they did not get enough sleep, and many spoke of being woken at night by their handicapped children. Some mothers found that the only solution was to sleep with the child so as to be able to attend to his or her needs without disturbing other family members. Some children were liable to wake up and wander, or to become destructive if not supervised, while others simply needed constant physical care, such as the hourly suction with an electric pump which was essential for one child with a tracheostomy.

THE IMPACT OF ADVERSITY

We were aware that some families experienced other sources of hardship not necessarily connected with the handicapped child, which might cause stress. Some of the families had many difficulties to face: 13% were single parent families; 17% of mothers and 10% of fathers had themselves suffered from ill-health in the preceding year; 40% of respondents said that their home was not suitable for the family's needs, usually because it was too small; 31% had an income of less than £5000 per year.

It is important to remember that there were these other stressful aspects in the lives of these families: even if they had not had handicapped children, many might have found life hard because of lack of money, poor housing, bad health, or because one or both parents was out of work. Table 9 demonstrates this point clearly. It shows that mothers in two-parent families had much lower malaise scores than mothers who were bringing up children on their own. In families where the husband was in a non-manual occupation, as measured by the Registrar General's classification, wives had lower mean malaise scores than where husbands were in manual occupations. This finding was reflected in a correlation between income and mean malaise scores: mothers in families with higher incomes had significantly lower malaise scores ($P < 0{\cdot}05$).

TABLE 9. *Mean malaise scores of mothers by family circumstances*

	Mean malaise scores	*N*	*Analysis of variance*
(a) Family composition:			
Two parent family	5·57	173	
One parent and other adult(s)	6·40	10	significant
One parent family	8·56	16	$P < 0{\cdot}05$
(b) Father's occupation:			
Non-manual	4·88	68	very significant
Manual	6·31	132	$P < 0{\cdot}01$

In order to assess the cumulative effects of economic and social disadvantage, we devised an adversity score, which drew together a number of different aspects of hardship. The adversity score took account of the following elements in the lives of our respondents: being a single parent; either husband, wife or sibling having a longstanding disability, or having been an in-patient during the previous year; housing that was unsuitable for the needs of the family; low income; money worries; having an unhappy marriage; lacking a close friend. Our adversity scale has some similarities with Brown and Harris's measure of on-going difficulties (Brown and Harris, 1978).

We divided our sample into a high adversity group of 40, who had four or more of the characteristics which we had used in defining adversity, and a low adversity group numbering 160, who had three or less of the characteristics of adversity. The difference between the malaise scores of these two groups was striking, as Table 10 shows. The high adversity group had a malaise score of 8·6 in contrast to the score of 5·1 of the low adversity group.

TABLE 10. *Mean malaise scores of mothers by family adversity*

	Mean malaise score	*N*
Low adversity	5·1	160
High Adversity	8·6	40

$P < 0{\cdot}001$, highly significant.

We have now isolated three factors which have a powerful effect on levels of stress in mothers with handicapped children: behaviour problems in the child, multiplicity of impairments in the child, and adversity in the family. But how do these interact? This is an important question. It is sometimes suggested, for example, that mentally handicapped children cause less stress in disadvantaged families than they do in more advantaged families. It is argued that in the former, aspirations are low and the handicapped child is not so disruptive of normal patterns of family life. By contrast, it is suggested, better off families expect their children to succeed both intellectually and socially and so experience the birth of a handicapped child as particularly painful (Wolfensberger, 1967, p. 337).

The question is this: do families whose lives are already difficult accept a behaviourally disturbed child with greater equanimity than those families who have grown used to a degree of comfort and affluence? In other words, do behaviour problems in the child and adversity in the family cancel each other out, or exacerbate each other? Table 11 gives the answer. It shows that the combination of severe behaviour problems and high levels of adversity produces the highest malaise score we have encountered so far in this study. The 27 mothers who have to cope with a child with severe behaviour problems and with adversity in four or more areas of family life have a mean malaise score of 9·5. Similarly, the combination of multiple impairments with high adversity produces very high malaise scores.

TABLE 11. *Mean malaise scores of mothers by behaviour problems and multiple impairments in the child and adversity score of the family*

	Low adversity families (score 0–3)	*High adversity families (score 4–7)*	*Number of families*
No behaviour problems	4·5	6·7	78
Mild behaviour problems	5·4	6·7	40
Severe behaviour problems	5·8	9·5	82
No or one impairment	4·8	6·8	64
Two to six impairments	4·9	9·0	113
Seven to ten impairments	6·8	8·0	23
Number of families	160	40	200

CONCLUSION ON THE FACTORS INFLUENCING STRESS

In this paper we have looked at different aspects of impairment and at the impact of impairment on those who cared for these children. We have seen the damaging effect on carers of being responsible for a behaviourally disturbed child, especially when the child is wakeful at night. We have documented the relationship between extra work and extra stress. We have shown that multiple impairments are associated with stress. We have analysed the effects of adversity on families caring for a mentally handicapped child. Finally, we assess the relative importance of all the various factors which affect the stress experienced by carers.

In order to make this assessment, we used a multiple regression analysis. Multiple regression allows one to study the linear relationships between a set of independent variables and a dependent variable, while taking into account the inter-relationships among the independent variables.

The strength of regression analysis is that it attempts to explain empirical findings in a way which reflects the total process underlying the situation. Up to this point, we have used analysis of variance and simple correlations between two variables: where a relationship was unlikely to have occurred by chance, we have presented this as important evidence. However, a further step is to assess the effect of variables independently of each other. For example, we have demonstrated statistically significant associations between difficult behaviour in the child and stress in mothers, and between night-time disturbance and stress. But perhaps night-time disturbance seems to cause stress only because it is closely associated with difficult behaviour? How important is night-time disturbance as a cause of stress when we look at children with similar day-time behaviour? Similarly, we have shown that stress is associated with both social class and adversity: to what extent is this a product of an inter-relationship between class and adversity?

In order to answer these and similar questions, we constructed a causal model which include all the variables which we hypothesized might be likely to affect maternal stress. We then used a stepwise regression analysis to sort out which variables were important in their own right as direct effects on stress. The result is shown in Table 12, which might be regarded as the most important table in this paper. It was produced after entering 28 different variables into the equation. The variables ranged from the child's age and sex, through household income, family composition and parents' employment status, to a variety of different impairments in the child. Of the 28 variables, 19 proved to have little effect on malaise after allowing for the 9 in the model. The results of the regression analysis were extremely robust in that entering slightly different assortments of variables into the analysis did not materially alter the ranking of the variables which appeared to be most significant.

TABLE 12. *What factors cause most stress in carers? Regression coefficients predicting stress levels*

Variables in order of importance	*Beta* coefficients*	*P*
Behaviour problems in the child	0·24003	0·0002
Night time disturbance	0·23347	0·0003
Social isolation of mother	0·21413	0·0009
Adversity in family	0·19361	0·0023
Multiplicity of impairments	0·14113	0·0298
Difficulty in settling child at night	0·11579	0·0537
Problems with child's health	0·11255	0·0617
Problems with child's appearance	0·10952	0·0696
Parents have money worries	0·10538	0·1056

These nine variables together explain 37% of the variance in malaise.

* The beta coefficient is a measure of the direct impact of the independent variable onto the dependent variable when all other variables are held constant.

Table 12 sums up the previous findings. It shows that stress in mothers is related most strongly to variables falling into two different areas. The first area focuses on the children, and here the most stressful factors are behaviour problems, night-time disturbance, multiplicity of impairments and the child having an unusual appearance. The second area is concerned with the social and economic circumstances of the family, and here the most stressful factors are social isolation, adversity, and worries over money.

CONCLUSION

This research has shown that it is possible to identify factors associated with stress on mothers caring for severely mentally handicapped children and to analyse the relative importance of different sources of stress. The study of physically and mentally handicapped children carried out by Bradshaw and Lawton, which was also reported in this journal, came to rather different conclusions. None of the independent variables they investigated had a great impact on maternal stress levels. They therefore concluded that 'the relief of emotional stress may not be a feasible aim for public policy' and that 'emotional disturbance . . . may not be relieved by the provision of goods' (Bradshaw and Lawton, 1978, p. 189). However, the study described here investigated two aspects of mental handicap neglected by Bradshaw and Lawton: multiplicity of impairments and behaviour disorders. Strong associations were found between these variables and maternal malaise. In addition, our study demonstrated that the plight of mothers with such children was exacerbated by adverse social and economic conditions. Our conclusion must be that the relief of stress in mothers with severely mentally handicapped children is both a feasible and an important aim for public policy.

What form should policy intervention take? What services might relieve stress in parents of mentally handicapped children? Our results suggest two rather different approaches. First, we would advocate policy initiatives aimed at helping families who are looking after children with multiple impairments or behaviour disorders. However, while multiply impaired children are usually seen as deserving of help, behaviour problems may even disqualify a child from receiving help because of the disruption caused in, for example, short term care centres, family support units and foster homes. Many service providers do not collect information about whether children have behaviour disorders or not, and so are unaware of the extent of the problems faced by parents. We would suggest that service providers should identify children with severe behaviour disorders and should consider offering specialized services to these families. These services could include assessment at home, the development of behaviour modification programmes in consultation with the parents, attention to appropriate medication and generous access to day and night time relief schemes.

The development of a mental handicap register is an important step towards identifying children with behaviour problems. Such registers are now becoming more commonplace, but they are still not universal and those which exist are often not used as effectively as they might be. A mental handicap register requires not only a computer but also a person whose job it is to up-date the register on a regular basis and to produce information for professionals and service planners. The register should be linked to a mental handicap team drawn from health, education and social services. Experience with registers held separately by these organizations shows that each bureaucracy will be aware of clients who are unknown to other bureaucracies, some potential clients will fail to appear on any register, and some people whose names appear will have moved from the area or died. It may be that the computerized lists of patients held by the Family Practitioner Committees would offer the best way of ensuring that contact has been made with all mentally handicapped people in any one area.

A second approach to intervention arises out of our finding that stress is exacerbated by social and economic adversity. Some aspects of adversity, such as parental ill-health, may be unavoidable: some, such as parental unemployment, may require policy intervention which is beyond the scope of the welfare services. However, poor housing and low income may both be capable of amelioration. The presence of a mentally handicapped child should give a family a degree of priority in any application for local authority housing, or for improved housing, if they are already local authority tenants. Grants for improvements, such as wheelchair ramps, bath hoists and so on should be available. Professionals who are in contact with families with mentally handicapped children should make sure that they are receiving all the financial benefits to which they are entitled, whether from social security or from the Family Fund. Mothers who wish to take paid employment should be helped to do so by the availability of flexible child care schemes. It is important to remember that 20 years ago parents whose children had multiple impairments or difficult behaviour would have been urged to place their children in long-stay hospitals. Keeping these children at home can place a heavy burden on families in terms of emotional stress, financial costs and sheer hard work. If 'community care' is to be more than a slogan we need to develop ways of sharing the stress of caring.

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Families with Mentally Handicapped Children

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3

Families with Mentally Handicapped Children

Jan Pahl and Lyn Quine

The birth of a mentally handicapped child does not necessarily imply, in the words of the title of this book, that there will be disorder in the family. It is important to begin by stressing that the skills and abilities of the children with whom we are concerned are very varied. Some are seriously intellectually impaired, immobile and incontinent, while others are able to read, write and count. The behaviour of some children is such that they can never be taken into a public place without fear of embarrassment, while others are cheerful, easy-going people who make friends wherever they go. There has been much debate about the appropriate term to use in describing this very varied group of children. The phrase 'mentally retarded' has given way, in Britain at least, to 'mentally handicapped', which is itself being replaced by 'children with severe learning difficulties'. This last phrase reminds us that these are first and foremost children, but children whose intellectual capacities are impaired.

There is a long-standing debate about the extent to which a family containing a handicapped child is likely to be a handicapped family. This debate is often presented in terms of a contrast between a 'pathological' and a 'normal' model of the family (Wilkin, 1979; Tew, Payne and Laurence, 1974). Studies which adopt the first model have devoted much effort to scoring the amount of guilt and shame, rejection and over-protection shown by parents of handicapped children. The pathological model still underlies much professional thinking about the care, treatment and support of mentally handicapped people and their families. On the one hand parents who adapt family life to cope with the child's impairments may be accused of being 'over-protective', while those who try to maintain normal patterns of family life may be accused of 'failing to accept' the child's handicap. Parents who demand more short-term care for their child may be seen as 'rejecting', while those who refuse offers of short-term care may be defined as 'over-anxious'. By contrast with the pathological model, the second approach emphasises the essential normality of these families. As Wilkin says:

> Where the normal family model is used, the fact that problems are experienced by the family is not denied, but the assumption that one should always look for harmful effects is questioned. (Wilkin, 1979, p. 33)

There is no doubt that the birth of a handicapped child can have profound effects on a family, but it is not necessarily accurate to see these effects in terms of 'disorder'.

There are problems, too, about the use of the term 'family'. The idea of the family as a social group consisting of an earning husband, a wife who is responsible for domestic work and their dependent children is increasingly anachronistic. In Britain in 1983 over half of all married women were in paid employment, 13 per cent of families were headed by a single parent, and families with one breadwinner were rarer than families with two or no breadwinners. Families with an earning husband, a dependent wife and two children composed a mere 5 per cent of all households (Study Commission on the Family, 1983). Thus it would be more accurate to replace the term 'the family' with 'families', and to recognise that, while some forms of the family typically face greater difficulties than others, the many different forms of the family all reflect individual choices about the ways people prefer to live (Barrett and McIntosh, 1982; Close and Collins, 1985).

This chapter will be concerned mainly with severely mentally handicapped children, who are defined as those whose IQs are around or below 50 and whose intellectual abilities are seriously impaired. Traditionally they are distinguished from the mildly mentally handicapped, who have IQs of between 50 and 70: however, recognition of the arbitrary nature of these classifications has led to an increasing reluctance to categorise children by IQ. It is estimated that between four and five children out of every thousand are likely to be severely mentally handicapped, and of these over 90 per cent live at home with their parents (Mittler, 1979a). What does the birth of a mentally handicapped child mean to a family? Is the child likely to be a source of stress, and, if so, which impairments are most stressful for parents? What is the impact on the parents' marriage and on the siblings? What aids and services do families find most helpful? This chapter will consider these and other questions: we shall draw evidence from a number of different studies, but the main source will be our own research into the needs of families with handicapped children (Pahl and Quine, 1984).

THE STUDY OF FAMILIES WITH SEVERELY MENTALLY HANDICAPPED CHILDREN

The aim of our study was to investigate the stresses involved in caring for a mentally handicapped child at home, and to assess the extent to which different services were able to relieve the burden on families. The research was funded by the South East Thames Regional Health Authority, the Medway Health Authority and the South East Kent Health Authority. The study had two main stages, which we have called the 'population survey' and the 'sample survey'. The first stage involved assessing the total population of severely mentally handicapped children aged 0-16 in two health districts, using the Disability Assessment Schedule developed by Holmes, Shah and Wing (1982). The second and main stage of the study involved interviews with a sample of 200 families, selected from the 399 whose children had been assessed in the population survey. A stratified random sample of 100 familes was selected from one health district and these were matched with 100 families from the other health district so that the study should have a quasi-experimental design. Structured questionnaires were used to interview the people who were responsible for the day-to-day care of the children: 190 of the carers were the natural mothers and the rest included foster parents, grandparents and one father. This chapter presents selected data from the study, setting this in a broader context by drawing on other studies of families with mentally handicapped children.

What impairments affected the children in our study? In the population survey the assessments collected information about mobility, continence, self-help skills, behaviour, medical and psychiatric conditions and sensory impairments. Table 3.1 sets out the main problems which the children faced, and shows how our population compared with a much larger, national sample of children surveyed in a study carried out for the Jay Committee (DHSS, 1979). The Jay Report made a distinction between children living in hospitals and those in hostels, and Table 3.1 shows that in many respects the children in our study were more akin to the hospital population. For example, about a third of the children in our study were unable to walk by themselves, a proportion similar to that for the hospital children and far higher than that for the hostel children. In a variety of other ways the children in our study were much more impaired than the mentally handicapped children which the Jay Committee found living in residential hostels. Two-thirds of our children were unable to wash and dress themselves, nearly half had some sort of behaviour problem, a third were doubly incontinent, a third suffered from epileptic fits, a fifth were blind or partially sighted, and an eighth had hearing difficulties. Twenty years ago many of these children would have been offered residential care, probably in a hospital, and their parents would have been urged to relinquish them, both for the sake of the rest of the family, and for the sake of the children themselves. Now, with the tide flowing in favour of community care, these children are remaining at home. The interviews showed what this meant for these families and for those who are responsible for the day-to-day care of severely handicapped children.

Table 3.1: Disabilities of mentally handicapped children

	Jay Report (DHSS, 1979)		Pahl/Quine Study
	Hospital units and wards (%)	Residential homes (%)	Children at home (%)
Unable to walk by themselves	34	8	34
Unable to feed without help	51	24	43
Unable to wash and dress themselves	79	44	68
Severe behaviour problems	50	34	45
Doubly incontinent during the day	55	15	33
Blind or partially sighted	11	4	19
Deaf and could not use hearing aid	5	3	13
Epilepsy (including controlled epileptics)	44	18	30
N	673	325	399

The effect on family living standards

The interviews with the 200 parents in the sample showed that the presence of a severely mentally handicapped child affected families in a variety of different ways. The employment pattern in these households differed from that which might have been expected in a sample of families with growing children. These differences mainly affected the mothers, of whom only 5 per cent were in full-time employment and 21 per cent in part-time employment. This was at a time when in Britain as a whole 17 per cent of women with children under 16 were in full-time employment and 35 per cent were in part-time employment (Martin and Roberts, 1984, p. 13). This means that the employment rate for mothers with a handicapped child is exactly half the rate of that for mothers whose children are not mentally handicapped. Of those mothers who were not in employment, half would have liked paid work; the majority of these said that they were prevented from taking a job by their responsibility for the handicapped child. As far as fathers were concerned, 83 per cent were in full-time employment, 13 per cent were unemployed and the remainder were either retired or disabled. This was at a time when the unemployment rate in South East England was 9.5 per cent, so there was a rather higher rate among the men in our sample, by comparison with the general population.

A number of other studies have explored the financial impact of caring for a mentally handicapped child at home (see, for example, Baldwin, 1985; Buckle, 1984; Townsend, 1979). Our data on housing, on consumer goods, and on income all support the findings of other research that having a handicapped child penalises families financially in a number of different ways. Firstly, the responsibility for the care of the child tends to reduce family income, particularly by making it difficult for mothers to earn, but also by limiting fathers' ability to do overtime. Of those mothers who did earn, 30 per cent said that their role as carers caused a reduction in earnings. Among employed fathers, 35 per cent said that loss of overtime or shift work reduced their earnings, while 20 per cent of unemployed fathers said that responsibility for the handicapped child reduced their capacity to work.

Secondly, the needs of the handicapped child meant extra expenditure on items such as clothing, bedding, footwear, and on washing and drying. Keeping immobile or sick children warm implies heavy heating bills. Incontinence and dribbling may result in heavy wear on clothes, as does constant rocking, pulling or rubbing. Footwear may be worn unevenly by a partly mobile or hyperactive child. Clothes or shoes may have to be specially made. Here are some of the comments parents made:

> She has to have her shoes made specially. These cost £120. They were paid for by a charity. I don't know what we'll do when they wear out.

> I spend more on clothes than for the others, partly to get a good fit, but mainly because I think it is important that she looks really good. It helps me when I take her out, if she is complimented, and it makes her more acceptable to other people.
>
> He tears all his clothes. I can't put him in anything constricting because he tears it straight off.
>
> She dribbles all the time, and after a while it sort of stains all her jumpers. I like her to look nice because I think it compensates.
>
> We get through ever such a lot of sheets. They have to be washed every day because he's doubly incontinent, and they wear out.

Thirdly, as a consequence of their lower incomes and greater financial responsibilites, families had to cut back in other areas. The proportions who owned cars, or who had central heating, were lower than national figures for ownership of these goods in households with children. Many of the families were worried about money: for a quarter of the families whom we interviewed money was a constant worry, while altogether 58 per cent had some anxiety about being able to cope financially.

Who does the work involved in caring?

The work of caring for a severely handicapped child has been described as 'the daily grind of care' (Bayley, 1973). Glendinning said:

> The day-to-day care needed by a severely disabled child in many respects represents a prolonging of the dependencies of early childhood long past the ages at which they would normally cease. Thus the bathing, feeding, toileting, lifting and carrying, continuous attention and supervision, disturbed sleep and restricted social life which are common features of looking after an infant can persist for many years and, indeed, can become increasingly difficult as the child gets heavier and the parents grow older. (Glendinning, 1983, p. 41)

A number of studies have shown that it is normally the mother who shoulders this burden (Bayley,1973; Hewett, Newson and Newson, 1970; Parker, 1985; Wilkin, 1979; Younghusband, Birchall, Davie and Kellmer-Pringle, 1970). In our study we were interested to know whether this pattern still continued, and whether, at a time of high unemployment, fathers without paid work did more of the work of caring. Respondents were asked whether their partners helped with child care 'every day', 'most days', 'once or twice a week', 'less often' or 'never'. In all cases where this question was appropriate the respondent was a woman living with her husband.

The number of husbands who helped every day was very small. The tasks which husbands were most likely to perform were lifting and carrying the child, but only a third of husbands whose child required lifting and carrying did this every day. For all the other tasks involved in the care of a handicapped child the numbers helping every day were much smaller. The percentages were based on the totals of those children whose care required that the task be done: we did not ask if a father changed nappies if the child was continent. The percentages of fathers who helped on a daily basis were as follows: feeding the child, 18 per cent; changing nappies, 15 per cent; toileting, 12 per cent; getting up in the night, 11 per cent; dressing and washing the child, 10 per cent.

When we looked at fathers who helped once or twice a week the numbers involved were somewhat larger, though it must be remembered that in some cases the help provided by these fathers represented a very small proportion of the work that had to be done. There were no significant differences between the social classes in terms of the amount of work which fathers did, but unemployed fathers were more likely to help than were employed fathers. This reflects partly the fact that unemployed fathers are likely to be at home during the day, and partly the recognition by some fathers that their help was badly needed. Thus the mother of a multiply handicapped 10-year-old, who suffered from cerebral palsy, said, 'We only just get by. Both of us spend all the time looking after Bob. In fact, I don't know how I'd manage if my husband got a job.'

Alternative sources of help might be the siblings of the handicapped child and the friends, neighbours and relations of the family. How much help did the chief carers get from these sources? Out of the total sample, 151 families had other children over 5, and these respondents were asked whether their children helped with the care of the handicapped child or with housework. The results showed that less than 10 per cent of the siblings carried out domestic tasks alone, 22 per cent sometimes helped the mother with the handicapped child and 28 per cent helped with housework. Thus, though siblings do help, they provide even less support to carers than do husbands. Our results are rather similar to those of Wilkin, who concluded:

> Whether or not children provided assistance was related to their age and sex. . . . Support rose to a peak in the 12-16 age group where three quarters provided some assistance and almost a third had a high level of participation. Among the 16+ age group the level of support dropped sharply as children found jobs and left home. Thus the greatest potential for support seems to be among the 12-16 group, but within this group it is quite heavily concentrated among girls. This difference between the contribution to the domestic routine of girls and boys suggests that the sexual division of labour in parental roles is in the process of being repeated in the next generation. (Wilkin, 1979, p. 137)

The point about the help provided by teenage sisters, and a few brothers, is important for those concerned with what happens to handicapped children when they reach adulthood. Policies for community care suggest that the ideal is that mentally handicapped adults should be able to live, like other citizens, in ordinary houses in the community. However, unless there is a very large expansion of provision for mentally handicapped people, it is likely that many will simply continue to live at home with their parents. As the other children of the family leave home these parents will have to take on an increasing burden of care.

Community care policies also stress the importance of help from outside the immediate family. For example, the 1971 White Paper, in its general principles, stated that:

> Understanding and help from friends and neighbours and from the community at large are needed to help the family to maintain a normal social life and to give the handicapped member as nearly a normal life as his handicap or handicaps permit. (DHSS, 1971, p. 10)

How much help do families actually get from friends, neighbours and relations? Table 3.2 shows the extent to which the families we interviewed could count on receiving help on a day-to-day basis. The only significant type of help given by people outside the immediate family was moral support. By comparison, little practical help was received with child care and household tasks. Though many mothers said that they valued the moral support they received, it was clear that people outside the family did little to lighten the burden of care.

The picture that we found was very similar to that described by Wilkin, who used a detailed questionnaire to document exactly how

Table 3.2: Families who received help from relatives, friends and neighbours

	Sources of help					
	Wife's family		Husband's family		Friends and neighbours	
Help with	Help most days (%)	Occasional help (%)	Help most days (%)	Occasional help (%)	Help most days (%)	Occasional help (%)
Baby-sitting	4	37	3	23	4	35
Housework	4	9	2	4	0	5
Taking children	5	21	2	11	1	17
Shopping/transport	3	15	2	7	1	15
Moral support	25	28	14	13	25	20

much help of different types was received from various different sources. Wilkin concluded:

> The term community care for a mentally handicapped child refers to care *in* the community and not care *by* the community. The nuclear family is the framework in which the child is cared for. Within the family it is mothers who carry the major burden of care usually with relatively little support from other family members. The contribution of people outside the family to the practical burden of care is almost negligible. (Wilkin, 1979, p. 146)

Social isolation

One effect of lack of support from friends and neighbours is that parents feel themselves to be socially isolated. In our study many parents had difficulties in finding a baby-sitter if they wanted to go out, and some never went out in the evening unless they took the handicapped child with them. Altogether 52 per cent of the mothers said that having a handicapped child prevented them from going out as frequently as they would have liked. In answer to the question 'Some people say that having a handicapped child makes a mother very lonely; do you think this is true from your experience?', 45 per cent of respondents said 'yes'. Mothers who said the child prevented them from going out, or who felt lonely because of the presence of the child, were significantly more likely to be stressed, as assessed by the

Malaise Inventory, which we describe below. Some mothers spoke of the embarrassment which people felt in the presence of the handicapped child, and described how this led to problems in making and maintaining relationships. One said: 'I feel like an outsider — I don't feel the same as everyone else — I have nothing in common with them.' The mother of a severely handicapped and behaviourally disordered teenager said: 'Geoffrey's problems are too embarrassing for someone else to cope with. His anti-social behaviour is difficult. Also cleaning him up after he has wet and dirtied himself is not something anyone else could be asked to do.' Some parents expressed an alternative view. One said: 'I have made friends through her — people from church show a special interest in her.'

However, in general the presence of the handicapped child, especially if he or she had behaviour problems, had the effect of cutting the parents off from others. This social isolation could extend to the mentally handicapped child and to other members of the family. Many of the handicapped children had no relationships with children outside the family, apart from those they met at school. Over half never went out to play with other children or had others in to play with them.

Effects on the siblings and on the marriage

Previous studies have suggested that having a handicapped child may present serious problems of adjustment to the family (Tizard and Grad, 1961). Some have suggested that the mental health of siblings may be affected. Gath, for example, measured psychiatric disorder in the siblings of Down's syndrome children by means of behaviour ratings made by parents and teachers. She found significantly more psychiatric disorder in these children by comparison with the siblings of normal children, with a particularly marked increase in psychiatric disorder among girls with handicapped siblings (Gath, 1978).

In our study, parents were ambivalent about the effects on brothers and sisters of having a handicapped sibling. Asked whether the other children had benefited at all, three-quarters agreed that there had been gains; however, about half the parents saw the difficulties surrounding the handicapped child as a disadvantage to the family. Some parents were concerned that the other children would suffer, for example, because the handicapped child disturbed their activities or because they felt inhibited about asking friends home; other parents suggested that the presence of the handicapped child had made the other children kinder and more tolerant. The sample were fairly evenly divided on this point, about half feeling that coping with handicap had been a disadvantage and a restriction to the family, while the other half felt it had not made much difference. Asked whether the overall impact on the family had been adverse, 44 per cent said 'yes', 42 per cent 'no' and 14 per cent were unsure.

When parents spoke of the effects on the other children the behaviour of the handicapped child was clearly important. Many made comments like these:

> He makes them appreciate good health — value life — live each day as it comes. It makes them less selfish.
>
> It's made them more understanding towards handicapped people and their problems, and more sympathetic.

But when the child was not only handicapped but also had severe behaviour problems, the parents were likely to see the effects on their other children as harmful:

> He affects their sleeping and dominates the house. They need protection from him as he is violently aggressive. The girls especially are physically hurt by him.
>
> The other children have had such a bad experience that they resent handicap — have nothing to do with it. We've lost contact with them to some extent.
>
> Emotionally and socially it has affected them. The sexual problem affects the girls — their friends' parents have to keep an eye on what is happening between them. The oldest girl is unwilling to stay in the house alone with James.

Having a handicapped child can also have important implications for the parents' marriage. We have explored this issue more fully elsewhere, and have demonstrated that the stress of caring for a mentally handicapped child can be mitigated by a good marriage or by a husband who gives real help with the work of caring for the child (Quine and Pahl, 1987). Other research has shown the importance of a close and confiding relationship in reducing the likelihood of depression in women (Brown and Harris, 1978). In our study of families with handicapped children we found that mothers who had someone in whom they could confide were less likely to be stressed than those who lacked such a relationship. Additionally, having a mentally handicapped child did seem to be associated with feelings of social isolation, both for the carer and for other members of the family.

The stress of caring for a mentally handicapped child

We have shown that mentally handicapped children have a variety of different impairments and that they can create a variety of problems for the families into which they are born. In this section we shall investigate exactly what it is about having a mentally handicapped child which is most stressful for the carer. Is a very dependent child necessarily a greater burden than a less dependent child? Are children with Down's syndrome really easier to care for? How stressful is difficult behaviour compared with incontinence or immobility? How much do financial worries, extra work and social isolation add to the stress of caring? In answering these questions we shall be summarising arguments which we have developed at greater length elsewhere (see especially Pahl and Quine, 1984; Quine and Pahl, 1985). A large body of literature has claimed that mothers of handicapped children are vulnerable to stress (see, for example, Bradshaw and Lawton, 1978; Glendinning, 1983; Parker, 1985; Pomeroy, Fewtrell, Butler and Gill, 1978; Tizard and Grad, 1961). Various aspects of caring for a severely handicapped child have been defined as stressful, from the physical burden of care to the emotional disturbance created by the child, and from the disruption of family life to the burden on family finances. In the following pages we shall explore these different aspects of caring and assess their relative importance for the families who took part in our study.

We assessed the stress experienced by mothers of mentally handicapped children by using the Malaise Inventory. This is a well-standardised instrument based on the Cornell Medical Index, which has met adequate standards of validity and reliability in a number of studies (see, for example, Rutter, Graham and Yule, 1970; Cooke, Bradshaw, Glendinning, Baldwin, Lawton and Staden, 1982; Tew and Laurence, 1975; Gath, 1978). In the Malaise Inventory the respondent is asked if he or she suffers from any one of 24 different health problems. Rutter, who obtained mean scores for parents of normal children of 3.12 in the Isle of Wight and 4.15 in London, suggested that scores of greater than 5 or 6 can be considered as outside the normal range, and as evidence of stress.

The mean malaise score for respondents in our study was 5.8, which indicates that many were experiencing a degree of stress. However, variations around this mean were very great. First we hypothesised that levels of stress in the carer might vary with the diagnostic category of the child's handicap. Thus children with Down's syndrome, who are usually communicating and mobile, might be expected to be less stressful for their parents than children with cerebral palsy, who are often immobile and multiply impaired, presenting additional physical burdens. However, when the mean malaise scores of the main diagnostic categories were compared, the differences did not reach significance, and such differences as existed were in the opposite direction to that which one might have expected. Thus the mean malaise score of parents of children with Down's syndrome was the same as the mean score of the whole sample, at 5.8, while the mean score for parents of children suffering from cerebral palsy was slightly lower at 5.1.

Secondly it was hypothesised that it might be the nature of the child's impairment which determined the level of stress in the carer. For example, were children who were incontinent or immobile more likely to cause their parents stress? Analysis showed that neither incontinence nor lack of mobility were associated with higher malaise scores in carers. Were children who could not talk, or who could not care for themselves, more stressful? Here again we found no significant associations between higher malaise scores and either lack of communication skills or lack of self-help skills.

However, combining impairments into a composite score produced a significant association between the number of impairments and malaise. The impairment score was calculated on the basis of data collected from teachers and care assistants in the first stage of the study, using the Disability Assessment Schedule, and was therefore quite independent of the 'stress' variable. The dimensions which were used were those which assessed each child's mobility, continence, self-help skills, sensory impairments, speech, behaviour, quality of social interaction, tendency to have epileptic fits, physical disorders and psychiatric disorders. The impairment score was a rather crude measure, combining as it did both physical and mental impairments and some of their handicapping consequences. However, it did give a rough measure of the multiplicity of a child's impairments, in addition to mental retardation. Each child scored one point for each dimension in which she or he was assessed as being severely impaired. The actual maximum score was 10. Mothers whose children scored 0 or 1 on the impairment scale had a mean malaise score of 5.04; those whose children scored between 2 and 6 had a mean malaise score of 6.03; finally, those whose children were so impaired that they scored 7 and above had a score of 7.00. So multiple impairments in children were associated with significantly more stress in carers.

Thirdly we investigated the relationship between stress and the burden of work involved in the care of the children. For this purpose we created an extra work scale, based on a series of questions which asked whether the child's impairments caused extra work for his or her chief carer. The questions covered cleaning and tidying, cooking, washing clothes, shopping, and other tasks. No extra work was scored as 0, a little extra work as 1, and a lot of extra work as 2, to give a maximum possible score of 10. The results of this analysis are presented in Table 3.3. As this shows, mothers who had a greater burden of extra work because of their handicapped child had very significantly higher malaise scores. These findings are similar to those of Cooke *et al.* (1982). In those families where husbands regularly helped with the care of the child, wives tended to have lower stress scores, especially when the help took the form of taking the child out so that mothers could have a break from caring (Quine and Pahl, 1987).

Table 3.3: Extra work score by malaise scores

Extra work score	Mean malaise scores	Standard deviation	*N*
0–1	4.59	3.69	59
2–3	5.01	3.87	63
4–10	7.43	4.18	76

$p < 0.001$; highly significant

Fourthly we investigated the effects on mothers of looking after children with behaviour problems. This term contains within it a variety of characteristics including temper tantrums, destructiveness, night-time disturbance, spitting, biting, screaming, wandering, and sexual delinquency. We have seen that physical impairments, such as immobility or incontinence, were not necessarily related to high malaise scores. However, when we considered behaviour disorders the picture was dramatic. There was a very significant association between the degree to which a child's behaviour was disordered and the level of stress in the carer, as Table 3.4 shows. The more severe the behaviour problems in the child, the more stressed the mother in the carer, as Table 3.4 shows. The more severe the behaviour problems in the child, the more stressed the mother was likely to be: the 82 mothers with children with severe behaviour disorders had a mean malaise score of 7.03, indicating a high level of stress. It is important to remember that the assessment of the child's behaviour was made by the teacher or care assistant in the course of the population study, while the malaise score was calculated on the basis of material collected in the course of the interview with the child's mother. The two measures are thus completely independent of each other.

Table 3.4: Behaviour problems by malaise scores

	Mean malaise scores	Standard deviation	*N*
No problems	4.66	3.32	78
Mild behaviour problems	5.62	4.40	40
Severe behaviour problems	7.03	4.34	82

$p < 0.001$; highly significant

The link between behaviour disorder and stress is an important finding. However, behaviour disorder is a broad category and we wanted to find out exactly which aspects of the child's behaviour contributed most to stress in the person doing the work of caring. Each carer was asked about a number of different aspects of the management of the child, and their answers were correlated with measures of stress based on the malaise score. The results showed that, in all the areas of daily life at which we looked, children who were more difficult to manage produced more stress in those who cared for them. The highest stress scores were found in mothers whose children were wakeful at night. Some children screamed for hours at night; some were liable to wander out of the house, or to become destructive if not supervised; others simply needed constant physical care, such as the hourly suction with an electric pump which was essential for one child with a tracheostomy. Mothers whose children prevented them from getting enough sleep had a mean stress score of 8.09.

Finally we investigated the effects on mothers of other aspects of family life, only some of which were related to having a mentally handicapped child. We have already seen that having a handicapped child imposed a financial burden on families, both by making it harder for both parents to earn and by causing extra costs. In addition, some of the families had other difficulties to face: 13 per cent were single-parent families; 17 per cent of mothers and 10 per cent of fathers had themselves suffered from ill-health in the preceding year; 40 per cent of respondents said that their home was not suitable for the family's needs, usually because it was too small; 31 per cent had an income of under £5,000 p.a. and 25 per cent said that money was a constant worry.

In order to assess the cumulative effects of economic and social disadvantage we devised an adversity scale which drew together a number of different aspects of hardship. The adversity score took account of the following elements in the lives of our respondents: being a single parent; either husband, wife or sibling having a long-standing disability, or having been an in-patient during the previous year; housing that was unsuitable for the needs of the family; low income; money worries; having an unhappy marriage; lacking a close friend. The adversity score divided the 200 respondents into a high-adversity group of 40, who had four or more of the characteristics which we had used in defining adversity, from a low-adversity group numbering 160 who had three or less characteristics of adversity. The difference between the malaise scores of these two groups was striking. The high-adversity group had a malaise score of 8.6 in contrast to the score of 5.1 of the low-adversity group.

In this chapter we have discussed many different aspects of the lives of families with mentally handicapped children. We have shown that having a handicapped child can impose considerable financial burdens on families. We have documented the extra work involved in caring for a handicapped child and the demands this makes on other family members, but especially mothers. We have described the social isolation which some families experience. Using the Malaise Inventory we have demonstrated the links between multiple impairment, extra work, behaviour problems and adversity, on the one hand, and stress in mothers on the other hand. But how do all these different factors relate to one another? In a book concerned with disorder in the family, which aspects of caring for a mentally handicapped child should we identify as particularly stressful?

In order to answer these and similar questions we constructed a causal model which included all the variables which we hypothesised might be likely to affect maternal stress. We then used a stepwise regression analysis to sort out which variables were important in their own right as direct effects on stress. The result is shown in Table 3.5. It was produced after feeding 28 different variables into the equation. The variables ranged from the child's age and sex, through household income, family composition and parents' employment status, to a variety of different impairments in the child. Of the 28 variables, 19 proved to have little effect on malaise after allowing for the nine in the model. The results of the regression analysis were extremely robust in that feeding slightly different assortments of variables into the analysis did not materially alter the ranking of the variables which appeared to be most significant.

Table 3.5: What factors are associated with stress in mothers? Regression coefficients predicting stress levels

Variables in order of importance	Beta coefficients*	*p*
Behaviour problems in child	0.24	0.0002
Night-time disturbance	0.23	0.0003
Social isolation of mother	0.21	0.0009
Adversity in family	0.19	0.002
Multiplicity of child's impairments	0.14	0.003
Difficulty in settling at night	0.12	0.05
Child's ill-health	0.11	0.06
Problems with child's appearance	0.11	0.07
Parents have money worries	0.11	0.11

Note: These nine variables together explain 37 per cent of the variance in malaise scores.

*The beta coefficient is a measure of the direct impact of the independent variable when all the other variables are held constant.

Table 3.5 shows that stress in mothers of severely mentally handicapped children is most strongly related to variables falling into two different areas. The first area focuses on the children, and here the most stressful factors are behaviour problems, night-time disturbance, multiplicity of impairments and the child having an unusual appearance. The second area is concerned with the social and economic circumstances of the family, and here the most stressful factors are social isolation, adversity, and worries over money.

HELPING FAMILIES WITH MENTALLY HANDICAPPED CHILDREN

Research on families with mentally handicapped children suggests that they may need help in a number of different areas. In Table 3.6 we set out the parents' answers to the question 'Here is a list of some of the things some parents want more help with. Do you feel that you would like more help to be available?' The answers give some indication of parents' priorities.

Table 3.6: Parents' felt needs for additional help

	Yes	No	Don't know
Advice/information	77	22	1
Financial help	51	48	1
Baby/child sitting	48	52	0
Short-term care	43	56	1
Equipment or aids	34	65	1
Help with household tasks	19	80	1
Full-time residential care	17	80	3

Another series of questions explored parents' feelings about professionals. The answers showed that parents were likely to perceive professionals as helpful when they had specialist knowledge of the problems involved in bringing up handicapped children, when they gave accurate and appropriate advice and information, and when they treated parents with kindness and respect. Professionals were likely to be seen as unhelpful if they appeared to be withholding information, if they lacked knowledge of possible sources of help, or if they treated parents with condescension or rudeness.

Many studies have stressed that families with handicapped children are likely to need financial help, if they are not to be substantially poorer than families without handicapped children. Even though many are in receipt of social security payments aimed at families with handicapped members, they are still likely to be poorer. One long overdue change was the extension of the Invalid Care Allowance to married women in 1986; this benefit is intended to compensate for loss of earnings, but until that date it was paid only to men and to single women, who made up a small proportion of all carers. The provision of adequate income maintenance to people whose capacity to earn is reduced by their responsibility for a handicapped child has been advocated by many researchers (see, for example, Townsend, 1979; Buckle, 1984; Baldwin, 1985; House of Commons, 1985; Parker, 1985).

Many of the problems which families face can be ameliorated by appropriate practical help. Given the heterogeneous nature of mentally handicapped children as a group, the help which their families need is likely to be equally varied. However, the majority of studies stress the value of giving the family some relief from responsibility for caring for the child, whether this takes the form of short-term care, holiday day-care, fostering schemes, or shared care with another family. In addition, there is likely to be a continuing need, for a minority of mentally handicapped children, for longer-term residential care, either in boarding schools or in home-like residential units in the community (Wilkin, 1979; Baldwin and Glendinning, 1983; Parker, 1985). It is very difficult to assess the effectiveness of services in meeting the needs of families. So many variables are involved that it is impossible to be absolutely confident about the effect of any one variable. For example, there were no differences in stress levels between those who did and those who did not use short-term care. However, if we selected only those children who had behaviour disorders, the results suggested that giving short-term care to these children does relieve stress: in families which did not use short-term care mothers had a mean malaise score of 8.00, compared with 6.22 for mothers who used short-term care. The same pattern occurred for children with multiple impairments. This finding has important implications for service providers. It implies that parents with behaviourally disordered or multiply impaired children should have priority in access to short-term care, and that it should be made as easy as possible for these parents to apply for and make use of this sort of care.

Elsewhere in this book it is suggested that self-help and mutual aid may play a valuable role in helping families with problems. What part does self-help play for families with severely mentally handicapped children? Since the 1970s self-help groups have been set up in many different parts of Britain. Some have grown out of voluntary organisations working for better services for mentally handicapped people, while others, such as Contact-a-family and Kith and Kids, are specifically aimed at enabling parents with handicapped children to meet each other (Ward, 1982). The central theme of these groups is that 'a problem shared is a problem halved', and they work from the assumption that parents are able to give each other help and support in a way that professionals cannot: the essence of self-help is mutuality. Some families speak warmly of the part these organisations play in the lives of themselves and their children. However, self-help may not be appropriate for very stressed families coping, for example, with multiply impaired or behaviourally disordered children, often with inadequate financial resources. To suggest that these families should tackle their problems through self-help resembles setting a physically disabled man to pull himself up by his own bootstraps.

Many families welcome forms of help which reflect the idea of partnership between parents and professionals, as recommended by the Warnock Committee (Department of Education and Science, 1978). In some instances professionals have become involved in parents' groups in a leadership or resource role; in other instances parents' workshops have been set up by teachers or other professionals (Cunningham, 1983). Another form of co-operation between parents and professionals is the Portage home teaching scheme. This involves a teacher working with child and parent at home on a weekly basis, following a programme of skill acquisition which is precisely geared to the child's own levels of ability (Pugh, 1981). Portage and other home intervention schemes have now been evaluated and the results suggest that these methods can bring significant gains in achievement and improvements in behaviour for the children involved (Revill and Blunden, 1977; Clements, Bidder, Gardner, Bryant and Grey, 1980).

In recent years important advances have been made in the development of techniques which can help parents both to reduce inappropriate behaviours in the child and also to develop positive new skills (Chazan, 1979: Gath, 1978). Gath reviews some of the literature on the use of parents as therapists for their own children, and concludes that parents can play a valuable role in promoting the development of their mentally handicapped children. An account of home-based treatment from a parent's viewpoint can be found in Fish and Fish (1975). Involving parents in this way may have an indirect effect on stress by giving parents a sense of being able to do something positive for their child, as well as acting on stress in a direct way by reducing the incidence of difficult behaviour. The many different schemes now in existence are reviewed by Ward (1982). Some of these schemes are run by parents for parents; others involve collaboration between parents and professionals. As Mittler has suggested, 'collaboration with parents must in the future be seen as one of the hallmarks of the well trained professional' (Mittler, 1979b, p. 12).

CONCLUSION

At the beginning of this chapter we outlined two models of the family which, explicitly or implicitly, shape much thinking on the topic of families with handicapped members. The research described in this chapter suggests that caring for a mentally handicapped child can be a cause of stress in those who do the work of caring, especially if the child is multiply impaired or behaviourally disordered. However, when one considers the work and the financial costs involved in caring, it is hardly surprising that this should produce some degree of stress even in the most normal of families.

Examining the ways in which families care for severely mentally handicapped children can throw light on the debate about the term 'the family'. This is particularly so at a time when the burden of care is shifting from institutional care to community care, which in effect often means care by the family. As the report of the House of Commons Social Services Committee put it:

> Many witnesses have told the Committee of the sometimes intolerable burden of care that is placed on the families of mentally ill and mentally handicapped people who are living at home. Constant demands may exact a heavy toll on families, and especially on parents. (House of Commons, 1985, p. lxxxvi)

However, the use of the words 'family' and 'parents' disguises the fact that within the family individuals may have very different interests. For severely mentally handicapped children who live at home the family provides most of the care they need. However, this care is not provided without costs, and the costs are not carried equally by all members of the family. There is a real sense in which the needs of family members conflict. For example, the need of the child for constant attention over many years may conflict with the need of the mother to take paid employment and to enjoy a normal social life. As Land said:

> Family members may have quite different and even opposing interests. Resources and responsibilities are not shared equally within the family. Just as the concept of 'the national interest' obscures crucial conflicts of interest within the nation, thus favouring the superordinate in society, the demand to preserve and protect 'the family' is to the advantage of its more powerful and privileged members. (Land, 1978, p. 259)

The evidence presented in this chapter suggests that the burdens of caring for mentally handicapped children are carried overwhelmingly by their mothers, and it is they who pay the price in terms of stress, social isolation and sheer hard work.

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PARENTS WITH SEVERELY MENTALLY HANDICAPPED CHILDREN: MARRIAGE AND THE STRESS OF CARING

LYN QUINE AND JAN PAHL

Introduction

With marriage comes the expectation that a couple will give birth to children and will be responsible for the care of those children until adulthood. However, about four out of every thousand children are severely mentally handicapped and for these parents their responsibilities may extend far beyond their initial expectations. As Glendinning has said (1983, p.41):

> 'The day-to-day care needed by a severely disabled child in many respects represents a prolonging of the dependencies of early childhood long past the ages at which they would normally cease. Thus, the bathing, feeding, toileting, lifting and carrying, continuous attention and supervision, disturbed sleep and restricted social life which are common features of looking after an infant can become increasingly difficult as the child gets heavier and the parents grow older'.

Children are typically seen as strengthening and enriching the marriage of their parents and so the birth of a child is anticipated with pleasure. However, when the expected child is handicapped, or becomes handicapped in his or her early years, the impact on the couple can be profound. What are the effects on the parents' marriage of their responsibility for a severely mentally handicapped child? How is the care of the child shared between the spouses and does the quality of the relationship suffer because of the extra work involved? Can a good marriage act as a buffer, protecting the chief carer from the stressful effects of caring for a handicapped child? The rest of this chapter investigates these questions, drawing on a recently completed study of families with mentally handicapped children.

The research described here was part of a larger study, carried out in 1982–84 in two health districts in South East England. The aims of the study were to discover what aspects of caring for a mentally handicapped child were most stressful for parents, to evaluate the effectiveness of services provided for families in terms of the extent to which they relieved the stresses and difficulties experienced by those who were responsible for the day-to-day care of the children, and to make recommendations for future service provision on the basis of the needs of the children and those who care for them. The full results of the study are presented elsewhere (Pahl and Quine 1984). However, the current analysis of data collected during the course of the study enabled us to examine a number of commonly held beliefs about the effect on marriage of caring for a child with severe handicap, and to explore the ways in which the quality of the marital relationship affected the experience of caring.

The design of the study

The study had two stages which we have called the 'population survey' and the 'main survey'. The first stage involved assessing the total population of severely mentally handicapped children in two health districts, using the Disabilities Assessment Schedule developed by Holmes, Shah and Wing (1982). Information was collected from the teacher or care assistant who knew each child best and included data about the child's mobility, continence, self help skills, vision, hearing, communication skills, social interaction, tendency to have epileptic fits, behaviour problems and medical conditions.

At the second and main stage of the study interviews were carried out with a stratified random sample of 200 families selected from the 399 whose children had been assessed in the population survey. The sample was chosen with proportional allocation for age and sex so that it matched the population from which it was drawn.

The interview was carried out using a structured questionnaire, with the chief carer of each child (usually the mother). This was a substantial and comprehensive study of which only a small part is presented here. The first part of the paper documents the stress experienced by mothers of children with severe mental handicap and the factors associated with stress. The second part will deal with how marriage affects and is affected by the stress of caring.

The stress experienced by mothers of children with mental handicap

Caring for young children can be seen as a major stressor in the sense that it makes numerous adaptive demands on the mother, often requiring a restructuring of her role priorities and lifestyle. It has been argued that the constant pressure of a child's needs and the maternal commitment to meet these needs weakens the mother's physical and mental state and increase her vulnerability to psychological distress. (Holmes and Masuda 1974; Richman 1976; Kitzinger 1980).

A great many factors are seen to contribute to produce emotional distress among mothers of young children. These include ambivalence about child-rearing, doubts about appropriate child-rearing methods, social isolation and problems in obtaining help and guidance. (Lopata 1971; Oakley 1984; Gove and Paterson 1980; Klerman and Wellsman 1980; Leifer 1980; Berg *et al* 1984).

There is a large body of literature which claims that mothers caring for severely handicapped children at home are *particularly* vulnerable to stress (Tew and Lawrence 1975; Bradshaw and Lawton 1978; Pomeroy *et al* 1978; Cooke *et al* 1982; Glendinning 1983). A number of different aspects of caring for a handicapped child have been defined as stressful, from the physical burden of care to the emotional disturbance created by the child, and from the disruption of normal patterns of family life to the impact on family finances.

Firstly, we wanted to investigate whether parents *were* stressed, and what it was about caring for a mentally handicapped child which was most stressful. For example, is a very dependent child more stressful? Are children with Down's Syndrome easier to care for than other mentally handicapped children? How stressful is difficult behaviour in comparison with incontinence or immobility?

The Malaise Inventory

The scale which was used to measure stress was the Malaise Inventory. This was adapted from the Cornell Medical Index by Rutter and Graham for their study in the Isle of Wight (Rutter *et al* 1970a). The scale has been used in a number of studies of handicapped children to measure the stress of carers (Rutter 1970b; Dorner 1975; Gath

1978; Burden 1980). In the Malaise Inventory the respondent is asked if he or she has had any of twenty-four emotional and physical/psychological symptoms in recent weeks. The number of affirmative answers is taken as the total score. Rutter considered that scores of five or six were outside the normal range and indicative of stress, and that scores of seven or more were 'critical'.

The Malaise Inventory has been subject to a considerable amount of evaluation (Philp 1978; Bradshaw 1982; Cooke *et al* 1982; Hirst 1983; Hirst and Bradshaw 1983; Bebbington and Quine (in preparation)). The conclusions by and large suggest that the scale meets adequate criteria of reliability and validity.

Factors associated with stress

The mean malaise score for respondents in this study was 5.83, a figure which is outside the normal range and which indicates that many carers were experiencing a degree of stress: 59 per cent of mothers had malaise scores of five or above. However, variations around this mean were very great. Comparisons between this study and others in which the Malaise Inventory has been used are shown in Table 1.

Table 1
Comparison of malaise scores

	Mean score	*Standard deviation*	*N*
This study	5.8	4.1	200
Bradshaw and Lawton, 1978 Parents of severely disabled children who had applied to the Family Fund	9.0	5.2	303
Cooke, 1982 Parents of ESN(S) children from the 1970 Cohort study	5.7	5.1	78
Burden, 1980 Parents of severely disabled infants	6.1	5.1	25
Rutter, 1970 Parents of normal children	3.2		

The table shows that parents of disabled children tend to have higher malaise scores than do parents of normal children, whose score in one large study was 3.22 (Rutter 1970b). At 5.83 the mothers in our study showed a similar level of malaise to other parents of disabled children, with the exception of those assessed in the study by Bradshaw and Lawton. However, Bradshaw and Lawton's sample was drawn from applicants to the Family Fund and may therefore have been composed of particularly stressed families.

Multiplicity of the child's impairment

Having established that caring for a child with mental handicap produces measurable stress in the carer, we turn now to the question of which particular problems are most stressful. We compared the impact of all the different impairments using analysis of variance, which involves comparing the mean malaise scores of mothers with children with particular impairments.

There were no significant differences when the mean malaise scores of different diagnostic categories were compared. Nor did the nature of the child's impairment determine the level of stress in the carer. Analysis showed that neither incontinence, nor lack of mobility, were associated with higher malaise scores in carers, nor were children who could not talk, or who could not feed, wash and dress themselves, more stressful.

However, combining impariments into a *composite score* produced a significant association between the *number of impairments and malaise*. The impairment score was calculated on the basis of data collected from teachers and care assistants in the first stage of the study, using the Disabilities Assessment Schedule, and was therefore quite independent of the 'stress' variable. The dimensions which were used were those which assessed each child's mobility, continence, self-help skills, sensory impairments, speech, behaviour, quality of social interaction, tendency to have epileptic fits, physical disorders and psychiatric disorders. The impairment score was a rather crude measure, combining as it did both physical and mental impairments and some of their handicapping consequences. However, it did give a rough measure of the multiplicity of a child's impairments. Each child scored one point on the scale for each dimension in which she or he was assessed as being severely impaired. Eleven different types of impairment were combined to produce an impairment scale which ran from 0 to a possible maximum of 11; the actual maximum score was 10. As Table 2 shows, the 64 mothers whose children scored 0 or 1 on the impairment scale had a mean malaise score of 5.04; the 113 mothers whose children scored between 2 and 6 had a mean malaise score of 6.03; finally, the 23 mothers whose children were so impaired that they scored 7 and above had a mean malaise score of 7.00. So multiple impairment is associated with maternal stress.

Table 2
Multiplicity of the children's impairments by malaise scores of carers

	Mean Malaise scores of carers	*Numbers of children*	*Analysis of variance*
Impairments			
(in addition to retardation)			
0–1	5.04	64	
2–6 impairments	6.03	113	significant
7–10 impairments	7.00	23	$p<0.05$
Mean Malaise Score	5.83	200	

The burden of care

Next, we investigated the relationship between malaise scores and the total burden of work involved in the physical care of the children, by creating an 'extra work' scale.

Table 3
Extra work score by malaise scores

Extra work score	*Mean malaise scores*	*N*
0–1	4.59	59
2–3	5.01	63
4–10	7.43	76

$p<0.001$: highly significant

This scale was based on a series of questions which asked whether the child's impairment caused extra work for his or her chief carer. The questions covered cleaning and tidying, cooking, washing clothes, shopping, and other tasks. No extra work was scored as 0, a little extra work as 1, and a lot of extra work as 2, to give a maximum possible score of 10. The results of this analysis are presented in Table 3. As this shows, mothers who had a greater burden of extra work because of their handicapped child had very significantly higher malaise scores. The significance of this will be shown when we look at the help husbands give their wives.

The association between behaviour problems and maternal stress

Next we turned to behaviour problems, a term which contains within it a variety of characteristics including head banging, temper tantrums, destructiveness, night-time disturbance, spitting, biting, screaming, wandering, and sexual delinquency. We have seen that physical impairments, such as immobility or incontinence, were not necessarily related to high malaise scores. However, when we considered behaviour disorders the picture was dramatic. There was a very significant association between the degree to which a child's behaviour was disordered and the level of stress in the carer, as Table 4 shows.

Table 4
Behaviour problems in the children of malaise scores of carers

	Mean score	*Standard deviation*	*N*
Severe behaviour problems	7.03	4.34	82
Mild behaviour problems	5.62	4.40	40
No problems	4.66	3.32	78

$p < 0.001$: highly significant

The more severe the behaviour problems in the child, the more stressed the mother was likely to be: the 82 mothers with children with severe behaviour disorders had a mean malaise score of 7.03, indicating a high level of stress. It is important to remember that the assessment of the child's behaviour was made by the teacher or care assistant in the course of the population study; the malaise score was calculated on the basis of material collected in the course of the interview with the child's mother. The two measures are thus independent.

The link between behaviour disorder and stress is an important finding. However, behaviour disorder is a broad category, and it was important to find out exactly which aspects of the child's behaviour contributed most to stress in the person doing the work of caring. Each carer was asked about a number of different aspects of the management of the child to determine their association with the malaise scores, and Table 5 gives us some measure of the relative impact of different aspects of the child's behaviour on the carer. In all the areas of everyday life at which we looked, children with greater problems of management were significantly more stressful than those with lesser or no management problems. The carers' mean malaise scores varied from 6.12 where children were hard to keep occupied, through 6.52 where children had behaviour problems, 7.05 where children had an unusual appearance, 7.76 where children were particularly difficult to manage, to 8.09 for those carers whose handicapped children prevented them from getting enough sleep. Here we see the very damaging effects of night-time disturbance.

Table 5
Management problems by malaise scores

	Mean malaise score	*N*	*Analysis of variance*
Child is easy to keep occupied	4.47	36	very significant
Not easy to keep occupied	6.12	164	$p<0.01$
No behaviour problems	4.66	78	very significant
Behaviour problems	6.57	122	$p<0.01$
Child's appearance is normal	5.53	161	significant
Child's appreance is unusual	7.05	39	$p<0.05$
Child is easy to manage	4.78	74	very
Difficult to manage	5.78	88	significant
Very difficult to manage	7.76	38	$p<0.01$
Parents get enough sleep	4.84	135	highly significant
Parents do not get enough sleep	8.09	42	$p<0.001$

In all, 21 per cent of the mothers said that they did not get enough sleep, and many spoke of being woken at night by their handicapped children. Some mothers found that the only solution was to sleep with the child so as to be able to attend to his or her needs without disturbing other family members. Some children were liable to wake up and wander, or to become destructive if not supervised, while others simply needed constant physical care, such as the hourly suction with an electric pump which was essential for one child with a tracheostomy.

In this study we were aware that some families experienced other sources of hardship, not necessarily connected with the handicapped child, which might be stressful. For example, 13 per cent were single parent families, 17 per cent of mothers and 10 per cent of fathers had themselves suffered from ill health in the preceding year, and 31 per cent had an income of less than £5,000. In order to assess the cumulative effects of economic and social disadvantage we devised an adversity scale which drew together a number of different aspects of hardship. We were able to confirm that mothers in the high adversity group had significantly higher levels of stress (8.6 in contrast to 5.1 in the low adversity group) and that the combination of severe behaviour problems or multiple impairments with high levels of adversity, produced the highest malaise scores we had encountered so far in the study. Finally, we were able to assess the relative importance of all the various factors which affect the stress experienced by carers using regression analysis. This allows one to study the linear relationships between a set of independent variables and a dependent variable while taking into account the inter-relationships among the independent variables. The result of the regression analysis is shown in Table 6.

We constructed a model which included all the variables which we hypothesised might be likely to affect maternal stress. We then used a stepwise regression analysis to sort out which variables were important in their own right as direct effects on stress. Of the 28 variables in the model, 19 proved to have little effect on malaise after allowing for the nine in the Table. Table 6 sums up the previous findings. It shows that stress in mothers is related most strongly to variables falling into two different areas. The first area focuses on the children, and here the most stressful factors are behaviour

Table 6
What factors are associated with stress in carers?
Regression coefficients predicting stress levels

Variables in order of importance	*Beta* coefficients*	*P*
Behaviour problems in the child	.24003	0.0002
Night time disturbance	.23347	0.0003
Social isolation of mother	.21413	0.0009
Adversity in family	.19361	0.0023
Multiplicity of impairments	.14113	0.0298
Difficulty in settling child at night	.11579	0.0537
Problems with child's health	.11255	0.0617
Problems with child's appearance	.10952	0.0696
Parents have money worries	.10538	0.1056

These nine variables together explain 37 per cent of the variance in malaise.

* The beta coefficient is a measure of the direct impact of the independent variable onto the dependent variable when all other variables are held constant.

problems, night-time disturbance, multiplicity of impairments and the child having an unusual appearance. The second area is concerned with the social and economic circumstances of the family, and here the most stressful factors are social isolation of the mother, and adversity.

How marriage affects the stress of caring

In the second half of this paper we consider how marriage affects, and is affected by, the stress of caring for a severely handicapped child. We have seen that 59 per cent of mothers caring for such children have stress scores outside the normal range.

The quality of marriage

It has been suggested in many studies that the risk of psychiatric illness is considerably reduced for women who have appropriate coping resources and supportive social networks (Mueller 1980; Andrews *et al* 1981). John Birtchnell has commented on some of these studies in this volume. Research has suggested that deficiencies in social support may contribute to psychiatric illness independently of other psychosocial stressors. Henderson *et al* (1981) and Thoits (1982) have reviewed the empirical evidence supporting this hypothesis and have confirmed the importance of conceptualising social support as an important sociological variable. Gove *et al* (1983), for example, have shown that marital status is a powerful predictor of mental health, and that it is the *quality* of the marriage rather than the fact of it that links marriage to mental health.

Other recent empirical research has suggested that high levels of social support, from primary group members such as the spouse, relatives and other members of personal social networks and from community-based sources, is particularly important for the mental health of *individuals under stress* (Lin *et al* 1979; Mueller 1980; Syrotuik and D'Arcy 1984). Specifically it is hypothesised that good social support will act as a protective device, buffering the individual faced with severe life events or difficulties.

However, social support will affect mental health only indirectly, when stressful life events or difficulties are being experienced.

Brown and Harris, for example, provide evidence of the positive effect of support among women classified as having a severe life event. Women who experienced a severe life event such as death in the family but who did not enjoy a close, intimate and confiding relationship with a husband or boyfriend were significantly more likley to become depressed than women who viewed their relationships as providing trust and closeness. However, lack of a close, confiding relationship was not in itself associated with depression.

Further evidence for the protective effect of confiding marital relationships is presented by Roy (1978) in a matched controlled study of 84 depressed women. Roy found that significantly more depressed women had non-confiding relationships with their husbands than the controls (non-psychiatric medical patients). In a study of women patients in a general practice, Miller and Ingham (1976) found that women who did not have an intimate confiding relationship had more severe symptoms of depression, tiredness and anxiety than those who did. Waring and Patton (1984) suggest that the absence of intimate confiding relationships may be a vulnerability factor in the development of depression of women living under adverse circumstances.

Pearlin and Johnson (1977, p.717) sum up theories concerning the protective function of marriage in producing or maintaining psychological well-being under conditions of stress:

> 'What we have learned suggests that marriage can function as a protective barrier against the distressful consequences of external threats. Marriage does not prevent economic and social problems from invading life but it can apparently help people fend off the psychological assaults that such problems otherwise create'.

It is evident from the findings of studies like these that emotional support may play a significant role in buffering the stressful experiences of women.

We were interested in investigating whether emotional support within marriage acted as a buffer against stress for mothers caring for a child with severe mental handicap. It seemed to us that giving birth to and caring for a mentally handicapped child might be viewed as being a severe life event and/or an on-going difficulty. The question we used to assess the presence of emotional support was the one employed by Brown and Harris (1976) which asks whether a woman feels she has a close, intimate and confiding relationship with her husband or boyfriend. Firstly, did those wives who felt they had a close confiding relationship with their husband suffer less stress? Secondly, in the face of particularly severe difficulties, such as caring for a severely behaviourally disordered child or a multiply impaired child, were wives who had a close confiding relationship less stressed? The results of this analysis are shown in Tables 7 and 8.

Table 7

Malaise scores of mothers by presence of emotional support from husband

	Mean	*N*
Wife has a close confiding relationship with husband	5.2	144
Wife does not have a close confiding relationship with husband	7.2	30
Total:		174

$p < 0.01$: very significant

There was a significant relationship between malaise and the perceived quality of the marital relationship, women who felt that they had a close confiding relationship with their husband having significantly lower scores than wives who thought that they did not have such a relationship. When we looked at whether good emotional support had a stress-buffering role for women who had a severely behaviourally disordered child or a multiply impaired child, we again found that significant differences existed between the groups.

Table 8
Malaise scores of mothers with a behaviourally disordered or multiply impaired child by perceived presence of emotional support within marriage

	Mean Malaise Score	*N*
Wife has a close confiding relationship with husband	5.6	89
Wife does not have a close confiding relationship with husband	8.4	19
Total:		108

$p < 0.01$: very significant

As Table 8 shows, having good emotional support *did* appear to buffer the stress engendered by caring for a severely behaviourally disordered child or a multiply impaired child. Wives who had a close, intimate and confiding relationship with their husbands had a mean malaise score of 5.6, while wives who did not have such relationships had a mean malaise score of 8.4. Interestingly, though, when we looked at the 66 least impaired children—those who were neither behaviourally disordered nor multiply impaired—there was little relationship between malaise and perceived quality of the marital relationship; mothers who perceived their relationship as close and confiding had a mean score of 4.5 while mothers who did not, had a mean score of 5.0. This suggests that while confiding relationships may act as a protective device to women under stressful circumstances, they may not act independently of stress. That is to say, the level of stress experienced by a woman is not related to the presence of a close, confiding relationship unless there is a stressful aspect to her life such as responsibility for a multiply impaired or behaviourally disordered mentally handicapped child.

Table 9
Malaise scores of mothers by presence of emotional support

	Mean Score	*N*
Mothers with close confiding relationships	5.2	144
Single parent with other adults present	6.4	10
Mothers without close confiding relationships	7.2	30
Single parent living on own with child(ren)	8.5	16
N		200

$p < 0.01$: very significant

This can be demonstrated in another way. Table 9 shows mean stress scores of several groups of mothers. The most stressed women are single parents living on their own, followed by women whose marriages do not offer emotional support. Women with close, confiding relationships with their husbands are the least stressed group.

Gove *et al* (1981) have made some attempt to illuminate some of the psychological functions which may link marriage to psychological well-being. Their discussion revolves around effects such as primary interaction and self validation: the family serves as a 'private world' which provides meaning and support to the individual.

It must be acknowledged that the present study has employed a cross-sectional design, so that support measures, stress measures and behaviour measures have been assessed simultaneously. A disadvantage of using retrospective procedures is that the direction of effect between marital support, maternal stress and behaviour disorder in the child cannot fully be determined. There are at least three possible interpretations of this data. The first is that children with behaviour disorder *cause* their mothers to be stressed, or at least that there is a direct reciprocal relationship between disturbed behaviour and stress (Lewis and Rosenblum 1974; Bell 1977). Mothers can be protected against the effects of stress by a close, confiding relationship within marriage. This relationship would be similar to that found in this study between impairment, stress and marital support. In the case of multiple impairment and stress there is less problem in determining which is antecedent.

Secondly, it might be argued that marital discord helps produce behavioural problems in the child, rather than that problematic child behaviour results in stress which a confiding relationship can buffer (Rutter 1974; Minuchin *et al* 1975; Richman *et al* 1982). However, when we looked to see if the children of marriages where a confiding relationship did not exist were more likely to be behaviourally disordered, there was no significant relationship. In such marriages 33 per cent of children were behaviourally disordered while 41 per cent of children in marriages where there was emotional support were behaviourally disordered.

Thirdly our data might be interpreted as showing that children with mentally distressed mothers are more likely to become disturbed (Rutter and Quinton 1984) and that existence of psychological symptoms in the mother lead to a reduction in the quality of actual or perceived support from the husband, eg symptoms may alienate others or distort one's perception (Henderson *et al* 1981; Teasdale 1983). Of course it is undoubtedly true that being stressed may affect one's parenting. However, most of the parents with behaviourally disordered handicapped children in our sample had demonstrated their capacity for good parenthood by the normality of their other children. Irving (1974) provides an excellent discussion of the general tendency to scapegoat parents in the search for factors implicated in the aetiology of behaviour disorder and concludes that as far as behaviourally disordered mentally handicapped children are concerned, the evidence is thin on the ground. Some evidence for an association between behaviour disorder and abnormality of brain function, however, is presented by Rutter in his Isle of Wight study (Rutter 1970b) and also by Cantwell and his colleagues (Cantwell 1976; Cantwell *et al* 1980). With mentally handicapped children it seems that each impairment tends to predispose children to peculiarities of behaviour arising out of the handicap and the way it is handled (Williams 1968). Our study is to be extended longitudinally. We hope that a longitudinal study will help to overcome some of these problems and enable us to untangle the complicated interrelationships between these variables and to determine the role social support may play in the genesis of stress. However, it is important to remember, as Korn *et al* (1978, p.229) have observed:

> 'Neither the child, the parents nor the physical environment can be viewed as *the* significant determinant of any specific adaptive outcome. Each child with his or her pattern of characteristics, is continuously being affected by the family and is reciprocally having an impact on the family. We are dealing with multi determined interacting systems that are

also undergoing changes over time. The child grows, the parents age, the marriage and family develop and the environment is never static'.

Joint and segregated conjugal roles

Next, we want to consider joint and segregated conjugal roles, and the impact of these roles on the stress experienced by the mothers. The terms joint and segregated conjugal roles were first used by Elizabeth Bott in a study of the domestic division of labour in twenty London families (Bott 1971). Bott identified two extremes of conjugal role relationship: joint relationships, where husband and wife shared tasks equally, and segregated relationships with a strict division of labour between working husbands and dependent home-making wives. In 1974 Ann Oakley interviewed 40 London housewives with young children. She concluded that only a minority of fathers participated in household tasks; that when they did participate, it was more likely to be in child care tasks than housework, and that patterns of participation were class-based, with joint marriages being more common among middle class than working class families. We wanted to investigate whether in families with handicapped children there was any evidence that the father shared the extra burdens of care. Does having a severely handicapped child produce a tendency towards joint, rather than segregated roles? Respondents were asked whether their partners helped with household tasks, physical child care and looking after the children 'every day', 'most days', 'once or twice a week', 'less than once a week' or 'never'. In all cases where this was appropriate the respondent was a woman living with her husband. The number of husbands who helped every day was very small. The tasks which husbands were most likely to perform were lifting and carrying the child, but only a third of husbands whose child required lifting and carrying did this every day. For all the other tasks involved in the care of a handicapped child the numbers helping every day were much smaller. The percentages were based on the totals of those children whose care required that the task be done: we did not ask if a father changed nappies if the child was continent. The percentages of fathers who helped on a daily basis were as follows: feeding the child, 18 per cent; changing nappies, 15 per cent; toileting, 12 per cent; getting up in the night, 11 per cent; dressing and washing the child, 10 per cent.

When we looked at fathers who helped at least once or twice a week the numbers involved were somewhat larger, though it must be remembered that in some cases the help provided by these fathers represented a very small proportion of the work that had to be done. We were interested in seeing whether the father's involvement in care reflected social class differences or differences in employment status. We used the Registrar General's classification to distinguish between manual and non-manual occupations.

Table 10 shows that differences do exist between social classes but that these were not statistically significant. Fathers in manual occuptions were slightly more likely to help with washing the child, changing its nappies, lifting and carrying and getting up in the night, while fathers in non-manual occupations were more likely to help with dressing, toileting and feeding the child. Table 10 also shows that in every area unemployed fathers were more likely to help than were employed fathers. This finding may indicate that high levels of unemployment provide a hidden subsidy to 'community' care.

Having established that husbands were unlikely to bear a large part of the burden of caring for the handicapped child, we considered whether they were doing more of the routine work of the household in order to reduce the burden on their wives. However, this was not so. The results from the study confirm the findings of other research in showing that in general, husbands do not normally do a very great deal of housework, whether or not they have a handicapped child (Young and Willmott 1973; Oakley 1974;

Wilkin 1979; Cooke *et al* 1982). Where husbands do participate in housework, washing up is the task they are most likely to perform. Even so, we found that the following percentages of all husbands never did the following tasks: 36 per cent never wash up; 38 per cent never shop; 50 per cent never do cleaning; 61 per cent never do cooking; 84 per cent never wash clothes.

Table 10
Father's participation in the care of the handicapped child by social class and employment status

At least once or twice a week, father participates in:	*Employed fathers*			*Unemployed Fathers*
	Non-manual	*Manual*	*All*	
	%	%	%	%
Lifting and carrying N = 85	71	78	75	100
Feeding the child N = 91	60	53	57	63
Dressing the child N = 155	54	51	53	65
Toileting the child N = 94	53	44	49	50
Changing nappies N = 82	37	51	44	58
Washing the child N = 155	37	43	40	57
Getting up in the night N = 125	36	41	39	62

Husbands were then assessed as 'high', 'medium' or 'low' on their participation in both housework and child care tasks. The criterion used was how much of a share the husband took in the total amount of domestic work and child care done. The figures resulting from this assessment were compared with those of Ann Oakley's study as shown in Tables 11 and 12. Three main conclusions can be drawn from these tables. First, only a minority of husbands give the kind of help that assertions of equality marriage imply. Fourteen per cent have a high level of participation in housework and thirty one per cent in child care. Secondly, there is a greater tendency for men to take part in child care than in housework. Thirdly, the overall level of male domesticity is strikingly similar to that of Oakley's study. This suggests that husbands are no more likely to participate in household and child care tasks if they have a handicapped child.

Table 11
Husbands' participation in housework

	High	*Medium*	*Low*
	%	%	%
This study	14	24	62
Oakley 1974	15	25	60

Table 12
Husbands' participation in childcare

	High	*Medium*	*Low*
	%	%	%
This study	31	25	44
Oakley 1974	25	30	45

We were interested to see whether there were any differences in stress levels between women whose husbands did participate regularly in child care, child minding or household tasks and those whose husbands did not. In every aspect of child care, including washing, dressing, nappies, toileting, carrying and feeding, women whose husbands helped regularly had lower stress levels than women whose husbands did not help. However the differences only reached a statistically significant level where dressing the child was concerned. When we looked at the husband's participation in child minding tasks, a clearer picture emerged, as Table 13 shows. Women whose husbands regularly helped with weekend care and those who took the children out so that their wives could have a break had significantly lower mean scores than women whose husbands did not help.

Table 13
Husbands' help with child minding tasks by malaise scores of mothers

	Malaise Scores	
	Mean Score	*N*
1. *Weekend Care:*		
Husband participates	5.21	142
Husband rarely participates	7.18	27
	$p < 0.05$: significant	
2. *Taking Children Out:*		
Husband takes child(ren) out on own	4.92	110
Husband rarely takes child(ren) out on own	6.57	64
	$p < 0.01$: very significant	

Next we looked at the husband's participation in household tasks. Wives whose husbands helped with household tasks tended to have slightly higher malaise scores than wives whose husbands did not help. The differences reached significance only where washing clothes was concerned, a task in which only 11 per cent of fathers participated ($p < 0.05$). Clearly one can only speculate about the causal ordering of variables here. However, a possible explanation might be that in household tasks there was a much clearer division of labour with husbands rarely performing these tasks or being expected to do so. However, if their wives were particularly stressed, husbands would help. In the case of washing clothes, as we have seen, wives who had a greater burden of work were particularly stressed, so their husbands helped them. Where child care was concerned there was not such a clear division of labour. Husbands more often performed child care tasks, and when they did, wives tended to be less stressed.

The findings of our study suggest then, that joint conjugal roles are no more likely to be found in families with severely handicapped children, although joint patterns may be better adapted to meet the demands of a handicapped child.

The effect of handicap on the marriage

It is sometimes suggested that the stress of bringing up a mentally handicapped child causes marital disharmony and increases the likelihood of marital breakdown. For example, Ann Gath in her longitudinal study of families with Down's Syndrome children found important differences between the quality of the marriage of the couples who had had a child with Down's Syndrome, compared with the control families. Three marriages had broken irretrievably in the first two years following the birth of the affected child and in six others there were major quarrels, open hostility, or marked lack of interest in each other. In contrast there were neither broken marriages nor severe discordance between the parents in the control group. (Gath 1977; Gath and Gumley 1984). Tew *et al* (1977) found the divorce rate among parents of children with spina bifida to be nine times higher than among the rest of the population. Marriages which followed a prenuptial conception resulting in a spina bifida child were particularly vulnerable, having a divorce or separation risk of fifteen per cent. These figures were questioned and reanalysed by Stevenson, Graham and Dorner (1978) who concluded that the divorce rate was at most increased by a factor of 1.5 rather than 9. Tew *et al* (1978) subsequently acknowledged errors of analysis in their early report which exaggerated the findings. However, they maintained that families with handicapped children are at risk in terms of marital stability.

Weale and Bradshaw (1980) in an analysis of handicapped children in the 1974 General Household Survey found that families with handicapped children were more likely to be one parent families if the child was severely or moderately handicapped and that lone mothers with such children were more likely to be divorced or separated than lone mothers in the general population. On the other hand, some studies have produced very different results, (Pringle and Fiddes 1970: Hewett 1970; Martin 1975). Some studies suggest that having a handicapped child can strengthen and enrich the marriage of the parents (Kramm 1963; MacAndrew 1976). Additionally, Cooke *et al* (1982) found no evidence that a handicapped child was more likely to cause marital breakdown, though their study did show that the presence of a handicapped child makes the reconstitution of families which have broken down more difficult.

Tracing the link between child handicap and marital breakdown is fraught with difficulties, as Bradshaw (1979) has pointed out. First, it is likely that children of lone parents are more likely to be born damaged. Secondly, one-parent families with handicapped children tend to be larger than one-parent families in the normal population. (Weale and Bradshaw 1980). This difference is an indication that handicapped children are more likely to be born to older mothers. It is difficult to tell whether any differences in the prevalence of divorce and separation among mothers of handicapped children are due to the age of the mothers or the presence of the handicapped child. Thirdly, most comparisons of marital status have been cross-sectional. They provide only limited evidence of episodes of lone parenthood. Marriage breakdown is increasing, but so too is re-marriage. Marriages containing a handicapped child may be more or less likely to break up but this may be hidden in a cross-sectional analysis if the re-marriage rate is different (Cooke *et al* 1982).

As a first step, we identified 26 (13 per cent) lone parents in our sample of handicapped children. This figure is only marginally higher than that in the population as a whole which has been estimated at 12.1 per cent of all families with dependent children (General Household Survey 1982). There were too few lone parents in the sample to be able to make comparisons on the basis of marital status, however, because only one parent was single, while four were widowed, fewer than one might have expected from the general population, and there were more divorced mothers. There was only one lone father. Not all lone parent families were living without another adult. In 10 (38 per cent) of the 26 lone parent families, another adult was present. These included several parents, a brother and a lodger. Sixteen lone parents (62 per cent) lived alone with their children, a figure which is slightly lower than the 1982 General Household Survey figure for lone mothers living alone, which was 76 per cent.

Secondly, we looked at the numbers of children in our study who were not living with both their natural parents. Seventeen per cent of children came into this category. Twenty-five children (12.5 per cent) were not living with their natural father and nine (4.5 per cent) were not living with their natural mother. This compares with 18 per cent of children under 16 in the 1982 General Household Survey.

So from our study there was no indication that mothers were more likely to experience marital breakdown if they had a handicapped child. However in our sample 29 marriages *had* broken down. Of these 25 (86 per cent) of women said that the stress of looking after the child had contributed to the breakdown. The mother of a boy with Down's Syndrome told us:

> 'My previous husband would not accept it. He told everyone the baby had died. My marriage ended because of David: He wanted to put him away'.

There was a good deal of evidence that the *quality* of a marriage was often affected by the stress of caring for a handicapped child. Questioning people about the happiness of their marriage is notoriously difficult, not least because the majority always say that they are 'happy' or 'very happy', and few admit to being unhappy. However, comparing the answers we received with the results of other studies, in which the identical question was asked of married couples without handicapped children, suggests that having a handicapped child does diminish marital happiness. Thus 46 per cent of our respondents said that their marriage was 'very happy', a smaller percentage was 'average' or 'unhappy', a larger percentage than that found elsewhere (Bernard 1982).

These findings are in accord with other research which has suggested that developmental dysfunction *can* adversely affect the quality of the marital relationship (Lerner and Spanier 1978; Howard 1978; Korn *et al* 1978; Sheger and Kotler 1979). When asked how the child affected them, 40 per cent said that it had put a strain on the marriage, while 25 per cent said that it had brought the couple closer together. These findings were corroborated by comparing the malaise scores of the two groups. Those who said that the presence of the child had been a strain had a much higher mean malaise score (7.2) than those who said it had brought them closer or had had no effect (mean malaise scores of 4.7 and 4.5 respectively).

In a number of cases, marriages were put under strain because the cause of the child's handicap was a genetic condition passed on by one of the partners, and the other partner found this hard to accept. One mother of a girl with Down's Syndrome said:

> 'I blamed my husband because it came from his side of the family. His aunt was a mongol. And his parents for not warning me. Of course, it's silly but it has caused a lot of bad feeling and our marriage has suffered'.

In other cases one partner, usually the father, was reluctant to take on the responsibility of a severely handicapped child and wanted to place the child in permanent residential care. The mother of a child with cerebral palsy said:

> 'My husband can't accept her. He didn't want to bring her home from hospital. He's embarrassed taking her out'.

Difficult behaviour in the child was sometimes stressful even for good marriages, especially if these difficulties included night-time disturbances, temper tantrums and the need for constant watchfulness. Here are four different mothers describing their lives:

> 'Joe's demands, and the lack of sleep, put a strain on the marriage. Our relationship has deteriorated'.
>
> 'My husband doesn't have anything to do with him. He doesn't talk to him. He finds Paul's behaviour hard to tolerate. He leaves me to deal with him'.
>
> 'My husband got into such a rage about the mess, he tried to strangle me. The social worker talked to him and calmed him down'.
>
> 'I have to sleep with Jane every night. She needs to be turned over regularly to be comfortable and it's easier if I just share her bed. Of course, it doesn't make relations with my husband very easy, and he resents it'.

Parents of children who displayed disturbed behaviour were no more likely to have poor marital relationships than those of children without presenting symptoms. However, as we have seen behaviour disorder was related to stress in the mothers, and stressed mothers were more likely to lack a close confiding relationship or to say that their marriage was unhappy.

Despite all the problems, it would be untrue to say that these parents did not love their children or that they did not get any happiness from caring for them. We suggested to parents, 'In spite of all the problems, some people say that having a handicapped child can bring a lot of happiness to a family' and then asked 'Would you agree?' In their answers, 65 per cent of mothers agreed that a handicapped child can bring a lot of happiness, while only 35 per cent were uncertain or disagreed. One mother's answer sums up the feelings of many others in its mixture of frustration, love and resentment:

> 'He is very difficult to settle at night. He screams for about two hours every night. It makes me frantic sometimes. I feel I can't cope any longer. And he wakes up about every hour most nights. We take it in turns to go to him. It's got to such a pitch that I resent him, though I do love him, because of the unhappiness and disruption to all the rest of the family'.

Another said of her profoundly handicapped son:

> 'In many ways he has been a fulfilment in our lives'.

Conclusion

In this paper we have been concerned with a number of very complicated relationships, between such factors as the presence in the family of a severely mentally handicapped child, the stress experienced by the mother, the support given by the father, and the quality of the marriage. We have shown that mothers who care for a mentally handicapped child are likely to show signs of stress, but that this stress can be mitigated if the woman has a close and confiding relationship with her husbnand or if he gives real help with the work of caring for the child. These are important findings. For many years it has been argued, in both popular and academic literature, that married women do more than their fair share of the unpaid work of family life: despite all the rhetoric about greater equality in marriage and about the growth of the symmetrical family, most married men still manage to avoid doing most of the domestic work, even when both they and their wives are in full time employment (Martin and Roberts 1984). Feminists, in particular, have argued that because of this marriage brings more benefits for men than it does for women (Barrett 1980; Barrett and McIntosh 1982; Bernard 1982; Segal 1983).

However, until now there has been little empirical investigation of the effect on married women of carrying the main responsibility for housework and child care. There have been many studies of the domestic division of labour, either in terms of time budgets or in terms of the allocation of specific tasks, but few attempts to quantify the burdens placed on women. The research described in this paper provides clear measures of the stress experienced by mothers, and makes firm links between that stress and the help given, or more often not given, by husbands. The results will be of interest not only to those concerned with providing support to families with mentally handicapped children, but to marriage guidance councillors, and also to all with an interest in developing a greater understanding of marriage and of family life.

NOTE

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Behaviour Problems in Severely Mentally Handicapped Children

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Behaviour problems in severely mentally handicapped children

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SYNOPSIS A population study was undertaken in two health districts of children with severe mental handicap. Prevalence figures for behaviour problems are presented. A stratified random sample of 200 families was drawn from the population. Detailed structured interviews were carried out with the children's parents. The children were divided into two groups comprising those with behaviour problems and those with no problems. There was a significant association between behaviour disorder and incontinence, lack of self-help skills, poor reading, writing and counting skills, and poor communication skills. Environmental correlates were few. There were no differences between groups in family size, birth order, age of parents, marital discord, social class or income. However, behaviour problems were more common in one-parent families. An association was found between maternal stress and problem behaviour. The possible mechanisms underlying this association are discussed.

INTRODUCTION

Serious behavioural problems are quite commonly found in school-aged children. A number of studies provide evidence for rates of significant disorders of this kind ranging from 6% to 20% (Miller *et al.* 1974; Rutter *et al.* 1970*b*; Richman *et al.* 1982). Prevalence studies of behaviour problems in severely mentally handicapped children are rare owing to difficulties in the definition of severe mental handicap and the fact that, until recently, registers of mentally handicapped children were not compiled by health districts. However, estimates from samples of children in hospitals, hostels and at home suggest that severely mentally handicapped children are particularly likely to have behaviour problems (DHSS, 1979; Wilkin, 1979). According to these estimates, up to 50% of mentally handicapped children have severe problems such as aggressive, destructive or overactive behaviour. Behaviour disturbance has been shown to be associated with the stress suffered by mothers caring for a severely handicapped child at home (Cooke *et al.* 1982; Chetwynd, 1985; Pahl & Quine, 1984). It has also been cited as one of the reasons for requests for long-term care (Wilkin, 1979; Primrose, 1971; Carter, 1984).

Studies of behaviour problems in children have repeatedly found associations between child behaviour and variables such as maternal stress and marital discord. These data have often been interpreted as evidence that disordered family relationships play a causal role in the onset of behaviour disorder in children. However, many of the studies are beset by methodological difficulties which make such an interpretation open to question. Some workers have made cross-sectional measurements of family relationships and child behaviour at one point in time, so that it is not possible to deduce which variable is antecedent (Kotler & Hammond, 1981). In some studies behaviour problems in the child and evidence of maternal stress are reported by the same respondent, which could allow bias to occur (Richman *et al.* 1982). Even in prospective longitudinal studies there may be problems in determining the causal ordering of variables (Rutter & Quinton, 1984).

How prevalent are behaviour problems in severely mentally handicapped children? What are the social correlates of behaviour problems in mentally handicapped children? What is the nature of the link between child behaviour disorder and the child's social environment? These and other questions will be investigated in

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this paper which reanalyses data from the first phase of a longitudinal study of severely mentally handicapped children and their families. The general results of the study are reported elsewhere (Pahl & Quine, 1984; Quine & Pahl, 1985, 1986*a*). This paper presents data on the prevalence of behaviour problems in a population of severely mentally handicapped children. The social and environmental correlates of behaviour disorder are investigated, and preliminary interpretations of the link between behaviour disorder and maternal stress are offered.

RESEARCH DESIGN AND METHODOLOGY

The current analysis is based on data obtained from assessments of the total population of severely mentally handicapped children in two health districts and interviews with a stratified random sample of two hundred mothers of the children.[1] The study had two stages, which we have called the 'population survey' and the 'sample survey'. The first stage concerned the total population of children who had been or were likely to be assessed as suitable for ESN (S) education. The Senior Medical Officers for Mental Handicap in the two health districts had been responsible for the initial assessment of the children, which was carried out by a multidisciplinary team using the Griffiths Mental Development Scales for younger children (Griffiths, 1970) and the Wechsler Scales for older children. With their cooperation, a comprehensive register of severely mentally handicapped children for each health district was developed by the research team. All children who were known to the health and social services for severely mentally handicapped children were included. Other children not previously known to the services were identified by screening all children receiving ESN (S) education, by visiting child development centres and play groups, and by contacting local societies for mentally handicapped children. A search was made of child health records. At the first stage all 399 children aged 0–16 in the two health districts were assessed by means of the Disability Assessment Schedule developed by Holmes *et al.* (1982). This is described below. Information was collected from the teacher or care assistant who knew each child best, about the child's mobility, continence, self-help skills, vision, hearing, communication skills, behaviour problems and medical conditions. At the second stage, a stratified random sample of 200 children was drawn from the population of 399 severely mentally handicapped children in the two health districts. The sample was chosen with proportional allocation for age and sex so that it matched the population from which it was drawn. An interview was carried out with the chief carer of each of the sample children (usually the mother) using a structured questionnaire.

Trained interviewers carried out the interviews which each lasted for approximately one and a half hours. The interviews collected data about all members of the families, about the nature of the children's impairments, about the problems these presented, about the impact of the child on the parents' health, marriage and social outlets, and about the families' use of and satisfaction with statutory and voluntary services. A full description of the methodology is given in earlier papers (Pahl & Quine, 1984; Quine & Pahl, 1985, 1986*b*).

The Malaise Inventory

Maternal stress was measured by the Malaise Inventory. This inventory is a 24-item binary choice questionnaire which was adapted from the Cornell Medical Index by Rutter & Graham for their study in the Isle of Wight (Rutter *et al.* 1970*b*). The scale has been used in a number of studies of handicapped children to measure the stress of carers (Gath, 1978; Burden, 1980; Cooke *et al.* 1982). The Malaise Inventory has been subject to considerable evaluation (Philp, 1978; Cooke *et al.* 1982; Hirst & Bradshaw, 1983; Bebbington & Quine, 1986).

Rutter checked the reliability of the scale by asking 35 mothers to complete the inventory on two occasions. He concluded that mothers tend to acknowledge fewer symptoms on the second occasion. However, there was a high correlation between the scores (0·91). In the present study, 20 mothers were asked to complete the inventory a second time. There was a correlation of 0·94 between their scores, confirming that the pattern of results was reliable. The inventory was investigated by Cooke *et al.* (1982), who calculated malaise scores in three different ways, comparing each with the others and also with the scores derived from the Symptom Scale: there

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[1] The full report of the study, entitled 'Families with mentally handicapped children: a study of stress and of service response' is available from the author.

was very little difference whichever scale was used, all scales correlating closely. In the second of a pair of papers Hirst & Bradshaw cast some doubts about the validity of the Malaise Inventory, but these are due to a change in the threshold of the measure used to assess association in the first paper (Bradshaw, 1982; Hirst & Bradshaw, 1983). In our study there was a highly significant association between maternal malaise scores and mental health rating, as measured by the Symptom Scale. We would argue, therefore, that the Malaise Inventory provides a valid measure of stress in our sample of mothers with severely mentally handicapped children.

The Disability Assessment Schedule

The Disability Assessment Schedule (DAS) was developed at the Medical Research Council Social Psychiatry Unit, London, from a combination of items modified from the Wessex Social and Physical Incapacity (SPI) scale, the Wessex Speech Self-help and Literacy (SSL) scale (Kushlick *et al.* 1973) and the Children's Handicaps, Behaviour and Skills (HBS) schedule (Wing & Gould, 1978). It is a structured interview designed to elicit from parents and care staff details of impairments, skills and behaviour problems in mentally handicapped children. The DAS includes items concerning a wide variety of behavioural abnormalities. The schedule consists of eight sections of which four are concerned with physical and developmental skills and four with behavioural abnormalities. The DAS is completed by conducting a structured interview with an informant who knows the mentally retarded child well. This could be a nurse, teacher or care assistant. Test–retest data and inter-rater reliability tests suggest that the schedule meets adequate criteria of reliability (Holmes *et al.* 1982).

In our study it was decided that information about the child's impairments and skills should be collected from an 'independent' informant to avoid potential bias in parental perceptions. For example, a stressed or unhappily married mother might perceive her child more negatively than a mother who was not stressed and happily married. Emery & O'Leary (1984) have argued cogently that research using non-independent ratings to examine the relation between marital and child problems may exaggerate the strength of the association between interparental conflict and child behaviour problems. However, the methods used in the present study have problems too. The figures in this paper reflect prevalence in day care facilities. Children may respond to family conflict more noticeably in the setting where it occurs – the home. Thus behaviour problems may be situational-specific. Theoretically, this might mean that teachers fail to report behaviour problems which are displayed only at home. This might undermine the likelihood of finding significant relationships between social and family problems and behaviour difficulties. The present study did not collect information about behaviour problems from both parents and teachers. However, Wing & Gould (1978), using a longer version of the same schedule, found that overall agreement between parent and professional informants was, in general, 70% or above. Parents, when compared with professional workers, tended to describe their children as having higher developmental skills and more difficult behaviour. This seems to be quite a common finding (Touliatos, 1981). Our study shows a high association between the behaviour problems as rated by professionals and parental ratings of the child being difficult to manage ($P < 0{\cdot}0001$). We believe, therefore, that there were relatively few instances where problem behaviour occurred at home but was not recognized at school.

Assessment of the parents' marriage

The study employed two methods of assessing the parents' marriage. First, the child's main carer was asked to rate the happiness of her marriage on a five-point scale. Secondly, the presence of emotional support within the marriage was assessed by the question used by Brown & Harris (1978) which asks whether a woman feels that she has a close, intimate and confiding relationship with her husband or boyfriend. A fuller description of the study's findings relating to marriage is published elsewhere (Quine & Pahl, 1986*b*),

COMPARISON OF THE POPULATION AND THE SAMPLE

When the sample was compared with the total population of severely mentally handicapped children living within the two health districts the impairments of the children were found to be very similar, rarely differing from the population by more than three percentage points. Thus, in the sample 35% of children were non-ambulant compared with 34% in the population; 41% had little or no use of communication compared with 42% in the population; and 42% had severe behaviour problems compared with 45% in the population. Sixty-three per cent of the sample were boys and 37% were girls compared with 61% and 39% of the total population. In terms of the *number* of impairments per child the sample was very similar to the total population: the proportion of children who had 7 or more impairments was 11·5% in the sample and 10·7% in the population.

THE PREVALENCE OF SEVERE MENTAL RETARDATION IN THE STUDY

Table 1 shows the prevalence of severe mental retardation as measured in this and a number of other studies (Kushlick & Cox, 1968; Kidd *et al.* 1967; Wing, 1971). The prevalence rates in Medway and South East Kent were calculated on the basis of the small area statistics of the 1981 Census. Prevalence rates in Medway and South East Kent were broadly comparable with those found in other studies, although rates for the age group 0–4 were rather lower than those found in Camberwell by Wing (1971). The prevalence of severe mental handicap was lowest among the youngest children. This probably reflects the fact that impairments are not detected or sometimes do not occur until children are over 4 years of age. However, these lower rates may reflect a real reduction in prevalence as a result of improved antenatal and perinatal care. Further work on this issue is in preparation.

Table 2 presents rates of social and physical incapacity of children aged 0–14 in the two health districts and compares them with Wing's

Table 1. *Prevalence of severe mental retardation in six areas of the UK (age-specific rates per 1000 population)*

Age groups (years)	Wessex 1963[a]	Scotland 1964[b]	Ireland 1967[b]	Camber-well 1967[c]	Medway 1983[d]	SE Kent 1983[d]
0–4	0·52	1·1	0·8	3·12*	1·65*	1·32*
5–9	2·53	3·4	3·5	4·09	3·56	2·94
10–14	3·00	3·7	2·3	3·66	2·94	2·66

[a] Kushlick & Cox (1968). [b] Kidd *et al.* (1967). [c] Wing (1971).
[d] Figures for the total populations taken from the small area statistics drawn from the 1981 Census.
* Children suspected of being severely retarded.

Table 2. *Mentally handicapped children aged* 0–14 *years in Medway and South East Kent* 1984. *Social and physical incapacity, numbers and rates per* 1000 *population. Comparison with Wing's* 1971 *figures for Camberwell*

Social and physical incapacity	Medway No	Medway Rate	SE Kent No.	SE Kent Rate	Camberwell No.	Camberwell Rate
Non-ambulant	62	(0·82)	34	(0·67)	33	(0·85)
Ambulant and						
(*a*) Severely incontinent	13	(0·17)	3	(0·06)	16	(0·42)
(*b*) Severely disordered in behaviour	37	(0·49)	30	(0·59)	11	(0·29)
(*c*) Severely incontinent and disordered in behaviour	28	(0·37)	12	(0·23)	10	(0·26)
(*d*) Not severely incontinent or disordered in behaviour	65	(0·86)	40	(0·79)	67	(1·74)
Total	205	(2·72)	119	(2·35)	137	(3·56)

Total population of children aged 0–14 years: * Medway, 75221; *SE Kent, 50563; Camberwell, 38460.
* Figures for the total populations taken from the small area statistics drawn from the 1981 Census.

(1971) figures for Camberwell. It can be seen from Table 2 that the overall prevalence figures for our sample are rather lower than Wing's. Rates for non-ambulant children are very similar to Wing's figures. So, too, are rates for children who are severely disordered in behaviour whether or not they are continent. But rates for children who are incontinent are somewhat lower, as are rates for children who are neither incontinent nor disordered in behaviour.

THE PREVALENCE OF BEHAVIOUR PROBLEMS IN THE POPULATION SURVEY

The DAS enquired about a wide range of behaviour problems. The teacher or care assistant who knew the child best was asked whether the child had severe or mild behaviour problems which caused significant social or psychological disability to himself or to others. The majority of the informants had been trained in behaviour modification techniques and were knowledgeable about behaviour disorder. The level of disability to be identified as severe or mild was agreed, using criteria involving the threshold above which a child presented management problems, or would become a matter for concern to an experienced professional in the field. The problems which affected the largest proportions of children are given in Table 3.

Table 3. *Behaviour problems in the population of children*

Behaviour problem	Children with severe or mild problems (%)	Boys	Girls	*P**
Attention seeking	29	30	29	NS
Overactive	21	25	14	< 0·01
Temper-tantrums	25	27	21	NS
Aggressive	21	23	17	NS
Screams	22	24	19	NS
Wanders	18	19	17	NS
Destructive	14	16	11	NS
Self-injuring	12	13	10	NS
Base for percentages	399	245	154	

* Significance level of chi-square test comparing boys and girls, df = 1.

Children with severe or mild behaviour disorders would certainly be regarded as requiring help from primary health care services, and might be regarded as needing assistance from specialized professionals such as social workers, psychologists and psychiatrists. Table 3 shows the proportion of children displaying each behaviour problem. Taken as a whole, 45% had severe behaviour problems. This compares with 50% of children in the hospital units and wards and 34% in the residential homes surveyed for the Jay Report (DHSS, 1979). Secondly, Table 3 shows that there were few sex differences in the sample. Although a greater proportion of boys were reported as presenting each behaviour problem, the differences between boys and girls reached a statistically significant level only for over-activity: significantly more boys than girls were assessed as over-active.

THE CORRELATES OF BEHAVIOUR PROBLEMS IN THE SAMPLE SURVEY

As has been noted, the sample of 200 children proved to be entirely representative of the total population; the proportion of sample children assessed as having each behaviour problem differed only by one or two percentage points from the proportion in the population. We can, therefore, have a high degree of confidence in the results. For the purpose of this analysis, the sample was divided into two groups: the first group contained children with severe or mild behaviour problems; and the second group contained children with no behaviour problems. This enabled us to examine the correlates of behaviour problems in mentally handicapped children.

Correlations between behaviour problems and other impairments

Table 4 presents information on the correlation between behaviour disorder and the children's other impairments. A major difference between the groups was in the area of communication, and reading, writing and counting skills. One half of the non-disordered group had good use and understanding of communication compared with only a third of the behaviour disordered group. Eighty-five per cent of the behaviour disordered group had poor reading, writing and counting skills, compared with 65% of the non-disordered group. Rutter reports broadly similar findings: children with organic brain pathology including epilepsy and cerebral palsy were more at risk of behaviour disorder if the

Table 4. *Correlations between behaviour problems and other impairments*

Impairment	Children with behaviour problems ($N = 122$)	Children without behaviour problems ($N = 78$)	P*
Use of communication			
Good	32	54	$P < 0{\cdot}001$, df = 2
Fair	25	9	
Poor	43	37	
Understanding of communication			
Good	33	57	$P < 0{\cdot}001$, df = 2
Fair	25	10	
Poor	42	33	
Literacy (ability to read, write and count)			
Good	2	12	$P < 0{\cdot}002$, df = 2
Fair	15	23	
Poor	84	65	
Self-help skills			
Washes without help	21	45	$P < 0{\cdot}0003$, df = 2
Washes with help	44	22	
Unable to wash self	35	33	
Feeds self without help	50	59	$P < 0{\cdot}05$, df = 2
Feeds self with help	30	15	
Unable to feed self	20	26	
Dresses self without help	21	49	$P < 0{\cdot}0001$, df = 2
Dresses self with help	42	18	
Unable to dress self	37	33	
Continence for age			
Continent	52	73	$P < 0{\cdot}004$, df = 1
Incontinent	48	27	

* Significance level of chi-square test.

Table 5. *Age of child by behaviour problems*

Age of child (years) ($N = 200$)	% of children with problems		
	Children with behaviour problems	Children without behaviour problems	P*
0–5	64	36	NS, df = 2
6–10	70	30	
11–18	53	47	

* Significance level of chi-square test.

child had a lower IQ or marked reading difficulties. These associations applied equally to children without brain damage (Rutter *et al.* 1970*a*, *b*; Rutter, 1974). In our study, the behaviour disordered group contained a significantly higher proportion of children who were unable to feed, wash and dress themselves. Also, significantly more of this group were incontinent. As Table 5 shows, behaviour disorder was not significantly associated with age which might have been an explanation for the differences consistently found between the two groups. There were no significant differences in health or weight between the two groups. Interestingly, children who were not mobile were no less likely to exhibit behaviour problems than children who were mobile.

Family circumstances

When family circumstances were examined our findings were remarkably similar to those reported in a longitudinal study of children in the general population (Richman *et al.* 1982).

The parents of the group of children with behaviour problems were no different from the parents of those with no problems in their ages or in the length of time they had been married. There was no significant difference between the two groups in the degree to which mothers were engaged in full- or part-time work. Size of family and birth order did not differ between the groups in our study, although Richman *et al.* found differences in family size (but not in birth order) between problem and non-problem children. When analysis of social class was carried out considering each occupational class separately, no significant differences were found. There were also no differences when all manual classes were combined and compared with all non-manual classes. These findings are at variance with those of Richman *et al.* (1982), who found social class differences in rates of behaviour disorders in girls only. The occupational class of the father is a rather crude indicator of social status, and therefore we examined the social circumstances of the children in greater detail. However, we found no differences between the two groups in terms of household income, or ownership of consumer durables.

There were, however, significant differences between groups in family composition, as Table 6 shows. Significantly more children in single-parent families had behaviour problems, although the causal ordering of these variables is unclear. It may have been that some factor associated with growing up in a one-parent family is implicated in the genesis of behaviour disorder or it may be that the difficulties of looking after a mentally handicapped child with behaviour problems drove the fathers away.

There were no significant differences in the

Table 6. *Family composition by behaviour problems in the child*

Family composition ($N = 200$)	% of children with problems: Children with behaviour problems	% of children with problems: Children without behaviour problems	P*
Two-parent family	58	42	$P < 0.01$, df = 1
Single-parent family	85	15	

* Significance level of chi-square test.

Table 7. *Nature of tenancy by behaviour problems in child*

Nature of tenancy ($N = 200$)	% of children: With behaviour problems	% of children: Without behaviour problems	P*
Owner-occupied	54	76	$P < 0.01$, df = 3
Rented from council	37	18	
Privately rented	4	1	
Other	5	5	

* Significance level of chi-square test.

type of housing or the length of time parents had lived in their present home, but there were significant differences in the *nature* of the tenancy, as Table 7 shows. A significantly lower proportion of parents of children with behaviour disorder owned their own homes. Richman *et al.* (1982) report similar findings in a general population survey. Additionally, significantly more parents of such children said that their house was unsuitable for the needs of the family ($P < 0.01$). This may reflect the greater ease with which owner-occupied housing can be altered, without recourse to social services departments or housing departments, etc., and without having to wait for such lengthy periods for permission to be given and work to be carried out.

The parents' marriage and social contacts

There were no differences between the groups in the wife's perception of the availability of emotional support in her marriage, the happiness of her marriage, or her reported contact with friends and relatives. In marriages where wives reported that a close, confiding relationship did not exist, 33% of children were behaviourally disordered, while 41% of children in marriages where there was emotional support had problem behaviour. This is interesting in view of the findings from a number of studies of children which have shown strong correlations between child behaviour disorder and marital discord (Richman *et al.* 1982; Kotler & Hammond, 1981; Rutter & Quinton, 1984).

When social activities were examined, a significantly higher proportion of parents whose children had behaviour problems said that the presence of the handicapped child prevented them from going out; however, they did not go out less than parents whose children had no behaviour problems, nor did they want to go out more. However, they did have more difficulty in finding someone prepared to babysit ($P < 0.05$). Social isolation was not more common among mothers of children with behaviour problems (although 50% did feel isolated), but a significantly larger proportion felt that the child's handicap had been a disadvantage to his or her siblings, had restricted their activities and that, on balance, the child had had an adverse effect upon the family as a whole ($P < 0.05$).

Maternal stress

Stress in the mothers in the sample was measured using the Malaise Inventory. Rutter considered that scores of 5 or 6 were outside the normal range and indicative of stress, and that scores of 7 or more were 'critical' (Rutter *et al.* 1970*a*). The mean malaise score for respondents in this study was 5·83, a figure which is outside the normal range and indicates that many carers were experiencing stress. Fifty-nine per cent of mothers had stress scores outside the normal range. When mean stress scores were analysed by behaviour problems in the child, there was a significant relationship between the extent to which a child's behaviour was disordered and the malaise scores of carers, as Table 8 shows. Richman *et al.* (1982) report similar results in their longitudinal study of the behavioural problems of pre-school children.

It is important to remember that the assessment of the child's behaviour was made by the teacher or care assistant during the course of the population study described earlier; the malaise score and information about childcare and management problems were assessed on the basis

Table 8. *Behaviour problems in the children by malaise scores of mothers*

	Analysis of variance		
	Mean score	S.D.	N
Behaviour problems	6·57	4·39	122
No behaviour problems	4·66	3·32	78
Total			200

One-way analysis of variance: $F = 10{\cdot}723$; df $= 1{,}198$; $P < 0{\cdot}001$.

Table 9. *Extra work having to be done by parents of children with behaviour disorders*

	Mothers who had to carry out tasks (%)		
Extra work required ($N = 200$)	Children with behaviour problems	Children without behaviour problems	P*
Cleaning and tidying the house			
No	47	67	$P < 0{\cdot}006$, df $= 2$
A little	19	19	
A lot	34	14	
Laundry			
No	30	46	$P < 0{\cdot}02$, df $= 2$
A little	20	23	
A lot	50	31	
Shopping			
No	49	63	$P < 0{\cdot}07$, df $= 2$
A little	26	23	
A lot	26	14	

* Significance level of chi-square test.

of material collected during the course of the interview with the child's mother. This is important because it ensures that the measures are independent. Studies of child behaviour which have used the mother's assessment of behaviour can encounter methodological problems because of the potential for contamination between variables assessing the child's problems and those which describe stress levels or social circumstances (Richman *et al.* 1982; Berg *et al.* 1984).

Parents' perceptions of the difficulties encountered in caring for a child with behaviour problems

Household tasks

Mothers of all the children in the sample were asked whether the children required them to carry out extra household tasks or made things more difficult for her when performing her tasks. Rutter & Brown (1966) have shown that reliable results can be obtained from questioning parents, provided that the questions asked are aimed at the performance of specific tasks over a specific time period. The series of questions in this study followed this precept.

The answers were broken down into cross-tabulations, showing the differences between children with behaviour problems and those without. It can be seen from Table 9 that children with behaviour problems do seem to cause mothers more work: mothers of disordered children had significantly more cleaning and tidying; they had extra laundry because of incontinence and heavy use of clothes; they had more difficulties when shopping because of the child's impulsive behaviour and the likelihood that he or she might wander off.

Child care

More parents of children with behaviour problems reported that their children needed help with dressing, undressing, washing, bathing and using the toilet. This should not be unexpected, since we have shown that children

Table 10. *Help required by children with behaviour problems*

	% of mothers who had to help		
Child requires help with ($N = 200$)	Children with behaviour problems	Children without behaviour problems	P*
Dressing			
No	6	21	$P < 0{\cdot}002$, df $= 2$
A little	25	30	
A lot	70	50	
Undressing†			
No	26	49	$P < 0{\cdot}005$, df $= 2$
A little	20	13	
A lot	54	38	
Washing			
No	9	20	$P < 0{\cdot}02$, df $= 2$
A little	25	30	
A lot	66	50	
Using toilet			
No	23	43	$P < 0{\cdot}01$, df $= 2$
A little	25	25	
A lot	51	32	

* Significance level of chi-square test.

† Information was not available for 3 subjects.

Table 11. *Management problems of children with behaviour problems*

Management problem (*N* = 200)	% of children with problems: Children with behaviour problems	% of children with problems: Children without behaviour problems	*P**
Ease of management			
Easy	24	58	*P* < 0·0001, df = 2
Difficult	48	37	
Very difficult	28	5	
Difficulties when shopping†			
Yes	67	54	*P* < 0·02, df = 2
No	33	46	
Attention to keep occupied (comparison with other children of same age)			
Less attention	4	10	*P* < 0·002, df = 3
As much attention	7	18	
A bit more attention	18	27	
A lot more attention	71	45	
Attention to keep safe (comparison with other children of same age)			
Less attention	2	8	*P* < 0·02, df = 3
As much attention	11	15	
A bit more attention	16	26	
A lot more attention	71	51	

* Significance of chi-square test.
† Information not available for 3 subjects.

with behaviour problems were more likely to be unable to carry out these tasks alone. Table 10 presents these findings.

Management problems reported by the parents

Differences in management problems reported by mothers between the behaviour disordered and the non-disordered groups were examined. As Table 11 shows, there were significant differences between the children with behaviour problems and those without problems. Significantly more parents of children with behaviour problems reported difficulties with managing the child, keeping her or him occupied and safe, and having difficulties when shopping.

Use of services

There were no differences in the frequency with which children in the two groups, or their parents, visited their general practitioner or were admitted to hospital. However, a significantly higher proportion of children with behaviour problems had been in touch with a social worker and had used short-term care, although there were no differences in whether they had seen community mental handicap nurses or health visitors.

Felt needs for additional help

Perhaps not surprisingly, there were a number of significant differences between the two groups when mothers' felt needs for additional help were examined. It can be seen from Table 13 that parents of children with behaviour disorder are not asking indiscriminately for all kinds of extra help. Holiday care is seen as a priority, along with more financial help. Weekend care is the help needed by the third largest group of mothers.

DISCUSSION

This paper has provided evidence of an association between behaviour disturbance and a number of impairments suffered by severely mentally handicapped children. Significantly

Table 12. *Use of services by behaviour problems in the child*

Service	Children with behaviour problems: %	Children with behaviour problems: *N*	Children without behaviour problems: %	Children without behaviour problems: *N*	*P**
Health visitor (contact in last year)	31	37	25	19	NS
Community nurse (contact in last year)	13	16	13	10	NS
Social worker (contact in last year)	50	61	27	21	*P* < 0·002, df = 1
Short-term care (use in last year)	62	76	45	35	*P* < 0·02, df = 1

* Significance level of chi-square test.

Table 13. *Mothers' felt needs for additional help by behaviour problems in the child*

	Children with behaviour problems		Children without behaviour problems		
	%	N	%	N	P*
Financial help	58	69	42	32	$P < 0{\cdot}04$, df = 1
Holiday care	51	52	34	21	$P < 0{\cdot}05$, df = 1
Weekend care	37	44	19	14	$P < 0{\cdot}01$, df = 1
Child care	28	33	18	14	NS
After-school minding	28	27	14	8	$P < 0{\cdot}05$, df = 1
Help with household tasks	21	25	17	13	NS

* Significance level of chi-square test.

more children with behaviour disorders were found to be incontinent, to have few self-help skills, to have poor communication skills, and to be unable to read, write and count than mentally handicapped children without behaviour disorder. Such children present their carers with more management problems; they are more difficult to keep occupied and to keep safe. Their dependence on others to perform simple tasks and their incontinence make extra work for their carers.

When the environmental correlates of behaviour disorders were sought it was found that there were remarkably few; there was no association between behaviour disorder and family size, birth order, age of parents, social class or income. However, there was a significant association between type of housing and the presence of behaviour disorder. Children who lived in council house accommodation were more likely to be disturbed than those who lived in owner-occupied housing. There was also a significant association between satisfaction with housing conditions and behaviour disorder. These findings are difficult to interpret, in view of the finding that social class was not associated with behaviour disorder. It may be that some parents who function poorly in various ways are more likely to be housed in council house accommodation. The disturbance in their children might be influenced by aspects of this functioning rather than the quality of their housing. Nevertheless, it seems that good housing circumstances may make it easier to cope with a disturbed child, and it seems equally possible that housing which is inadequate, overcrowded or otherwise unsuitable may exacerbate behaviour problems.

Although most of the parents in both groups were married and living together, the proportion who were not was more than three times as high in the behaviour disordered group. Children living in one-parent families were no more likely to live in council housing than two-parent families, nor were their mothers more likely to be dissatisfied with their housing conditions. Thus this association cannot account for the relationships between the type of housing, satisfaction with housing conditions and behaviour disorder.

The high rate of behaviour disorder found in one-parent families deserves further consideration, since it could not be accounted for by other significant relationships. Tracing the link between child handicap and marital breakdown is fraught with difficulties, as Bradshaw (1979) has pointed out. In our sample of behaviourally disordered mentally handicapped children, 18% were from single-parent families. This figure is rather higher than that in the population as a whole, which has been estimated at 12·1% of all families with dependent children (OPCS, 1982). However, from cross-sectional data it is impossible to judge whether some factor associated with growing up in a one-parent family is implicated in the genesis of behaviour disorder or whether the difficulties of looking after a mentally handicapped child with behaviour problems contributed to the breakdown of these marriages.

Studies of behaviour disorder in children have often found an association between marital discord in the parents and behaviour disturbance in the child, but this study found that there was no tendency for mothers of children with behaviour problems to report that their marriage lacked closeness or that it was unhappy.

The mean stress score of mothers with a behaviourally disordered child was significantly higher than the mean score of mothers of children without problems. Again, there is the problem of interpreting this finding. A number of studies of behaviour problems in children have hypothesized a causal relationship which suggests that stressed or psychiatrically disturbed mothers may produce children with behaviour problems (Richman *et al.* 1982; Kotler & Hammond, 1981). Rutter & Quinton (1984), for example, have conducted a 4-year prospective study of newly-referred psychiatric patients and their children and a control group of families in the general population. The main focus of the study was 'the identification of the key features of parental mental illness that put children at psychiatric risk'. Rutter & Quinton found that patients' families differed in terms of a higher rate of psychiatric disorder in spouses and a much higher level of family discord, both of which tended to persist over a 4-year period. The children of psychiatric patients had an increased rate of persistent emotional/behavioural disturbance which tended to involve disorders of conduct. The psychiatric 'risk' to the children was greatest in the case of personality disorder associated with high levels of exposure to hostile behaviour. However, while parental mental illness constituted an important indicator of psychiatric risk for children, the overall pattern of Rutter & Quinton's findings showed that the main risk stemmed not from the illness itself, but from the associated psychosocial disturbance in the family, manifested by marital discord and hostile behaviour.

Problems of interpreting the causal ordering of variables occur in our study. It is necessary to ask whether behaviourally disordered children cause their parents to be stressed, or whether stress in the parents causes disorder in the child. Is marital discord implicated in the genesis of behaviour disorder, or does caring for a mentally handicapped child put the parents' marriage at risk? It may well be that a direct reciprocal relationship exists, where the child's difficult behaviour is stressful for the mother, and the mother's stress makes it impossible for her to interact normally with her child and husband. Data from a single phase of a longitudinal study cannot answer these questions fully. However, we would like to put forward some tentative interpretations of the findings.

Table 14. *Malaise scores of married women with a behaviourally disordered child by perceived presence of emotional support within marriage*

Emotional support in marriage	Analysis of variance Mean score	S.D.	*N*
Wife has a close confiding relationship with husband	5·7	4·2	83
Wife does not have a close confiding relationship with husband	8·5	2·9	18
Total			101

One-way analysis of variance: $F = 7{\cdot}05$; df $= 1{\cdot}99$; $P < 0{\cdot}01$.

In our work, there is some support for rather a different process from the one described by Rutter. Our study shows no relationship between marital/family discord and the presence of behaviour disorder. However, there was a significant relationship between *mother's assessment of her marriage as supportive* and *levels of stress*. Women with behaviourally disordered children who perceived their marriage to be supportive and harmonious were significantly less stressed than women with behaviourally disordered children who felt that their marriage lacked trust and closeness.

As Table 14 suggests, it seems that the *quality of the marriage* may influence the risk of *emotional stress* by the sort of mechanism which Brown & Harris (1978) have suggested. Women who have a severe life event or ongoing difficulty, such as a behaviourally disordered child, may be protected from the effects of such stress if they have a close and confiding marriage relationship.

Interestingly, when we studied the children who were not behaviourally disordered, there was no relationship between malaise and the perceived quality of the marital relationship; mothers of children who were not behaviourally disordered who perceived their relationship as close and confiding had a mean score of 4·6, while mothers who did not had a mean score of 5·2 (a non-significant result). This suggests that, while confiding relationships may act as a protective device to women under stressful circumstances, they may not act independently of stress. That is to say, the level of stress experienced by a woman is not related to the presence or absence of a close confiding relationship unless there is a stressful aspect to her life such as responsibility for a behaviourally disordered mentally handicapped child.

Further support for a hypothesis which suggests that mentally handicapped children with behaviour disorder may induce or maintain stress in their carers, rather than that stress in the parents causes behaviour abnormality in the child, comes from the other correlates of behaviour disorder in this study. Children with behaviour disorder impose a much greater physical burden of care on their parents. They are harder to manage and to keep safe. They are generally more dependent. They are less likely to be able to communicate, which may be frustrating for them and for their parents. Behaviour disorder tends to be associated more with the child's communication skills than with factors in the social environment. There is no doubt that being stressed may affect one's parenting; however, it seems unlikely that maternal stress constitutes the main explanation for the appearance of behaviour disorder in mentally handicapped children. Most of the parents with behaviourally disturbed children in our study had demonstrated the adequacy of their parenting by the normality of their other children. No firm conclusions on the nature and direction of the causal relationships are possible. However, it seems that with the mentally handicapped child, behaviour problems may arise as much from the nature of the child's impairment and the way in which it is handled as from social and economic factors in the child's environment.

These findings carry important implications for service providers faced with the task of ameliorating the difficulties experienced by parents with behaviourally disordered children. In recent years, important advances have been made in the development of effective methods for setting and attaining educational objectives among children with a wide range of behaviour problems. It has been shown that parents can be taught the skills to implement training of their own children at home (Chazan, 1979; Gath, 1979; Berkowitz & Graziano, 1972). Home teaching techniques for mentally handicapped children have been developed, which aim both to reduce inappropriate behaviour in the child, and to teach the child positive new skills which are incompatible with inappropriate behaviour (Cunningham & Jeffree, 1975; Callias & Carr, 1975; Bidder *et al.* 1975; Shearer & Shearer, 1972; Pugh, 1981). The best known of these packages, which is called the Portage Guide, enables staff with no previous experience or training in precision teaching, after minimal training, to visit parents in their own homes and to teach them how to set and attain educational objectives for their own child (Shearer & Shearer, 1972; Clements *et al.* 1980). Our study showed that very small numbers of parents had been in contact with either the health visitor or the community nurse who might have had access to these techniques (see Table 11).

Intuitively, it seems that involving parents in this way may have an indirect effect on stress by allowing parents to feel effectual and able to influence their own lives in a positive way, as well as acting on stress in a direct way by reducing inappropriate child behaviour (Beck *et al.* 1979). Consideration of methods of involving parents positively in teaching their child seems a more fruitful approach that the search for the parents' role in the genesis of their mentally handicapped child's behaviour disorder.

This study is now to be extended; the families of all the children in the sample will be interviewed a second time, three years after the first interview. It is hoped that longitudinal data will enable us to study further the processes by which mentally handicapped children acquire behaviour problems and their carers becomes stressed.

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Stress and Coping in Families Caring for a Child with Severe Mental Handicap : A Longitudinal Study

Report to the Department of Health

Lyn Quine and Jan Pahl

1989

CONTENTS

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SUMMARY

Chapter 1: Introduction

This project extends our previous work with 200 families caring for a severely mentally handicapped child (Pahl and Quine 1984), forming the second phase of a longitudinal study. The families provide a representative sample of children with severe mental handicap and their carers from two health districts in South East England. The first phase of the study was funded by the South East Thames Regional Health Authority, and by Medway and South East Kent District Health Authorities, and the second phase by the Department of Health. The families were interviewed in 1982 and 1985.

In this second phase we wanted to investigate a number of issues which grew out of findings in our previous work. The study, therefore, had five broad aims. The first was to gain a better understanding of the impact on family functioning of caring for a child with severe mental handicap, by considering changes in child, parent and family characteristics over time. The second was to examine continuities and discontinuities in the behaviour problems exhibited by the children over time, to explore their social and environmental correlates, and to consider how prevalence rates for behaviour problems compare with rates for non-handicapped children and for children with Down's Syndrome. We chose to examine sleep disturbance in detail. The third aim was to study the process of stress and coping in families caring for a child with severe mental handicap. The fourth aim was to examine felt needs, patterns of service use and satisfaction among families. The fifth aim was to focus on the transition to adult life of young people with mental handicap.

During the two phases of the study we have produced a set of longitudinal descriptive data on a very wide range of child and family variables which enables us to examine both

the antecedent risk factors for poor family and child outcomes, and how families cope with the task of bringing up a child with severe mental handicap.

Chapter 2: Methodology and description of the sample

The first phase of the study had two stages which we have called the 'population survey' and the 'sample survey'. The first stage involved assessing 399 children representing the total population of ESN(S) children in the two health districts. The second stage involved interviews with a stratified random sample of the main carers of 100 children from Medway and a matched sample of 100 from South East Kent. Findings from the first phase of the study are to be found in Pahl & Quine (1984) *Families with mentally handicapped children: a study of stress and of service response.*

In the second phase of the study which was funded by the Department of Health, 178 children were reassessed and their carers reinterviewed. The chapter documents the assessment of the subjects, the content of the interview schedule, and the establishment of measurement procedures and reliabilities. The main outcome measures and descriptor variables are listed together with a description of the methods of data analysis. The characteristics of the sample at the second phase (Time 2) of the study are described.

At Time 2, many of the children had acquired new skills. Significantly more children could walk, feed, wash and dress themselves and were continent. Significantly more had good use and understanding of communication. However, over fifty per cent of children were reported by their mothers as difficult to manage and 75% of mothers thought that the child required more attention to keep occupied than did ordinary children.

As reported at Time 1, mothers still carried the main burden of responsibility for care tasks.

Women caring for a child with severe mental handicap were more likely to report that their health was not good or only fairly good than were women of comparable age in the general population. Additionally, a higher proportion of mothers in our sample were suffering from symptoms of psychological distress than were mothers of non-handicapped children. The stressed women in the sample had consulted their doctors significantly more over the previous year than those who were not stressed. Nearly 30% of women in our sample reported consulting their doctor in the 14 days before interview, a figure almost double that found in women of similar age in the general population in the General Household Survey.

The second phase of the study confirmed the considerable financial costs arising from caring for a child with mental handicap which we documented in our first report. The chapter concludes by examining the other stresses in the lives of the families in our sample.

Chapter 3: **Behaviour problems in the sample of children with mental** handicap

The chapter presents the prevalence of behaviour problems in the sample of children at Time 1. There were no sex differences in rates of behaviour with the exception of overactivity: boys were more likely to exhibit overactive behaviour than girls. The children were split into two groups: those with one or more severe behaviour problems and those without problems. Analysis showed that there were a number of significant differences between children with problem behaviour and those with no problems at Time 1. Significantly more children with behaviour disorders were found to be incontinent, to have few self-help skills, to have poor communication skills and to be unable to read, write and count than mentally handicapped children without behaviour disorder. Such children presented their carers with more management problems: they were more difficult to keep occupied and to keep safe. Their dependence on others to perform tasks and their incontinence made extra work for their carers.

When the environmental correlates of behaviour disorders were looked for it was found that there were remarkably few; there was no association between behaviour disorder and family size, birth order, age of parents, social class or income. However, there was a significant association between type of housing and presence of behaviour disorder. Children who lived in council house accommodation were more likely to be disturbed than those who lived in owner-occupied housing. There was also a significant negative association between satisfaction with housing conditions and behaviour disorder. Although most of the parents in both groups were married and living together, the proportion who were not was more than three times as high in the behaviour disordered group. The high rate of behaviour disorder found in one-parent families deserves further consideration, since it could not be accounted for by other significant relationships.

Maternal stress has been found to be associated with behaviour disorder in studies of both mentally handicapped and non-handicapped children. In our study, the mean stress score of mothers with a behaviourally disordered child was significantly higher than the mean score of mothers of children without problems. The chapter concludes with some tentative interpretations of the causal ordering between child behaviour, marital discord and maternal stress.

Chapter 4: Behaviour problems in the sample at Time 2

This chapter presents the prevalence of behaviour problems in our sample of children at Time 2. Behaviour problems showed remarkable similarity in prevalence between Time 1 and Time 2. The only exception to this was overactivity which decreased in prevalence between Time 1 and Time 2. Our analysis showed that there was also continuity in the persistence of behaviour problems; 71% of the sample remained unchanged between Time 1 and Time 2 while 29% of children moved into or out of the behaviour problem group. Discriminant analysis showed that it was possible to predict group membership in 80% of cases from factors concerned with the child's and family's characteristics. It is interesting to note, that when all the factors were controlled, marital discord emerged as a significant predictor of membership of the behaviour problem group, alongside maternal stress and maternal irritability. This is in accord with studies of non-handicapped children, although the causal ordering of these variables has not always been clear. Family income was also a significant factor. In terms of child characteristics, the child's ability to read, write and count, communication skills, continence, mobility, severity of physical impairment and age were all significant factors. Longitudinal analysis of factors predicting change in behaviour over time produced similar results. Child characteristics predicting change in behaviour were academic skills, self help skills, communication skills, mobility and age. Family characteristics were maternal stress, marital discord and family income. It is likely that these factors are causally related to the risk of poor outcome in terms of behaviour disorder. The policy implications of the findings are discussed at the end of the chapter.

Chapter 5: Sleep problems in children with mental handicap

Children with a mental handicap are more likely to present problems of night settling, night waking and sleeping in their parents' bed than are non-handicapped children. This study found that large numbers of children had such problems. Sleep problems were related to age, though significant numbers of young people aged 15 or over still had irregular sleeping patterns. Sleep problems were very strongly associated with maternal stress. A path model showed that communication skills are a key factor and this may reflect the difficulty parents experience in trying to train children with limited communication skills to present more socially appropriate behaviour. The path model also drew attention to the fact that families containing children with irregular sleeping patterns are often families with many other problems of family functioning possibly, though not necessarily, causally associated with the sleep difficulties. This highlights the complex problems for intervention work in families.

The findings carry important implications for service providers who are faced with the task of providing help for parents caring for a child who presents sleeping problems or other challenging behaviour. These are discussed at the end of the chapter.

Chapter 6: Stress and coping in mothers of children with mental handicap

The chapter reports an attempt to assess the outcome of caring for a child with

severe mental handicap, and to test a transactional model of coping. Three measures were used: the Malaise Inventory, to measure symptoms of psychological distress; the Problem Inventory (PINV), to measure the impact on the family of child-related problems; and the Judson Scale, to measure the mother's adjustment to and acceptance of her child. There was considerable overlap between the scales, with mothers who had high Malaise scores tending to have high scores on the PINV and low scores on the Judson Scale. However, correlation between the scales was only moderate, indicating that each was identifying mothers with a specific range of problems.

Results from the analysis of the Malaise Inventory scores suggested that the most important child variables affecting mothers' stress were behaviour problems and the child's age. Coping resource variables predicting Malaise were lower social class, financial worries, negative assessment of coping skills, poor acceptance of and adjustment to the child, and recent maternal ill-health. There was evidence that coping resources were able to mediate the effects of stressful child behaviour on mothers' Malaise scores. An investigation of factors predicting change in Malaise scores between Time 1 and Time 2 showed that recent maternal illness, social class, feelings of loneliness, and the child's age were the most important variables affecting change in stress scores.

Analysis of the Problem Inventory scores showed that here a rather different set of child variables came into play. High scores on the PINV were predicted by the presence of children with severe care taking demands - those who had greater supervisory needs, created extra work for their carers, or were difficult to keep safe. Behaviour problems were again among the child-related predictor variables. The unremitting care demands of such children led to perceived unmet service needs appearing as a further important predictor variable. Coping resource variables which were important were those concerning ability to share the costs of caring - social support, marital satisfaction and reported coping by use of social support networks. Feelings of loneliness were associated with higher scores on the PINV and these seemed to be related to perceived inadequacy of

social support. Whether such feelings are related to actual amount of social support is not clear, however.

Analysis of Judson scores showed that a number of child variables emerged as significant predictors: taking off clothes in inappropriate circumstances, poor understanding of communication, rocking, severe nailbiting, worrying about plans or changes and night waking. In addition, two care tasks were significant predictors: having difficulties doing the shopping because of the child's behaviour and not getting enough sleep. Coping variables which emerged as significant predictors when the other variables had been partialled out were perceived ability to help the child's development, Malaise scores and household income. The chapter concludes with a discussion of the ways families might be helped.

Chapter 7: Contacts with professionals and services

In this chapter we were concerned with a number of issues. We considered the parents' views of the problems their children face, the help received from services and the extent of unmet need.

Parents were asked a series of questions about the problems their children faced. The first question concerned the child's "most serious" problem. The current problems of the children, in order of the frequency with which they were mentioned, were challenging behaviour, poor physical health, communication problems and developmental delay. In the analysis, we examined the extent to which parents had sought help with these problems, and found that help satisfactory. We found that when health and behaviour problems had been mentioned to professionals, parents thought that something had been done to resolve the problem. When communication problems or developmental delay were mentioned as the "most serious" problem, parents were significantly less likely to have consulted a professional and less often thought that something had been done.

Parents were asked about the child's greatest handicap from their own and the child's point of view. The two most frequent answers from the child's point of view were lack of communication skills and lack of freedom. Poor academic skills, poor sight, illness, behaviour problems and lack of awareness of danger were also mentioned. From the parents' point of view, lack of communication skills was cited most often, followed by the extra work involved in caring for the child, and behaviour problems.

When asked about the sorts of help they would like, parents' priorities were for information, a chance to discuss their child's progress regularly, help with teaching new skills, help with developing communication skills, access to an emergency service, help with babysitting and childminding and the opportunity to attend classes or workshops to learn how to help the child. All these were wanted by at least 50% of parents.

In order to determine the characteristics of parents who had high felt need, we produced a Felt Need Scale. We examined the child, family and service contact characteristics associated with high felt need. Multiple regression analysis indicated that the most important child variables predicting high felt need were the child having behaviour problems, being younger in age, and suffering from epilepsy. The most important family characteristics were having had stressful life events in the previous year, perceived inadequate social support, money worries and a large number of family problems relating to the child.

We focussed on three sources of help for parents: the provision of information, access to speech therapy and financial assistance. These were chosen because the analysis suggested they were particularly valued by parents. In Medway, where a Helping Booklet had been provided, parents were significantly less likely to feel they needed information about services. This highlights the importance of providing information, in an accessible form and regularly updated, for parents. Parents listed lack of communication skills among the 'most serious' difficulties facing their children. In earlier chapters, we have shown that children with behaviour problems often had poor use and understanding of communication. In Chapter 5, communication skills played a central role in the model predicting sleep problems. When we asked parents about the speech therapy received by their children, we discovered a large amount of unmet demand. About half the children had seen a speech therapist in the previous year and another 17% of parents would have liked their child to have seen one. Two thirds of parents were dissatisfied with the amount of therapy their child received. The national crisis in speech therapy is discussed in some detail.

Money plays a crucial role in enabling families to care for a child with a mental handicap. We discuss the financial help parents were getting to compensate them for the costs involved in caring for a child with mental handicap. Over half the parents in the sample were worried about money.

Finally, the chapter discusses the new plans for child health services, making a plea that the special needs of children with mental handicap should not be forgotten in any restructuring toward a more generic service.

Chapter 8: The transition to adult life

The chapter examines the transition to adult life of the young adults in our sample. The skills of the 71 young people showed considerable improvement between Time 1 and Time 2. The young adults were less stressful for their parents than the younger children, requiring less help with basic tasks. Their mothers reported less demands on their time and energy than did mothers of the younger children. They were easier to keep safe and occupied and could be left unsupervised for longer. Their mothers were more likely to report that they were easier to manage than were the mothers of the younger children. They were significantly less likely to have behaviour problems. In comparison with non-handicapped young adults, they were still much more dependent on help with personal care and mobility, and many still required supervision because of behaviour problems.

Parents' felt needs for additional service provision fell into three categories: information needs, help with the development of communication and other skills, and practical help. As our earlier study showed, the greatest need was for information. Parents wanted advice and information about a range of issues, from advice about the child's progress and specific impairments, to information about the services and help available. Help with teaching communication and other basic skills was an important priority. Parents pinpointed lack of communication skills as one of the young adults' greatest handicaps both from their own and the parents' point of view. We have discussed what might be done to help in earlier chapters.

At Time 1, parents had been asked what they perceived as their greatest worry or problem with their son or daughter. By far the greatest concern was lack of communication skills, followed by concern about the future. While parents were generally satisfied with the preparation for leaving which schools had given to their children, only 30% felt they had been given enough information and choice about opportunities available for their son or daughter.

Most young adults who had left school attended a Social Education Centre. None were in open employment, although about half had been given work experience while attending the SEC. Over half the parents would have liked their son or daughter to find a job, but there was a substantial lack of advice on careers or educational courses.

The majority of parents were realistic about their children's chances of independent living. Living at home was seen to be the best option, followed by living in sheltered accommodation. Over 50% of parents reported that they might have to ask for longer term care at some time in the future.

Chapter 9: Recommendations for services

The report concludes with recommendations for future service provision.

INTRODUCTION

This project extends our previous work with 200 families caring for a severely mentally handicapped child (Pahl and Quine 1984), forming the second phase of a longitudinal study. The families provide a representative sample of children with severe mental handicap and their carers from two health districts in South East England. The first phase of the study was funded by the South East Thames Regional Health Authority, and by Medway and South East Kent District Health Authorities, and the second phase by the Department of Health. The families were interviewed in 1982 and 1985.

The first phase of the study was carried out from April 1981 - August 1984 and achieved a 95% response rate. At the beginning of the present study in January 1985 there were 178 families in the sample. Attrition was entirely due to deaths and families moving out of the area. A close relationship of trust and co-operation has been developed over the years between the research team and families in the sample.

Aims of the Study

In phase two of the study we wanted to investigate a number of issues which grew out of findings in our previous work. The study, therefore, had five broad aims. The first was to gain a better understanding of the impact on family functioning of caring for a child with severe mental handicap, by considering changes in child, parent and family characteristics over time. The second was to examine continuities and discontinuities in the behaviour problems exhibited by the children over time, to explore their social and environmental correlates, and to consider how prevalence rates for behaviour problems compare with rates for non-handicapped children and for children with Down's Syndrome. We chose to examine sleep disturbance in depth. The third aim was to study the process of stress and coping in families caring for a child with severe mental handicap in order to address certain questions: which mothers cope with and adapt to caring for a handicapped child and which become stressed? what factors are related to maternal well being? are there certain coping resources which women draw on in order to mediate or buffer the effects of stress? why are children with behaviour disorder particularly stressful? The fourth aim was to examine patterns of service use and satisfaction among families. The fifth aim was to focus on the transition to adult life of young people with mental handicap: what are the skills and abilities of the young people? what help do parents feel they need? what kind of living environment and day care arrangements do parents favour for their son or daughter?

In choosing these aims, we are conscious of focussing quite specifically on particular issues. These were decided upon during discussions with the Department of Health and grew out of the findings from Phase 1 of the study which generated specific hypotheses which required to be tested using longitudinal data. However, the data set offers a great deal of potential for further analysis.

The Longitudinal Data Set

During the two phases of the study we have produced a set of longitudinal descriptive data on a very wide range of child and family variables which can be used by practitioners and policy makers as a basis to predict the future needs of children and their families. The data base allows comparisons with other studies to be made and further hypotheses for testing in future research to be generated. There are very few longitudinal studies of families caring for a child with severe mental handicap although there have been a number of cross sectional studies (Phillips and Smith 1976; McCormack 1978; Wilkin 1979; Burden 1980; Ayer 1984; Chetwynd 1985). Longitudinal data are important because they enable the researcher to consider continuities and discontinuities in behaviour and to examine the antecedent risk factors for poor family and child outcomes, such as maternal stress, poor adjustment to the child, poor family functioning, or child behaviour problems.

Issues Arising from the Previous Study

The findings from the first phase of the study suggested a number of questions for further study. Significant numbers of children were found to exhibit severe problem behaviour. The prevalence of behaviour problems was much greater than that reported in studies of non-handicapped children (Rutter 1970). In phase 2 of the study, we wanted to compare prevalence rates in our sample with a sample of non-handicapped children and with a sample of Down's Syndrome children (Cunningham et al 1986). We also wanted to examine the social and environmental correlates of behaviour problems in children with severe mental handicap to discover whether they were similar to those reported for non-handicapped samples. A finding of particular interest in the first phase of the study was the association between maternal stress and children's sleeping problems. About 50% of mentally handicapped children have severe sleeping problems. We decided to examine the nature and correlates of sleeping problems in more detail in the second phase of the study.

A further finding from the first phase of the study was that maternal stress levels as measured by the Malaise Inventory (Rutter 1970) were very much higher than those found in studies of mothers with non-handicapped children. Caring for a behaviourally disordered child was particularly stressful and was exacerbated by the presence of social adversity. A multivariate regression analysis showed that maternal stress was predicted by behaviour problems in the child, night waking problems, perceived social isolation of the mother, family adversity, multiplicity of the child's impairments, night settling problems, the child's ill-health, problems with the child's appearance, and financial worries. These variables explained 37% of the variance in stress scores. The findings raised a number of questions: how persistent is the experience of stress? which factors identified in the regression analysis are likely to be causally related to stress? does caring for a behaviourally disordered child cause mothers to be stressed or do stressed mothers cause disorder in the child? why are some families able to cope with caring for a child with severe handicap while others become stressed? are there "protective" factors which help mothers to cope with the difficulties of caring for a child with severe handicap? These questions will be examined in the second phase of the study.

When phase two was being planned, discussions with the Department of Health indicated that it would be of interest to look closely at those children who were leaving school and making the transition to adult life. At this point, there were 71 young people aged between 15 and 21 in our sample. We, therefore, decided to include the group of young adults as one of the focusses of our research. We saw it as important to make an assessment of the skills and abilities which the young people had acquired, the patterns of day-care facilities provided for them, the vocational advice and skills training they received, and their parents' views about future living arrangements.

Finally, we focussed on the families' patterns of service use and parents' satisfaction with services. We used a problem-centred approach to investigate the areas in which parents felt they needed help or more help and we investigated the child and family characteristics of families with high peceived unmet service need.

The Study in Context

The study took place at a time when policy emphasis was on the desirability of care in the community for people with mental handicap. A number of government reports had advocated this principle and had set out recommendations for its implementation (Department of Health and Social Security 1971, 1979, 1980, 1981a and 1981b). A range of policy initiatives had aimed to move mentally handicapped people who were living in hospitals into housing in the community and to prevent new admissions to hospitals. As far as children were concerned, the aim was to provide whatever support was necessary for them to remain with their own families and to prevent admissions to long term care wherever possible. It was stressed that the reduction in the number of places in hospitals would imply the development of comprehensive and flexible forms of community support, provided ideally by a partnership between health, education and social services.

At the local level there had been a number of planning documents which advocated inter-agency collaboration in order to provide a locally-based service for people with mental handicap (Kent Area Health Authority and Kent County Council 1981; Medway Health Authority 1983). Here the service for children was seen in terms of five different components: family support, assessment and care centres, education, social services alternatives to family care, and long term care. The overall aim was "to ensure that all mentally handicapped persons and their parents or relatives receive the responsive and integrated service to which they are entitled" (Kent Area Health Authority and Kent County Council 1981: 6). Following the Jay Report it was recommended that mentally handicapped children should be able to live with, or as, a family.

However, there were considerable anxieties about the implementation of these policies among professionals involved in providing services for people with mental handicap. "Community care" might seem attractive in theory, but what would it mean in practice? There were at least three responses as we have noted in our earlier work (Pahl and Quine 1984). First, there were those who saw the issue primarily in terms of the services and who noted that the reduction in the number of places for children in hospitals had not been balanced by an increase in other services (Department of Health and Social Security 1980: 18). The development of community services implied a high degree of co-operation between health, education, and social services, and this in itself posed problems. Transferring people from health services to social services care, involved complicated transfers of financial resources (Department of Health and Social Security 1981b). In addition the new patterns of care meant the development of structures for joint planning and joint working between health, education and social services (Ferlie, Pahl and Quine 1984).

The second response was to see the issue primarily from the point of view of the families, and to point to the evidence that families already carried a heavy burden and that changes in service provision might exacerbate rather than ease their problems. Numerous research studies have described the impact on family life of caring for a mentally handicapped child (Carr 1976; Gath 1978; Wilkin 1979; Glendinning 1983; Chetwynd 1985;

Quine and Pahl 1985). Many of these studies have documented the problems which parents face in their dealings with the services set up to help them. Wilkin, for example, found that the structure of the services was itself a source of problems: parents reported that there was often a marked lack of co-ordination between services and between different sections of the same service (Wilkin 1979: 168).

The third response was to see the issue in terms of those who did the work of caring. From this point of view the move to "community care" was a euphemism for increasing the burden of unpaid work carried by women. Feminists argued that women's role as unpaid carers reflected powerful material and ideological forces whose interests were represented in the introduction of a pattern of services which purported to increase welfare but which actually reduced State expenditure by transferring costs from welfare services to women. It was suggested that using the term "the family" was a way of concealing the fact that it is upon women that the main burdens of care fall. A number of research studies have documented the high price women pay, in terms of time, money and effort, for the fact that they carry the main task of caring (Baldwin 1981; Baldwin and Glendinning 1983; Buckle 1984; Equal Opportunities Commission 1982; Finch and Groves 1983; Piachaud, Bradshaw and Weale 1981; Ungerson 1983; Wilkin 1979).

Evidence to the House of Commons Social Services Committee on community care from the Social Policy Research Unit at the University of York argued "The community care of young mentally handicapped and multiply impaired young adults involves arduous and unremitting physical work and watchfulness similar to the care and supervision needed by a young child but extending over a lifetime and becoming increasingly onerous as both parents and the young person grow older. Despite this growing burden, there is no evidence of any involvement by the wider community - friends, neighbours, volunteers or even extended family members - in providing any of the care which is needed from day-to-day. Instead the burden of care falls largely on the young person's mother and results in marked financial, physical and emotional costs" (HMSO 1985: xxxvii).

Format of the Report

The report is organized into nine chapters including this introduction. The second chapter describes the methodology of the study and provides a description of the sample. The third and fourth chapters deal with the prevalence of behaviour problems at Time 1 and Time 2, and their social correlates. Comparisons are made with children with Down's Syndrome and non-handicapped children. The fifth chapter considers sleep disturbance which is a particularly widespread form of challenging behaviour among children with mental handicap. The sixth chapter contains an examination of stress and coping patterns in the families, considering factors which may protect women from the adverse effects of stress. Chapter seven examines patterns of service use and satisfaction. Chapter eight concerns the transition to adult life. The report concludes with recommendations for service provision in chapter nine.

Note: 1) The world of mental handicap is something of a terminological minefield, with new euphemisms continuously being introduced as replacements for terms which have become stigmatising. To keep this report consistent with the report on the first phase of the study we have used the term "mental handicap" rather than "severe learning difficulty" since this is the term which was favoured by mothers in our sample.

2) The interviews were carried out with the young person's 'main carer' who was defined as the person who took the heaviest burden of care in terms of time and work. We have referred to the carers as 'mothers' throughout the report. In reality one main carer was the child's grandmother. For the 12 children who were living in full-time residential care family data and data on mothers' views is missing. Some of the analysis therefore excludes these children and is based on 166 cases.

METHODOLOGY AND DESCRIPTION OF THE SAMPLE

Design of the Study

The study builds on and extends our earlier study of 200 families caring for a child with severe mental handicap (Pahl & Quine 1984), forming the second phase of a longitudinal study. The first phase of the study was funded by South East Thames Regional Health Authority, Medway District Health Authority and South East Kent District Health Authority, and it had three aims. The first was to assess the difficulties of families caring for a child with severe mental handicap. The second was to evaluate the effectiveness of the package of services provided for families in terms of relieving the stresses experienced by those who were responsible for the day-to-day care of the children. The third was to make recommendations for future services on the basis of the needs of the children and of those who care for them.

The initiative for the study came from Medway District Health Authority which was concerned about providing more help, and more appropriate help, for families caring for a child with severe mental handicap. At an early stage the study was extended into the South East Kent District Health Authority. Both health districts are situated in Kent: Medway is predominantly urban and includes the towns of Chatham, Gillingham, Rochester, Sheerness, Sittingbourne and Strood, while South East Kent is more rural, though it includes Ashford, Dover, Folkestone and Hythe. The first phase of the study was carried out from 1981 to 1984, and the second phase from 1985 to 1988.

The First Phase of the Study

The Population Survey

At the first phase 399 children aged 0 - 16 from the two health districts were assessed using the Disability Assessment Schedule (Holmes, Shah & Wing 1982). This represented the total population of children with severe mental handicap in the two districts, 238 in Medway and 161 in South East Kent. The aim was to build a comprehensive data base for the main part of the study and for planning purposes at the local level. In addition, the population survey provided an opportunity to make comparisons between this and other studies about the prevalence of impairment. The assessments were carried out by the research team in schools, child care and assessment centres, and social education centres and information about the child's skills and abilities was collected from the teacher or care assistant who knew each child best.

The Sample Survey

A stratified random sample of 100 children with proportional allocation for age and sex, was selected from the Medway population and was matched with 100 children from the South East Kent population. The two samples were precision matched for impairment variables, frequency matched for socio-economic variables, and band-matched for age. With precision matching, for each case in the experimental group, another one with identical characteristics is selected for the control group. Frequency matching on the other hand, requires that both control and experimental groups are made similar for relevant variables separately rather than in combination. Instead of one to one matching the two groups are matched on central characteristics so that they have the same proportion of cases with a given characteristic. Band matching requires that for each case in the experimental group, another is selected from the same age band for the control group. The impairment matching concerned continence, mobility, communication skills, self help skills, and behaviour. Criteria for categorisation were drawn from the Disability Assessment Schedule (Holmes, Shah & Wing 1982). Matching enabled us to hold certain variables constant so that we could properly compare the outcome of different packages of services in the two health districts.

The Interviews

The main carer in each of the 200 families was interviewed by a trained interviewer, using a structured questionnaire which took an average of one and a half hours to complete. The main carer was the mother in all but four instances. The questionnaire covered the following areas:-

a) background information about the household and household members: household composition; housing tenure and condition; transport patterns; ownership of consumer durables; age, sex and marital status of each member of the household; employment patterns; income; division of labour within the household.

b) information about the child him or herself: impairments and diagnoses; patterns of daily care; problems in caring; special adaptations made to the house, or equipment obtained for the benefit of the child; household members' responsibility for particular forms of care required by the child; extent to which care was provided by relatives, friends and neighbours.

c) information about the chief carer: felt needs for further help; restrictions imposed by the needs of the child; social and marital relationships; feelings about the way the news of the impairment was first communicated; evidence of stress.

d) information about the family's use of services: social security benefits; use of the Family Fund; health services; social services; voluntary services; education services; sources of short term care; degree of satisfaction with each service used; needs for further support; preferences for future service development.

The Findings

Findings from the first phase of the study are to be found in a report entitled "*Families with severely mentally handicapped children: a study of stress and of service response*". (Pahl & Quine 1984) and in numerous papers in journals (Quine & Pahl 1985; Quine & Pahl 1986a and b; Quine 1986; Pahl & Quine 1987; Bebbington & Quine 1987; Quine & Pahl 1987; Quine 1988).

The Second Phase of the Study

The Sample

For the second phase of the study, which was funded by the Department of Health, 178 children were reassessed and, their main carers were re-interviewed. In all but thirteen cases, the main carer was the child's mother. Twelve children were in residential care and one child was cared for by his grandmother. Of the original 200, six children had died, ten families had moved out of the health district, and six families could not be traced. (See Table 2.1).

Table 2.1 Design of the Study

	Time 1		Time 2	
	Assessments of total population of ESN(s) children	Interviews with stratified random sample	Assessments of sample	Interviews with sample
Medway	238	100	93	93
South East Kent	161	100	85	85
Total	399	200	178	178

Assessing the Subjects

The assessments were carried out as before in schools and social education centres. Each school or centre named a teacher who knew each child well. Information was collected from the named person about the child's mobility, continence, self help skills, communication skills, academic skills, sensory impairments, behaviour problems, epilepsy and other physical conditions. Teachers also supplied information on the help each child required with basic care tasks, how difficult the child was to manage and to keep occupied and safe, and on the severity of the child's physical and mental impairment.

The Interviews

The interviews were carried out with the children's mothers by trained interviewers using a structured questionnaire. The interviews included measures of demographic and socio-economic factors, child functioning and behaviour, family environment and relationships, social support, ways of coping, maternal and paternal health, adjustment to and acceptance of the child, life events, maternal stress, the impact of the child on the family, marital satisfaction, felt needs, and the family's use of and satisfaction with services. The choice of information to be collected was informed by the aims of the study, our review of the literature, and our previous work with the families. Where possible, we used standard measures of variables such as family impact and marital satisfaction since these are measures of known reliability and validity which allowed us to make comparisons with other studies. We also used open-ended questions which allowed individuals to express their own views and to indicate what they felt were important issues and concerns. All the information was collected by interviewing the parent, with the exception of information about stress and acceptance of and adjustment to the child. For these, parents filled in the Malaise Inventory and the Judson Self-Rating Scale at the end of the interview.

Establishing Measurement Procedures and Reliabilities

We ensured that the interviews were carried out in a standardised manner by training the interviewers, using role play, and audio-taping the interviews so that we could examine the quality of the data on the interview schedules. Marital satisfaction ratings were made from the audio-tapes by three "judges" who rated each marriage from the audio-tape material. Great care was taken in the selection of appropriate measures and instruments for the study, and checks were made on the reliability and validity of them all. The reliability of each measure was checked by asking 20 informants to complete it twice in a three week period. Scales were computed and checked for internal consistency using Cronbach's alpha. (Cronbach 1970) (See Appendix 1). Further details about the design of the questionnaire, the training of the interviewers, the coding of responses, and the reliability and validity checks can be obtained from the research team.

Selection of Outcome Measures and Descriptor Variables

The selection of outcome measures for the analysis was informed by our earlier work and by a review of the literature. Table 2.2 provides a list of the main descriptor variables and outcome measures used for the study. Much of our analysis was concerned with examining the factors which were associated with poor outcome, in terms of behaviour problems for the children, or stress or poor adjustment to the child for the parents. Accordingly, variables may sometimes be defined as descriptor or outcome variables depending upon the specific analysis being carried out.

Table 2.2 Outcome and descriptor variables used in the study

Outcome Measures	
Child related outcome measures	
The Behaviour Screening Questionnaire (Richman et al 1982)	(See Appendix 1)
The Behaviour Problem Index (Cunningham et al 1986)	(See Appendix 1)
The Disability Assessment Schedule (Holmes, Shah & Wing 1980)	(See Appendix 1)
Family related outcome measures	
The Problem Inventory (Tavormina et al 1981)	(See Appendix 1)
The Judson Scale (Judson & Burden 1980)	(See Appendix 1)
The Malaise Inventory (Rutter et al 1970)	(See Appendix 1)
Descriptor Variables	
Child Variables	
Age	
Sex	
Birth Order	
Health	
Appearance	
Severity of Physical Impairment	
Severity of Mental Impairment	
Multiple Impairment Score	(See Appendix 1)
Academic Skill Score	(See Appendix 1)
Communication Skills	
Self-help skills	
Mobility	
Continence	

Table 2.2 Outcome and descriptor variables used in the study (continued)

<u>Child Variables</u> (continued)	
Behaviour Problems	(See Appendix 1)
Sleep Problem Index	(See Appendix 1)
Quality of social interaction	
Stereotypies	
Epilepsy	
Dependency	
Diagnosis	
<u>Family</u>	
Social class	
Mother's age	
Father's age	
Father's employment/unemployment	
Mother's employment/unemployment	
Home ownership	
Housing adequacy	
Household composition	
Natural/foster/adoptive family	
Family size	
Measure of Daily Coping	(See Appendix 1)
Life Events Score	(See Appendix 1)
Marital Relationship Score	(See Appendix 1)
Availability of Social Support	(See Appendix 1)
Adequacy of Social Support	
Income	
Financial Worries	
Assessment of Coping	
Self esteem	
Self efficacy	
Illness of parent in last year	
Hospitalisation of parent in last year	
Stress Score (Malaise Inventory)	(See Appendix 1)
Acceptance of and adjustment to child (Judson Score)	(See Appendix 1)
Impact of child on family (PINV Score)	(See Appendix 1)
Supervision needs of child	
Extra work score	
Attention to keep occupied	
Attention to keep safe	
Management difficulties	
Use of services	
Satisfaction with services	
Unmet service need score	(See Appendix 1)

Data Analysis

The information collected from the assessments and interviews were analysed by means of the Statistical Package for Social Sciences (SPSSX 3rd Edition 1988). After the data had been examined for reliability and validity, indices of the main measures were created (see Appendix 1).

Relationships between a descriptor variable and an outcome measure were examined in three steps: (1) Univariate analysis - correlation, one way analysis of variance or univariate regression. This gave us a set of descriptor variables which were significantly associated with the dependent variable for use in later multivariate analysis. (2) Bivariate analysis, which was used to examine the relationship between two descriptor variables and a dependent variable. This involved bivariate regression or first order partial correlation, and was used when two variables were confounded in order to decide which to use in the later multivariate analysis. (3) Multivariate analysis: multiple regression analysis was used to examine the relationships between sets of predictor variables and the outcome measure, while taking account of the relationships between the predictor variables.

Where tables demonstrate statistically significant findings we have noted the level of significance by one ($p<0.05$), two ($p<0.01$) or three stars ($p<0.001$). By convention, significance begins at the 0.05 level of probability, that is to say, the relationship would occur by chance only five times out of one hundred, and extends to the 0.001 level where the relationship would occur by chance only one time in a thousand.

Characteristics of the Sample at Time 2

As at Time 1, there were no significant differences between the two health districts in terms of the characteristics of the children. The children will therefore be treated as one sample numbering 178 children, 109 of whom were boys and 69 girls. The greater proportion of boys reflects the fact that the sample was stratified with proportional allocation for sex, since there are more boys than girls with a mental handicap. Table 2.3 shows the numbers of children in each age group.

Table 2.3 Numbers of children in each age group

Age Group	Percentage of children (Numbers in brackets)
4 - 10	30 (54)
11 - 15	30 (54)
16 +	40 (70)
	100 (178)

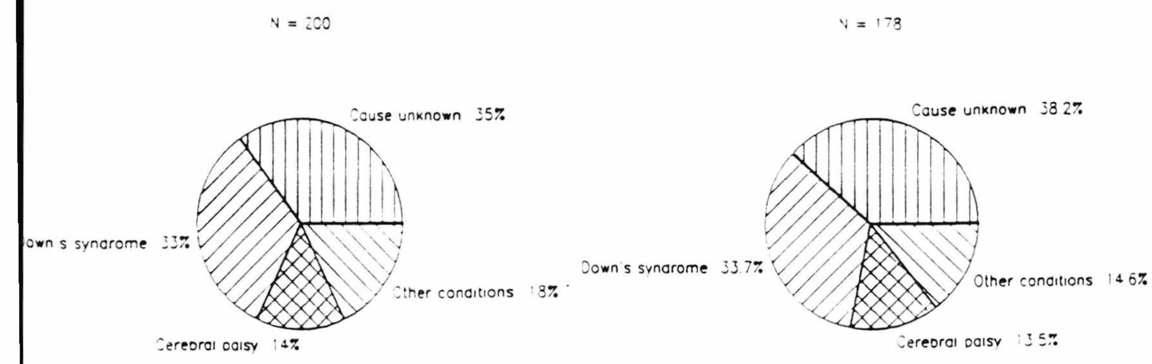
A particularly neglected age group is that which contains those children who are nearing adulthood. It is for these children that community services must now be planned if they are to "have the right to enjoy normal patterns of life within the community", the first principle of the Jay Report (DHSS 1979: 35). Chapter 7 in our report deals with the transition to adulthood and considers the needs of young adults and the concerns of their parents.

Diagnostic Category of the Children

Table 2.4 shows the main diagnostic categories of children in the sample at Time 1 and Time 2. The percentage of children with a diagnosis of Down's Syndrome and Cerebral

Table 2.4 Diagnostic category of children in the sample at Time 1 and Time 2

Time 1 Time 2



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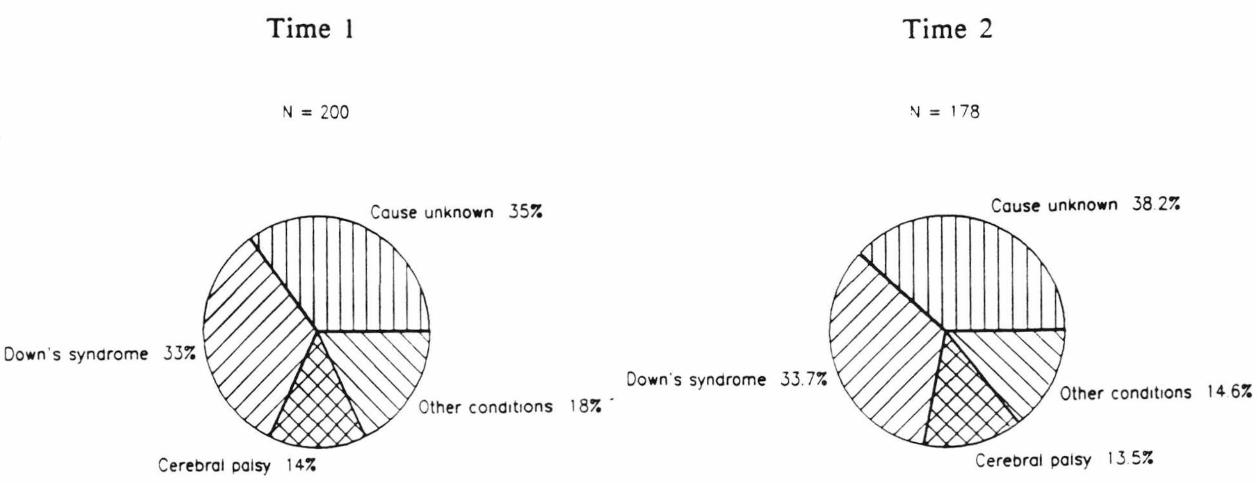

Palsy remained similar, while the percentage of children with other conditions of aetiological significance decreased by 3% and the percentage with non-specific mental handicap increased by 3%.

More than one third of the children had non-specific mental handicap, which means that the cause of their handicap was unknown. This is similar to the figure given by Laxova et al 1977, which was 37%. About one third of the children were suffering from Down's Syndrome. This is similar to the figure of 30% given for the general population of ESN(s) children (Office of Health Economics 1973) and to that given by Bundey (1980).

Disabilities of the Children

Table 2.5 presents the disabilities of the children. It shows that a large proportion were quite seriously impaired. At Time 1, one third of the children were unable to walk, two thirds were unable to wash and dress themselves, over one third were unable to feed themselves, half had poor use and understanding of communication, a fifth were blind or partially sighted, almost a third suffered from epilepsy, over a third were incontinent, and over half suffered from one or more severe behaviour problems.

We used the McNemar Test to examine differences in the changes in proportions of children showing each disability. At Time 2, many of the children had acquired new skills as Table 2.5 shows. Significantly more children could walk, feed, wash and dress themselves, and were continent. There were also significant differences in the acquisition of communication skills. The number of blind, partially sighted, deaf and epileptic children remained almost constant, as would be expected. There were no significant changes in the rates of behaviour problems.

Table 2.5 Disabilities of children in the sample at Time 1 and Time 2

	Time 1	Time 2	McNemar Test
Unable to walk by themselves	32 (57)	26 (47)	*
Unable to feed themselves without help	44 (78)	32 (57)	***
Unable to wash themselves without help	67 (120)	54 (96)	***
Unable to dress themselves without help	65 (116)	50 (89)	***
Poor use of communication	57 (101)	42 (75)	***
Poor understanding of communication	56 (99)	36 (64)	***
Blind or partially sighted	17 (30)	18 (33)	N/S
Deaf or almost deaf	12 (21)	11 (20)	N/S
Severe behaviour problems	61 (109)	61 (107)	N/S
Epilepsy (including controlled epilepsy)	26 (46)	25 (44)	N/S
Wets at least twice a week during the day	43 (77)	30 (53)	***
Wets at least twice a week during the night	44 (82)	32 (56)	***
Soils at least twice a week during the day	34 (61)	22 (39)	***
Soils at least twice a week during the night	35 (62)	26 (45)	*

N = 178

Child Management

Over half the children at Time 2 were reported by their mothers as being difficult to manage. Thirty seven per cent (66) were rated as difficult and 15% (26) as very difficult. Seventy five per cent (132) of mothers thought that the child required more attention to keep occupied than ordinary children of the same age and 84% required more attention to keep safe. About half (47%) could not be left unsupervised for more than fifteen minutes, a quarter (25%) could be left for at most an hour and only 28% could be left for more than one hour. Almost 3/4 of mothers (73%) reported difficulties when out with their sons and daughters. The problems included difficulties in manoeuvring clumsy wheelchairs, having to be constantly vigilant in case the child strayed, the child refusing to walk and aggressive or inappropriate social behaviour.

Fourteen per cent of mothers and 14% of fathers reported being irritable with their children at least every day. A quarter of mothers were sometimes or often afraid of losing self- control. Forty nine per cent of mothers reported using physical punishment at least once a week, while 35% of fathers were said by the mothers to smack their children at least once a week.

Educational Placement of the Children in the Sample

The day placement of children in the sample at Time 1 and Time 2 is shown in Table 2.6. The vast majority of the sample attended a special day school for children with severe learning difficulties. The main differences between Time 1 and Time 2 were that the children attending special playgroups had mostly started school by Time 2, and that some of the older children had left school and had started to attend a Social Education Centre.

Table 2.6 Educational placement of children in sample

	Numbers of children	
	Time 1	Time 2
Ordinary day school	0	2
Special day school	145	127
Residential/boarding school	16	14
Social Education Centre	4	22
Child care and development centre/playgroup	33	2
Other/residential hostel/Home Farm Trust etc.	0	5
At home	2	6
	200	178

Who Helps with the Work of Caring?

A number of studies have shown that it is normally the mother who does most of the work of caring for a child with severe mental or physical handicap (Bayley 1973; Hewett 1970; Wilkin 1979; Younghusband et al 1970; Carey 1982; Glendinning 1983). In our previous work (Pahl & Quine 1984), we found the same. Respondents were asked whether their partners helped with childcare 'every day', 'most days', 'once or twice a week', 'less often' or 'never'. In all cases where the question was appropriate, the respondent was a woman living with her husband. The numbers of fathers who helped every day was very small:

32% helped with lifting and carrying, 18% with feeding the child, 13% with changing nappies, 12% with toiletting, 11% with getting up in the night, 10% with washing and dressing the child. Unemployed fathers were more likely to help with all childcare tasks. Having established that husbands were unlikely to bear a large part of the burden of childcare, we considered whether they were doing more of the routine work of the household. They were not: 36% never washed up, 38% never shopped, 50% never did cleaning, 61% never did cooking, and 84% never washed clothes.

At Time 2, the pattern was very similar, with 70% of mothers doing all or most of the household tasks, and 64% doing all or most of the childcare tasks. The most likely task for husbands to share was child-minding. While 36% of wives did all or most of the child-minding, 59% said that it was shared by their husbands and 5% said their husbands did most of it.

Family Environment

The vast majority of children (71%) were living with their natural mother and father, as at Time 1. Single parents made up 13% of the total at Time 1, and 15% at Time 2 and they were all mothers living with their children. This figure is only marginally higher than in the population as a whole, which has been estimated at 12.1% of all families with dependent children (O.P.C.S. General Household Survey 1983). Sixty two per cent of lone parents lived alone with their children, a figure which is slightly lower than the General Household Survey figure for lone mothers living alone with their children which was 77% (O. P. C. S. General Household Survey 1983). Two per cent of children were fostered or adopted, 6% of children lived with their natural mother and step-father; one child lived with his grandmother; and twelve (6%) lived in hostels or residential homes. In 44% of cases the child was the youngest in the family, and this was rather different from Time 1 when 59% of children were the youngest child. While at Time 1, 18% of children were the only child in the family, at Time 2 just 5% of children were the only child.

Our measure of social class used the Register General's classification of occupations (Registrar General Classification of Occupations 1985) but we collapsed them into four groups. The classifications were thus 1) Professional/Managerial, 2) Intermediate non-manual, 3) Skilled manual, 4) Semi and unskilled manual. The social class distribution of the sample was as follows: Professional/Managerial 15%, Intermediate Non-Manual 19%, Skilled manual 45%, Semi and unskilled manual 21%.

Employment Patterns

The employment pattern in the households differed from that which might have been expected in a sample of families with growing children. These differences mainly affected the mothers of the children of whom only 5% were in full time employment and 21% in part time employment at Time 1. This was at a time when 59% of married women aged 25 - 44 were in paid employment and 69% of those aged 45 - 54 (Central Statistical Office 1983: 58). The majority of women in the sample were in their thirties or early forties, so 26% represents a very low employment rate. Of mothers who were not in employment, most said that they would have liked paid work and, of those, 83% said that they were prevented from taking a job by their responsibility for the handicapped child. At Time 2, slightly more women (9%) were in full time employment and 23% were in part time employment. Similar findings have been reported by Bradshaw (1980), Cooke (1982) and Baldwin (1985).

As far as fathers were concerned at Time 1, 82% were in full time employment, and 13% were unemployed. The remainder were retired or disabled. At Time 2, 76% of fathers were in full-time employment and 13% were unemployed. This was at a time when the unemployment rate for the United Kingdom was also 13%. The families in our sample were, therefore, little different from the general population in terms of male employment patterns.

Housing and Lifestyle

As to housing and life style, the sample was different in small but important ways from families in the general population. Figures for Britain as a whole show that in households where the head is aged 30 - 44, 67% own their own homes, 24% rent from the local authority and 8% rent privately; at Time 1, in our sample 63% owned their own home, 30% rented from the local authority and 8% rented privately (Central Statistical Office 1983: 122). At Time 2 slightly more parents owned their own home. These figures suggest a tendency for our families to be rather poorer than average. The same tendency appears in the ownership of certain consumer durables: at Time 1, 72% of our sample owned a car and 67% had central heating, both of which are lower than national figures for households with children. However, the families in the sample had higher than average rates of ownership for washing machines (96%); tumble driers (51%) and telephones (89%). All these figures are above the average for British households with children (Central Statistical Office 1983: 93). One part of the explanation seems to be that families are forced to economise in some areas in order to be able to afford things such as washing machines and tumble driers which are near-necessities in caring for very dependent children. Another reason for the higher than average ownership of washing machines and tumble driers is that these are the items most often provided by the Family Fund from which 44% of the families had received help. This represents about 59% of those who fulfilled the eligibility criteria (Lawton & Quine, in press).

Health of Mothers and Fathers in the Study

At Time 2, mothers were asked to rate their own and their husband's health on a three point scale: good, fairly good, not good. Twenty two per cent of mothers reported that their health was not good, 35% that it was fairly good and 43% that their health was good. This compares unfavourably with women of comparable age group from the general population in the General Household Survey. Only 11% of these women rated their health as not good, 24% as fairly good and 65% as good (O.P.C.S. General Household Survey 1985).

The health of fathers as reported by their wives was rather better, with 55% of mothers reporting that their husband's health was good, 32% that it was fairly good and only 13% that it was not good. Mothers were more likely to take medication in the form of tranquillizers and sleeping pills than fathers; 9% of mothers reported taking tranquillizers and 6% sleeping pills. Only 2% of husbands took tranquillizers and 2% sleeping pills.

A higher proportion of mothers in our sample were suffering from symptoms of psychological distress than were mothers of non-handicapped children. Fifty four per cent of mothers in the sample at Time 1 and 51% at Time 2 had a score of 6 or more on the Malaise Inventory (the cut-off point indentified by Rutter et al (1970) as indicating psychological distress) compared with 20% of mothers in the control group of Richman et al's 1982 general population sample of mothers of young children. The mean Malaise (stress) score for the 166 mothers caring at home for a child was 6.01 at Time 1 and at Time 2 it was 6.06. Studies of mothers of young children in the general population have found much lower mean scores (Rutter et al 1970). The stressed women in our sample had consulted their family doctors more than twice as many times over the previous year as those who were not stresed. Mean number of consultations in the stressed women was 4.1 as opposed to 1.8 among the unstressed women. Twenty seven per cent of women reported consulting their doctor in the 14 days before interview, a figure almost double that found for women of similar age in the general population in the General Household Survey which was 15% (O.P.C.S. General Household Survey 1985). Additionally, stressed women were significantly more likely to have consulted their doctor in the 14 days before interview and to view their health as not good. These results suggest that women caring for a severely mentally handicapped child have a poorer view of their health, are more likely to be stressed, and consult their doctors more frequently than do women of the same age in the general population. These are important findings; either the health of women caring for a handicapped child is objectively poorer than that of women in the general population, or they tend to be more pessimistic about it. There is some research evidence which suggests that depressed people may make negative assessments of themselves (Coyne & Gotlib 1983;

Williams 1984; Teasdale 1983). However, health pessimism itself has been found to be related to mortality and morbidity in a recent longitudinal study by Kasl (1989).

The Expense of Caring for a Child with Severe Handicap

Research has shown that there are considerable financial costs arising from caring for a mentally handicapped young person (Buckle 1984; Baldwin 1985). These are threefold; loss of earnings for the individual, loss of earnings for the carer and higher living costs. According to evidence by the Disablement Income Group given to the House of Commons Social Services Committee on Community Care, an average family with a mentally handicapped member may lose about £32 per week or £1,664 per annum in earnings, and might add 8% to their weekly household expenditure. In addition, during the mentally handicapped person's life, the average family might spend £3,645 on capital improvements of some kind (HMSO 1985 xxxvii). We asked mothers whether they had to spend more than they would normally expect on particular items because of the child's disability. Their answers at Time 1 and Time 2 are summarized in Table 2.7. At Time 1 laundry and clothes in particular were proving unexpectedly expensive for over half the families, while bedding, transport, shoes and furnishings were proving expensive for a third of families. At Time 2 the proportions of mothers reporting extra expense were very similar.

Table 2.7 Extra expense incurred by families

	More expense than normal Time 1 %	 Time 2 %
	N = 200	N = 178
Laundry	57	54
Clothes for child	55	52
Transport	44	41
Bedding for child	34	34
Shoes	34	34
Furnishings	32	18
Special Toys	28	17
Food	19	22
Outings	15	22
Special Equipment	13	11

Perhaps as a result of these expenses, mothers reported alterations in the way they managed their household budgets since the birth of the handicapped child. We asked mothers whether they had to change the way they managed their money in the last year as a direct result of the child's needs. Table 2.8 gives the results.

Table 2.8 Ways parents have had to alter money management in last year

	% parents reporting
Borrow money	10
Buy more on credit	9
Delay paying bills	18
Spend money from long term savings	8
Stop saving	18
Cash in or give up insurance policies	5

Table 2.8 shows that about one fifth of the sample felt that they had had to stop saving or delay paying bills as a direct result of the child's needs, while about 10% had had to buy more on credit, borrow money from the bank, or spend their long term savings. Many parents were worried about their financial circumstances. At Time 1 25% said money was a constant worry, while 58% had some worries about being able to cope financially; at Time 2, 20% said that money was a constant worry and 54% had some worries.

Receipt of Mobility and Attendance Allowance

At Time 1 82% (164) of mothers received Attendance Allowance for their children and 27% (54) of parents received the Mobility Allowance. At Time 2, 96% (158) received the Attendance Allowance and 37% (61) the Mobility Allowance. Twenty six per cent of mothers who had received the Mobility Allowance reported problems in applying for and getting the allowance, and 9% of mothers in receipt of the Attendance Allowance reported difficulties. Three families had received compensation for vaccine damage to their children.

Family Stress and Severe Life Events

In order to explore other stresses and problems in the lives of the families in our sample we asked mothers if they or anyone in their immediate household had experienced a series of difficulties and life events unrelated to the study child. We used a scale adapted from Tennant & Andrews (1976) and Richman (1982). Table 2.9 shows the proportions of families experiencing adverse life events or difficulties. The most common response was

Table 2.9 Life events or difficulties experienced by families in the sample

In the last year, have you or anyone in your household	% of families experiencing: Mild problems	Severe Problems	N
a) had an accident or illness or been in hospital	15	18	55
b) had someone close to you die or fall seriously ill	14	19	57
c) had someone in the family with a chronic illness/need constant care because of disability	8	15	38
d) become pregnant/had a baby	6	2	14
e) started the change of life	14	2	28
f) had marital difficulties or become separated or divorced from your husband	5	8	21
g) had rows/difficulties with a close friend or neighbour	5	7	21
h) had problems with other children	13	10	38
i) had difficulties at work - become downgraded, unemployed	3	5	11
j) had difficulties with your husband's job - redundancy/ unemployment	10	12	32
k) had housing problems	5	3	14
l) moved house	6	5	18
m) had financial difficulties	15	15	50
n) had difficulties of a legal nature possibly involving a court appearance	6	5	18
o) had something you valued greatly lost or stolen	3	2	8
p) any other event or difficulty which caused you distress (unrelated to study child)	3	4	12

personal accident or illness (33%) and death or illness of someone close (33%). Financial difficulties were common: 30% of mothers reported financial trouble or money worries. Twenty two per cent of mothers had experienced difficulties with their husband's job, and this may be related to their financial difficulties. It is clear that, in addition to caring for their son or daughter, many families in our sample had had other severe life events and difficulties to contend with which may have affected both their stress levels and their parenting.

Summary

This chapter has outlined the design and methodology of the study. It has described the range of information collected by the interviews and the assessments. The main outcome and descriptor variables have been presented, and the creation of indices has been detailed. The chapter has tried to present a picture of the families who took part in the study. The following chapters will consider the behaviour problems of the children, sleep problems in children with a mental handicap, the stress levels and coping resources of the parents, the services used by parents, and the transition to adult life. The report will end with recommendations for future service provision. We have tried to take into account the interaction between family and social variables and child characteristics, mindful of the observation of Korn et al (1978) that

> "Neither the child, the parents nor the physical environment can be viewed as the significant determinant of any specific adaptive outcome. Each child with his or her pattern of characteristics is continuously being affected by the family and is reciprocally having an impact on the family. We are dealing with multi-determined interacting systems that are also undergoing changes over time. The child grows, the parents age, the marriage and family develop and the environment is never static" (Korn et al 1978, p229).

BEHAVIOUR PROBLEMS IN THE SAMPLE OF CHILDREN WITH MENTAL HANDICAP

Introduction

Serious behaviour problems are quite commonly found in school-aged children. A number of studies provide evidence for rates of significant disorders of this kind ranging from 6% to 20% (Miller et al 1974, Rutter et al 1970, Richman et al 1982). Prevalence studies of behaviour problems in children with severe mental handicap are relatively rare owing to difficulties in the definition of severe mental handicap and the fact that until recently, registers of such children were not compiled by health districts. However, estimates from samples of children in hospitals, hostels and at home suggest that children with severe mental handicap are particularly likely to have behaviour problems (DHSS 1979, Wilkin 1979, Rutter et al 1970(a), Gath and Gumley 1986, Cunningham et al 1986). Rutter and his colleagues defined disorder in children as a

> disturbance of behaviour or emotions sufficiently severe and prolonged to cause suffering to the child, to the family or to the community.

Using this definition, the prevalence of behaviour disorders in children with severe mental handicap in Rutter's Isle of White study was 50% compared with 6.6% among the children of normal intelligence. Corbett (1977) found a similarly high proportion of severely mentally handicapped children with behavioural problems in his Camberwell study, noting a wide range of disorders from conduct disorders, childhood psychosis, adjustment reactions, hyperkinetic behaviour disorders to isolated symptoms such as pica, self injurious behaviour and severe stereotypies. Gath and Gumley (1986) compared the behaviour disorders found in Down's Syndrome with those in children with a similar degree of mental handicap. They found that 38% of the children with Down's Syndrome and 49% of the control children had significant behaviour disorder. Cunningham et al (1986) compared BSQ item scores in their sample of Down's Syndrome children with scores from a reconstituted sample of 98 children of 3, 4 and 8 years of age considered to be representative of Richman et al's (1982) population sample. A significantly higher percentage of children in the Down's Syndrome group exhibited problems of night settling, waking at night, sleeping with parents, poor concentration , attention seeking and fears, though the non-handicapped group had significantly higher scores on items such as poor appetite, faddy eating, overactivity, dependency, relationships with siblings and night wetting. However, Cunningham et al pointed out that the two samples differed in several ways and were therefore not strictly comparable.

Behaviour disturbance has been shown to be associated with the stress suffered by mothers caring for a severely handicapped child at home (Cooke et al 1982, Chetwynd 1985, Quine and Pahl 1985; Pahl and Quine 1987). It has also been cited as one of the reasons for requests for long term care (Wilkin 1979, Primrose 1971, Carter 1984).

Studies of behaviour problems in children in the general population have repeatedly found associations between child behaviour and such variables as maternal stress and marital discord. These data have often been interpreted as evidence that disordered family relationships play a causal role in the onset of behaviour disorder in children (see reviews by Hinde 1980, Rutter 1984; 1985a, b). However, many of the studies are beset by methodological difficulties which make such an interpretation open to question. Some have been cross-sectional measuring family relationships and child behaviour at one point in time so that it is not possible to deduce which variable is antecedent (Kotler and Hammond 1981). In some studies behaviour problems in the child and evidence of maternal stress are reported by the same respondent, which could allow bias to occur (Richman et al 1982). Even in prospective longitudinal studies there may be problems in determining the causal ordering of variables (Rutter and Quinton 1984).

The wide range of information collected about the children and their families in our study enabled us to address a number of issues: How prevalent are behaviour problems in children with severe mental handicap? What are the social and situational correlates of behaviour problems in children with mental handicap? What is the nature of the link between child behaviour disorder and the child's social environment? Do some young people grow out of their behavioural difficulties? These and other questions will be investigated in the next two chapters which reanalyse data from the first and second phase of the longitudinal study.

Methods used for the Assessment of Behavioural Problems

It will be recalled that the Disability Assessment Schedule (Holmes, Shah and Wing 1982) was used in the first phase of the study to assess behavioural problems. In the second phase of the study we again used the schedule for comparative purposes. In addition, we used the Behaviour Problem Index which is a schedule adapted by Cunningham et al from The Behaviour Screening Questionnaire (Richman et al 1982) so that it covers a wider range of problems considered more appropriate to a population of mentally handicapped children (see Appendix 1). In this way we were able to achieve comparisons with the first phase of our own study and also to compare results from the second phase of our study with those of both Cunningham's and Richman's studies.

It was decided that information about the child's behaviour problems for the D.A.S. should be collected from an independent informant. Accordingly we collected this information from the teachers or day-care staff member who knew the child best. Our reasoning was that a stressed or unhappily married mother might perceive her child more negatively than a mother who was unstressed and happily married. Emery and O'Leary (1984) have argued cogently that research using non-independent ratings to examine the relation between marital and child problems may exaggerate the strength of the association between interparental conflict and child behaviour problems. However, reliance on independent assessments may have problems too. Firstly, the assessments reflect prevalence in day care facilities. Children may respond to family conflict more noticeably in the setting where it occurs - the home. Thus behaviour problems may be situational-specific. Theoretically, this might mean that teachers fail to report behaviour problems which are displayed only at home. This might undermine the likelihood of finding significant relationships between social and family problems and behaviour difficulties. The first phase of the study did not collect information about behaviour problems from both parents and teachers. However, Wing & Gould (1978) using a longer version of the same schedule, found that overall agreement between parent and professional informants was in general 70% or above. Parents, when compared with professional workers, tended to describe their children as having higher developmental skills and more difficult behaviour. This seems to be quite a common finding (Touliatos, 1981). Phase one of our study shows a high association between the behaviour problems as rated by professionals and parental ratings of the child being difficult to manage ($p<0.0001$). We believe, therefore, that there were relatively few instances where problem behaviour occured at home but was not recognised at school. In phase two of the study, the D.A.S. was again completed in schools and day care centres, while information incorporated in the Behavioural Index was collected from parents so as to be comparable with Richman's and Cunningham's work.

The Prevalence of Behaviour Problems in the Sample at Time One

The D.A.S. enquired about a wide range of behaviour problems. The teacher or care assistant who knew each child best was asked whether the child had severe or mild behaviour problems which caused significant social or psychological disability to himself or to others. The majority of the informants had been trained in behaviour modification techniques and were knowledgeable about behaviour disorder. The level of disability to be identified as severe or mild was agreed using criteria involving the threshold above which a child presented management problems, or would become a matter for concern to an experienced professional in the field. Children with severe or mild behaviour disorders would certainly be regarded as requiring help from primary health care services and might be regarded as needing assistance from specialised professionals such as social workers, psychologists and psychiatrists. The problems which affected the children are given in Table 3.1.

Table 3.1 **The prevalence of behaviour problems in the sample at Time 1**

Behaviour	% of children[2]	Boys	Girls	P[1]
Aggressive	22	25	16	N/S
Destructive	14	16	11	N/S
Overactive	22	29	12	**
Attention seeking	32	33	28	N/S
Self injury	11	13	9	N/S
Wanders	19	21	15	N/S
Screams	21	21	19	N/S
Temper tantrums	23	25	18	N/S
Objectionable habits	15	17	11	N/S
Scatters objects	15	15	13	N/S
Night settling problems	34	30	39	N/S
Disturbs parents at night	37	42	30	N/S
Anti-social habits	5	4	7	N/S
Sexual delinquency	4	4	3	N/S

[1] Significance level of chi-squared test

[2] N = 200

There are two points to note. Taken as a whole, 61% of children had severe or mild behaviour problems. This compares with 50% of children in the hospital units and wards and 34% in the residential homes surveyed for the Jay Report (DHSS, 1979).

Secondly, Table 3.1 shows that there was only one sex difference in the sample. Although a greater proportion of boys were reported as presenting each behaviour problem, the differences between boys and girls reached a statistically significant level for over-activity only. Significantly more boys than girls were assessed as over-active.

The Correlates of Behaviour Problems in the Sample Survey at Time One

As has been noted, the sample of 200 children proved to be entirely representative of the total population of children from which it was drawn; the proportion of sample children assessed as having each behaviour problem differed only by one or two percentage points from the proportion in the population. We can, therefore, have a high degree of confidence that the sample was representative of mentally handicapped children in general.

For the purpose of further analysis, the sample was divided into two groups: the first group contained children with severe or mild behaviour problems; and the second group contained children with no behaviour problems. This enabled us to examine the correlates of behaviour problems in children with severe mental handicap. These fall into four groups: characteristics of the child which may be associated with problem behaviour, such as age, use and understanding of communication and academic skills, characteristics of the family, such as family composition, social class, and maternal stress, management problems caused by the child such as extra work with household tasks and child care, and use of services.

Associations between Behaviour Problems and Other Impairments

Table 3.2 presents information on the association between behaviour disorder and the children's other impairments. A major difference between the groups was in the areas of communication, and reading, writing and counting skills. One half of the non-disordered group had good use and understanding of communication compared with only a third of the behaviour disordered group. Eighty-five per cent of the behaviour disordered group had poor reading, writing and counting skills, compared with 65% of the non-disordered group. Rutter reports broadly similar findings: children with organic brain pathology including epilepsy and cerebral palsy were more at risk of behaviour disorder if the child had a lower IQ or marked reading difficulties. These associations applied equally to children without brain damage (Rutter et al 1970 a) and b), Rutter 1974). In our study, the behaviour disordered group contained a significantly higher proportion of children who were unable to feed, wash and dress themselves. Also, significantly more of this group were incontinent.

Table 3.2 **Associations between behaviour problems and other impairments**

Impairment	Children with behaviour problems[1]	Children with no behaviour problems[2]	Chi-square
Use of communication			
Good	32	54	
Fair	25	9	12.3**
Poor	43	37	df = 2
Understanding of communication			
Good	33	57	
Fair	25	10	12.8***
Poor	42	33	df = 2
Academic skills (ability to read, write and count)			
Good	2	12	
Fair	15	23	12.4**
Poor	84	65	df = 2
Self-help skills			
Washes without help	21	45	
Washes with help	44	22	16.2***
Unable to wash self	35	33	df = 2
Feeds self without help	50	59	
Feeds self with help	30	15	5.8*
Unable to feed self	20	26	df = 2
Dresses self without help	21	49	
Dresses self with help	42	18	19.7***
Unable to dress self	37	33	df = 2
Continence for age			
Continent	52	73	9.1**
Incontinent	48	27	df = 1

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[1] Children with behaviour problems N = 122
[2] Children with no behaviour problems N = 78

As Table 3.3 shows, behaviour disorder was not significantly associated with age which might have been an explanation for the differences consistently found between the two groups. There were no significant differences in health or weight between the two groups. Interestingly, children who were not mobile were no less likely to exhibit behaviour problems than children who were mobile.

Table 3.3 **Age of child by behaviour problems**

	% of children with problems		
Age of Child	Children with behaviour problems	Children without behaviour problems	Chi-square
0 - 5 years	64	36	
6 - 10 years	70	30	4.7 N/S
11 - 18 years	53	47	df = 2
	N = 122	N = 78	

Family Circumstances

When family circumstances were examined our findings were remarkably similar to those reported in a longitudinal study of children in the general population (Richman et al 1982). The parents of the group of children with behaviour problems were no different from those without problems, in their ages or the length of time they had been married. There was no significant difference between the two groups in the degree to which mothers went out to full or part-time work. Size of family and birth order did not differ between groups in our study though Richman et al, found differences in family size (but not in birth order) between problem and non-problem children. When analysis of social class was carried out considering each occupational class separately, no significant differences were found. Nor were there any differences when all manual classes were combined and compared with all non-manual classes. These findings are at variance with those of Richman et al (1982) who found social class differences in rates of behaviour disorders in girls only. The occupational class of the father is a rather crude indicator of social status and, therefore, we examined the social circumstances of the children in greater detail. However, we found no differences between the two groups in terms of household income or ownership of consumer durables.

There were, however, significant differences between groups in family composition, as Table 3.4 shows. Significantly more children in single-parent families had behaviour problems, though the causal ordering of these variables is unclear. It may have been that some factor associated with growing up in a one-parent family is implicated in the genesis of behaviour disorder or it may be that the difficulties of looking after a mentally handicapped child with behaviour problems drove the fathers away.

Table 3.4 Family composition by behaviour problems in the child

	% of children with problems		
Family composition	Children with behaviour problems	Children without behaviour problems	Chi-square
Two-parent family	58	42	7.0**
Single-parent family	85	15	df = 1

N = 200

There were no significant differences in type of housing or length of time parents had lived in their present home but there were significant differences in the *nature* of the tenancy, as Table 3.5 shows. A significantly lower proportion of parents of children with behaviour disorder owned their own homes. Richman et al (1982) report similar findings in a general population survey. Additionally, significantly more parents of such children said that their house was unsuitable for the needs of the family ($p<0.01$). This may reflect the greater ease with which owner-occupied housing can be altered, without recourse to social services departments or housing departments, etc., and without having to wait for such lengthy periods for permission to be given and work to be carried out.

Table 3.5 **Nature of tenancy by behaviour problems in child**

	% of children with problems		
Nature of tenancy	Children with behaviour problems	Children without behaviour problems	Chi-square
Owner occupied	54	76	10.6**
Rented from council	37	18	df = 3
Privately rented	4	1	
Other	5	5	

N = 200

The Parents' Marriage and Social Contacts

There were no differences between groups in the mother's perception of the availability of emotional support in her marriage, the happiness of her marriage, or her reported contact with friends and relatives. In marriages where mothers reported that a close, confiding relationship did not exist, 33% of children were behaviourally disordered, while 41% of children in marriages where there was emotional support had problem behaviour. This is interesting in view of the findings from a number of studies of children which have shown strong correlations between child behaviour disorder and marital discord (Richman et al 1982, Kotler & Hammond 1981, Rutter & Quinton 1984).

When social activities were examined, a significantly higher proportion of mothers whose children had behaviour problems said that the presence of the handicapped child prevented them from going out; however, they did not go out less than mothers whose children had no behaviour problems, nor did they want to go out more. However, they did have more difficulty in finding someone prepared to babysit ($p<0.05$). Social isolation was not more common among mothers of children with behaviour problems (although 50% did feel isolated). However, a significantly larger proportion felt that the child's handicap had been a disadvantage to his or her siblings, that it had restricted their activities, and that, on balance, the child had had an adverse effect upon the family as a whole ($p<0.05$).

Maternal Stress

Stress in the mothers in the sample was measured using The Malaise Inventory (see Appendix 1). It will be recalled that Rutter considered that scores of five or six were outside the normal range and indicative of stress, and that scores of seven or more were 'critical' (Rutter 1975). The mean Malaise score for respondents in this study was 5.83. When mean stress scores were broken down by behaviour problems in the child, there was a significant relationship between the extent to which a child's behaviour was disordered and the Malaise scores of carers. Table 3.6 shows the scores of mothers of children with and without behaviour problems - 6.6 on avergage for those whose children have behaviour problems and 4.7 on average for those whose children were without problems, a difference which was highly significant statistically. Richman et al (1982) report similar results in their longitudinal study of the behavioural problems of pre-school children.

Table 3.6 Behaviour problems in the children by Malaise scores of mothers

	Analysis of variance		
	Mean Score	Standard Deviation	N
Behaviour problems	6.6	4.4	122
No behaviour problems	4.7	3.3	78
Total:			200

One way analysis of variance
F = 10.723*** df = 1,198

It is important to remember that the assessment of the child's behaviour was made by the teacher or care assistant during the course of the population study described earlier; the Malaise score and information about childcare and management problems were assessed on the basis of material collected during the course of the interview with the child's mother. This ensures that the measures are independent. Studies of child behaviour like Richman et al's (1982) which have used the mother's assessment of behaviour can encounter methodological problems because of the potential for contamination between variables assessing the child's problems and those which decribe stress levels or social circumstances.

Parents' Perceptions of the Difficulties Encountered in Caring for a Child with Behaviour Problems

Household tasks Mothers of all children in the sample were asked whether the children required them to carry out extra household tasks or made things more difficult for the mother when performing her tasks. Rutter & Brown (1966) have shown that reliable results can be obtained from questioning parents provided that the questions asked are aimed at the performance of specific tasks over a specific time period. The series of questions in this study followed this precept. The answers were broken down into cross-tabulations showing the differences between children with behaviour problems and those without.

Table 3.7 Extra work having to be done by parents of children with behaviour problems

	% of mothers who had to carry out tasks		
Extra work required	Children with behaviour problems	Children without behaviour problems	Chi-square
Cleaning and tidying the house			
No	47	67	
A little	19	19	10.1**
A lot	34	14	df = 2
	N = 122	N = 78	
Laundry			
No	30	46	
A little	20	23	7.3*
A lot	50	31	df = 2
	N = 122	N = 78	
Shopping			
No	49	63	
A little	26	23	4.8 p<0.06
A lot	26	14	df = 2
	N = 122	N = 78	

It can be seen from Table 3.7 that children with behaviour problems do seem to cause mothers more work: mothers of disordered children had significantly more cleaning and tidying; they had extra laundry because of incontinence and heavy use of clothes; they had more difficulties when shopping because of the child's impulsive behaviour and the likelihood that he or she might wander off.

Child care More mothers of children with behaviour problems reported that their children needed help with dressing, undressing, washing, bathing and using the toilet. This should not be unexpected since we have shown that children with behaviour problems were more likely to be unable to carry out these tasks alone. Table 3.8 presents these findings.

Table 3.8 Help required by children with behaviour problems

	% of mothers who had to help child		
Child requires help with:	Children with behaviour problems	Children without behaviour problems	Chi-square
Dressing			
No	6	21	
A little	25	30	12.4**
A lot	70	50	df = 2
	N = 122	N = 78	
Undressing			
No	26	49	
A little	20	13	10.4**
A lot	54	38	df = 2
	N = 122	N = 78	
Washing			
No	9	20	
A little	25	30	7.2*
A lot	66	50	df = 2
	N = 122	N = 78	
Using toilet			
No	23	43	
A little	25	25	8.3**
A lot	52	32	df = 2
	N = 122	N = 78	

Management problems reported by the parents Differences in management problems reported by mothers between the behaviour disordered and the non-disordered groups were examined. As Table 3.9 shows, there were significant differences between the children with behaviour problems and those without problems. Significantly more mothers of children with behaviour problems reported difficulties with managing the child, keeping her or him occupied and safe, and having difficulties when shopping.

Table 3.9 Management problems of children with behaviour problems

	% of children with problems		
Management problem	Children with behaviour problems	Children without behaviour problems	Chi-square
<u>Ease of management</u>			
Easy	24	58	
Difficult	48	37	29.0***
Very difficult	28	5	df = 2
N = 200			
<u>Difficulties when shopping</u>			
Yes	70	54	5.1*
No	30	46	df = 2
N = 197			
<u>Attention to keep occupied</u> (comparison with other children of same age)			
Less attention	4	10	
As much attention	7	18	14.3**
A bit more attention	18	27	df = 3
A lot more attention	71	45	
N = 200			
<u>Attention to keep safe</u> (comparison with other children of same age)			
Less attention	2	8	
As much attention	11	15	
A bit more attention	16	26	9.2*
A lot more attention	71	51	df = 3
N = 200			

Use of Services

There were no differences in the frequency with which children in the two groups, or their parents, visited their general practitioner or were admitted to hospital. However, a significantly higher proportion of children with behaviour problems had been in touch with a social worker and had used short term care, though there were no differences in whether they had seen community mental handicap nurses or health visitors.

Table 3.10 Use of services by behaviour problems in the child

Service	Children with behaviour problems		Children without behaviour problems		Chi-square
	%	N	%	N	
Health visitor (contact in last year)	31	37	24	19	0.97 N/S
Community nurse (contact in last year)	13	16	13	10	.00 N/S
Social worker (contact in last year)	50	61	27	21	10.5***
Short-term care (use in last year)	62	76	45	35	5.2** df = 1

Felt Needs for Additional Help

There were a number of significant differences between the two groups when mothers' felt needs for additional help were examined. Table 3.11 presents these findings, and it can be seen that parents of children with behaviour disorder were not asking indiscriminately for all kinds of extra help. Financial help was the priority, followed closely by holiday care, and then weekend care.

Table 3.11 **Mothers felt needs for additional help by behaviour problems in the child**

Felt need	Children with behaviour problems		Children without behaviour problems		Chi-square
	%	N	%	N	
Financial help	58	69	42	32	4.8* df = 1
Holiday care	51	53	35	22	3.8* df = 1
Weekend care	37	44	19	14	6.5** df = 1
Child care	28	33	18	14	2.4 N/S
After-school minding	28	27	14	8	4.2* df = 1
Help with houshold tasks	21	25	17	13	.47 N/S df = 1

Discussion

This chapter has presented the prevalence of behaviour problems in the sample of children at Time 1. There were no sex differences in rates of behaviour with the exception of overactivity: boys were more likely to exhibit overactive behaviour than girls. The children were split into two groups: those with one or more severe behaviour problems and those without problems. Analysis showed that there were a number of significant differences between children with problem behaviour and those with no problems at Time 1. Significantly more children with behaviour disorders were found to be incontinent, to have few self-help skills, to have poor communication skills and to be unable to read, write and count than mentally handicapped children without behaviour disorder. Such children present their carers with more management problems: they are more difficult to keep occupied and to keep safe. Their dependence on others to perform tasks and their incontinence make extra work for their carers.

When the environmental correlates of behaviour disorders were looked for it was found that there were remarkably few; there was no association between behaviour disorder and family size, birth order, age of parents, social class or income. However, there was a significant association between type of housing and presence of behaviour disorder. Children who lived in council house accommodation were more likely to be disturbed than those who lived in owner-occupied housing. There was also a significant negative association between satisfaction with housing conditions and behaviour disorder. These findings are difficult to interpret in view of the finding that social class was not associated with behaviour disorder. It may be that some parents who function poorly in various ways are more likely to be housed in council house accommodation. The disturbance in their children might be influenced by aspects of this functioning rather than the quality of their housing. Nevertheless, it seems that good housing circumstances may make it easier to cope with a disturbed child, and it seems equally possible that housing which is inadequate, overcrowded or otherwise unsuitable may exacerbate behaviour problems.

Although most of the parents in both groups were married and living together, the proportion who were not was more than three times as high in the behaviour disordered group. Children living in one-parent families were no more likely to live in council housing than two-parent families, nor were their mothers more likely to be dissatisfied with their housing conditions. Thus the association between family composition and behaviour disorder cannot account for the relationships between type of housing, satisfaction with housing conditions and behaviour disorder.

The high rate of behaviour disorder found in one-parent families deserves further consideration, since it could not be accounted for by other significant relationships. Tracing the link between child handicap and marital breakdown is fraught with difficulties, as Bradshaw (1979) has pointed out. In our sample of behaviourally disordered mentally handicapped children, 18% were from single parent families. This figure is rather higher than that in the population as a whole which has been estimated at 12.1% of all families with dependent children (General Household Survey, 1982). However, from cross-sectional data it is impossible to judge whether some factor associated with growing up in a one-parent family is implicated in the genesis of behaviour disorder or whether the difficulties of looking after a mentally handicapped child with behaviour problems contributed to the breakdown of these marriages. Studies of behaviour disorder in children have often found an association between marital discord in the parents and behaviour disturbance in the child, but this study found that there was no tendency for mothers of children with behaviour problems to report that their marriage lacked closeness or that it was unhappy.

Maternal stress has been found to be associated with behaviour disorder in studies of both mentally handicapped and non-handicapped children (Richman et al 1982; Cunningham et al 1986). The mean stress score of mothers with a behaviourally disordered child in our study was significantly higher than the mean score of mothers of children without problems. Again interpretation is difficult. A number of studies of behaviour problems in children have hypothesized a causal relationship which suggests that stressed or psychiatrically disturbed mothers may produce children with behaviour problems (Richman et al 1982, Kotler & Hammond 1981). Rutter & Quinton (1984), for example, have conducted a four-year prospective study of newly-referred psychiatric patients and their children and a control group of families in the general population. The main focus of the study was 'the identification of the key features of parental mental illness that put children at psychiatric risk'. Rutter & Quinton found that patients' families differed in terms of a higher rate of psychiatric disorder in spouses and a much higher level of family discord, both of which tended to persist over a four-year period. The children of psychiatric patients had an increased rate of persistent emotional/behavioural disturbance which tended to involve disorders of conduct. The psychiatric 'risk' to the children was greatest in the case of personality disorder associated with high levels of exposure to hostile behaviour. However, while parental mental illness constituted an important indicator of psychiatric risk for children, the overall pattern of Rutter & Quinton's findings showed that the main risk stemmed not from the illness itself, but from the associated psychosocial disturbance in the family, manifested by marital discord and hostile behaviour.

Problems of interpreting the causal ordering of variables occur in our study. It is necessary to ask whether behaviourally disordered children cause their mothers to be stressed, or whether stress in the mother causes disorder in the child. Is marital discord implicated in the genesis of behaviour disorder, or does caring for a mentally handicapped child put the parents' marriage at risk? It may well be that a direct reciprocal relationship exists, where the child's difficult behaviour is stressful for the mother and the mother's stress makes it impossible for her to interact normally with her child and husband. Data from a single phase of a longitudinal study cannot answer these questions. However, it is possible to put forward some tentative interpretations of the findings.

In our work, there is some support for rather a different process from the one described by Rutter. Phase 1 of our study shows no relationship between marital/family discord and the presence of behaviour disorder. However, there was a significant relationship between *mother's assessment of her marriage as supportive and levels of stress.* Women with behaviourally disordered children who perceived their marriage to be supportive and harmonious were significantly less stressed than women with behaviourally disordered children who felt their marriage lacked trust and closeness (Quine & Pahl 1986).

Table 3.12 Malaise scores of married women with a behaviourally disordered child by perceived presence of emotional support within marriage

	Analysis of variance		
Emotional support in marriage	Mean Score	Standard Deviation	N
Wife has a close confiding relationship with husband	5.7	4.2	83
Wife does not have a close confiding relationship with husband	8.5	2.9	18

One way analysis of variance F = 7.05** df = 1,99

As Table 3.12 suggests, it seems that the *quality of the marriage* may influence the risk of *emotional stress* by the sort of mechanism which Brown & Harris (1978) have suggested - namely buffering. Women who have a severe life event or ongoing difficulty such as a behaviourally disordered child may be protected from the effects of such stress if they have a close and confiding marriage relationship. When we looked at the children who were not behaviourally disordered, there was no relationship between malaise and the perceived quality of the marital relationship; mothers of children who were not behaviourally disordered who perceived their relationship as close and confiding had a mean score of 4.6, while mothers who did not had a mean score of 5.2 (a non-significant difference). This suggests that while confiding relationships may act as a protective device to women under stressful circumstances, they may not act independently of stress. That is to say, that the level of stress experienced by a woman is not related to the presence or absence of a close confiding relationship unless there is a stressful aspect to her life such as responsibility for a behaviourally disordered mentally handicapped child.

Further support for a hypothesis which suggests that mentally handicapped children with behaviour disorder may induce or maintain stress in their carers, rather than that stress in the parents causes behaviour abnormality in the child, comes from the other correlates of behaviour disorder in this study. Children with behaviour disorder impose a much greater physical burden of care on their parents. They are harder to manage and keep safe. They are generally more dependent. They are less likely to be able to communicate, which may be frustrating for them and for their parents. Behaviour disorder tends to be associated as much with the child's communication skills as with factors in the social environment such as maternal stress. There is no doubt that being stressed may affect one's parenting; however, it seems unlikely that maternal stress constitutes the main explanation for the appearance of behaviour disorder in mentally handicapped children. Most of the parents with behaviourally disturbed children in our study had demonstrated the adequacy of their parenting by the normality of their other children.

No firm conclusions on the nature and direction of the causal relationships can be drawn from analysis of the cross-sectional data. The next chapter, which discusses the findings from the longitudinal data, enables us to shed more light on these questions. The longitudinal data will allow us to examine the continuities and discontinuities in maternal stress and child behaviour disorder and to consider the antecedent risk factors for behaviour disorder.

BEHAVIOUR PROBLEMS IN THE SAMPLE AT TIME TWO

Introduction

As we have already suggested, our reasons for carrying out a follow-up study of the children three years later, were two-fold - firstly we wished to examine the course of the problem behaviours we had identified at Time 1 and secondly we wanted to try to understand the roots of behaviour disorder in children with severe mental handicap to determine whether they were similar to those suggested by the literature on non-handicapped children. As we have indicated, we considered important factors to be of two types, those aspects or characteristics of the child's own functioning such as his or her communication skills, which might influence behaviour, and those factors exerting an external influence on the child such as maternal stress or poor housing conditions. Examining the links between variables, patterns of associations and possible causal chains is a complex business, however we felt it was relevant to the issues we had raised. We wanted to know whether particular types of behaviour might disappear with age and whether others might remain relatively stable. We had discovered that maternal stress was associated with difficult behaviour but were so far unable to determine the direction of causality.

As has been indicated in chapter two we were able to trace and collect information on 178 (89%) of the original sample. Six (3%) children had died and we were unable to trace sixteen (8%). Twelve children were now living in residential care and we have excluded them from the following analyses because of the absence of family data. The analysis is therefore based on 166 cases.

Continuity and Discontinuity of Items of Behaviour at Time One and Time Two

Assessment of the child's skills, ability and behaviour problems was made by questioning the teacher or care assistant who knew each child best using the Disability

Assessment Schedule. (see Appendix 1). In Table 4.1 the percentages of children with particular items of behaviour problems at Time 1 and Time 2 are presented. We believe that these comparisons are meaningful because we were careful to ensure that information was collected in a comparable way at Time 1 and Time 2. It can be seen that the proportion of children with each behaviour problem remained remarkably stable throughout the period in question. Conduct disorders, night settling and night waking showed similar rates of prevalence. The only conduct problem which showed a clear difference in prevalence between Time 1 and Time 2 was overactivity. A smaller proportion of children were described as overactive by teachers at Time 2 than at Time 1. Hyperactivity is known to decrease with age in non-handicapped children although it has been suggested that it is often replaced by other problems (Richman et al 1982; Minde et al 1972). Other problems such as attention seeking, aggressive and destructive behaviour, temper tantrums and screaming tended to remain static in prevalence between Time 1 and Time 2.

Table 4.1 Percentage of behaviour problems at Time 1 and at Time 2

Specific items of problem behaviour	Percentage of children with item of behaviour present at Time 1 N = 166	Percentage of children with item of behaviour present at Time 2 N = 166
Aggressive	23	17
Destructive	14	14
Overactive	22	15
Attention Seeking	33	32
Self Injury	11	10
Wanders	21	21
Screams	19	19
Temper tantrums	24	21
Objectionable habits	13	18
Scatters objects	15	15
Anti-social habits	5	8
Sexual delinquency	4	3
Difficulty settling at night	34	37
Disturbs parents at night	37	34

Continuity of Problems within Children

So far, we have considered continuities and discontinuities in overall rates of problems in the children at Time 1 and Time 2. It is also of course, possible to examine whether it is the same children or different ones who exhibit the behavioural problems. Tables 4.2 and 4.3 show the persistence of specific items of problem behaviour between Time 1 and Time 2.

Table 4.2 Persistence of specific items of problem behaviour

Specific items of problem behaviour	Percentage of children with item of behaviour present at Time 1 still showing problem at Time 2	Percentage of children with item of behaviour present at Time 2 who also showed problem at Time 1
Aggressive	39	54
Destructive	57	57
Overactive	49	72
Attention Seeking	59	60
Self Injury	42	47
Wanders	53	53
Screams	53	55
Temper tantrums	55	63
Objectionable habits	68	52
Scatters objects	46	46
Anti-social habits	0	0
Sexual delinquency	0	0
Difficulty settling at night	46	42
Disturbs parents at night	66	71

Table 4.2 shows that of the 38 children who were aggressive at Time 1, 15 (39%) still had the problem at Time 2. Of the 28 children who had a problem at Time 2, 15 (54%) had had such a problem at Time 1. These percentages are an indication of the chances of a specific problem persisting in a particular child, and of the likelihood of a problem present at a later age also being present at an earlier one. As Table 4.2 shows, about 50% of the children who exhibited items of behaviour at Time 1 still showed them at Time 2, the problem behaviours which showed greatest continuity being destructive behaviour (57%), attention seeking (59%), objectionable habits (68%) and night time disturbance (66%).

Similarly the difficulties suffered by the largest proportion of children at Time 2 which were also present at Time 1 were overactivity (72%), attention seeking (60%), temper tantrums (63%) and night time disturbance (71%). The exceptions were anti-social habits and sexual delinquency which displayed no persistence or continuity at all. None of the children who were identified as having anti-social habits or sexual problems at Time 1 still had these difficulties at Time 2, and similarly of the children who were identified as having these problems at Time 2, none had these problems at Time 1.

We used the McNemar Test to examine differences in the changes in proportions of children showing each behaviour problem between Time 1 and Time 2. The McNemar Test is an appropriate test for use with dichotomous variables when the two samples are related. Table 4.3 shows there are no significant differences in the proportions of children showing any item of behaviour at Time 1 and Time 2 with the exception of overactivity.

Table 4.3 **Persistence of specific items of problem behaviour between Time 1 and Time 2**

Specific item of problem behaviour	Percentage of children with item of behaviour definitely present (numbers in brackets)				
	Time 1 only	Time 2 only	Time 1 and Time 2	Neither	McNemar Test
Aggressive	14 (23)	8 (13)	9 (15)	69 (115)	N/S
Destructive	6 (10)	6 (10)	8 (13)	80 (132)	N/S
Overactive	12 (19)	4 (7)	11 (18)	73 (122)	*
Attention Seeking	13 (22)	13 (21)	19 (32)	55 (91)	N/S
Self Injury	7 (11)	5 (9)	5 (8)	83 (138)	N/S
Wanders	10 (16)	10 (16)	11 (18)	69 (115)	N/S
Screams	9 (15)	9 (14)	10 (17)	72 (119)	N/S
Temper tantrums	11 (18)	8 (13)	13 (22)	68 (113)	N/S
Objectionable habits	4 (7)	8 (14)	9 (15)	79 (129)	N/S
Scatters objects	8 (13)	8 (13)	7 (11)	77 (128)	N/S
Anti-social habits	5 (8)	8 (13)	0 (0)	87 (144)	N/S
Sexual delinquency	4 (7)	3 (5)	0 (0)	93 (153)	N/S
Difficulty settling at night	18 (30)	22 (36)	16 (26)	44 (74)	N/S
Disturbs parents at night	13 (21)	10 (16)	24 (40)	53 (88)	N/S

Probability of being placed in the "Behaviour Problem" Group

As it will be recalled, children were identified as having behavioural difficulties if they had one or more severe behaviour problems or two or more mild ones. Of the 100 children who satisfied the criteria for the behaviour problem group at Time 1, 76 (76%) still did so at Time 2. Of the 100 children who fell into this group at Time 2, 76 (76%) had been in it at Time 1. Table 4.4 shows that there were no significant changes in the proportions of children who were in each group at Time 1 and Time 2.

Table 4.4 **Children in "behaviour problem" group at Time 1 and Time 2**

	Percentage of children falling into behaviour problem group (numbers in brackets)				
	Time 1 only	Time 2 only	Time 1 and Time 2	Neither	McNemar Test
Behaviour problems	14.5 (24)	14.5 (24)	46 (76)	25 (42)	N/S

There are two important points to note. First that 71% of the sample remained unchanged between Time 1 and Time 2, 46% falling into the behaviour problem group both times and 25% neither time, while 29% changed into or out of the behaviour problem group. Secondly these figures are rather higher than the percentages for individual behaviour problems and this suggests that some children may cease to display one behaviour problem only to replace it with another, thus still satisfying the "behaviour problem" group criteria.

Factors Related to Behaviour Problems at Time Two

Our next step was to begin to tease out the importance of some of the child and family variables related to the risk of behaviour disorder. To do this, it was necessary to move from correlational analysis of individual variables to multivariate analysis where a number of variables can be considered together. Before we could do this, however, we needed to examine the correlates of behaviour problems at Time 2 in order to see whether the pattern at Time 1 and Time 2 had changed.

Examination of the correlations between family circumstances and behaviour disorder at Time 2 revealed that the pattern of associations was similar to that at Time 1. The parents of the children with behaviour problems were no different from the parents of those with no problems in their ages or the length of time they had been married. There was no difference between the two groups in size of family, birth order, social class or income, or in the proportion of mothers who worked full or part time. There were no differences between groups in the mother's perception of the availability of emotional support in her marriage or her marital happiness. The difference between groups in maternal stress levels found at Time 1 was also present at Time 2.

Where child variables were concerned, the pattern of associations with behaviour at Time 1 and Time 2 was similar with respect to use and understanding of communication, academic skills and self help skills. Children with behaviour problems were less likely to have these skills than children without problems. At Time 1 there had been a significant difference between groups in incontinence, but at Time 2 this had disappeared. The major difference in associations between behaviour and child variables between Time 1 and Time 2 was in age. Whereas the association between age and behaviour problems at Time 1 did

Table 4.5 **Age of child by behaviour at Time 1: percentage of children showing problems (numbers in brackets)**

Problem	% of children with problems		
	0-10 yrs	11-15 yrs	16 + yrs
Behaviour problems	66 (61)	54 (28)	52 (11)
No problems	34 (32)	46 (24)	48 (10)
	100(93)	100(52)	100(21)

Chi-square = 2.54 d.f = 2 Not significant

Table 4.5 (continued) **Age of child by behaviour at Time 2: percentage of children showing problems (numbers in brackets)**

Problem	% of children with problem		
	5-10 yrs	11-15 yrs	16 + yrs
Behaviour problems	81 (43)	53 (27)	49 (30)
No problems	19 (10)	47 (24)	51 (31)
	100(53)	100(51)	100(61)

Chi-square = 13.9 *** d.f = 2

not reach significance, (although there was a clear linear trend toward decreasing problems with increasing age), there was a very significant association at Time 2. Examination of the tables shows that behaviour problems peak at between five and ten years of age, dropping sharply after that. The association between behaviour and age helps to explain why incontinence was no longer related to behaviour disorder at Time 2.

How are we to explain the clear age/behaviour relationship at Time 2? There are two possible explanations: either the data had thrown up spurious results, or there exists an association between age and behaviour which tests on the data at Time 1 could not detect. Examination of the data revealed a change in the distribution of children in each age group. At Time 2 the proportions of children in each group were more even. Calculations showed that the effect of this was to increase the power of the statistical test used, making it more likely that genuine differences between age groups would be detected. We therefore conclude that there is a significant relationship between age and behaviour which tests on the data at Time 1 failed to detect.

What Factors best Discriminate between Children with Problems and those Without?

In order to distinguish between children with and without behaviour problems we introduced discriminant analysis. Discriminant analysis is a form of multivariate analysis which can be used when the dependent variable is dichotomous rather than continuous. The aim of this analysis is to select and link together child characteristics and family and social characteristics in terms of how effectively those variables discriminate between the two groups of children, those with behaviour problems, and those with no problems. Each of the variables is examined in turn, and those showing the greatest differences between the groups of children have the greatest influence on the final result. The value of this analysis is that it picks out the factors which are important in distinguishing between the two groups of children and gives an indication of the relative importance of each factor. It also helps us to develop a procedure for predicting membership for new cases whose group membership is undetermined. Such a tool might provide prognostic indicators for professionals such as health visitors, community nurses and general practitioners who deal with mentally handicapped children in clinical situations.

We included in the analysis those family, social and child characteristics which were shown to be correlated with behaviour problems at Time 1, to predict group membership of the behaviour problem group at Time 2. Table 4.6 shows the results of this analysis. Ten variables predicted group membership, correctly classifying 80% of the cases (Wilk's Lambda 0.66). The variables fall into two groups: child characteristics, such as the child's ability to read, write and count, the severity of his or her physical impairment, continence, mobility, communication skills and age; and family characteristics such as the mother's irritability score, maternal stress score, family income and marital discord. These variables together account for 33% of the variance in group scores. The two groups of variables will be discussed in turn.

Table 4.6 **Summary table of variables discriminating the behaviour problem group**

Variable	Wilk's Lambda	Significance
Academic skills	.87	***
Maternal irritability	.84	***
Maternal stress	.81	***
Mobility	.80	***
Severity of physical impairment	.73	***
Communication skills	.70	***
Age	.69	***
Marital discord	.68	***
Household income	.68	***
Incontinence	.67	***

The characteristics of the child which predicted membership of the behaviour problem group were younger age, being mobile, having poor reading, writing and counting skills, being incontinent, lacking severe physical impairment and having poor communication skills. Thus it is the mobile younger child who is less intellectually able who is more likely to have behaviour problems. These findings accord with the findings from epidemiological studies which indicate that psychiatric/behavioural disorders become more common with decreasing levels of intellectual functioning (Rutter 1971, Corbett 1977). Gath & Gumley (1986) for example, suggest that severity of intellectual handicap is an important factor in the development of behaviour disorder in Down's Syndrome children. The association between poor communication skills and behaviour may simply be a reflection of intellectual deficit. Other possible explanations are that having poor use and understanding of communication produces frustration for the child which is expressed in difficult behaviour or that poor communication skills in the child make it less easy for the parent to initiate effective training procedures. The relationship between communication skills and behaviour is an interesting one which has been documented in a number of recent studies (Leudar et al 1987) and deserves further study.

The family characteristics which predicted the membership of the behaviour problem group are maternal irritability, maternal stress, marital discord and family income, and it is here that we come to the problem of determining the causal direction of variables. It will be remembered that we used variables at Time 1 to predict behaviour at Time 2 in order to help clarify the causal ordering. This makes it more likely that an association found between a variable at Time 1 and behaviour at Time 2 is "causal". However, we still cannot say with certainty that poor marital relationships, maternal irritability and maternal stress "cause" behaviour problems because we have no information about the time of onset of the behaviour disorder which may have been longstanding and have occurred before Time 1. Indeed, it is clear from our data that many children's behaviour problems are persistent and longstanding. In a review of family and school influences on child behaviour, Rutter (1985) discusses the association found in many studies between maternal stress, marital discord and child behaviour problems, and how to interpret it. Do marital discord and maternal stress cause the child to develop behaviour problems or does the presence of a child with difficulties in the family lead to stress and discord? He concludes that there is good reason to suppose that both mechanisms operate.

So far we can simply say that certain variables are related to the risk of poor outcome in terms of behaviour problems, and may be instrumental in maintaining disorder. It seems likely that there is a circular relationship: while hostile marital relationships may be stressful for children and contribute to the onset of behaviour difficulties, difficult behaviour may be stressful for mothers and may make them irritable, putting a strain on the parents' marriage. Coleman et al (1977) for example, have argued that mothers and their children can become locked in a vicious circle in which stress and disturbance in turn affect the other.

Longitudinal Analysis of Change in Behaviour over Time

An alternative way of examining the causal direction of variables is to look at change in behaviour over time. It will be recalled that while the behaviour of 71% of children in the sample did not change, 29% of children moved either into or out of the behaviour problem group. In order to examine the factors predicting such change we carried out the discriminant analysis again, this time controlling for the effects of behaviour at Time 1. The results of this analysis produced a group of Time 1 factors which predicted change in group membership between Time 1 and Time 2, and, therefore, provided logical support to our belief that their relationship is probably causal.

Table 4.7 **Summary table of variables predicting change in behaviour between Time 1 and Time 2**

Variable	Wilk's Lambda	Significance
Behaviour at Time 1	.84	***
Academic skills	.76	***
Self-help skills	.74	***
Household income	.73	***
Mobility	.72	***
Maternal stress	.71	***
Marital discord	.70	***
Quality of social interaction	.69	***
Communication skills	.69	***
Age	.68	***

The results were remarkably similar to the previous analysis. Ten variables predicted change in behaviour group membership between Time 1 and Time 2, correctly classifying 79% of cases (Wilks Lambda 0.68) and accounting for 34% of the variance in scores. The characteristics of the child which predict change in group membership were younger age, having poor academic skills (reading, writing and counting), poor self help skills, poor communication skills, poor social skills (interaction with others) and being mobile. The family characteristics which predicted change in group membership were marital discord, maternal stress and low household income. Maternal irritability did not discriminate between the two groups in this analysis and it is likely therefore that this is a response to difficult behaviour rather than a cause of it. Poor self help skills replaces incontinence, and both are probably a reflection of intellectual deficit, which would make the child more difficult to train. Thus the findings shown in Table 4.7 provide support for our belief that the above variables act as risk factors for behaviour disorder.

Prevalence, Range and Nature of Behaviour Problems as compared with a non-handicapped Sample and a Down's Syndrome Sample

This section deals with the nature and prevalence of behaviour problems at Time 2, and a comparison is made with the non-handicapped sample of Richman *et al* (1982) and the Down's Syndrome sample of Cunningham *et al* (1986). It will be recalled that the Behaviour Screening Questionnaire developed by Richman *et al* (1982) was included in the parent's interview for this purpose. We also used the Behaviour Problem Index devised by Cunningham *et al* (1986) which was adapted from the Behaviour Screening Questionnaire so that it included a wider range of problems considered more appropriate to a population of mentally handicapped children (See Appendix 1). Mothers were asked if the child presented marked problems, mild problems or no problems for each item of behaviour. Short descriptions were offered to help mothers to rate the severity of each of the child's problems.

Prevalence of Behaviour Problems assessed by the Behavioural Index at Time 2

Mothers were asked whether they felt that anything in the behaviour of their child was a problem at the present time. 42% reported a definite problem, 19% were not sure and 39% reported that there were no problems. This question was followed by the Behaviour Screening Questionnaire and Behaviour Problem Index questions relating to specific behavioural items. Table 4.7 presents the percentage frequency occurrence and the severity ratings for each problem. Behaviour Screening Questionnaire items are asterisked. The correlation between the Behaviour Screening Questionnaire and the Behavioural Index was r=0.81. The scores on the Behaviour Screening Questionnaire ranged from 0 to 21 (mean 8.0, s.d. 4.4). The mean scores on the Behavioural Index (i.e. total score for each item divided by total number of items scored for each child) ranged from 1.25 to 13.75 (mean 5.5, s.d. 2.3).

Table 4.8 **Percentage Occurrence of Behaviour Problems in Sample at Time 2**

	% of children with		
Behaviour problem	No Problems	Some Problems	Marked Problems
Eating			
*Poor appetite	82	15	3
Pica	84	8	8
*Faddy eating	73	18	10
Toiletting			
*Soiling	61	11	28
Night wetting	54	10	36
Day wetting	64	12	24
Sleeping			
*Difficulty settling at night	63	10	27
*Sleeping in parents' bed	71	18	11
*Waking at night	49	17	34
Problems			
*Dependency	48	28	25
*Overactive/Restless	58	27	15
*Tantrums	49	37	14
*Miserable/Irritable	65	25	10
*Relationship with siblings	60	19	6
Obsessional behaviour	58	31	11
*Concentration	37	28	35
*Worries	58	35	7
*Attention seeking	45	28	27
*Peer relationships	48	8	4
*Management/discipline	46	40	15
*Fears	36	48	16
Problems at school			
Truanting	100	0	0
Stealing	87	8	5
Doesn't stand up for self	78	18	4
Bullied/teased	73	25	2
Disruptive	89	9	2
Fighting	88	10	2

Table 4.8 Percentage Occurance of Behaviour Problems (continued)

	% of children with		
	No problems	Some problems	Marked problems
Behaviour Disturbances			
Playing with fires	94	5	1
Destructiveness	78	11	11
Inappropriate use of WC	85	12	3
Spitting	87	7	5
Shouting/screaming	60	19	21
Taking off clothes	86	10	4
Aggressive gestures	79	11	10
Hoarding	74	14	12
Inappropriate behaviour to strangers	76	13	11
Running away	74	11	15
Throwing objects	63	19	19
Interfering with others' belongings	69	16	15
Other embarrassing behaviour	27	32	41
Habits			
Head banging	92	7	1
Rocking	75	16	8
Sucking objects	81	8	11
Picking, pulling, scratching	69	20	11
Twiddling objects	75	15	10
Making irritating noises	66	19	15
Biting nails	71	17	12
Sucking thumb or finger	65	17	19
Playing with genitals	76	16	8
Nervous movements	61	24	15

N = 166

* These items constitute the BSQ scale, all items are included in the BPINDEX

Table 4.8 shows that the most common behaviour problems were night wetting (36%), poor concentration (35%), night waking (34%), soiling (28%), difficulty settling at night (27%), attention seeking (27%), dependency (25%), day wetting (24%) and fears (16%). In the behaviour disturbance list, other embarrassing behaviour (41%), shouting and screaming (21%), throwing objects (19%), running away (15%) and interfering with other peoples' belongings (15%) were all assessed as marked for quite large numbers of children. Marked habits were also quite frequent, with sucking fingers (19%), making irritating noises (15%), nervous movements (15%), nail biting (12%), picking, pulling and scratching (11%), sucking objects (11%) and using objects for twiddles (10%) exhibited by significant numbers of children. The pattern of behaviour problems and habits occurring most frequently corresponds closely with Cunningham *et al*'s (1986) list, though as we shall see, larger numbers of children in the present sample tended to exhibit the behaviours in question.

When the "less marked but present" category was included, behaviour disturbances and habits increased and many were reported in over a third of the sample. Similarly problems such as soiling, day and night wetting, difficulty settling at night, waking at night, dependency, overactive behaviour, tantrums, moods, obsessional behaviour, poor concentration, worries, attention-seeking and management problems were present in over a third of the sample. Problems at school occurred rarely with only about 10% of the mothers reporting marked or mild problems with stealing, disruptive behaviour or fighting. The school problems reported most frequently were lack of ability to stand up for oneself and being bullied or teased. Truanting did not seem to occur, probably because most children are "bussed" to and from school. The more bizarre behaviours often associated with severe mental handicap such as pica, headbanging and rocking were rare as in Cunningham's sample of children with Down's Syndrome.

Prevalence of Behaviour Problems: Comparison with Cunningham *et al* (1986)

In order to achieve a meaningful comparison with the sample of children with Down's Syndrome aged 5 - 10 years by Cunningham *et al* (1986), we drew out all the 53 children aged 5-10 from our sample. We argued that since behaviour problems were related to age our sample of young people from 3-21 years could not fairly be compared with the Down's Syndrome cohort. Our sample of 53 children with mental handicap was similar to the Down's Syndrome cohort in a number of ways. There was no difference in social class, nature of tenancy, father's employment status or size of family. However, fewer mothers were in employment - 32% compared to 46%. This may reflect the greater level of physical impairment suffered by children in our mentally handicapped sample. There were also more single parents - 15% compared with 7% in Cunningham's sample, which may reflect the greater stresses and strains involved in bringing up these children. The 5-10 year old age group is the best approximation we can use for comparison purposes, though because of differences between this group and the Down's Syndrome Cohort, the comparisons should be treated with caution.

Table 4.9 **Percentage of children exhibiting items of behaviour: present sample of children aged 5-10 compared with Cunningham et al's sample of children with Down's Syndrome aged 5-10 years.**

Behaviour (Richman criteria - adapted)	Present sample 5-10 years N = 53	Down's Syndrome Sample N = 120	X^2sig level	Sample with more problems
Eating				
Poor appetite	9	1	**	Q&P
Pica	13	2	**	Q&P
Faddy eating	20	3	***	Q&P
Toiletting				
Soiling	49	8	***	Q&P
Night wetting	62	18	***	Q&P
Day wetting	41	23	***	Q&P
Sleeping				
Difficulty settling at night	41	20	**	Q&P
Sleeping in parents' bed	19	24	N/S	
Waking at night	49	41	N/S	
Dependency	32	0	***	Q&P
Overactive/Restless	21	1	***	Q&P
Tantrums	17	4	**	Q&P
Miserable/Irritable	15	2	***	Q&P
Relationship with siblings	7	2	N/S	
Obsessional behaviour	8	4	N/S	
Concentration	49	13	***	Q&P
Worries	0	2	N/S	
Attention seeking	32	20	N/S	
Peer relationships	4	4	N/S	
Management/discipline	23	9	*	Q&P
Fears	19	15	N/S	

Table 4.9 **Percentage of children exhibiting items of behaviour: present sample of children aged 5-10 compared with Cunningham et al's sample of children with Down's Syndrome aged 5-10 years. (continued)**

Behaviour (Richman criteria)	Present sample 5-10 years N = 53	Down's Syndrome Sample N = 120	X^2sig level	Sample with more problems
Problems at school				
Truanting	0	0	N/S	
Stealing	7.5	1	N/S	
Doesn't stand up for self	3.8	4	N/S	
Bullied/teased	1.9	0	N/S	
Disruptive	3.8	3	N/S	
Fighting	0	4	N/S	
Behaviour Disturbances				
Playing with fires	1.9	4	N/S	
Destructiveness	17.0	10	N/S	
Inappropriate use of WC	1.9	7	N/S	
Spitting	9.4	11	N/S	
Shouting/screaming	24.5	14	N/S	
Taking off clothes	3.8	9	N/S	
Aggressive gestures	15.1	17	N/S	
Hoarding	21.0	16	N/S	
Inappropriate behaviour to strangers	17.0	22	N/S	
Running away	34.0	27	N/S	
Throwing objects	22.6	29	N/S	
Interfering with others' belongings	26.4	31	N/S	
Other embarrassing behaviour	18.9	18	N/S	
Habits				
Head banging	0	1	N/S	
Rocking	5.7	6	N/S	
Sucking objects	13.0	8	N/S	
Picking, pulling, scratching	7.5	9	N/S	
Twiddling objects	7.5	13	N/S	
Making irritating noises	15.0	15	N/S	
Biting nails	13.2	11	N/S	
Sucking thumb or finger	35.8	17	**	Q&P
Playing with genitals	3.8	10	N/S	
Nervous movements	13.2	21	N/S	

DS = Cunningham et al (1986) Down's Syndrome sample

Q&P = Quine & Pahl sample

Table 4.9 shows the percentage of children exhibiting items of behaviour compared with the children with Down's Syndrome, and the results are striking. There are significant differences between the two samples on many of the Behaviour Screening Questionnaire items, including poor appetite, faddy eating, soiling, night and day wetting, difficulty settling at night, dependency, overactive or restless behaviour, tantrums, moods, concentration and difficulties in management. There are no significant differences in sleeping in parents' bed, waking at night, relationships with siblings and peers, obsessional behaviour, attention seeking and fears. In each case significantly more of our sample present each behaviour problem than do the Down's Syndrome sample. However, for all the extra items of behaviour included by Cunningham as being more appropriate for a mentally handicapped population there were no significant differences between the two samples except for finger or thumb sucking.

Prevalence of Behaviour Problems: Comparison with Richman et al (1982)

Comparison figures for non-handicapped children were taken from a study of child behaviour by Richman *et al* (1982). Richman and her colleagues present data from a representative sample of the population they studied in order to show how children in general developed over the years (see Richman et al 1982 p.75). We have presented their figures for 3 year old children who are the closest group to our sample in terms of developmental age. The problems exhibited by a significantly higher percentage of children in the mentally handicapped sample are settling at night, waking at night, poor concentration, dependency, attention-seeking, tantrums, being difficult to manage, moods, fears, soiling and day and night wetting. The non-handicapped group do not exhibit significantly higher rates of any of the problems on the BSQ. The list of problems exhibited by children in our sample is similar to the comparisons made by Cunningham between his own and Richman's data with the addition of dependency, moods, soiling and day and night wetting. These may reflect the difficulties caused by multiple impairments suffered by a proportion of our sample rather than behavioural disturbance.

Table 4.10 **Percentage of children exhibiting items of behaviour: present sample of children aged 5-10 compared with Richman et al's 3 year old sample**

Behaviour (Richman criteria)	Richman et al N = 705 %	Present Sample 5-10 year olds N = 53 %	X^2sig level	Sample with more problems
Poor appetite	16.3	9	N/S	
Faddy eating	11.8	21	N/S	
Difficulty settling at night	12.1	41	***	Q&P
Waking at night (>3/wk)	14.5	49	***	Q&P
Sleeping with parents	11.2	19	N/S	
Overactive/Restless	12.9	21	N/S	
Poor concentration	5.7	49	***	Q&P
Dependency	5.4	32	***	Q&P
Attention seeking	9.2	32	***	Q&P
Tantrums	5.1	17	***	Q&P
Difficult to control	10.7	23	**	Q&P
Miserable/Irritable	3.8	15	***	Q&P
Worries	2.3	0	N/S	
Fears	9.2	19	*	Q&P
Relationships with siblings	8.5	7	N/S	
Relationships with peers	5.8	4	N/S	
Soiling (>1/wk)	12.8	49	***	Q&P
Night wetting (>3/wk)	37.4	62	***	Q&P
Day wetting (>1/wk)	16.9	41	***	Q&P

R = Richman et al sample
Q&P = Quine & Pahl sample

To sum up, in our sample of children with mental handicap, much larger proportions of children exhibit almost all behaviour problems on the BSQ than do the non-handicapped group or the Down's Syndrome group. The exceptions are problems with siblings and peers and worries, where there are no differences between groups. However, although greater proportions of children suffer from each problem, the pattern of problems suffered by our sample and the Down's Syndrome sample is noticeably similar. The differences appear to concern items which may reflect both the greater level of physical and intellectual impairment of the mentally handicapped children; children with Down's Syndrome are often at the more intellectually able end of the scale among mentally handicapped children. It is interesting to note that there are almost no differences between our sample of children with severe mental handicap and the sample of children with Down's Syndrome investigated by Cunningham and his colleagues on the items added to the BSQ to make it more appropriate for children with a mental handicap. While mentally handicapped children in general are more likely than both normal children and children with Down's Syndrome to suffer from the range of behaviour problems which can be found in epidemiological studies of child populations, they do not differ markedly from children with Down's Syndrome in the behaviour often associated with mental handicap.

Discussion

This chapter has presented the prevalence of behaviour problems in our sample of children at Time 2. Behaviour problems showed remarkable similarity in prevalence between Time 1 and Time 2. The only exception to this was overactivity which decreased in prevalence between Time 1 and Time 2. Our analysis showed that there was also continuity in the persistence of behaviour problems; 71% of the sample remained unchanged between Time 1 and Time 2 while 29% of children moved into or out of the behaviour problem group. Discriminant analysis showed that it was possible to predict group membership in 80% of cases from factors concerned with the child's and family's characteristics. It is interesting to note, that when all the other factors were controlled, marital discord emerged as a significant predictor of membership of the behaviour problem group, alongside maternal stress and maternal irritability. This is in accord with studies of non-handicapped children, although the causal ordering of these variables has not always been clear. Family income was also a significant factor. In terms of child characteristics, the child's ability to read, write and count, communication skills, continence, mobility, severity of physical impairment and age were all significant factors. Longitudinal analysis of factors predicting change in behaviour over time produced similar results. Child characteristics predicting change in behaviour were academic skills, self help skills, communication skills, mobility and age. Family characteristics were maternal stress, marital discord and family income. It is likely that these factors are causally related to the risk of poor outcome in terms of behaviour disorder.

What form should policy intervention take? What services might relieve stress in parents of children with behaviour disorder? The task of developing methods of dealing with various aspects of challenging behaviour is a vital one facing planners and service providers. Our results suggest a number of different approaches.

Firstly, we would advocate policy initiatives directly targetted at helping families who are looking after children with difficult day or night time behaviour. While multiply impaired children are usually seen as deserving of help, behaviour problems may even disqualify a child from receiving help because of the disruption caused in, for example, short term care centres, family support units and foster homes. Many service providers do not collect information about whether children have behaviour disorders or not, and so are unaware of the extent of the problems faced by parents. We would suggest that service providers should identify children with severe behaviour disorders and should consider offering specialized services to these families. These services could include assessment at home, the development of behaviour modification programmes in consultation with the parents, attention to appropriate medication and generous access to day and night time relief schemes.

The development of a mental handicap register is an important step towards identifying children with behaviour problems. Such registers are now becoming more commonplace, but they are still not universal and those which exist are often not used as effectively as they might be. A mental handicap register requires not only a computer but also a person whose job it is to up-date the register on a regular basis and to produce information for professionals and service planners. The register should be linked to a mental handicap team drawn from health, education and social services.

Secondly, we would recommend the training of health professionals in behavioural methods which have been shown to be effective in decreasing undesirable behaviours. In recent years, important advances have been made in the development of effective methods for setting and attaining educational objectives among children with a wide range of behaviour problems. It has been shown that parents can be taught the skills to implement training of their own children at home (Chazan 1979, Gath 1979, Berkowitz & Graziano 1972; Clements 1985; Cunningham 1985; Helm and Kosloff 1986). Home teaching techniques for mentally handicapped children have been developed, which aim both to reduce inappropriate behaviours in the child and to teach the child positive new skills which are incompatible with inappropriate behaviours (Cunningham and Jeffree 1975, Callias and Carr 1975, Bidder *et al*, 1975, Shearer and Shearer 1972, Pugh 1981). The best known of these packages, which is called the Portage Guide, enables staff with no previous experience or training in precision teaching, after minimal training, to visit parents in their own homes and teach them how to set and attain educational objectives for their own child (Shearer and Shearer 1972, Clements *et al* 1980). For a review of the effectiveness of such methods see Berkowitz & Graziano (1972), O'Dell (1974), Gath (1979) and Milne (1985). Our study showed that very small numbers of mothers had been in contact with either the health visitor or the community nurse who might have had access to these techniques (see Chapter 3, Table 3.10).

Intuitively, it seems that involving parents in training their children may have an indirect effect on stress, by allowing parents to feel effectual and able to influence their own lives in a positive way as well as a direct effect, by reducing inappropriate child behaviours (Beck *et al*, 1979). Consideration of methods of involving parents positively in teaching their child is a more fruitful approach than a search for the parents' role in the genesis of their mentally handicapped child's behaviour disorder. Many parents of handicapped children may change their usual methods of child rearing, particularly when the child is small (Murphy & Oliver 1980), and these alterations may result in encouraging undesirable behaviours in the child. Thus, if the child is ill at night, parents may be more likely to allow the child to share their bed, or go to him/her every time there is the slightest noise. The child will be slow to learn that night time is a time for sleeping rather than waking and night waking problems may result (Clements et al, 1986). Other undesirable behaviour problems in the child may originate from the greater anxiety and concern which the parent shows for a handicapped child.

Thirdly, we would recommend greater attention to language and communication training programmes to help develop receptive and expressive language in children with poor communication skills (Lovaas 1977; Howlin 1980; Howlin 1984; Rowe and Rapp 1980). It is well established that children who have difficulties in language exhibit increased rates of behaviour problems (Richman *et al* 1982). Undesirable behaviour can sometimes serve linguistic functions in such children - for example, as a way of gaining attention. Difficult behaviour can also be a way of protesting about the level of task difficulty, or can indicate disapproval in a variety of situations if the child has no useful language. For those children who have little chance of acquiring useful speech, greater emphasis should be placed on teaching alternative or augmentative communication systems such as the Makaton vocabulary (Walker 1980) or the Paget Gorman system (Paget *et al* 1972). For multiply handicapped children even simpler forms of communication need to be devised. Alternatives to signing might be the use of symbols (Premack and Premack 1974), pictures (Murphy *et al* 1977), Bliss symbols (Bliss 1965) and communication boards (Bailey and Jenkinson 1982).

Two studies have attempted to estimate the likely prevalence and incidence of speech and language disorders (Quirk 1972; Enderby & Philipp 1986). Enderby & Philipp (1986) suggest that about 55% of all mentally handicapped people suffer a disorder causing a speech or language problem. These figures are greater than those which Quirk (1972) suggested and which have been used to assess the requirements for staffing levels for speech therapists. One speech therapist suggested to us that it is not the child's contact with a speech therapist which contributes to more effective communication skills so much as the organization of the child's daily environment to provide opportunities for interaction and effective communication. At present there are often so few speech therapists that it is difficult for them to be involved in the organizational aspects of the school curriculum which is vital if effective communication environments are to be created. More speech therapists are certainly needed, but what is also required is a restructuring of the work of speech therapists so that their role is to assess the needs of individual children and help teachers plan how these needs can be met in the classroom, and to evaluate and monitor progress and advise on the implementation of augmentative communication systems. (Kee personal communication 1989).

Lastly, we would recommend attention to the welfare benefits of families who have a mentally handicapped child. Behaviour disorders are especially stressful when they are combined with family adversity in the form of low income, poor housing conditions, or marital problems. As our previous study showed, (Pahl & Quine 1985) the combination of a behaviourally disordered child and a disadvantaged family is likely to indicate a high level of stress and need for support, even if parents are unable to express that need. Families with mentally handicapped children have lower standards of living than comparable families without handicapped children, even if they claim the relevant benefits. All too often families are unaware of their eligibility for such benefits. Our study shows there was an appreciable number of parents who had not heard of the Family Fund adminstered by the Joseph Rowntree Memorial Trust, for example. It is important that the value of these benefits be increased and that families should be made aware of their eligibility.

SLEEP PROBLEMS IN CHILDREN WITH MENTAL HANDICAP

Introduction

Sleep disturbance is a widespread form of challenging behaviour, which affects families bringing up both handicapped and non-handicapped children. Many children have sleeping patterns which are seen as problems by their parents (Richman, 1981a). Studies have estimated that up to 20% of two-year old children and 14% of three-year old children wake regularly during the night (Richman *et al*, 1975; Jenkins *et al* 1980; 1984)). In the Isle of Wight survey, Rutter *et al* found that even at ten to twelve years old up to 20% of children are regarded by their parents as having problems of this nature (Rutter *et al*, 1970). Night-time difficulties are known to be associated with maternal distress (Richman, 1981a) and with day-time behavioural difficulties (Richman, 1981b).

The most common types of sleep problem are settling problems and sleep disruption. Settling problems refer to difficulties in getting the child to bed and settled to sleep. Some children will not go to bed, gradually falling asleep downstairs or going to bed at the same time as their parents. Some will only go to sleep if the parent lies down with them, or if they sleep in their parents' bed. Sometimes the child may keep coming out of his or her room or insist on a lengthy bed-time ritual. Settling problems can be exhausting for the parents, who may be unable to have any time to themselves at the end of the day, or may find it hard to find a sitter who is prepared to cope.

Sleep disruption refers to waking up at night after the child has gone to bed. Some wake up many times during the night and disturb their parents by calling for attention. Sometimes the child will not go to sleep until very late at night and wakes up very early in the morning, seeming to need very limited hours asleep. Severe lack of sleep can cause enormous stress to parents already tired out by the extra work of caring for a young person with mental handicap and may have serious effects on family functioning (Clements *et al*, 1986).

Young people with severe mental handicap seem to be particularly likely to present sleep problems, although evidence is relatively sparse. Table 5.1 shows the prevalence of sleep problems in four studies. Bartlett *et al* (1985), in a study of 214 children with mental handicap under 16 years of age, found that 86% of those under 6 years old, 81% of 6 to 11 year olds, and 77% of the 12 to 16 year olds were reported by parents as having sleep problems: 56% woke on average once a night, 53% had difficulty getting the child to go to bed and 56% in settling the child.

Another study, by Clements, Wing & Dunn (1986), found sleep problems in 34% of their sample of 155 children under 15. These children were drawn from the Camberwell Register and were known to the services for the severely mentally handicapped and had some of the symptoms found in early childhood psychosis. Night waking was particularly prevalent among the younger children and showed strong associations with self-injurious behaviour. Limited hours of sleep were associated with attachment to routines in other areas of behavioural functioning and were evenly spread across the age range. Both problems were found to disturb the families' sleep and to have a serious impact on family functioning. Both, in addition, were associated with day-time behavioural difficulties such as tantrums and destructiveness. The authors speculated that these two behaviours may be distinguishable in terms of their origins, maintenance and treatment.

In a recent study of the effects of early intervention into the occurrence and nature of behaviour problems in children with Down's Syndrome, Cunningham *et al* (1986) compared their sample with a general population sample investigated by Richman *et al* (1982) of children aged 3, 4 and 8, and found that a significantly higher proportion of the mentally handicapped children had marked problems in night settling, waking at night and sleeping with their parents than did the non-handicapped children. These differences remained statistically significant at all ages.

Cunningham's analysis (Cunningham *et al*, 1986) revealed that sleeping behaviours showed consistently strong associations with demographic socio-cultural factors, but not with child development variables. When cluster analysis techniques were applied, sleeping problems formed a distinct cluster, though problems to do with waking at night and going to bed had strong cross-cluster associations with other behavioural disturbance clusters. The most severe category of waking at night (three or more times per week) was significantly correlated with self-reported stress in mothers (measured by the Malaise Inventory) and frequency of smacking. An index score of sleeping problems reflecting increasing severity correlated with both maternal stress and poor marital relationships. Cunningham *et al* considered that sleep problems were largely influenced by social/cultural factors and/or child management procedures. The authors concluded: "Since these problems appear to relate to environmental factors, occur in a large number of families and cause disturbance in many, they would appear to be a worthwhile target area for intervention." (Cunningham *et al*, 1986, page 105).

Table 5.1 **Sleep disturbance in four studies of children with a mental handicap**

Study	N	Age	%
Bartlett et al (1985)			
Night settling problems	214	up to 16	56
Night waking problems			56
Going to bed			53
Clements et al (1986)			
Sleep problems	155	up to 15	34
Cunningham et al (1986) (Downs Syndrome Cohort)			
Night settling problems	120	up to 11	31
Night waking problems			59
Sleeping in parents' bed			41
Pahl & Quine (1984)			
Night settling problems	200	up to 18	51
Night waking problems			67
Parents do not get enough sleep			32

Assessment of Settling and Waking Problems in the Study

Assessment of settling and waking problems in the sample of children was carried out using the items in the Behaviour Screening Questionnaire (Richman and Graham 1971) (see Appendix 1). A settling problem is defined as severe on the BSQ if it occurs 3 or more times a week and the child takes more than an hour to settle and finally fall asleep. A waking problem is defined as severe on the BSQ if it occurs 3 or more times a week and the child wakes for more than a few minutes and disturbs parents or goes into the parents' room or bed. A mild settling problem is one which occurs once or twice a week and the child settles in less than an hour. A mild waking problem is one which occurs only once or twice a week. Below we provide randomly selected illustrations of our ratings in order to indicate the threshold for disturbance. Names have been changed to ensure anonymity.

1) **Michael M** **Case No.204**

Michael is the second of three children. He is 12 years old. He goes to bed unwillingly at 9pm but does not fall asleep usually until about 10pm. He is difficult to settle, calling out several times to his parents and sometimes coming downstairs. This happens once or twice a week and Michael takes half an hour to settle again. Michael has Down's Syndrome. He can read and write at a simple level and is friendly and outgoing. He has poor concentration. He can easily become over excited in company or frightened by loud noises and settling problems then become worse.

Rating: Mild settling problem.

2) **Sarah D** **Case No.380**

Sarah is the 13 year old daughter of divorced parents. She lives with her mother and younger sister. Sarah goes to bed at 9pm but does not go to sleep until midnight. When told it is bedtime she swears and shouts, and she calls out constantly from the bedroom or comes downstairs. This happens most nights. Her mother sees this as part of a general behaviour pattern. Sarah likes to wind her up in order to get a reaction. Sarah's mother gets angry and shouts at her. She often resorts to bribery to get Sarah to bed. It usually takes at least an hour and a half to settle Sarah. Sarah finds it difficult to get on with people and is often irritable and angry. Her concentration is poor, and she can't be left unsupervised for any length of time. She has prolonged rituals and some fears although these are not severe.

Rating: Severe settling problem.

3) **Rebecca W** Case No.66

Rebecca is the 18 year old youngest child. She wakes about twice a night once or twice a week, but goes back to sleep after reassurance from her mother. Any disturbance in daily routine will trigger waking problems. Her concentration is poor but she can be left for up to half an hour unattended. She is generally good natured and gets on well with people, but sometimes she tries to kiss people in the street or get hold of them by the hand.

Rating: Mild waking problem.

4) **John S** Case No.102

John is the 15 year old youngest child of elderly parents. He has five brothers and sisters. John wakes at least twice a night five nights a week. He calls out to his parents when he wakes. He may wake because he needs to go to the toilet or because he has something on his mind that he needs reassurance about. If he gets over excited or upset during the day, he always wakes and calls out. John is a very active boy who has variable concentration. Although he is quite good at occupying himself he can't be left alone for any length of time because he plays with electrical switches. When he is up during the night he is likely to play with the 'Economy 7' buttons. He has a tendency to pester people in a rather aggressive way. He worries a lot.

Rating: Severe waking problem.

Sleep Problems at Time One

In our sample (Pahl & Quine, 1984), at Time 1 as Table 5.1 shows, 51% of mothers reported difficulties in settling their children at night, 67% reported that their child woke during the night at least once or twice a week, disturbing their parents, and 32% of parents said they rarely got enough sleep. There was a significant association between maternal stress and mothers' reported lack of sleep, night waking problems and night settling problems. As Table 5.2 shows, reported lack of sleep and night waking problems were significantly related to the age of the child, but settling problems were not. Examination of the raw data shows that settling problems decrease until about age 15, increasing again thereafter, as perhaps young people begin to exert their rights as an adult to choose their own bedtimes.

Table 5.2 Night waking/settling problems by age of child at Time 1

Age of child	% of children with problems	
	Problems	No Problems
<u>Night Waking Problems</u>		
0 - 5	84	16
6 - 10	63	37
11 - 18	60	40
N = 199		
Chi-square = 9.0 ** d.f = 2		
<u>Night Settling Problems</u>		
0 - 5	62	38
6 - 10	49	51
11 - 18	46	54
N = 200		
Chi-square = 3.4 d.f = 2 not significant		
<u>Reported lack of sleep</u>		
0 - 5	36	65
6 - 10	27	73
11 - 18	16	84
N = 177		
Chi-square = 6.0 * d.f = 2		

Sleep Problems at Time Two

At Time 2 the data are based on 166 cases. Of the original 200 children, six had died, ten had moved out of their original health district and six could not be traced. In the following analysis the 12 children living in residential hostels and homes are excluded, since family data are not available for them. Table 5.3 shows that large numbers of children still presented disturbed sleeping patterns. Night settling and night waking have decreased between Time 1 and Time 2 and this is due to age: older children present fewer sleeping problems.

Table 5.3 Sleep problems at Time 2

	N	%
Night settling problems	62	37
Night waking problems	84	51
Sleeping in parents' bed	49	29
Parents do not get enough sleep	41	32

The pattern of associations between maternal stress problems and sleep problems which was found at Time 1 was also present at Time 2. As can be seen from Table 5.4, the mean stress scores of mothers whose children exhibited night settling or waking problems were significantly higher than those whose children had no problems. Parents reporting severe lack of sleep had significantly higher scores than parents who did get enough sleep.

Table 5.4 **Sleep problems of child by maternal stress**

	Mean	s.d.	N
Night settling problems by maternal stress			
Night settling problems	7.0	3.8	61
No problems	5.4	4.1	101
F = 6.3 ** d.f = 1 N = 162			
Night waking problems by maternal stress			
Night waking problems	7.0	4.1	82
No problems	5.0	3.6	80
F = 10.9 *** d.f = 1 N = 162			
Parental sleep disruption by maternal stress			
Parents do not get enough sleep	7.2	3.6	41
Parents get enough sleep	5.2	3.7	84
F = 7.6 ** d.f = 1 N = 125			

Association between Night Settling Problems, Night Waking Problems and Daytime Behaviour Problems

First, we examined the association between night settling problems and items of daytime behaviour, measured by the Behaviour Problem Index (see Appendix 1). Night settling problems were found to be related to a large number of daytime behaviour problems. These were management problems, hyperactivity, concentration, attention seeking, sexual problems with no social awareness, running away, inappropriate behaviour with strangers, interfering with other peoples' activities, being destructive, scattering

Table 5.5 Association between night settling problems and daytime behaviours

Behaviour N = 166	Children with settling problems %	Children without settling problems %	Chi-square
Management problems			
Problems	33	7	15.8***
No problems	67	93	
Activity			
Problems	38	7	22.5***
No problems	62	93	
Concentration			
Problems	56	27	10.3***
No problems	44	73	
Attention seeking			
Problems	44	21	8.2 **
No problems	56	79	
Sexual problems (No social awareness)			
Problems	17	1	11.8***
No problems	83	99	
Runs away			
Problems	36	7	18.1***
No problems	64	93	
Inappropriate behaviour with strangers			
Problems	27	6	12.1***
No problems	73	94	
Interferes with other peoples' activities			
Problems	31	8	12.0***
No problems	69	92	
Destructive			
Problems	22	7	6.7 **
No problems	78	93	
Scatters objects			
Problems	31	14	5.2 *
No problems	69	86	
Pica			
Problems	18	4	6.7 **
No problems	82	96	
Swears			
Problems	18	5	5.7 **
No problems	82	95	
Embarrassing behaviour			
Problems	71	30	21.5***
No problems	29	70	
Disruptive at school			
Problems	10	0	7.6 **
No problems	90	100	

objects, pica, swearing, embarrassing behaviours and being disruptive at school. Table 5.5 shows the items of daytime behaviour which were found to be associated with settling problems.

Next we examined the association between night waking problems and daytime behaviour problems. Table 5.6 shows the items of daytime behaviour which were found to be associated with night waking problems. These were encopresis, temper tantrums, moods, hyperactivity, concentration, problems with peers, attention-seeking, sucking objects, making noises, using objects for twiddles, having a number of habits, running away, stripping inappropriately, inappropriate behaviour with strangers, scattering objects, embarrassing behaviour, sexual problems without social awareness, problems with social interaction, repetitive activities and delayed echolalia.

It can be seen from the tables that many of the items associated with settling problems were also associated with waking problems and indeed there was a strong association between night settling and night waking problems. That is, children who had night settling problems also tended to have night waking problems.

Table 5.6 Association between night waking problems and daytime behaviours

Behaviour N = 166	Children with waking problems %	Children with no problems %	Chi-square
Encopresis (soiling)			
Problems	46	18	13.4***
No problems	54	82	
Tantrums			
Problems	23	9	5.0 *
No problems	77	91	
Moods			
Problems	18	6	5.2 *
No problems	82	96	
Activity			
Problems	25	10	5.4 *
No problems	75	90	

Table 5.6 Association between night waking problems and daytime behaviours (continued)

Behaviour N = 166	Children with waking problems %	Children with no problems %	Chi-square
Concentration			
Problems	46	29	4.1 *
No problems	53	71	
Problems with peers			
Problems	16	2	5.2 *
No problems	84	98	
Attention seeking			
Problems	38	22	3.9 *
No problems	62	78	
Sucks objects			
Problems	21	6	8.2 **
No problems	79	94	
Makes noises			
Problems	23	10	4.2 *
No problems	77	90	
Uses objects for twiddles			
Problems	18	6	4.2 *
No problems	82	94	
Habit score			
Problems	57	29	11.2***
No problems	43	71	
Runs away			
Problems	25	10	5.4 *
No problems	75	90	
Strips			
Problems	11	0	9.3 **
No problems	89	100	
Inappropriate behaviour with strangers			
Problems	21	6	6.9 **
No problems	79	94	
Scatters objects			
Problems	29	14	4.5 *
No problems	71	86	
Embarrassing behaviour score			
Problems	56	35	4.8 *
No problems	46	65	
Sexual problems (No social awareness)			
Problems	11	2	3.9 *
No problems	89	98	

Table 5.6 **Association between night waking problems and daytime behaviours (continued)**

Behaviour N = 166	Children with waking problems %	Children with no problems %	Chi-square
<u>Quality of social interaction</u>			
Problems	43	23	6.3 *
No problems	57	77	
<u>Repetitive activities</u>			
Problems	7	0	5.3 *
No problems	93	100	
<u>Delayed echolalia</u>			
Problems	29	11	3.6 *
No problems	71	89	

Characteristics of Children with Sleep Problems

Given the fact that settling problems and night waking problems were associated, we next went on to divide the sample into two groups, those children who had sleep problems (96) and those who had no sleep problems (70). The criteria for inclusion in the problem group were that the child had severe or mild settling or waking problems or both, as assessed by the Behaviour Screening Questionnaire (see pages 76-77).

Table 5.7 presents information on the association between sleep problems and the children's other impairments. A major difference between the groups was in the area of communication skills (use and understanding of language, signing) and academic skills (reading, writing, counting). About a third of the disordered group had poor use and understanding of communication compared with only a tenth of the non-disordered group. About two thirds of the sleep problem group had poor reading, writing and counting skills compared with a quarter of the children with no sleep problems. The sleep problem group contained a significantly higher number of children who were unable to wash, feed and dress themselves. Also, significantly more of the problem group were incontinent. As we saw in the Time 1 data, sleep problems were significantly associated with age, which may have been an explanation for some of the differences found between the two groups:

increasing age was associated with decreasing problems.

Table 5.7 Characteristics of children with sleep problems

Child variable	% of children with problems Children with sleep problems	 Children without sleep problems	Chi-square
Using Communication			
Good	44	81	
Fair	16	6	23.9***
Poor	40	13	
Understanding Communication			
Good	49	87	
Fair	16	4	26.0***
Poor	35	9	
Academic skills (Ability to read, write and count)			
Good	21	37	
Fair	18	39	22.7***
Poor	62	24	
Self help skills			
Good	28	72	
Fair	38	17	30.8***
Poor	34	11	
Continence			
Fully established	49	84	
Occasional lapses	15	9	22.6***
No control	36	7	
Age			
5 - 10	45	14	
11 - 15	29	33	19.77***
16 - 21	26	53	
Epilepsy			
No medication/no seizures	67	87	
Medication required/only occasional seizures	26	11	9.5 **
One or more seizures per month	7	2	

A further finding was that children with sleep problems were more likely to have a diagnosis of cerebal palsy or named conditions excluding Down's Syndrome. Table 5.8

shows that 71% of children with cerebral palsy, and 83% of children with other named conditions associated with mental handicap had sleeping problems. By contrast, only 44% of children with Down's Syndrome and 57% of children with non-specific mental handicap had problems. This may explain why Cunningham's study of children with Down's Syndrome found lower rates of sleep problems than were found in this study. The children with sleep problems were also significantly more likely to suffer from epilepsy: 33% of children with sleep problems were epileptic compared with 13% of children without sleeping problems. Given that epilepsy is a sign of neurological impairment, this finding, in combination with the association with diagnosis, suggests that there may be a neurological component in sleep disorder.

Table 5.8 Diagnosis of children with sleep problems

Diagnosis	Sleep problems	No sleep problems
Downs syndrome	44	56
Cerebral Palsy	71	29
Non-specific mental handicap	57	43
Other known conditions*	83	17

* Other known conditions include brain damage caused by accident or illness, developmental defects such as spina bifida, foetal environmental syndromes such as rubella, and primary genetic or chromosomal abnormalities and metabolic disorders.

Day Time Behaviour of Children with Sleep Problems

The children with sleep problems were significantly more likely to have day time behaviour problems, as we saw earlier. They had a higher score on both the Behaviour Screening Questionnaire (Richman *et al* 1982) and the Behaviour Problem Index (Cunningham *et al* 1986). As Table 5.9 shows, children with sleep problems had a mean score of 10.1 on the Behaviour Screening Questionnaire, while children with no problems had a mean score of 5.0. Similarly, on the Behaviour Problem Index, children with sleeping problems had a mean score of 6.6 while children with no problems had a mean score of 3.9. Richman (1981b; 1985) reports similar findings for non-handicapped children as do Clements, Wing and Dunn (1986) with a sample of mentally handicapped children.

Table 5.9 **Daytime behaviour problems in children with sleep problems**

	Children with sleep problems (96)		Children without sleep problems (70)			
	Mean	S.D	Mean	S.D.	d.f	F[1]
Behaviour Screening Questionnaire (Richman et al 1982)	10.1	3.9	5.0	3.3	1,164	76.4***
Behaviour Problem Index (Cunningham et al 1986)	6.4	2.1	3.9	1.4	1,165	70.9***

[1] Analysis of variance

As with the parents of children with behaviour problems, parents of children with sleep problems were significantly more likely to report that their child was difficult to manage, could not be left unsupervised and was difficult to keep occupied and safe. Over two thirds of children with sleep problems were described as very difficult or difficult to manage compared with a fifth in the non-disordered group. Similarly 83% could be left unsupervised for less than an hour compared with 43% of children without sleep problems. Two thirds of children with sleep problems required a lot more attention to keep safe and occupied than other children of the same age compared with only a third of children with no problems.

Table 5.10 Management difficulties of children with sleep problems

Management problem	% of children with problems Children with sleep problems	 Children without sleep problems	Chi-square
<u>Ease of management</u>			
Easy	30	77	
Difficult	47	19	36.4***
Very difficult	23	4	d.f = 2
<u>Time can be left unsupervised</u>			
About 15 minutes	67	30	
About 30 minutes	16	13	40.7***
About 1 hour	6	14	d.f = 3
More than 1 hour	11	50	
<u>Attention to keep occupied</u> (comparison with other children of same age)			
Less attention	6	11	
As much attention	8	30	25.4***
A bit more attention	15	26	d.f = 3
A lot more attention	71	33	
<u>Attention to keep safe</u> (comparison with other children of same age)			
Less attention	7	3	
As much attention	4	19	24.9***
A bit more attention	10	30	d.f = 3
A lot more attention	79	48	

Association between Family Variables and Sleep Problems

There were relatively few associations between socio-demographic variables and sleep problems. However, there were significant differences between the two groups of children on the Problem Inventory (Tavormina *et al*, 1981), the Malaise Inventory (Rutter *et al* 1970) and a measure of Maternal Irritability (Richman *et al* 1982). Mothers of children with sleep disorders were more likely to have higher scores on the Problem Inventory than were mothers of children without problems. The Problem Inventory records problems the family has to face because of the child's handicap, such as extra demands on time and energy, decreased social life, tense home atmosphere, shortage of family friends and disruption of

Table 5.11 Association between family variables and sleep problems

Family variables	% of children with problems Children with sleep problems	 Children without sleep problems	Chi-square
Social class			
Non manual	28	39	1.6 N/S
Manual	72	61	
Income			
<£5,000 p.a.	87	93	1.0 N/S
>£5,000 p.a.	13	7	
Family composition			
Two parent family	82	88	0.8 N/S
Single parent family	18	12	
Housing			
Owner occupied	62	70	0.8 N/S
Council/other	38	30	

	Mean	S.D	Mean	S.D	F[1]
Maternal stress score	7.0	4.0	4.7	3.6	13.9***
Impact score (PINV)	23.5	8.9	14.2	8.5	45.9***
Acceptance and adjustment to child (Judson)	113.4	17.2	117.0	16.3	1.9 N/S
Marital disatisfaction score	17.1	4.0	16.7	3.7	.5 N/S
Frequency of smacking	1.7	.85	1.5	.66	2.8 N/S
Feared loss of control	1.4	.62	1.2	.54	3.5 $p<0.06$
Maternal affection	1.7	.51	1.5	.60	2.7 N/S
Maternal irritability	2.7	1.1	2.2	.8	13.8***

---

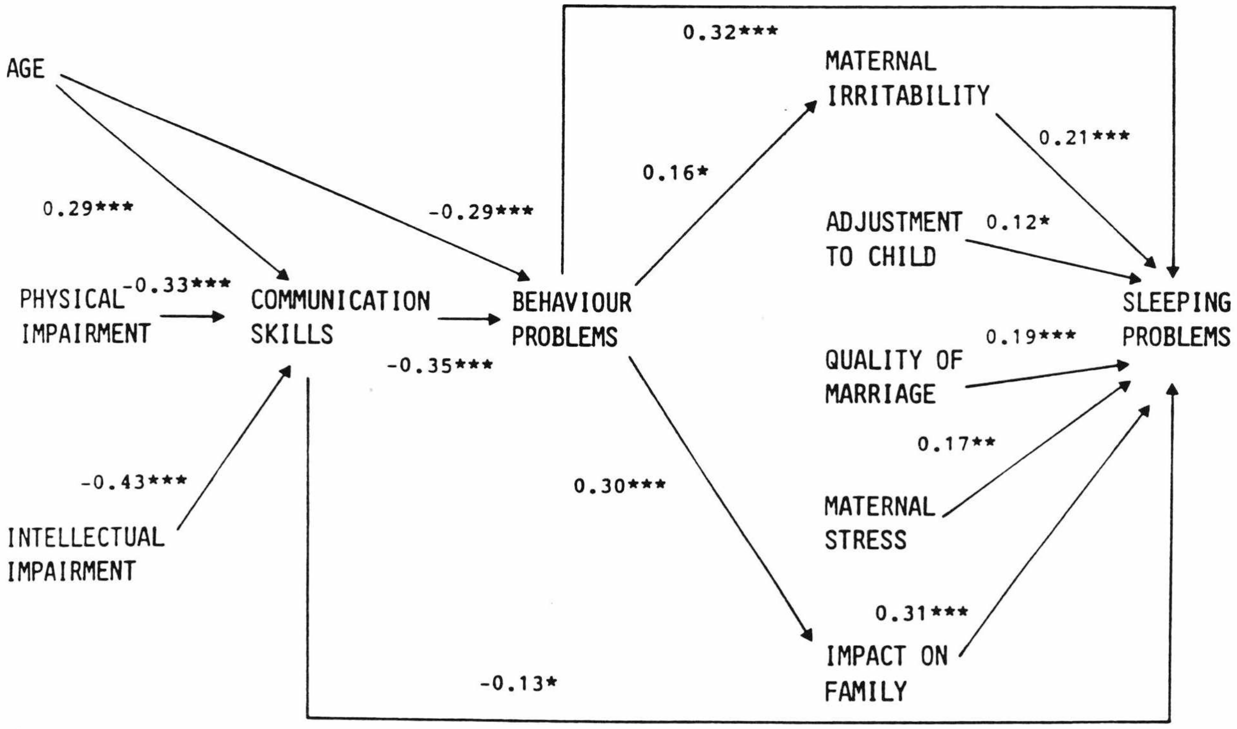
[1] Analysis of variance

family routine. Mothers were also more likely to report frequent irritability with the child and they had significantly higher stress scores as we have shown earlier.

A Path Model of Sleep Problems

To conclude our analysis we produced an index of sleep problems reflecting increasing severity, and used multiple regression analysis to determine which of the child's, parents' or family's characteristics were the main predictors of sleep disturbance. The Sleep Index had high internal consistency, with an alpha coefficient of .76 (see Appendix 1). Regression analysis it will be recalled, calculates how much effect each of the set of possible descriptor variables has on the outcome measure, whilst simultaneously allowing for any effects which those variables may have on one another. From a detailed regression analysis we were able to plot the main "causal" pathways.

Figure 5.1 Path model of sleeping problems



NB: These variables explain 50% of the variance in sleep scores

As can be seen from the model in Figure 5.1, there is no direct link between the Sleep Index and the level of physical and mental impairment: the severity of physical or mental impairment does not in itself determine whether the child will have sleep disturbance. These factors work through communication skills which have both a direct effect on sleep (perhaps by making a child more difficult to train) and an indirect effect through the behaviour index, as one might expect. Inability to communicate needs may be frustrating for the child, and difficult behaviour may be a response to this. There is a growing body of evidence which shows that increased rates of behaviour problems occur in children with poor communication skills (Quine, 1986; Gould, 1977; Leudar *et al*, 1987). Behaviour itself has a direct effect on sleep and also works through maternal irritability and family impact. It seems likely that poor communication skills may result in frustration for both mother and child. For the child this may result in agressive and difficult day and night-time behaviour. For the mother, the inability to communicate with the child may make it much harder to initiate the training practices which might establish more appropriate behaviour and better sleeping patterns. Undesirable behaviour may also sometimes have linguistic functions in non-speaking children (Kiernan, 1986). For example, if a child behaves badly at night time, he is likely to attract his parents' attention. Difficult behaviour can be a useful way of gaining attention in a non-speaking child.

The model shows that maternal stress, the quality of the parents' marriage, acceptance of and adjustment to the child and maternal irritability exert direct effects on sleeping problems alongside communication skills and behaviour problems. There are two points to note. Firstly, the causal direction of the three parental variables cannot precisely be determined by a non-recursive model such as this. These variables are important predictors of whether the child will have sleep disturbance, but their role may not necessarily be causal. They may be both a cause and an effect of sleep disturbance. That is to say, feedback loops almost certainly exist from the sleep index back to maternal irritability, maternal stress and marriage. Having a child who sleeps badly, waking a large number of times during the night, and disrupting his/her parents' sleep, may have serious effects on maternal irritability and stress levels and on the quality of the parents' marriage. Marital intimacy may be made difficult by a child who regularly insists on sharing his parents' bed, for example. Loss of sleep may make mothers tired, irritable and stressed. Secondly, the figures over the paths are beta coefficients which show the strength of the paths. To put it simply, the model suggests that a 100% increase in behaviour problems would lead to a 32% increase in sleeping problems on the direct path. Similarly, a 100% increase in age would lead to a 29% increase in communication skills.

The overall effect of behaviour can be assessed by multiplying the beta coefficients of the paths from behaviour to maternal irritability and maternal irritability to sleep problems, and the paths from behaviour to impact on the family and impact on the family to sleep problems, and adding the resulting figures to the beta coefficient of the direct path from behaviour to sleeping problems. The effect of behaviour on sleep is thus found to be 44%: a one hundred per cent increase in day time behaviour problems would lead to a 44% increase in sleep problems. Altogether, the factors in the model account for 50% of the variance in the Sleep Index.

Discussion

Children with a mental handicap are more likely to present problems of night settling, night waking and sleeping in their parents' bed than are non-handicapped children. This study found that large numbers of mentally handicapped children had such problems. Sleep problems are related to age, though significant numbers of young people aged 15 or over still have irregular sleeping patterns. Sleep problems are very strongly associated with maternal stress. A path model shows that communication skills are a key factor and this may reflect the difficulty parents experience in trying to train children with limited communication skills to present more socially appropriate behaviour. The path model also draws attention to the fact that families containing children with irregular sleeping problems are often families with many other problems of family functioning possibly, though not necessarily, causally associated with the sleep difficulties. This highlights the complex problems for intervention work in families as described by Sandow & Clarke (1978). Sleep disturbance in young people often coexists with family disarray and maternal stress, but the causal links may be complex. Families may be short of time, energy and resources, or they may be reluctant to disturb a precarious equilibrium with which they may have lived for some time. Sloper and her colleagues have discussed the possible difficulties which can arise from intervention work which does not fully appreciate these issues (Sloper *et al* 1983).

Our findings carry important implications for service providers who are faced with the task of providing help for parents caring for a child who presents sleeping problems or other challenging behaviour. As has been noted in the last chapter, significant advances have been made in the development of effective methods for dealing with sleep problems and other challenging behaviour. Night sedation appears to be of limited value for managing sleep problems in young people (Kales *et al*, 1970; Douglas & Richman 1984; Richman 1985a; Bax, 1980), but behavioural approaches have recently been developed (Anderson, 1979; Milan *et el*, 1981; Hewitt, 1981, 1985; Sanders *et al*, 1984; Howlin, 1984; Douglas & Richman 1984; Richman, 1985b; Richman *et al* 1985). These seem to offer promise in the management of many children's problems. A number of behavioural techniques such as stimulus control, contingency management, shaping, positive reinforcement and extinction have been used with success to help children establish and maintain more regular sleep patterns. Research suggests that parents can be effective teachers of their own children (Yule 1975; Cunningham 1985; Whitaker 1985) and can be taught to use behavioural methods (Ayllon & Roberts 1973; Berkowitz & Graziano 1972; Gath 1979; O'Dell 1974).

Success has also been achieved in introducing behavioural techniques to professionals such as nurses and health visitors, and teaching them how to advise parents to use them to help eliminate a range of behavioural problems (Bidder *et al*, 1975; Clements *et al* 1980; Hewitt & Burden 1984; Callias & Carr, 1975; Sanger *et al* 1981). Research suggests that favourable outcomes may be achieved quite quickly - within a few months (Hewitt, 1985). A research study to investigate the feasibility and effectiveness of such methods is now being carried out by one of the researchers (Quine, 1988), funded by the Joseph Rowntree Memorial Trust.

STRESS AND COPING IN MOTHERS OF CHILDREN WIH MENTAL HANDICAP

Introduction

In recent years a growing number of studies have examined the effect on family functioning of caring for a child with severe mental handicap. Early studies adopted a pathological approach (Holt 1958; Kanner 1953; Kew 1975; Schonell & Watts 1957) in which it was assumed that psychological distress was inevitable among family members, particularly mothers, and that families in which there is a mentally handicapped child are a homogeneous group. Many of the studies had methodological weaknesses such as lack of adequate control groups, or narrow focus upon the difficulties of families. A failure to consider socio-economic variables and the nature and severity of the child's impairments as possible sources of difference in family response contributed to the self-fulfilling nature of the assumptions of homogeneity and pathology (Byrne & Cunningham 1985).

More recent approaches to studying the effects of mentally handicapped children on family functioning include investigating which families or family members are vulnerable to the stress engendered by the presence of the mentally handicapped child, what are the unmet service needs of families, which families cope with and adapt to the stresses and how they do so (Beckman 1983; Quine & Pahl 1985; Burden 1980; Crnic, Friedrich and Greenberg 1983; Turnbull, Brotherson & Sumners 1984; Kazak & Marvin 1984; Kornblatt & Heinrich 1985; Schilling et al 1984; Chetwynd 1985; Kirkham et al 1986). Byrne & Cunningham (1985) provide a comprehensive review of these studies. Stress experienced by the carers of children with mental or physical handicaps is an important issue because it affects both the well-being of the mothers themselves and the outcome for the children. The experience of stress symptoms may influence the ability of individuals to perform the tasks of caring, increasing the likelihood of requests for long term care (Wilkin, 1979; Sherman & Cocozza, 1984). Stress may also affect the willingness of carers to perform the caring role and may lead to neglect and abuse of children with physical and mental handicaps (Sandgrund, Gaines & Green, 1974; Martin 1976; Embry 1980; Schilling & Schinke, 1984).

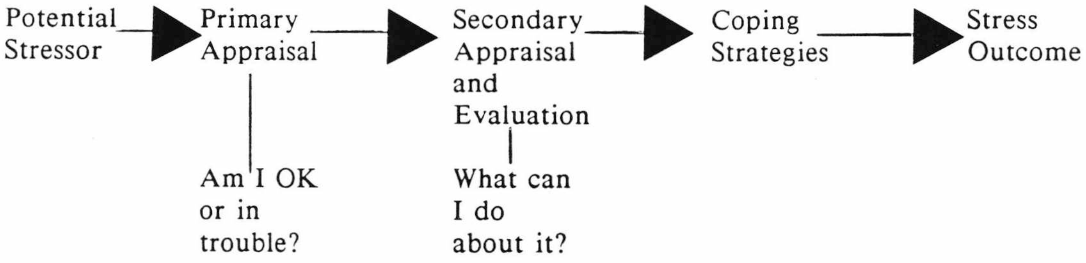
The aims of the analyses reported in this chapter are to determine which child characteristics are associated with maternal stress and to examine the family and social characteristics which may buffer or mediate the effects of stress. We wanted to trace the mechanisms which might help to explain the nature of the links between life strains such as caring for a child with severe mental handicap and the presence or absence of symptoms of stress.

A Model of Stress and Coping

There have been three main approaches to the study of stress. The first approach describes stress as the person's <u>response</u> to negative or disturbing factors in the environment (Selye, 1956; Kagan & Levi, 1971; Levi, 1974). The second approach focusses on stress in terms of the stimulus characteristics of those negative or disturbing environments (Symonds, 1947; Weitz, 1970; Welford, 1973). In the third approach, stress is viewed as the outcome of a 'lack of fit' between the person and his/her environment (Sells, 1970; Cox & MacKay, 1981; Lazarus, 1976; Folkman 1984; Folkman & Lazarus 1985; Lazarus 1981). The main difference between these approaches is in the emphasis in the definitions proposed and the methods adopted.

For the purposes of our present research the third approach is the most satisfactory, emphasising as it does the relationship between the person and his/her environment. The approach defines stress as the psychological state which derives from peoples' appraisals of their adaptation to the demands which are made of them (Lazarus 1966; Cox et al 1983). Stress resides in the peoples' perceptions of the balance or transaction between the demands on them and their ability to cope with these demands (Cox 1987). A central feature of the transactional approach to stress and coping is the process of cognitive appraisal (Lazarus 1966). Holroyd and Lazarus (1982) have defined this as "the evaluative process that imbues a situational encounter with meaning". Cox (1987) has elaborated on this definition suggesting that cognitive appraisal contains four elements: 1) peoples' perceptions of the demand on them, 2) their personal characteristics and coping resources, 3) the constraints that they are under when coping and 4) the support they receive from others in coping. The absolute magnitude of demands is, therefore, not the most important factor which determines the experience of symptoms of stress. What is important is the discrepancy between a person's perception of the demands made upon him/her and his/her ability to cope with those demands. There may thus be significant individual differences in the stress experienced by people faced with demands such as caring for a severely mentally handicapped child because of differences in ability to cope.

Figure 6.1: **A Model of Stress and Coping**



Coping Resources - physical, material, social, psychological

Lazarus et al (1974) define coping as problem solving efforts made by an individual when the demands of a given situation tax adaptive resources. Coping efforts may be directed toward the threat itself, or toward efforts to regulate the emotional distress caused by the threat. It is important to distinguish between coping resources and coping strategies. Coping resources are "aspects of the individual's external and internal environment which are able to mediate in a positive or negative direction the individual's response to the advent of a stressor" (Shapiro 1983). The nature and type of coping generated by the individual will be determined by the coping resources in the person's environment. Folkman et al (1979) outline five categories of coping resource including utilitarian resources, e.g. socio-economic status, money, available services; health, energy or morale, e.g. depression, pre-existing physical and psychiatric illness; social networks e.g. close interpersonal relationships; general and specific beliefs, e.g. self-efficacy, mastery, self-esteem; and problem solving skills, e.g. intellectual skills, cognitive flexibility and complexity and analytic ability which enable people to formulate alternative courses of action. In most discussions of coping the assumption is made that coping is an organized activity and that "coping strategies" are employed. Coping strategies are actions taken in specific situations that are intended to reduce stress such as expressing emotions, beginning a new activity, appraising the problem or asking for help. This definition of coping does not carry any negative connotation for the person who fails to cope: demands may simply exceed resources. A person may be overwhelmed by the sheer weight of demands made upon him/her.

Stress and Coping in Mothers of Children with Mental Handicap

The aims of this chapter are to determine the variables associated with stress in our sample of mothers of children with severe mental handicap, and to investigate the factors which may buffer or mediate the effects of stress. We hoped to gain some insight into the relationships between the categories of coping resource described by Lazarus and his colleagues, and vulnerability to or resistance to stress.

We characterized the consequences of poor coping and stress in three ways. Firstly, we reasoned that if the mother of a handicapped child was suffering from the effects of stress, this might show itself in measurable physical and psychological symptoms. Secondly we believed that poor coping might result in the mother perceiving herself to have a greater number of child-related problems. Thirdly we expected that poor coping resources and stress might result in poor acceptance of and adjustment to the handicapped child. We used the Malaise Inventory (Rutter et al 1970a) to measure the constellation of physical and psychological symptoms commonly associated with stress. The Problem Inventory (PINV) (Tavormina et al 1981) was used to tap the mothers' perceptions of family problems related to the handicapped child, and the Judson Scale (Judson and Burden 1980) was used as a measure of mothers' acceptance of and adjustment to the child (see Appendix 1).

Our first measure, the Malaise Inventory, is a 24 item binary choice questionnaire designed to measure physical and psychological symptoms associated with emotional distress. It was used in our previous work (Pahl & Quine, 1984; Quine & Pahl, 1985). Its reliability and validity have been investigated in a number of studies and found to be satisfactory (Bebbington & Quine 1987; Quine and Charnley 1987). It has been used in a number of studies of handicapped children (Dorner 1975; Gath 1978; Burden 1980; Quine & Pahl 1985; Shepperdson 1988).

Our second measure was the Problem Inventory (PINV) (Tavormina et al 1981). The Problem Inventory is a check list of difficulties which may be encountered by mothers caring for disabled children. Each mother rates the following areas in terms of frequency of occurence from (0) never to (4) always: extra demands on time and energy, decreased social life, tense home atmosphere, pressure to do the right thing to take proper care of the child, the extent to which life is centred on the child's needs, special problems the family has to cope with, shortage of family friends, constant need to watch over the child, less time to devote to other children, and disruptions of family routine. It was hypothesized that mothers who cope well would achieve low scores on this scale. Although the scale does not assess all possible outcomes indicative of successful coping, it does address a number of critical variables reflecting the outcome of coping.

Our third measure was the Judson Scale (Judson & Burden 1980). The Judson Scale consists of 22 bipolar items. The respondent places a tick along a seven point scale to indicate how strongly she agrees or disagrees with each item. The items are designed to tap four areas: the mother's self concept, her feelings about the child, her judgement of the child's capabilities, and her feelings about her interactions with professionals. Scoring these items produces a scale which makes possible an operational definition of positive adjustment to the child. (See Appendix 1). We hypothesized that mothers who coped poorly would have low scores on the Judson scale.

To investigate the relationships between the three dependent (outcome) variables and a wide range of independent (descriptor) variables, we used multivariate analysis. Our choice of predictor variables which were theoretically important for inclusion in the analyses were guided by our own earlier research and the research of other investigators. There are useful reviews by Byrne & Cunningham (1985), and Gallagher et al (1983). The variables can be divided into three groups: characteristics of the child, mothers' perceived need for help from the services, and characteristics of the family which may also be conceptualized as coping resources.

Characteristics of the child which were considered important as potential sources of stress were the severity of the child's physical and intellectual impairment, academic skills, communication skills, age, behaviour, supervision needs and caretaking demands. Expressed need for help from the services for a variety of problems concerned with the handicapped child was included in the analysis since it provided an implicit measure of whether the mother felt her resources to be stretched. Characteristics of the family which were considered to be potentially influential as coping resources were parental age, family composition, family size, birth order, social class, income, financial worries, adequacy of housing, parental health, perceived control of events, confidence, perceived ability to cope on the part of the mother, marital satisfaction, family stress, social support and maternal adjustment to the child.

We also included the Measure of Daily Coping (MDC) developed by Stone & Neale (1984) to provide information about the coping strategies utilized by mothers (see Appendix 1). The MDC consists of a description of eight coping styles and asks subjects to indicate whether they use each or any of them to help them cope with specific problems they encounter (in this case, the problems encountered in caring for a child with severe mental handicap). The coping styles and descriptions are presented below.

Description of the Coping Categories

Category		**Description printed on the form**
1.	Distraction	Divert attention away from the problem by thinking about other things or engaging in some activity.
2.	Situation redefinition	Try to see the problem in a different light that make it seem more bearable.
3.	Direct action	Think about solutions to the problem, gather information about it, or actually do something to try to solve it.
4.	Catharsis	Express emotions in response to the problem to reduce tension, anxiety or frustration.
5.	Acceptance	Accept that the problem has occurred, but that nothing can be done about it.
6.	Seeking social support	Seek or find emotional support from loved ones, friends or professionals.
7.	Relaxation	Do something with the implicit intention of relaxing.
8.	Religion	Seek or find spiritual comfort and support.

Our choice of predictor variables was determined mainly by theory as we made clear above. To reduce the number of variables to a manageable set, we chose to include in the main multivariate analyses only those which univariate analysis showed were related significantly to one or more of the outcome measures. Correlation, analysis of variance and univariate regression were used as appropriate and the 5% level of significance was taken as our criterion for inclusion.

Physical and Psychological Symptoms of Stress: the Malaise Inventory

Preliminary analyses

From our univariate analyses, a large number of child and family variables were found to be related to maternal stress (Malaise). The child variables which were significantly related to higher Malaise scores were the child being less than fifteen years of age, having higher scores on the behaviour problem index, higher scores on the sleep problem index, having poorer academic skills, having poorer communication skills, being difficult to manage, being difficult to keep occupied, having a higher dependency score and having greater care-taking demands. The family variables which were significantly related to higher Malaise scores were greater marital dissatisfaction, lower social class, lower income, financial worries, not having a car, a tense home atmosphere, more severe life events, maternal unemployment, being punitive and irritable towards the child, poorer acceptance of and adjustment to the child, pereived inadequacy and unavailability of social support, higher scores on the problem Inventory, higher extra work scores, recent maternal and

Table 6.1 **Univariate regression analysis showing variables associated with Malaise scores**

Child Variables	% of variance explained	sig level	N
Childs age (>15) (-)	5	**	166
Academic skills (-)	2	*	166
Use of communication (-)	4	*	166
Behaviour problems (+)	9	**	162
Sleep problems (+)	6	***	162
Management difficulties (+)	5	**	162
Attention to keep occupied (+)	2	*	162
Care-taking demands (+)	5	**	166
Dependency (+)	2	*	166
Mobility	N/S		166
Parent Variables			
Social class (+)	9	***	162
Income (-)	2	.07	164
Financial worries (+)	10	***	159
Family size	N/S		164
Family composition	N/S		164
Housing problems	N/S		164
Family problems (PINV) (+)	7	***	162
Life events (+)	12	***	166
Acceptance of child (Judson) (-)	14	***	164
Mother employed/unemployed (-)	3	*	156
Recent maternal ill-health (+)	39	***	166
Recent paternal ill-health (+)	4	*	166
Marital satisfaction (-)	3	*	139
Tense home atmosphere (+)	10	***	164
Perceived adequacy of social support (-)	5	***	164
Perceived availability of social support (-)	3	*	162
Parental attitudes to child (+)	4	**	164
Possession of car (-)	3	*	161
Maternal confidence (-)	9	***	162
Coping through catharsis (+)	8	***	155
Perceived coping skills (-)	26	***	162
Feeling lonely (+)	11	***	144
Extra work score (+)	5	**	162
Expressed need for help from services (+)	8	***	162

NB: +/- = direction of relationship

paternal ill-health, higher expressed need for help with the services, lack of confidence, feeling lonely, poor assessment of coping abilities, and coping through catharsis (weeping, expressing emotion).

As Table 6.1 shows the pattern of results was similar to that found in our previous study (Pahl & Quine 1984) where lower social class, low income, money worries, family adversity, feelings of social isolation, extra work, child management problems, recent maternal ill-health, maternal unemployment, lacking a confiding marital relationship, the child having an unusual appearance, and child behaviour problems at night and during the day were all found to be associated with higher Malaise scores. In the current study, age of the child also was found to affect Malaise scores: it was found that children older than 15 were less stressful for their mothers. This was not found in the previous study where age was considered only as a continuous variable. One variable which was associated with Malaise in our first study was feeling that the child had an unusual appearance. We were particularly interested in this variable since it seemed to identify mothers who had a negative appraisal of their child. At Time 2, we used a more sophisticated measure, the Judson Scale, (Judson & Burden 1980) to tap positive and negative feelings toward the child, and Judson scores were significantly associated with Malaise scores at Time 2.

As a next step, the intercorrelations among the independent variables in Table 6.1 were calculated to test whether any pair of independent variables was confounded - that is, correlated at 0.6 or above - since it was important to avoid multicollinearity in our main multivariate analyses. Four pairs of confounded variables were discovered: sleep problems and daytime behaviour problems; communication skills and academic skills; mobility and dependency scores; and dependency and extra work scores. A series of bivariate regression analyses were performed in order to decide which of the confounded independent variables was the stronger and so should be included in the multiple regression analysis. The result was that behaviour problem scores, academic skill scores and extra work scores were retained and the remainder were rejected.

Testing the model of maternal stress and coping

So far we have identified a number of family and child characteristics and aspects of caring which are significantly associated with maternal stress. These associations do not take account of the interaction between variables nor do they allow us to test our model. Multiple regression analysis, however, does both these things, and was therefore used in our main analyses to identify the most important factors among child and family characteristics and aspects of caring.

Three multiple regression analyses on the Malaise Inventory were performed. The first was exploratory, including all the independent variables selected from our preliminary analyses. These were entered in a stepwise procedure. It was important to do this to ensure that we chose the most powerful stressor and coping resource variables from among the predictor variables in order to achieve an adequate test of the model at the second stage. The second procedure entered variables in a hierarchical order exemplified by Freidrich et al (1985) in order to test our model of coping. The third analysis investigated the factors predicting change in the outcome of stress over time.

Table 6.2 **Stepwise multiple regression analysis of parent and child variables and Malaise Scores**

Step variable entered	% of variance explained	addition to % variance	Sig. of beta in final equation
1. Recent maternal ill-health	36.1	36.15	***
2. Behaviour problems	43.0	6.9	**
3. Assessment of coping skills	47.2	4.2	**
4. Social class	50.2	3.0	***
5. Acceptance of and adjustment to child	52.2	2.0	**
6. Financial worries	53.6	1.4	*
7. Age of child	54.8	1.2	**
8. Academic skills of child	56.0	1.2	*

F = 25.0*** d.f = 8,157 N = 166

The results of the first analysis are presented in Table 6.2. The maternal characteristic explaining the greatest proportion of the variance in Malaise scores was recent maternal ill-health. The relationship between physical and emotional health has been found in a number of studies (Bebbington et al 1988; Brown & Harris 1978; Henderson et al 1981). Malaise was also associated with behaviour problems in the child, maternal assessment of coping skills, social class, acceptance of and adjustment to the child (Judson scores) financial worries, age, and poor academic skills of the child. These variables explained 56% of the variance in Malaise scores. Among the child variables, behaviour problems are the major stressor for mothers, followed by younger age and poor academic skills. The latter may well be a reflection of the child's IQ, which was not tested, and suggests that children who are more intellectually impaired are more stressful.

Figure 6.2: A Model of Stress and Coping

Stressors	Coping Resources	Coping Strategies	Stress
Child characteristics	- Utilitarian	- Distraction	Malaise Scores
	- Health/Energy/Morale	- Situation redefinition	
	- Social Networks	- Direct action	
	- General & specific beliefs	- Catharsis	
	- Problem solving skills	- Acceptance	
		- Seeking social support	
		- Relaxation	
		- Religion	

The second analysis was designed to test our model of coping which is shown in Figure 6.2. The variables were entered into the regression analysis in a hierarchical order, in a way which reflected their assumed causal priority. The variables were grouped into stressors and coping resources, as the model requires. Stressors were variables related to the child which were seen to affect mothers' stress scores, namely child behaviour problems, age, and academic skills scores (see Appendix 1). Coping resources were those variables identified by Folkman et al (1979) as factors which may mediate the effects of stress. Folkman et al (1979) identified five categories of coping resources: utilitarian resources, health/energy/morale, social networks, general and specific beliefs and problem solving skills. The variables conceptualized as potential stressors were entered first, since they were assumed to predate the coping process, having existed since the child's birth.

Secondly the variables conceptualized as coping resources were entered: social class and financial worries from utilitarian resources; Judson scores from general and specific beliefs; marital satisfaction from social support; and assessment of coping skills from problem solving skills. Recent ill-health (from health/morale), which can also be seen as a coping response to stress, was entered last as a third "block" in order to determine its contribution to stress when all other variables had been partialled out. The results of the analysis can be seen in Table 6.3 below.

Table 6.3 Hierarchical regression analysis of child variables and coping resources

Step variable entered	% of variance explained		% additional variance explained	F Change	Sig. of beta in final equation
<u>Child stressor variables</u>					
1. Behaviour problems index	9.0	} 12%	9.0	16.3***	*
2. Age of child	11.7		2.7	5.0 *	*
<u>Coping resources</u>					
3. Coping skills assessment	30.5		18.7	43.8 ***	**
4. Social class	35.9		5.3	13.4 ***	***
5. Judson score	39.0	} 43%	3.2	8.4 **	**
6. Money worries	42.0		3.0	8.2 **	*
7. Recent ill-health	54.8		12.7	44.6 ***	***

F = 27.4*** d.f = 7,158 N = 166

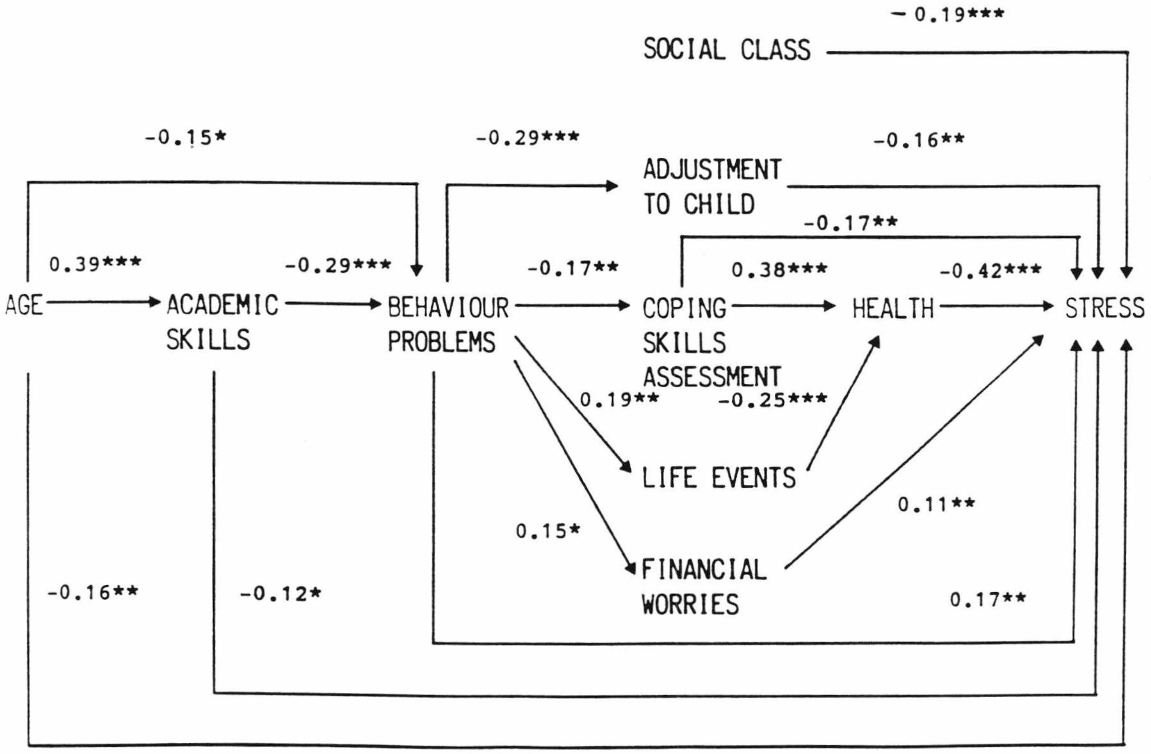
Table 6.3 shows that behaviour problems in the child and age contribute 12% of the variance in the outcome measure. The more important was behaviour problems, and this replicates the findings of Sloper et al 1988 who conducted a similar analysis. Of the six coping variables, five were significant and included in the regression statement. These were assessment of coping skills, social class, Judson scores, money worries and recent ill-health. Marital satisfaction was not significant. Coping resource variables added an additional 43% of explainable variance. This was greater than that accounted for by the stress of behaviour problems and age. Each variable entered into the analysis explained a significant proportion of additional variance as shown by the significance of the F change. Altogether the variables explained 55% of the variance in Malaise.

The hierarchical analysis was repeated, entering the coping variables first followed by the child characteristics, in order to investigate whether the coping resource variables were able to "wash out" the effects of the stressor variables. This time, the Behaviour Problems Index failed to enter the final equation after the other variables, suggesting that the variables conceptualized as coping resources did in fact mediate the effects of behaviour problems on stress. A further variable, family conflict, also entered the equation, contributing an additional 2% of the variance. Age still entered the equation, but contributing far less variance than in the previous equation - 2% only.

The results of these analyses elaborate the findings of our previous research (Quine & Pahl 1985) and offer support for the Folkman/Lazarus model of stress. Being middle class with few financial worries appears to buffer the effect of stressful behaviour for mothers of children with severe mental handicap, showing the strong impact of "utilitarian coping resources". In this study we have chosen to conceptualize such factors as class and financial resources as coping factors, but it must be emphasized that they could also be viewed as stressors. In these analyses they have been shown to have the ability to mediate the harmful effects of behaviour disorder, and so we believe they are more usefully conceptualized as coping resources. Mothers of higher social class and greater financial resources are more able to cushion the effects of caring for a child with severe handicap by buying child minding and cleaning services to give them a break from caring and household duties. They are also more likely to own household equipment such as washing machines and tumble driers which will make the task of caring less onerous. They are more likely to own their own home and to have more room for the child to play. They are more likely to have been educated to a higher level, giving them more access to information and also the analytic skills to enable them to formulate more positive coping strategies. They generally enjoy better health than working class women.

As to the other coping resources, "general and specific beliefs" were represented by the Judson scores. Mothers who had positive adjustment to and acceptance of their child had lower stress scores. The "health/energy/morale" coping resource was represented by the mother's appraisal of recent ill-health. Mothers who reported little recent ill-health had lower scores. The association of this variable with stress is not surprising since health could itself be conceptualized as a coping outcome or at least as a coping response, and is highly correlated with Malaise. "Problem solving skills" were represented by mothers' assessment of their coping skills. Women who felt that they were able to influence their own lives and achieve positive outcomes had lower scores on the Malaise Inventory. The Folkman/Lazarus model of stress has its origins in cognitive theory, emphasizing the process of appraisal as an important mediator related to coping. Cognitive appraisal involves the individual in a continual monitoring of the balance between the demands made on him/herself and his/her perceived ability to deal with those demands.

Figure 6.3: A Path Model of Stress Scores



NB THESE VARIABLES EXPLAIN 56% OF THE VARIANCE IN STRESS SCORES

Thus the presence of the mothers' assessment of their coping skills in the solution to the regression analysis lends further support to the model.

It is important to note the interrelatedness of the variables we are discussing. It is clear that difficult behaviour can be stressful for mothers, but conversely, stress may make mothers tired and irritable, less affectionate toward and less able to deal with a difficult child, who in turn becomes even more difficult to deal with. Thus, difficult behaviour may both cause and be caused by stress. Analysis of the cross sectional data cannot conclusively demonstrate causality, but it can suggest possible causal models for further testing. We found it useful to plot the effects on stress scores of the variables we have discussed, using path analysis, which is a way of showing in diagrammatic form the "causal" pathways suggested by multiple regression. We used the findings from the hierarchical analysis to present a possible causal model. The model is presented above in Figure 6.3 which shows the strengths of the paths (beta coefficients) between variables.

All the variables in the model have a direct effect on maternal stress, except for life events which works through recent ill-health. Age and social class are original causes, having no incoming links (distal causes), while academic skills, behaviour problems, Judson scores, assessment of ability to cope, financial worries, life event stress and recent illness have both incoming and outgoing links (mediating causes). There are no variables with only incoming links (proximal causes). It can be seen that child behaviour influences a number of variables, affecting the mother's acceptance of and adjustment to the child (Judson scores), her assessment of her coping skills, and financial worries, whilst also affecting life event stress. Recent ill-health is affected directly by life event stress and poor assessment of coping abilities and indirectly (through assessment of coping skills), by behaviour problems, age, and academic skills of the child. The nine variables explain 56% of the variance in stress scores.

Predicting changes in stress over time

The final stage in our analysis of maternal stress was to investigate the factors predicting change in the outcome of stress over time. The first step was to examine the relationships between the measures at Time 1 and Time 2.

The mean score at Time 1 for mothers in the sample caring for children at home was 6.01 (s.d 4.1 N = 162) and at Time 2 the mean score was 6.06 (s.d 4.0 N = 162). A matched pairs t-test showed that these differences were not significant (t = 0.14 sig = .88). At Time 1, 62% of mothers had scores of 5 or over, the cut off point which Rutter et al considered to indicate severe psychological distress; at Time 2, 61% of mothers scored 5 or over. If a cut off point of 6 is used as is the case for some researchers, 54% of the sample of mothers were significantly stressed at Time 1 and 51% at Time 2. A McNemar Test confirmed that the same mothers were stressed (i.e. had a score of 5 or over) at Time 2 as at Time 1. This showed that there were no significant differences: 51% (82) of women were stressed at both Time 1 and Time 2, and 27% (44) at neither time. Ten per cent (17) had become stressed between Time 1 and Time 2 and 12% (19) had stopped being stressed. It must be emphasized that any cut off point is arbitrary and that it is possible for mothers to change from one category to another simply by reporting one less/more symptom.

Another way of examining change over time in symptoms of stress is to examine the individual symptoms reported. Table 6.4 shows the frequency with which mothers reported each symptom in the Malaise Inventory at Time 1 and Time 2.

There were no significant differences in the proportions of subjects reporting the majority of symptoms of stress. Early waking showed a significant increase and flying into rages a significant decrease. The data thus confirms that stress symptoms have remained remarkably persistent over time.

Table 6.4 **Frequency of occurrence of symptoms at Time 1 and Time 2**

Symptom	% of mothers reporting symptoms		
	Time 1	Time 2	McNemar Test
Backache	49	52	N/S
Tired	54	46	N/S
Depressed	37	35	N/S
Headaches	42	38	N/S
Worried	63	64	N/S
Difficulty sleeping	28	34	N/S
Early waking	29	39	**
Health Worries	10	10	N/S
Rages	20	7.5	***
Annoyed by others	42	39	N/S
Twitching	12	15	N/S
Easily scared	19	23	N/S
Scared to be alone	13	8	N/S
Easily upset	37	33	N/S
Agarophobic	14	14	N/S
Keyed up	10	15	N/S
Indigestion	23	30	N/S
Upset Stomach	15	18	N/S
Poor appetite	11	9	N/S
Nervous exhaustion	13	12	N/S
Palpitation	21	24	N/S
Eye pain	11	13	N/S
Rheumatism	29	27	N/S
Nervous breakdown	7	7	N/S

By partial correlation, we next selected the child and family variables to include in our multiple regression of change over time. Partial correlation allowed us to detect variables which still predicted stress at Time 2 when their relationship with stress at Time 1 had been partialled out. The variables in question proved to be those in Table 6.5.

The significant variables from the univariate analyses were now entered into a multiple regression analysis in a stepwise procedure. The outcome measure was Malaise score at Time 2 and the first variable to be entered into the analysis was Malaise score at Time 1. The effect of this was to control for the variance shared by the two measures so that the independent variables which entered the equation were those that were significantly related to change in outcome. The solution for the regression analysis

Table 6.5 **Variables significantly associated with Malaise scores at Time 2 controlled for Malaise scores at Time 1: Partial Correlations**

Independent Variable	Partial r	Significance
<u>Child Variables</u>		
Child's age	-.1309	*
Child inpatient in last year	-.1236	*
<u>Family Variables</u>		
Marital satisfaction	.1260	0.06
Social class	.2501	***
Mother's health	.622	**
Loneliness	.2177	**
Adverse effect on family	.1437	*
Morale/life satisfaction	.1211	0.06

N = 159

predicted change in outcome over time. The results are shown in Table 6.6. Four variables were associated with <u>change</u> in Malaise scores: recent maternal ill-health, low social class, feelings of loneliness, and the child's age being younger than fifteen. We now need to consider the mechanisms by which these variables have their effect on maternal stress.

Our earlier analyses have shown the impact on the mother's health of child variables such as behaviour problems; these variables work both through assessment of ability to cope and through the experience of severe life events. Having an exceptionally difficult child who is difficult to manage and train may affect the mother's perception of herself, weakening her self esteem and her perceptions of her ability to control her life. This may affect her perceptions of her ability to cope with other social and domestic aspects of her life and may affect her physical health which in turn creates stress. Behaviour problems also seem to have an effect on health through life events, perhaps by creating marital difficulties, quarrels with other members of the family and difficulties with other siblings. The social class of parents represents a whole constellation of factors or a life style which

Table 6.6 **Multiple regression analysis of Malaise Scores at Time 2 with Malaise scores at Time 1 controlled**

Independent Variable	% variance explained	% additional variance explained	F change	Sig. of beta in final equation
1. Malaise scores at Time 1	29.2	29.2	67.6***	***
2. Recent maternal ill-health	34.8	5.6	14.0***	**
3. Social class	38.3	3.5	9.3 **	**
4. Feelings of loneliness	40.0	1.7	4.5 *	*
5. Child's age	41.4	1.4	3.9 *	*

F = 22.6 *** d.f = 5,160 N = 166

may either act as a mediator against stress or make families more vulnerable to the effects of caring for a handicapped child because of lack of material resources. Difficult socio-economic circumstances may also impose a degree of stress upon the family which is independent of the handicapped child.

Feelings of loneliness is an interesting factor to enter the equation. Peoples' perception of isolation and loneliness are not necessarily a function of the absolute quantity or the quality of available social support. Indeed the availability and adequacy of social support factors did not enter the final regression equation. MacKeith (1973) suggested that the attitudes of other people may influence parental reactions to their handicapped child, causing parental embarassment and subsequent social withdrawal. Kozloff (1979) has argued that the attainment of socially significant symbols forms a basis for maintaining self-esteem and social integration. A normal well behaved child is such a symbol. Negative social reaction to deviant behaviour in the child may imply to the parent that his or her capacity as a parent as well as his/her status in general is being questioned. Kozloff concludes that this may understandably lead to withdrawal on the part of the parent and to subsequent feelings of social isolation and of being different from other people. In this way, the extent to which the parent internalizes social values such as this may provide another source of stress.

The child's age was the last variable to enter the equation. Change in Malaise scores was associated with change in the age of the child. We have shown in earlier chapters that behaviour problems are related to age and that age is related to stress. Mothers of younger children are more likely to be stressed than parents of children aged 15 and over. The findings from this analysis corroborate the findings from both our chapter on child behaviour problems and the chapter on young people with mental handicap as they reach adolescence.

The Number of Child-Related Problems: The PINV

The Problem Inventory (Tavormina et al 1981) was the second measure which we used to measure the outcome of coping. We have argued above that a high score on the PINV would identify mothers suffering from the effects of stress. The PINV consists of ten problems which the family may experience as a result of caring for the handicapped child. These are extra demands on time and energy, decreased social life, tense home atmosphere, pressure to do the "right" thing to take proper care of the child, life centred on the child's needs, special problems the family has to cope with, shortage of family friends, constant need to watch over the child, less time to devote to other children, and disruptions of family routine. It provides a measure of the impact of the child on the family. The items were scored from (0) never to (4) always (see Appendix 1). The mean score on each item is given in Table 6.7 below.

The items were then summed to produce a scale from 0-38 (mean 19.57 s.d 9.84). The coefficient of reliability (Cronbach's alpha) was high, .89 which shows that the scale had good internal consistency. The mean problem score of 19.6 was similar to the value of 21.7 (s.d. 7.7) reported by Tavormina et al (1981) for mothers caring for a physically handicapped child.

Table 6.7 **Mothers mean scores on the Problem Inventory**

	Mean	Standard Deviation
Extra demands on time and energy	2.9	1.2
Decreased social life	1.8	1.4
Tense home atmosphere	1.3	1.0
Pressure to do the right thing	1.8	1.6
Life centred around child's needs	2.8	1.5
Special problems the family has to cope with	2.0	1.4
Shortage of family friends	1.0	1.4
Constant need to watch over child	2.6	1.5
Less time to devote to other children	1.3	1.4
Disruption of family routine	1.5	1.4
Total Problem Score	**19.6**	**9.8**

N = 166

Preliminary Analyses

The first question to examine was the association between the Malaise Inventory and the PINV. This was investigated by analysis of variance. The following table presents the analysis of variance.

Table 6.8 **Malaise scores by scores on the Problem Inventory**

PINV score	Mean Malaise Score	s.d.	N
0 - 14	4.7	3.6	50
15 - 24	5.5	3.8	60
25 - 38	7.9	4.0	52

F = 17.8 *** d.f. 1,159

It shows that there is a significant relationship between the two measures. The 50 mothers who score between 0 - 14 on the PINV have a mean Malaise score of 4.7, the 60 mothers who score between 15 - 24 have a mean score of 5.5, while the 52 mothers who score between 25 - 38 have a mean Malaise score of 7.9.

Testing the model of maternal stress and coping

A multiple regression analysis was next carried out on the Problem Inventory to examine which combination of our descriptor variables best predicted a high score on the inventory. The procedures followed were the same as those for the Malaise Inventory. First, we carried out univariate analyses to discover which variables were significantly associated with scores on the Problem Inventory at the univariate level. Secondly, we calculated the intercorrelations between the independent variables in order to test whether any variables were confounded. Thirdly, we entered the significant variables into a multiple regression using stepwise procedures. Finally, we entered the principal measures in a hierarchical regression analysis. As we have argued, it was important to identify precisely which of the stressor and coping resource variables best predicted child related problem scores in order to ensure an adequate test of the model.

Table 6.9 **Stepwise Multiple Regression Analysis of parent and child variables on Problem Inventory scores**

Step variable entered	% of variance explained	addition to % variance	Sig. of beta in final equation
1. Extra work score	35.1	35.1	*
2. Unmet service need score	43.5	8.4	*
3. Caretaking demands	49.5	6.0	***
4. Feelings of loneliness	54.3	4.8	***
5. Behaviour problems	56.4	2.1	**
6. Attention to keep safe	58.0	1.6	**
7. Coping through social support	61.2	1.5	**
8. Coping through direct action	62.3	1.1	*

F = 28.7 *** d.f = 9,156

Table 6.9 shows the results of the stepwise regression analysis. The independent variables were selected from our univariate analysis and nine of them predicted scores on the Problem Inventory, explaining 62% of the variance. Each variable entered into the analysis explained a significant proportion of additional variance. The most important variable was an index of the extra work the mother had to do because of the child's impairment. The Extra Work Index developed by Cooke et al (1982), was based on a series of questions which asked whether the child's impairment caused extra work for the mother. The questions covered cleaning and tidying the house, cooking and preparing meals (because of fads, special diets, etc), laundry (because of incontinence, heavy use of clothes), shopping (because of difficulty looking after the child) and other extra work (such as keeping hospital appointments, planning activities, etc). No extra work was scored as 0, a little extra work as 1 and a lot of extra work as 2. The items were summed to give a maximum score of 10 (see appendix 1). This variable explained 35% of the variance in Problem Inventory scores.

The next most important variable was an index of perceived unmet service needs specially developed for this study. Mothers were asked whether they felt they needed more professional help with a number of problems which included the child's behaviour, dealing with nightime disturbance, teaching self help and other skills, management problems, mobility problems, problems regarding the child's appearance, inappropriate social behaviour, assistance with childcare at home, developing communication skills, child minding, coming to terms with the child's handicap, marital problems, housing problems, financial problems, hearing and sight problems, information about services, information about the child's condition, a chance to discuss the child's progress, classes to learn how to help the child, and an emergency service for times of difficulty. The resulting scale had a range from 0 - 22 (see Appendix 1). The Unmet Service Needs score explained an additional 8% of the variance in Problem Inventory scores.

Other variables to enter the equation were the caretaking demands of the child (an assessment of the total number of hours per day spent in caring for the child) feelings of loneliness, child behaviour problems, attention to keep safe, and perceived adequacy of social support. Two coping strategies entered the equation, and these were coping through social support and coping through direct action.

The factors predicting a high Problem Inventory score fall into three groups. The first group of factors is concerned with the caretaking demands of the child. Mothers who have a great deal of extra work around the house because of the child's impairment, and whose child requires more hours supervision and care, is difficult to keep safe and has difficult behaviour, have higher scores on the Problem Inventory. The second group of factors is concerned with the isolation caused by the burden of work engendered by such a child, and includes feelings of loneliness, and feeling that social support is inadequate. These mothers seem to be cut off from normal social contacts, perhaps because they lack the time and energy to meet other people. They are therefore less likely to report using social support as a coping strategy. They are also less likely to utilize direct action as a coping strategy, perhaps because they are too tired and exhausted to formulate plans and solutions. The third group of factors associated with high scores on the Problem Inventory are high unmet service needs. These mothers seem to be in danger of being overwhelmed by the care demands of the child. They have a high need for information and services which they feel is not being met.

In our final analysis on the PINV, to test the model of coping which we had previously tested using the Malaise Inventory, we entered variables into a regression analysis in a hierarchical order in a way which we believed reflected their causal priority. As before, the variables were grouped into stressors and coping resources. The factors which we conceptualized as stressors were severity of the child's behaviour, measured by the Behaviour Problem Index, the Extra Work index, the index of caretaking demands of the child, and the child being difficult to keep safe. Coping resources were again divided into categories. Social class, income, and financial difficulties were chosen as utilitarian resources; recent ill-health and Malaise scores as health/energy morale resources; marital satisfaction and perceived social support as social support resources; perceived self-confidence and perceived control over events from general and specific beliefs resources; and perceived coping skills as problem solving skills resources. The child variables or potential stressors were entered first, followed by perceived service needs which were seen as a response to the stressors. Coping resources and coping strategies were entered last.

Table 6.10 Hierarchical regression analysis of child variables and coping resources

Step variable entered	% variance explained		% additional variance explained	Sig. of F change	Sig. of beta in final equation
<u>Child Stressor variables</u>					
1. Extra work score	35.1		35.1	88.8 ***	**
2. Care taking demands	43.2	} 50%	8.0	23.1 ***	***
3. Behaviour problems	48.9		5.6	17.7 ***	**
4. Attention to keep safe	49.9		1.1	3.6 *	*
<u>Perceived Service Needs</u>					
5. Unmet service needs	53.7	} 4%	3.8	13.1 ***	**
<u>Coping resources</u>					
6. Availability of social support	56.3		2.6	9.4 **	***
7. Coping through social support	58.5	} 7%	2.2	8.3 **	***
8. Quality of marital relationship	59.9		1.4	5.5 *	**
9. Financial worries	61.0		1.1	4.5 *	*

F = 27.1 *** d.f = 9,156

The results can be seen in Table 6.10 which shows that child variables contribute 50% of the variance in Problem Inventory scores. Perceived unmet service needs contribute a further 4%. Only three of the coping resource variables were significant. These were perceived availability of social support and marital satisfaction from the <u>social support</u> category, and financial worries from the <u>utilitarian resource</u> category. One of the coping strategies, coping through social support was also significant. Each variable entered into the analysis explained a significant proportion of additional variance. Altogether 61% of the variance in PINV scores was explained.

The results of this analysis show a very different pattern from the analyses conducted with the Malaise Inventory. Although mothers with high PINV scores also had significantly higher Malaise scores, high Malaise was not one of the significant predictors of high scores on the Problem Inventory, nor was the measure of physical health which had predicted Malaise scores. We are apparantly dealing with two parallel processes: high scores on the

Problem Inventory seem to be a function of the excessive care demands of the child while high scores on the Malaise Inventory seem to be a function of the child's age, behaviour and intellectual skill level. Often it is children with severe physical impairments who create excessive care demands. Coping resources which appear to provide resistance to the adverse impact of such children on the family are social support and quality of the marital relationship. Mothers with low scores on the PINV - those who do not perceive that the child has an adverse impact on the family - are more likely to report using their social support networks as a coping strategy, perhaps by receiving such help as child minding and babysitting from friends and relatives. Having a good marriage is also important, perhaps because of the quality of emotional support it provides or because the husband helps his wife more with household and childcare tasks. Wahler, Leske and Rogers (1979) have suggested that mothers of difficult children may be isolated from social support such as contact with friends and that this insularity may be predictive of poor coping and stress. Reporting symptoms of stress on the Malaise Inventory on the other hand - appears to be associated with having a younger and more intellectually impaired child with severe behavioural difficulties. Here, social class appears to mediate the effects of stress. Having financial difficulties or recent ill-health in addition to caring for such children appears to increase stress symptoms.

Acceptance and Adjustment to the Child: The Judson Scale

Preliminary analyses

The third scale we used to tap the outcome of stress was the Judson scale which measures maternal acceptance of and adjustment to the child. Item analysis showed that the scale had high internal consistency, with an alpha coefficient of .81. The scale had a possible range of 22-154. The actual maximum score was 154 and the minimum score was 63. The mean score was 114.9 (s.d 16.92) (see Appendix 1). Scores on the Judson Scale were broken down into three groups with approximately equal numbers in each group. Analysis of variance showed that there was a significant relationship between Judson scores and Malaise scores as the following table shows. The mean Malaise score of mothers with the lowest Judson scores was 8.2. The mothers in the middle group had a mean score of 5.7, while mothers in the high scoring group had mean Malaise scores of 4.1.

Table 6.11 Relationship between Malaise and Judson Scores

Judson Score	Mean Malaise Score	s.d.	N
63 - 110	8.2	3.9	59
111 - 121	5.8	3.5	43
122 - 154	4.1	3.3	60

F = 119.9 *** d.f. = 2,159

There was also a significant relationship between Judson and Problem Inventory scores. Table 6.12 shows that mothers in the group with the lowest Judson scores had the highest mean scores on the Problem Inventory, mothers in the middle group had a somewhat lower mean score, while the mothers with the highest scores, showing good acceptance of and adjustment to the child had the lowest mean score on the Problem Inventory.

Table 6.12 Relationship between Judson and Problem Inventory scores

Judson Score	Mean PINV scores	s.d.	N
63 - 110	23.8	9.6	63
111 - 121	18.8	9.2	43
122 - 154	15.7	8.9	60

F = 12.1 *** d.f. = 2,163

Testing the model of maternal stress and coping

Which child and family characteristics affected the mother's ability to accept and adjust to her child? After the usual preliminary univariate and stepwise regression analyses had been carried out to select the best predictor variables to test the model, we entered variables in a hierarchical multiple regression analysis in an order which reflected their assumed causal priority. First, child characteristics were entered. For this analysis we entered each behaviour item separately because we were interested in the precise aspects of the child's behaviour which might affect the mother's acceptance of and adjustment to her child. Variables entered in this group were each of the variables which make up the Behaviour Problem Index (see page 182): diagnosis, the child's academic skills, communication skills, multiplicity of impairment, mobility, health, sensory impairments, behaviour and epilepsy. Secondly, a group of variables which reflected the care tasks which resulted from the children's impairments were entered. These included management problems, being difficult to keep occupied and safe, needing help with dressing, undressing, washing, at meals, bathing and toileting, creating extra work for the mothers such as extra shopping, laundry, cooking and cleaning, and preventing parents from getting enough sleep because of night time disturbance. Finally, variables from the five coping resource categories were entered: these were social class, income, adequacy and availability of social support, marital satisfaction, recent illness, stress scores, a measure of perceived ability to help the child's development, and perceived assessment of coping skills.

The results are shown in Table 6.13. Eleven variables entered the equation, explaining 55% of the variance in Judson scores. Child variables accounted for 27% of the variance, and they were taking off clothes inappropriately, poor understanding of communication, rocking, worrying about plans or changes, night waking, and severe nail biting. In addition to the problems created by these behaviours, two care tasks done by mothers explained a further 5% of variance. These were having difficulties doing the shopping because of the child's behaviour, and not getting enough sleep because of having to attend to the child at

Table 6.13 Hierarchical analysis of child variables and coping resources

Step variable entered	% variance explained	% additional variance explained	F. change	Sig. of beta in final equation
<u>Stressors</u>				
1. Takes off clothes inappropriately	8.5	8.5	15.2 ***	**
2. Understanding communication	14.3	5.8	11.1 ***	**
3. Rocking	18.3 } 27.2%	4.0	7.9 **	**
4. Worries	22.0	3.7	7.7 **	*
5. Night waking	24.7	2.7	5.7 **	***
6. Nail biting	27.2	2.5	5.6 **	*
<u>Care tasks</u>				
7. Extra work when shopping	30.8 } 5.3%	3.6	8.2 **	*
8. Parental sleep distribution	32.5	1.7	4.0 *	*
<u>Coping resources</u>				
9. Can help child's development	47.7	15.2	45.3 ***	***
10. Malaise scores	52.8 } 22%	5.1	16.8 ***	***
11. Household income	54.5	1.7	5.8 **	**

F = 16.8 *** d.f = 11,154

night. Variables from three of the coping resource categories contributed an additional 22% of the variance when all other variables had been partialled out. These were a rating of the extent the mother felt able to help her child's development from <u>general and specific beliefs</u>, Malaise score from <u>health energy and morale</u>, and household income from <u>utilitarian resources</u>.

<u>Child behaviour problems</u> predicting poor adjustment to the child, such as taking off clothes at inappropriate times, rocking, and constant nail biting, are classes of stereotyped behaviour often associated with profound intellectual handicap. It is clearly more difficult to accept a child who indulges in bizarre and possibly embarrassing public behaviour than a child who does not cause such embarrassment. The presence of poor understanding of communication in the equation is striking. Mothers seem to find it more difficult to adjust to a child who is unable to understand them and with whom they cannot communicate. Such children are also more difficult to manage and to teach and, therefore, perhaps less

rewarding for parents. It is likely to be more difficult to establish a close and loving relationship with such children. Children who wake often during the night and who prevent their parents from getting enough sleep are also perceived more negatively.

The three coping resource variables which affect Judson scores are the mother's perception of being able to influence her child's development, stress scores, and income. It is important to note the relationship between failure to accept and adjust to the child and the feeling of powerlessness in ability to help the child develop, though the causal links between these variables are unclear. It may be that the severity and specific nature of the child's impairments cause the mother to have a bleak view of her ability to influence development which results in poor acceptance of the child, but it is also possible that poor adjustment to the child leads the mother to negative perceptions of her ability to influence matters. Experiencing symptoms of stress may influence both the mother's acceptance of the child and her perceptions of her ability to help the child (see the continuing debate about negative thinking and depression [Teasdale 1983; Willner 1984; Brewin 1985; Coyne & Gotlib 1983]). Cognitive changes occuring in depressed people are thought to produce a decrease in the ability to maintain concentration and effort, an increase in the relative salience of aversive events, perceptions and memories, and a corresponding decrease in the salience of pleasant events. Whether negative perceptions are a cause or an effect of depression or whether the two have a reciprocal relationship is the subject of heated argument in the literature.

The presence of household income in the equation shows that possessing adequate financial resources may be able to mediate the effects of caring for a handicapped child and produce a more positive outcome. Households with adequate financial resources are able to make life easier in a variety of ways which have been discussed earlier in this chapter and thus to minimise the negative impact of the difficulties experienced.

To summarize, our analyses of acceptance and adjustment to the child show a different pattern again from the analyses conducted with the Malaise Inventory and the

Problem Inventory. Very specific items of child behaviour are implicated as stressful when the Judson Scale is used to measure the outcome of stress. Problems which are particularly severe in terms of their impact on maternal well-being seem to be embarrassing public behaviour and night waking problems. These are reflected too in the care tasks which indicate vulnerability to stress, extra work when shopping and night time disturbance. It appears that taking some children out shopping is a particularly difficult task because of their behaviour in public which may lead to the mother feeling embarrassed and harassed. Looking after such a child can be exhausting for mothers who are already tired from lack of sleep caused by night time disturbance. These mothers may be highly stressed, as the presence of Malaise scores in the equation indicates. The combination of stress and tiredness perhaps leads them to be doubtful of their ability to help their child's development. Low household income also indicates vulnerability to the effects of stress. The analyses of the Judson Scale thus lend further support to the model of stress and coping. The model allows us to specify a number of different outcomes of the coping process and facilitates our understanding of the variables which act as stressors and those which indicate vulnerability to stress.

Discussion

This chapter has reported an attempt to assess the outcome of caring for a child with severe mental handicap, and to test a transactional model of coping. Three measures were used: the Malaise Inventory, to measure symptoms of psychological distress; the Problem Inventory, to measure the impact on the family of child-related problems; and the Judson Scale, to measure the mother's adjustment to and acceptance of her child. There was considerable overlap between the scales, with mothers who had high Malaise scores tending to have high scores on the PINV and low scores on the Judson Scale. However, correlation between the scales was only moderate, indicating that each was identifying mothers with a specific range of problems.

Results from the analysis of Malaise Inventory scores suggested that the most important child variables affecting mothers' stress were behaviour problems and the child's age. Coping resource variables predicting Malaise were lower social class, financial worries, negative assessment of coping skills, poor acceptance of and adjustment to the child, and recent maternal ill-health. There was evidence that coping resources were able to mediate the effects of stressful child behaviour on mothers' Malaise scores. An investigation of factors predicting change in Malaise scores between Time 1 and Time 2 showed that recent maternal illness, social class, feelings of loneliness, and the child's age were the most important variables affecting change in stress scores.

Analysis of the Problem Inventory scores showed that here a rather different set of child variables came into play. High scores on the PINV were predicted by the presence of children with severe care taking demands - those who had greater supervisory needs, created extra work for their carers, or were difficult to keep safe. Behaviour problems were again among the child-related predictor variables. The unremitting care demands of such children led to perceived unmet service needs appearing as a further important predictor variable. Coping resource variables which were important were those concerning ability to share the costs of caring - social support, marital satisfaction and reported coping by use of social support networks. Feelings of loneliness were associated with higher scores on the PINV and these seemed to be related to perceived inadequacy of social support. Whether such feelings are related to actual amount of social support is not clear, however. We have shown that the individual's appraisal of the situation is important, as Lazarus suggests.

We have tried to indicate how easy it is to enter a cycle where being tired out and stressed by care demands may lead to low self-esteem and low perceived ability to cope- which may in turn result in dissatisfaction with supportive networks, a bleak view both of the child's abilities and of one's ability to help the child's development. Children are known to be sensitive to their mothers' moods, and may become disturbed, fractious, and difficult to manage. Normally supportive friends and relatives may be discouraged from helping by the apparent lack of response from depressed and stressed mothers.

Analysis of Judson scores showed that a number of child variables emerged as significant predictors: taking off clothes in inappropriate circumstances, poor understanding of communication, rocking, severe nailbiting, worrying about plans or changes and night waking. In addition, two care tasks were significant predictors: having difficulties doing the shopping because of the child's behaviour and not getting enough sleep. Coping variables which emerged as significant predictors when the other variables had been partialled out were perceived ability to help the child's development, Malaise scores and household income.

There are a number of interesting points to note here. Firstly, the presence of embarrassing behaviours such as taking off clothes inappropriately, rocking and nailbiting are related to acceptance of and adjustment to the child. Strange or socially unacceptable behaviour in public is clearly difficult for mothers to cope with. This may lead to the mother being embarrassed and harrassed when she has to take the child out, for example when shopping. Secondly, the presence in the analysis of poor understanding of communication shows how important it is for the mother to be able to interact with her child either with language or signs, and the effect on her acceptance of and adjustment to the child when communication is difficult. Thirdly, two variables associated with sleep disturbance, night waking and not getting enough sleep, point to the seriousness of disturbed sleeping patterns. These affect both stress scores and acceptance of and adjustment to the child. Finally, a number of coping resource variables proved to be important: ability to help the child's development, stress scores, and household income. It is likely that households with fewer financial resources are already hardpressed, and may lack the money to pay for equipment which might help the child. They may also lack the time, resources and energy to involve themselves in programmes to maximise the child's potential, unlike families with higher incomes who also have greater access to books and information about skill acquisition.

The findings from these analyses lend considerable support to the transactional model of stress and coping developed by Lazarus and his colleagues, suggesting that stress is indeed a function of "lack of fit" between a person and his/her environment, and that a person's cognitive appraisal of a situation may play a major role in determining stress. In the analyses of all three of our outcome measures, child characteristics which acted as stressor variables appeared in the solution to the regression equation. Additionally, coping resource variables from one or more of the five coping resource categories identified by Folkman and Lazarus appeared in each of the equations. Some of the coping resource variables were relatively objective measures, such as social class and income, while others involved the mother's cognitive appraisal of her situation, such as perceived adequacy of social support or perceived ability to help the child's development.

Each of our measures which we have conceptualized as possible outcomes of the coping process was predicted by a different combination of variables, though there was considerable overlap. Important child variables which acted as stressors in the Malaise analysis were the child's behaviour, age, and academic skill level, while in the PINV analysis the extra work involved in caring for the child and the care demands in terms of time involved were the best predictors. The Judson analysis pointed to specific items of behaviour as predictor variables. As the precise nature of the stressor variables varied, so to did the coping resource variables which were found to be important in each analysis. In the Malaise Inventory analysis, low social class and financial worries indicated vulnerability to physical and psychological symptoms of stress. In the PINV analysis, having low social support and high marital dissatisfaction predicted mothers' perceived impact of child related problems upon the family. In the Judson analysis, high stress scores, low income, and perceived inability to help the child's development were important predictors of outcome.

The results from these three analyses suggest that the needs of mothers caring for a handicapped child are threefold: material, practical and psychological. This indicates the importance of a structured but flexible approach to the provision of services for families.

The results of both the Malaise and the Judson analyses indicate that attention should be paid to the financial aspects of caring for a child with severe mental handicap. It is important that all families receive the allowances and benefits to which they are entitled, and particular attention should be paid to working class families to ensure that their financial, housing and informational needs are met. We have shown that the presence of symptoms of stress are chronic and persistent, and that these seem to be associated in part with the presence of severe financial hardship or low socio-economic status which may be exacerbated by the presence of a child with severe impairment. As Baldwin (1985) has pointed out, the costs of caring for severely disabled children at home are considerably greater than the existing level of support from cash benefits, services in kind, and the Family Fund. There is a strong case for improving financial support. Baldwin suggests a number of ways in which relatively small increases in government expenditure could greatly reduce the financial stress currently experienced by some families, and reduce inequalities in current provision. A number of ways of improving the general level of cash support through new cash benefits are suggested, too, varying from an expenses benefit to an earnings-replacement benefit or a compensatory benefit. Attention to the physical health of mothers caring for a child is also indicated since this is strongly associated with stress in our longitudinal analysis of Malaise scores.

Mothers with high Problem Inventory scores seem to be in danger of being overwhelmed by the sheer burden of work involved in caring. These mothers may be helped by the provision of Crossroads or Link family schemes (Kings Fund Centre 1980; Bristow 1981). Such help may provide both social and emotional support and practical help in the form of a break from the monotonous duties of caring. In a pilot study, to evaluate a local Link Family scheme, one of my postgraduate students found differences between families provided with a Link Family and a control group of families who were on the waiting list. The linked families felt more supported, and maternal stress was lower (Bose, 1989).

An interesting service innovation which addresses the problems of low self-esteem, morale, and feelings of loneliness identified as important in both our longitudinal analysis of stress and the Problem Inventory analysis, has been the Parent Adviser scheme set up by the Child Development Team at Tower Hamlets, East London and evaluated by Davis et al (1988). Davis et al developed an explicit framework to guide the intervention work. The central assumption was that parental support was a crucial ingredient of intervention, both as an aim in its own right in terms of facilitating family adaptation and as a means of enhancing the developmental progress of children with disabilities. Davis et al conducted a series of studies to investigate the effectiveness of providing parental support and to evaluate his team's ability to train the necessary counselling skills. The results showed that experienced professionals such as health visitors were quickly able to gain counselling skills. Families who were allocated trained Parent Advisers showed significant improvements in the extent to which they felt supported by and involved with professionals and in their overall positiveness toward their child, themselves and their husbands. The children in these families showed greater developmental improvements.

It seems to us that such schemes, which are relatively inexpensive, offer great promise in addressing the problems faced by mothers caring for children with disabilities. Parent adviser training might also include skills teaching in behavioural methods. The aim would be to pass on these skills to mothers to help them to reduce inappropriate behaviour in their child and to teach positive new skills which are incompatible with inappropriate behaviour. We have discussed these methods at greater length in chapter 5.

A further challenge to researchers is to discover why some families cope in the face of severe stress whereas others do not, and to understand those elements of family functioning which make families vulnerable to stress or resistant to stress. We think that this analysis has gone some way toward indicating the child and family variables that may lead to stress and inadequate coping. The complex and interrelated nature of child and family variables which we have uncovered lends support to the idea that parents should be provided with a single doorway into services by coordinating them through a link person (Warnock 1978; Griffiths 1988). The analyses indicate that there is a need for a comprehensive method of assessing child and family in order to identify needs and to target resources accurately. Such an assessment would take account of all the factors relating to the specific problem in order to arrive at suitable intervention strategies. The present organization of services into health, education, and social services makes it difficult for families to know where to go for help, since their needs often cut across the boundaries of different service agencies. We believe that such an approach would require the appointment of a named person for each family who was able to liaise with other professionals in order to provide the best possible package of services for each family.

CONTACTS WITH PROFESSIONALS AND SERVICES

Introduction

In this chapter we shall be concerned with a number of linked questions. What do parents see as the main problems their children face? What help have the different services provided for each family? To what extent have the services helped the children to cope with, or overcome, their problems? What needs remain unmet?

Answering these questions poses many problems. First, there is the problem of defining needs, an issue discussed at length in the first report on this study (Pahl and Quine 1985). There are important differences between expressed need, felt need, normative need and comparative need (Bradshaw 1972). In this chapter we shall be concerned mainly with felt need, that is to say with parents' answers when they are asked what help they need, in the context of a series of questions about services.

Secondly, there is the problem of setting the standards by which services are to be judged. Many children with mental handicap will be in contact with much the same range of services as their non-handicapped peers: they will receive visits from a health visitor in the first years of life, attend the doctor when necessary, go to the dentist regularly, start school at five and so on. When parents assess these services they may be using standards which the parents of non-handicapped children would share, or they may be assessing the extent to which the services are able to meet the special needs of their own child. In addition there are the services designed to meet the needs of children with handicaps: these include support services such as respite care, financial benefits, special schooling and therapies of different sorts. Here parents may find it hard to assess the services because they do not know what to expect. Many parents of handicapped children say that they would like more information about services: this may reflect their uncertainty about what is available and what they are entitled to expect.

In this study we examined the services through the eyes of parents, a perspective which is very much in line with the current emphasis on responsiveness to consumer opinion (Kent County Council 1987; McIver and Carr Hill 1989; South East Thames Regional Health Authority 1989). Despite the problems involved in defining needs and setting standards, the study produced some very clear indications about what parents value for their children and what they currently lack.

Current Problems

Parents were asked a series of questions about the problems their child faced. Each of these questions tackled the topic in a slightly different way. For example, one question asked about the child's 'most serious' problem, in terms of health, development or behaviour; other questions asked about his or her 'greatest handicap', specifying, first, the handicap as judged from the child's perspective and, secondly, from that of the parents. One problem was that it became difficult to make exact comparisons between the different sets of answers, because the categories used varied. However, it was striking to see how much the answers to different questions told what was essentially the same story.

The current problems of the children, in order of the frequency with which they were mentioned, were challenging behaviour, poor physical health, communication problems and developmental delay. In the analysis we examined the extent to which parents had sought help with these problems and had found that help satisfactory. We found that health and behaviour problems had typically been mentioned to professionals and that generally parents felt that something had been done to resolve the problem. On the other hand when parents mentioned communication problems or developmental delay as the most serious problem, they were significantly less likely to have consulted a professional and less often felt that something had been done to relieve the problem ($p<0.001$).

Parents were remarkably unanimous about their child's greatest handicap, considering this from his or her own point of view. The two most commonly given answers were lack of communication skills, mentioned by 42% of parents, and lack of freedom, mentioned by 31%. Other answers given by many fewer parents were, poor academic skills, poor eyesight, illness, behaviour problems and lack of awareness of danger; 22 parents said that their child experienced no handicaps or was unaware of any handicaps he or she might have.

When parents considered what constituted the child's greatest handicap, thinking about their own rather than the child's point of view, there was a wider spread of answers. Again lack of communication skills was cited most often, being mentioned by 25% of parents; 20% mentioned the extra work involved in caring for a handicapped child, while 15% mentioned behaviour problems. Other answers included poor academic skills, lack of independence and anxieties about the future.

What Help did Parents Want?

In this study we adopted a new approach to questions about the adequacy of the help which families received from services or professionals. Previously, like many other researchers, we had simply asked parents what services they used and then had enquired about the helpfulness or otherwise of each one. In this study we adopted a more problem-oriented and less service-oriented approach. Each parent was asked:

> Here is a list of some help which children with special needs sometimes need. Do you feel you need more help with any of the following?

They were then asked to choose between the different options, in regard to each item of the list. The options were:

1. Getting enough help
2. Getting help but would like more
3. Not getting help but need it
4. Not getting help but do not want it
5. No problem

The result was a very complicated set of data; the key results are set out in Table 7.1.

There were some types of help which the majority of parents wanted. Identifying these meant bringing together those who were getting enough of a particular sort of help, those who were getting help but would have liked more, and those who felt they needed help but were not getting it. Table 7.1 shows what parents regarded as the priorities. They were information about services, a chance to discuss their child's progress regularly, help with teaching the child new skills, help in particular with developing communication skills, access to an emergency service, help with baby sitting and child minding and the opportunity to attend classes or workshops to learn how to help the child. All these were wanted by at least half of the parents: all should be regarded as essential components of any plan for services for this group.

Table 7.1 Proportions of parents receiving and needing different sorts of help

Type of help	Getting enough help	Getting help but would like more	Not getting help but need it	No help needed
Information about services for the child	24	30	31	15
Chance to discuss child's progress regularly	46	25	12	17
Help with teaching child new skills	33	31	11	25
Help with developing communication skills	17	40	15	28
Emergency service for times of difficulty	25	11	31	33
Advice and information about child's condition	29	18	15	38
Help with childminding or babysitting	22	13	21	44
Classes/workshops to learn how to help child	12	13	26	49

One striking characteristic of these parental demands is the extent to which they reveal a willingness to be actively involved with professionals in the care and education of the child. These are not the responses of people seeking to off-load responsibility onto the services. Professionals should consider how best to involve parents in the process of helping their children to acquire new skills.

There were considerable variations, however, in the extent to which the demand for services was met. Table 7.1 presents the percentages of parents who felt they were getting enough help. It shows a great contrast between, for example, having a chance to discuss the child's progress, where 46% of parents were satisfied with what they received, and receiving help with communication skills, where only 17% of parents felt that their child was adequately catered for. Other areas where parental demands were largely met included help with sight problems and hearing problems.

Unmet demand was calculated by adding together those who were getting help but wanted more and those who were not getting help but wanted it. This produced the following list: more information about services (61% of parents); more help with developing communication skills (55%); more emergency services for times of difficulty (52%); more help with teaching child new skills (42%); more classes or workshops for parents to learn how to help their children (39%); more opportunities for parents to discuss their children's progress (37%); more help with child minding or baby sitting (34%). We shall return to some of these specific services later in the chapter. At this stage it is important to note that the study revealed substantial unmet needs, which affected many different aspects of the lives of these families. In planning future services priority should be given to developing new ways of meeting these needs or to expanding existing services.

Which Parents Felt Most Need of Help?

The question of targeting services is a complex one. Should service providers plan to give a little help to all who ask, or select some to receive more help than others? Do middle class families demand more help than working class families? Are those who feel most in need of help not receiving services, or do they feel that what they are receiving does not meet their needs?

In order to answer these questions we examined the association between felt need and other variables. A 'Felt Need Score' was calculated by scoring one each time a parent said that the family needed help or more help with any one of the items on the list of potential types of help. The resulting scale had a range from 0-22. High scores for felt need were associated with many different aspects of the child, of the family and of their contact with services.

First, we tested to see whether the felt need score was higher for the parents of some <u>children</u> rather than others. Table 7.2 shows the results. It confirms that where children had more difficulties, parents were more likely to say that they needed more help. This is, of course, what one might expect, but it provided welcome confirmation of the validity of the felt need score.

Table 7.2 Child characteristics significantly associated with high felt need in parents

Child characteristics	Level of significance
Challenging behaviour	***
Sleep disturbance	***
Multiple impairments	***
Poor communication skills	***
Difficulties in management	***
Younger age	***
Severe medical problems	**
Poor academic skills	**
High levels of dependency	**
Epilepsy	**
Lack of mobility	*

These results parallel those reported in Chapter 6, where many of the same child characteristics were shown to be related to high maternal stress. It is interesting to see that the parents of younger children were more likely to express a need for help than those whose children were older. This must be related to the pattern described in Chapter 8, where behaviour and management problems were shown to reduce in severity as the young people moved into their teens and early adulthood.

Secondly, we considered whether felt need scores were higher for some families than others. Contrary to what might have been expected, there was no association between material circumstances and demand for additional help. That is to say, the felt need score was not associated with income, social class, family size and composition, housing conditions or car ownership. However, as Table 7.3 shows, felt need was associated with a number of variables related to the family and its circumstances.

Table 7.3 Family characteristics signficantly associated with high felt need in parents

Family characteristics	Level of significance
Money worries	***
Perceived inadequacy of social support	***
Perceived availability of social support	***
Extra work caused by child	***
High score on Problem Inventory (PINV)	***
High maternal stress	***
Many stressful life events	**
Poor adjustment to the child (Judson)	**
High on adversity scale (see Appendix 1)	**

Many of the variables associated with high felt need resulted from the family having responsibility for a handicapped child, but some were independent variables, such as money worries, a lack of social support and recent experience of stressful life events. When service providers are concerned about targeting services so that they reach those with greater need, this table gives some indication of the characteristics which should give a family priority.

Thirdly, we examined the relationship between felt need and service use. Were parents with high felt need failing to contact services, or were those contacts failing to provide the help needed? Table 7.4 gives a clear answer to this question. It shows that parents who had high scores for felt need were likely to make greater use of services than those whose felt needs were fewer.

Table 7.4 Contact with services and high felt need in parents

Service contacts	Level of significance
Frequent visits to GP	***
Frequent visits to hospital	***
Dissatisfaction with education system	***
Frequent visits to clinic	**
Has seen physiotherapist	**
In contact with community nurse	*
Makes use of short term care	*

Table 7.4 shows that high felt need in parents was significantly associated with the child making frequent visits to the GP, the hospital and the clinic, receiving help from the physiotherapist and the community nurse, and using short term care. So it seems that more needy families are indeed more likely than others to be in touch with the services. There were no associations between felt need and levels of satisfaction with the services, except in the case of the education system, where high scores for felt need were associated with greater dissatisfaction. Taken as a whole, Table 7.4 suggests that services are targeting families who need help with considerable accuracy, but then often fail to give them sufficient help.

The next stage was to examine all the variables listed in Tables 7.2 to 7.4; the aim was to find out which of the variables were most important when all the others had been taken into account. This involved carrying out a hierarchical stepwise regression analysis of felt need, in which the child characteristics shown in Table 7.2 were entered first, followed by the family characteristics shown in Table 7.3, and the service use variables in Table 7.4. The results are set out in Table 7.5.

Table 7.5 Hierarchical stepwise regression analysis of felt need in parents

Step variable entered	% of variance explained	% additional variance explained	F change	Sig. of beta in final equation
Behaviour problems	20.7	20.7	51.7 ***	**
Age of child younger	23.3	2.6	6.9 **	*
Epilepsy	25.7	2.3	6.1 **	**
Stressful life events	32.5	6.8	19.7 ***	*
Inadequate social support	35.9	3.4	10.5 ***	**
Money worries	37.8	1.8	5.6 **	**
High on problem inventory	39.6	1.8	5.9 **	**

As Table 7.5 shows, seven variables proved to explain 40% of the variance in felt need scores. The child variables which were most important were behaviour problems, epilepsy and the child being younger in age. The most important family variables were having a high score for stressful life events, inadequate social support, money worries and a high score on the Problem Inventory. The presence of epilepsy among the most important variables is interesting. It is likely that this reflects both the impact of epilepsy itself, and also the fact that children with epilepsy are often more severely impaired than others.

Those who are concerned about the targeting of services may find Table 7.5 a useful guide. It gives a clear picture of the sorts of children and families who are likely to want substantial support from services. The most significant characteristic of the children is their tendency to behave in a way which other people find problematic; they are likely to be in the middle years of childhood and to suffer from epilepsy. The families are likely to be socially isolated and faced with considerable financial worries; they may have recently experienced stressful life events and are likely to feel that they are facing considerable problems because of the child's impairments.

The Response of the Services

A child with a mental handicap is likely to receive help from a wide range of health and welfare services. Children with Down's Syndrome, for example, were on average in contact with five different professionals in the study carried out in Manchester by Byrne, Cunningham and Sloper (1987). In our report on the first stage of this study we focussed on the professionals with whom the families were most frequently in contact: these were the general practitioners, social workers, health visitors, community mental handicap nurses and child health doctors; we also presented information about the use of short term care and about the demand for longer term residential care.

In this report we focus on three other sources of help: the provision of information, access to speech therapy and financial assistance. We choose these because the analysis suggested that they were particularly valued by, or needed by the parents. 'Information about services' was requested by parents more than any other type of help (see Table 7.1). 'Help with developing communication skills' appeared as the area where demand most exceeded supply (see Table 7.1). 'Money worries' was one of the family characteristics most strongly associated with high felt need (see Tables 7.3 and 7.5).

Information about services

The study was carried out in two health districts in the south east of England, Medway and South East Kent. We were interested to see whether there were any differences between the two districts in terms of whether parents' felt needs were being met. In general there were few statistically significant differences. The most striking exception related to information about services. As we saw in Table 7.1, parents were more likely to say they wanted information about services than any other sort of help, so this led us to examine differences between the two districts in terms of their provision of information.

In 1982 the Medway mental handicap team produced a 'Helping Booklet' specially designed to provide information to parents with a handicapped child. The booklet lists sources of help, both locally and nationally, gives the names of key service providers, and generally encourages parents to make use of what is available. In theory the booklet was distributed to all parents, through the schools, paediatric units and child care and assessment centres. In practice, the interviews carried out in 1983 showed that only 49% of parents remembered receiving a copy (Pahl and Quine 1984). This research finding caused the district to produce a revised version of the booklet and to distribute it more thoroughly. When the second interviews took place three years later 58% of parents said they had received the booklet and another 20% were not sure whether they had received it or not; 80% of recipients had found it useful.

The 'Helping Booklet' is a modest publication, but the evidence suggests that it had made a significant contribution to meeting the need for information about services. As Table 7.6 shows, 47% of parents in South East Kent, but only 18% in Medway, felt that they were not getting information which they needed; by contrast 32% of parents in Medway were getting all the information they wanted, compared with 14% in South East Kent. These results suggest that despite all the efforts there were still parents in Medway who had not received the 'Helping Booklet'.

Many health districts and social services departments now produce information booklets specifically designed for particular client groups. This study confirms that such publications are highly valued. Innovations in desk top publishing should make it easier to produce attractive booklets at relatively low cost, and to bring them up-to-date on a regular basis. The job of up-dating the booklet, and ensuring that the relevant families receive a copy, should be written into the job description of the most appropriate person.

Table 7.6 Satisfaction with information about services: comparison between Medway and South East Kent

Parental satisfaction with information about services	Medway %	South East Kent %
Getting enough information	32	14
Getting some information but would like more	37	21
Not getting information but need it	18	47
No information needed	13	18

*** $p<0.001$

Speech Therapy

Communication skills have appeared as a key issue at many different points in this report. In this chapter we have seen that many parents listed communicaton problems among the 'most serious' difficulties facing their children and that communication was listed as the 'greatest handicap' more often than any other issue. In Chapter 4 we showed that children with behaviour problems often had poor use and understanding of communication. In Chapter 5 communications skills played a central part in the model predicting sleep problems. In Chapter 8 communications skills will emerge as the greatest concern of parents as their sons and daughters face adult life.

When we asked parents about the speech therapy received by their sons and daughters their answers revealed an enormous amount of unmet demand. About half of the children had seen a speech therapist at some time during the previous year, a proportion very similar to that reported by Byrne, Cunningham and Sloper (1988); another 17% of parents would have liked their children to have seen one. Nearly two thirds of parents were dissatisfied with the amount of speech therapy which their children were currently receiving. Some of these children were already seeing a speech therapist but other parents wanted more time and attention; others were currently getting nothing but felt that their children would benefit from regular speech therapy. There was a consistent trend for parents in Medway to be more satisfied with the speech therapy service than parents in

South East Kent, but the differences did not reach statistical significance on any one table.

These results highlight an issue which is of national importance. The shortage of speech therapists affects every district and has done for many years. At the time of writing, for example, Medway has 3.5 vacancies out of an establishment of 15 posts. Recruitment difficulties reflect the low salaries paid to speech therapists working in the public sector, where the average salary is £11,390, and competition from the private sector. A recent survey carried out by Therapy Weekly showed that morale is much lower among speech therapists than among physiotherapists or occupational therapists. Speech therapy emerged as the profession least satisfied with its standard of living, least satisfied with the current machinery for pay negotiations, least satisfied with working conditions and most pessimistic about the future of the therapy professions. Only 4% of speech therapists said that they were satisfied with the current pay negotiating machinery, compared with 43% of physiotherapists and 36% of occupational therapists (Therapy Weekly, 1989).

There are various possible responses to the crisis in speech therapy. It is now twenty years since the Quirk Committee set out to review the speech therapy services (Department of Education and Science, 1972). Since Margaret Thatcher herself signed the foreward to that report, the time may be ripe to initiate an enquiry which would review what has been done, as well as give more attention to pay than the Quirk Committee did. At national level there is an urgent need for a review of the pay structure of the speech therapy profession. At local levels any district which wants to provide an adequate speech therapy service will have to take advantage of the discretionary incremental points on the current pay scale. In the short term speech therapists might spend some of their time training teachers, or speech therapy aides, so that as many children as possible may receive as much help as possible in developing the communication skills which are so vital to them and their families.

Financial Help

In previous chapters we have shown that money plays a crucial part in enabling families to care for a child with a mental handicap without too great a level of stress. In Chapter 4 we saw that low household income was significantly associated with behaviour problems in children. Income was one of the factors which predicted the development of behaviour problems: a child living in a household which had a low income at the time of the first interview was more likely to have developed behaviour problems by the time of the second interview. In Chapter 6 we showed that money worries contributed significantly to stress in mothers.

There is plenty of research confirming that caring for a child with a mental handicap is costly (Buckle 1984; Baldwin 1985). Firstly, responsibility for the care of the child tends to reduce family income, mainly by making it difficult for mothers to earn, but also by limiting fathers' ability to do overtime. Secondly, the needs of the handicapped child mean that the family has larger bills for items such as clothing, footwear and bedding.

What sorts of financial help were parents getting to compensate them for the costs involved in caring for a handicapped child? Table 7.7 shows the main benefits they were receiving. Attendance allowance is paid at a lower rate for people who only require care during the day time. Compared with the study carried out by Byrne, Cunningham and Sloper (1988) our results show fewer families receiving the low rate than those receiving the higher rate. More families in our study had received help from the Family Fund (59% of those eligible as compared with 33%) and many more were receiving the Mobility Allowance (37% as opposed to 5%). This last figure gives a measure of the physical disabilities which affected the children who took part in our study.

Table 7.7 Benefits claimed by families

Benefit	Received %	Problems Receiving %	Pending %
Attendance allowance			
lower rate	51	9	1
higher rate	44	-	-
Mobility allowance	37	26	5
Severe disablement allowance	21	-	-
Rowntree Trust Family Fund	59	-	-

Despite receiving these financial benefits many of the families faced considerable financial problems. Over half the parents said that they worried about money, while 17% worried about it 'most of the time'. Many said that they had extra expenses because of the child's handicap: the most common expenses were extra heating, mentioned by 55%, extra laundry (54%), extra clothes (52%), extra transport costs (41%) and extra expenditure on bedding, mentioned by 34%. Despite their financial position, a substantial minority had experienced problems in getting the benefits to which they were entitled. This especially applied to the mobility allowance. A quarter of the parents said that they had had problems with their application for this benefit: the problems took the form of insensitivity on the part of the doctor responsible for assessing the child, lack of understanding of the problems the parents faced and disbelief in the parents' accounts of what the child could and could not do.

Child Health Services

There is likely to be considerable change in the child health services over the next few years. Many health districts have plans for a more integrated service, bringing together the community health services and the local general practitioners. These plans have been disrupted by the uncertainty produced by the White Paper and the changes in GP contracts (Secretary of State, 1989). The proposal that GP's should be paid for undertaking child health surveillance and immunisation raises questions about the ability of the average GP to carry out this work without additional training and about the relationship between GPs and other members of the primary care team (Butler, 1989). As far as the study is concerned, there must be anxiety about the extent to which the new pattern of services can respond to the special needs of children with mental handicap and their families.

Table 7.8 provides some reassurance on this issue. The figures reflect the fact that these children were almost all either in school or were young adults: few were of pre-school age and so few were in contact with the health visitors and clinic doctors who have particular responsibility for very young children. The table suggests that the great majority of the families were in contact with a general practitioner and were satisfied with the care which they were receiving from him or her. Indeed, satisfaction rates with GPs appeared to have risen since our first round of interviews (Pahl and Quine, 1984).

Table 7.8 Contact and satisfaction with the child health services

	% of families in contact with each professional	% of those in contact expressing satisfaction
General practitioner	80	82
School doctor	63	78
Hospital doctor	41	75
Community nurse	17	77
Health visitor	8	71
Clinic doctor	6	60

It is our impression that both the health and social service departments are moving toward more generic way of working, and away from specialized services for children with mental handicap. This reflects growing committment to the principle of normalization: children with mental handicap are no longer identified by their impairment but are seen first and foremost as children with the same basic rights and needs as non-handicapped children. However such children do have many additional special needs and it is of paramount important that they are protected against losses of specialized professionals and services that the restructuring of the health and social services may bring.

Summary

In this chapter we have been concerned with a number of issues. We have considered the parents' views of the problems their children face, the help received from services and the extent of unmet need.

Parents were asked a series of questions about the problems their children faced. The first question concerned the child's "most serious" problem. The current problems of the children, in order of the frequency with which they were mentioned, were challenging behaviour, poor physical health, communication problems and developmental delay. In the analysis, we examined the extent to which parents had sought help with these problems, and found that help satisfactory. We found that when health and behaviour problems had been mentioned to professionals, parents thought that something had been done to resolve the problem. When communication problems or developmental delay were mentioned as the "most serious" problem, parents were significantly less likely to have consulted a professional and less often thought that something had been done.

Parents were asked about the child's greatest handicap from their own and the child's point of view. The two most frequent answers from the child's point of view were lack of communication skills and lack of freedom. Poor academic skills, poor sight, illness, behaviour problems and lack of awareness of danger were also mentioned. From the parents' point of view, lack of communication skills was cited most often, followed by the extra work involved in caring for the child, and behaviour problems.

When asked about the sorts of help they would like, parents' priorities were for information, a chance to discuss their child's progress regularly, help with teaching new skills, help with developing communication skills, access to an emergency service, help with babysitting and childminding and the opportunity to attend classes or workshops to learn how to help the child. All these were wanted by at least 50% of parents.

In order to determine the characteristics of parents who had high felt need, we produced a Felt Need Scale. We examined the child, family and service contact characteristics associated with high felt need. Multiple regression analysis indicated that the most important child variables predicting high felt need were the child having behaviour problems, being younger in age, and suffering from epilepsy. The most important family characteristics were having had stressful life events in the pervious year, perceived inadequate social support, money worries and a large number of family problems relating to the child.

We focussed on three sources of help for parents: the provision of information, access to speech therapy and financial assistance. These were chosen because the analysis suggested they were particularly valued by parents. In Medway, where a Helping Booklet had been provided, parents were significantly less likely to feel they needed information about services. This highlights the importance of providing information, in an accessible form and regularly updated, for parents. Parents listed lack of communication skills among the 'most serious' difficulties facing their children. In earlier chapters, we have shown that children with behaviour problems often had poor use and understanding of communication. In Chapter 5, communication skills played a central role in the model predicting sleep problems. When we asked parents about the speech therapy received by their children, we discovered a large amount of unmet demand. About half the children had seen a speech therapist in the previous year and another 17% of parents would have liked their child to have seen one. Two thirds of parents were dissatisfied with the amount of therapy their child received. The national crisis in speech therapy is discussed in some detail.

Money plays a crucial role in enabling families to care for a child with a mental handicap. We discuss the financial help parents were getting to compensate them for the costs involved in caring for a child with mental handicap. Over half the parents in the sample were worried about money.

Finally, the chapter discusses the new plans for child health services, making a plea that the special needs of children with mental handicap should not be forgotten in any restructuring toward a more generic service.

THE TRANSITION TO ADULT LIFE

Introduction

The problems of adolescence and the transition to adult life can be a source of anxiety and difficulty for any parent and are well documented in the literature (Muuss 1962; Rogers 1972). When a young person has a physical or mental handicap, the development of independence and the achievement of personal responsibility which are the hallmarks of adolescence may pose particular problems, occurring much more slowly than in non-handicapped young people. In addition, parents are growing older and may have less energy to cope with the difficulties of adolescence, such as the awakening of sexuality and their children's growing need for independence. A recent study has estimated that about a third of mentally handicapped people living at home have parents aged 65 or over (Richardson and Ritchie 1986). A particular anxiety for parents is what will happen to their son or daughter when they are no longer able to provide for them (Card 1983; Sanctuary 1984). The House of Commons Social Services Committee regarded this as "an approaching crisis" and urged local authorities to estimate the numbers involved and to inform the Department of the service consequences (DHSS 1985, p.XVI and IXXXIX).

It is widely established that the burden of care falls largely upon the mother of the young adult with mental handicap and results in severe financial, physical and emotional costs (Pahl & Quine, 1984). Hirst (1985a) showed that young adults with severe disabilities were heavily dependent on others for help with personal care and mobility. Many required considerable supervision because of severe behaviour disturbance. In a later paper Hirst (1985b) compared the health and employment of mothers caring for a severely disabled young adult with those of women in the general population. He found that mothers in his sample were much more likely to suffer from a severe chronic illness and to experience symptoms of psychological distress. Their participation in the workforce, hours of work, and earnings were lower than for women in the general population.

The transition to adult life poses problems for the young person with a mental handicap too. For most young people, entering adult society means living independently of their parents and securing employment. Public attention has been drawn recently to the difficulties which young adults with disabilities face in these two areas. The Campaign for People with Mental Handicaps (CMH), in its evidence to the Select Committee, endorsed the Jay Committee's position that mentally handicapped young people should have the chance to leave home if they wish (CMH 1984). Similarly the Independent Development Council for People with Mental Handicap have argued that service providers should be accountable directly to the client and have pressed for early preparation of both parent and client for a move from home (IDC 1984). Advocates of normalisation too are concerned with the timing of the move from home and have emphasized the importance of training for independent living (Ward 1982, Macredie and Bradshaw 1984).

There has been much interest in the kind of provision which is appropriate. This has focussed on producing an ordinary life for young people with mental handicaps who "should be in the mainstream of life, living in ordinary houses in ordinary streets with the same range of choices as any citizen" (Kings Fund Centre 1980). However, the reality is that the majority of young adults continue to live in the parental home. The Select Committee was greatly concerned about the imbalance of service provision arguing that:

> "Concern for those in hospital has led to a relative neglect of an issue of at least equal importance: the fate of those already living outside hospitals. If the present uneven balance of concern is not redressed, all energies will be bent on providing services for people coming out of hospital, only to find equal pressure to use these facilities coming from people not currently in hospital." (p.XVI)

Richardson and Ritchie's (1986) study of parents' views about adults with a mental handicap leaving the parental home showed that there was an imbalance between what parents would like for their son or daughter and what is actually available. Richardson and Ritchie found that parents had very clear views about what future living arrangements should be like, and many of the parents of more severely handicapped young adults were dissatisfied with the provision they had seen. There were severe gaps in parents' knowledge of what provision was available. The authors concluded that parents needed "much more accessible information, and much more support provided over a more extensive period of time." P.61.

The second issue which has received public attention concerns the employment prospects of the young person with physical or mental handicap and the preparation for leaving school and entering adult life which is received at school. Three recent studies show that young adults with special needs are much less likely than young people in general to have received careers education and advice at school. School leavers' programmes were underdeveloped and there were limited opportunities for work experience (Anderson and Clarke 1982, Walker 1982, Hirst 1985c). In Hirst's 1985c study, 58% of disabled young people said that they had had insufficient help with learning about the world of work, about 40% felt they had had insufficient help with learning about everyday living and learning independence skills, and 79% had had insufficient advice about welfare benefits.

These young people face much more severe difficulties in securing employment than do other young people, as a review by Parker (1984) confirmed. Hirst (1987) in an investigation of the vocational activities of young people with moderate or severe mental and/or physical disablement, showed that only 5% found a job in open employment, while 1 in 4 young people were wholly unoccupied or still in transitional placements at age 21. Physically impaired young people experienced a more difficult transition to adult life, while mentally impaired young adults faced a more limited range of vocational choices. Walker (1982) found that young people with disabilities were five times more likely than the general population of young adults to be unemployed.

How did the young people in our sample fare as they reached adulthood? What skills and abilities did they have? How did they compare with other young people of the same age? What preparation did they have for leaving school? What plans did they and their parents have for leaving home and securing employment? These and other questions were investigated at Time 2 of our study.

Skills and Abilities of Young Adults

At Time 2, there were 71 young people aged 15 - 21 in the sample. We have chosen this age range in order to include those young people who would have been receiving preparation for leaving school, as well as those who had already moved on to a Social Education Centre, and the following analyses are all concerned with Time 2 data. Table 8.1 summarizes the information provided by the teachers' assessments. The proportion of young people with each skill at Time 1 and Time 2 is presented. It can be seen that greater proportions of the young people have acquired each skill by Time 2. Although the proportions differ by only a few percent there is a clear trend toward skill acquisition between Time 1 and Time 2. This shows that the learning of basic skills continues in young people with a mental handicap well past the age at which most non-handicapped young people have acquired these skills.

Table 8.1 **Skills and abilities of young people aged 15 - 21 at Time 2 and proportions of the group with similar skills at Time 1**

	% of young people aged 15 - 21 (numbers in brackets)	
	Time 1	**Time 2**
Able to dress without help	59 (42)	69 (49)
Able to feed themselves without help	76 (55)	82 (58)
Able to wash themselves without help	56 (40)	63 (45)
Able to read simple books	17 (12)	18 (13)
Able to write simple sentences	11 (8)	20 (14)
Able to sort and count	13 (9)	21 (15)
Fair understanding of communication	45 (32)	63 (45)
Fair use of communication	39 (28)	61 (43)
Continent	73 (52)	76 (54)
Able to walk by themselves	75 (53)	80 (57)
No behaviour problems	48 (34)	54 (38)

The Disability Assessment Schedule (DAS) (Holmes Shah and Wing 1982), which was filled in by the teacher or care assistant who knew each young person, enquired about a wide range of skills. These included the young person's continence, self help skills, use and understanding of communication, reading, writing and counting skills (see Appendix 1). For each of these skills there was a very significant relationship between age, measured in three age bands (0-7) (8-14) (15-21), and skill acquisition ($p<0.001$). There was a clear linear trend toward greater skill acquistion in the older children.

The group of young people had acquired social skills too. Ninety per cent were thought by their mothers to be able to occupy themselves for short periods of time, 62% could stay out of danger at home, 39% could find their way around the neighbourhood, 31% could cross a road safely, 31% could stay alone in the house for an hour, and 13% could even travel alone on public transport.

Parental Stress and Management of Young Adults

At Time 2, the mothers of the young adults were significantly less stressed than mothers of the younger children. The mean Malaise score of mothers whose children were aged 15-21 was 4.9, while the mean score of the mothers with younger children (0-14) was 6.8 ($p<.001$). It is well known that caring for young children is associated with maternal stress (Richman 1976; Berg et al 1984). It has been argued that the constant pressure of a child's needs and the maternal commitment to meet these needs weakens the mother's physical and mental state and increases her vulnerability to psychological distress (Holmes and Masuda 1971; Kitzinger 1980). A great many factors are seen to contribute to emotional distress among mothers of young children. These include ambivalence about child-rearing, doubts about appropriate child-rearing methods, social isolation and problems in obtaining help and guidance (Oakley 1984, Gove and Peterson 1980, Klerman and Weisman 1980). Where mentally handicapped and often multiply impaired children are concerned, the sheer physical burden of care, the emotional disturbance created by the birth of an impaired child, and the disruption of normal patterns of family life can be included.

As the children grow older and become young adults, some of these stresses disappear, as new skills are acquired which ease the burden of care on the mothers. The young adults in this age band (15 - 21) were significantly less likely than the younger children to require help with tasks such as dressing, undressing, eating, washing, bathing and using the toilet as Table 8.2 shows.

Table 8.2 Help required by young people with mental handicap by age

	% of children requiring help		
Child needs help with	0 - 14	15 - 21	Chi-square
a. Washing	82	68	3.9 *
b. Dressing	92	63	18.1 ***
c. Undressing	70	41	13.5 ***
d. At meal times	75	41	18.0 ***
e. Using toilet/toiletting	72	38	17.3 ***

N = 166

The mothers of the young adults also reported less work with cleaning, cooking, laundry and shopping and less overall demands on their time and energy than did the mothers of the younger children aged 0 - 14. The older children were significantly easier to keep occupied ($P<0.001$) and were able to be left unsupervised for longer than the younger children ($P<0.01$). Their mothers also reported feeling significantly less irritable with them ($P<0.001$), and they were reported by both parents and teachers as significantly easier to manage ($P<0.001$). They were significantly less likely to be in the behaviour problem group (see page 53) ($P<0.001$). Young adults were significantly less likely to exhibit a large number of behaviour problems than were the younger children. They were less likely to have a poor appetite ($P<0.05$), to be a faddy eater ($P<0.05$), to have soiled themselves in the last few weeks ($P<0.05$), to have problems with night settling ($P<0.001$), night waking ($P<0.01$), being difficult to manage ($P<0.05$), being overactive ($P<0.05$), lacking concentration ($P<0.001$), being worried ($P<0.05$), thumb sucking ($P<0.05$), using objects for twiddles ($P<0.01$), having difficult habits ($P<0.01$), running away ($P<0.001$), screaming ($P<0.01$), having inappropriate behaviour with strangers ($P<0.05$), interfering with other peoples' activities (P<0.01), being destructive (P<0.01), scattering objects (P<0.01), exhibiting embarrassing behaviour (P<0.01), and stealing things (P<0.05). Not surprisingly, 60% of mothers thought that the last few years had been less difficult for them. Nevertheless, it must be remembered that quite sizeable proportions of these young adults were still dependent on others for help with personal care and mobility, and many still required a great deal of supervision because of severe behaviour problems. Although the young adults were generally easier to care for than the younger children with mental handicap, compared to other young adults of the same age they were still heavily dependent upon their mothers.

Expenses Incurred by Parents of Young Adults

Mothers were asked whether they had to spend more than they would normally expect on particular items because of the child's impairment. Mothers with younger children were significantly more likely to report extra expense on laundry (P<0.05), heating (P<0.05), special equipment (P<0.05), special toys (P<0.05), consumer durables (P<0.05) and transport (P<0.001). There were no differences in age bands in mothers' reported extra expense on hospital costs, holidays, shoes, clothes, food, furnishings or bedding.

Felt Needs of Parents of Young Adults

What did the mothers of these young adults see as priorities in terms of services? In order to explore parents' felt needs for additional services, we adopted a problem-centred approach. We offered a list of various problems and difficulties which might be encountered by parents of young adults and asked whether they would like more help with each one. Mothers of the young adults were significantly less likely than parents of the younger children to express the need for help with behaviour problems (P<0.01), sleep problems (P<0.001), teaching self help skills (P<0.001), management problems (P<0.01), mobility problems (P<0.01), inappropriate social behaviour (P<0.01), childcare at home (P<0.001), developing communication skills (P<0.01), childminding (P<0.001), marital difficulties (P<0.01), information about the young person's condition (P<0.05), self help classes (P<0.01) and access to an emergency service (P<0.01). There were no differences between the two age bands in respect of help with the child's appearance, adjusting to the handicap, hearing problems, sight problems, housing problems, financial problems, service information and discussing progress.

Despite the differences in mothers' expressed need for help between the age groups, very significant proportions of mothers of young adults, nevertheless, reported requiring help. Table 8.3 sets out the proportion of mothers who requested help with certain problems in addition to whatever they were currently receiving. It shows the large amount of unmet felt need in families with young adults, and it also gives some idea of their priorities.

Table 8.3 Parents' felt needs for additional help with problems

Problems requiring help:	%	N
Information about services	61	42
Developing communication skills	47	31
Access to emergency service	41	28
Teaching new skills	33	22
More chances to discuss young person's progress	32	22
Self help classes	26	18
Financial help	26	18
Advice about child's condition	25	17
Child Minding/Baby Sitting	24	16
Care of child at home	18	12
Teaching self help skills	14	9
Improve housing	10	7
Behaviour problems	10	7
Mobility problems	8	5
Inappropriate social behaviour	8	5

The felt needs of mothers, as shown in Table 8.3 can be grouped into three categories. First there were needs for more information. As our previous report (Pahl and Quine 1984) showed, the need for information about services is the need most frequently expressed, while chances to discuss the young person's progress (31%) and advice about his or her condition (25%) are still felt to be important needs. One of the health districts had produced a Helping Booklet, detailing services and sources of help, and there were significant differences between the two health districts. Families living in Medway (which produced the booklet) were significantly less likely to report needing help with both service information ($P<0.01$) and help and advice about the child's condition ($P<0.05$). However, a considerable number of mothers still reported that they required more help and advice. It may be that the needs being expressed here represent more individualised needs for formal and informal social support, where mothers can talk to health professionals about their concerns and receive help and advice tailored to their individual needs. Mothers also expressed a need for self help groups which would provide non-professional social support. Davis et al (1988) have discussed the nature of effective intervention for families of children with intellectual or multiple disabilities and have pointed to the importance of social support. The study showed that it is possible to train experienced professionals, such as health visitors and physiotherapists, in counselling skills, and it demonstrated that families who received support from these parent advisers showed significant improvements in the extent to which they felt supported by and involved with health professionals and in their overall positiveness toward the child, themselves and their husbands. Davis et al concluded that parental support should be a crucial ingredient of intervention.

The second category to emerge from Table 8.3 was felt needs for help with the development of communication and other skills, which were seen as important priorities by a large number of mothers. The development of communication skills was considered to be particularly important. It is interesting to remember from earlier chapters that poor communication skills were associated with the presence of behavioural problems, particularly difficulties with disturbed sleeping patterns. As we have noted, poor communication may create frustration for both parent and young person, and may make it more difficult for the parent to teach and train the young person in appropriate social behaviour. This emphasizes the importance of continuing teaching for those young people who have a chance of acquiring useful speech, and points to the importance of teaching alternative or augmentative communication systems such as Makaton or Bliss symbols for the young people who are unable to acquire speech.

The third category of felt needs is for practical help with such things as childminding, babysitting, financial and housing difficulties, and access to an emergency service. Looking after young people with mental handicap is particularly difficult for mothers in the holidays. At this point in their lives many women are beginning to go back to work full-time as their children have grown up and become independent. Mothers of young people with mental handicap may find this difficult, if not impossible, since they are still required at home to look after the young person after school and during holiday time. Not surprisingly, therefore, they may feel the need for more financial help. Twenty six percent of mothers expressed this need. As our previous research showed, having a handicapped young adult imposes additional financial burdens on a family as well as making it more difficult for both parents to be regular earners. Only 31% of the mothers were in employment, compared with 69% of mothers of comparable age in the general population (Social Trends 1987).

What are the characteristics of those families with high felt need? Is it possible to identify them from characteristics of the young person or the family? In order to examine this question, we produced a simple additive scale of felt needs from the questions we had asked mothers. In addition to the items in Table 8.3, we included a number of items for which smaller proportions of mothers had reported requiring help. These were sleeping problems, management problems, help with the child's appearance, adjusting to the young person's handicap, help with sight and hearing problems, and help for marital problems. The scale had a possible range of 0 - 22; the actual range was 0 - 18 (see Appendix 1). Table 8.4 shows the child and family characteristics associated with high felt need.

Table 8.4 Felt need by child and family characteristics

	Mean felt need scores			
	Mean	s.d	N	F
Child Variables				
Poor communication skills	5.6	2.5	14	6.4 *
Good communication skills	3.7	2.7	52	
High impairments	5.1	2.8	20	3.9 *
Low impairments	3.6	2.6	46	
Poor self help skills	5.1	2.9	18	3.9 *
Good self help skills	3.7	2.6	48	
Behaviour problems	4.9	2.9	29	5.2 *
No behaviour problems	3.3	2.5	36	
Sleeping problems	5.0	2.9	23	4.8 *
No sleeping problems	3.0	2.5	43	
Poor academic skills	5.1	2.4	19	4.1 *
Good academic skills	3.7	2.7	47	
High dependency	5.1	2.6	20	4.4 *
Low dependency	3.6	2.7	46	
Family variables				
High PINV scores	5.1	2.6	25	6.5 **
Low PINV scores	3.4	2.6	41	
High stress (score 5 or more)	4.8	2.8	33	4.1 *
Low stress (score 4 or less)	3.5	2.4	31	
High extra work scores	5.3	2.6	19	
Low extra work scores	3.6	2.6	47	6.1 **

High reported felt need was not related to social class, income or adversity in the family, nor was it related to acceptance of the young person or availability or adequacy of social support. Overall, that the more severe the physical and mental impairment the greater the amount of felt need is reported. High felt need was significantly associated with poor communication skills, greater number of impairments, poor self help skills, behaviour problems, sleeping problems and poor academic skills. In terms of family variables, it was associated with greater number of child related problems, greater stress, and greater amount of extra work.

Concerns of mothers of young adults

At Time 1 when the young adults were all three years younger, we had asked mothers what they perceived as their biggest worry or problem with their son or daughter. The results are given in Table 8.5 which shows that by far the greatest concerns of parents were communication skills.

Table 8.5 **Concerns of mothers of young adults at Time 1**

	% of parents who mentioned problem	N
Lack of communication skills	32	23
Worries about the future	18	13
Child's health	14	10
Behaviour problems	10	7
Dependency on others	10	7
Sexual problems	8	6
Other problems	8	6

Many mothers spoke of their sons and daughters becoming frustrated and angry when they were trying to be understood by parents, brothers and sisters. One mother said *"The worst thing for us is watching him trying desperately hard to communicate something to us time and time again and failing. He sometimes cries tears of frustration, and I think, I would give anything to be able to understand"*. Many parents thought that more could be done to improve their son's or daughter's communication skills, or wished that they could be taught the skills to help their own child.

The second greatest concern was the future. Many mothers were looking to the time when their sons and daughters had left school and were worried about two main issues: the young person's employment prospects, and who would care for their son or daughter when they were unable to care any longer. Mothers felt that they had not received much advice about the kind of living arrangement which might be available for their sons or daughters should they no longer be able to cope at home, and media stories about poor care or ill treatment had served only to increase their anxieties.

Other concerns were the young adult's health, behaviour and dependence on others. A small number of mothers had worries about their son's or daughter's sexual behaviour. One parent told us *"A few months ago we discovered that he was going out and exposing himself. The police were involved. Now he is prescribed drug therapy to reduce his sexual drive. But we have to watch him all the time and never let him out on his own. He doesn't really understand what he is doing."* Other concerns included the young person being aware that he/she was different from others and was unable to do the things that other young people of the same age could do, such as go to the pub or disco. One father said sadly *"He's like a child in a man's body. He doesn't understand why he can't go out like his brothers"*.

Three years later, at Time 2, we asked mothers if the concern they had mentioned at Time 1 was still a problem for them. Eighty one percent thought that the problem was still there, showing the unremitting nature of parents' worries. We then asked mothers who acknowledged a chronic problem whether they had discussed their worries with anyone. Teachers were the largest group to be consulted (29%), followed by health professionals (community nurses and doctors) (23%), friends and relatives (21%), and social service professionals (2%). A quarter of mothers had not felt able to talk to anyone about their concerns. Fifty percent thought the problem had not been resolved satisfactorily, and these tended to be the mothers who had mentioned the young person's lack of communication skills or worries about the future.

The particular professional chosen for consultation probably reflects the particular concern. It is likely that teachers are thought to be knowledgeable about communication skills, employment possibilities, future educational placements and the like, while health professionals are likely to be consulted about health problems. It is surprising that social workers were not more often consulted about future living arrangements, but perhaps this reflects the fact that families were not in touch with a social worker unless they had a specific problem. What does seem to be lacking are professionals who are knowledgeable about all the services which are available for this age group, whilst also having a good knowledge of each individual young adult's needs. This indicates the need for a comprehensive method of child and family assessment, ideally co-ordinated by a link or named person (Warnock, 1978; Griffiths 1988).

Additionally, mothers were asked what they currently considered to be the young adult's greatest handicap, both from their point of view and from the young person's point of view. Mothers perceived the greatest handicap from their own point of view to be dependence on others (32%), poor communication skills (27%), the young person's future (21%), lack of intellectual ability (10%), and behaviour (10%). From the young adult's point of view, 37% mentioned lack of communication skills, 31% lack of freedom, 9% lack of intellectual ability, and 4% illness. Nineteen per cent of young people were said to be unware of their handicaps.

Contact with the Services

Young adults were significantly less likely to have had contact with a number of professionals in the mental handicap services than were the younger children. Table 8.6 presents the differences between age bands in their contact with professionals in the last year.

It can be seen from the table that the young adults were less likely to have been in contact with the school or clinic doctor, a hospital doctor, a physiotherapist, or a speech therapist in the last year. They were also significantly less likely to have received short-term care. The mothers of forty one percent of the 15-21 age group reported receiving short term care in the previous year, and of those about one third said that short term care had been more difficult to arrange since the young person was 16. There were no differences between age bands in contact with the family doctor, community nurse, dentist, health visitor, social worker or psychologist. The differences found were somewhat

Table 8.6 **Contact with health professionals by age**

	% of mothers reporting contact in each age group		
	0 - 14	15 - 21	Chi-square
<u>School/clinic doctor</u>			
Seen	73	54	5.4 **
Not seen	27	46	
<u>Hospital doctor</u>			
Seen	50	31	4.7 *
Not seen	50	69	
<u>Family doctor</u>			
Seen	83	76	.96 N/S
Not seen	17	24	
<u>Community nurse</u>			
Seen	24	13	2.5 N/S
Not seen	76	87	
<u>Dentist</u>			
Seen	84	74	2.7 N/S
Not seen	14	26	
<u>Health visitor</u>			
Seen	11	4	1.4 N/S
Not seen	89	96	
<u>Physiotherapist</u>			
Seen	37	20	4.6 *
Not seen	63	80	
<u>Social worker</u>			
Seen	34	37	.08 N/S
Not seen	66	63	
<u>Short term care</u>			
Received	63	41	7.4 **
Not received	37	60	
<u>Speech therapist</u>			
Seen	62	33	11.7 **
Not seen	38	67	
<u>Psychologist</u>			
Seen	12	7	.46 N/S
Not seen	88	93	

disturbing, suggesting that once some of the young people leave school and enter the Social Education Centre they are less well-served by some professionals, and that the continuous assessment which is so important in such young people lapses.

Current Placement of the Young Adults

Table 8.7 shows the placements of the 71 young people. Fifty nine per cent were attending a special day school, 7% attended a residential school, 30% were at a Social Education Centre or other day centre, and 4% had no day placement.

Table 8.7 **Placement of the young adults in the study**

	% of the young adults attending
Special school - day pupil	59
Residential school	7
Social Education Centre	30
No placement	4
Total	100

Mothers' Assessment of Preparation for Leaving School

Forty six of the 71 young people aged 15 - 21 were still at school. We asked mothers a number of questions about when they expected their son or daughter to leave school, and about their satisfaction with the preparation for leaving received by their children. The vast majority of mothers (95%) reported that their child would leave school at 19 years of age. Only 2% wanted their child to leave earlier, while the rest were unsure. Fifty four per cent had decided what they would like their child to do after leaving school, as Table 8.8 shows. Teachers were the most likely to be consulted about daycare plans (72%) while social workers, particularly those at short term care establishments had been consulted by 10% of parents. Eighteen per cent of parents had not yet talked to anyone about future daycare plans.

Table 8.8 Parents plans for daycare after leaving school

Parents choice of daycare	% of parents choosing
Social Education Centre	39
Sheltered work	7
Stay at home during day	2
Other plans (college)	6
Not sure	46
Total	100

N = 166

Overall, mothers reported being generally satisfied with the preparation for leaving which the schools had given to their children, though a quarter thought it unsatisfactory. Only 30%, felt however, that they had been given enough advice and information about all the possibilities for their son or daughter when he/she left school. Of the 23 young people who had recently left school, 77% reported that a comprehensive review of the child's needs had been carried out, 11% said no review had been done, and 12% were not sure. Seventy seven per cent of mothers reported that they had been invited to attend the assessment, and had in fact been present, and of these 74% reported that they had been consulted during the assessment. Three quarters of mothers were satisfied with the assessment made.

Vocational Activities of Young Adults

The vast majority of young adults who had left school attended Social Education Centres in the two health districts. Comparative information for young people in the general population suggests that the pattern of vocational activities in this sample is very different from that of young people in general. Firstly, young people in this sample were much more likely to have continued their education after 16 at school than at college. This reflects a lack of further education facilities for this particular group. Secondly, most young people in our sample entered adult day provision after leaving school, while most young people in the general population enter the labour market (Department of Education and Science 1985). Most parents were satisfied with their son or daughter's placement, though 12% were definitely not satisfied and 8% were unsure. Parents were asked to express what they liked and disliked about the Social Education Centre. Among the things which were appreciated were the variety of activities available, the opportunity for social contact, the caring qualities of staff, the young person's happiness, and the respite given to parents. Critical comments focussed on staff shortages, low quality of care, and lack of skills teaching. Four per cent of the young adults had no day placement at all. In most cases they were young people who had very severe impairments. One young man was suffering from Friedreich's Ataxia, which is an inherited degenerative disease of the nervous system, and was only able to crawl about the house. This family was under severe strain and was receiving little help.

Preparation for Working

About half of the young people had been given some sort of work experience while attending the SEC, and parents generally appreciated the opportunity, although the work was sometimes described as repetitive and boring. Fifty seven per cent of mothers would have liked their son or daughter to get a job, and suitable work mentioned was simple factory work or work with children. However, only one parent had made an effort to get her son a job. For the rest, high youth unemployment and lack of knowledge about suitable work opportunities had prevented them from trying to secure either open or sheltered employment for their sons and daughters. Only 6% of young people had been given vocational guidance by a specialist careers officer, and no parents had talked to any officers from the Youth Training Scheme, Disablement Resettlement Officer, Job Centre or Remploy.

It appears that the range of vocational choices is very limited: attendance at a social education centre is the most that a young person can hope for, and this makes comprehensive review of the young person's needs before leaving school which is a requirement of the 1981 Education Act and the Disabled Persons Act (1986) largely an academic exercise. The Social Education Centres are expected to provide education, social skills training, and occupational training and also to cater for the leisure needs of young adults. Our findings confirm those of Hirst (1987) that young people with mental handicap have little contact with the careers service. As Hirst comments, this lack of involvement by careers officers perhaps results in fewer leavers entering further education or work training and subsequently finding sheltered employment. It seems that Social Education Centres have become viewed as providing permanent placements for adults with mental handicap. There appear to be negligible opportunities to move on to less sheltered and less segregated occupational settings and this is inconsistent with the general principles of normalization. As Hirst (1987) observes, if Social Education Centres are intended to provide a route to normal adult life, a major rethink is necessary.

As our own and other studies have shown, mentally handicapped people of all ages are able to respond to skilled teaching and to learn further skills. Educational services for this group could perhaps be further integrated with further education services so that some courses could take place where lively and stimulating day care activities could be provided. Some colleges of further education already run courses for mentally handicapped adults, though the numbers of people involved are usually small. Only one of the young adults in our study had attended such a course. Closer liaison between colleges and Social Education Centres might help to ensure that service provision satisfies the continuing educational needs of these young adults.

Plans for Independent Living

Mothers were asked if they had thought about what their sons and daughters would do when they were adults and if they had formulated any plans for future living arrangements. Table 8.9 shows parents' plans. The vast majority of parents were realistic about their children's chances for independent living. Most mothers expected that their son or daughter would continue to live with them. A few had been in contact with charitable organizations which provide residential facilities for disabled young people such as the Home Farm Trust, the Canterbury Oast Trust or the L'Arche community.

Table 8.9 Parents plans for future living arrangements

	% of young adults
Young adult will continue to live in parents' home	59
Other firm plans	6
No firm plans	35

Mothers were then asked which living arrangement they felt would be best for their child. As Table 8.10 shows 78% reported that living at home would be the best option, 13% thought that living in an ordinary home with other people like him/her, and getting support when needed, while 9% preferred living in a staffed house. As a second choice, living with relatives came top (32%), while living in a sheltered house was the choice of 34%, and living in a staffed house was chosen by 30%. This shows that parents thought it extremely important for their child to be amongst people whom he/she knew and who loved and cared for him/her. However, if this were not possible, either staffed or unstaffed houses in the community were thought to be suitable alternatives. Foster homes, lodgings or hospital care were not chosen by any parent as a first or second choice, and this accords with the findings of Richardson and Ritchie (1986). While mothers held strong negative attitudes about hospital care, they were probably unaware of individual fostering schemes.

Table 8.10 Parents' preferred choice of living arrangements

	% of parents choosing	
	First choice	Second choice
Live at home	78	4
Live with other relatives	-	32
Live in supported house	13	34
Live in staffed house/hostel	9	30

The findings that parents would favour their children living at home as the best living arrangement is perhaps surprising. However, many mothers commented that there was little chance of securing a place in a staffed or unstaffed house for their son or daughter and they had perhaps accepted and adjusted to this situation. One parent told us *"Of course I would like her to be able to leave home - both for her sake and for ours. She is an adult now and she has seen our other children leave. But the important thing is to empty the hospitals, isn't it? I've seen television programmes of the lives they lead in those institutions, poor souls. At least our daughter has a happy home with parents who love her"*. Many other mothers made similar comments. Additionally many mothers expressed concern about the quality of life in houses in the community once community care had been in operation for some time. Parents were worried that cuts might be made, that adequate staffing would be unavailable, and that supervision and quality control would be lacking. One mother told us *"I think it's right that they should be able to live in the community. They should have their own homes. But saying that institutions are bad places to live doesn't mean that community houses are good. It would be very easy for abuse to take place, and for standards to slip"*. Despite this, asked to assess their future need for long term care, 56% of mothers reported that this might be necessary at some time in the near future. Ill health or old age were usually given as reasons why continued care at home might not be possible.

Discussion

The skills of the 71 young people in our study showed considerable improvement between Time 1 and Time 2. The young adults were less stressful for their parents than the younger children, requiring less help with basic tasks. Their mothers reported less demands on their time and energy than did mothers of the younger children. They were easier to keep safe and occupied and could be left unsupervised for longer. Their mothers were more likely to report that they were easier to manage than were the mothers of the younger children. They were significantly less likely to have behaviour problems. In comparison with non-handicapped young adults, however, they were still much more dependent on help with personal care and mobility, and many still required supervision because of behaviour problems.

Parents' felt needs for additional service provision fell into three categories: information needs, help with the development of communication and other skills, and practical help. As our earlier study showed, the greatest need was for information. Parents wanted advice and information about a range of issues, from advice about the child's progress and specific impairments to information about the services and help available. Help with teaching communication and other basic skills was an important priority. Mothers pinpointed lack of communication skills as one of the young adults' greatest handicaps both from their own and the parents' point of view. We have discussed what might be done to help in earlier chapters.

At Time 1, mothers had been asked what they perceived as their greatest worry or problem with their son or daughter. By far the greatest concern was lack of communication skills, followed by concern about the future. Mothers were concerned both about the young person's employment prospects and about care when they could no longer care themselves. At Time 2 most parents were still concerned about these problems. While they were generally satisfied with the preparation for leaving which schools had given to their children, only 30% felt they had been given enough information and choice about opportunities available for their son or daughter.

Most young adults who had left school attended a Social Education Centre. None were in open employment, although about half had been given work experience while attending the SEC. This was usually simple assembly work and was often described as repetitive. Over half the parents would have liked their son or daughter to find a job, but there was a substantial lack of advice on careers or educational courses. The range of vocational choice is severely limited. Social Education Centres have come to be viewed as providing permanent placements for severely mentally handicapped adults and many are understaffed and oversubscribed. There are few opportunities to move to less sheltered environments. A radical rethink of this type of provision is required if it is to provide for all the educational, training and leisure needs of young adults.

The majority of mothers were realistic about their children's chances of independent living. Living at home was seen to be the best option, followed by living in sheltered accommodation. Parents had a general lack of information about other possible living arrangements. Over 50% of mothers reported that they might have to ask for longer term care at some time in the future.

RECOMMENDATIONS FOR SERVICES

1. Every district should develop a mental handicap register: this should be linked to a mental handicap team drawn from health, education and social services. The register requires first, a computer, secondly, staff qualified to assess the children's skills and abilities, and thirdly, an operator whose job it is to enter and process information. Information on the children's skills and abilities should be collected and updated regularly.

Behaviour Problems

2. The register should be used to identify children with severe behaviour problems, since their parents are likely to have particular needs for help from service providers.

3. Children with behaviour problems should not be disqualified, because of their behaviour, from services such as short term care and family support units; young adults should not be barred from social education centres. Rather, staff should be trained in the management of difficult behaviour.

4. Additional services should be provided for children with behaviour problems; these could include assessment at home, the development of behaviour modification programmes in consultation with the parents, attention to appropriate medication and generous access to day and night time relief schemes.

5. Training in behavioural methods should be provided to professionals working within the mental handicap services. This training should aim to help parents to reduce inappropriate behaviour in children and should help staff to manage difficult behaviour. A number of helpful training packages dealing with problems such as feeding problems, sexual abuse, anti-social behaviour, and the withdrawn, anxious or isolated child, are available from NFER/Nelson.

6. There should be particular attention to helping parents to cope with sleep problems. Techniques which have been found to be useful include stimulus control, contingency management, shaping, setting conditions, positive reinforcement and extinction. An intervention trial to evaluate these techniques is currently being carried out by a team led by Lyn Quine in the Medway Health District.

Communication Skills

7. Urgent attention should be paid to the crisis in the speech therapy profession. There are too few speech therapists and the many unfilled posts reflect the low rates of pay and low morale in the profession. The fact that the Department of Health and the Department of Education and Science share responsibility for the provision of speech therapy should not prevent these two organisations from getting together to set up an inquiry, similar perhaps to the Quirk Committee.

8. Until more speech therapists are available, any district which wants to provide an adequate service to this group of children should take advantage of the discretionary incremental points on the current pay scale.

9. Speech therapists themselves, should consider ways of sharing their skills with teachers, or with speech therapy aides, in order to provide the best possible service despite the lack of qualified therapists.

Financial Support

10. Benefits to handicapped people should be increased; these people, and those who care for them, are still likely to experience considerable financial hardship because of the handicap even when the full range of benefits is received.

11. Service providers should ensure that parents are aware of all the benefits to which they, or their child, are entitled. This means that service providers themselves should be familiar with the relevant range of benefits and with the eligibility criteria.

Support to Families

12. Short term care and linked family schemes should be available in every district since the study showed that these are welcomed by families and can serve to reduce stress.

13. Parent Adviser Schemes should be more widely available: they have been shown to provide help with some the problems experienced by mothers caring for a handicapped child, such as low self esteem, low morale and feelings of loneliness.

14. Each handicapped child should have a Named Person, who would be responsible for carrying out a regular assessment of his or her needs and for liaising with other professionals in order to provide the best service package for each family. The named person should be responsible for checking the accuracy of the information which is entered on the mental handicap register.

15. Every district should produce an information booklet to meet the information needs of families caring for a handicapped child or adult. This should be up-dated every two or three years and issued free to all parents directly, not through schools or other agencies.

Transition from School to Adult Life

16. There should be a major reappraisal of daytime activity for young adults with mental handicaps. Many parents wanted a wider range of work experience and a less segregated service.

17. The schools careers service should take more responsibility for this group of young people: at present few have any contact with the careers service and this seems to result in few entering further education or training for employment.

APPENDIX ONE

Scales and Measures used in the Study

ACADEMIC SKILL SCORE

The Academic skill score was derived from the three items concerning reading, writing and counting in the Disability Assessment Schedule (Holmes, Shah & Wing 1982). Reading and writing items are scored from 0 to 7 and counting from 0 to 3, giving a possible range of 0 to 17. The mean score was 6.5 (s.d. 4.1). The actual minimum score was 0 and the maximum score was 17. The child's academic skill score was found to be an important predictor of Malaise scores. Internal reliability of the scale was high (Cronbach's alpha .85).

THE ADVERSITY SCALE

In order to assess the cumulative effects of economic and social disadvantage, we devised an adversity scale which drew together a number of different aspects of hardship. The adversity score took account of the following elements in the lives of our respondents: being a single parent; either husband, wife or sibling having a longstanding disability, or having been an in-patient during the previous year; housing that was unsuitable for the needs of the family; low income; money worries; having an unhappy marriage; lacking a close friend. Our adversity scale has some similarities with Brown and Harris' measure of ongoing difficulties (Brown and Harris, 1978). We divided the 200 respondents into a high adversity group of 40, who had four or more of the characteristics which we had used in defining adversity, from a low adversity group numbering 160 who had three or less characteristics of adversity. The high adversity group had significantly higher Malaise scores. As would be expected, adversity was also associated with social class ($p<0.01$).

THE BEHAVIOUR SCREENING QUESTIONNAIRE

The Behaviour Screening Questionnaire (Richman & Graham, 1971) was used to assess behavioural difficulties of children at Time 2 in our study. The Behaviour Screening Questionnaire is a semi-structurred interview in which descriptions of child behaviour are obtained in twelve areas: sleeping, eating, bowel control, attention seeking and dependency, relationships with other children, activity, concentration, ease of management, temper tantrums, moods, worries and fears. The Behaviour Screening Questionnaire is suitable for the developmental level of the children in our sample. It also allows us to make comparisons with non-handicapped children.

Using objective descriptions of behaviour obtained from parents and carefully laid down criteria for scoring, each behavioural item is rated 0, 1 or 2 points by the interviewer. A score of 0 signifies no or trivial difficulties, a score of 1 signifies mild difficulties, and a score of 2 signifies marked difficulties. Scores for all the items are summed to produce a total BSQ score and Richman et al have suggested that a cut off point of 10 or more indicates the presence of severe behaviour disturbance. The Behaviour Screening Questionnaire appears to meet adequate criteria of reliability and validity (Richman & Graham 1971) and has been used in a number of studies of non-handicapped children (Richman 1974; Richman 1977; Richman, Stevenson & Graham 1975; Richman, Stevenson & Graham 1982). It has recently been used with some adaptation by Cunningham and his colleagues in a study of the effects of early intervention on the occurrence and nature of behaviour problems in children with Down's Syndrome (Cunningham et al 1986). It should be stressed that these instruments would be of limited use for clinical purposes with individual children, but their value for investigating large groups of children seems well established.

In our study the mean BSQ score was 8.0 (s.d. 4.4). This was somewhat higher than the mean score found by Cunningham et al (1986) for Down's Syndrome children which was 5.3 (s.d. 3.2). The minimum score was 0 and the maximum was 21. Thirty eight per cent of children had a score of 10 or over. This compares with 14% for Richman's population study of three year old children, and 12% for Cunningham's sample of chilren with Down's Syndrome. Seventeen per cent of the children with Down's Syndrome in our sample had scores of 10 or over. The coefficient of reliability (Cronbach's Alpha) for the BSQ was .72 indicating good internal consistency.

THE BEHAVIOUR PROBLEM INDEX

The Behaviour Problem Index is an adaptation of the Behaviour Screening Questionnaire (Richman & Graham 1971) by Cunningham and his colleagues (Cunningham 1986). The Behaviour Problem Index (BPINDEX) extended the Behaviour Screening Questionnaire by the addition of a list of problems derived from work by Wing & Gould (1987) and Gath (1978). This produces an index of a wider range of behaviour problems thought to be more suitable for a population of children with mental handicap. This allows us to compare our results with both general population sample studied by Richman et al (1982) and the sample of children with Down's Syndrome studied by Cunningham et al (1986).

The mean score on the BPINDEX (i.e. total score for each item divided by the total number of items scored for each child) was 5.5 (s.d. 2.3). The minimum score was 1.25 and the maximum 13.75. This is similar to the mean for children with Down's Syndrome found by Cunningham et al (1986) which was 5.2 (s.d. 2.6). The coefficient of reliability (Cronbach's alpha) was .87 confirming that the scale had good internal consistency.

Correlation between the BSQ and the BPINDEX was r = .82 (P<0.001). Behaviour Problem Index scores were found to be a predictor of sleep disorder, maternal Malaise scores, PINV scores and Judson scores.

THE DISABILITY ASSESSMENT SCHEDULE

The Disability Assessment Schedule (DAS) was developed at the Medical Research Council Social Psychiatry Unit, London, from a combination of items modified from the Wessex Social and Physical Incapacity (SPI) scale, the Wessex Speech Self-help and Literacy (SSL) scale (Kushlick *et al* 1973) and the Children's Handicaps, Behaviour and Skills (HBS) schedule (Wing & Gould, 1978). It is a structured interview designed to elicit from parents and care staff details of impairments, skills and behaviour problems in mentally handicapped children. The DAS includes items concerning a wide variety of behavioural abornormalities. The schedule consists of eight sections of which four are concerned with physical and developmental skills and four with behavioural abnormalities. The DAS is completed by conducting a structured interview with an informant who knows the mentally retarded child well. This could be a nurse, teacher or care assistant. Test-retest data and inter-rater reliability tests suggest that the schedule meets adequate criteria of reliability (Holmes *et al* 1982).

In phase one of our study it was decided that information about the child's impairments and skills should be collected from an 'independent' informant to avoid potential bias in parental perceptions. For example, a stressed or unhappily married mother might perceive her child more negatively than a mother who was not stressed and happily married. Emery & O'Leary (1984) have argued cogently that research using non-independent ratings to examine the relation between marital and child problems may exaggerate the strength of the association between interparental conflict and child behaviour problems. However, the methods used in phase one of the present study have problems too. The figures reported reflect prevalence in day care facilities. Children may respond to family conflict more noticeably in the setting where it occurs - the home. Thus behaviour problems may be situational-specific. Theoretically, this might mean that teachers fail to report behaviour problems which are displayed only at home. This might undermine the likelihood of finding significant relationships between social and family problems and behaviour difficulties. Phase one of the present study did not collect information about behaviour problems from both parents and teachers. However, Wing & Gould (1978), using a longer version of the same schedule, found that overall agreement between parent and professional informants was, in general, 70% or above. Parents, when compared with professional workers, tended to describe their children as having higher developmental skills and more difficult behaviour. This seems to be quite a common finding (Touliatos, 1981). Phase one of our study showed a high association between the behaviour problems as rated by professionals and parental ratings of the child being difficult to manage ($P < 0.0001$). We believe, therefore, that there were relatively few instances where problem behaviour occurred at home but was not recognized at school.

THE EXTRA WORK SCALE

The Extra Work Scale was based on a series of questions which asked whether the child's impairment caused extra work for the mother. The questions covered cleaning and tidying the house, cooking and preparing meals (because of fads, special diets, etc.), laundry (because of incontinence, heavy use of clothes), shopping (because of difficulty looking after the child) and other extra work (such as keeping hospital appointments, planning activities, etc.). No extra work was scored as 0, a little extra work as 1 and a lot of extra work as 2. The items were summed to give a possible score of 10. The mean score for mothers in our study was 2.7 (s.d. 2.2). The actual minimum score was 0 and the maximum score was 8. The coefficient of reliability (Cronbach's alpha) was .70.

The scale has been used by Cooke et al (1982) in their study of disabled children, and in our previous study of children with severe mental handicap (Pahl & Quine 1984). In both studies there was a relationship between Malaise scores and extra work scores: the greater the amount of extra work generated by the child's impairment, the higher the mother's stress score was likely to be.

THE JUDSON SELF-RATING SCALE

The Judson Scale was designed to measure the acceptance and adjustment of mothers towards a child with mental or physical handicap (Judson & Burden 1980; Burden 1980). It consists of 22 bipolar items separated by a seven point scale. Burden (1981) identified four sub scales: there were labelled self-esteem, feelings about the child, judgements of the child's capabilities and interactions with professionals and others.

The scale has been used by Cunningham et al (1986) who found that Judson scores were significantly associated with scores on the Malaise Inventory, behaviour problems, marital satisfaction and ratings of mother-child affection.

In our study there was no evidence of the four factors in the scale which were identified by Burden 1981. Factor analysis of the individual items did not reveal a clear cut factor structure. We have, therefore, used only the total scores. The scale has high internal consistency, with Cronbach's alpha of .81. The mean Judson score of mothers in our study was 114.9 (s.d. 16.9). The maximum score was 154 and the minimum score was 63.

Judson scores were found to be a predictor of scores on the Sleep Index and of maternal Malaise.

THE LIFE EVENTS SCALE (FAMILY STRESS)

The Life Events Scale was adapted from the Life Events Inventory of Tennant & Andrews (1976) and the family stress measure used by Richman et al (1982). It asks whether the respondent or anyone in the respondent's close family have experienced a number of recent adverse experiences or events in the last year. The items include accident, sudden or chronic illness, bereavement, pregnancy or childbirth, changes in relationships (such as divorce or separation), marital difficulties, rows with friends or neighbours, problems with children (excluding study child), difficulties at work (unemployment, redundancy), difficulties with partner's job, housing problems (damp, expired lease, etc.), moving house, financial difficulties, legal difficulties (possibly involving a court appearance), theft, and any other event or long term difficulty causing distress. Each difficulty or event was scored 0) no problems, 1) mild problems or 2) severe problems. The resulting scale had a possible range from 0 - 32. The actual range was from 0 - 16 (mean 3.8, s.d 3.5, N = 166). Cronbach's alpha for the scale was .66 indicating satisfactory internal reliability.

There was a strong association between life events and Malaise scores: women who reported significant numbers of life events were more likely to have high stress scores.

THE MALAISE INVENTORY

The Malaise Inventory is a 24 item binary choice questionnaire which was adapted from the Cornell Medical Index by Rutter and his colleagues for their study of child behaviour in the Isle of Wight (Rutter et al 1970). The scale has been used in a number of studies of handicapped children to measure the stress experienced by carers (Gath 1978; Burden 1980; Cooke et al 1982; Quine & Pahl 1985; Cunningham et al 1986). Rutter considered that scores of 5 or 6 were outside the normal range and indicative of stress, and that scores of 7 or more were 'critical' (Rutter et al 1970a).

The reliability of the scale was investigated by Rutter who asked 35 mothers to complete the inventory on two occasions. He concluded that mothers tend to acknowledge fewer symptoms on the second occasion. However, there was a high correlation between the scores ($r = .91$). In the present study 20 mothers completed the inventory on two occasions. There was a high correlation between the scores ($r = .94$) confirming, that the pattern of results was reliable.

The inventory has been investigated by Cooke et al (1982) who compared Malaise scores with scores derived from the Symptom Scale (Pomeroy et al 1978). The two scales were highly correlated, suggesting that the scale has good construct validity. In our earlier study (Quine & Pahl 1984) there was found to be a highly significant association between maternal Malaise scores and a mental health rating derived from the symptom scale.

Quine & Charnley (1987) investigated the empirical validity of the Malaise Inventory in two samples: carers of elderly people and carers of severely handicapped children. In both samples dependency and behaviour problems of the clients, and adverse life events in the carers were found to be associated with stress in the carers, showing that the inventory has good empirical validity.

Hirst (1983) examined the internal consistency of the Malaise Inventory by item analysis concluding that there was only slight evidence of a single dimension of emotional disturbance underlying the set of items and that, therefore, Malaise scores might be untrustworthy for testing empirical hypotheses about degrees of stress. Recent work by Bebbingham and Quine (1987) using a more appropriate analysis for scales which are made up of dichotomous variables, suggests that the inventory does yield a single moderate factor of stress. The value of the adjusted goodness of fit index (AGFI) proposed by Joreskog & Sorbom (1985 p.140) to assess the goodness of fit of single factor models yielded by confirmatory factor analysis is .92. The distribution of mothers' scores on the scale was a follows:-

mean = 6.0 (s.d. 4.0)   minimum score 0   maximum score 16

THE MARITAL RELATIONSHIP

The parents' marital relationship was assessed by the schedule used by Richman et al 1982 and by Cunningham et al 1986. This was adapted from the Interview Assessment of Marriage (Quinton et al 1976). The quality of the marital relationship is assessed from the reported feelings, attitudes and behaviour of the married people. Ratings are made in 8 areas: the amount of expressed affection and concern (warmth/sympathy), the amount of criticism made by the wife about her partner (criticism), the amount of hostility or aggressive dislike reported (hostility), agreement in decision making, enjoyment of husband's company, ability to confide in husband, satisfaction with help in household activities and frequency of rows and quarrelling. Each of these areas is scored 0) low warmth/agreement/satisfaction, 1) medium warmth/agreement/satisfaction, or 2) high warmth/agreement/satisfaction. The resulting scale has a range from 0 - 16.

The marital rating is as follows:-

Total Score	Marital Rating	
13 - 16	Good	1
9 - 12	Average	2
5 - 8	Poor	3
0 - 4	Very Poor	4

Ratings made in this way have been validated by follow-up studies demonstrating the much higher rates of subsequent divorce and separation in marriages rated poor (Quinton et al 1976).

In our study the actual maximum score was 0 and the minimum was 16. The mean score was 11.8 (s.d 3.5). Fifty five percent of marriages were rated as good, 32% as average and 13% as poor. No marriages were rated as very poor. Cronbach's alpha for the scale was .83.

The study found that the marital relationship was a predictor of both sleeping problems and behaviour problems.

MEASURE OF DAILY COPING

The Measure of Daily Coping (MDC) was developed by Stone & Neale (1984) to provide information about the coping strategies used by people to deal with severe life events or on-going difficulties. The MDC consists of a description of 8 coping styles and asks subjects to indicate whether they use each or any of them to help them to cope with specific problems they encounter. The coping styles and descriptions are presented below.

Measure of Daily Coping

Description of the Coping Categories

Category	**Description printed on the form**
1. Distraction	Divert attention away from the problem by thinking about other things or engaging in some activity.
2. Situation redefinition	Try to see the problem in a different light that make it seem more bearable.
3. Direct action	Think about solutions to the problem, gather information about it, or actually do something to try to solve it.
4. Catharsis	Express emotions in response to the problem to reduce tension, anxiety or frustration.
5. Acceptance	Accept that the problem has occurred, but that nothing can be done about it.
6. Seeking social support	Seek or find emotional support from loved ones, friends or professionals.
7. Relaxation	Do something with the implicit intention of relaxing.
8. Religion	Seek or find spiritual comfort and support.

The MDC has been used in a study of coping and appraisal in the general population (Stone & Neale 1984). It was found that sex of respondent and problem appraisal were associated with type of coping. A moderate amount of within subject consistency in coping with the same problem over time was observed.

THE MULTIPLE IMPAIRMENT SCALE

The Multiple Impairment Scale was adapted from items on the Disability Assessment Schedule for the first phase of our study (Pahl & Quine 1984). It is a simple additive scale of impairments including each item for which the child is assessed as having severe problems on the DAS. Items included are, mobility, continency, self help skills (feeding, washing, dressing), academic skills (reading, writing, counting), having one or more severe behaviour problems, being able to use and understand communication, having sight or hearing problems, being unable to interact socially with other people, having additional physical disabilities, and being epileptic. The resulting scale has a possible range of 0 to 14. The actual range for this study was 0 - 12, (mean 3.5 s.d. 3.5). The scale had good internal consistency (Cronbach's alpha .88). In his study a relationship was found between perceived unmet service need and multiple impairment.

PERCEIVED AVAILABILITY AND ADEQUACY OF SOCIAL SUPPORT

Perceived availability and adequacy of social support were assessed by using the items which make up these factors in the Interview Schedule for Social Interaction (Henderson et al 1980, Henderson et al 1981). Availability of social support consists of eight items concerning whether the respondent has partner, friends and relatives whom she can confide in or who confide in her. The scale has a possible range from 0 - 8. The actual range was from 0 - 8 (mean 2.0, s.d 1.7, N = 166). Cronbach's alpha for the scale was .74.

Adequacy of social support consists of six items concerning whether the respondent feels she is receiving enough support from her partner, friends and relatives. The scale has a range of 0 - 6 (mean 1.6, s.d 1.5, N = 166). Cronbach's alpha for the scale was .74. High scores on each scale indicate dissatisfaction with availability or adequacy of social support. Perceived adequacy and availability of social support were related to Malaise at the univariate level: mothers who believed that social support was generally unavailable and inadequate, were more likely to be stressed.

THE PERCEIVED UNMET SERVICE NEED SCALE (FELT NEED)

The Felt Need Scale is a measure of the total amount of perceived need for additional services. Mothers were asked whether they felt they needed more professional help with a number of problems which included the child's behaviour, dealing with night time disturbance, management problems, inappropriate social behaviour, teaching self-help and other skills, mobility problems, problems regarding the child's appearance, assistance with child care at home, developing communication skills, childminding, coming to terms with the child's handicap, marital problems, housing problems, financial problems, hearing and sight problems, information about services, information about the child's condition, a chance to discuss the child's progress, classes to learn how to help the child, and an emergency service for times of difficulty. Each item was scored either 0) no help needed or 1) help needed. The scale had a possible range from 0 - 22. The actual range was from 0 - 18. The mean score was 5.3 (s.d 3.8) Cronbach's alpha for the scale was .85, confirming good internal consistency.

THE PROBLEM INVENTORY

The Problem Inventory (Tavormina et al 1981) was derived to asses the mother's perceptions of problems her family has to face because of the child's handicap. It is a checklist of ten difficulties which the parent rates in terms of frequency of occurence from (0) never to (4) always. The following problems are included: extra demands on time and energy, decreased social life, tense home atmosphere, pressure to do the right thing to take proper care of the child, life is centred round the child's needs, special problems the family has to cope with, shortage of family friends, constant need to watch over the child, less time to devote to other children, disruptions of family routine. Tavormina and her colleagues used the inventory to assess the psychosocial effects on parents of caring for a physically handicapped child and reports a mean score for mothers of 21.7 (s.d. 7.7). The inventory has also been used in a study of family adaptation and psychosocial adjustment to a child with cystic fibrosis (Cowen et al 1985).

The mean score of mothers in this study was 19.6 (s.d. 9.8), the maximum score was 38 and the minimum was 0. The internal consistency of the scale was high (Cronbach's alpha .89).

THE SLEEP INDEX

The Sleep Index was computed from the night settling and night waking items in the Behaviour Screening Questionnaire (Richman et al 1982) with the addition of two extra items used in our first study (Pahl & Quine 1985). These were whether the parents had to get up to attend to the child, and whether the parents reported losing sleep because of the child's sleeping difficulties. Each item was scored 0 (no problem), 1 (mild problem) or 2 (severe problem). The resulting scale had a possible range of 0 - 8. The mean score for children in our sample as 2.8 (s.d. 2.5). The minimum score was 0 and the maximum score 8. Internal reliability for the scale was high (Cronbach's Alpha .78).

The study found a strong correlation between the Sleep Index and the Behaviour Problem Index, showing the well known association between daytime and night time behavioural difficulties (Richman et al 1981a).

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