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by

Sara Graham



Social Welfare Research Centre

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FOREWORD

This study reports the results of a careful and intensive assessment of the lives of a small sample of families caring for a child with a disability. As with all case studies, the sample size is such that it would not be appropriate to draw general conclusions from the results presented. This is not the intention of such studies. Rather, their aim is to provide greater detail and insight into the actual living circumstances of the families sampled, and the daily stresses and difficulties they face. Such information can rarely be obtained by large scale social surveys which, in seeking to maintain statistical respectability in their analysis, often do so at some cost in terms of lack of detail on individual cases. There is an important role for both types of study in social welfare research, in providing information on economic and social conditions in society, and on the impact and relevance of social service provisions to family living standards. Ultimately, such information can serve as an input into improved and more responsive social policies.

The author of this study, Sara Graham, spent a year at the Social Welfare Research Centre on leave from the Department of Health and Social Security in Great Britain. The great skill, dedication and commitment she brought to her work is evident in the Report itself, and does not need further emphasis here. The study grew out of an increasing awareness that little was known of the circumstances of families caring for disabled children and, in particular, of the additional economic, personal and social costs they faced as a result. This study has made a major contribution to our understanding of these issues and provides an extremely good foundation for further work in this important area.

The questionnaire from which the quantitative and qualitative data presented in this Report were derived is itself an important contribution to research on disability in Australia. Because of the length of the questionnaire, it was decided not to include it as part of the Report itself. However, for those who wish to study the questionnaire in detail, or base their own survey research on it, copies may be obtained by submitting a written request to: The Director, Social Welfare Research Centre, University of New South Wales, P.O. Box 1, Kensington, New South Wales 2033, Australia.

Finally, it should be noted that the study was completed before the introduction of those changes to the social security system announced in the 1987 May Economic Statement delivered by the Treasurer and those foreshadowed in the Family Assistance Package announced by the Government in June 1987. Both have implications for the Handicapped Child's Allowance which is discussed in several places in the Report. The effects of these announced changes should be borne in mind when assessing these particular sections of the Report.

Peter Saunders
Director
Social Welfare Research Centre

ACKNOWLEDGEMENTS

Although my study was only a small one the list of people whose help and support I should like to acknowledge is large. The research was undertaken during the year that I was a Visiting Fellow at the Social Welfare Research Centre. I should like to thank all my colleagues at the Centre for their welcome, hospitality and help. I should like to thank the families who participated in the study. I hope that my report does justice to the very great variety of their experiences.

I have greatly appreciated the help that my two colleagues at the Centre, Richard Mathews and Jennifer Doyle, have given me. Richard Mathews provided great assistance in planning the analysis of the data. Jennifer Doyle conducted a considerable amount of the SPSS Computer analysis and took an important role in production and presentation of results. The study would certainly not have been completed on schedule without their assistance. June Crawford (Macquarie University) gave most generously of her time and expertise to undertake the regression analysis. I am very grateful to her. I also appreciate the assistance of Philip Graham (Institute of Child Health, London) and Helen Malony (Prince of Wales Hospital, Sydney). They undertook the clinical assessments and gave me a great deal of advice on the clinical aspects of the study.

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I am grateful to the Department of Social Security, and in particular to Cheryl Hammond, for the co-operation they gave me in the study. I also owe thanks to Jonathan Bradshaw (Director Social Policy Research Unit, University of York) for allowing me to use a modified version of the questionnaire Sally Baldwin developed for her study of the costs of caring for a disabled child. A number of colleagues at the Centre advised me and commented on the draft report of the study. I owe thanks to Jill Hardwick, Adam Jamrozik, Peter Saunders and Joan Vipond for their very helpful comments. I am particularly grateful to Peter Whiteford for the advice and support he gave me throughout the study.

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CHAPTER 1

INTRODUCTION

In this report I describe the results of a study undertaken between June 1986 and May 1987. During this period, I visited 50 families, all of whom had a disabled child between 12 and 16 years of age. I talked to them about the costs they incurred as a consequence of their children's disabilities. The study is quite narrowly focused on economic effects, attempting to tease out only those costs which would not have been incurred had there been no disability. I have been concerned with costs of two kinds: firstly direct costs, money actually spent on meeting the child's needs, and, secondly indirect costs, the income forgone by the family because of the child's special needs and dependency. These latter hidden costs arise because the child's dependency can in some cases prevent one or even both parents from full participation in the labour force. It may also inhibit job mobility or career advancement, and thereby earnings, for those who are able to work full time. It may affect long-term earning capacity by, for example, preventing a parent from undertaking further education essential to the pursuit or enhancement of a particular career.

Although this study concentrates on economic costs, parents and others caring for children with disabilities will know that the consequences are by no means exclusively economic. Neither are the economic consequences necessarily of greatest significance to family members. There are many ways in which a child's disability can affect a family. These are likely to vary considerably, according to the age of the child and his or her changing needs, and according to the circumstances of the family. There may also be social consequences, such as isolation of the family from the community, relatives and friends, or emotional consequences leading to the breakdown of marriages or the deterioration of other relationships within the family. There can be consequences for the health of family members, resulting from the physical and mental strain of caring for a disabled child. These effects are not felt equally by all family members.

Social, physical, emotional and economic consequences fall overwhelmingly on women who, except in rare instances, are likely to be responsible for most of the tasks connected with the care of the child. However, it is very important to recognise that while these burdens fall most obviously on women, they are by no means borne exclusively by women. Consequences will also vary with the circumstances of the family. Extra expenditure is likely to have a greater impact on lower income families. Locality, too, can be a factor. The availability of good support services, which are not at all evenly distributed, can mean a great deal in terms of quality of life. Finally, and most important, the consequences will vary according to the nature and degree of severity of the disability of the child.

It is only too easy to focus on the negative consequences and to ignore the positive consequences which accrue from having a child with a disability. I am sure that many of the parents I spoke to would want me to mention these positive aspects.

Having a child with a disability can weld a family together, making it a cohesive and exceptionally caring unit. Whilst the disability of one of its members can bring great sorrow, it can at the same time and from the same people draw out inner resources, which enable them to realise themselves in the most unexpected and rewarding ways. It can enhance their ingenuity, competence, knowledge and technical skills and humanity. As one parent said to me, 'We owe a lot to our child. She has made us what we are'.

Although the economic effects are only one, and for some families not the most important, of the consequences of having a child with a disability, I focus on economic issues here for several reasons. To have attempted an overall coverage would inevitably have led to a very superficial study in which it would have been difficult, if not impossible, to disentangle the various components of the life experience of those who care for a disabled child. It seemed to me better to focus on a single theme, and to obtain good, detailed information in that area, allowing other material to emerge naturally as the context might prompt. For example, the discussion of costs often led people to talk quite spontaneously about their brushes with the health services or the Department of Social Security or about their anxieties over the reaction of relatives and neighbours to their child. Similarly,

when the question of the cost of respite care was raised in the interview, the inadequate provision of this kind of support service became very clear. In many cases it was obvious that parents found the strain of continual care almost intolerable. These are only a few of many possible illustrations of the way in which the discussion of costs led more or less inevitably to other areas of concern.

The economic dimension is clearly central. People's financial resources have such a direct bearing on their standard of living, quality of life and capacity to meet contingent material needs, that to ignore the question would be perverse. For the families of children with a disability it highlights their needs and the question of what sorts of services should be provided and at whose expense. Cash represents one kind of support for parents, services another. What is their relative value to families? What determines the preference of some families for help in the form of cash and of others for help in the form of services? The discussion of cash income as a need and a source of support inevitably raises wider issues as to what actual needs families have and how they would prefer these to be met.

This leads to a further reason for looking at financial costs and support. It is something tangible for policy makers and politicians to address. It is much easier to do something about the economic burden of family care than to alleviate the social and emotional consequences, though it might be added that economic relief can have a significant indirect effect on these areas.

The current concern with community care, which underpins the Home and Community Care (H.A.C.C.) programme and also finds expression in **New Directions: The Report of the Handicapped Person's Review**⁽¹⁾, is another reason for considering costs. It is now a guiding principle of policy that the interests of people with disabilities are best served when they can live and be cared for in the community, particularly at home. The effect of this policy is to locate the burden and responsibilities of care firmly with the family. This raises questions about the extent of support, including financial support, that parents need in order to perform their caring tasks effectively. Another issue is that of incentive. It is reasonable to ask to what extent the Government will need to provide incentives, and what specific incentives will be needed, to ensure that its policies are to be realised.

It was not lost on many of the families that I spoke to, even those who did not appear to have any contact with pressure groups, that they provided high quality care, very cheaply. They recognised that if they were not providing care some other agency, either a government or government-supported body would have to do so; and the cost to the community of that other provider would be far greater than the cost of what they were providing.

This study has unquestionably been timely, taking place as it has, at the same time as the Review of the Social Security System.⁽²⁾ One of the areas on which this Review has focused is on the matter of income support for families with children, and the Review intends to look critically at the existing social security provision for families caring for a child with a disability. Even before I had completed interviewing the families in my study the Social Security Review had published a consultative paper **Income Support for Families with Children, Issues Paper No.1.**⁽³⁾ This identified three major areas of concern about income support for families with a disabled child:

(a) the two categories of payment for

- (i) 'severely' handicapped children requiring constant care and attention and
- (ii) 'substantially' handicapped children requiring marginally less care and attention create considerable problems associated with the definition of 'severity' of handicap and 'constant care of attention'.

(b) families with a child classified as less than severely handicapped are eligible for additional assistance on grounds of financial hardship resulting from the disability of their child. Such families are subject to an income test and are required to demonstrate that they incur additional costs in caring for their disabled child. The definition of allowable costs is imprecise and leads to administrative difficulties and uncertainties for the claiming family.

- (c) the Handicapped Child's Allowance is not indexed, and the current level is not considered adequate.

These concerns were broadly similar to some of those addressed in the **Report of the Handicapped Programme Review**,

which included:

- . the adequacy of The Handicapped Child's Allowance for parents who have a disabled child living at home;
- . the inadequate treatment of significant extra costs associated with a child's disability;
- . the need for additional incentives for families to care for disabled children at home;
- . the complexity of administrative procedures;
- . the need for better information about the Allowance.⁽⁴⁾

Although my study is not an evaluation of the **Handicapped Child's Allowance**, I hoped that it would provide useful and well grounded insights into the financial needs and circumstances of families caring for a disabled child and that, in turn, these insights might contribute to a social policy debate about the most appropriate ways of meeting the needs of such families.

Despite the importance and topicality of this area of research there has in fact been very little information on the subject systematically collected for an Australian population. The economic consequences may be easiest to attack but they are certainly not the easiest aspect of the problem to investigate.

The economic consequences for families caring for a disabled member has not, however, been an entirely neglected field in this country. Between 1980 and 1982 Stuart Rees and Anneke Emerson undertook a study of 51 families in Sydney all of whom had an intellectually disabled child (some with additional physical handicaps), under five years of age.⁽⁵⁾ Rees and Emerson identified

13 broad areas of additional expenditure and concluded that families' extra expenditure amounted on average to \$230 dollars a month. At that time the Handicapped Child Allowance, the principal form of financial support for families, tied to the child's disability, was \$73 dollars a month, so Rees' and Emerson's figure suggests a shortfall of \$157 a month. However, their study did not focus specifically on costs and there are grounds for treating their estimate with a good deal of caution. One problem is the rather narrow focus of the study in terms of its sample population but a more significant problem is that they provide an incomplete account of how they arrived at this figure, and what relationship it bears to their empirical data.

Another study, undertaken by Craig Moore of Disabled People's International in 1984, amongst a group of intellectually, physically or multiply disabled adults of widely varying age, revealed an average extra expenditure of \$164 per month on account of their disability.⁽⁶⁾ However, he also found that there were very wide variations in costs between disability groups. Just as in Rees' and Emerson's study, it is difficult to determine from the report how the average figure of costs is arrived at and there is virtually no discussion of the nature of the variation between groups or what might account for it. This study provides a useful discussion of some of the methodological issues but, as Craig Moore admits, the data were no more than indicative.

Berry and Gunn have undertaken a promising study of the extra costs incurred by families who are caring for a child with Down's Syndrome. They considered expenditure in five broad areas: medication, special foods, transport, activities and use of specialists. Unlike the other studies I have referred to, and my own, Berry and Gunn attempted a comparison between the expenditure on the Down children, their non-handicapped siblings and another unrelated group of non-handicapped children. The children in all groups were selected to include those of different ages as well as both urban and rural residents. The research workers concluded that compared with the non-handicapped children some of those with Down's Syndrome represented a very heavy financial burden for their families. Average and maximum expenditure were considerably higher for the Down Syndrome children in all areas except, interestingly, social activities. It is a pity that Berry and Gunn did not provide details of variations in expenditure in these three groups, or of

income forgone, because their study represents a genuine attempt to deal with some of the complexities of this area of research.⁽⁷⁾

All three studies to which I have referred have used small and unrepresentative samples. Yet they have emerged with average figures of extra costs from which either they or others may be tempted to draw conclusions about the population generally. These studies are useful because they represent different, independent attempts at the study of a complex topic. In my view however, they would have been rather more useful if they had indicated what methodological lessons about the investigation of costs could be learnt from their attempts; for example, what type of enquiry is likely to be of most practical value, how the research could have been improved and what were its pitfalls. Instead of providing an **average** cost, I believe it would have been preferable to look at the **variation** in costs and the multiplicity of factors contributing to it. Unless this is done, one is unlikely to emerge with any other finding than that financial support needs to be increased. How the needs of different groups can most effectively be catered for, and whether, in particular, by means of financial benefits or services, is unlikely to emerge from such a study and therefore unlikely to further discussion of social policy options. A bold statement about the inadequacy of current social security benefit provision is unlikely to be greeted with much enthusiasm by policy makers, and it is no service to the cause of those who advocate improvements in the provision of services to base recommendations on inadequate data.

Regrettably, then, there are no good data on the costs of caring at home for disabled children in Australia. These, in any event, are likely to vary from State to State according to the way in which support mechanisms are provided locally. Some of the most interesting work in the area has been concerned with conceptualizing the problem and of suggesting ways in which one might go about collecting good data. These studies have tended to categorize costs in a variety of ways, by distinguishing for example, between recurrent and capital expenditure and income forgone and by identifying costs arising from a range of needs, such as medical, social, educational or other requirements. They have also considered ways in which one might account for variations in costs (e.g. according to type and level of disability).⁽⁸⁾⁽⁹⁾

There have, however, been some useful studies undertaken in other parts of the world. Sally Baldwin's book, **Costs of Caring**, describes one particularly relevant piece of research which she carried out in England.⁽¹⁰⁾ Nearer to home, Jane Chetwynd has recently undertaken a study in New Zealand of the various costs associated with caring for an intellectually disabled child at home.⁽¹¹⁾ One might ask why, if relevant empirical studies have been done in other parts of the world, one needs to do yet more research in Australia. In fact I would suggest that whereas the conceptualisation of the problem and the methodologies that have been developed are extremely helpful for studies here, the substantive results of the studies are likely to be different from these. First, there are the cultural differences affecting variations in costs because people live differently with different values and expectations in different parts of the world. Second, the different ways in which social, health and educational services are organized will undoubtedly affect outlays by families and hence the amount of money spent on their disabled children. One simply cannot extrapolate from one country to another. In one country child care services may be so good that mothers are not prevented from going to work. In another, medicines or mobility aids may be automatically available, free of charge; or there may be a free nappy service. Consumer preferences vary from country to country and so does service provision.

This study, therefore, sets out to examine the particularities of the situation as it affects a sample of Australian families. In the following chapter I shall consider some important features of the context of the study.

FOOTNOTES

- (1) **New Directions: Report of The Handicapped Persons Review**, Australian Government Publishing Service, Canberra, 1985.
- (2) This Review was established by the Minister of Social Security, The Honourable Brian Howe MP in February 1986.
- (3) **Social Security Review: Issues Paper No.1, Income Support for families with children**, Canberra, October 1986, pp 66, 67.
- (4) **New Directions**, 54-56.
- (5) S. Rees and A. Emerson, **Disabled children, disabling practices**, Social Welfare Research Centre, Reports and Proceedings No.37, January 1984.
- (6) C. Moore, **The cost of disability: A survey**, Disabled People's International (NSW), 1984.
- (7) P. Berry and P. Gunn, **Financial Costs of rearing a Down Syndrome child at home**, Final report to the Reserve Bank of Australia, St. Lucia, Brisbane, Fred and Eleanor Schonell Educational Research Centre, University of Queensland, 1986.
- (8) R. Horn, **Extra costs of disablement: Background for an Australian study**, Social Welfare Research Centre, Reports and Proceedings No. 13, September 1981.
- (9) E. Ogren and J. Lauricella, **Costs of disability: Review of issues**, Australian Council for Rehabilitation of Disabled (ACROD), December 1983.
- (10) S. Baldwin, **The cost of caring: Families with disabled children**, Routledge and Kegan Paul, 1985.
- (11) J. Chetwynd, **Some costs of caring at home for an intellectually handicapped child**, Australian and New Zealand Journal of Developmental Disability, 1985, Vol.II, No.1, pp 35-40.

CHAPTER II

THE CONTEXT OF THE STUDY: POLICY AND DEMOGRAPHY

Numerous incidental documents emanating from Commonwealth and State Governments over the last 10 years or so have endorsed the principle of community living; of the integration of people with disabilities into everyday social life. Traditional institutions and other segregated residential arrangements are widely regarded as having been discredited, particularly as far as disability lobby groups and many professional and research workers are concerned. It would seem that only some professional workers in institutions and a certain number of parents still perceive a value in institutions. Both groups do so on the grounds of the greater and more appropriate care and protection which they believe institutions can offer to highly vulnerable people.

In the planning and provision of new services for people with disabilities a guiding principle and a measure of their adequacy is the extent to which they permit people to live their lives as others do, or rather in a way which others find acceptable. This ideology underpinning service provision is usually expounded in relation to adults.

RESPONSIBILITY FOR CARE

It has always been seen as the responsibility of the family to nurture and care for its young, and the fact that offspring may on account of their disabilities make extra, long-term demands is not generally seen as a reason for families to abandon these traditional responsibilities. Only in extreme cases, where parents are quite unable to cope, or where the gross medical needs of the child make it unavoidable, is it socially acceptable to allow one's child to be placed in an institution. A stigma is undoubtedly attached to the 'abandonment' of any child to an institution except **in extremis**; but who is to define this state when it comes to the needs of the child? It could be said that the trend towards de-institutionalisation and the promotion of the values supporting it, though mainly relevant to adults, can

easily serve to generate guilt feelings in parents who ever think of placing their child in an institution. Thus it is expected that parents will keep their disabled child at home, and they generally do, often at considerable cost to the family. Such costs need to be measured in much more than merely financial terms.

A corollary of the doctrine that offspring are the responsibility of their parents is the view that families should not look too quickly for state support. Indeed many families are ambivalent about government support or interference in what they see as their private domain. There may be, on the one hand, a need for support, but on the other a feeling that it is wrong to ask for or expect this, to expect too much. It can take courage to express one's needs: hence, of course, the value of the lobby groups which collectively have done so much to help individuals negotiate their needs with the state. But even then some families see lobby groups as too demanding. 'I'm embarrassed by how much they ask for' one parent said to me.

In this study I asked parents about the adequacy of social security benefits and about the government's financial provision for families with a disabled child. Though by no means universal there was certainly a considerable body of opinion that it was wrong to use one's disabled child 'to get more' or to make further demands on the government. Some parents also expressed the view that they had no greater claims on the community's resources than other groups. The government, it was felt, had so many claims on its limited resources that it would be wrong for them as parents of disabled children to push too hard. Rather they felt that they should take their rightful place in the queue of supplicants. These parents seemed to see the government, or more vaguely 'the economy' as some sort of victim. Not content with their principal caring role they have extended it to embrace the government. One doesn't want to take this too far, however. The same parents could also express an awareness and a deep resentment that the government was getting 'care on the cheap' from them.

The view that the responsibility for children lies with the family is reflected in the demographic picture. The most recent figures that are available are from the survey handicapped persons which was conducted by the Australian Bureau of Statistics in 1981.⁽¹⁾ At that time, out of a total

handicapped population of 136,500 under 15 year olds, only 3,900 lived in institutions. That is to say, about 97 percent of handicapped children live at home, although it should be noted that this is not necessarily the parental home; it could be an adoptive or foster home, or that of a relative.⁽²⁾ However, when we look at the relationship between severity of handicap and place of residence we find that 64 percent of children living at home and 90 percent of those living in institutions had a severe handicap. These figures indicate that about 38,000 families in Australia are caring at home for a child with a severe handicap. They also suggest that severity of handicap is by far the most important factor in the institutionalisation of children. We must remember, however, that these figures are out of date. It is likely that, as a result of the current policy of de-institutionalisation, more families than in 1981 will be caring at home for a child with a severe handicap but there are no data to substantiate this assumption.⁽³⁾

RATIONALE FOR FAMILY SUPPORT

Although in all industrial countries the support of children is still seen as primarily the responsibility of their parents, provision is also made by the state to assist with some of the costs. Financial assistance is given to families out of a recognition that children are an indispensable social resource on which the continuation of the society and its economy rests. This provision is made on the basis of the 'recognition that at any level of family income people with children will incur greater costs and have greater needs than do people without children at the same level of income... The objective of Family Allowance is to provide universal support which will increase the disposable incomes of all families so as to offset, at least in part, the additional cost of raising children'.⁽⁴⁾

In some countries, including Australia, the state provides additional support or benefits for families looking after a child with a disability. The usual rationale for this additional support is that disabled children generate extra costs because of their unusual additional needs.⁽⁵⁾

The question is, in what terms are we to assess the adequacy of an allowance for children with disabilities? What are we to take its objectives to be?

Is it an incentive payment to parents to enable or to encourage them to care at home for children who would otherwise need institutional care? Is it intended to meet or contribute towards additional expenditure made necessary by the child's condition? Is it intended to compensate families for that wider range of costs, some of them indirect, which they incur as a consequence? Is it simply an acknowledgement of the family's tragic misfortune and of the social value of their work in caring for the child?

Without answers to these questions it is hard to assess the effectiveness of any allowance of this kind. When we come to look at financial provision in Australia, the objectives are far from clear and the evaluation correspondingly difficult.

There are, of course, a number of ways of supporting parents who have a child with a disability living at home. Direct financial support is only one; various other non-monetary forms of support are also possible. The provision by government or other agencies of services such as respite care, home help, personal or nursing care, a range of aids and adaptations to the home, special transport and medical treatment are among the more obvious forms of help. These may be provided on a universal basis, free of charge, or on a selective basis, according to certain criteria of eligibility. Yet a third form of support is the informal kind provided by relatives, friends, and neighbours. Finally, there is support or help provided in the form of environmental adaptations designed to facilitate the participation of people with disabilities in the life of the community. Ramps at shopping centres, doors wide enough to take a wheelchair and toilets which disabled people can use are small enough things, but they may actually determine whether a mother can take her child shopping; they may determine whether a person with a disability is or is not socially handicapped as well.

FINANCIAL PROVISION IN AUSTRALIA

The Handicapped Child's Allowance, a social security benefit designed to help parents caring at home for children with severe disability, was introduced in 1974.⁽⁶⁾ At that time, the benefit was set at \$10 a week. It was estimated that 20,000 families would qualify and that the annual cost would be about

\$10 million a year. In fact, in the first full year of the benefit for which data are available (June 1975-June 1976) some seven and a half thousand families were receiving the Allowance.⁽⁷⁾

In 1981, the year that the ABS survey of handicapped persons in Australia was carried out, about 26,000 families were receiving the Handicapped Child's Allowance⁽⁸⁾ - although the survey identified 40,600 under 16 year olds with a severe handicap living at home. Although this may seem to indicate a rather low take up of the benefit, it is almost certainly the case that the handicapped persons survey defines severity of handicap differently from the Social Security Department. It is regrettable that there is no up-to-date data from which one could derive more accurate estimates of take-up. But in any case it is impossible to draw any conclusions about this because, as my subsequent discussion of this benefit will indicate, the eligibility criteria for the Handicapped Child's Allowance are far from clear.

The last available figures⁽⁹⁾ show that some 31,000 families receive the Handicapped Child's Allowance and that the estimated expenditure is \$29 million for the year.⁽¹⁰⁾ When I began my study, the full rate of the Allowance was \$85 a month (increased during the progress of the interviews to \$92) while the lower rate (which is described later in this chapter) ranged from \$20 to \$85 per month (the maximum was similarly increased to \$92). Thus, given the size of the population it covers it is a relatively low-cost benefit. If the benefit had maintained its real value since it was introduced, beneficiaries would now be receiving around \$126 a month. In fact the benefit for families caring for a severely handicapped child is currently \$92, a shortfall of \$34 dollars a month. When the Handicapped Child's Allowance was introduced in 1974, Mr. Hayden, then Minister of Social Security, described it as intended 'to meet the additional expenditure that having a severely handicapped child at home entails'. Mr. Hayden also suggested that 'the Allowance could be used towards the cost of obtaining services that will afford some relief from the stresses that are experienced, especially by the mother, in these situations'.⁽¹¹⁾

When the Allowance was first introduced it was available to the parents of children living at home who had an intellectual or physical impairment or disability and were in consequence in need of 'constant care and attention'

for an extended period. Such children were deemed 'severely handicapped' and qualified for the benefit on these criteria alone. These eligibility criteria, a disability or impairment, and the need for constant care and attention, have remained unchanged since the introduction of the benefit.

It should be noted that an important addition to the provision was made in 1977.⁽¹²⁾ Recognising that other parents were also in straitened circumstances, the government extended the benefit to cover handicapped children needing somewhat less care and attention than those for whom the benefit had originally been intended. The eligibility criteria for the benefit were extended to a group with a 'substantial', as compared to a 'severe' handicap; a group who were in need of marginally less constant care and attention but who were nevertheless facing hardship because of the additional economic burden imposed on them by their child's disability. For the families of children with a less severe level of handicap, the granting of the benefit and its amount was (and remains) based, apart from the medical criteria, on an exceedingly complicated formula which takes into account both the income of the family and the extra cost incurred.

It is perhaps not surprising that with so many eligibility criteria, none of which are without their ambiguities, there are so many appeals against Departmental decisions concerning the award of this benefit. In recognition of the many associated problems the Department of Social Security is reviewing the situation.

To return now to the rationale for the Allowance. It would appear that it was provided firstly in recognition of the additional expenditure incurred for severely handicapped children cared for at home but also, given the term 'constant care and attention', to compensate parents for the sacrifice, effort and time that they were required to expend in caring for their child. However one must ask, if the Allowance was to offset additional expenditure, why was the actual extra expenditure not taken into account? On the other hand, if the Allowance was provided to compensate for the extra care and attention, why was it only set at \$10 a week (about \$29 a week in current prices). For a mother who surrenders her earning capacity to undertake her caring role, this would seem to be an exceedingly poor compensation. It seems then, that the Allowance was given to parents simply as a token

acknowledgement that there are costs involved in looking after a child who is in need of constant care and attention. It has been said that the Allowance was introduced as an incentive to parents to look after their children at home rather than have them placed in institutions - an inferior and, for the government, more costly option than parental care. Although the Allowance may have some incentive effects, it is doubtful whether these are very great and in any case most parents seem unlikely to need any additional incentive, given the strength of their bond with their children, to say nothing of all the other social pressures on them to continue caring for their child at home. In any event, although one should certainly not underestimate the importance of this extra amount of money to families, especially to low income families, the level at which the Allowance has been set seems too small to be an effective inducement except, perhaps, in a very limited number of cases.

To assess the incentive effect of this Allowance would be extraordinarily difficult. But, in any event, it is undoubtedly in any government's interest for children to be looked after in the parental home rather than in a state institution, since home care, whatever the quality and extent of community based supports for families, cannot fail to be a much cheaper option. This is largely because there is a saving on the staff costs which are the greatest part of the expense of institutional care. This fact was not lost on many of the parents I spoke to, who were well aware that their willingness to care for their children at home made them particularly 'cheap labour'. One parent said:

'You can't put a price on the time you put in but if you put the child in care full time and you worked out ... I don't know how much it costs the government. I don't know. But even if a quarter of it was paid to the mother who kept the child at home Because its bad enough with the emotional and what you've got to go through and not having any money. And without those medications that he got when he was 10, the thought went through my mind He'd have destroyed the whole family. That way I reckon they could financially you know We are saving the government a lot of money.'

In fact, the estimated average cost of hospital care for people with an intellectual disability in New South Wales is \$35,000 a year.⁽¹³⁾ The maximum level of the Handicapped Child's Allowance is currently \$1104 a year.

My study focuses on the financial consequences of disablement so that although, as I have already noted, the study is by no means an evaluation of the Handicapped Child's Allowance, of necessity it pays a good deal of attention to it. It seems clear that the financial support provided through the social security system is of great importance to families if for no other reason than that, so long as their children satisfy the eligibility criteria, it is, however limited, the only regular, long term and reliable form of support they are likely to receive. It is important, too, as an official acknowledgement of the social value of their caring role. But the reliability of the benefit is important because the lives of families with disabled members are, in other respects, so frequently dominated by uncertainties that it is important there should be a regular and reliable source of support for them. Initial and subsequent contact with the bureaucracy may be fraught, antagonistic and traumatic. Quite a number of parents told me how frightened they had been at the thought of the interview with the Commonwealth Medical Officer which some, though not all, parents are required to attend if they want to receive the benefit. However, once the benefit has been agreed, it doesn't have to be fought for and perhaps most important, there is no sense in which the parents are competing with other families for a scarce resource. The very impersonality of the bureaucracy would seem to have at least some advantages. The fact that the Handicapped Child's Allowance is paid in conjunction with the Family Allowance, means that it is not yet another thing to have to worry about. Regrettably, this contrasts sharply with the services that parents so frequently would like to use, and feel they need, to help them out. These have to be found, appraised and, if satisfactory, clung to and defended.

Services such as respite care and child minding, and to a lesser extent help in dealing with the personal needs of the child, are both sparsely and unevenly distributed and clearly insufficient to meet the demand. Thus some parents described how after getting regular respite care for three or six months they found themselves having to make way for other parents in need, without being given any idea when this help might become available again. Parents identified other problems with these services. It was difficult to find respite care which would accept or could deal competently with their children's special needs. The care was inadequate in the sense that they felt that their child was neglected. Their child was placed with other

children with more severe problems. Their own child picked up bad ways. One parent expressed strongly anxieties which others expressed more tactfully:

'I'd have put her into which is definitely an institution. But all the work I'd been doing in making her normal Yes, a couple of days off. But then all the good things I'd done she'd unlearn. And then I thought that if she came out with her tongue hanging out that would be enough to make me rip my hair out. And then all the nits. Some rest!!!'

Most of the parents appreciated the help they got; there were no complaints about the cost of care when it was provided by either a government or non-government agency. The complaint was that there simply wasn't enough of the right kind of help and it would be quite beyond the capacity of most families to purchase private services. A particularly scarce form of care was child minding after school hours and in the school holidays. This tends not to be provided for children over the age of 12, when non-disabled children are presumably deemed capable of looking after themselves.

This is not to suggest that cash might be a substitute for the services that I have just described. Clearly they are not and should not be seen as simple alternatives (unless, improbably, the Allowance were to be set at such a high level that individual families could purchase the services they need on the open market). I am simply contrasting the ways in which services and financial allowances impinge upon parent's lives. In fact, to obtain services of the standard and of the sort I have described would be beyond the capacity of most parents I met. Those in the most difficult circumstances were in no position to consider any kind of privately provided service and I suspect that any additional financial benefit would be more likely to be put towards the basic needs of these families than to the purchase of private services.

Since this is a study of the economic costs of caring at home for a child with a disability, it is essential to look at the extent to which allowances and services lighten the economic burden borne by families. This, at the very least, enables us to assess the contribution of the HCA in terms of its stated objectives.

FOOTNOTES

- (1) Australian Bureau of Statistics, **Handicapped Persons, Australia, 1981**, Catalogue No.4343.0. AGPS, Canberra.
- (2) Ibid. Table 1.3.
- (3) Ibid. Table 2, Unpublished table provided on request by ABS. The figures provided in the text are only approximate as, for certain groups, the numbers were very small and the data were suppressed due to high relative standard error. Furthermore, there was a substantial number of children for whom severity of handicap had not been determined. The proportions given in the text are based on totals for which severity had been determined.
- (4) Social Security Review: **Issues Paper No.1**, op.cit, p.3.
- (5) S. Baldwin, **Cost of Caring**, op.cit. Chapter 2. Baldwin has provided an excellent discussion of the arguments for additional financial provision for disabled people and their families.
- (6) Australia, **Social Security Bill**, Second Reading, 16 October, 1974.
- (7) Department of Social Security, **Ten Year Statistical Summary, 1976-1986**.
- (8) Department of Social Security, **Four Weekly Digest of Statistics**. Period ending June 1981.
- (9) Ibid. 3rd April 1987.
- (10) Department of Social Security, Unpublished data (verbal communication).
- (11) Australia Social Security Bill, 1974, op.cit.
- (12) Australia: **Social Services Amendment Act 1977**.
- (13) New South Wales Department of Health, Richmond Implementation Unit (verbal communication).

CHAPTER III

AIMS, DESIGN AND METHOD

AIMS

The main aim of this study is to examine the extra costs borne by families caring at home for a child with a disability. My aim is not simply to arrive at an average figure, but rather to discover the actual costs borne by particular families, how these vary and what factors account for the variation. Only the economic costs were included in the study although it is recognised that these economic costs can derive from a number of sources. For example, the emotional and physical strain of looking after a child can, and in this sample occasionally did, result in medical expenses for the parents, but I considered these only incidentally. It is, after all, difficult to attribute with any certainty the need for psychiatric treatment to the stress of looking after a disabled child and it is even more difficult to put a specific price on it. Thus I tried to confine my study to those economic costs of which I could say, with reasonable certainty, that they derived from the needs of the disabled child, by virtue of his or her disability. As we shall see, even this is not always easy.

I have viewed costs as having two components. The first is actual extra expenditure on goods and services such as medicines, medical expenses, nappies, aids and respite care. While it may at first glance appear easy to identify these extra costs there are nevertheless grey areas. For example, does one include as an extra cost the charges for attendance at a camp organised by the child's special school? Or does one exclude these because attending a school camp is something that any child might expect to do? Does one include the cost of a second car because, though that car might well have been bought anyway, it is nevertheless essential for transporting the child to the doctor, to swimming lessons, respite care etc.?

The second component of costs is income **forgone**. This I have looked at in terms of the declared inability of the mother to earn money on account of the

dependency of her child. It is even more difficult to be certain that income said to have been forgone in this way is directly attributable to the child's disability. Parents themselves frequently do not conceptualise this connection in an entirely clear-cut fashion. It simply is not an easy matter to disentangle the relative contributions of such influences as single parenthood, the child's disability, the demands of particular kinds of employment, and so on. The views of a single parent with two intellectually disabled children reflect this complexity:

'I think myself that their disability doesn't affect my working at all. But I find that its very hard to have a baby sitter when you've got children with a disability. I've tried to go to work and I've worked for about 6 weeks and it hasn't turned out very good at all I wouldn't leave them on their own. I mean, we've never had accidents with fire or scalding themselves. They are very aware in that sense but, I mean, there's always the chance. I say that it isn't the children's disabilities in a sense only because if I went back to nursing I would only do night duty. I would not work during the day because I would rather be with my children. I've always been like that, regardless of whether they have disabilities or not When I went back to work, I worked 8 weeks and I had a baby sitter to come in. All she did was sleep here. I was home to breakfast the children every day and make sure they're dressed and put them in a taxi. She'd ring up at ten to ten to say "I can't come tonight, I'm sick.".'

Some carers, of course, would not want to work either full or part-time because they would simply prefer to stay at home and confine themselves to domestic and/or social activities; others have other young children and would prefer to stay at home for their sake rather than go out to work. Then there are other mothers who would simply not be able to find work that they could or would want to do. A woman may have been out of the work force for a very long time or have professional training, but be unable to find work in her area of competence. It is not always easy to identify the primary reasons for mothers' non-participation in the work force even though at first sight their children's disabilities may appear to be the most compelling.

In fact what one is really doing in discussing the income that mothers have lost in this way is putting a value on the time that they spend looking after their disabled children.

Even mothers who go out to work incur costs as well as earning income. They may have to take time off work to attend to their children's needs. Although most mothers with young children have to do this, a mother who has a child with a disability is likely to have to do so much more often. How much more is extremely difficult to quantify.

The problem of determining income forgone is not relevant to mothers alone. Fathers may also have their job mobility restricted because of their child's condition. They too may have lost earnings because of the need to take time off work to attend to their child. They may have forgone training and thereby career advancement. But because fathers do not as a rule have such a consistently demanding caring role as mothers, we are entering the realm of conjecture to an even greater extent. It should be clear that indirect costs in the form of income forgone are far more elusive and difficult to estimate than the costs which involve actual expenditure.

DESIGN

Despite the apparently ambitious aims of my study, the time at my disposal (a year from start to finish) has set strict limits to what I could hope to achieve. Within this framework I hope that my study might first provide a critical appraisal of a methodology for collecting information on costs and perhaps suggest directions that future research might take. I have devoted an entire chapter to the detailed examination of methodology for collecting information on costs and perhaps suggest directions that future research might take.

This investigation was inspired by, if not modelled on, an English study undertaken by Sally Baldwin in the late 70s.⁽¹⁾ Baldwin's study, which also aimed to examine the extra costs borne by families with a disabled child, is the most thorough one of its kind. One difficulty encountered by such studies is that of distinguishing costs incurred as a direct result of the child's disability from others to be expected in the case of an otherwise comparable child without a disability. Whilst there are certain costs that one can unequivocally attribute to a child's disability, such as the purchase of a wheelchair, it is less easy to do so in the case of other costs, for

example the cost of a swimming pool which may have therapeutic value, but which might have been built in any case, even if the child had not had a disability. Another, more mundane example relates to the cost of clothing. Parents may say they go to extra expense clothing their disabled child, but unless one knows how much that family would have spent on clothes for a child with no disability, there is no way of testing their claim. Baldwin overcame this problem by comparing the expenditure patterns of a group of families with disabled children with those of a control group with no disabled children, but otherwise matched as closely as possible. Both groups of families were asked to keep diaries of their expenditure over a two-week period. Baldwin was then able to compare the expenditure patterns of the two groups and thus to ascertain where their costs differed: in which areas of expenditure costs were higher for the families of the disabled than for the control group, in which they were lower and in which they were about the same.

In addition, Baldwin interviewed a small number of families very intensively. In this way she established in much greater detail what expenditure there had been on a wide range of items on which families were likely to have spent money on account of their children's disabilities but which were unlikely to have emerged in a single two-week period. Through this in-depth interview she was able to look in some detail at such hidden costs of the child's disability as the impact on mother's or father's employment. She was also able in this way to determine whether families had received help with any items they needed; for example, was there a nappy service, had the family had help with transport cost for hospital visits? In addition Baldwin used this in-depth survey to pinpoint costs which subjectively meant the most to parents and to examine families' attitudes to the financial and other types of help they were receiving, with regard to its adequacy and appropriateness. Finally, her interview examined in considerable detail the nature and level of the children's disabilities, enabling both the data collected in the expenditure diaries and the data collected by means of the interview to be examined in the light of this information.

The combined use of these two methods, the first comparative, the second more direct, enabled Baldwin to undertake a very detailed and rigorous examination of costs. Regrettably, I did not have time to undertake such a complex study

in Sydney. Whilst I believe that the data obtained through my interview-based study undoubtedly has a good measure of validity, there is no question that the use of a control group would have added weight to the findings.

It is important to recognise at the outset, that my study was not designed to produce an estimate of the costs borne by Australian families generally or even by any families beyond the 50 included in my study. The families I spoke to were both too few in number and also insufficiently representative of any wider group, including the recipients of the Handicapped Child's Allowance, for me to be able to make confident generalisations. What I did expect my study to be able to do, however, was to provide an indication of the sorts of costs one might expect families to incur, and of the factors affecting these costs. I hoped that it would point to the sorts of factors that policy makers should bear in mind when they come to consider how families might best be helped. The study aimed, therefore, at providing no more than a profile, a descriptive account of a group of families and the costs they incur because they are caring for children with disabilities.

The actual number of families in the study and their location (confined to the Sydney metropolitan area) was determined by the timescale of the study and the fact that the field work was being undertaken by a single research worker. However, I must emphasise that whilst these limitations undoubtedly represent a disadvantage, they certainly do not mean that the study lacks point, because its whole purpose is exploratory rather than definitive. As the details of the study unfold, it should become apparent how complex an area the study of costs is and how greatly needed, at least initially, is a minute and detailed account of these complexities.

The criteria upon which I selected the families were determined with regard to the nature of the study and of its aims and objectives. First, because I wanted to ensure that the parents I talked to represented a broad spectrum of economic circumstances, I tried to ensure that families with a wide range of incomes were included in the study. An account of how I selected the sample is provided in Appendix A.

Another defining characteristic of the sample was the age of the disabled child. The study was confined to families caring for children between the

ages of 12 and 16. The reason for confining the sample to a single age group was that because the sample was so small I wished to restrict its variability to some extent. It was not that I thought that age was likely to prove irrelevant to the level of costs. On the contrary, I thought it likely to be highly relevant, which subsequent anecdotal evidence has tended to confirm. Many parents told me how much greater their costs were when their children were younger. The experiences of one parent serve as an illustration:

'We were less well off and it was a lot. I owed the hospital \$3000. There was no way I could pay the debt back. Fifteen years down the track things are a lot better. Back when Janie was a baby, the strain of the expense was enormous. I was 19 when I went to hospital and had this baby back 14 years ago. I was insured for public with MBF and this baby was born with all these multiple problems and they did all these tests and we were in hospital for three months. And by the time Janie came out - this may not seem a lot of money but it was absolutely insurmountable. I owed \$3000 and there was no way ... My husband was just starting out and his wages were low and there was no way that I could ever work to pay this debt back. I was lucky that the doctors (and she's seen masses of them - pediatrician, immunologist, neuro-surgeon, plastic surgeon, the lot)... Yes, I was lucky that they were good to me but the hospital said that I'd have to pay it off. It was depressing and bad enough as it was but then we had to pay off those hospital bills. With no means really to be able to pay it off. We were on a very low income and just starting out ... We never dreamt'

Although one of the recommendations I would make if a larger study were to be undertaken, is that all age groups should be included, there are considerable difficulties in including younger children. The main difficulty is that it is far more difficult to attribute costs specifically to their disability as distinct from their dependency as children. I am thinking particularly of the costs incurred because the mother cannot go out to work. In the case of a young child one cannot confidently attribute the fact that the mother is not in gainful employment to the disability alone.

As children grow older the likelihood that the mother will rejoin the labour force, either full-time or part-time, increases. I was interested in finding out whether this tendency is less pronounced for mothers with disabled children than other mothers. Of course, it is not possible to draw firm conclusions about the effect of the child's disability on the mother's employment if the mother has children who are younger than the disabled

child. To overcome this difficulty I did ask the mothers whether they would be working were it not for the disability of their child and also what were the specific factors that constrained them. One must admit, however, that hypothetical questions of this sort have their limitations.

Yet another reason for selecting families with a 12 to 16 year old is that this can be a particularly difficult time for parents. It is an age at which children can develop quite severe difficulties, in particular, behaviour problems. It can therefore be a time when parents are emotionally stressed, and although it was not my intention to examine the emotional costs to carers, they are important because the relief from these stresses can have an economic cost. In the case of children who are physically dependent the child's increasing weight can pose serious physical problems for carers, particularly lone parents. It seemed important to find out whether parents receive help with their growing children, and if so whether there are any costs involved in obtaining this support.

There are several reasons why one might expect younger disabled children to be more expensive on the whole than those who are older and than those who have no disability. Older disabled children, on the contrary, might be expected to be less costly in certain respects than children of the same age without a disability. Younger children are likely to make greater use of medical services, there are likely to be more assessments and greater use of therapies than when the child is older and has, in many cases, reached some form of plateau. The older disabled child is likely to be less expensive than a non-disabled child to the extent that the disability restricts participation in the youth culture with all its attendant costs in terms of clothes, entertainment, equipment etc.. This, sadly, reflects the difficulty facing many young people whose condition prevents them joining in the ordinary activities of their age mates. This is very much echoed in the comments of some parents who remarked anxiously on the social isolation of their child. On the other hand, it should be recognised that some parents put a lot of time and money into making their children as little handicapped as possible. This is the aim of some of the quite costly independence training that special schools provide and is also reflected in the fact that many parents said that they tried to make their child look better dressed and

groomed than a normal child. As one parent remarked 'I don't want my child to look like a dog'.

The way the disability impacts on the family, then, is likely to be partly a reflection of the age of the child. The age group on which this study focused was sufficiently narrow to enable me to say something about 'the older child' and sufficiently broad for me to examine whether amongst this age group there were differences in costs which could be attributed to age. The selection of this age group precludes me from offering anything other than impressions about the costs of disabled children under 12.

A third limiting feature of the sample is that it is confined to parents caring for a moderately or severely handicapped child. There were a number of reasons for this. First, it is much easier to designate costs as extra costs with a moderately or severely, rather than mildly disabled child, because they are much more clearly related to the needs arising specifically from the disability. Moreover, it seems a reasonable conjecture that costs will increase with the severity of the disability. In fact, an unintended effect of the way I drew the sample was that I was enabled to examine the effects of different levels of severity of disability on costs. Although I had expected my sample to be confined to the most severely disabled children, since it consisted entirely of recipients of the Handicapped Child's Allowance, I discovered a much wider range of measurable disability than I had expected.

While I was concerned to restrict my study to families with a moderately or severely disabled child, I hoped at the same time that my sample would include as wide a range of types of disability as possible. I wished to examine the extent to which the extra costs incurred by families were affected by whether the child had a physical or an intellectual or a sensory disability, or multiple disabilities. Whilst it is clear that if one were trying to make a case for enlarging the benefit for a particular group of people, for example, asthmatics or quadriplegics, a detailed study of the costs borne by sufferers of these conditions would be worth doing, it was not my chief purpose to make out a case for the enhancement of the HCA, but rather to look at the relationship between the size of the benefit and the

costs generated by the wide range of disabling conditions to which it applies.

METHOD

Selection of Sample

The sample of families that comprised my study was selected from amongst recipients of the Handicapped Child's Allowance. Given the characteristics that I had decided the sample families should have, namely that they should be caring for moderately or severely disabled children between the ages of 12 and 16, that the children should have a range of disabilities and that the families themselves should vary in terms of their economic circumstances, it seemed that the only suitable population whose characteristics could be known before the interview would be recipients of this benefit.

I was not able to select the sample of HCA recipients myself, because this would have involved access to the confidential records of the Department of Social Security (DSS). However, I nominated six social security regions in the Sydney area, which I chose with a view to maximising the range of socio-economic levels amongst respondents.

The six social security regions were Baulkham Hills, Blacktown, Dee Why, Maroubra, Mount Druitt and Petersham. Each region includes areas well outside the boundaries of the suburb from which it takes its name. The Dee Why region, for example extends as far north as Palm Beach, the Petersham region embraces Five Dock and Blacktown includes Seven Hills within its boundaries. Each region corresponds to a known grouping of census districts, for which the mean income of households according to the 1981 Census of Population and Housing can be determined. It was on the basis of this information that I selected the six regions, so that two, Baulkham Hills and Dee Why, had mean incomes that could be classed as high. Two, Maroubra and Blacktown, had mean incomes which could be called medium on a three point scale. Mount Druitt and Petersham had relatively low mean incomes.

The geographical dispersal of these regions, though not encompassing the entire range of the Sydney metropolitan area, at least samples widely,

providing representation of the older inner city, the newer sprawling western fringe, some well-established intermediate areas of medium density, some affluent coastal suburbs and some equally well-to-do semi-rural outer suburban districts. This dispersion is significant, not only in as far as it represents a reasonably wide range of socio-economic circumstances, but also varying levels in the provision of public services. Transport, health services, education, communication and other essentials are notoriously under-provided in Sydney's outer Western areas, by contrast with the more adequate services in longer and more closely settled districts. All of which has significant implications in terms of cost, convenience and well being for families caring for disabled children.

DSS selected potential participants on my behalf including recipients of both the 'severe' and the 'substantial' levels of the Allowance. DSS wrote to the selected recipients and enclosed a letter from me which described the study, and asked them to write directly to me if they were willing to participate. Thus I did not know the names of any of the benefit recipients or anything about them or their child's circumstances until they got in touch with me in reply to the DSS and my letter. The DSS, in turn, **remain unaware** which of the families they approached chose to participate in the study.

Although, on the face of it, HCA recipients were an ideal population from which to draw the sample, given the aims of the study, in the event, the selection of the sample in this way proved to have certain disadvantages. The number of families who actually contacted me as a result of receiving the DSS letter was small. In order to achieve the target sample of 50 families the DSS had to send out something in the region of 250 letters.

Because I do not know some of the more crucial characteristics of the families to whom the DSS wrote, for example, the disabling condition of the children or the income level of the parents, I do not know how representative the sample might be of that population. However it is interesting that so many people chose not to participate in the study. One can only conjecture as to the reasons for this. The most obvious possible explanation is perhaps antagonism or mistrust of the DSS. Despite assurances of confidentiality and the independence of the research, they could have been concerned about the effect that their participation in the study might have on their benefit.

There are also other reasons why families may not have wished to participate. Families with a disabled child are constantly being asked to provide information about their own and their child's circumstances. Some no doubt reach saturation point. Parents may wonder, not without reason, what good will come of participating in a research study. They may ask what possible benefits could accrue to them. Introduced as I was by the DSS, some families may have wondered whose interests I represented. There may have been fears that the research would result in a reduction of their Allowance. There may also have been a suspicion that the DSS had deviously asked a research team to check on the costs and/or the resources of their benefit recipients. Certainly it was clear from my interviews that the relationship between the research and the DSS was, perhaps not surprisingly, not properly understood by many respondents. It was from my interviews that I gained the possible clues sketched above, for the non response.

The Interview

I have referred earlier to Sally Baldwin's study of the costs of caring. I was very fortunate to be able to make use of one of the questionnaires she had developed, which I modified for use in this study.*

The questionnaire I used had 5 sections. The first section had to do with the family, its size and composition and the current employment status of members. This section also contains an important question on the health of the family members other than the disabled child.

The second section of the questionnaire seeks to elicit full details of the disabled child's health, disabilities and dependencies and the extent to which these have changed in the course of his or her life. An important aspect of this concern relates to the child's independence, in terms of self care skills, such as washing, bathing, eating and using the toilet. A further set of questions associated with the child's independence focused on the length of time the child could be left alone or without a responsible adult present.

* Copies of the Questionnaire are available from the SWRC on request.

The third section of the questionnaire related to the occupational histories of the parents and the impact of the child's disability on their earnings and employment. The important issue was how far the child's disability had affected the parents' opportunities for job and occupational mobility or career advancement or for training. There was further, an examination of what specific aspects of the child's disability had proved problematic in relation to the parents' past and present employment. This section of the questionnaire also sought information on parents' gross annual income from all sources - their earnings, savings, investment and benefits. In keeping with the concept of the 'family unit' employed by the Department of Social Security and the Australian Bureau of Statistics only the parents' incomes were taken into account and not those of other family members also in the household.

The fourth section of the questionnaire explored the additional expenditure of families. Several items were listed but there were many further opportunities for parents to add items not specifically identified in this way. Identified expenses were always related to a specific period: last week, last month, last year, for example. With larger consumer durables and non-recurrent expenditure, for example, wheelchairs, extra bathrooms, pools, the year when the cost was incurred was sought. In addition to the questions on expenditure, respondents were asked about the help they had received from statutory or other agencies in meeting the needs of their child.

The fifth broad section of the questionnaire I used, related to the parents' views on the impact of the child's disability on the family, their views on the Handicapped Child's Allowance and the process by which the family had received this benefit, as well as their views as to its adequacy. In this section I sought parental views on the question of their preference for increased financial support as opposed to better and increased services. Views on the kinds of services parents either do or would find most helpful were also sought. Throughout the questionnaire, an attempt was made to gauge the impact of the child's disability on the other children in the family, both in terms of any problems to which it had led and in terms of its effect on the resources directed towards them.

As Baldwin's questionnaire was devised for use in England it was naturally not entirely suited to the Australian context and, as I have already noted, required some modification. In particular, that part of the questionnaire dealing with medical expenses and social security benefits was inappropriate, given marked differences between the British and Australian health service arrangements and social security systems. However, the nine pilot interviews I conducted indicated that in nearly all other respects, Baldwin's questionnaire was usable.

Apart from the pilot interviews, I consulted fairly widely about the content and terminology of the questionnaire. I received many helpful comments from people knowledgeable about the disability field. One concern shared by practically everyone I consulted was the length of the questionnaire. Admittedly it was a rather intimidating document: a centimetre thick, 92 pages long and with 143 questions, many of which had numerous subsections. However, despite the fact that no interview took less than two hours, and a few took as many as four, it is worth noting that not a single respondent objected to the length of the questionnaire. When I apologised at the end of each interview for taking up so much time, many respondents, though they agreed that it had been a lengthy interview, remarked that the topic was one which deserved to be tackled thoroughly. I gained the impression that those to whom I spoke had something to get off their chests. It may be that respondents so ready to talk constituted a biased sample. But experiences and life histories cannot be discounted simply because they may not be totally representative. They are in themselves an important aspect of reality. And in any case there is no means of knowing to what extent they are or are not representative.

Not only were there no complaints about the length of the questionnaire but there was also very little resistance to providing the information that was sought. Apart from two cases in which respondents did not wish to give details of their incomes, no other questions or sections of the questionnaire met with any non-response. There were, however, some areas which I found difficult to explore with some respondents. I found that with some less well educated respondents and those who were not native speakers of English there were difficulties with some of the questions which were intended to elicit views or opinions. Whilst these respondents had no difficulty answering the

questions on the child's health and disability, or the questions which sought information on employment history, on income and earnings and expenditure, other questions that were more conjectural, hypothetical or abstract presented some respondents with difficulties, for example, questions as to whether the mother would like to go out to work or whether the respondent would prefer extra financial support or additional or better services or what particular services the respondent would find most helpful. Where there were difficulties of this sort I did not dwell on these topics. They were, after all, not the main focus of the study. The difficulties no doubt reflect faults in the formulation of the questions as much as any incapacity on the part of my informants. Asking people who have become habituated to a certain level of deprivation which of two improbable alternative improvements they would prefer and doing so in a second language, does invite a degree of incomprehension.

The main focus of my study is on the question of costs and it was of course, important that the information obtained should be as complete and accurate as possible. However, the study relied almost totally on recall, the potential inaccuracy of which is notorious.

To overcome this problem, survey researchers frequently ask people for documentary evidence in the shape of tax assessments, statements of earnings or shopping receipts. However, while this may be quite appropriate in studies concerned simply and unequivocally with money, I was dealing with the rather more sensitive area of the relationship between disability and money. I decided therefore to use a somewhat different approach. I believe in my case that this was more realistic, as it seems to me unlikely that respondents would systematically have preserved all relevant receipts. Furthermore, I was not too worried about the exact income or earnings of the respondents. I was satisfied to consider these in terms of income groups.

In an attempt to improve the quality of my data, I explained the purpose of my study to respondents when I made my initial contact with them. At this point I asked respondents whether they would try to complete a form which I proposed to send them before the interview. This listed most of the items of expenditure to be covered in the questionnaire. I asked the parents to indicate whether they had spent money on each item over a given period and if

so how much. I also asked them to add to the list any items of expenditure I had not included. By using this method I avoided the difficulty likely to be caused by arriving on the doorstep and almost immediately asking how much had been spent, for example, on nappies, in the last month. The preliminary form served as an **aide memoire**; it enabled the family to prepare and to consider in advance what expenditure there had been. Of course, many families did not actually complete the form. However, even in these cases I believe the list served a useful purpose in preparing the family for the interview. Some families wrote extremely detailed accounts of their expenditure and these proved very helpful. There were a few instances where I believe the form was disadvantageous. Some families could not think of any extra expenditure that they had incurred for their child. They therefore felt that I would not be interested in talking to them. It sometimes took some time to reassure them that I was just as interested in families which appeared to have low expenditure as in those whose costs were high. I also explained that my survey was not simply looking at expenditure but at a number of other costs.

I was concerned that since the study was about the economic costs borne by families, I should talk to all members who might have incurred costs on account of the child. There were 38 two-parent families in my sample and in these cases I endeavoured to talk to both parents. In the event, however, I was only able to meet 29 of the fathers. I believe that the fact that I was able to talk to the fathers at first hand about the impact of their child on their employment histories and their incomes enhanced the value of the data considerably. Furthermore, in some families the father assumed the chief responsibility for all major financial matters and was more knowledgeable about these, even though less *au fait* with the details of day-to-day expenditure and housekeeping than the mother. The fathers' input was in some cases crucial. Unquantifiable though this effect is, I believe that the joint interview led to the collection of more accurate information. Apart from what I have written above, the figure on expenditure that was given to me was often given only after a fairly long discussion, which had sometimes taken place before the interview, but at other times took place in the course of the interview itself. The discussion between the parents also revealed how very subjective the information I was receiving so often was. There was sometimes a considerable measure of initial disagreement between the parents as to the extent of the child's disability or the child's dependence (for

example, how long he or she could be left alone, or the cost of a walking frame).

Whilst the presence of both parents was a decided asset, the presence of the disabled child at the interview usually presented difficulty. After the first couple of interviews, I realised that the child's presence was inhibiting me. There were certain questions I found that I could either not ask at all, or which I felt uncomfortable asking in the child's presence. Questions such as the progress of the child's disability, or about the child's continence, or about any emotional or personal problems the child experienced as a result of his or her disability, or about the parents' concerns for the child's future.

I do have evidence that the information given in front of the child was not always accurate. One mother took me aside, ostensibly to show me a piece of her child's medical equipment, but actually to tell me that the child's disability was progressive and terminal and that she did not feel that she could talk to me about this in front of the child. Admittedly I felt more inhibited when the child was of normal intellect, but even when the child would have had difficulty understanding the conversation, either because of deafness or an intellectual disability, I felt that there was something improper about discussing in front of the child the costs incurred and therefore the sacrifices made by the family. It seemed to be adding insult to injury. In fact, in one fifth of the cases the child was present at the interview, in about half the child was not present and in 15 cases the child was in and out of the room. Whilst I had a clear preference for the child not being present at the interview, I did not feel that I could impose this preference on the parents. I usually raised the issue on the phone when I made the appointment to see the family. Some parents said that they did not mind the child being present and that they had no secrets from the child. In some cases the parent said that he or she would prefer the child not to be present and others said that it was up to me. A few parents expressed appreciation that they had been asked and complained that some professionals had been very careless and insensitive about what they had said in front of the child. Some parents who had originally not minded their child being present, when they realised the form that the interview was taking asked their child to go and play in another room. But of course by this time the

child had become completely hooked and resented being asked to leave! As the interviewer I could only make a judgement as to what I believed I could ask and what I had to omit in front of the child. A considerable amount of the missing data on the questionnaires arises because of the child's presence and, to a lesser extent, as a result of my failure to communicate with some of the respondents on the conjectural and attitudinal questions.

I shall return to some of the themes of this chapter in the course of later analysis. I now turn to an account of the evidence collected in the course of my study.

FOOTNOTES

- (1) S. Baldwin, *op. cit.*

CHAPTER IV

THE SAMPLE OF RESPONDENTS

In this chapter and the next I shall describe selected characteristics of the 50 sample families, most particularly of the parents and of the children whose disabilities were the reason for my interviews. Naturally, the characteristics on which I shall focus attention are chosen because of their bearing on the purposes of the study. I am concerned to identify factors which seem likely to affect the extent of the extra costs incurred by families and to help us to understand better the reasons for variation in this respect.

As I have already noted, I make no claim that this sample of families can be regarded as representative of the population or of all recipients of the Handicapped Child's Allowance, let alone of all families with children who have disabilities. Nevertheless, the table below compares, for the characteristics I shall be looking at in the rest of this chapter, the sample population with the Australian population and where possible, the population of recipients of the Handicapped Child's Allowance.

THE FAMILIES

One and Two Parent Families

The resources of a family, as well as the quality of life it can enjoy, are of course likely to be affected by the absence of one of the parents. The extra costs consequent on a disability are likely to impact much more severely on a single parent family in which there is at best, likely to be only one income-earner, and more probably no income-earner at all.

As we may see from Table 4.1 twelve families, or 24 percent of those interviewed, were headed by a single parent. In 38 (76 percent) both parents remained part of the household. All the single heads were women, in 11 of the 12 cases the mother, in the remaining one, the maternal grandmother.

TABLE 4.1 - SELECTED CHARACTERISTICS OF SAMPLE FAMILIES AND AUSTRALIAN FAMILIES WITH DEPENDENT CHILDREN

Characteristics	Sample Families % (rounded)	Australian Families % (rounded)	Characteristics	Sample Families % (rounded)	Australian Families % (rounded)
1. Family Type⁽¹⁾			5. Employment of Mothers and Age of Youngest Child⁽⁸⁾		
Married couple families	76	87	works full-time	0	25
Single parent families	24	13	works part-time	75	12
1A. Female Heads of Single Parent Families⁽²⁾	100	88	not in work force	21	67
2. Size of Families⁽³⁾			0-4 years	0	25
2 Persons	4	6	5-9 years	10	10
3 Persons	12	33	10-14 years	10	37
4 Persons	42	40	15-20 years	0	33
5 + Persons	42	21			
2A. Average Size of Families⁽⁴⁾			6. Occupational Group of Women⁽⁹⁾		
1 All Families	4.5	4.0	Managers, professional and semi professional and tradespeople	10	29
11 Married Couple Families	4.8	4.1	Clerical workers	32	31
111 Single Parent Families	4.1	2.9	Salespersons and personal service	41	23
3. Number of Dependent Children in Families⁽⁵⁾			Manual workers	17	16
3A. All Families					
1	18	34			
2	44	40			
3 +	38	25			
3B. Married Couple Families					
1	18	32			
2	45	42			
3 +	37	27			
3C. Single Parent Families**					
1	17	51			
2	42	33			
3 +	42	16			
3D. Average Number of Dependent Children⁽⁶⁾					
1 Married Couple Families	2.3	1.7			
11 Single Parent Families	2.3	1.7			
4. Employment of Mothers⁽⁷⁾					
4A. All Families					
(i) works full-time	8	21			
(ii) works part-time	30	26			
(iii) not in labour force ***	62	53			
4B. Married Couple Families					
(i) works full-time	8	21			
(ii) works part-time	34	28			
(iii) not in labour force	58	51			
4C. Single Parent Families					
(i) works full-time	8	22			
(ii) works part-time	25	15			
(iii) not in labour force	67	63			

- * Australian families with offspring only.
 ** Australian female headed single parent families only.
 *** 'Not in labour force' for the Australian population includes unemployed mothers because technically there were no unemployed women in the sample.

* For Australian population the percentages relate to all women not just those with dependent children.

Characteristics	Sample Families % (rounded)	Australian Families % (rounded)
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7. Gross Annual Income of Income Units⁽¹⁰⁾

Below \$10400	10	10
\$10401-\$18000	30	11
\$18001-\$26000	18	18
\$20001-\$52000	30	60
Over \$52000	8	

8. Dependent on Government Cash Benefits⁽¹¹⁾

Sample Families % (rounded)	Australian Families % (rounded)
34	12

9. Place of Birth⁽¹²⁾

9A. Fathers		
Australia	50	68
Other English speaking country	13	12
Non English speaking country	37	20
9B. Mothers		
Australia	64	72
Other English speaking country	8	11
Non English speaking country	28	17

* The Australia figures refer to the Income and Housing Survey 1981-82 which have been updated by a factor of 1.5414 to take account of movements in household income.

Sources: See Footnotes (1) to (12) on page 52.

In 1985, 13 percent of Australian families with dependent children were headed by single parents, 88 percent of whom were women. Single parent families were therefore nearly twice as prevalent in the sample as in the population at large. The proportion of female heads among those families was also somewhat higher in the sample than generally.

This over-representation of single-parent families seems likely to be strongly related to the presence of disabled children. Other studies⁽¹³⁾ have considered the effect of the disability of a child on parental relationships. Commonsense suggests that the over-representation of women amongst single heads of families in the sample is also likely to be related to the presence of disabled children. Although this study does not permit any confident conclusions on this matter, it is worth noting that as one respondent put it:

'It's not hard to work out why marriages break up. The child takes up all your time, all your energy, all your patience.'

Size of Family

Family size is obviously an important variable because it determines the number of people amongst whom resources have to be distributed. This, in turn, may well affect the amount of expenditure on the disabled child the family can afford. Table 4.1 shows that there were quite considerable differences between the sample population and the Australian population in the distribution of families according to size. The average size of families in the sample was 4.5 persons. The average for families headed by married couples was 4.8, by single parents 4.1. In 1982, the most recent year for which the best comparative figures for the Australian population are available, the average size of families with offspring was 4.0, for married couples, 4.1 and for single parent families, 2.9.

A more useful figure, however, is the number of dependent children, defined for these purposes as any non-earning children of the parent(s), irrespective of age. The average number of dependent children per family both for married couples and for single parent families was 2.3. The average number of dependent children in Australian families in general was a little lower than in the sample: 1.7 for both married couples and single parent families.

Employment Status and Occupation

The employment status of adult members of the family has an obvious bearing on its economic resources. Other things being equal, families in which both parents are earning are likely to be better off than those in which only one does. It seems highly probable however, that the presence of disabled children will restrict the extent to which parents can earn. In fact, in 19 (or 38 percent) of families in the sample, mothers were in employment, but only 4 (8 percent) of them worked full-time. In the general population 47 percent of mothers of dependent children were working in 1985, 21 percent full-time, 26 percent part-time. In 16 (42 percent) of the 38 two-parent families in the sample, both parents were earning but in only three of these were they both working full-time. In the general population, in 49 percent of two-parent families the wife was at work, 21 percent of these in full-time employment. Mothers in the sample, therefore, though somewhat less likely to be in the workforce, were much less likely than mothers in the general population to be working full-time. Of the remaining 22 two-parent families in the sample, when there was a full-time earner that person was always the father.

Only three of the 12 single parents, who were all women, were in gainful employment and only one of those worked full-time. Though the numbers are too small to permit conclusions, it is worth noting that the proportion working is below that for single mothers in the general population, i.e. 33 percent as against 37 percent. The proportion is considerably lower when only those working full-time are considered.

The difference between the sample of families with a disabled child and Australian families generally is sustained when we take account of the age of the youngest dependent child (see Table 4.1).

The impact of the child's disability on the mothers employment is well illustrated by one mother's comment:

'Well, I used to work 40 hours and then the days that I used to go up to his appointments I used to use those sick days that I had. Then it got that it came a lot more and I found it a bit hard to do that so I went on to part-time work that only worked at 30 hours and then it increased a lot more than that. There

were a lot more days when I had to go up to the Kid's Hospital so I changed it then for a job that only works out at nine hours. In other words, after hours. I only work 5-7 at night and on the weekends 8-12. So I work at night only and that gives me my days free to go to the Kid's Hospital for the appointments for A..... I've been doing that for four months and in that time I've only had a few days off in between.'

The distinction between regular and casual part-time jobs is also important. Mothers saw casual work as giving them much more flexibility. Though I cannot say exactly how many mothers were undertaking each type of part-time work, the extent of casual employment was clearly considerable. This was evident from the job-histories that I collected. It is worth noting as well that six of the 19 women in the workforce at the time of the interview were working in family businesses, either owned jointly with husbands or by their husbands alone. Most of these women pointed out that it was only because they were working in this way, with the relative freedom it permitted, that they were able to work at all.

Another characteristic of the mothers in the workforce was their propensity to work at home. The last or current job of eight of the women I interviewed was undertaken at home. Several of them stressed that in this way they could both work and keep an eye on their children, and that work of this sort was less routinised than it would be in a factory.

If we look at the actual current or last employment of the women in the sample, it is clear that most of them (41 percent) were in service occupations, such as a shop assistant, waitress, cook, teacher's aid, school housekeeper. Clerical occupations were also common (32 percent). Seventeen percent were in manual occupations and 10 percent had professional, semi-professional or managerial jobs.

The mothers in the sample were, not unexpectedly, less likely to have managerial and professional occupations than Australian women generally. On the other hand they were more likely to have service occupations which are often temporary and casual in nature, and which can accommodate women who wish to work on a part-time basis (see Table 4.1).

Eight of the fathers were not working at the time of the interview. Of these, one had retired, three were unemployed and four had only temporarily, they hoped, left the workforce on account of injury or poor health. One of the fathers, a diabetic, worked only part-time, and expected to do so for the rest of his life.

Fathers were asked to describe their present, or, if not currently employed, their last job. In terms of occupation, the fathers had a generally higher socio-economic standing than mothers, though it is doubtful that their formal qualifications were on the whole any better.

The most common form of employment for fathers (16 cases) was skilled or semi-skilled manual work. The second largest occupational group consisted of own-account retailers, small shopkeepers in catering or fast foods. One of the most striking features of the distribution was the number of self-employed fathers. Thirteen, that is, 34 percent of the fathers, were currently, or had in their last occupation been, self-employed. By way of comparison, in 1983 only 18.0 percent⁽¹⁴⁾ of males in the Australian workforce were self-employed. This result may be attributable in some degree to sampling error. However, just as women have felt the need for a flexible work situation because of the irregular needs of their children, it is clear that many fathers of disabled children would find it an advantage to be in charge of their own work situation. This point of view was certainly expressed by a number of fathers. Perhaps a degree of self-selection was involved, such that self-employed people felt particularly moved, for whatever reason, to take part in a study of the costs of disabled children.

Fathers' work situations were certainly affected by their children's disabilities. They were asked whether their child's disability had affected their work, earnings or chances of promotion in any way. As many as 16 (42 percent), of the fathers in the sample thought that it had. When asked whether they had been obliged to take time off work in their present job on account of their child's disability, 10 of the fathers currently working claimed that they had, and this was when their child had reached the age group 12-16. Many described how much greater the impact had been when their children were younger.

Gross Income

Respondents were asked to state their gross incomes for last year. This income comprised the earnings of the parents, interest from savings, any other income and social security benefits. In the case of the families in my sample, the latter always included Family Allowance and Handicapped Child's Allowance for at least one child.

The gross incomes of the families in the sample varied widely. Ten percent fell below \$10,400 per annum; 30 percent were in a low middle range of \$10,401 - \$18,000; 18 percent were in a middle range of \$18,001 - \$26,000; 30 percent were in the high middle range of \$26,001 - \$52,000, and the remainder (eight percent) had incomes of over \$52,000. Two families were not prepared to disclose their incomes. Although no strictly comparable statistics are available for Australia as a whole, the latest figures, adjusted for inflation, suggest that the incomes of the sample families tended to be much lower on average than those families with dependent children generally. Whereas 40 percent of the sample had a gross annual income last year of less than \$18,000, only 21 percent of Australian families with dependent children did so. The proportion of two parent families with dependent children in which both parents were working full-time was much lower in the sample than in the general population. More important still was the high proportion of single parent families in the sample.

The relatively low average income of the families in the sample also reflects the large number dependent on social security benefits. Over one third of the families relied exclusively on benefits (34 percent) and a majority of these (59 percent) were headed by single mothers. In Australia as a whole, a much lower proportion of families with dependent children, 12 percent, relied on benefits alone, though of those doing so, just as in the sample, a very large proportion were headed by single mothers. There seems undoubtedly a connection between the high level of welfare dependency and female-headness in the sample and the presence of children with disabilities.

Family Disability

Parents were asked whether any members of their family, other than the disabled child on whom the interview was focused, had a long-term illness or disability which limited their activities. The amount of disability reported was considerable. Over half the families (52 percent) reported at least one other person with a long-term disability in the family. There were nine families in which there was another child with the same disability as the one who was the subject of the interview. There were in addition two families with another differently disabled child - one of them very severely disabled. Not included in these figures is yet another family with a child living in an institution because of disability. In the four families having two or more children aged 12 -16 with disabilities, I selected at random the child on whom to focus.

The issue of families in which there are multiple cases of disability is undoubtedly important, and deserves close attention in future research. The impact on costs, both direct and indirect, is clearly likely to be considerable. I did not tackle the question in this study because I had not expected to find in my relatively small sample such a large number of families having two or more disabled children. My questionnaire simply did not explore this situation.

Mothers and fathers in the sample seemed almost equally prone to disability. Fifteen mothers and 14 fathers mentioned a long-term disability. There were seven cases where parents, in all instances mothers, attributed their disabilities to the mental and/or physical strain of caring for their disabled children. A further five parents reported that their health had in the past been affected by their child's disability. However, the effect of the children's disabilities on parents' health is probably understated, because parents were not asked directly about this matter.

Place of Birth

Experience suggests that the extent of a family's cultural assimilation should influence their ease of access to the benefits and services which can help them in dealing with the disability of their child. Access to those benefits and services is likely to lead in turn to lower net costs of care.

Whilst language can constitute a major barrier where access to services is concerned, strong ethnic community affiliations may on the other hand, provide a useful support network as well as important channels of information. It should not be assumed that because people do not speak the dominant or official language, they are of necessity totally isolated. However, it is clear that language is an important facilitator and that people are likely to have much more control over their circumstances when they can communicate in the same language as those who have power.

While none of the disabled children were born abroad, a number of their parents were. Thirty two (or 64 percent) of the mothers were born in Australia, four in other English speaking countries, and 14 (28 percent) in non-English speaking countries. Four of these mothers were born in Italy and four in Greece. Only 19 (50 percent) of the 38 fathers were born in Australia, five in other English speaking countries and 14 (37 percent) in non-English speaking countries. Five most recent figures on the birthplaces of the Australian population are to be found in the 1985 Labour Force Status and other characteristics of Families. These show (see Table 4.1) that about 17 percent of the women with dependent children and 20 percent of the men with dependent children were born in non-English speaking countries.

One can only speculate about the reasons for the relatively high proportions of people in the sample born in non-English speaking countries. There is nothing that might lead one to expect a particularly high incidence of handicap in this segment of the population, nor any reasons to suppose that people in this category are more likely than others to be receiving the Handicapped Child's Allowance.

It may be that some people approached about participation in the study believed, mistakenly, that it was being conducted by the Department of Social Security, and concluded that it would therefore be prudent to co-operate; but this is mere conjecture. The most likely explanation lies in the areas of Sydney from which the sample was drawn, certain of which have relatively high proportions of residents born in non-English speaking countries.

Parents born in non-English speaking countries had in general a relatively long association with Australia. Their disabled children were all born here,

and 13 years was the shortest period of Australian residence reported by any of them. Half the mothers had been in Australia for at least 17 years and half the fathers for at least 22 years. Nearly two-thirds of the parents born in non-English speaking countries either spoke English exclusively at home or did so as much as they spoke their native tongue. However, as I noted earlier, I did find some difficulty in communicating with many such respondents, especially when dealing with topics of a hypothetical or abstract sort. Discussing ideas of this kind in a second language presented many respondents with significant difficulties. In general, fathers showed greater proficiency than mothers, probably due to their wider contacts outside the ethnic community as well as to the greater length of time they had, on average, spent in Australia. The question of varying cultural values, as these relate to the more public aspects of care for a disabled child, also deserve closer attention. For example, will a man regard it as clearly his duty, rather than that of his wife, to take the child to hospital whenever necessary? There may well be cost implications in the form of income forgone. Regardless of the question of cultural values, of course, these implications may arise in a situation where the need to communicate adequately with medical staff makes it expedient for a husband who is more proficient in English than his wife to take part in hospital visits and the like.

We may conclude from this brief account of the characteristics of the sample families that in most respects it differs, sometimes considerably, from the population. In the case of some of the characteristics - for example, single parenthood, labour force participation of women, occupation and gross income - it would not be unreasonable to find at least a part of the explanation for the disparity between the sample families and Australian families in the presence of a child with a disability in the family. In respect of other characteristics - for example family size and ethnicity - the explanation for the differences is more likely to lie in the overall size of the sample and its location in Sydney.

THE CHILDREN

Age, Sex and Schooling

Nineteen (38 percent) of the children were girls and 31 (62 percent) were boys. Although this ratio is not identical with that found by other studies, these show a similar tendency to male over-representation. For example Dykes (1978) reports a ratio of 42:58 and in the Survey of Morbidity:

Characteristics of Children Receiving the Handicapped Child's Allowance, March 1982, the ratio was similarly 42:58.⁽¹⁵⁾⁽¹⁶⁾

Families were selected for interview on the basis of the child's age. Only children between the ages of 12-16 years were included in the study.

TABLE 4.2 - DISTRIBUTION OF CHILDREN WITH DISABILITY
ACCORDING TO SEX AND AGE: SAMPLE AND HCA
RECIPIENTS IN SIX SOCIAL SECURITY REGIONS
IN THE STUDY, SYDNEY METROPOLITAN AREA.

Age	SAMPLE		HCA RECIPIENTS IN SIX SOCIAL SECURITY AREAS		HCA RECIPIENTS IN SYDNEY METROP. AREA	
	Females %	Males %	Females %	Males %	Females %	Males %
12	10	19	22	28	25	27
13	37	29	26	25	27	25
14	16	23	27	30	23	26
15	32	23	25	17	25	22
16	5	6	*	*	*	*
Total	100	100	100	100	100	100
% distribution of females/ males						
	38	62	42	58	41	59

* There were no 16 year olds in the sample at the time of its selection.

There was a gap between the time of selection of the sample by DSS and my visits to the families for interviews. During this interval, of course, some children had birthdays. The number under 13 years is therefore apparently depleted, and there are a few over the maximum age of 16 years.

Table 4.2 compares, in respect of their sex and ages, the disabled children included in the study with recipients of the Handicapped Child's Allowance in the six Social Security regions from which the sample was drawn and the Sydney Metropolitan area. The populations compare reasonably well.

Birth Order of Disabled Children

The following table indicates the position of the children sampled vis-a-vis other dependent children in their families.

TABLE 4.3 - BIRTH ORDER OF DISABLED CHILDREN
IN RELATION TO DEPENDENT SIBLINGS

No. of Dependents	Position of Disabled Child				Total
	Oldest/Only	Second	Third	Youngest	
1	9				9
2	14			8	22
3	7	4		4	15
4	2	1	1		4
Total	32	5	1	12	50

The distribution is hardly surprising. Given that the disabled children were chosen as being between the ages of 12 and 16, it could be expected that they would tend to be among the oldest of their families' dependent children. In 64 percent of families they were the oldest or only child and in only 24 percent were they the youngest. There were 22 disabled children in two-child families, 15 in three-child families and four in four-child families.

Schooling

All but two of the children were at school. The two who were not had already left school. One of these, a 15 year old girl with asthma, was having a waiting period before seeking a job; the other was a 15 year old boy who depended on a kidney dialysis machine. His mother did not think that he would be able to go out to work. Ideally, she was looking for a job that they could do together at home.

Of the children who were attending school, 21 were at regular schools, five were in special units at regular schools and 22 were in special schools. Of the 27 children in special schools or units, two were in a unit for physically disabled children, 17 in units for intellectually disabled children, one at a school for multiply handicapped children, one in a school for the blind and partially sighted and two in a school for the deaf. Parents' views on the relative advantages of integrated and non integrated education were highly polarised.

For our purposes, the most important characteristics of the children were of course, their disabling conditions, and these we shall turn to in the next chapter.

FOOTNOTES

1. Robinson, J. and Griffiths, B., **Australian Families: Current Situation and Trends; 1969-1985**, The Social Security Review, Background Paper No.10, Department of Social Security, November, 1986. Table 1.
2. ABS, **Labour Force Status and Other Characteristics of Families**, July 1985, Cat.No.6224.0. Table 17.
3. Ibid. Tables 2, 13, 20.
4. ABS, **Australian Families**, 1982, Cat. No. 4408.0. Table 2.
5. ABS, **Labour Force Status and Other Characteristics of Families**, Op. cit., Table 7.
6. ABS, **Australian Families**, 1982, op. cit., p 7.
7. ABS, **Labour Force Status and Other Characteristics of Families**, op. cit., Tables 7, 16.
8. ABS, **Labour Force Status and Other Characteristics of Families**, op. cit., Table 17, Table 9 of Corrigendum, 4 July, 1986.
9. ABS, **Weekly Earnings of Employees**, Cat.No.6310.0. Table 13.
10. ABS, **Income and Housing Survey, Income of Income Units, Australia, 1981-82**, Cat. No. 6523.0. Table 1, p 6.
ABS, **Quarterly Estimates of National Income and Expenditure, Australia**, December Quarter, 1986, Table 43, p 44.
11. ABS, **Australian Families**, 1982, op. cit., Table 29.
12. ABS, **Labour Force Status and Other Characteristics of Families**, op. cit., Tables 12, 28.
13. C. Glendinning, **Unshared Care**, Routledge and Kegan Paul, 1983, pp 86-89.
14. W. J. Merrilees, **Professional Incomes**, Bureau of Labour Market Research Monograph Series No. 13, Australian Government Publishing Service, 1986, p 35.
15. J. Dykes, **Ten Thousand Severely Handicapped Children in New South Wales and the Australian Capital Territory**, Australian Government Publishing Service, 1978.
16. **Survey of Morbidity: Characteristics of Children Receiving Handicapped Child's Allowance**, Department of Social Security, Canberra, December 1983.

CHAPTER V

THE DISABILITIES OF THE CHILDREN

The Handicapped Child's Allowance is awarded in circumstances of widely varying kinds. A child who is permanently blind, but otherwise unimpaired, has needs of a different kind from those of, say, the victim of a motor accident who, given continuous support and intensive therapy, may hope to recover some limited degree of mobility and perhaps a little speech. Both have quite different needs from the child suffering from an incurable, perhaps terminal condition, and all three of them are incapacitated in different ways from the robust, physically active but intellectually retarded and emotionally unstable victim of brain damage. These examples do not by any means exhaust the range of disabilities which may attract the HCA. The question is, is there any fair, practically applicable standard for the comparative assessment of so heterogeneous a set of conditions? For many purposes, there is clearly no need to refer to any such standard. What matters is that each child should have access to whatever services, facilities or support his or her condition calls for, regardless of how it compares with the condition of other children with different needs.

DETERMINING DISABILITY

When it comes to a question of eligibility for such a benefit as the HCA however, the issue of comparability becomes unavoidable. What minimum level of each kind of disability is necessary to qualify for the benefit at the full rate?

How much will be sufficient to qualify for the reduced rate of benefit? The criterion actually specified by the Department of Social Security circumvents the virtually impossible task of comparing and equating the levels of severity of quite different conditions, by considering instead the impact of the disability on the carer rather than the child being cared for. The formula requires that the child's disability be such that he or she is in need of constant care and attention. This is a far from unambiguous

criterion, but it does at least have the merit of establishing a common standard of reference underlying the provision of the benefit.

For the purposes of this research however, we have needed to go some way beyond the determination of a simple criterion of this sort. In order to answer questions about the relationship between the relative severity of childrens' disablement and the extent of extra expenditure or the degree to which parental employment has been restricted, we need to develop measures of a more discriminating kind. In doing so, we must still take account of problems of comparability. What follows is an account of the disabilities of the children and a description of the methods used to aggregate the data on their condition in order to produce composite measures which are both informative and useful in further analysis.

The questionnaire was designed to produce a thorough picture of the nature and extent of the children's disabilities and ensuing dependency, but did not include either a clinical examination, a psychiatric or psychological assessment. The account provided in this chapter is therefore based primarily on the parents' perception, understanding and assessment of their children's disabilities, capabilities and limitations. In joint interviews of married couples there was usually agreement between parents as to the nature and extent of their child's disabilities although this agreement sometimes only emerged after some discussion.

Although the interview did not include a clinical assessment of the child, such an assessment or judgement was made subsequently by a medical specialist in children who had access, in an anonymised form, to the accounts provided by the parents. These parental assessments were only used to make a clinical judgement of the disabling conditions of the children and of their level of intellectual functioning. Reliability was tested by seeking the independent opinion of a second medical specialist. Agreement between the assessors was found to be high.

The diagnosis for each child is given in Table 5.1. From this we may see that the fifty children suffered from a very wide range of disabling conditions. The table also describes the level of severity of each child's disability using the scale developed for this research. This scale will be

**TABLE 5.1 - CONDITIONS OF CHILDREN IN THE SAMPLE AND
THEIR LEVEL OF DISABILITY/DEPENDENCY**

Clinical Diagnosis	Disability/Dependency
1. Limb deformities, epilepsy cardiac defect, deafness	Severe
2. Non-specific brain damage	Severe
3. Deafness	Severe
4. Deafness	Mild
5. Leukaemia	None
6. Neurofibromatosis	Mild
7. Diabetes mellitus	Mild
8. Non-specific brain damage	Severe
9. Asthma	Mild
10. Epilepsy, Stevens-Johnson Syndrome	Mild
11. Cystic fibrosis	None
12. Asthma	Severe
13. Reye's Syndrome, epilepsy	Severe
14. Hydrocephalus, visual impairment	Severe
15. Fragile-X Syndrome	None
16. Limb deformities	Severe
17. Visual impairment, ocular malformation	Mild
18. Epilepsy	Severe
19. Down Syndrome, vision impairment	Severe
20. Non-specific brain damage	Mild
21. Spina bifida	Severe
22. Non-specific brain damage	Severe
23. Craniostenosis, hearing impairment	Mild
24. Cystic fibrosis	Mild
25. Non-specific brain damage	Severe
26. Asthma, vision impairment	Mild
27. Diabetes mellitus, vision impairment	Severe
28. Diabetes mellitus	None
29. Non-specific brain damage, epilepsy, cerebral palsy (probably)	Severe
30. Blind	Severe
31. Coeliac disease	Severe
32. Non-specific brain damage, hearing impairment	Severe
33. Spina bifida	Severe
34. Down's Syndrome	Severe
35. Central core myopathy	Severe
36. Epilepsy	Severe
37. Hydrocephalus, visual impairment	Severe
38. Hydrocephalus, limb deformities	None
39. Craniostenosis, visual impairment	Severe
40. Non-specific brain damage, epilepsy	Severe
41. Chronic renal failure	Severe
42. Deafness, cerebral palsy (possibly), post-Rubella Syndrome	Severe
43. Sub-acute sclerosing pan-encephalitis, epilepsy	Severe
44. Non-specific brain damage, hearing impairment, visual impairment	Severe
45. Epilepsy, cerebral palsy	Severe
46. Non-specific brain damage, epilepsy, asthma, autism	Mild
47. Fragile-X syndrome	Severe
48. Galactosaemia, visual impairment, glaucoma	Severe
49. Cerebral palsy	Severe
50. Cerebral palsy	Severe

described in more detail later in the report. For the moment it is enough to note that some children whose condition was undoubtedly serious were classified by the research scale as having no disability.

The point is that we have on the one hand, a classification of clinically identifiable conditions, on the other an attempt to measure the extent of observable disability and dependency, regardless of underlying cause. People can be immobilised in a variety of ways: temporarily or permanently as a result of trauma or as a consequence of a degenerative condition or of a congenital abnormality and so on. The mobility scale is quite indifferent to these causes. The only question is, can the child walk unaided, or only with assistance, or not at all? Similarly, when it comes to sight and hearing, communication, self-care and the other components of our aggregated scale of disability, it does not matter how or why the subject performs at a given level of competence. It is important only that the level be accurately assessed. For most practical purposes, this is exactly the kind of objective, systematic measure of disability we require. It is necessary to acknowledge, however, that it does not give an exhaustive account of the disabling problems of the children in the sample.

This was a group of children who, on the whole, had serious problems. From Table 5.1 we may see that 16 of the children had sensory/perceptual problems and nine had epilepsy. In addition, according to the parents' assessment, 31 of the children had a behavioural or personality problem.

TABLE 5.2 - DISTRIBUTION OF CHILDREN ACCORDING TO LEVEL OF INTELLECTUAL FUNCTIONING

Level	No.	%
Normal	21	42
Mild disability	6	12
Moderate disability	15	30
Severe disability	6	12
Profound disability	2	4
TOTAL	50	100

Although Table 5.1, together with the summary table (5.2) of the children's intellectual disabilities give some clue as to likely extra costs, a closer and more detailed examination of the children's disabilities is required if we are to provide a more adequate indication of their needs.

THE DISABILITY/DEPENDENCY SCALE

The questionnaire explored various dimensions of the children's disabilities or dependence and the information obtained was sufficient to make a relatively simple assessment of their competence in certain basic activities and of the degree to which they depended on others for assistance. The data fell relatively easily into three divisions, and it was therefore possible to construct summary three point measures of disability, competence and dependence with the aim of better describing the children's capacities and limitations. These summary measures provide both a useful basis for describing the children and for analysing the effects of their disabilities and dependence on their parents expenditure and employment. The measures are similar in style and conceptualisation to the scales used in the ABS handicapped persons survey.⁽¹⁾

The scales used in the present study⁽²⁾ relate to the following areas:

- 1 Mobility
- 2 Communication
- 3 Sight and hearing
- 4 Self-care
 - (a) Basic (dressing, eating, bathing)
 - (b) Need for toilet assistance and/or nursing care
 (e.g. catheters, enemas, injections etc.)
 - (c) Supervision

The ABS survey examined mobility, communication, basic self care and education. In the present survey, I have been particularly concerned with the child's need for parental assistance, so the area of self-care has been emphasised by its subdivision into the three categories above. In addition to the elements of basic self-care covered by 4(a), the intimate services grouped under 4(b) have been distinguished, initially at least, because they are associated with high dependency and perhaps a certain emotional stress.

Area 4(c), relating to the child's need for supervision, really indicates the parents' perception of the time they must devote to the child, expressed in terms of its impact on their freedom to be elsewhere. The area of sensory disability, that is, of sight and hearing, was included because it was observed that a reasonably large number of children in the sample had difficulties of this kind which probably limited their social independence.

In general, the scales are based on a comparison with average, unimpaired children of the same age. A value of 0 means that there is no special problem, and that the parents believe the child to be as competent or independent in that sphere of activity as the average child of the same age. A value of 1 means that the child has mild difficulties, and although less competent than the average child of the same age is capable of a reasonable degree of independent activity (using aids if necessary); for example, the child doesn't walk as well as others of the same age, but can certainly manage more than just a few steps, perhaps with crutches. A value of two means that the child has moderate or severe problems, and can only perform the activity, if at all, with considerable help from others. It will be clear, of course, that these are only ordinal scales; they provide a ranking in terms of disability/dependency, but permit no more precise comparative measurement. A child at level 2 is in no sense twice as dependent/disabled as another at level 1. The defining characteristics of the components of the scale are given in Appendix B.

TABLE 5.3 - DISTRIBUTION OF CHILDREN ACCORDING TO LEVEL OF DISABILITY IN SIX AREAS OF ACTIVITY

Level	0		1		2		Total	
	No.	%	No.	%	No.	%	No.	%
Area of activity								
Mobility	31	62	12	24	7	14	50	100
Communication	24	48	7	14	19	38	50	100
Sight & Hearing	34	68	7	14	9	18	50	100
Basic Self-care	27	54	10	20	13	26	50	100
Toilet &c.	37	74	3	6	10	20	50	100
Supervision	16	33	14	29	19	39	49*	100

* The total is 49 because one mother was unable to assess the length of time she could leave her child alone.

From Table 5.3 it is clear that the greatest problem areas for these children had to do with their need for supervision and with the difficulties they experienced with speech and other communication. Although a quarter or more of the children had moderate or severe problems with at least one of the basic self-care skills, few of the children had a problem with mobility and few had even moderate hearing impairment.

To simplify analysis, the three self-care variables, basic self-care, toilet help and supervision, were amalgamated to constitute a single self-care measure. The values of this variable were determined by assigning to each child the highest of his or her scores on the three component variables. As Table 5.4 shows, over half had a moderate to severe disability in at least one of the three areas, though a sizeable proportion appeared to have no problems at all.

TABLE 5.4 - DISTRIBUTION OF CHILDREN ACCORDING TO LEVEL OF SELF CARE DISABILITY (COMPOSITE MEASURE)

Level of disability	No.	%
No problem	12	24
Mild problem	11	22
Moderate to severe problem	27	54
Total	50	100

One issue of interest is the relationship between different problem areas. The three self-care variables, for example, were strongly associated with each other⁽³⁾ so that a child with a moderate or severe disability in one area was more likely than not to have a similar level of disability in at least one of the others. Similarly, children with no problem or only mild problems in one area were more likely than not to have only mild problems, if any at all, in other areas. Not surprisingly, children who had severe mobility problems tended also to have difficulties with basic self-care and to need help in the toilet. On the other hand, mobility was not as strongly

related to the supervision variable as it was to the other two self-care variables. Some children who had no mobility problems required quite a lot of supervision, others needed much less; neither did impaired mobility always entail a need for close surveillance.

Difficulty in communication was also significantly associated with self-care disability and need for supervision. Problems with sight and hearing, on the other hand, were not significantly associated with disability in any other of the areas we have been considering, even that of communication, which one might have felt tempted to guess would pose difficulties. Children with defective or totally impaired sight or hearing were in most cases quite competent in other areas, and were not thought by their parents to be in need of much, if any, special supervision.

On the other hand, there was quite a strong association between problems with communication and the need for surveillance as well as between problems with communication and problems with self-care. I have already noted that children who have difficulties with self-care are likely to have the greatest need for supervision: an intuitive supposition borne out by the data.

The data were finally simplified further by the creation of a combined measure of disability embracing all the areas previously reviewed. Table 5.5 below shows the distribution of children according to this composite measure which in each case takes on the greatest value attained by any of the six variables concerned. Sixty-eight percent of all cases (see Table 5.5) had a moderate or severe disability in at least one area. It will be recalled that 54 percent of the children had moderate to severe self-care difficulties (Table 5.4), so it is clear that the independent contribution of the other three variables (sight and hearing, communication and mobility) amounts to a further 14 percent. Ten percent of the children, on the other hand, were not considered to have a problem in any of the areas reviewed.

TABLE 5.5 - DISTRIBUTION OF CHILDREN ACCORDING TO MAXIMUM LEVEL OF DISABILITY (BROAD COMPOSITE MEASURE)

Maximum Level of Disability	No.	%
No disability	5	10
Mild disability	11	22
Moderate to severe disability	34	68
Total	50	100

In summary, 14 percent of the children had moderate to severe problems with mobility, 18 percent with sight or hearing, 20 percent needed help in the toilet, 26 percent with basic self care and 38 and 39 percent in the areas of communication and supervision respectively. Table 5.6 shows how multiple disability contributes to this diverse pattern.

TABLE 5.6 - DISTRIBUTION OF CHILDREN ACCORDING TO NUMBER OF AREAS OF MODERATE/SEVERE DISABILITY.

No. of Areas of moderate/severe disability	No.	%
0	16	32
1	12	24
2	10	20
3	6	12
4	3	6
5	3	6
Total	50	100

Ninety percent of the children have a disability at some level in at least one area. Table 5.7 summarises the position.

**TABLE 5.7 - DISTRIBUTION OF CHILDREN ACCORDING TO NUMBER
OF AREAS OF DISABILITY OF ANY LEVEL.**

No. of areas of disability	No.	%
0	5	10
1	13	26
2	5	10
3	10	20
4	8	16
5	9	18
Total	50	100

DISCUSSION

The children under discussion in this chapter belong to families receiving the Handicapped Child's Allowance. Eligibility for the benefit hinges on whether the child is 'in need of constant care and attention'. These are the terms in which 'severe handicap' is officially defined. Yet it is clear that only 39 percent of these children posed a severe problem by virtue of their need for supervision. If we take the other five areas of disability on which data were obtained, we find a further thirty percent moderately to severely affected. This leaves sixteen children, 32 percent, with only a mild disability or with no disability at all in the areas we considered. Does this mean that according to the Department of Social Security's eligibility criteria some of these children should not be receiving the benefit?

The first thing to be said is that the question is strictly speaking unanswerable because the Department has not actually spelled out its criteria, though it does provide some guidelines on the evaluation of eligibility. It suggests that the following indicators may be used:

- (a) the child requires from another person frequent attention in connection with bodily functions;
- (b) the child requires attention and supervision substantially in excess of that normally required by a child of the same age and sex; or
- (c) the child requires regular supervision from another person in order to avoid substantial danger to himself and others.

The point to be made about these guidelines is that the application form for the benefit does not elicit information in a way which makes it possible for them to be applied at all effectively. At the extremities of the spectrum of disability, utter dependency and complete independence, there is no real difficulty. It would almost be true to say that in these cases it scarcely matters how the Department chooses its terms in defining disability. However, there is a large intermediate 'grey area', and the interpretation of undefined terms such as 'frequent' and 'substantial' leaves obvious room for confusion, ambiguity and inconsistency.

The point of this discussion is not simply, or indeed at all, to suggest that the Handicapped Child's Allowance is being carelessly awarded to strictly ineligible recipients. To begin with, I do not believe that the scale(s) of disability I have relied on here are sufficiently sensitive to pick up some of the less obvious but nonetheless important needs of children. For example, it is important to note that nine of the children with no more than a mild disability, according to the parents assessment, had a behavioural or personality problem. Of the five children with no apparent disability, there was only one whose case I would say might be difficult to defend, and even there it was abundantly clear why the benefit had initially been awarded. The common feature of these cases is the dependency of children unusually susceptible to illness, who remain a source of nagging anxiety from which parents can never feel free.

These comments provide some idea of what it can be like to be a parent:

'When Janie was born and I was 19, I turned 55. I've never been young since they gave Janie to me. Life is never carefree or free of trouble.'

'I've had no support. It just goes on and on like having a child that never grows up.'

'She's nice, likeable, but so draining.'

'At the end of 6 weeks, the school holidays, I'm off my face. She has a constant voice. Its going, going, going. It starts boring into your brain. In the end, it wears me out.'

'I feel like howling then screaming and letting it all out; all of it.'

'There's a build up of tension that comes of never being able to do what you want to do.'

'We came home from that assessment and we looked at each other and I said "What about if we'd had two normal children. Can you imagine the difference in our lives, in our finances". Like to me our life would be a breeze, just a breeze instead of the constant never-ending nagging worry.'

On the other hand, such frail, vulnerable children frequently generate strong feelings of protectiveness, almost amounting in themselves to a kind of dependency. This is scarcely surprising when one considers that the child has been at the centre of the mother's life, an all-consuming responsibility extending her ingenuity and creativity, not to mention her technical skills.

This is an immensely difficult area of social policy because, unlike many of the other areas in which social security payments are made, there is, in a large number of cases, so much instability. The situation can fluctuate from year to year and even from day to day. In each of the cases in which I found it necessary to re-contact respondents later, in order to collect fuller information or clarify points in their original interviews, I found there had been a dramatic change in circumstances. In the first such case, in the period of about six weeks since I had interviewed the family, the father had suffered a heart attack and the child had also been hospitalised with a severe attack of asthma. This, in fact, was one of the cases in which, according to our scale, the child had no disability. In another case, the child had stopped eating and become very depressed. After a period in hospital, the child had been discharged, undiagnosed and unhelped. When I called she was still not eating and was still depressed. In a third case, a diabetic child had 'hyped'. In this, as in the first case, we have an

illustration of episodic acute dependency as distinct from the much more common chronic form.

In several of the cases of mild disability or even no apparent disability, given my knowledge of the family and the child, I can see why they have been judged eligible for the HCA even though the scales we have devised for this research might seem to suggest that they should not qualify. The situation is one in which recommendations as to eligibility call for the exercise of an informed professional judgement in complex and ambiguous circumstances. This leaves applicants heavily dependent on the medical practitioners and social workers who act, in a sense, as their advocates in this uncertain situation.

It would clearly be preferable for applicants to feel that the eligibility criteria were straightforward and comprehensible, even though it might have to be acknowledged that an element of ambiguity is unavoidable and professional assessment of the disability is essential. What kinds of professional assessment is a question which represents an important part of the continuing uncertainty. Medical specialists, while best fitted to diagnose and treat children's disabilities are not necessarily best equipped to make judgements about the full range of their needs.

FOOTNOTES

- (1) ABS, **Handicapped Persons, Australia, 1981**, Catalogue No.4343.0.
- (2) Richard Mathews (Social Welfare Research Centre) was primarily responsible for the development of these scales.
- (3) When measured by the Spearman correlation co-efficient all correlations at the 0.05 level for the two-tailed test were significant, except for surveillance, with toileting which approached significance.

CHAPTER VI

THE EXTRA COSTS

APPROACHES

The subject of this chapter is the main focus of my study: namely the extra costs directly occasioned by the disabilities of the children in the sample and met by the children's families. Two kinds of costs are considered: direct costs, or extra expenditure, and indirect costs, usually in the form of income forgone because of lost or abandoned employment.

There is evidence that costs may not only be considerable but may also vary quite widely as between families and in any one family over time. Accurate determination of the effect of disablement on additional expenditure is a formidable task. There are two major problems. The first is that accurate recall of past expenditure is often difficult. The second is that identifying what can legitimately be regarded as extra expenditure is not always as easy a task as it might seem. Previous studies have tended to use one or other of two approaches, occasionally both. One, the direct approach, is simply to ask people caring for children with disabilities to identify all relevant additional expenditure over a given period. The comparative approach, on the other hand, relying on specially designed expenditure diaries, seeks to compare the respective expenditure patterns of families with and without a disabled member.

Both methods have their advantages and disadvantages. The first approach is simpler, less expensive, and easier for respondents, because it does not rely on systematic record-keeping. This is a significant consideration, bearing in mind the already heavy burdens of many parents. Its principal disadvantage is that it is not possible to establish clearly the extra expenditure of families because this approach does not compare the expenditure patterns of a group having disabled children with those of a control group which does not. Thus, it is not possible to investigate the effect of the extra costs of disablement on the overall expenditure of

families, or on their standard of living. While the alternative, comparative approach gives a more reliable picture of differences between families with and without a disabled member, it does have some shortcomings. It relies on the accurate maintenance of expenditure diaries which can be a demanding, in some cases over-demanding task. In the most favourable circumstances respondents cannot reasonably be asked to maintain such diaries for more than a few weeks, which is too short a period to capture instances of every variety of household expenditure.

The expenditure diaries by themselves provide no information about the ways in which families adapt their **overall** household expenditure as a result of the extra costs of the disablement. Because the diaries tend to be designed for a population with normal expenditure patterns, it is often impossible to identify the costs arising from particular aspects of the disablement, incontinence for example. Furthermore, particular items of expenditure which arise from the disablement may be concealed within larger categories (for example, the diary may contain a section for 'services', but within this category home help may not be specifically identified). Another problem is that accounting for the value of services in kind and accounting for expenditure financed from savings or met by relatives, is difficult using expenditure diaries.

I have used the first, or 'direct' approach; that is, I simply asked parents what specific costs they have incurred over a given period. The time period varied according to the particular commodity or service, relying on assumptions about the typical mode of purchase of different items. Thus information on expenditure for items bought frequently (such as foods, medicines, and nappies) was sought over a much shorter period than items purchased less frequently, like bedding or handshowers. I recorded details of purchase of large consumer durables or capital expenditure, for example, an additional bathroom or shower room, a swimming pool or ramps for a wheelchair, made at any point in the child's lifetime.

I chose the direct rather than the comparative approach for several reasons. In the first place my study, of necessity, embraced only a small number of families and was undertaken over a short time span. I did not have time to select a suitable control group, nor was the sample large enough to enable me

to undertake a useful, detailed comparison of families with and without a disabled member. However, even ignoring these constraints, there were positive advantages in the direct approach. The first of these is that the comparative approach inevitably places a very great emphasis on the direct, monetary costs of the child's disability, whereas I was equally interested in the non-cash economic costs, in particular the effects on parental employment. The study was also able to give some consideration, albeit secondary, to the social and emotional costs. I was concerned, too, to say something about the contribution of services provided by various government and other agencies in helping families, and about the way those families view the services, particularly what they feel about the relative merits of cash benefits and services. I wanted to be able to say something about the perceived needs of parents and children, something about the impact of the extra expenditure on household budgets and especially on the quality of life or standard of living of families, as they themselves see it.

A second reason for preferring the direct approach was that I conceived of my study as being primarily concerned with the impact of disablement on the families affected. I was therefore more concerned with the internal variation within this group of families with disabled children than with the differences between groups with and without disabled children.

Though I think there are sound arguments for using the approach I have adopted in such a small quickly executed study as this one, I believe that any more thorough examination of the topic must involve, as did Baldwin's study, a combination of this and the comparative approach. Only in this way can one tease out with any degree of rigour or confidence the extra costs of the disability.

DIRECT COSTS

Problems In Obtaining Expenditure Data

It is perhaps worth summarising at this point the principal problems associated with obtaining direct costs data.

- (i) The problem of recall. Unless the process is on-going, as with an expenditure diary, it is unlikely that without the benefit of receipts, families will be able to give accurate information about their expenditure. One's own efforts to recall accurately small items of recent expenditure can be a salutary reminder of this fact. It is unlikely that complete accuracy will be achieved, however recently the spending occurred. It also seems likely that the level of accuracy will relate not just to the time elapsed since the expenditure took place but also to the amount. Larger items seem to be remembered for longer and perhaps with more accuracy than smaller items.
- (ii) Disentangling expenditure details. It is often difficult if not impossible for people to give anything but an estimate of the expenditure on a particular item because it is intermingled with other items. A good example of this is special food for a child with dietary problems. This is usually bought at the same time as the rest of the household food and it is unlikely that the mother will have more than a rough notion of what she has spent on it. On the other hand, much of the expenditure for a disabled child has a regularity which may make accurate recall more likely.
- (iii) Shared amenities. The item may not have been either purchased for or be used exclusively by the disabled child. For example, a pool in the garden may have been built for the disabled child, but be used and enjoyed just as much by other members of the family. If the pool was built for the disabled child but is used to a greater extent by the rest of the family, it would seem reasonable to attribute the building but not the running costs to the child. A similar problem may arise in attributing costs in the case of the purchase of an expensive television set with a teletext facility for a deaf child, which is nevertheless enjoyed by the whole family because it is the only television set in the house. In this case, it would perhaps be appropriate to attribute the difference in price between an ordinary television set and a teletext set to the child. But this, of course,

involves assumptions about the price the family might otherwise have paid for an 'ordinary' television set.

- (iv) Who paid? Another problem relates to expense incurred by people other than the respondent. Sometimes this may be the other parent who was not present at the interview, either because the couple no longer live together or because he (the absentee was always male) was simply unavailable at the time.
- (v) Age-specific details. One inherent problem of this study is that it can only tell us about the costs of 12-16 year olds. Very many parents told me how much more expensive their child had been when younger. This was typically in the period just after diagnosis, when there had been repeated visits to hospital for consultations and treatment and periods when the child was an inpatient. This was how many parents recalled the past. In only very rare instances did parents tell me that their child had become more expensive as he or she grew older. In many instances I gained the impression I was meeting the family at something of a plateau in their child's life.
- (vi) Recognising extra expenses. In a study quite explicitly concerned with extra expenditure, parents are very likely to feel that they ought to be able to find some to report. I have already drawn attention to the way in which some parents seemed to feel guilty that they could not 'dredge up' any extra expenses. At the same time, it was clear that many parents simply did not recognise some expenses which had become so much part of their way of life as to be taken for granted: the cost of transporting the child everywhere, or the time and money spent searching for appropriate child care arrangements, for example. Some parents scrupulously acknowledged the lower expenses of their child. They recognised that their child was not part of what is, for most parents, a very expensive teenage culture, and that they therefore had considerably lower expenses on certain items, such as clothes, sport and entertainment, than did the parents of most other children of the same age. As a consequence

of the disability of their child, some parents led very restricted social lives and may have spent less on entertainment outside the home. Some such families compensate by buying a fair amount of home entertainment - home videos are an immense boon to families who have a child with a disability. But it must be acknowledged that parents do not undertake complicated calculations which relate the extra costs component of actual expenditure to possible savings. They are in general much less impressed by savings than by costs (which are, of course, much easier to calculate).

EXTRA EXPENDITURE OF THE SAMPLE FAMILIES

There are several ways of looking at expenditure data. In this chapter I illustrate these, using data collected from the families I interviewed.

Items for Extra Expenditure

Families identified 37 items for which they were able to nominate the amount of their extra expenditure. These items were either included on the questionnaire (this was the great majority of items) or came to light in the course of the interview. For the purposes of analysis, the items are categorised in two ways. The first categorisation (see Appendix C) is according to the nature of the goods or services obtained. Here I identify six major groupings:

1. Goods or services required specifically because of the child's disabling condition;
2. Transport;
3. Education;
4. Help/Care arrangements;
5. Aids and adaptations to the home; and

6. Miscellaneous.

The second categorisation (see Appendix D) is according to frequency, that is whether the expenditure was for items:

1. Regularly, or
2. Irregularly consumed, or
3. A large single consumer durable purchase or a capital outlay for home improvement or modification.

These lists represent the full range of items whose costs parents were able to quantify. The most important omission from the list is extra clothing. Additional clothing or alterations to clothing were mentioned by many parents as an extra expense and it was clear that for incontinent children who often needed several changes of clothing and bedding each day, children with poor motor skills, children who are unco-ordinated, careless, messy or hyperactive, and children with limb deformities, clothing constituted a very considerable extra expense. However, most parents were quite unable to tell me even roughly how much extra expense was involved. This is no doubt partly because they had no standard by which to judge how much is 'normal' and how much 'extra' in the cost associated with altogether routine items which the disabled child simply wore out more rapidly than other children tend to do.

I collected information on items included in the lists in Appendices C and D for different periods but in each case I have expressed these results in annual expenditure terms. Thus, regular weekly expenditure, like food, I multiplied by 52. Regular monthly expenditure, such as health insurance contributions or incontinence purchases I multiplied by 12, (the latter on the assumption that expenditure of this kind would follow a regular pattern). Regular term-by-term expenditure on school fees I multiplied by three to arrive at an annual expenditure but extra lessons I tried to cost on the basis of the number of weeks in the school year (39) and I multiplied the lessons paid for on a weekly basis by this figure to give a year's expenditure. Some of the items included in the regular and irregular consumption categories I had asked for over the year and in these cases no

standardisation was required. Items involving capital expenditure or the purchase of consumer durables I treated rather differently. I tried to identify all items included in these categories over the child's lifetime, determining when the outlay was made. For reasons that I discuss below I then distinguished expenditure made during the past year from that made prior to last year.

The information on consumer durables and capital expenditure given in this chapter and the next relates only to costs incurred by families in the year preceding the interview. This is done because of doubts as to the reliability of information about the cost of items procured earlier. There is not only the problem of inaccurate recall of prices paid years ago, but the added complication of converting these dubious values to current price terms in the interests of comparability.

However, the omission of material on such past expenditure does not mean that I regard the subject as unimportant. I have commented elsewhere that many parents believed their children had been more expensive when they were younger. It does not seem that the previous year's expenditure can fairly be regarded as representative of the lifetime level of capital and consumer durable costs, either for individuals or for the sample as a whole. We are investigating the situation of children who were, at the youngest, 11 years old at the beginning of the 12 month period in question, ranging in age to 15. For many of these, major outlays on equipment, domestic remodelling and other such items had already been made at some time in the past, so that recent expenditure had become more a matter of maintenance. This was not true of all cases, of course. By no means all the disabilities were of such long standing or so stable in character. My point is that expenditure on large items seems likely to vary both according to the phases of each child's life and in the light of previous expenditure. No single year's expenditure is likely to be typical. Though no expenditure data are presented, a list of items bought earlier than last year, is set out in Appendix D. It should be noted in this connection that some items which in the past were free, are not necessarily so any longer. Many respondents remarked on how much more difficult it has become to obtain aids through Program of Aids and Appliances for People with Disabilities (PADP) than it was in the past. One family, for example, was provided a few years ago with a buggy, free of charge. At that

time the family's net income was taken into account. This year the same family applied for a wheel chair, but was deemed ineligible on the basis of their gross income. These developments no doubt reflect recent budgetary constraints, but there are, as well, inconsistencies in the application of eligibility criteria from one Health Area to another, as both parents and professionals have remarked.

A decision had to be made as to whether to include as an extra expense the cost of items used by the disabled child, or items upon which the family depended in caring for their disabled child, but which might not have been purchased exclusively for that child. For example, a family car or a second family car may have been bought expressly to meet the needs of the disabled child. In this case the family would not have bought the car or the second car but for the child's disability. On the other hand, a child might be utterly dependent on the car, but according to the parents the car would have been bought even if the child had not needed it. The question is whether, or to what extent, the cost of the car can legitimately be regarded as an extra expense, in either of the cases described above. I took the advice of the NRMA (National Roads and Motorists' Association) on this matter because of their knowledge of the operation of the law as it relates to insurance and compensation for accidental injury. I was advised that it is only legitimate to include the car as an extra expense if it was purchased for the disabled child and would not have been purchased had it not been for the child's special needs. I took this advice and applied the principle to other similar items. If not the car but a particular model of car (like a station wagon or a passenger van) had been bought entirely because of the child's needs, I counted the additional cost of the model as an extra expense. Naturally, this additional amount was difficult to assess with any precision and I used the parents' figure. By the same token, I included the cost of household appliances, such as washing machines, dryers and microwave ovens, but only if the sole reason for buying the machine was, according to the parents, to meet the needs of the child or needs that arise because of the child's disability.

Similarly with health insurance, I only included the cost of health insurance if the family stated that they would not have taken it out had it not been for their disabled child. Finally, private school fees were included if the school had been selected because in the parent's view it was the one that

best met those needs of the child arising from the disability. If the reasons for electing to send the child to a private school were extraneous to the child's disability, for example, religious belief, private school fees were not included as an extra expense.

A decision had to be made about the the running costs of the car for journeys made for the disabled child. This included journeys to the GP, to hospital, to visit the child in hospital, to take the child for special treatments, therapies or lessons, to take the child to respite care and so on. Again, I took the advice of the NRMA, and I used their estimates of running costs per kilometre, taking into account each vehicle's age and engine capacity. Following this advice also, if a car had been purchased solely on account of the child's needs, I included with running costs depreciation, interest on any loan to finance the purchase of the car, registration, licence and NRMA subscription as well as fuel and maintenance. If the car had not been bought solely on account of the child, the rate per kilometre was based only on the fuel and maintenance costs. Naturally, the basis adopted for calculating transport costs makes a very great deal of difference to the final estimate of expenditure.

There are a number of extra costs incurred by parents which they were in general simply unable to quantify. I have already mentioned clothing in this connection, but another instance is the running cost of equipment purchased to meet the child's needs. Though the questionnaire did not seek a figure for these running costs, many parents referred to the high cost of washing clothing and bedding for an incontinent child, bearing in mind the excess electricity and water costs, the cost of washing powder and the accelerated wear and tear on washing machines, but most were not able to suggest even an approximate figure. In the very rare cases in which parents offered an estimated running cost, this has been included. In this context it is worth noting that information on any cost has been included, whenever parents were able to offer a figure.

There were many potential sources of extra expenditure but, in some cases there was, in fact, no cost or only a small cost to the family. Special shoes might either be provided free or subsidised by government or other agencies. Mobility aids could be similarly provided; respite care and home

care when it was provided by a government or non-government agency, was usually subsidised and provided at fairly low cost. For families living in Housing Commission accommodation housing adaptations were made free of charge; some parents did not have to pay for medical consultations because the doctor direct or bulk-billed, some parents were pensioners and so either paid half or none of the prescription charge for medicines on the free list. Only the amount actually paid by the parents is included as an extra cost. Where there was no cost, or help was provided, this was noted. Sadly, respondents reported that these sources of help seemed to be diminishing.

The Relevance of Items

One way of examining extra costs is to consider what I shall call the 'relevance' of particular items of expenditure. By this I mean the pertinence or applicability of an item to a given family or families. Travel to school, for example, is a relevant item in all cases where a child does, or could, use some form of transport to make the daily journey to school, whether or not the child incurs any cost in doing so. The item does not cease to be relevant merely because there is a free school bus or the child is given a regular lift to and fro, without charge. It is not relevant, however, in cases where the child does not attend a school, or lives so close that no form of transport is necessary. Travel to school is a widely relevant item though in fact it costs most families little or nothing. Travel to doctors and hospitals are other widely relevant items, but in these cases families do tend to incur some costs because there is no free or subsidised service.

In Table 6.1 below the various items of expenditure identified by families are ranked in terms of the extent of their relevance across the sample. Column 1 of the table shows for how many of the sample families an item was relevant and column 3 shows for how many families that item involved a cost. Thus we see from column 1 that 'travel to school' was relevant to 35 families and in column 2 that only five families incurred costs. Going down the list we see that for 31 families, travel to hospital was a relevant item and that for as many as 29 this involved expenditure. The reasons for which an item can be relevant to a family and yet involve no cost, vary. It usually implies that the family is receiving help, but the sources of this help are

TABLE 6.1: ITEMS OF EXTRA EXPENDITURE

ITEM	Number of Cases		Excluding No		Mean Expenditure		Excluding No		Maximum	Minimum		Expenditure
	Including No		Expenditure	Rank	Including No		Expenditure	Rank	Expenditure	Including No		Excluding No
	Expenditure	Rank	Expenditure	Order	Expenditure	Rank	Expenditure	Order	\$	\$		\$
	Column 1	Column 2	Column 3	Column 4	Column 5	Column 6	Column 7	Column 8	Column 9	Column 10		Column 11
Transport to school	35	1	5	17	58	30	404	12	1010	0		221
Travel to hospital*	31	2	29	1	74	28	79	31	1040	0		1
Medical or paramedical consultancies*	30	3	13	5	76	27	176	22	1040	0		3
GP Consultation*	26	4	7	13	18	34	66	32	380	0		5
Travel to GP*	24	5	19	2	9	35	12	35	52	0		1
Prescriptions*	22	6	19	2	303	10	351	13	2400	0		15
Childcare in school holidays & after school	20	7	4	19	124	22	620	6	2080	0		35
Across counter medicines*	19	8	18	4	197	16	208	17	676	0		10
Respite care outside home	17	9	8	9	84	25	179	21	600	0		10
Incontinence*	14	10	12	6	468	9	546	7	1768	0		42
Special foods*	11	11	11	7	525	6	525	8	1200	120		120
Inpatient costs*	11	11	10	8	137	20	151	24	623	0		1
Care in school holidays, camps, etc.	8	13	8	9	127	21	127	26	500	20		20
Independence training	8	13	8	9	230	12	230	16	585	45		45
Extra lessons	8	13	8	9	291	11	291	14	1040	57		57
Health insurance*	7	16	7	13	758	4	758	5	1116	325		325
Educational and communication equipment	7	16	7	13	498	8	498	10	2000	36		36
Respite care at home	7	16	4	19	52	31	92	30	160	0		9
Subscriptions, membership fees	7	16	7	13	24	33	24	34	50	10		10
School fees	7	16	5	17	1173	3	1643	3	2967	0		711
House adaptations	6	21	4	19	703	5	1053	4	3000	0		20
Home care, help in house	6	21	3	20	81	26	161	23	234	0		60
Independence aids	5	23	4	19	196	17	245	15	600	0		30
Special shoes*	4	24	3	20	70	29	93	29	150	0		60
Other therapy	4	24	2	25	221	13	442	11	455	0		429
Special catchup lessons	3	26	3	20	95	24	95	28	150	5		5
Mobility aids*	3	26	-	-	-	-	-	-	0	0		-
Special bedding	3	26	3	20	114	23	114	27	120	109		109
Medical equipment*	3	26	3	20	190	18	190	20	200	179		179
Heating, air conditioning	2	30	2	25	2605	2	2605	2	5200	10		10
Running costs (medical equipment, air conditioning, etc.)	1	31	1	27	150	19	150	25	150	150		150
Courses, training, seminars	1	31	1	27	40	32	40	33	40	40		40
Outings	1	31	1	27	5	36	5	36	5	5		5
Travel overseas	1	31	1	27	500	7	500	9	500	500		500
Kitchen appliances	1	31	1	27	199	15	199	19	199	199		199
Car	1	31	1	27	7000	1	7000	1	7000	7000		7000
Legal fees	1	31	1	27	200	14	200	18	200	200		200

* Items arising directly from child's disabling conditions.

This table excludes extra expenditure on clothing because it was not possible to obtain accurate information on the amounts spent. However, 25 families said they incurred extra expenses on clothing for their child on account of his or her disability.

many. We shall be looking in more detail at some of these later. At this stage, it is important simply to draw the distinction between 'no cost' items and those items which did cost some thing, however little. A cost can be low because the value of the item is genuinely low, or it may be low because there is a subsidy. Travel by car was often assessed as costing relatively little, because the formula for calculating expenses for vehicles which have other uses allows only fuel and maintenance costs. On the other hand, respite care is often a low cost item because it is subsidised either by the agency that provides it, or indirectly by a government grant which enables the agency to charge the recipients only a small amount.

It is useful to distinguish items which arise directly from the child's disabling condition (henceforth referred to as 'condition-related items') from those which relate to developmental or educational needs or to the quality of life of the child or the family. The items which relate broadly, to the condition-related needs of the child such as incontinence, diet or special foods are all asterisked in Table 6.1. As the table indicates, the items which had the most widespread relevance for families tended to be those arising from condition-related needs. There is a cluster of these items at the top of the list. Because they tend to be concerned directly with the child's disabling condition, their cost perhaps is particularly important. It is clear that some of these items involved a very large proportion of families in some expenditure. Condition-related items of widespread relevance likely to involve costs were travel to hospital or to GP consultations, medicines, materials for dealing with the child's incontinence, special foods or diets and in-patient costs. Condition-related items of widespread relevance but involving a relatively lower proportion of families in expense were medical and paramedical consultations. Some of the condition-related items listed in Table 6.1 were of fairly limited relevance. That they did not occur often in the sample is merely a reflection of the fact that children with those special needs were not heavily represented. One such category of expenditure is medical equipment: a nebuliser for an asthmatic child, for example, or a glucometer for one with diabetes. Condition-related items of limited relevance which involved some expense for a relatively large proportion of families were medical insurance and medical equipment. The only condition-related item of limited relevance which also

involved no expenditure was mobility aids; those which had been acquired last year were provided free of charge.

Items needed by the child to enhance his or her development, or those with some therapeutic value, or items that enhanced the quality of life for the child or the family, tended to have low relevance. They were also somewhat more likely than condition-related items to involve the families in expense. Exceptions to this are the items 'respite care' and 'child care' which are relevant to quite a number of families but for many of whom there is also no cost. The explanation for this lies in the way that respondents interpreted the terms 'respite care' and 'child care arrangement'. They did not necessarily use these terms to refer to care provided by an agency, either public or private, but rather to include any help they received, from whatever source, in these tasks. In the case of respite care, this was frequently provided by a relative, usually a grandmother. Similarly, child care arrangements after school hours and in the school holidays was often provided by a relative, either a grandmother or, more likely, an older or younger sibling of the disabled child. Assistance from bodies or organisations outside the family was relatively uncommon in the sample as a whole.

We have looked at the relevance of items and also at whether or not these items involved the family in expense. We shall now be looking at the average costs to families in the sample, confining this part of the analysis to those families which did actually incur costs. That is, we shall be looking at the average costs for families which did incur costs rather than to costs averaged over all families for whom the various items were relevant (i.e. including those who obtained goods or services free of charge).

Column 7 of Table 6.1 gives the mean cost per family. If we look first at the condition-related expenses we see that for the items of greatest relevance the highest expenditure was for items purchased because of incontinence. The 12 families incurring costs on this item spent an average of \$546 over the year preceding the interview. The maximum cost was \$1,768, the minimum \$42. The next item in order of cost is special foods or diets. These were mentioned by 11 families who were themselves entirely responsible for the total cost. For these families the average cost was \$525 over the

past year; the maximum expenditure was \$1,200, minimum \$120. It must be noted that these diets were not always medically prescribed although in the case of the diabetic children of course they were, as also in certain other cases where they were dictated by the children's special needs or limitations. However, in at least as many cases again, parents were giving their child special food free from chemical additives or artificial colouring, or especially large quantities of fresh fruit and vegetables with a view to controlling hyperactive behaviour. In some of these cases a doctor had suggested the diet, in others not.

The next highest cost was for prescribed medicines. This averaged \$351 over the last year amongst 19 families. Once again the maximum cost was very high - \$2,400. It is of some interest that these high cost items were not only amongst the 'essential items' on the list but they were also items which in relatively few cases were also 'no cost' items. Many families were somewhat bitter about the high cost of these essential items. A source of particular annoyance and concern was that some of the medicines needed by their children had recently been removed from the 'free list' (a list of items provided at low cost, subsidised by the Commonwealth Government). The increased charges for prescriptions and the new provision of 'no cost' prescriptions for medicines on the 'free list' after the first 25 for the family, had not been in force for sufficient time when I undertook my interviews for families to gauge the impact. On the other hand, some items which were highly relevant to families were of quite low cost. Conspicuous in this group were travel costs. The level of these is only in part a reflection of the distances and frequency with which people need to travel to obtain medical services. It is also a reflection as I have noted earlier, of the basis on which such costs were calculated.

The rank order of mean costs does however indicate that, on the whole, the condition-related items of widest relevance were of relatively low cost. Not only did quite a large number of families incur no costs for GP and hospital consultations because the doctor direct or bulk-billed, but even amongst those families for whom there was some cost, this was, on average, quite low. Either the family was covered by Medicare, or by private insurance, in which case of course, there was the concealed cost of insurance coverage. I have not taken account of this in the medical expenditure data. Seven of the

families said that they had taken out private insurance specifically because of their child's disability. For these families the average annual cost of insurance was \$758 a year. The maximum was \$1116 a year, the minimum \$325. A further 24 families had private medical cover which, though not specifically taken out on account of the child, undoubtedly served to reduce the cost of the child's actual treatment. It is perhaps worth noting here that families receiving their health care under Medicare did not, on the whole, express dissatisfaction with the system although one mother did complain, with some bitterness, that her asthmatic child had been prematurely discharged from hospital, heavily, and in her view, inappropriately, medicated, because the hospital needed the bed for a private patient. Given the general satisfaction with Medicare, however, one is led to ask why parents took out private health insurance for their child. There were two main reasons. The first is that parents are frequently concerned that the child continues to see the same consultant to ensure consistency of treatment. Parents are anxious to maintain the relationship of trust that they have built up with the child's medical consultant. This is undoubtedly a matter of immense concern to many parents. The other reason is that the health care system in Australia has in recent years been modified so often that some parents see their insurance as a protection against the possibility of future changes. Parents are aware that health insurance cover does not usually offer immediate protection. So, because the child might need health care at any time, parents prefer to maintain their insurance against the possibility that the system will suddenly change, leaving those covered only by state provision at a disadvantage, perhaps at a time when their child most needs medical care.

Looking down the list we see that condition-related items of relevance to few families, with the exception of medical insurance, are also of relatively low cost. However, though a given condition-related item may in itself be of fairly low cost, it may be only one amongst many other items required by the child. One such family was suddenly confronted by the fact that their child was diabetic. The expensive glucometer was only one cost amongst many with which this quite poor family was unexpectedly faced. As the father said:

'These are costs that **must** be met. It's no good thinking that because you haven't got the money this week you'll buy the

needles and the syringes next week. This is a continuing lifetime expense for a lifethreatening condition.'

This child's disability had a very considerable effect on the family. The father had taken an evening job to help pay for the various items needed by the child and the mother had gone through a period of acute anxiety. She had not only been immensely worried about the expense but she had also been concerned that she would not be able to cope with her new role as nurse. The thought of giving her child injections terrified her. She had never dreamed that she would be called upon to do this. The result was further expense associated with the psychiatric treatment that this mother sought. Fortunately this was only brief, but the example serves to illustrate the nature of costs, and their potentially sudden onset, which together with the trauma of the diagnosis can be quite debilitating to a family, undermining its cohesion and sense of well-being. This mother, like the mother of the other diabetic children in the sample, expressed a good deal of pleasure that needles for diabetics were shortly to be obtainable free of charge. This recognition of the high cost of diabetes, which the families involved felt had not generally been known or recognised previously, was cause for considerable satisfaction.

Unquestionably there was a tendency for the high cost items to be those which did not strictly arise from children's disabling condition but rather were obtained to meet their developmental needs or because they enhanced the quality of life of the child or the family. We have already noted that these items, with the very important exceptions of respite and child care arrangements, tended to have less frequent relevance to the families than the medical items. But the limited relevance may, at least in part, have been a reflection of their generally high cost. The only non-condition-related expense that was of relatively widespread relevance and also of fairly high cost were child care arrangements. For most families these arrangements did not constitute a cost because in many cases family members were supplying the child care, but for the four families for whom such arrangements did involve costs, these were very high indeed. They averaged \$620 over the past year, with a maximum of \$2080 incurred in the case of a diabetic child. Other non-condition-related items, of both relatively wide relevance and high cost, were private school fees, adaptations to either the inside or outside of the

house (ramps and rails, door widening, and a pool for example), aids to enhance the child's independence (for example a hoist) and educational or communication equipment (a braille printer, a computer, private computer lessons, a video camera). Also in this category of high expense is a suitable model of car bought specifically for the child and his special needs. It is clear that in the main these high cost items are 'one-off' expenditures on consumer durables or capital outlay. Quite often they are expenditures incurred for children with a physical disability. Sometimes these expenditures are absolutely essential in that they make movement possible - a ramp or a hoist are but two examples.

Sometimes they may seem less essential, verging even on luxuries, but I found that parents were rarely merely indulging their child. One parent whose child had a terminal illness spoke with great force of his conviction as to the importance of providing whatever is appropriate to the child's needs. The child in question was very intelligent and creative, but entirely dependent on the family for his mobility. The father wanted the child to be able to fulfill his potential to the utmost during his remaining years and was quite deliberately trying to pack as many stimuli into the child's short life as possible. Seen in this light, the photographic equipment, the computer and the family camping holidays were all ways of meeting the child's legitimate needs. No doubt the fact that the child was able to enjoy these things was partly a reflection of the family's resources and of the sacrifices they were prepared to make, and given that the father was permanently out of the work force with a disability of his own and the mother, because of the child's disability, was able only to take casual part-time work, the sacrifices were quite substantial. But it was also undoubtedly a reflection of the parents' philosophy and attitudes to the disability of their child and his needs, as they saw them.

We now examine particular categories of expenditure. These comprise the items listed under each heading in the first list in Appendix C. Table 6.2 sets out the actual and average expenditure in each category incurred in the year before the interview.

Thus, the mean expenditure over all categories which had any expenditure at all last year was \$1766 but as the first column of figures in this table

TABLE 6.2: TOTAL EXPENDITURE OF FAMILIES OVER LAST YEAR BY ITEM OF EXPENDITURE - RANKED BY TOTAL EXPENDITURE PER FAMILY

	TOTAL	1. CONDITION RELATED		2. CAR		3. EDUCATION		4. CARE ARRANGEMENTS		5. AIDS, ADAPTATIONS & ACCOMMODATION		6. MISCELLANEOUS	
	\$	\$	%	\$	%	\$	%	\$	%	\$	%	\$	%
1.	9333	2220	23.8	7000	75	63	.7	50	.5	-	-	-	-
2.	6552	752	11.5	-	-	0	-	600	9.2	5200	79.4	-	-
3.	5521	1442	26.1	-	-	3890	70.5	189	3.4	-	-	-	-
4.	5329	1215	22.8	-	-	614	11.5	500	9.4	3000	56.3	-	-
5.	5052	1695	33.6	-	-	3207	63.5	0	-	150	3	-	-
6.	4697	4432	94.4	-	-	45	1	220	4.7	-	-	-	-
7.	4324	1040	24.1	-	-	3040	70.3	244	5.6	-	-	-	-
8.	3864	3548	91.8	-	-	281	7.3	35	.9	-	-	-	-
9.	3846	1766	45.9	-	-	-	-	2080	54.1	-	-	-	-
10.	3510	2548	72.6	-	-	0	-	362	10.3	600	17.1	-	-
11.	1958	1958	100	-	-	0	-	0	-	-	-	-	-
12.	1788	1579	88.3	-	-	-	-	0	-	209	11.7	-	-
13.	1721	10	.6	-	-	1711	99.4	0	-	-	-	-	-
14.	1707	707	41.4	-	-	-	-	0	-	1000	58.6	-	-
15.	1621	1116	68.8	-	-	-	-	160	9.9	345	21.3	-	-
16.	1566	1206	77	-	-	360	23	-	-	-	-	-	-
17.	1507	621	41.2	-	-	756	50.2	120	8	-	-	10	.7
18.	1308	408	31.2	-	-	900	68.8	-	-	-	-	10	.8
19.	1254	1244	99.2	-	-	-	-	-	-	-	-	-	-
20.	1139	718	63	-	-	421	37	0	-	-	-	-	-
21.	1095	648	59.2	-	-	447	40.8	0	-	-	-	-	-
22.	1035	764	73.8	-	-	271	26.2	-	-	-	-	-	-
23.	930	551	59.2	-	-	379	40.8	0	-	-	-	-	-
24.	877	877	100	-	-	0	-	-	-	-	-	-	-
25.	843	833	98.8	-	-	-	-	0	-	-	-	10	1.2
26.	731	731	100	-	-	-	-	0	-	-	-	-	-
27.	721	562	77.9	-	-	159	22.1	-	-	-	-	-	-
28.	635	-	-	-	-	585	92.1	50	7.9	-	-	-	-
29.	604	-	-	-	-	396	65.6	208	34.4	-	-	-	-
30.	520	410	78.8	-	-	40	7.7	20	3.8	-	-	50	9.6
31.	516	71	13.7	-	-	0	-	0	-	220	42.6	225	43.6
32.	449	71	15.8	-	-	0	-	328	73.1	-	-	50	11.1
33.	420	360	85.7	-	-	0	-	50	11.9	-	-	10	2.4
34.	420	-	-	-	-	390	92.9	0	-	30	7.1	-	-
35.	405	100	24.7	-	-	255	63	50	12.3	-	-	-	-
36.	322	322	100	-	-	-	-	-	-	-	-	-	-
37.	255	192	75.3	-	-	0	-	63	24.7	0	-	-	-
38.	200	0	-	-	-	200	100	-	-	-	-	-	-
39.	196	-	-	-	-	78	39.7	118	60.2	-	-	-	-
40.	195	45	23.1	-	-	0	-	150	76.9	-	-	-	-
41.	180	0	-	-	-	0	-	180	100	-	-	-	-
42.	163	34	20.8	-	-	129	79.1	0	-	-	-	-	-
43.	155	55	35.5	-	-	100	64.5	-	-	-	-	-	-
44.	25	25	100	-	-	0	-	0	-	-	-	-	-
45.	13	13	100	-	-	-	-	-	-	-	-	-	-
46.	0	-	-	-	-	0	-	0	-	-	-	-	-
47.	0	0	-	-	-	-	-	-	-	-	-	-	-
48.	0	-	-	-	-	0	-	0	-	-	-	-	-
49.	0	-	-	-	-	0	-	0	-	-	-	-	-
50.	0	-	-	-	-	0	-	-	-	-	-	-	-
Mean *	1766	946		7000		749		275		1195		52	
Expen- diture **	1590	878		7000		468		152		1075		52	

Note:

* Excludes items that involved no expenditure.

**Includes items that involved no expenditure.

0 Indicates that a good or service was acquired but no expenditure was incurred.

- Indicates that no goods or services were acquired.

shows, this average figure conceals a very great range of expenditure, from a maximum of \$9333 to a minimum of zero. In fact, five families did not have any expenditure on any of the items identified as potentially leading to expenditure. That is, five families did not identify any extra expenditure associated with the disability of their child. This did not mean that the above items were not relevant to these families. More important, it does not mean that these five families did not incur any costs in relation to their child because, as we have already noted, we are concerned not just with the direct costs, but with the indirect or hidden costs. Two of these five families had incurred extra expenditure on consumer durables more than one year before the interview.

Yet another way of classifying the costs that families have to meet is to do so in terms of the frequency and regularity of expenditure, distinguishing regular recurrent expenditure, irregular recurrent expenditure and capital or consumer durable expenditure. Expenditure for the year preceding the interview is set out under these headings in Table 6.3.

We also looked at the consumer durables acquired for the child before last year, at any time in the child's life.

People spend more, on average, on regular than on irregular recurrent items. It is not simply a matter of the greater frequency of regular expenses, it is also the case that this category includes, in particular, private school fees and medical insurance. But this category did not just contain these 'non-essential' items. It also contained other items to meet the physical needs of the child, which as we have already shown, can be very expensive, such as items bought for the child's incontinence, or medicines bought on prescription. With the exception of GP consultations, the items included in the 'irregular' category not only turned out to be less widely relevant but also to consist of lower cost items. It is important that the items in the regular recurrent category are more expensive than those in the irregular recurrent category. And it is particularly important if the individual items have been correctly categorised.

Finally, it is not surprising that the average expenditure on consumer durables is high when compared to the items bought regularly. The items

TABLE 6.3: TOTAL EXPENDITURE OF FAMILIES (RANKED) IN THE YEAR PRIOR TO THE INTERVIEW:
CLASSIFIED BY FREQUENCY OF EXPENDITURE

		TOTAL REGULAR RECURRENT EXPENDITURE		IRREGULAR RECURRENT EXPENDITURE		CONSUMER DURABLE EXPENDITURE	
		\$	%	\$	%	\$	%
1	9333	2214	23.7	119	1.3	7000	75.0
2	6552	692	10.6	660	10.1	5200	79.4
3	5521	5520	100.0	1	-	-	-
4	5329	1212	22.7	1003	18.8	3114	58.4
5	5052	4277	84.7	575	11.4	200	3.9
6	4697	4003	85.2	694	14.8	-	-
7	4324	2314	53.5	10	.2	2000	46.3
8	3864	3475	89.9	389	10.1	-	-
9	3846	3784	98.4	62	1.6	-	-
10	3510	2849	81.2	61	1.7	600	17.1
11	1958	1888	96.4	70	3.6	0	-
12	1788	947	53.0	632	35.3	209	11.7
13	1721	721	41.9	0	-	1000	58.1
14	1707	707	41.4	-	-	1000	58.6
15	1621	1116	68.8	160	9.9	345	21.3
16	1566	1565	99.9	1	.1	-	-
17	1507	1387	92.1	120	7.9	-	-
18	1308	1299	99.3	9	.7	-	-
19	1254	920	73.4	155	12.4	179	14.3
20	1139	1046	91.8	93	8.2	-	-
21	1095	607	55.4	488	44.6	-	-
22	1035	1008	97.4	27	2.6	-	-
23	930	701	75.4	150	16.1	79	8.5
24	877	727	82.9	150	17.1	-	-
25	843	626	74.3	27	3.2	190	22.5
26	731	731	100.0	-	-	-	-
27	721	510	70.7	52	7.2	159	22.1
28	635	0	-	635	100.0	-	-
29	604	124	20.5	444	73.5	36	6
30	520	455	87.5	65	12.5	-	-
31	516	96	18.6	200	38.8	220	42.6
32	449	121	26.9	328	73.1	-	-
33	420	370	88.1	50	11.9	-	-
34	420	390	92.9	0	-	30	7.1
35	405	160	39.5	245	60.5	-	-
36	322	322	100.0	-	-	-	-
37	255	174	68.2	81	31.8	0	-
38	200	0	-	200	100.0	-	-
39	196	0	-	196	100.0	-	-
40	195	44	22.6	151	77.4	-	-
41	180	0	-	180	100.0	-	-
42	163	34	20.9	129	79.1	-	-
43	155	48	31.0	7	4.5	100	64.5
44	25	0	-	25	100.0	-	-
45	13	13	100.0	-	-	-	-
46	0	0	-	-	-	-	-
47	0	-	-	0	-	-	-
48	0	0	-	0	-	-	-
49	0	0	-	0	-	-	-
50	0	0	-	-	-	-	-
Mean *		1766		221		1203	
Expen- diture **		1590	1004	192		1083	

Note: 0 indicates that a good or service was acquired but no expenditure was incurred.
- indicates that no goods or services were acquired.

* excludes items that involved no expenditure

** includes items that involved no expenditure

included in this category tend to be large, one-off purchases. Equipment and aids are expensive, as are house adaptations; but they are also very important, because they enhance the quality of life of both the child and family. It is difficult to overstate the physical strain that some mothers experience as a result of their child's disabilities. Whilst the less well off families in the sample last year received mobility aids free of charge, it was apparent that the increasing tendency to means test these items is causing a good deal of anxiety. But house adaptations, some of which are available free of charge for tenants in New South Wales Housing Commission accommodation, are beyond the means of many families who either own their own houses, or worse, rent in the private sector. This is an area that is currently under consideration by the New South Wales Department of Housing.

As it has already become clear all average expenditure figures conceal very considerable variations. The table below gives, for each broad grouping of expenditure, the five highest expenditures amongst the sample families.

TABLE 6.4 - THE FIVE HIGHEST SPENDERS IN EACH CATEGORY OF EXPENDITURE

	Regular Recurrent	Irregular Recurrent	Consumer Durables	Total Last Year
	Highest Spenders	Highest Spenders	Highest Spenders	Highest Spenders
1	5520	1003	7000	9333
2	4277	694	5200	6552
3	4003	660	3114	5521
4	3784	635	2000	5329
5	3475	632	1000	5052

The explanation for these exceptionally large expenditures gives some flavour of the individual families that comprised the study.

Regular Recurrent Expenditure

The top five families:- There was no consistent reason for the exceptionally high regular recurrent expenditure incurred by some families in the sample. The first family's expenditure of \$5520, was largely accounted for by the fact that the child attended an expensive private school. This child was intellectually normal but had some autistic characteristics. The mother neither wanted her child to go to a special school, nor did she feel that what she thought would be the rough and tumble of a public school would be appropriate for her child. Hence she had selected what she believed was the more protective and caring environment of the private school where she thought the child's special individual needs would be taken into account. Regrettably the school involved daily travel amounting to nearly 350 kilometres a week for the mother, who drove the child to school and picked her up at the end of the day. Thus, not only were the school fees substantial but so too were the travel costs. The child's father had taken an extra job in the evenings so that the family could afford the school fees.

The second family's regular recurrent expenditure was \$4277. Once again private school fees accounted for the greater part. As in the previous case, the child was intellectually normal and once again the parents chose the school because they felt that it would be more caring than a public school about the child's individual and health needs. As the mother said, they would be more likely to notice if anything was wrong. However, in this case other costs besides school fees were quite considerable, in particular, the cost of prescription medicines.

The third highest expenditure of \$4003 was incurred on account of the child's medical needs. The child had a rare syndrome and a profound intellectual disability. The family spent \$2400 on medicines and a further \$864 on various items that the child needed on account of her incontinence. The remainder of the expenditure was incurred to meet other medical needs.

The fourth highest expenditure was incurred to meet the needs of a child with diabetes. The annual cost of the child's medical needs was \$480 but the mother also calculated that the special diet was a further \$1200 over and above what she would have spent if the child had not had diabetes. However,

most of the annual expenditure of \$3784 went on child care arrangements. This mother went out to work and it was extremely important to her peace of mind that even though the child was 13 there should always be someone with her. These child care arrangements amounted to \$2080 a year.

The fifth highest expenditure was \$3475. These large costs arose from the very severe medical needs of the child who had a musculoskeletal disease. Items bought for this child's incontinence in the last year amounted to \$1644. The child needed to make constant visits to the hospital for examination and treatment and the estimated cost of these visits was \$1040. Medicines amounted to a further \$480 and inpatient costs had been \$623. The parents faced the future of this 14 year old boy with a great deal of anxiety. The costs were undoubtedly going to increase as the child became progressively more dependent.

Irregular Recurrent Expenditure

The top five families:- Once again, the types of items that accounted for the relatively high expenditure in the irregular recurrent category varied quite considerably. Only one of the families with high irregular recurrent expenditure also had high recurrent expenditure. This was the family already mentioned whose child had the rare syndrome. Once again, medical expenses in this category were high.

The first family's high expenditure on items in this category were largely accounted for by the cost of school camps and the fact that the family had paid for their child's participation in an overseas sports meeting for young people with disabilities. They described vividly how the child's participation in these games had boosted her morale and done wonders for her self esteem. Of course the expense had not merely been the travel and accommodation costs of this trip. The child had also needed quite an extensive new wardrobe for the games. Another relatively large expense in this category for the same family had been a school camp. I have included this because it was a camp arranged by the child's special school and therefore had its therapeutic aspect. However, a hazard mentioned by a number of families in attendance at these camps is the cost in clothing. Many parents told me how many of their child's clothes have been lost or

stolen. This particular child's very expensive new glasses had been smashed. Whether it is legitimate to include school camps as an extra expense is open to debate.

The high expenses of the second family in this category of expenditure were due in part to a particularly large amount of money being spent on GP consultation charges (this child needed to see the GP very frequently) and to independence training that the child was receiving at her special school. Many parents praised the efforts of special schools to make their children more independent, but for some parents this was quite a major expense. One parent told me that she gave her child money for shopping expeditions organised by the school. Children were supposed to buy goods their parents needed with this money, but quite often returned either with the wrong articles or with something costing more than the mother herself would have paid. The average cost to the eight families in the sample who incurred some expense for the independence training of their child mounted to an average of \$229 over the last year. This represents a relatively small sum perhaps, but to a poor family with other expenses, trying to do the best for their child, it is by no means an insignificant outlay.

The third family with high expenses in this category earned their place in the top five by virtue of the high cost of their child's respite care. This was the only family paying for private respite care, and the cost had been \$600 for a period of three weeks. Though this might not be an enormous cost for a reasonably affluent family (and this particular family was the most affluent in the sample), it is a great deal of money for most families to pay. It provides a salutary reminder of how expensive certain types of services can be when they have to be bought on the open market and it is also important to bear in mind that HCA payment may be temporarily lost whilst the child is away from home. However important these services may be to a family's capacity to continue caring for their child, the cost is likely to place them beyond reach.

The fourth family's high costs were again attributable to the independence training of their child and the fifth to costs incurred when the child had been a hospital inpatient. This child had been in hospital for three months; the cost of bringing in special food treats, of games and books bought to

keep the child entertained and the hire of a television set with remote control, had been high for this poor family. Most families did not see the periods when the child was away from home, whether in hospital or in respite care, as a source of financial saving. On the contrary, they quite often saw it as entailing additional costs, because of the need to provide special food perhaps or to teach the carers how to prepare special food, to make sure the child had a supply of nappies and anything else required to meet medical needs whilst he or she was away from home. On the child's return there would often be a need to replace clothes that had been lost, stolen or damaged. Spells away from home, whether in hospital, respite care or at school camps are by no means necessarily low-cost.

Expenditure on Consumer Durables

The top five families:- If we now look at the five cases of particularly high capital and consumer durables expenditure we see that over the last year the highest expenditure was \$7000. This was the estimated extra cost of an eight seater passenger van to enable the family to go out together as a family. The disabled child needed three of the eight seats to stretch out. Like so many families who have a child with a disability they really feel the need for a particularly spacious, perhaps specially adapted vehicle to enable them to go out together, as a family, in any comfort. Of course, only a limited number of families could afford the luxury of a passenger van. This is important. For many people who have a child with a disability, a family outing is the only practicable form of entertainment outside the home. It may take the form of just driving around, of picknicking or even of camping. But a potentially pleasant outing can be ruined if it does not take place in reasonable comfort. Parents described how their family outings could be spoilt as a result of the resentment that other children build up because they have been forced to squeeze into the small space that remains after their disabled brother or sister has been settled.

The second highest expense in this category (\$5200) was for the installation of airconditioning for the entire house. The third highest spender on consumer durables spent \$3114 last year of which \$3000 represented one fifth of the cost of a swimming pool. These two families illustrate well the problem of deciding whether or to what extent it is legitimate to attribute

certain costs to their child. The family which had installed the airconditioner said that the control of the temperature was very important for their child, but at the same time there was some doubt as to whether they would have airconditioned the entire house (which was part of an extensive general renovation in which they were engaged) just for their disabled child. Similarly, the parents who built the pool believed that it would be wrong to attribute the entire cost of this pool (\$15,000) to the child since all the members of the family enjoyed it and the family were not entirely sure whether or not they would have built it just for the child with the disability.

The fourth highest spending family in this category over the last year had bought a computer for their child. This child was intellectually normal but had a very severe physical disability. The family were very anxious to provide the opportunity for this child's intellectual potential to be fulfilled. As well as the computer, the family had paid for the child to have lessons in computing. This expenditure was possible because of the quite substantial resources of the family.

The fifth family in this category was a low to middle income family with a hyperactive child who was apparently being scapegoated by other children in the neighbourhood. The parents reported that they had been forced to screen their windows against the vandalism of neighbouring children at a cost of \$1000. This investment gained the family their place among the top five families for expenditure on consumer durables last year.

Higher Consumer Expenditure Over the Lifetime of the Child

It is clear that there are two items that make families into 'big spenders'. The first is a car and the second are adaptations made to the house to meet the needs of the child. One family had chosen their present house mainly because it had the facility of a pool which they thought would be both therapeutic and enjoyable for their child who had cerebral palsy. But, of course, the pool by itself was unusable. The area around the pool had to be resurfaced to make it suitable for a wheelchair, ramps had to be built and also a hoist had to be installed over the pool. As the parents said, rather sardonically 'it's a pity he's stopped enjoying swimming!'.

Indirect Costs

I have already presented in Chapter 4 an overview of the scale on which mothers are prevented from working because of their children's disabilities. Of course we cannot conclude simply from the fact that a mother does not work or only works part-time, that her child's disability is what restricts her. But it is a fact that mothers in the sample have a lower rate of participation in the labour force than their counterparts in the general population, and a much greater propensity to work only part-time. This, coupled with the views of the mothers themselves about the difficulties they have in combining the care of their children with anything more than a part-time job, represents good grounds for supposing that children's disabilities do have a considerable impact on their mothers' labour market participation. It is difficult to impute a monetary value to income foregone, but it seems reasonable to estimate that families are losing an average of between \$225 and \$476 a week gross (in net terms between \$172 and \$357 a week) in those cases where the mother says she cannot work because of the child and would be working otherwise.⁽¹⁾ On the other hand, there can be no grounds for attributing this loss of income to mothers who give other reasons for not working.

In the interview, I explored in some detail the question of how far the child's disability had affected the mother's labour market participation. Of the 31 mothers who were not currently working, a majority (19, or 61 percent) had worked at some time since their child's disability was diagnosed. Thirty five percent had not worked since the diagnosis, but one cannot conclude on that evidence alone that they had not worked because of their child's disability.

The 31 mothers not **currently working** were asked why they had left their job. The reason most often given (15 cases) was exclusively for the purpose of looking after the disabled child. A further eight left work only partly on account of their disabled child. For the remainder, the child's disability had played no part in the decision to leave their job. The reason most often given by these women was their responsibility for all their children. Other reasons, given with less frequency were their own health, their husband's

wishes or the difficulty experienced by women of the respondents' age in finding work.

The 19 mothers referred to earlier who **had worked** since the child's disability was diagnosed, but who were not currently working, offered a number of explanations for their giving up work. The most frequent single response (eight cases) was that they felt unable to combine a job with their caring responsibilities. However, others gave a range of reasons; for example, their own health problems, a wish to remain at home to look after all the children - not exclusively the disabled child, their husband's wishes for his work situation and, in one case, pregnancy.

Of the 19 mothers **currently** working, a majority (15 cases) thought that their work situation had been affected by the disability of their child. These mothers gave the need to be at home at particular hours, in order to be available when the child required attention, as the factor which has had the greatest effect on their working lives, or work situation.

As many as 16 (31 percent) considered that their careers had been affected by their child's disability. One needs to consider this in the light of the fairly modest average level of education attained by these women. They were not claiming to have lost spectacular professional opportunities, but simply to have been frustrated in their hopes for stable, reasonably rewarding work.

'It's affected my career definitely. Yes I'd like to have been able to work as a secretary and at one stage I did try and go back to it but then he got sick so it just didn't work.'

For the mothers, then, what emerges is a picture of constant adaptation and re-adaptation to the child's current needs. True, many of the mothers had worked, but that work, either in its location or its regularity was greatly influenced by the child's disability. Very many mothers alluded to the fact that because the child's needs were not only great but tended to emerge unpredictably, they could not avoid being somewhat unreliable employees.

Over and again mothers explained that it was not so much their child's average or usual state of health that caused them concern as the inherent unpredictability of the child's condition. The existence of a constant

potential for disaster created a level of uncertainty that dictated quite narrow limits to the mothers' freedom.

'It's her health. You can't take a job and then have every Thursday off. I couldn't guarantee myself ... You couldn't send a child so ill to school. Her health's so bad in wintertime and who's going to employ you in the summer and not in the winter?'

The work patterns of many mothers, however, had not been exclusively determined by their disabled child. There were some who clearly felt that a mother's place was with her children, disabled or not, though unquestionably the presence of a disabled child made the mother's link with the work force even more tenuous.

It is necessary to note here that it is much harder to make child care arrangements for a disabled child than for one without disabilities.

'But put it this way. If a service was available to put the child into child care they could get the job they wanted and they could earn their own money. We can't expect to drain the country. You can work at putting in better care so that you're able to work and provide better for your handicapped child. I'm better able to cope when I've had a mental break. I'm a better mother. I can start a new angle.'

The problem is compounded if the disabled child has special or additional difficulties, such as behaviour problems, and is especially true of older children for whom statutory provision in many areas is poor, if it exists at all. This was a complaint of many parents, and confirmed by my enquiries on the subject with the Department of Youth and Community Services, which is chiefly responsible for child care. The Disability Council of New South Wales recently organised a phone-in to obtain consumers' views on the subject of respite care. Their report describes the difficulties that consumers experienced in obtaining adequate respite care. The exclusion from respite care of 'difficult' groups was noted.⁽²⁾

CONCLUSION

In this chapter we have looked at the type and levels of extra expenditure. The average amount incurred by families in the sample in the year preceding the interview was \$1590 or if we confine attention to those who actually

identified expenditure, \$1766. Either figure conceals very considerable variation in expenditure between families. When we look at particular high spending families, it is clear that total expenditure is very much affected by the inclusion of a single high-cost item such as a car or private school fees. In other cases, however, high total expenditure reflects frequent, regular purchase of items made necessary in a more direct way by the child's condition. Items bought because of the child's incontinence, special foods and medicines fall into this category. The costs incurred by any given family are also very much influenced by the extent to which different items are subsidised. Because of the way in which the health care system is organised, items of widest relevance are not usually those of the highest cost. On the other hand, for some families, medicines on prescription and material to deal with a child's incontinence are very costly.

The point is that the variability of direct costs reflects the complex interplay of a number of factors which are by no means easy to disentangle. The scale of indirect costs is a good deal more difficult to estimate though there can be no doubt as to their reality. It will be the task of the following chapter to account, as far as possible, for the variation in costs of both kinds.

FOOTNOTES

1. ABS, **Weekly Earnings of Employees**, Table 13, Cat. No. 6310.0. This table gives average weekly earnings according to occupational group. It combines full time and part time earnings.
2. Disability Council of New South Wales, **Time for a Break: Result of the Respite Care Phone-In 1986**, February 1987.

CHAPTER VII

WHO BEARS THE BURDEN

In this chapter I describe and attempt to explain variation in costs, both direct and indirect. I first consider variation in direct costs or actual expenditure, and then turn to the indirect costs, mainly experienced in the form of restrictions on the employment opportunities open to mothers.

VARIATION IN EXPENDITURE

Characteristics of Families and Children

Our examination of individual cases in the last chapter suggested that in trying to account for variation in extra expenditure it would be sensible to look first at the contribution made by the circumstances of the family, and second at the effects produced by the child's disability and dependency. To begin, therefore, I have considered the relationship between extra expenditure and each of five other **family** variables:

1. The total gross income of the family last year.
2. Whether only one parent or both were living in the household.
3. Whether both, either or neither of the child's parents were born in an English speaking country.
4. Whether the mother was currently employed full-time, part-time or not at all.
5. The number of dependent children in the family.

I have next examined the relationship between expenditure and 12 diagnostic/child variables:

6. The age of the child.

7. Whether and to what extent the child had disabilities, limitations and consequent dependency in any of the following area:

- (a) mobility,
- (b) continence,
- (c) using the toilet,
- (d) dressing,
- (e) eating,
- (f) bathing,
- (g) speech and communication,
- (h) need for supervision
- (i) need for nursing care,
- (j) number of prescribed medicines,
- (k) level of intellectual functioning.

I have tried to see how far each factor helps to explain the variation in extra expenditure. Precise definitions of these variables are set out in Appendix E.

CLASSIFYING EXPENDITURE

I have examined expenditure firstly with regard to its regularity and secondly according to the type of goods or services procured, as follows:

Regularity

1. Regular recurrent,
-

2. Irregular recurrent,
3. Consumer durable and capital expenditure.

Type of Goods Or Services

1. Items needed to manage or alleviate the disabling condition of the child, that is, condition-related items,
2. Education,
3. Care arrangements,
4. Aids and adaptations to the house.

These two classifications are merely alternative ways of looking at the same data, and certain categories tend to overlap quite considerably. Education expenses, for example, represent a substantial part of regular recurrent costs. Aids and adaptations account for most of the capital and consumer durable expenditure. Detailed lists setting out the constituents of all these categories are presented in Appendices C and D. It will be noted that 'Transport' and 'Miscellaneous' which appear in the Appendix are omitted from this part of the analysis, as there were not enough cases involved to make their inclusion worthwhile. For each category we have data (see Tables 7.1A and 7.1B and 7.2A and 7.2B) on expenditure by families in the sample for the twelve months preceding the interview.

RESULTS

Average Overall Extra Expenditure

The average overall extra expenditure in the year before the interview for all families incurring any extra expenditure was \$1766. What are the characteristics of families which last year spent more than this amount, and how is their expenditure distributed in terms of the framework just outlined? Families with higher than average extra expenditure overall tended to be:

TABLE 7.1A: MEAN EXPENDITURE IN DOLLARS IN THE YEAR PRIOR TO THE INTERVIEW
CLASSIFIED BY TYPE OF EXPENDITURE: FAMILY VARIABLES

VARIABLE	NO. OF CASES INCURRING EXPEN- DITURE **	OVERALL EXPENDITURE		CONDITION RELATED EXPENDITURE		EDUCATION		CARE ARRANGEMENTS		AIDS, ADAPTATIONS & ACCOMMODATION	
		MEAN EXPEN- DITURE	VARIATION FROM MEAN*	MEAN EXPEN- DITURE	VARIATION FROM MEAN*	MEAN EXPEN- DITURE	VARIATION FROM MEAN *	MEAN EXPEN- DITURE	VARIATION FROM MEAN*	MEAN EXPEN- DITURE	VARIATION FROM MEAN*
1. Income											
Low	16	768	-998	677	-268	244	-504	85	-190	209	-985
Medium	15	1614	-152	891	-54	969	+221	455	+180	575	-619
High	14	3071	+1305	1355	+410	1094	+346	245	-30	1565	+371
2. Family Type											
Single Parent	11	1253	-513	1052	+107	281	-467	592	+317	209	-985
Married Couple	34	1932	+166	913	-32	896	+148	200	-75	1318	+124
3. Place of Birth											
Both parents born in English speaking country	32	2000	+234	1007	+62	672	-76	317	+42	1325	+131
One parent born in English speaking country	2	2022	+256	3548	+2603	281	-467	107	-168	-	-
Neither parent born in English speaking Country	11	1041	-725	457	-488	1000	+252	85	-190	150	-1044
4. Mothers Employment											
Full Time	3	363	-1403	270	-675	129	-619	150	-125	-	-
Part Time	15	2553	+787	1457	+512	740	-8	370	+95	269	-925
Neither	27	1485	-281	745	-200	798	+50	208	-67	2352	+1158
5. Number of Dependent Children											
None	9	1803	+37	1409	+464	778	+30	117	-158	185	-1009
One	20	1545	-221	817	-128	1106	+358	361	+86	493	-701
Two or More	16	2023	+257	835	-110	295	-453	242	-33	2803	+1609
Mean Expenditure For All Families Incurring Expenditure		1766		946		748		275		1194	
No. of Families Incurring Expenditure		45		39		25		21		9	

Note: * The figures presented are: the differences between mean expenditure for each sub-category defined by the variables in the first column, and mean expenditure for each category of expenditure (shown at the foot of the column.)

** These figures relate only to overall expenditure. Sub-totals for other categories of expenditure are smaller.

TABLE 7.1B MEAN EXPENDITURE IN DOLLARS IN THE YEAR PRIOR TO THE INTERVIEW
CLASSIFIED BY TYPE OF EXPENDITURE: CHILD/CONDITION RELATED VARIABLES

VARIABLE	NO. OF CASES INCURRING EXPEN- DITURE **	OVERALL EXPENDITURE		CONDITION RELATED EXPENDITURE		EDUCATION		CARE ARRANGEMENTS		AIDS, ADAPTATIONS & ACCOMMODATION	
		MEAN EXPEN- DITURE	VARIATION FROM MEAN*	MEAN EXPEN- DITURE	VARIATION FROM MEAN*	MEAN EXPEN- DITURE	VARIATION FROM MEAN*	MEAN EXPEN- DITURE	VARIATION FROM MEAN*	MEAN EXPEN- DITURE	VARIATION FROM MEAN*
1. Age of Child With Disability											
12 Years	8	2002	+236	1421	+476	1245	+497	621	+346	30	-1164
13 Years	13	2930	+1164	1245	+300	654	-94	226	-49	4100	+2906
14 Years	8	1036	-730	719	-226	242	-506	256	-19	410	-784
15 Years	13	956	-810	613	-332	711	-37	115	-160	453	-741
16 Years	3	1550	-216	511	-434	1305	+557	160	-115	345	-849
2. Mobility Problem											
None	27	1082	-684	634	-311	677	-71	320	+45	398	-796
Mild	11	2561	+795	1244	+299	776	+28	312	+37	1831	+637
Mod/Severe	7	3157	+1391	1498	+553	976	+228	139	-136	-	-
3. Continence											
Continent	30	1453	-313	754	-191	960	+212	345	+70	724	-470
Incontinent	15	2392	+626	1252	+307	298	-450	161	-114	2136	+942
4. Toileting Problem											
None	33	1344	-422	754	-191	759	+11	330	+55	854	-340
Mild	3	2407	+641	292	-653	100	-648	600	+325	2710	+1516
Mod/Severe	9	3102	+1336	1737	+792	837	+89	126	-149	209	-985
5. Self Care Problem (dressing, bathing, eating)											
None	24	1492	-274	901	-44	947	+199	389	+114	460	-734
Mild	9	983	-783	887	-58	390	-358	142	-133	30	-1164
Mod/Severe	12	2903	+1137	1052	+107	769	+21	243	-32	2806	+1612
6. Speech and Communication Problem											
None	22	1419	-347	884	-61	836	+88	378	+103	183	-1011
Mild	7	2644	+878	1223	+278	1367	+619	275	0	1533	+336
Mod/Severe	16	1860	+94	915	-30	405	-343	202	-73	2710	+1516
7. Need For Supervision											
None	15	1055	-711	692	-253	735	-13	68	-207	175	-1019
Mild	13	2941	+1175	1255	+310	1257	+509	476	+201	1202	+8
Mod/Severe	17	1495	-271	938	-7	403	-345	202	-73	2710	+1516
8. Need For Nursing Care											
None	41	1768	+2	892	-53	812	+64	314	+39	1194	0
Mild	2	2476	+710	2312	+1367	45	-703	141	-134	-	-
Mod/Severe	2	1013	-753	515	-430	398	-350	70	-205	-	-
9. Number of Prescribed Medicines											
0	22	963	-803	658	-287	649	-99	185	-90	325	-869
1	9	1707	-59	988	+43	1164	+416	73	-202	610	-584
2	5	2148	+382	1609	+664	72	-676	787	+512	209	-985
3 +	9	3577	+1811	1048	+103	874	+126	317	+42	2783	+1589
10. Intellectual Disability											
No/Mild Problem	26	1564	-202	869	-76	1098	+350	355	+80	346	-848
Moderate/Severe Problem	19	2043	+277	1081	+136	369	-379	225	-50	2255	+1061
Mean Expenditure For All Families Incurring Expenditure		1766		946		748		275		1194	
No. of Families Incurring Expenditure		45		39		25		21		9	

Note: * The figures presented are: the differences between mean expenditure for each sub-category defined by the variables in the first column, and mean expenditure for each category of expenditure (shown at the foot of the column).

** These figures relate only to overall expenditure. Sub-totals for other categories of expenditure are smaller.

TABLE 7.2A: MEAN EXPENDITURE IN DOLLARS IN THE YEAR PRIOR TO THE INTERVIEW
CLASSIFIED BY FREQUENCY OF EXPENDITURE: FAMILY VARIABLES

VARIABLE	NO. OF CASES INCURRING EXPEN- DITURE**	OVERALL EXPENDITURE		REGULAR RECURRENT EXPENDITURE		IRREGULAR RECURRENT EXPENDITURE		EXPENDITURE ON CONSUMER DURABLES	
		MEAN EXPENDITURE	VARIATION FROM MEAN*	MEAN EXPENDITURE	VARIATION FROM MEAN*	MEAN EXPENDITURE	VARIATION FROM MEAN*	MEAN EXPENDITURE	VARIATION FROM MEAN*
1. Income									
Low	16	768	-998	647	-582	159	-62	126	-1077
Medium	15	1614	-152	1461	+232	198	-23	441	-762
High	14	3071	+1305	1707	+478	307	+86	2313	+1110
2. Family Type									
Single Parent	11	1253	-513	1171	-58	165	-56	122	-1081
Married Couple	34	1932	+166	1249	+20	243	+22	1338	+135
3. Place of Birth									
Both parents born in English speaking country	32	2000	+234	1213	-16	200	-21	1357	+154
One parent born in English speaking country	2	2022	+256	3475	+2246	284	+63	-	-
Neither parent born in English speaking country	11	1041	-725	1013	-216	292	+71	433	-770
4. Mothers Employment									
Full Time	3	363	-1403	269	-960	140	-81	-	-
Part Time	15	2553	+787	1775	+546	311	+90	1342	+139
Neither	27	1485	-281	1023	-206	179	-42	1115	-88
5. Number of Dependent Children									
None	9	1803	+37	1663	+434	292	+71	193	-1010
One	20	1545	-221	1390	+161	122	-99	589	-614
Two or More	16	2023	+257	816	-413	289	+68	2630	+1427
Mean Expenditure For All Families Incurring Expenditure		1766		1229		221		1203	
No. of Families Incurring Expenditure		45		40		39		18	

Note: * The figures presented are: the differences between mean expenditure for each sub-category defined by the variables in the first column, and mean expenditure for each category of expenditure (shown at the foot of the column.)

** These figures relate only to overall expenditure. Sub-totals for other categories of expenditure are smaller.

TABLE 7.2B MEAN EXPENDITURE IN DOLLARS IN THE YEAR PRIOR TO THE INTERVIEW
CLASSIFIED BY FREQUENCY OF EXPENDITURE: CHILD/CONDITION RELATED VARIABLES

VARIABLE	NO. OF CASES INCURRING EXPEN- DITURE *	OVERALL EXPENDITURE		REGULAR RECURRENT EXPENDITURE		IRREGULAR RECURRENT EXPENDITURE		EXPENDITURE ON CONSUMER DURABLES	
		MEAN EXPENDITURE	VARIATION FROM MEAN*	MEAN EXPENDITURE	VARIATION FROM MEAN*	MEAN EXPENDITURE	VARIATION FROM MEAN*	MEAN EXPENDITURE	VARIATION FROM MEAN*
1. Age of Child With Disability									
12 Years	8	2002	+236	2181	+952	145	-76	30	-1173
13 Years	13	2930	+1164	1277	+48	304	+83	2923	+1720
14 Years	8	1036	-730	782	-447	106	-115	235	-968
15 Years	13	956	-810	881	-348	267	+46	392	-811
16 Years	3	1550	-216	1045	-184	84	-137	672	-531
2. Mobility Problem									
None	27	1082	-684	946	-283	155	-66	323	-880
Mild	11	2561	+795	1450	+221	386	+165	1570	+367
Mod/Severe	7	3157	+1391	1996	+767	159	-62	4500	+3297
3. Continence									
Continent	30	1453	-313	1238	+9	185	-36	667	-536
Incontinent	15	2392	+626	1215	-14	285	+64	2274	+1071
4. Toileting Problem									
None	33	1344	-422	1139	-90	204	-17	577	-626
Mild	3	2407	+641	278	-951	289	+68	1840	+637
Mod/Severe	9	3102	+1336	1827	+598	251	+30	3069	+1866
5. Self Care Problem (dressing, bathing, eating)									
None	24	1492	-274	1289	+60	185	-36	391	-812
Mild	9	983	-783	964	-265	248	+27	54	-1149
Mod/Severe	12	2903	+1137	1279	+50	261	+40	2939	+1736
6. Speech and Communication Problem									
None	22	1419	-347	1208	-21	141	-80	414	-789
Mild	7	2644	+878	1952	+723	333	+112	1198	-5
Mod/Severe	16	1860	+94	931	-298	273	+52	2259	+1056
7. Need For Supervision									
None	15	1055	-711	927	-302	159	-62	188	-1015
Mild	13	2941	+1175	1947	+718	231	+10	1754	+551
Mod/Severe	17	1495	-271	986	-243	263	+42	1335	+132
8. Need For Nursing Care									
None	41	1768	+2	1199	-30	219	-2	1203	0
Mild	2	2476	+710	2088	+859	387	+166	-	-
Mod/Severe	2	1013	-753	921	-308	92	-129	-	-
9. Number of Prescribed Medicines									
0	22	963	-803	829	-400	177	-44	584	-619
1	9	1707	-59	1398	+169	171	-50	470	-733
2	5	2148	+382	1791	+562	295	+74	154	-1049
3 +	9	3577	+1811	1506	+277	309	+88	2642	+1439
10. Intellectual Disability									
No/Mild Problem	26	1564	-202	1298	-69	141	-80	490	-713
Moderate/Severe Problem	19	2043	+277	1116	-113	305	+84	2324	+1121
Mean Expenditure For All Families Incurring Expenditure		1766		1229		221		1203	
No. of Families Incurring Expenditure		45		40		39		18	

Note: * The figures presented are: the differences between mean expenditure for each sub-category defined by the variables in the first column, and mean expenditure for each category of expenditure (shown at the foot of the column).
 ** These figures relate only to overall expenditure. Sub-totals for other categories of expenditure are smaller.

- (a) High income families.
- (b) Two-parent families.
- (c) Families where one or both parents were born in an English-speaking country,
- (d) Families where the mother worked part-time rather than full-time or not at all.
- (e) Families with no other dependent child, or two or more other dependent children.

Expenditure varied not only in amount but also in terms of its distribution. To highlight a few observations, high income families, spent above average on everything but child care arrangements. Single-parent families, despite lower than average income and extra expenditure, spent both relatively and absolutely more on care arrangements and on condition-related items than did two-parent families. Families with a non-English speaking background tended to have lower than average overall extra expenditure, and markedly lower expenditure in the area of consumer durables and aids and adaptations to the home. On the other hand, they spent somewhat above the average on the education of their disabled children.

These few observations give some indication of some of a variability masked by figures for overall average expenditure. With so small a sample, however, it is important to bear in mind that what looks like evidence of a strong association between two variables may merely reflect the characteristics of one or two individual cases with extreme values. For example, while the higher than average expenditure of single-parent families on care arrangements seems to make sense, insofar as it is easy to see why single parents might feel a particularly acute need for this kind of support, the truth is that the average computed for the 12 single-parents in this sample is very much influenced by the fact that one of them had an outlay of over \$2,000 on child care in the preceding year. Many others spent nothing at all.

With this kind of caveat in view, let us look at the characteristics of the disabled children which appear to affect expenditure. Families who spent more than the average amount were more likely than others to have a child with:

- (a) **severe mobility problems** - mean extra expenditure of the families of children who walk without difficulty is \$648 below the sample mean, whereas it is \$795 above the sample mean for those who have a mild problem, and \$1391 above where the problem is severe. The only area in which poor mobility appears to lead to lower costs is that of care, whether because of a less acutely felt need or because of the greater difficulty of finding willing, competent carers is not clear;
- (b) **incontinence** - families of incontinent children had extra expenditure of \$626 above the sample mean, and had higher costs than others in all areas except care and education, no doubt reflecting a lower likelihood of attending a private school and a greater difficulty in making care arrangements;
- (c) **severe problems using the toilet** - parents had a pattern of expenditure broadly similar to that for the families of incontinent children;
- (d) **severe problems in the area of 'basic self-care'** - a composite variable which embraces eating, dressing and bathing. Parents whose children had severe problems in this area spent considerably above the average for the sample as a whole, and this held true in most of the subdivisions of expenditure, except education and care;
- (e) **problems in the area of speech and communication** - this relationship does not appear to be as strong as that between expenditure and other disability variables;
- (f) **some need for supervision** - beyond a certain threshold increasing need does not appear to be reflected in increased expenditure;
- (g) **moderate/severe intellectual disability** - the effects of which on expenditure of different kinds is quite variable. Expenditure on

education and child care tends to be below average, whereas expenditure on consumer durables and aids and adaptations to the home tends to be high;

- (h) **more prescribed medicines** - hardly a surprising result, given that medicines, however subsidised, are rarely provided free. The more medicines required, the higher the expenditure one might expect. Moreover, a greater need for medicines implies more severe or numerous disabilities, and consequently other attendant costs.

Considering each of the variables separately in this way undoubtedly tells us something; but we need to take account of the fact that they are not independent of one another. The variables themselves interact. As the table of correlation co-efficients in Appendix F shows, whether one or both parents are present in the household strongly influences family income; and in two-parent families, whether only one or both parents are employed affects income. Where both parents are from non-English speaking backgrounds, family income tends to be low. Limitation of mobility tends to be associated with limitation in all the self-care areas. Limited self-care capability tends to be associated with need for supervision. Need for supervision tends to be associated with difficulties in the area of communication, and so on. When it comes to explaining expenditure it is clearly not easy to say on superficial inspection exactly how far which variables are having an effect. To approach such questions it is necessary to undertake a more complex investigation, in this case by means of multiple regression analysis.

MULTIPLE REGRESSION ANALYSIS

The first step is to acknowledge that figures for overall expenditure submerge important differences between the various component costs. The most fundamental distinction is that between expenditure directly related to the child's disability, and expenditure on other more remotely but no less significantly related objectives such as education, care and general 'quality of life' measures which in this part of the analysis we have found it useful to combine. So, we speak of two dependent variables: condition-related expenditure and **quality of life** expenditure. These we analyse in turn in

relation to two classes of independent variables: **family** variables and **child/diagnostic** variables, distinguished along exactly the same lines as those established earlier in this chapter.

Condition-Related Expenditure

The distribution of this variable is skewed. Many families reported low levels of expenditure, while a few reported levels which were quite high. Values ranged from \$0 to \$4432, with a median of \$481 and a mean of \$738.

There are too many variables in the child/diagnostic category to be examined simultaneously. We therefore treat these in two stages: first by examining 10 variables relating to the child's independence (Appendix E), and then dealing with the remaining four, (number of prescribed medications, age, improvement and level of disability).

The ten **independence** variables account for 38 percent of the variance in **condition-related** expenditure, or 22 percent when adjusted to take account of the number of variables in relation to sample size, a result which is statistically significant.⁽¹⁾ The most important single variable in this group is **continence**, which accounts for 20.4 percent of the variance, and can be treated as alone adequately accounting for the relationship between the **independence** variables and **condition-related** expenditure.⁽²⁾ In other words, condition-related medical, paramedical and quasi medical expenditure varies to some extent in accordance with the severity of a substantial cluster of inter-related disabilities, among which incontinence is so influential as to make it effectively representative of all the others.

The four remaining variables account for 17.6 percent of the variance (10.2 percent when adjusted). This is no more than marginally significant. Only **number of prescribed medications** seems at all important. The relationship between this variable alone and **condition-related** expenditure accounts for 12.8 percent of the variance. This is statistically significant.⁽³⁾

Continence and **number of medications**, taken together, explain 25.3 percent of the variance in **condition-related expenditure**, a parsimonious, statistically significant account of the relationship between the child's state and the

cost of treating or alleviating it.⁽⁴⁾ It may seem disappointing that 75 percent of the variation in that cost remains unexplained. Of course it would be satisfying to explain more, but in social research it is often necessary to remain content with what appear to be vague or sketchy conclusions. In any case, it is possible to go further, even on this basis.

The next step is to examine the relationship between **family** variables and **condition-related expenditure**. These six variables account for only 12.6 percent of the variance, or 0.4 percent adjusted, which is not statistically significant.⁽⁵⁾ This negative result leaves us with nothing beyond the already established relationship with medications and continence to help us explain condition-related expenditure. Two conclusions may be drawn from this. First, it is obvious that there are many factors affecting this kind of expenditure which our investigation, though systematic and carefully prepared, has not picked up. Quantification has its uses, but it can lead us to exclude relevant information at the same time as it aids our analysis of the material in hand. Second, whatever the unidentified factors may be, they do not appear to be connected with one important possible source of extraneous influence, viz. family circumstances. Expenditure in this category does appear to be truly condition-related to the extent that it is free of the influence of such things as family income, number of other children, number of parents or parental employment. This conclusion, though negative, is nonetheless important.

Quality of Life Expenditure

The distribution of families according to **quality of life** expenditure is highly skewed. Many families reported no expenditure at all in this category. The range extended from \$0 to \$7,113, with a median of \$268 and a mean of \$852. In attempting to explain this variable, we follow the same procedure as before.

Analysis of quality of life expenditure in relation to the independence variables accounts for 29.9 percent of the variance, but this is not statistically significant.⁽⁶⁾ Further, more detailed analysis reveals nothing else in the way of connection with these variables.

The remaining four child variables prove on examination to account for 30 percent of the variance, which is statistically significant. Of these, number of medications alone accounts for 21.3 percent of the variance, while none of the other three contributes significantly.⁽⁷⁾

We are left, then, with the superficially puzzling conclusion that the only thing about the disabled children themselves which appears to have any connection with the amount of money spent on them for non-medical purposes is the number of medicines they are taking.

Analysis of the relationship between **quality of life expenditure** and the six family variables indicates that these account for 33 percent of the variance (23.8 percent adjusted), which is statistically significant.⁽⁸⁾ Further investigation shows that income and mother's employment account for 30.4 percent of the variance and that these two variables add significantly to each other. If mother's employment is held constant, quality of life expenditure increases with family income. If family income is held constant, quality of life expenditure increases with the extent of mother's employment.⁽⁹⁾

Final analysis shows that **number of medications, family income and mother's employment** together account for 53.5 percent of the variance in **quality of life expenditure**, a statistically significant and agreeably comprehensive result for an investigation of this kind. Precisely what it might mean is not entirely obvious, but taken together with the outcome of our analysis of **condition-related expenditure** it begins to look like the beginning of the outline of an explanation.

Overall extra expenditure on children with disabilities has two major components. Firstly, there are costs directly arising from the disability (**condition-related expenditure**) which appear to be influenced, from among the factors we have examined, only by the amount of medicine required (**number of medications**) and the relative helplessness of the child, represented most effectively by the single variable **continence**. Secondly, there are costs connected with care, education and more general enhancement of the quality of life. It is clear that family circumstances play a more significant part in determining this sort of expenditure. Income and, independently of this,

whether the mother is in employment, are both influential factors. The higher their income, the more easily can parents afford a second car, a swimming pool, private schooling and other amenities. Where the mother is in employment, such expenditure may not only be more easily afforded but may be more necessary, perhaps indispensable, when it comes to arrangements for the care of the child in her absence. As well as these more or less transparent relationships, there is the more obscure influence of **number of medications**. Fairly obviously, however, this variable is important mainly insofar as it represents another factor or factors not specifically identified, perhaps aspects of the child's condition most suggestive of need or dependence. Expenditure on the enhancement of quality of life for the child or the family as a whole clearly depends in large measure on what income will permit. It seems likely, however, that it may also be influenced by perceptions of need and of how much difference it seems possible to make by spending more. Number of medications is a measure of one sort of intervention to improve the child's situation. Perhaps it also reflects, indirectly, the scope for other action. This is, of course, no more than conjecture.

INDIRECT COSTS

In a previous chapter we saw that mothers were most likely to attribute their non-participation in the work force to the fact that they had a child with a disability. However, when we try to account for variation in mothers' current participation or non-participation in the workforce it does not appear that the nature or severity of the child's disability has a particularly powerful effect. Compared with mothers who do not work somewhat fewer of the mothers who do work have children with severe difficulties. Likewise, fewer have children with severe self-care problems when compared with those who do not work, though these differences are not significant. This is an area in which the limitations of quantitative analysis are very evident. Where all that can be done is to distinguish working from non-working mothers, and part-time from full-time workers, the much more fine-grained material of interview responses is lost. How people see the meaning and purpose of the work they do, and its relationship to their own and their children's needs, is a very complex matter. To consider the work they **might** have been able to do but for their disabled children, and to assess what that

loss of opportunity has meant to them, is to face even more difficult questions.

It is certainly not simply a question of whether or not mothers work. For some who feel they must work as a matter of economic necessity, it is very much a problem of what kind of work they can find which is compatible with the child's need for care.

'When I was doing the 9-3 and because I was having appointments at the hospital I was getting called into the office and getting told off which was a shame because there was nothing much I could do about it. I felt much better when I noticed this other job come up which was night hours and weekends when Rob could take over from me. I'm much happier now because it relieves me of having to go and get into trouble and that sort of thing. No, I don't have any extra costs with the play group now. That's an expense that's gone although so has the wage, hasn't it?'

'Yes, I used to work for 10 hours a week from 5.15 to 9.15 but I could see that it was bad on Paul, and Pam was only three or four at the time and I was trying to help out. I loved it. I'd love to be in the workforce but the money wasn't worth what you had to go through and I couldn't rely on others. I lasted for 10 weeks. I couldn't work now. I'd be tired and I wouldn't have the patience and in the long term, I suppose I'm a mother at heart and I always have this vision. I'll do my thing later in life.'

The conflict between the family's need for more income to meet the costs of caring for a child and the obstacles to a mother's employment to earn that income created by the very existence of the child, is not found only in families with a disabled child. It simply shows up more starkly there. Though this study is about people who might seem to be set apart by their special problems, it would be a mistake to think of them and their difficulties as being neatly segregated from the mainstream of social life, waiting for special remedies. To a large extent their problems are the problems of all families just magnified by the strain of caring for a disabled child. This is not to belittle their difficulties or to suggest that they do not need special consideration. It is to say that if we want to understand their plight we must take account of important features of the wider society. It is not just a matter of working out how to fix things when illness, accident or genetic irregularity leave children with disabilities behind. A large part of the problem has to do with what the wider world

takes for granted. For all the anti-discrimination, equal pay and equal opportunity legislation of recent years, when it comes to the point, the almost invariable answer to the question of how to care for a disabled child is that the mother should assume full responsibility at the expense of any other potentially conflicting activity. The pervasive assumption that free female domestic labour should always be available is nowhere more obvious than it is here.

FOOTNOTES

1. $F^{10,39} = 2.41, p < .05.$

Variable names, abbreviations and correlation matrix are set out in Appendix F.

2. $F^{19,39} = 1.23, p > .25.$

3. $t^{48} = 2.65, p < .02.$

4. $CBEX = -178 + 526.7 \text{ CONT} + 174.73 \text{ NMED}$
 $F^{2,47} = 7.9, p < .001.$

5. $F^{6,43} = 1.03, p > .25.$

6. $F^{10,39} = 1.70, p > .10.$

7. $QLEX = 286.7 + 554.6 \text{ NMED}$
 $F^{4,45} = 4.32, p < .01.$

8. $F^{6,43} = 3.55, p < .01.$

9. $QLEX = -408 + 215 \text{ INC} - 673 \text{ MEMP}.$

10. $QLEX = -51218 + 220.68 \text{ INC} - 563.4 \text{ MEMP} + 581.9 \text{ NMED}.$
 $F^{3,46} = 17.8, p < .001.$

CHAPTER VIII

SUMMARY AND CONCLUSIONS

In this report I have been describing the economic impact on 50 families of caring at home for a child with a disability. In doing so I have been looking both at the extra expenditure that these families incur on this account and at the effect on the employment of the parents. The families themselves had certain distinctive characteristics: all lived in the Sydney metropolitan area; all were caring for a child between the ages of 12 and 16; all were recipients of the Handicapped Child's Allowance. But in other respects, the families were very different, genuinely representing a wide spectrum of human diversity. In some families there was only one parent; in others two. In some families, either one or both of the parents came from a non English-speaking background. The size of the families varied a great deal; so did their economic circumstances. The children on whom the study focused were also very different from one another. There were boys and girls of different ages, attending different sorts of schools. They had different types of impairment and disability and differing degrees of dependency. Above all, each parent and each child was an individual with a distinctive personality, set of values, attitudes and expectations and with a distinctive set of circumstances and needs.

It is important to recognise these differences because I have been trying to explain or account for the wide variation on the ways that the parents respond to their children's disabilities as far as their economic behaviour is concerned. Given the fact that the families I spoke to were so different from one another, I can only hope for partial success with a method which tries to interpret their behaviour in terms of arbitrarily imposed categories.

THE ECONOMIC IMPACT

The Direct Costs: Extra Expenditure

The extra expenditure of families in the year before the interview varied a great deal. The average amount for the 50 families in the sample was \$1590, but if we only include in our calculation those who actually had identifiable expenses (this is 45 of the 50 families) the amount rises to \$1766. We noted it was possible that any particular need of a child (or, indeed of a parent) could be met without any expenditure; for example, a wheelchair could be provided free of charge by the Department of Health or by a non government agency. Similarly medicines, for certain low income families, were provided at low cost. Respite care or after school child care arrangements might be provided free of charge by a relative, most commonly a grandparent or a brother or sister of the child. Thus, the fact that the family did not incur any extra expense for an item did not necessarily mean that the child's needs were not being met or that the item was forgone, or that the need did not exist, or that an additional burden was not being borne somewhere.

I have noted that the average expenditure figures conceal a very wide range of variation, both of total annual expenditure and of expenditure on particular items. Total expenses in the previous year ranged from \$9,333 to zero. In fact, median expenditure was \$860. Extremely high expenditure tended to reflect the purchase of a single major item or service; for example, a special model of car, an expensive house adaptation or piece of equipment, private school fees or child care arrangements paid for at market price.

We found it helpful to distinguish items according to whether they had been acquired to meet needs arising directly from the child's disabling condition or whether they were concerned with developmental, educational or therapeutic needs, or enhanced the quality of life of the child or the family as a whole. Merely by way of shorthand we have called items of the first type 'condition-related' and the others 'quality of life' items. We have been at pains to avoid any suggestion that one type of expenditure might be more important than the other. Parents' capacity to meet any of the needs of their child will vary according to their circumstances and their resources, as will their

perception and interpretation both of their child's needs and of how these can best be met.

We found that 'condition-related' items tended to be obtained by more of the families and to be lower in cost than items that met the other ('quality of life') needs referred to above. Whereas the average cost for families in the sample was \$946 these 'condition related' items could cost as much as \$4432 or as little as \$10 a year. On individual items in this category of expenditure there could also be a great deal of variation; a family could spend as much as \$2400 a year on prescription medicines for their child or as little as \$15 and over \$1700 or as little as \$42 a year on items bought to meet the needs of a child with incontinence. Naturally the expenditure could vary partly on account of the actual cost of the item and the amount that was bought, but we noted that it could also vary according to whether or not it was subsidised. Subsidies themselves vary. Some are selective and related to the circumstances of the family, others are universal.

The expenditure of families thus varied enormously and one task of this research has been to try to understand why. Part of the explanation lies in the types of items the children needed and their cost. We can explain some of the variation therefore by examining in some detail the actual items of expenditure of these individual families. But we have also sought to explain the variation in terms of some general characteristics of the families and to answer the question, 'Do some kinds of families spend more than others in meeting essentially the same needs?' We did not find it particularly fruitful to look at overall expenditure but when we considered 'condition-related' and 'quality of life' expenditure separately certain patterns did begin to emerge. In the case of expenditure on 'condition-related' items, we found that various aspects of the child's disability, in particular, whether the child was incontinent or needed a number of medications, seemed to make a great contribution to the variation in expenditure. On the other hand, when it came to 'quality of life' items it was family income and whether the mother worked that provided the best explanation of variability, although the number of medicines the child needed also contributed.

These findings are important because they suggest that low income families, once they have met the 'condition-related' needs of the child, are unlikely

to have surplus income to purchase 'quality of life' items; certainly less likely than the higher income families. This in turn suggests that the impact a child's disability has on the family will depend on that family's resources. Of course, this is precisely what one would intuitively expect. However, it is valuable to have this sort of intuition confirmed. And with this knowledge, one can perhaps begin to consider ways in which families might be helped more equitably to meet the needs of their disabled children. At the same time, it is important to recognise that the costs of some of the wealthier families are high too. Their expenditure is a reflection of their resources. So whilst these families have the capacity to pay, it is also at some cost to the standard of living that they might expect to enjoy were it not for the disability.

Indirect Costs: The Effect On Parental Employment

Extra expenditure is not the only economic cost likely to be measured by families who have a child with a disability. We have also looked at the effect of having a child with a disability on employment and earnings. Since the mother tends to be the main caregiver in families where there is a child with a disability we focused on the mother's labour market participation, but it is important also to consider the effect on the father's employment. One of their effects may be that the father will have to take on a second job. 'He always had to work a couple of jobs to supplement our income because I could never work.'

Not only was the proportion of working mothers in the sample lower than for mothers of teenage children in Australia as a whole but we also found that a considerably higher proportion of those in the sample were part time workers. We calculated that, as a result, household income could suffer to the extent of between \$11,700 and \$24,750 gross or \$8,944 and \$18564 net a year in the 15 families where the mother said categorically that she would work but for the disability of her child. But for the women this is not the only effect. It is clear that in some cases women felt their opportunity to have their own career had been seriously restricted as a result of their caring responsibilities. As one mother put it:

'I'd like to have studied. I'd like to have done something.
I'd like to have gone to University but my life came to an

instant halt first when my mother died when I was 12 and then to a full stop when I had Lisa.'

In other cases it was the opportunity to enhance the family's resources, to enjoy social stimuli, just to be normal, that mothers missed; indeed, sometimes craved. What prevented the mothers from working when in virtually all cases the child was attending school? For most mothers it was the very restricted hours that they could work. In the overwhelming majority of cases mothers felt that they had to be at home when the child returned from school. Of course, whereas many a mother might want to be at home when her child came home from school, in the case of the mother of a child with a disability, her reliable availability is a great deal more important and certainly weighs heavily on her. In very many cases if she knows she is going to be late she cannot just tell the child to pop next door to a neighbour; not least, because in many cases the child may lack the capacity to understand. Whereas our questionnaire focused on the child's capacity to communicate his or her needs to others, the child's capacity to receive messages from others, an area which we failed to treat, is equally important.

In addition, most mothers did not see their caring role as interchangeable with other people, either because they would not want to burden another or because they would not feel that any other person would have the appropriate skill or confidence. By the time the child has reached the age of 12, a mother has developed a high level of understanding of her child's needs and a considerable degree of competence in dealing with these. Some mothers found it difficult to 'hand over' to others. Professional child care arrangements in which the mother could have as much confidence as she had in herself were according to most mothers, simply insufficient. Occasionally child care arrangements were procured on the open market but these were far too costly for most parents. Only grandparents and siblings were, on occasion, trusted with this care role but here again, there was often a concern not to burden others. Furthermore, it should not be assumed that even a grandmother will be ready to accept the disability of her grandchild. Many a mother told me that, at the time of initial diagnosis, the problem of dealing with her mother's emotions was as great as dealing with her own. There was another reason that women sometimes did not feel able to work outside the home. This is because they knew that they were likely to be unreliable members of the

work force. Many mothers described the frailty of their child's health and the susceptibility of their child to infection and bouts of illness. They felt that they would never know when they might have to be away from work on account of their child's health or to take their child to hospital. So whilst the care of the child might not be at all times onerous, its very unpredictability makes it very restricting indeed. I found that in some cases it was not so much that a child had to be left alone that constrained the mother or indeed both parents. Rather it was a dependence born of a special kind of vulnerability. It was because of this that I found mothers acutely aware of their need to be reliable. Because they had to be particularly reliable members of the family they could not also be reliable members of the work force. And it was precisely because of this that some mothers found working in their own business, in partnership with their husbands, so convenient.

Of course even those mothers who did work could hardly, except perhaps in one case, be described as following a career path. Some of the mothers said that had it not been for the child they would have liked to get ahead, do something worthwhile, interesting. But amongst these there was undoubtedly a feeling of having 'missed the boat'. Others would not perhaps have had any such desire. As we have noted, many of the children involved in this study have made very great demands when they were younger - there was no way that their mothers, given their traditional caring role could have pursued a job, let alone a career.

Though in not all cases was the child perpetually dependent on the parent, the strong impression was that parents were often at the beck and call of the child. It was not just transporting the child to hospital, or to swimming lessons. It was that efforts to enhance the quality of life for the child inevitably placed considerable physical demands on the parents. The distances that some parents had to travel both for essential services for their children, and to maintain the companionship of school friends were huge. One of the greatest concerns expressed by parents was about the social isolation of their children. Overcoming this isolation almost inevitably places very considerable demands on the parents both in time and in energy. Even the use of respite care, though welcomed in many ways, places more demands on some parents than they feel is worthwhile in terms of the benefits they gain.

More often than not these demands were felt most sharply by mothers and although this was most certainly not always the case we should not forget how many of the parents were single and were carrying the burden alone. I have discussed this issue in some detail because I think that it is important to understand the sorts of issues that influence a mother's decision to work outside the home.

The administrative qualification for the Handicapped Child's Allowance is that the child should be in need of constant care and attention. The scale of disability that we developed did not actually explore this. It considered the severity of the child's disability in a number of areas and when we applied this scale to the sample of children we found that quite a high proportion of them (32 percent) had either no disability or only mild disability in the areas that we considered. These, though very important areas of disability and dependence, failed to identify the much more subtle interdependence of the parents and the child. This is a very difficult and important area and further work on the assessment of levels of disability and dependency might be worth pursuing, if only because there is such a clear need for these in the determination of eligibility for benefit. This work might develop further dimensions for describing disability, such as the child's behavioural problems or his or her dependency on the parents. In order to construct more detailed measures it could also be necessary to reassess the amount of information one needs to collect about any particular aspect of disability.

The effect on the father's employment is perhaps even less easy to quantify than on the mothers. Many fathers initially said that the child's disability had had no impact whatsoever on their employment. However, it quite often emerged later that the father had, at some time in the past, been offered a job in another city or state but that the parents had thought it better not to move away from a service, perhaps a school, or a medical specialist with whom they had built up a relationship and in whom they had developed a confidence. Some parents had moved from the country to Sydney to be nearer the services. But as one father said:

'Who knows what the effect of this move has been on my employment, my income? Maybe I've done better than I would have done if I'd stayed put.'

Some fathers have achieved more occupationally than they might otherwise have done, having put more effort into their working life to ensure that their child's future is protected. Some fathers may even find it easier to be at work than to be at home. That was an accusation of a few of the mothers.

'I believe when he was younger he couldn't handle the stressful situation at home so he indulged himself in work. I suppose lots of men do it. I don't blame them. I wish I could do it.'

I think that it is fair to say that in some cases, now that their child is over 12 years of age, fathers may have almost forgotten the impact of the child's disability on their employment. Certainly the greatest impact was when the child had been younger, at the stage of frequent assessment and treatment. Then the father might have accompanied the mother and the child to hospital, either out of concern or perhaps because of a greater facility with the English language or because his wife was unable to drive.

The extent to which parents shared the responsibility for the child varied enormously as did the way in which fathers performed the caring role. Frequently it was by being of necessity, the sole earner, sometimes by taking time off work to accompany the mother and child to hospital, sometimes it was by coming home from work earlier than he might otherwise have done to help with the bathing of the child or the cooking of a meal. Unquestionably, there were many fathers who could not cope with the disability of their child, who opted out in one way or another. But there were other cases in which fathers assumed very considerable responsibility. Sometimes this seemed to come as somewhat of a surprise to the wife, 'He may not always be there but I'm lucky to have him at all. A lot of women I know in my position, don't'. But there were several cases where a much more positive attitude was adopted. 'We realised right from the start that we'd only get through this, if we did it together.'

I mention these attitudes to parenting because they can significantly affect the relationship that a husband has with his job. However, another very important consideration is the nature of the job itself. Self-employed people may on the one hand, find it easier to take time away from their work, but the impact on their earnings if they do can be quite considerable,

especially in the case of a salesperson. In this context we noted that a number of mothers worked with their husbands. Whilst taking time away from the job was easier for these women than it would have been had they been an employee, it should not be assumed that it was cost free. Quite often the wife would need to be replaced by a paid employee during her absence. Fathers who were employees themselves sometimes said that their earnings had been affected as a result of having to take time off work, though the goodwill and understanding of a supervisor or employer sometimes meant that the father had suffered no loss of earnings on account of his child. But this could not, of course, be taken for granted. I gained the impression that fathers, indeed parents generally, were very anxious not to lay blame on their child for what had happened in their lives.

We have provided a far from clear cut picture of the economic impact of the child's disability on the family. The mapping of human experience does not lead to simple patterns or enable us to arrive at simple solutions. It is nevertheless clear that having a child with a disability can have a very considerable impact on families though I would argue that this does not necessarily increase with the disability of the child but is rather related to the subtle interplay of disability, and social and economic circumstances on the one hand and values, attitudes and personality on the other.

It is easiest, of course, to suggest social policies to deal with concrete problems, and this is what I shall try to do here, recognising that this is only partially satisfactory.

THE ROLE OF THE HANDICAPPED CHILD'S ALLOWANCE

The Handicapped Child's Allowance has featured as a recurrent theme in this report. This is a study of costs. The HCA is a cash benefit. The invitation to compare is more or less irresistible. However this study is not an evaluation of the HCA even though the sample is drawn from recipients of the benefit. An adequate evaluation of the HCA would clearly require a much larger sample, and would have a rather different focus from that of the present enquiry. Such an evaluation would need to pay more direct attention

to the benefit itself, rather than treating it tangentially as I have done here.

Nevertheless it is the case that a good deal of this study has implications for the HCA, which it would be irresponsible to ignore. I shall try therefore to bring out here what seem to be the main issues.

Australia is one of the relatively few countries which provide a cash benefit of this kind, which represents grounds for satisfaction, for as long as it is maintained as a realistic, fair and administratively practical benefit.

The HCA is an important benefit because, in contrast with other services, which are in short supply, it represents a regular, reliable, non competitive form of support for parents of a child with a disability; the only such help they can expect to receive. This is not to say, of course that its administration is entirely satisfactory. Here I shall outline some problems to which my research has drawn attention.

The discussion in Chapter V highlights the difficulties of arriving at consistent, reliable and equitable judgements about eligibility for the Allowance, and clearly raises questions as to what procedures, to be followed by whom, should be used for this purpose. It is clearly necessary to take into account, as our composite disability scale cannot, that some children whose apparent disabilities are limited may present at least as many difficulties of care and management as others who are more obviously disabled. Perhaps the most serious area of confusion surrounds the decision as to which applicants shall be entitled to the Allowance at the 'severe' and which at the 'substantial' level. In all cases, however, the point is that the medical diagnosis alone is unlikely to be an adequate guide. The strongly voiced opinion of some respondents was that decisions as to eligibility and level of Allowance should be based on the total needs of the family rather than on narrow consideration of the condition of the child. The often-repeated argument was that 'circumstances' should be the primary consideration. It is doubtful whether proposals along these lines would be administratively feasible, but the fact that they are expressed as they are indicates the existence of a problem widely recognised by recipients.

Thirty nine of the sample families were receiving the benefit at the 'severe' rate, the remaining 11 at the 'substantial' rate. the numbers are too small to permit a thorough comparative analysis of cases according to benefit level, but it does emerge fairly clearly that there is not a close correspondence between the severity of the children's disabilities and the level at which the Allowance is paid.

Six of the families being paid at the lower 'substantial' rate had a child with a severe disability, as assessed on our scale. More disquieting, and quite independent of our scale, is the fact that families with children whose disabilities were not discernibly different were receiving the Allowance at different levels. The parent of one of the children with asthma was receiving the Allowance at the 'severe' rate whilst the parents of another were being paid at the 'substantial' rate. One two-parent family whose child had diabetes, was receiving more than a single parent family whose child had the same complaint, though the needs of these children appeared indistinguishable.

A significant source of dissatisfaction for some parents was that they had not been told on what basis their Allowance had been calculated. This was particularly so in cases where it appeared that children who had the same disability as their own had qualified for the Allowance at a different level. Parents obviously compare notes.

Eligibility for the Allowance at the 'severe' rate is determined with reference to medical criteria. Eligibility at the 'substantial' level depends, as we have seen, not only on medical criteria but on financial criteria as well.

It seems to me that the means tested part of the Allowance for the 'substantial' level is not really workable, because it involves too many criteria, none of which can be exactly formulated and all of which relate to changeable conditions. Income, disability and expenses are all subject to fluctuation, and to be just and administratively workable a benefit needs to minimise elements that are unstable, arbitrary or ambiguous. This research demonstrates quite clearly, for one thing, the difficulty of establishing any

fair and straightforward measure of allowable costs as the basis of eligibility to benefit.

However, I asked parents their views on the eligibility criteria for the benefit. A majority of the less well-off respondents thought that the benefit should be means tested because the burden of caring for a child with a disability was proportionately heavier for poorer people than for those who are better off. But other low income parents believed that the benefit should not be means-tested because this would unjustifiably penalise those who improved their situation by their own efforts. Most, though not quite all, of the better-off parents thought that all tax payers should be entitled to the same level of benefit; and further, that the expenses of a child with a disability had as great an effect on their higher standard of living as it did on the albeit lower standard of poorer parents. I have already noted, however, that a considerable number of parents, amongst both the better and the less well-off, supported the view that the total needs and circumstances of the family should be the primary consideration determining the level at which the benefit is awarded.

I also asked parents whether, if there was to be an improvement in the level of support, they would prefer this to be in the form of financial benefits or services. Again whilst many parents could not see the justice or necessity of posing these as alternatives, there was a tendency for opinion to divide along income lines, although the division was by no means clear cut. The poorer families tended to opt for more money, because this is what they felt they most needed. But some of the less-well-off families, as well as most of the better-off, opted for better services, and when they mentioned services it was to improvements in educational and training facilities, to more advice and counselling, and to better care arrangements that they were most likely to point, in that order. However, some parents opted for more money rather than better services because, sadly, they simply did not have confidence in service providers, planners and professionals to provide the right kind of services on an adequate scale. Disillusioned with what was currently available and lacking confidence that anything better might emerge, they opted for more money so that they could buy their own, of a sort and quality that they felt could only be bought on the private market. More money would, in the view of these parents, give them the power to obtain what they wanted

rather than be obliged to take the inferior services they felt they were being offered.

Though it may seem perverse, there are good reasons for seeking to detach discussion of the HCA and what its proper level should be from the question of expenditure. The whole question of what represents 'legitimate' expenditure, which inevitably arises in this connection, can be something of a red herring. Though in the course of this report we have discussed cars and swimming pools, amongst many other things, it is perfectly clear that the HCA will never be set at such a level as to put these within the reach of many people who would not otherwise have been able to afford them. The fact is that the HCA is unlikely in many cases even to approach the true cost of providing the most basic care and services.

As in many other contexts, the whole problem has been solved by taking for granted the unpaid domestic labour of women. In occasional revealing instances, it is found necessary to pay for services which, in general, mothers are expected to provide free of charge. The most compelling illustration of this point in my sample is the case of a foster family. They receive, to begin with, the fostering allowance of \$45 p.w., in itself an extremely cheap alternative to residential care from the point of view of the state. They also, of course, receive the HCA. Both foster parents work full time in jobs significantly connected with objectives of the Department of Youth and Community Services. The Department pays for three and a half hours of care daily to cover the period between the end of school and the time at which the foster-mother can take charge again. These care services, procured at market prices, amounted to \$160 weekly. And the state still has a bargain, compared with the cost of maintaining the same child, its ward, in an institution. The child's problems, though severe, are no worse than those of many other children in the sample, whose parents receive no support beyond the HCA. I am certainly not suggesting that the Department should not be meeting these costs of fostering. On the contrary, it has a duty to do so. I am simply pointing to the striking, almost outrageous demonstration this case provides of the true, officially acknowledged, market valuation of a small part of the child care services which are routinely expected of women, at no charge. I believe that this is the kind of consideration which needs

to be held in mind when we notice that some families appear to have 'no costs'.

In view of the findings of this research, what should be the policy response to this complex pattern of costs and sometimes conflicting set of public attitudes? First, it would seem that a benefit which has been designed, if not to meet, at least to acknowledge the extra costs of disability should be doing just that and that alone. Other social security benefits, such as the Family Allowance or the Family Income Supplement should be set at a level such that those with low incomes have an adequate standard of living. This is not to make light of the needs of low income families. On the contrary it is to argue for a state of affairs in which it becomes possible for them to use the HCA for the purpose for which it was intended. Whilst it would clearly not be appropriate for me to suggest a level for the Handicapped Child's Allowance, on the basis of this small piece of research, it is surely not acceptable that the benefit should have dropped in real terms to less than two thirds of its original value. On the other hand it would almost certainly not be possible to set the benefit at a level which would enable the users of services to buy them on the open market.

It is clear from this research that poorer people are already at a disadvantage when it comes to buying goods and services which could enhance their child's quality of life and that of the family generally. To raise the level of the benefit with the intention of enabling people to buy these goods and services would probably lead to a justification for even less public provision of services than there is at present. At the same time, parents on low incomes might well need to use any extra cash they received to meet their own basic needs. They would therefore lose out in both ways. It would seem to me preferable to bring the benefit up to its original real terms level immediately, to ensure that it maintains this value and then to look to a range of other mechanisms, not necessarily cash, for helping people caring for a child at home. We shall return a little later to a consideration of these mechanisms. Meanwhile, it is important to take note of certain other features of the administration of the HCA and of the uses to which people put the benefit.

How did people hear about the Handicapped Child's Allowance? The most usual source of information was at the hospital, typically a doctor or a nurse, rather than a social worker. Friends and voluntary organisations were also important sources of information. It is a little disquieting that professionals working in community settings were sometimes sources of misinformation:

'No, I don't think that diabetics are eligible'

or,

'No, your child isn't eligible for the Allowance because she attends a normal school. I think it is better for her to go to a normal school than to receive the HCA.'

These instances of advice given by GPs make it clear that some professionals are not particularly well-informed about the Allowance and consequently not effective in bringing to the attention of parents this important source of support.

Another less than completely satisfactory aspect of the administration of the benefit was that in some cases parents were not notified in writing that it had been granted. In other cases they were not told how much they were to receive. Several parents told me that an additional amount had suddenly appeared in their bank account without prior explanation. They could only surmise, lacking any official notification, that it represented the first payment of their Allowance. Similar circumstances attended back payments or additional sums resulting from reviews of entitlement. One parent told me that she discovered that her bank account had been credited with \$1000, quite without explanation. Understandably, she felt insecure about her right to these funds until she had assured herself as to their source. There is surely good reason for the Department of Social Security, if not out of courtesy to their clients, at least as an indication of sound financial practice, to ensure that their notification of payment either precedes or at least coincides with any change in payment of the Allowance. It should not be necessary for this to result in a delay in the notification of payment.

It is of some interest to explore the question of how long an interval separated the diagnosis of each child's condition from the granting of the

Allowance. In some cases, of course, the condition was diagnosed before the introduction of the benefit in 1974, and here it is not possible to draw any inferences from the interval between diagnosis and benefit. In these cases I have simply considered the interval between 1974 and the granting of the Allowance. In other cases, however, it is fair to ask what this interval might tell us about lack of information or administrative delay. In many cases there was either no lapse of time or only a brief interval between diagnosis and the receipt of the benefit. This would be the time that the Department needed to process the claim. But in 18 cases there appears to have been a hiatus ranging from 2 to 12 years. There are reasons for treating this information with some caution. There may have been some inaccuracy of recall of the dates of diagnosis and the receipt of benefit. There may also in some cases have been a change in the level of the child's disability and hence of eligibility to benefit. Some recipients may have only become eligible since the introduction of the second, lower rate in 1977 and some have had a child with a condition that was not originally 'allowable'. Nevertheless, the results suggest grounds for some concern about the amount of benefit being lost by parents and about the need for more effective channelling of information.

How do people use the Allowance? Twenty two families put it towards general housekeeping, together with the Family Allowance. Others used it for items specifically related to the needs of their child, clothes, for instance. One single parent was using it, together with the Family Allowance, to meet the monthly payments on her car. Some parents put it into a special account in their child's name. One parent was putting it toward the purchase of a home unit, in which she hoped that it would become possible in time, as a result of her own most strenuous efforts, for her daughter to live independently. I found that lump-sum back payments were often used to buy consumer durables, not infrequently some form of home entertainment, such as a video-recorder or a larger television set, a reminder of the importance of home entertainment for families whose mobility is often very restricted.

A relationship between family income and the use to which the Allowance is put does emerge. Low income families were much more likely to put the Allowance towards general housekeeping than were middle and high income

families. A higher proportion of high income families than of middle and low income families saved the Allowance.

CONCLUSIONS

Whilst it is clear that the declared expenditure of some recipients of the Handicapped Child's Allowance is below the current level of the Allowance, in other cases it is considerably above it. This is hardly to be wondered at as one would expect a scatter, but equally important is the fact that many of the mothers were not in the labour force or only participating in a limited way on account of the disability of their child. It is clearly essential to include as a component of the cost of caring, income forgone. Some women might not have worked in any case because of their responsibility for the care of their other children; but what is relevant is the absence of a choice. The research pointed to the shortfall in appropriate and convenient child care arrangements. Education and community services simply have not taken sufficient account of the many special needs of children with disabilities, certainly not of those in the older age group.

One of the most important findings of this research is that some families are spending a great deal on items that enhance the quality of life of their child or alleviate the burden of care for themselves. These items, identified earlier, include housing adaptations, educational and developmental goods or services, and specialised transport facilities.

High income families are more likely to spend money on these items. It should be possible to devise schemes that will make at least some of the more obviously essential of these more widely available. For example, in the case of house adaptations, whilst those who live in accommodation provided by the Housing Commission had a great deal of praise for the adaptations that the Commission was prepared to make to the family home it was clear that these adaptations would be far too expensive for the majority of families in either privately owned or rented accommodation. The New South Wales Department of Housing is launching some pilot schemes which involve assisting people either directly by meeting the adaptations (this is a scheme financed through the Home and Community Care Program) or by lending people money so that they can

make the adaptations themselves. Since the loans will be more likely to be available to those who are more financially secure, it is to be hoped that the less well off will receive priority treatment with help provided through the HACC Program. This of course, leaves the private rented sector. Admittedly this is a very problematic group to help but one which perhaps needs, for just this reason, to be given special consideration.

Thus the Handicapped Child's Allowance, is not the only way of covering extra expenditure to meet the needs of children. This research has pointed to a variety of ways in which the multi-faceted needs of the child are actually being met, though often only partially: for example, from the families' own resources, its earned and unearned income and a range of services provided by its members, by financial support in the form of social security benefits, through the health service, by a range of support services provided by government and other agencies and so on. What is important is that these mechanisms are all a result of a hodge podge of social policies designed for children with disabilities and their families. How adequately do these policies meet their needs?

The International Year of Disabled People in 1981 was a landmark. It served to put a great many problems into the foreground of public attention. Both State and Commonwealth Governments displayed their readiness to meet long neglected needs, setting up special units concerned with the problems of disabled people in a number of departments.

In the light of all this, disabled people might well be seen as a priority group. Yet on visiting and interviewing the fifty families in the sample, I found little evidence that this official recognition of their problems had so far made much difference to their lives. Services remain thinly distributed, information hard to obtain. Parents still do not know where to turn when in difficulty. Reliable sources of local support are not easily found.

It must be acknowledged that many schemes of support are still too newly-developed to be assessed. There is, without any doubt, a great deal of government effort being devoted to the problems of the disabled. The question is, how to reach those by whom the support is most acutely needed?

It seems clear that there are many families whose needs are not being met by the allowance. Cash benefits, although important, are not the only way of helping people and I have suggested that the needs of the children and their families call for a flexible and generous response at the level of both financial and service support. This would be a real recognition of the role that parents are performing in the Government's 'Community Care' policy and of the help they require to perform it well.

APPENDIX A: THE SELECTION OF THE SAMPLE

The sample of families was selected from amongst the recipients of the Handicapped Child's Allowance, in 6 social security regions of Sydney: Baulkham Hills, Blacktown, Dee Why, Maroubra, Mount Druitt and Petersham.

The initial selection of families was carried out by the Department of Social Security in Sydney. The procedure adopted was that the computer masterfile of recipients was searched and as each case that met the age criterion (12-16) was found, it was selected. It was necessary to select 253 recipients of the Allowance in order to achieve the target sample size of 50 families. Within the 6 regions, the total number of families, whose disabled child was between 12 and 16, was 316. Hence, 63 families were not selected for interview.

Table 4.2 in the body of the report compares the ages and sex of the children included in the study with those of the HCA recipients in the 6 regions and in the Sydney metropolitan area. Table A.1 compares the sample families with the 253 families contacted by Department of Social Security, in respect of
1) the ages of the disabled children and
2) whether the family was in receipt of a full or partial Handicapped Child's Allowance. The populations compare reasonably well, for the two variables considered.

TABLE A.1

CHARACTERISTIC	SAMPLE % (rounded)	FAMILIES CONTACTED % (rounded)
1. Ages of children:		
12	16	25
13	32	26
14	20	21
15	26	28
16	6	*
2. In receipt of:		
1. Full Allowance	78	84
2. Partial Allowance	22	16

* Only families with a disabled child aged 12-15 were contacted by Department of Social Security. Some of the children had reached the age of 16 by the time of the interview.

Table A.2 below compares the sample families with all recipient families in the 6 regions and Sydney metropolitan area in respect of whether the family was:

- 1) a married couple or single parent and
- 2) in receipt of the full Allowance or the partial Allowance.

The table shows that a considerably higher proportion of the sample families than of the other populations were single parent and in receipt of the partial allowance.

It is regrettable that comparisons were not possible for two of the most crucial variables, namely the disabling condition of the child and the income of the family. This information was not available on the masterfile used by Department of Social Security to select the sample.

TABLE A.2

CHARACTERISTIC	SAMPLE % (rounded)	HCA RECIPIENTS IN 6 SOCIAL SECURITY REGIONS % (rounded)	HCA RECIPIENTS IN SYDNEY % (rounded)
1. Family type:			
Married Couple	76	93	94
Single Parent	24	7	6
2. In receipt of:			
Full Allowance	78	92	92
Partial Allowance	22	8	8

APPENDIX B: CONSTRUCTION OF DISABILITY SCALES

Disability scales were constructed from the parents' responses to questions about their disabled child's capacity to perform various activities. The relevant question numbers in the questionnaire are provided for each variable.

Mobility - based on questions 6 and 8

- None: Can walk as far as most children that age.
- Mild: Can walk less far than other children of that age (with or without use of aids), but can do so without help from other people and can also manage more than just a few steps.
- Moderate/Severe: Cannot walk at all, or only a few steps, or is habitually helped by others.

Communication - based on question 12

- None: Speech and communication as proficient as most children that age.
- Mild: Has no difficulty communicating with family or strangers, but communication is less proficient than other children that age.
- Moderate/Severe: Has difficulty communicating with strangers and/or family; or cannot speak at all.

Speech and hearing - based on questions 10 and 11

- None: Can see and hear as well as most children that age.
- Mild: Sight and hearing good with use of aids.
- Moderate/Severe: Poor sight or hearing; or cannot see or hear at all.

Basic Self-Care - based on questions 23, 24 and 25.

The level assigned is the highest level of disability recorded for any of three tasks: eating, dressing or bathing. The level for each of these is determined by the following categories:

- None: Child needs no assistance with the task.
- Mild: Some assistance needed with the task.
- Moderate/Severe: A great deal of assistance needed with the task.

Toileting and Nursing Care - based on questions 27 and 31.

The level assigned is the highest level of disability recorded for toileting or nursing care needs. The level for each of these was determined by the following categories:

None: No assistance needed.
Mild: Some assistance needed.
Moderate/Severe: A great deal of assistance needed.
Supervision - based on questions 33 and 42.

None: Child can be left alone for as long as most child that age.
Mild: Can't be left alone for as long as most children that age. However, Mother can be away from the house for more than an hour without needing to leave the child in the care of another responsible person.
Moderate/Severe: Mother can't leave the house for more than an hour without needing to leave the child in responsible care.

Maximum Disability: The level assigned is the highest level of disability recorded for any one of the disability variables: basic self-care; toileting and nursing care; supervision; mobility; communication; speech and hearing (all variables described above). Levels are:

- . None
- . Mild
- . Moderate/Severe

APPENDIX C: ITEMS GROUPED ACCORDING TO TYPE OF EXPENDITURE

EXPENDITURE GROUP	ITEM
I. Items arising directly from the child's disabling condition or condition - related expenditure	Special foods Incontinence Special shoes Special bedding Travel to GP GP consultation Travel cost for regular hospital consultations Inpatient costs (including travel) Medical and paramedical consultancies Health insurance Prescription medicines Non-prescription medicines, lotions, creams etc. Medical equipment Other therapy Mobility aids
2. Transport	Car
3. Education	School fees Transport to school Extra lessons Educational and communication equipment Outings Courses, training, seminars for parents Travel overseas Independence training Special catch up lessons
4. Care Arrangements	Respite care at home Respite care away from home Childcare in school holidays and after school Care in school holidays, camps etc. Home care, help in the home
5. Aids, adaptations and accommodation	Adaptions to house Heating and Air conditioning Independence aids Kitchen appliances Running costs (medical equipment, air conditioning etc.)
6. Miscellaneous	Legal fees Subscriptions, membership fees

**APPENDIX D: ITEMS GROUPED ACCORDING TO REGULARITY OF
EXPENDITURE**

EXPENDITURE GROUP	ITEM
I. Regular recurrent (expenditure) last year	Special foods Incontinence Travel Costs for regular hospital consultations Medical or paramedical consultancies Other therapy Health insurance Prescription Medicines Non prescription medicines, lotions etc. Transport to school Extra lessons Home care, help in house Childcare in school holidays and after school Subscriptions, membership fees School fees
II. Irregular recurrent (expenditure) last year	Special shoes Travel to GP GP consultation Inpatient costs (including travel) Respite care outside home Respite care at home Care in school holidays, camps etc. Independence training Special catch-up lessons Running costs (medical equipment, air conditioning etc.) Special bedding Outings Travel overseas Legal fees Courses, training, seminars for parents
III. Expenditure on consumer durables and capital expenditure last year	Car Educational and communication equipment Adaptions to house Mobility aids Independence aids Kitchen appliances Heating, air conditioning Medical equipment

IV. Expenditure on consumer
durables and capital
expenditure before last year

Washing, drying appliances (washing
machine)
Washing, drying appliances (drier)
Car
Educational and communication equipment
Adaptions to house
Mobility aids
Independence aids
Special furniture
Repairs
Heating, air conditioning
Medical equipment
Moving house

APPENDIX E: DESCRIPTION OF VARIABLES USED IN CHAPTER VII

Income: Levels⁺^{*} were calculated from question 59 and refer to gross family income. They were constructed to form a tripartite division of the sample i.e., low corresponds to the third of the sample with the lowest income, medium to the middle third, and so on. In dollar terms, the levels are:

+	Low = \$0 - 13,000	* Income Group 0-18
	Medium = 13,001 - 26,000	
	High = 26,001 +	

Family Type⁺^{*}: Based on question 1. Indicates whether child is currently being raised by a single parent, or a married couple (or equivalently are living together as married). Categories are:

1. Single parent
2. Married couple

Place of Birth⁺^{*}: Based on question 1b. Distinguishes between respondents in terms of whether they were born in predominantly English-speaking, or non-English-speaking countries. Categories are:

1. Both parents born in English-speaking country
2. One parent born in English-speaking country
3. Neither parent born in English-speaking country

Mother's Employment⁺^{*}: Based on question 1. Refers to employment status at the time of interview, as reported by the mother. Categories are:

1. Employed full-time
2. Employed part-time
3. Neither of the above

Number of Dependent Children⁺^{*}: Excludes the disabled child. This variable records the number of other household members who are younger than eighteen and not currently in full-time or part-time employment. Categories are:

1. None
2. One
3. Two or more

Dependent on government cash benefits:^{*}

1. Family totally dependent
2. Family not totally dependent

Age of Child with Disability⁺*: Disabled Child's age, as reported at the interview. Categories are:

12 years
13 years
14 years
15 years
16 years

Mobility problem⁺* (already described in 'Construction of Disability Scales'): Based on questions 6 and 8. Mother's assessment of disabled child's capacity to walk:

None: Can walk as far as most children that age
Mild: Can walk less far than other children of that age (with or without use of aids), but can do so without help from other people and can also manage more than just a few steps
Moderate/Severe: Cannot walk at all, or only a few steps, or is habitually helped by others.

Continence⁺*: Based on questions 67 and 68. A child is classified as incontinent if s/he does not have complete control over his/her bowels or bladder. Categories are:

. continent
. incontinent

Toileting problem⁺*: Based on question 27. Refers to level of child's need for assistance with toileting:

None: Child needs no assistance with the task
Mild: Some assistance needed
Moderate/Severe: A great deal of assistance needed.

Self-care problem⁺* (already described as 'basic self-care' in 'Construction of Disability Scales'): Based on questions 23, 24 and 25. The level assigned is the highest level of disability recorded for any of three tasks: eating, dressing or bathing. The level for each is determined by the categories:

None: Child needs no assistance with the task
Mild: Some assistance needed
Moderate/Severe: A great deal of assistance needed with the task.

Speech and Communication problem⁺* (already described as 'communication' in 'Construction of Disability Scales'). Based on question 12. Refers to the child's perceived ability to speak and communicate:

- None: Speech and communication as proficient as most children that age.
- Mild: Has no difficulty communicating with family or strangers, but communication is less proficient than other children that age.
- Moderate/Severe: Has difficulty communicating with strangers and/or family; or cannot speak at all.

Need for Supervision⁺* (already described as 'surveillance' in 'Construction of disability Scales'): Based on question 33 and 42. Refers to the period the disabled child can be left alone without responsible care. Levels are:

- None: Child can be left alone for as long as most children that age
- Mild: Child can't be left alone for as long as most children that age. However, the mother can be away from the house for more than an hour without needing to leave the child in the care of another responsible person.
- Moderate/Severe: Mother can't leave the house for as long as an hour without needing to leave the child in responsible care.

Need for Nursing Care⁺: Based on question 31. Refers to the level of child's need for assistance with nursing care tasks. Levels are:

- None: Child needs no assistance
- Mild: Some assistance needed
- Moderate/Severe: A great deal of assistance needed

Number of Prescribed Medicines⁺*: Based on question 32. Describes the number of different medicines prescribed for the child by a doctor. Categories are:

- 0 types of medicine
- 1 types of medicine
- 2 types of medicine
- 3+ types of medicine

Intellectual Disability⁺*: An assessment of the child's intellectual functioning made independently by two clinical practitioners from mother's response. Levels are:

- | | | |
|---|---------------------------|---------------|
| + | . No/mild problem | * Normal 1 |
| | . Moderate/severe problem | Mild MR 2 |
| | | Moderate MR 3 |
| | | Severe MR 4 |
| | | Profound MR 5 |

Maximum Disability^{*} (already described in 'Construction of Disability Scales'). The level assigned is the highest level of disability recorded for any one of the disability variables: basic self-care; toileting and

nursing care; surveillance; mobility; communication; speech and hearing (for a description of these variables refer to 'Construction of Disability Scales'). Levels are:

- . None
- . Mild
- . Moderate/Severe

Improvement in Condition^{*}: Based on question 4a. Describes whether the child's disabling condition has improved or not since it was first discovered. Categories are:

- . Improved
- . Worsened
- . Stable

Problems with Eating^{*}: Based on question 24. Describes the help needed by the child at mealtimes. Categories are:

- None: No assistance needed
- Mild: Some assistance is needed
- Moderate/Severe: A great deal of assistance needed, or has to be fed by someone else.

Problems with Bathing^{*}: Based on question 25. Describes the help needed by the child in bathing and showering. Categories are:

- None: No assistance needed
- Mild: Some assistance needed
- Moderate/Severe: A great deal of assistance needed, or has to be bathed/showered by someone else.

Problems with Dressing^{*}: Based on question 23. Describes the help needed by the child when dressing. Categories are:

- None: No assistance needed
- Mild: Some assistance needed
- Moderate/Severe: A great deal of assistance needed, or has to be dressed by someone else.

+ variables used in Tables 7.1A, 7.1B, 7.2A, 7.2B.

* variables used in multiple regression.

APPENDIX F: INTERCORRELATIONS OF 2 EXPENDITURE VARIABLES 6 FAMILY VARIABLES AND
14 CHILD/DIAGNOSTIC VARIABLES

	QLEX	CREX	NCH	SPAR	MEMP	NENG	INC	BEN	AMB	CONT	TLT	DRES	MEAL	BATH	CARE	SPCH	TIME	NMED	INT	COND	AGE
CREX	0.299																				
NCH	0.111	-0.165																			
SPAR	0.181	-0.031	0.020																		
MEMP	0.007	0.120	-0.127	0.111																	
NENG	-0.258	-0.116	-0.203	-0.705	-0.148																
INC	0.491	0.146	0.027	0.530	0.463	-0.530															
BEN	0.325	0.174	-0.012	0.585	0.451	-0.501	0.766														
AMB	0.360	0.415	-0.108	-0.107	-0.117	0.080	0.045	-0.054													
CONT	0.169	0.450	-0.057	-0.085	-0.009	0.038	-0.098	-0.013	0.552												
TLT	0.223	0.412	-0.171	-0.082	0.064	0.035	0.131	-0.007	0.709	0.768											
DRES	0.362	0.300	-0.108	0.197	0.027	-0.204	0.331	0.158	0.635	0.491	0.759										
MEAL	0.370	0.400	0.130	0.122	-0.076	-0.157	0.195	0.120	0.669	0.524	0.581	0.757									
BATH	0.287	0.194	-0.177	0.132	-0.025	-0.112	0.265	0.080	0.721	0.442	0.699	0.801	0.612								
CARE	0.302	0.230	-0.117	0.165	-0.036	-0.136	0.253	0.115	0.754	0.501	0.716	0.876	0.770	0.958							
SPCH	0.207	0.095	-0.083	0.219	0.040	-0.074	0.239	0.260	0.303	0.353	0.381	0.533	0.562	0.491	0.563						
TIME	-0.033	-0.058	-0.002	-0.093	0.171	0.075	0.106	0.097	-0.300	-0.409	-0.367	-0.385	-0.337	-0.409	-0.427	-0.596					
NMED	0.461	0.358	0.050	-0.028	-0.110	-0.174	-0.076	0.044	0.288	0.322	0.258	0.275	0.333	0.162	0.210	0.048	-0.130				
INT	0.235	0.145	0.012	0.186	0.063	-0.135	0.295	0.244	0.328	0.349	0.386	0.588	0.591	0.489	0.571	0.720	-0.484	0.074			
COND	0.280	-0.024	0.142	0.114	-0.126	-0.064	-0.028	-0.202	0.137	0.145	0.197	0.119	0.101	0.133	0.106	-0.215	0.070	0.206	-0.308		
AGE	-0.195	-0.198	-0.180	-0.080	-0.108	0.164	-0.269	-0.271	-0.076	-0.055	-0.085	-0.160	-0.236	-0.163	-0.212	-0.124	0.158	-0.022	-0.174	0.109	
DISAB	0.083	0.049	-0.110	0.067	-0.204	0.014	-0.028	-0.199	0.375	0.290	0.326	0.365	0.283	0.414	0.436	0.407	-0.675	-0.014	0.368	0.071	0.071

KEY:

QLEX	'Quality of life' expenditure	DRES	Dressing
CREX	Condition-related expenditure	MEAL	Eating
NCH	Number of Children	BATH	Bathing
SPAR	Number of parents	CARE	Self-care (composite variable)
MEMP	Mother's employment	SPCH	Speech Communication
NENG	Parents birthplace (English-/Non-English speaking)	TIME	Need for Supervision (how long can be left)
INC	Family Income	NMED	Number of prescribed medications
BEN	Dependent of benefits	INT	Intellectual level
AMB	Mobility	COND	Condition improving?
CONT	Continence	AGE	Age of child
TLT	Help with toilet	DISAB	Disability level (Composite measure)

Definitions of these variables will be found in Appendix E.

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