

The Extra Costs of Participation in Work, Education or Training for People with Disabilities: An Exploratory Study

Author:

Graham, Sara; Stapleton, Clare

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by

Sara Graham and Clare Stapleton



Social Policy Research Centre

THE UNIVERSITY OF NEW SOUTH WALES
P.O. BOX 1 • KENSINGTON • NEW SOUTH WALES • AUSTRALIA • 2033

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Social Policy Research Centre
The University of New South Wales
P O Box 1 · Kensington · NSW · 2033 · Australia

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FOREWORD

This report describes a study undertaken by Sara Graham and Clare Stapleton, and is the second to be concerned with the important issue of the extra costs incurred by people with disabilities. The first study focused on the extra costs borne by families who have a child with a disability. That study is described in SWRC Reports and Proceedings No. 68, 'The Extra Costs Borne by Families Who Have a Child with a Disability', which was published in September 1987.

Both studies have been similar in design. They have been small, exploratory and locally based and have sought not so much to yield generalisable findings as to provide useful insights and a detailed examination of the issues involved, illustrated with considerable anecdotal material. In addition, both studies indicate the problems associated with undertaking rigorous research in this complex and important area of social policy.

The study described in this report was commissioned by the Department of Social Security. Its impetus arose from the Social Security Review's recommendations for reform of that part of the social security system concerned with income support for people of working age who are sick or who have disabilities. One of the recommendations of the review was for a Disability Allowance which would provide a recognition of the additional costs which people with disabilities have to meet if they are to participate in the life of the general community; for example in paid employment, further education and training. This study provides a detailed examination of the extra costs incurred in participation in these activities and attempts to explain their variation. It also draws attention to some of the methodological issues involved and would, it is hoped, be a useful precursor to any larger study which might be undertaken in this important area.

Peter Saunders
Director
Social Policy Research Centre

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CHAPTER I

INTRODUCTION

POLICY BACKGROUND

People with disabilities have come increasingly to expect that they should have the opportunity to participate as fully and autonomously as possible in social and economic life. There is a growing recognition in the wider society, and on the part of government, that there should be a sustained effort to remove obstacles that have hitherto restricted the access of people with disabilities to key areas of activity and, more positively, that there should be efforts to encourage and facilitate their participation. The present study reflects this recognition.

The initial impetus for this study of the extra costs borne by adults who have disabilities came from the Department of Social Security (DSS) and from the Social Security Review's recommendations for reform of that part of the social security system concerned with income support for people of working age who are sick or who have disabilities.

These recommendations are described in the Social Security Review's Issues Paper No. 5 *Towards Enabling Policies: Income Support for People with Disabilities* (Cass et. al., 1988). As the authors note

A major focus of this paper is on the development of enabling policies which will provide encouragement and support for people with disabilities to realise their potential for employment, education and training and participation in other major activities of adult life. Underlying this is a fundamental concern with the adequacy and incentive effects (our emphasis) of income support arrangements for people whose capacity for employment is restricted either by sickness or by a physical, intellectual or psychiatric disability.

The review paper raises a number of questions. Some of these relate to the eligibility criteria for income support measures for sick and disabled people. Others address such inter-related questions as the adequacy of benefits, the special needs of particular groups, the incentive effects of provision on participation in employment, education and training and other community activities, and the additional costs incurred by people with disabilities who participate in these activities.

This last question, which is the one most directly relevant to the present study, called for an evaluation of the possible role of an allowance provided in recognition of the additional costs which people with disabilities have to meet if they are to participate in the life of the general community; for example, in paid employment, further education and training, parenting, caring, volunteering or other community activities.

One of the recommendations in Issues Paper No. 5 relates to this question. It is for a disability allowance which recognises first that participation in certain activities may involve extra expense for people with disabilities and second that the additional costs incurred on account of disability may limit such participation. The purpose of the proposed allowance would be to augment the incomes of people with disabilities who are of working age, who have a designated level of impairment likely to persist into the foreseeable future and who participate in education, training, job search, employment, community activities or household work and child care or care of relatives. The Issues Paper recommends that the allowance be non-income tested, non-taxable and set initially at \$20 a week, with staged increases to be made over a three year period culminating in indexation of the payment.

It was recognised that further work was needed to establish 'benchmarks' for an appropriate level of payment and it is to this need that the study described here is addressed. Before proceeding to an account of the study it will perhaps be helpful to clarify some of the concepts that may be implicit in the notion of a disability allowance. It is worth pointing out at the outset that the disability allowance was not proposed in order to compensate people for their extra costs. A flat rate benefit as proposed, obviously would not achieve this, since people's costs vary considerably. It is really only possible to provide just and adequate compensation for measurable costs, and even economic costs, let alone those which are social, emotional or physical, can be extraordinarily difficult to quantify. However, the allowance was conceived as having the less precise and ambitious objective of recognising the additional costs. Recognition is, of

course, a relative notion. Clearly, at the conceptual level, the adequacy of recognition will depend on the relationship between the amount at which the allowance is set and the amount of extra financial cost incurred. For the person whose extra expenses are below \$20 a week, the allowance would represent substantial recognition. For a person whose extra financial costs are say \$100 a week, an allowance set at \$20 a week might seem less significant.

The disability allowance was conceived as part of a total package that would provide encouragement and support for people with disabilities to realise their potential in the life of the community. This introduces the notion of the allowance as an incentive, a measure that might help to overcome, at the very least, the economic barriers to participation. The extent to which additional costs constitute a barrier is likely to depend, in some measure at least, on the relationship between the costs of participation and the resources of the person who is meeting them. But the situation is complicated by the existence of publicly funded forms of assistance which under certain conditions are available to people with disabilities. If their income-level determines the amount of assistance to which they are entitled, employment is likely to reduce or eliminate their eligibility. The financial disincentive effect of participation is therefore the sum of the extra expenditure involved in participation and the value of any lost entitlement to publicly funded assistance. In a recent report undertaken for The Government Insurance Office (GIO) of NSW (Cuff Consultants, 1988), which looks in some detail at the barriers to participation, it was estimated that the annual PAYE earnings needed to cover the loss of social security and other welfare provision which would be forgone on account of entry to full-time work were \$18,600. This calculation assumes a single person with a low level of quadriplegia living alone and requiring no attendant care. Unless such a person could earn at least \$18,600 it would not be worthwhile, in financial terms, for him or her to work. The example illustrates one of the problems of assessing obstacles to employment. Since the eligibility criteria for most forms of public assistance involve reference both to level of disability and to income level it follows that the amount of public assistance at stake will vary according to an individual's circumstances. In general, it seems likely that the more disability-related items are required, the greater will be the disincentive to participate, because of the greater potential loss from publicly funded assistance.

Our research design did not allow us to assess the extent to which additional economic costs represented an obstacle to participation because our sample did not include people who were not participating. Nor was it within our specific terms of reference to examine these obstacles. In fact, since everyone we spoke to was participating either in paid employment or in education and training (it was on the basis of their participation that members of our sample were selected in the first place) we must presume that they had surmounted all relevant obstacles. We should not assume however that this was accomplished without cost in the broader sense or, equally important, without compromise. However, our study did help to identify the range of obstacles people encountered in the process of participation as well as the costs they and others were meeting to make their participation possible.

The people in our sample naturally exhibited a wide range of disability histories. Some had their disability from birth or early childhood. In some such cases the condition was stable, in some it was deteriorating, in others it was intermittent. Some members of the sample had experienced a traumatic accident and had returned to the workforce in vastly changed circumstances after a period of absence. In some cases the disability was accompanied by poor health; in others not. In some cases the condition was well controlled medically, in others less so. Naturally these factors have a crucial influence on occupational histories, and questions of cost will assume quite different degrees of importance according to circumstances. A recent small study of Invalid Pensioners who had returned to work (the only Australian study of which we are aware that deals with workforce participation of people who are disabled) looks at the factors prompting their re-entry (Newey, 1987). Financial considerations were given the greatest importance by the people interviewed, but a preference for working as opposed to being at home was also cited as an important reason. The interesting question, as to what differentiates those who do participate from those who do not, even when their medical problems appear similar, could not be explored in our study.

Another matter requiring clarification has to do with the meaning of the term 'costs'. There is a strong suggestion in Issues Paper No. 5 that the term 'extra costs' is intended to refer to the tangible items of expenditure incurred by people with disabilities, or by others on their behalf. The examples offered in Issues Paper No. 5 all pertain to 'direct' costs which are clearly of a kind which can most readily be quantified. However, if one is considering costs as barriers one must surely expand this definition to include the wide range of other 'indirect' or opportunity costs encountered by people with disabilities, and possibly also by their caregivers: effects on earnings or work opportunities, for example. These may be related either to the nature of the impairment itself and to any associated health problems, or to the social and physical environment which will have to be confronted in the process of participation. Very commonly it is the interaction between the impairment and social and physical environment which constitutes the real barrier to participation. Employers and work colleagues may not understand or not accept the

behaviours of people with psychiatric illnesses. An office building may be inaccessible to a person with a physical impairment.

These questions are raised here because it seems just as important to clarify the issues raised by the proposal for a disability allowance as it is to deal directly with the issues which our data enable us to address.

The study we were commissioned by the DSS to undertake was intended to inform discussion of the proposed disability allowance by examining the economic costs associated with participation in the activities in question. It was decided in the early stage of consultation with the DSS to focus on participation in work, education and training and parenting. During the planning stage, however, it was agreed that the study would concentrate more specifically on employment, education and training and omit parenting.¹ It was, in fact, proving difficult to access a random sample of married parents with disabilities.

The Department was interested in obtaining the results as quickly as possible and their timetable necessitated a small scale study of limited scope, particularly in geographical terms. In some respects the need to confine the study in this way was unfortunate, because of regional variations in respect of those types of provision which are likely to affect costs and expenditure. For example the local availability of appropriate work will affect both the extent of participation in the workforce and the costs, particularly those of the journey to work. Publicly funded forms of support can make a considerable difference to the costs incurred and thereby to an individual's capacity to participate. The availability of support services is patchy, there can be considerable problems of access, especially in rural areas and there are also important local variations in the application and interpretation of eligibility criteria for these. Whilst the effect of some local variations emerged in the study (Sydney Metropolitan Area is, after all, large and heterogeneous) it might have been useful to have extended the study to cover a wider range of area types, including for example, a rural area and a small town. Though systematic comparisons between areas are always difficult unless sample sizes are relatively large, at the broad level of analysis such comparisons can throw light on significant differences.

However, quite apart from the timescale imposed by the DSS requirements, there were other good reasons for not embarking at this stage on a large study even though such a study might have provided more reliable and definitive information on extra costs. It is, of course, a quite usual and appropriate practice for a large quantitative study to be preceded by a smaller exploratory piece of research which draws out some of the methodological and conceptual issues and guides the design of the larger study. Some of the exploratory work can be undertaken by means of a literature review but since each study is likely to have unique objectives it is usually also necessary to undertake some of this work in the field.

There is no need to defend or excuse the exploratory character or the scale of the study described but the reader needs to remain aware of its limitations. Whilst its findings can contribute to a policy debate it provides an inadequate basis for anything more. Later in the report we shall be discussing the lessons learned from this study which we hope will contribute to the design of a larger investigation.

RESEARCH ISSUES

Community care policies make the study of costs of disability a very pertinent area for research. To assist in the formulation of effective and responsive policies it is important to have answers to certain questions. What are the needs of people with disabilities and of those who care for them? How are these needs met and what determines which needs are met and how? What kinds of costs are incurred and how much expenditure do they entail? What impact do the costs of disability have on the individual and family standard of living? How is this cost shared within the family and as between the family and the wider community? Despite the relevance of these questions for policy formulation the study of the costs of disability is largely untrodden ground at present and we are not aware of any Australian studies specifically concerned with the extra costs of participation in the community. There is, however, a

1. In fact, the sample included 5 lone parents because the decision to exclude parents was taken after the selection of the sample.

small but helpful research literature on broader aspects of the extra costs of disability. This literature, together with some from overseas, has been summarised in two reviews. Evelyn Ogren and John Lauricella (1983) reviewed the research literature on the costs of disability for ACROD and Richard Mathews (Mathews, unpublished) has more recently reviewed and summarised the Australian and relevant British research literature in this area.

It would appear that the literature has two broad interests. The first is to report on the extra costs of disability. The data from which estimates of extra costs are derived are usually drawn from quite small, locally-based samples. Some are confined to a limited number of impairment categories or to particular groups in the population; for example, children or family carers. Despite these limitations they have emerged with average figures of extra costs from which either their authors or others may be tempted to draw conclusions about the population generally. As we have noted elsewhere:

These studies are useful because they represent different, independent attempts at the study of a complex topic. They would have been rather more useful if they had indicated what methodological lessons about the investigation could be learnt from their attempts; for example, what type of enquiry is most likely to be of practical value, how the research could have been improved and what were its pitfalls. Instead of providing an average cost ... 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 particular 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. (Graham, 1987, p. 7)

Whilst our study shared many of the limitations of some of those that we refer to above it did at least have a reasonably reliable sampling base, the respondents were selected at random, it dealt in detail with the various dimensions of costs and with the variations in these and it is unequivocally exploratory.

The second concern of the research literature has been with suggesting ways in which one might go about collecting good data and with the conceptual and methodological issues involved. Consideration of these guided the design of our study of costs:

- a) **Defining 'extra cost'.** In most studies extra costs refers to those costs incurred by or on behalf of a person with a disability which would not otherwise have been incurred but for the disability. In our study, which was concerned with participation, the term included extra costs as defined above, but also took account of costs which would not otherwise have been incurred but for the participation, including cash and services forgone as a result. Costs are usually differentiated according to whether they are economic or social, emotional, or affecting mental or physical health. Our study was confined to economic costs but took note of costs of other kinds to which one cannot attach a monetary value. Even those to which a monetary value can in principle be attached are not always easy to specify, however. This is partly a matter of the evidence on which we must rely, but it is also a matter of definition.

The concept of 'extra costs' is potentially ambiguous. Having a disability is very likely to impose significant financial outlays on the people affected, or on those who accept responsibility for their care and maintenance, including the State, of course. These costs, to begin with, are likely to be 'extra' in the sense of amounting to more than would have had to be paid in the absence of disability. Able-bodied people do not need wheelchairs, guide dogs, prostheses, special modifications to their houses and cars or any other form of physical aid necessary to put people with disabilities in a position to take part in everyday life. The cost of readily identifiable items such as these is clearly 'extra'. It is an expense directly connected with the disability, for which there would have been no need in the absence of the disability. For the most part, too, it is an expense to which no able-bodied person would be tempted by way of self-indulgence. Expenditure on items of this kind represents an incontestable, hard-core instance of 'extra cost'.

Beyond these very tangible, hard-core instances, however, there are other kinds of expense which can be associated with disability, which may be undertaken with the objective of alleviating risk or distress associated with disability, but which can also be undertaken by people without disabilities for quite other reasons. People with disabilities sometimes need air-conditioning or central heating specifically because of their condition. At

the same time a great many other people use these things too, and regard them simply as desirable domestic amenities. They are not specially designed for people with disabilities, and most people with disabilities find them desirable (or not) for just the same reasons as other people do, using them neither more nor less. They can only be regarded as an 'extra cost' in circumstances where they are demonstrably necessary for the management of a specific disability, such as an hyperallergic condition, and would not have been bought but for the disability.

A second area of ambiguity arises in connection with the concept of 'extra costs of participation'. Consider those additional expenses which people with disabilities incur in order to take part in employment or education and training. Some of these are costs which they have to meet in much the same way as people without disabilities. Such costs as those for travel, tools of trade, or uniforms and protective clothing fall on people with and without disabilities alike. They are not costs which have only been incurred because of disability. In another sense however, though they may in no way be specific to any disability, they are nevertheless 'extra costs' which people with disabilities must face before they can participate in work or training. If we are concerned about the deterrent or disincentive effect of the expense associated with employment or training, these must surely be taken into account. Less ambiguously, in many cases expenses of this kind are in fact higher for people with disabilities than they are for the able-bodied. People whose disabilities make it impossible for them to use public transport may find that travel to work is only possible by taxi, for example. Or they may be obliged to drive to work each day in an expensively modified car. These represent 'extra costs' in both senses: (a) as being additional expenses necessary to enable the person with a disability to work or study; (b) as being greater than the expense that would be incurred by an able-bodied person for the same purpose.

But consider again the case of the 'hard-core' extra costs, above. Aren't these expenses, which would have been incurred in any case, regardless of plans for employment or education, a sort of general, base-line cost of disability? Wouldn't it be more accurate to conceive of the extra costs of participation as consisting only of those which are incurred in addition to these base-line costs? The argument has a certain force, at first glance. But we have to be careful. People with quadriplegia need wheelchairs whether they work, study or stay at home. The cost of wheelchairs might seem, then, to be part of the basic costs of disability, and in no sense part of the extra cost of participation. But what if wheelchairs are available free of charge to those who earn no income while they become a heavy charge on the resources of those who are in work? They are a prerequisite of participation, they are undoubtedly an extra cost of disability, and they become an expense because their owners enter employment. This begins to look very much like an extra cost of participation, however basic an all-purpose item the wheelchair might be. The point is that 'extra costs' are not quite as self-evident as may at first appear.

The following schematic representation may help to clarify the issues

Expenditure according to work and disability status *

	Not Working	Working
No disability	E1	E2
Disability	E3	E4

* A corresponding table relating to education and training is implied.

The expenditures of which we have direct evidence from this study are included in E4. Those in E3 can to some extent be inferred from our survey questions about the general costs of disability but a more comprehensive investigation would certainly be needed to cover people with disabilities who are not working.

We should then have direct evidence of E3. Costs represented by E1 and E2 are not covered at all by our survey, though some information on the cost of participating in the workforce is available from other sources.²

This study is mainly concerned with differences between E4 and E3, that is, with the difference between the expenditure of people with disabilities who are working and the expenditure of people with disabilities who are not. The question of the difference between E4 and E2, that is, between the expenditures of working people with and without disabilities respectively is also significant although we have argued against this rather narrow conception of 'extra cost'. The whole question of how much less people might have been spending had they not had disabilities is entirely hypothetical, perhaps relevant in the legal area where questions of compensation are decided, but hardly in the everyday world where people themselves decide whether or not to join the workforce. There the appropriate contrast to emphasise is that between staying at home and going to work, particularly if a major concern is one of incentive.

- b) **Classifying costs.** Costs have been classified in a variety of ways. In economics, a distinction is usually drawn between those costs which are direct and those costs which are indirect. Direct costs are defined as those for which there is an observable, monetary payment. Indirect costs, on the other hand, are costs which, because they involve no market transaction, have no observable associated monetary value. But despite this, indirect costs are an important element of total costs and must be incorporated into any comprehensive cost calculus. Often, the most important indirect cost component is that associated with the earnings foregone as a result of not being able to participate in paid work activity.

In this study, direct costs represent expenditure on goods or services required to meet the special needs of the disability. Indirect costs are defined to take the form of income forgone on account of disability, either by the disabled person or by that person's caregiver(s). There is broad agreement that the direct costs, though their measurement is not without difficulty, present fewer problems of quantification than indirect costs. Direct costs are normally classified according to whether they are recurrent (which can mean either that they are incurred on a regular basis or that they meet on-going or continuing needs) or non-recurrent, occasional or 'one off' expenditure (which usually, but not necessarily, involves large sums of money). It is important to emphasise that this distinction depends upon the frequency with which costs are borne, rather than the frequency with which the goods or services purchased with that money are used. Goods and services may be consumed on a regular basis but may or may not be acquired or paid for regularly. Alternatively, single items may be paid for in regular instalments over an extended period. Furthermore, recurrent costs can flow from non-recurrent costs; for example, power-driven wheelchairs will need batteries from time to time, air-conditioners and heaters mean regular power bills, and so on. The considerable effort put in to the quantification and classification of costs in this study should not detract from the fact that there are also benefits associated with each of those costs. As with costs, the benefits may be direct or indirect, and private or social in impact. That this study does not deal with the quantification of benefits does not imply that these do not exist. To provide an economic evaluation of the issues addressed in this study obviously requires account to be taken of both costs and benefits. This however, is a difficult and far more ambitious exercise than that attempted here. Identification and quantification of costs alone is, however, an important element in that broader exercise.

- c) **Quantifying direct costs.** This presents considerable difficulty. First there is the problem of accurate recall of amounts of expenditure. It is usually argued that the use of expenditure diaries to record expenditure as it occurs is preferable to reliance on memory. Another problem relates to the estimation of normal expenditure for example, on telephone, fuel, clothes, the running costs of a car, kitchen equipment and appliances, which may have increased as a result of disability. In these cases, it will be necessary to apportion the overall expenditure between that which is disability-related and that which would have been incurred in any case. Whilst if asked, survey respondents may well be prepared to provide such a breakdown, it may not be an accurate one. A comparison of the expenditures of matched groups of families with and without a disabled member may partially overcome this difficulty but in our view it would be naive to suppose that for many

2. For example, the Social Policy Research Unit's comparison of poverty lines for those income units where the head is in work and out of work.

items the amount of disability-related expenditure will, in any circumstances, be anything more than an approximation.

- d) **Determining who bears the cost.** This will involve the apportionment of costs, both direct and indirect, between the individual with the disability, members of his or her family, co-resident and other, the wider social network and the community through which statutory and other cash and service provision is channelled. Disentangling how payments are made and how resources are transferred is an important and complex task in research of this kind.
- e) **Establishing the determinants of direct and indirect costs.** One approach has been to examine cost in terms of its relationship to the nature of the impairment or to levels of dependence on both personal and medical care. This calls for the use of valid and reliable scales of dependency which need to be built into the design of the study. Another important explanation of expenditure has been the level of income. Whilst many studies have shown that people with disabilities, overall, are poorer than the population generally, (Henderson, 1975) it is unclear whether needs arising from impairment are neglected on account of inadequate resources or whether there is a tendency to divert resources from other expenditures to meet the requirements of the disability. The effect of disability on overall consumption, standard of living and quality of life is therefore an important issue.

All the above considerations have played a substantial part in the design of our study. We do not claim to have resolved any of these quite fundamental questions, but we hope at least to have kept them clearly in view.

CHAPTER II

AIMS AND METHODS

The terms of reference for this study, which were agreed at an early stage of consultation between the DSS and ourselves, was that its main focus should be on the direct costs; that is the **additional expenditure**, both recurrent and non-recurrent, incurred by people with disabilities to enable them to participate in employment or education and training. It was agreed that whilst the Department was interested in other indirect costs of participation such as earnings and income opportunities forgone and other indirect costs (for example, the effect on the opportunities of other family members to earn), these were matters of less immediate concern in terms of the particular policy questions being addressed. It was agreed that the study should attempt to cover the full range of impairments and would pay exclusive attention to people who, given their age, were most likely to be participating in relevant activities, namely those between the ages of 20 and 50 years. In the event, because of the method of sample selection, two people just over the age of 50 were included in the study. Finally, it was agreed that for the purposes of determining income and the network of immediate support, the 'income unit'¹ of the person with the disability would be the most appropriate unit of study.

These were the broad parameters of the study and the other features which were the subject of specific agreement between the DSS and ourselves. In reformulating these in operational terms it became clear that the following related issues needed to be clarified.

- a) Any study of the expenditure incurred to enable people to participate in the ordinary life of the community must take as its starting point not just the expenses that people do actually incur but also the question whether these cover all their needs. Is the expenditure involved in meeting needs incurred by the individual himself or herself, or by others? Our study placed some emphasis on the question of who bears the economic burden of meeting an individual's needs and we tried to establish the extent to which these are met by the individual, by the family, by the employer or by the wider community in the form of statutory or other support.
- b) To what extent is it appropriate, or for that matter possible, to distinguish extra expenditure associated with participation from the extra expenditure associated with disability more generally? It could reasonably be argued that a good deal of expenditure incurred on account of a disability amounts to a prerequisite to participation in the workforce or in education. Obvious examples are outlays on the materials required for the management of incontinence, or on items required to maintain otherwise precarious health and well-being, such as medicines, bandages or extra heating; People need access to the buildings in which they work, but they must first be able to come and go from the buildings in which they live. They must meet basic requirements for survival before they can undertake wider participation. Distinguishing the two kinds of expense is inescapably arbitrary.
- c) Whilst we recognised the rationale for the Department's requirement of a full and accurate account of expenditure, our early pilot work alerted us to the importance of defining this in terms which have meaning for people with disabilities and for their families. Thus, as far as we could, we looked at expenditure in the context of other relevant costs. Though these may not always be as tangible as actual expenditure, they may nevertheless have such an important effect on lifestyle that they cannot be ignored. For example, expenditure on transport is clearly connected with the range of choice of available modes of transport. Expenditure on clothes to wear at work is likely to be affected by the number and type of the shops to which access is possible. The possibility of incurring expenditure is, to begin with, heavily influenced by income, hence significantly by employment. Expenditure can only be interpreted in the context of enabling opportunities, access and choice.
- d) Although we recognised that our sample was too small to enable us to establish causal links between expenditure and the characteristics and circumstances of the people we spoke to, we hoped at least to be able to provide some idea of the relationships between them. On the basis of our pilot work and our knowledge of

1. An income unit comprises one or more individuals who are dependent upon the same source(s) of income. In our study this can be taken to refer specifically to: a married or de fact couple with children; a married or de facto couple without children; a single person with dependent children; and a single person.

other similar studies, we collected information on type of impairment, physical capacities, competence in personal or self-care and behavioural problems (from which we hoped to devise a scale of disability), and type of domestic unit, income, employment status and socio-economic group, to enable us to see how far extra expenditure varied in accordance with these factors.

PARAMETERS OF THE STUDY

Our study comprised 60 people of working age, drawn from the Sydney Metropolitan area. Since the main aim of the study was to examine the extra expenditure incurred by people who were in employment or full-time education, our first task was to identify people in these categories whom we could invite to participate in the study. Since we also wished to examine whether their extra costs were affected by the nature of their disabilities, it was important that these should include the widest possible range of types of impairment.

METHOD OF SAMPLE SELECTION

As in other similar studies, the problems of identifying a representative sample of the relevant population loomed large. In the end, aware that our solution was by no means perfect, we decided to select the sample primarily from amongst recipients of the Mobility Allowance, the only group for whom we could establish the impairment category of members who would also, by definition, be in employment, education or training. We added to this group a number of recipients of the Invalid Pension, in order to draw into the study a) some lone parents with disabilities - a group in which, as we have already noted, there was originally an interest and b) some people receiving income from part-time earnings. The New South Wales State Headquarters of the DSS selected the sample on a random basis stratifying, in the case of Mobility Allowance recipients, according to the nature of their impairment: viz. intellectual; paralysis or restricted mobility; sensory and other. In order to preserve confidentiality, the DSS sent a letter from us to the selected members of the sample inviting their participation in the study and asking them to reply directly to us if they agreed to participate. The identity of the people to whom letters were sent was not disclosed by the DSS to the research team and the identity of those who responded to our letter was similarly not disclosed to the DSS.

PROBLEMS ASSOCIATED WITH THE SAMPLE SELECTION AND DESIGN

The response to our letter was disappointing. In order to achieve our target sample of 60 people the DSS had to send out 271 letters. This represents a positive response of no more than 22 per cent. Apart from this low response rate, there was another probable source of bias in our sample. The Mobility Allowance is believed to have a low take-up and it is certainly selective. Though there is no direct evidence, it is worth noting that in 1981 there were about 54,500 adults in employment and further education who had disabilities and who had a consequent difficulty using public transport (ABS, 1981, special tabulations). In 1988 12,632 people (that is 23% of the number who were experiencing difficulties in 1981) were receiving a Mobility Allowance (DSS, 1988). We are aware that not all the people who experienced difficulties with public transport would have been eligible for the Mobility Allowance, but the figures do suggest that there is probably a considerable shortfall. Furthermore, we do not know just how far from representative of the whole population with disabilities recipients of the Mobility Allowance actually are; but we do know that 63 per cent of recipients have an intellectual disability, whereas only 4.8 per cent of the people between the ages of 15 and 64 covered by the Handicapped Persons Survey had a disability of this sort (ABS, 1981).

THE QUESTIONNAIRE

Information was collected by means of a personal interview in the respondent's own home, using a detailed, structured questionnaire. This was modelled on a questionnaire used in a similar study in the United Kingdom², but considerably modified and tested for the present study in pilot and prepilot work. The questionnaire was divided into 13 sections, each dealing with a broad topic. These were:

1. A profile of the respondent and of members of his or her household in terms of age, sex, household type, employment status, and day time activity;
2. The incidence of long term disabilities amongst other members of the respondent's household;
3. The medical diagnosis of the respondent's condition;
4. An account of the respondent's physical, intellectual and behavioural disabilities and of his or her level of dependency in the area of personal or self-care;
5. The work-related needs/expenses of respondents, with an account of how these are met and how much extra expenditure is involved for the respondent. This section included a number of questions on the cost of travel to work and an examination of the respondents' perception of the impact of his or her disability on earnings, fringe benefits, and work opportunities;
6. The needs/expenses of respondents associated with education and training, with an account of how these are met and how much extra expenditure is involved for the respondent. Again, this section included a number of questions on travel costs;
7. The financial impact of caring for children on parents who have disabilities. This section was developed in the pilot study and included in the questionnaire. However, in view of the decision to exclude the extra costs of child care from the study, this section was not used;
8. The leisure activities of respondents over the preceding year and their perception of associated extra costs attributable to their disabilities;
9. The work situation of the respondent's primary caregiver, where this person, whether spouse, relative or friend, was also co-residential;
10. The respondent's employment history and the explanation for job changes;
11. The respondent's income group, and that of parents where respondents were clearly still living with them as dependants, though not necessarily as financial dependants;
12. The extra expenditure that arises on account of a disability. The specific items on which information was sought were:
 - occasional expenditure on equipment needed for food preparation
 - expenditure on special foods or diets*
 - regular and occasional expenditure on requirements related to incontinence
 - regular and occasional medical expenses, including private health insurance
 - occasional expenditure on car(s) and car modifications
 - regular and occasional expenditure on special footwear
 - expenditure on special or additional clothing*
 - occasional expenditure on communication aids, heating, air-conditioning, home modifications, mobility aids, special equipment and furniture;

2. This questionnaire was developed at the Social Policy Research Unit, University of York.

- additional expenditure on phone and power bills*
- additional expenditure on house maintenance and repairs*
- regular expenditure on formally provided homecare and personal care.

Note: Asterisks imply that the actual amount of extra expenditure was not sought but simply the respondent's view as to whether the expenditure was above average. Where information on regular expenditure was sought, this was for what seemed a reasonable period in terms of the average purchasing time of that item. In the case of occasional expenditure, information was sought for last year and over the lifetime of the individual; in all cases information was sought on any help that was received in the acquisition of a good or service.

13. Attitudes towards the social security system; the adequacy of benefits and, given a choice, whether there was a preference for increased cash benefits or better services.

THE INTERVIEW

We had decided, partly because of the length of the interview and partly because of the detailed, complex and personal nature of the information we were seeking, that it was preferable for the interview to take place in the respondent's own home rather than in the workplace. All the interviews except one, which took place in a sheltered workshop, took place in the respondent's own home. Part of the questionnaire pertained to the respondent's principal caregiver and/or their spouse, and we therefore requested that this person be at the interview. In the very few cases where this was so difficult to arrange that we thought our insistence might jeopardise the chances of obtaining an interview at all, we did not attempt to persuade. However, a problem did arise when we tried to arrange interviews with people with an intellectual impairment. In all of these cases it was a caregiver (all but two of whom were the respondents' parents) who responded to our letter seeking an interview. Thus even when the respondent lived in a hostel, it was the parents who would normally reply on behalf of their offspring. It was regrettable that we actually failed to meet 8 of the 16 intellectually impaired respondents themselves. Not always, but in a number of cases sufficiently large to be noticeable, this was because the parents or other caregiver did not seem to think that it would have served any useful purpose for us to see the respondent him or her self.

When a respondent selected for the study had an intellectual impairment, a parent or other caregiver was always present at the interview. In cases of severe intellectual impairment, caregivers answered the entire questionnaire on behalf of respondents. There was no case in the main study (although there was in the pilot study) in which the respondent was able to answer all the questions without assistance. Undoubtedly for people with intellectual impairments the questionnaire presented many problems. The questions on expenditure required both the capacity to recall in some detail and to make quite complex calculations. Some of the questions involved abstract notions and probed attitudes; for example on the adequacy of benefits and allowances; other questions sought to elicit preferences; others asked hypothetical questions. These are all styles of questioning which a person with an intellectual impairment would be likely to find very difficult. Nevertheless, we felt that there were several cases in which the respondent could have managed with a little less help than was given. In some cases the presence of parents, though helpful, did appear to inhibit and embarrass the respondents and this was perhaps even more pronounced for those with a physical impairment than it was for those with an intellectual impairment.

The interviews ranged in duration from one to about four hours. The length of the interview was, of course, partly a reflection of the length of the questionnaire. Detailed information was requested on a fairly wide range of topics. Whilst it was important that we obtained information from the sample systematically and in a consistent form - for which reason we adopted a highly formal and structured approach - the style of interviewing was intended to encourage respondents to explore in as much detail as they wished any ideas that might be prompted by the formal questions. It was apparent that although some respondents were keen to finish the interview as soon as possible, many others took advantage of the opportunity to talk at length about a much wider range of topics than was covered by the questionnaire itself. At the end of the interview we often felt that we had been given at the very least a glimpse of the way that disability had shaped our respondents' lives. Money had certainly played an important part, but it appeared that other experiences, having to do with social attitudes to disability, discrimination and access, had been no less important.

With the agreement of the respondent, most of the interviews were tape-recorded. This enabled us to attend to people. We felt that it was quite inappropriate to write down everything that a person told us especially where this was of a personal nature or merely tangential to the topic of the question asked. Yet it is the seemingly irrelevant and extraneous information, those ideas which have been inadvertently triggered by questions, that provide the research with a texture, and often allow an invaluable interpretation of the other information.

The questionnaire itself presented few difficulties. A small number of carers were not prepared to disclose their earnings or income but apart from this no other questions posed difficulties. The least successful section of the questionnaire was the last one in which an attempt was made to elicit attitudes to the benefit system and to gain some ideas from consumers as to how it might be improved. These questions seemed of little interest to respondents and to be somewhat removed from their principal interests. Rather it was the questions pertaining to the history, nature and impact of the disability that aroused the greatest interest and appeared to have the greatest salience. Of all the issues raised in the questionnaire, for those with a physical impairment, the effect of disability on their chances in the labour market, that is, indirect costs, aroused most interest. On the other hand, respondents whose offspring had an intellectual impairment found this question quite absurd.

CAVEATS

The findings of this study should be treated with caution. The sample, although randomly selected, was too small and localised to enable us to make generalisations about any wider population. In addition, the low response rate will almost certainly have led to a bias in the results. The factors responsible for this low response are in themselves of some significance and will be explored later. At this stage, suffice it to say that despite our reservations this study has still had its purpose and value. The information gathered is extremely detailed and we feel that what the study may lack in terms of sample size is offset to a large degree by the quality of the insights it offers. The sample is quite heterogeneous, particularly with regard to type of impairment and household composition. Confident generalisation may not be possible, but there is a wealth of suggestive clues to be found by pursuing the manifold connections between impairment, dependence, household form, employment, income and costs. We feel that even at this stage we have gained a considerable understanding of what it means, in terms of costs, to have a disability.

CHAPTER III

THE PEOPLE IN THE STUDY

In this chapter we shall for the most part be presenting the data in aggregate form. The very brief biographical sketches below are intended to provide a glimpse of the sixty people who lie behind the figures and to draw attention to the considerable diversity in their disabilities, their histories, their personal characteristics and social circumstances. We must emphasise that the identities of the individuals have been disguised. This group has one unifying feature. All participate, or have participated in the very recent past, in the life of the community, either as parents, workers or students. It will be the task of the research to uncover and describe the costs of this participation and to try to understand the effect of the widely varying circumstances of respondents on their needs and the way these are met. We shall also be concerned with the effect of the different routes by which they have arrived at their current circumstances. A person who has had a physical disability from birth is likely to have quite different needs from someone whose impairment results from a traumatic accident as a teenager and quite different again from someone whose physical disability arose in middle age from a stroke. Not only are their circumstances but also their vision of the world and their processes of adaptation likely to be vastly different. As we shall see, their very diversity draws attention to the difficulties of formulating policies which can effectively meet their manifold needs.

THE AGGREGATE PICTURE: PERSONAL CHARACTERISTICS, SOCIAL CIRCUMSTANCES AND THE INFLUENCE OF IMPAIRMENT

Tables 1 and 3 provide an aggregate picture of the sample population. The particular variables we describe in these tables are those which we considered, both on the evidence of other studies and our knowledge of the social structure, likely to be associated with the needs and hence the expenditure patterns of the people we interviewed. The variables are of two types. First are the disability-related variables which have to do with the type of impairment and with the severity of the consequent disability. Second are the social variables which relate to the individual's personal characteristics and circumstances: age, type of domestic unit, employment status, occupational status and level of income.

Table 1 shows how far people with similar impairments also share particular personal and social characteristics. The table indicates that the overall picture of the sample is greatly affected by the type of impairment. At the stage of selection we had hoped to recruit a stratified sample of three roughly equal groups representing three broad categories of impairment, namely those with a paralysis or impairment affecting mobility (henceforth to be referred to as a 'physical' impairment), those with mental retardation, degeneration due to brain damage, or those who are slow at learning or have specific delays in development, (henceforth to be referred to as an 'intellectual' impairment) and a third group containing people whose impairments were neither physical nor intellectual, as defined above. For this latter group we deliberately attempted to recruit people with sensory impairments because we thought that these might entail specific costs that we should investigate. In the event the people who actually responded to our invitation to participate did not fall equally into the three groups. Thirty people had physical impairments, 17 had intellectual impairments and 13 fitted into neither of these two broad groupings. Three of those people in the third category had sensory impairments, four had psychiatric illnesses and the remaining six had a variety of impairments and form a group named 'other'. As can be observed from Table 1 these three latter groups have been considered separately in our analysis. The composition of the 'other' group is described in Appendix I.

Table 1 indicates clearly that where personal characteristics and social circumstances are concerned there are wide differences according to type of impairment. Focusing our attention on the two main categories of primary impairment, intellectual and physical, we observe firstly that respondents with an intellectual impairment are on the whole younger than those with physical impairments. This reflects differences to be observed between the two impairment groups in the disabled population at large (ABS, 1981).

The difference in age structure probably provides at least a partial explanation for the different domestic arrangements of the two groups. Whereas people with physical problems are found in a wide variety of domestic circumstances, those with an intellectual impairment or a psychiatric illness are likely to live either with their parents or in a group home or hostel, in cases of intellectual impairment often dividing their time between the two.

THE PEOPLE IN OUR SURVEY

Oliver Jackson is aged 38 and has brain damage as a result of a road accident. He lives with his wife and children and is a part-time itinerant worker. The family income is approximately \$12,700 p.a.

Julian Benson is aged 38 and has paraplegia as a result of a road accident. He lives alone and is a full-time student. His income is approximately \$8,500 p.a.

Peter Foreman is aged 25 and has a muscular degeneration in his lower limbs. He lives with his parents and is employed full-time as a personnel officer. He is also studying part-time. He has an income of approximately \$23,000 p.a.

Veronica Simpson is aged 33 and has had one leg amputated. She lives alone and is employed part-time as a receptionist. Her income is approximately \$25,000 p.a.

Jillian Henderson is aged 27 and has spina bifida. She lives with her husband and is employed full-time as a secretary. The family income is approximately \$43,000 p.a.

Frank Murphy is aged 46 and has quadriplegia resulting from a sports accident. He lives with his wife and non-dependent child and is employed part-time as a wood worker. The family income is approximately \$13,500 p.a.

Roland Porter is aged 27 and has muscular dystrophy. He lives with his parents and is employed full-time as an administrator. His income is approximately \$21,000 p.a.

Marjory Ridley is aged 41 and has cerebral palsy. She lives with her husband and is employed full-time as a telephonist. The family income is approximately \$21,000 p.a.

Adam Booker is aged 30 and has quadriplegia resulting from a sports accident. He lives with his wife and is employed full-time as a computer programmer. The family income is approximately \$21,000 p.a.

Ruth Peters is aged 22 and has poliomyelitis. She lives with her parents and is in full-time education. Her income is approximately \$5,000 p.a.

Jo DeLuca is aged 25 and has brain damage from birth. He lives with his parents and attends an Activity Therapy Centre. His income is approximately \$5,500 p.a.

Anna Rushton is aged 33 and has cerebral palsy. She lives with her husband and is employed full-time as a receptionist. The family income lies between \$29,000 and \$31,000 p.a.

John Davidson is aged 23 and has cerebral palsy and brain damage. He lives with his parents and attends an Activity Therapy Centre. His income is approximately \$7,500 p.a.

Glenn Phillips is aged 49 and has cerebral palsy. He lives with a friend and is in full-time education. His income is approximately \$7,500 p.a.

Pam Draper is aged 38 and has poliomyelitis. She lives with her parents and is employed full-time as a public relations officer. Her income is approximately \$25,500 p.a.

Brenda MacPherson is aged 47 and has multiple sclerosis. She lives with a friend and is employed part-time as a personnel officer. Her income is approximately \$26,500 p.a.

Rachel Renato is aged 52 and has multiple sclerosis. She is a sole parent without paid employment. Her income lies between \$10,000 and \$13,000 p.a.

Debbie Carey is aged 41 and has rheumatoid arthritis. She lives with her parents and is employed full-time as a financial consultant. Her income lies between \$36,000 and \$39,000 p.a.

Anita Rivera is aged 44 and has cerebral palsy. She lives with her husband and children and works part-time as a telephonist. She is also studying part-time. The family income is approximately \$20,500 p.a.

Fay Pritchard is aged 34, and has had one leg amputated. She lives with her husband and children and is employed part-time as a clerical worker. The family income is approximately \$29,500 p.a.

Peter Rawlings is aged 33 and has quadriplegia resulting from a sports accident. He lives in a boarding house and is employed part-time as a computer operator. He is also studying part-time. His income is approximately \$9,000 p.a.

Rupert Elias is aged 35 and has quadriplegia resulting from a sports accident. He lives with his wife and is employed full-time as a graphic designer. The family income is approximately \$55,000 p.a.

Michael Hutchinson is aged 47 and has quadriplegia resulting from a road accident. He lives with his wife and children and is employed full-time as an office worker. The family income is approximately \$22,000 p.a.

Dan Richards is aged 47 and has defective muscle co-ordination. He lives with his wife and children and is employed full-time as a process worker. The family income is approximately \$25,000 p.a.

Jim Rankin is aged 38 and has spondylitis. He lives with his wife and children and is employed part-time as an office worker. The family income is approximately \$19,000 p.a.

Jason Briggs is aged 30 and has quadriplegia resulting from a road accident. He lives in a hostel and attends a training centre. His income is approximately \$8,500 p.a.

Paul Mendez is aged 43 and has cerebral palsy. He lives with his wife and children and is employed full-time as a storeman. The family income is approximately \$29,500 p.a.

Mark Lim is aged 40 and has polynueritis. He lives with his wife and children and is employed full-time as a clerical worker. The family income is approximately \$29,500 p.a.

Bill Lennox is aged 30 and has Freidrich's Ataxia. He lives with his parents and is currently not working. His income is approximately \$13,000 p.a.

Fergus Ralston is aged 34 and has muscular dystrophy. He lives with a friend and is currently employed full-time as an administrator. His income lies between \$23,000 and \$26,000 p.a.

THE PEOPLE IN OUR SURVEY (CONT'D)

David Hart is aged 22 and has Apert's Syndrome. He lives with his parents. He is currently not working but is enrolled for an educational course. His income is approximately \$7,000 p.a.

Simon Field is aged 24 and has a severe intellectual impairment. He lives with his parents and is currently attending an Activity Therapy Centre. His income is approximately \$7,000 p.a.

Sharon Harding is aged 28 and has Prader-Willy Syndrome. She lives with her parents and is employed full-time in a sheltered workshop. Her income is approximately \$7,500 p.a.

Athena Papadopoulos is aged 24 and has a severe intellectual impairment. She lives in a hostel and attends an Activity Therapy Centre. Her income is approximately \$7,000 p.a.

Bradley Rice is aged 21 and has autism. He lives in a hostel during the week and with his parents at weekends. He attends an Activity Therapy Centre. His income is approximately \$7,500 p.a.

Lynette Simons is aged 26 and has myotonic dystrophy. She lives with her parents and is employed full-time in a sheltered workshop. Her income is approximately \$8,500 p.a.

Sean Thompson is aged 21 and has autism. He lives in a group home and with his parents at weekends. He attends an Activity Therapy Centre. His income is approximately \$8,000 p.a.

Samantha Whiteside is aged 44 and has Down's Syndrome. She lives in a hostel and is employed full-time in a sheltered workshop. Her income is approximately \$7,500 p.a.

Ross Perry is aged 27 and has Down's Syndrome. He lives with his mother and is employed full-time in a sheltered workshop. His income is approximately \$7,000 p.a.

Stephen Kelly is aged 35 and has Down's Syndrome. He lives in a hostel and is employed full-time in a sheltered workshop. His income is approximately \$7,500 p.a.

Jane Fletcher is aged 21 and has a severe intellectual impairment. She lives with her parents and attends an Activity Therapy Centre. Her income is approximately \$7,000 p.a.

Martin Rogers is aged 27 and has Down's Syndrome. He lives with his mother and attends an Activity Therapy Centre. His income is approximately \$10,000 p.a.

Mario Capulet is aged 27 and has Down's Syndrome. He lives with his parents and attends an Activity Therapy Centre. His income is approximately \$7,500 p.a.

Rick Ellis is aged 23 and has autism. He lives in a group home and with his parents at weekends. He attends an Activity Therapy Centre. His income is approximately \$8,000 p.a.

Brett Cambourn is aged 24 and has autism. He lives in a group home and with his parents at weekends. He attends an Activity Therapy Centre. His income is approximately \$8,000 p.a.

Myron Golding is aged 20 and has a severe intellectual disability. He lives in a group home and attends an Activity Therapy Centre. His income is approximately \$7,500 p.a.

Tom Harding is aged 22 and has a mild intellectual disability. He lives with his mother and is employed full-time as a packer. He is also studying part-time. His income is approximately \$10,500 p.a.

Charles Fowler is aged 42 has a sight and hearing impairment. He lives with his wife and is employed full-time in publishing. He is also studying part-time. The family income is approximately \$36,500 p.a.

Rosemary Jones is aged 44 has a sight and hearing impairment. She lives with a friend and is employed full-time as an administrator. Her income is approximately \$34,000 p.a.

Ron Cameron is aged 43 and has a sight impairment and a progressive hearing impairment. He lives with his wife and children and is employed full-time as a factory worker. The family income is approximately \$23,500 p.a.

Ken Long is aged 28 and has schizophrenia. He lives in a hostel and is employed full-time in a sheltered workshop. His income is approximately \$7,000 p.a.

Eugene Beale is aged 43 and has alcoholic psychosis. He lives in a boarding house and is employed full-time in a sheltered workshop. His income is approximately \$11,500 p.a.

Beverley Grace is aged 42 and has borderline schizophrenia. She is a sole parent and is without paid employment. Her income is approximately \$8,500 p.a.

Elizabeth Dunn is 39 and has paranoid schizophrenia. She lives with friends and is employed part-time as an information officer. She is also studying part-time. Her income is approximately \$8,000 p.a.

Bruce MacDonald is aged 51 and has multiple ailments including arthritis, hernias, diverticulitis and dermatitis. He is a sole parent without paid employment. His income is approximately \$7,000 p.a.

Fran Walsh is aged 30 and has severe headaches. She is a sole parent without paid employment. Her income is approximately \$13,000 p.a.

Ivan Joss is aged 28 and has severe epilepsy and a bad back resulting from a car accident. He lives with his wife and children and is currently unemployed. The family income is approximately \$15,000 p.a.

Lillian Ravilico is aged 44 and has a minor paralysis, a hearing impairment and an ulcerated eye. She lives alone and is currently working part-time as a cleaner. Her income is approximately \$8,500 p.a.

Vivienne Fischer is aged 41 and has scleroderma. She lives alone and is employed part-time as a real estate agent. She is also studying part-time. Her income is approximately \$8,500 p.a.

Valerie James is aged 35 and has agoraphobia and neurotic depression. She is a sole parent without paid employment. Her income lies between \$8,000 and \$10,000 p.a.

Note: Pseudonyms have been used in all cases to avoid identification. Other details have also been slightly modified in some instances in order to safeguard the confidentiality of survey participants.

TABLE 1: THE AGGREGATE PICTURE: THE CHARACTERISTICS OF THE SAMPLE ACCORDING TO THE IMPAIRMENT CATEGORY

Social Characteristics	Impairment Category											
	Physical		Intellectual		Sensory		Psychiatric Illness		'Other'		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Age:												
20 - 29 years	6	20.0	15	88.2	0	0	1	25.0	1	16.7	23	38.3
30 - 39 years	13	43.3	1	5.8	2	66.7	1	25.0	2	33.3	19	31.7
40 - 49 years	10	33.3	1	5.8	1	33.3	2	50.0	2	33.3	16	26.7
50 years and over	1	3.3	0	0	0	0	0	0	1	16.7	2	3.3
TOTAL	30	100.0	17	100.0	3	100.0	4	100.0	6	100.0	60	100.0
Household Type:												
Nuclear family with children	9	30.0	0	0	1	33.3	0	0	1	16.7	11	18.3
Nuclear family without children	5	16.7	0	0	1	33.3	0	0	0	0	6	10.0
Lives with parents	8	26.7	9	52.9	0	0	0	0	0	0	17	28.3
Sole parent	1	3.3	0	0	0	0	1	25.0	3	50.0	5	8.3
Lives alone	2	6.7	0	0	0	0	0	0	2	33.3	4	6.7
Lives with friends	3	10.0	0	0	1	33.3	1	25.0	0	0	5	8.3
Hostel/group home	2	6.7	4	23.5	0	0	2	50.0	0	0	8	13.3
Family and hostel/group home	0	0	4	23.5	0	0	0	0	0	0	4	6.7
TOTAL	30	100.0	17	100.0	3	100.0	4	100.0	6	100.0	60	100.0
Employment Status:												
Employed, full-time	13	43.3	0	0	2	66.7	0	0	0	0	15	25.0
Employed, part-time	6	20.0	0	0	0	0	0	0	1	16.7	7	11.7
In education and training	3	10.0	0	0	0	0	0	0	0	0	3	5.0
Full-time parent	1	6.7	0	0	0	0	1	25.0	3	50.0	5	8.3
Sheltered workshop employee	0	0	4	23.5	0	0	2	50.0	0	0	6	10.0
Trainee at Activity Therapy Centre	2	6.7	12	70.0	0	0	0	0	0	0	14	23.3
Part-time work and part-time education and training	2	6.7	0	0	0	0	1	25.0	1	16.7	4	6.7
Full-time work and part-time education and training	1	3.3	1	5.8	1	33.3	0	0	0	0	3	5.0
Other	2	6.7	0	0	0	0	0	0	1	16.7	3	5.0
TOTAL	30	100.0	17	100.0	3	100.0	4	100.0	6	100.0	60	100.0
Current or Last Occupational Status:												
Never employed	4	13.3	12	70.6	0	0	1	25.0	1	16.7	18	30.0
Manager/administrator/professional/para-professional	7	23.3	0	0	2	66.7	0	0	0	0	9	15.0
Other white-collar	14	46.7	0	0	0	0	1	25.0	3	50.0	18	30.0
Semi-skilled blue-collar	0	0	0	0	1	33.3	0	0	1	16.7	2	3.3
Unskilled blue-collar	2	6.7	1	5.9	0	0	0	0	1	16.7	4	6.7
Sheltered workshop employee	2	6.7	4	23.5	0	0	2	50.0	0	0	8	13.3
Other	1	3.3	0	0	0	0	0	0	0	0	1	1.7
TOTAL	30	100.0	17	100.0	3	100.0	4	100.0	6	100.0	60	100.0
Income Group of Income Unit:												
\$10 400 or less	7	23.3	16	94.1	0	0	3	75.0	4	66.7	30	50.0
\$10 401 to \$20 800	5	16.7	1	5.9	0	0	1	25.0	2	33.3	9	15.0
\$20 801 to \$31 200	15	50.0	0	0	1	33.3	0	0	0	0	16	26.7
\$31 201 to \$41 600	1	3.3	0	0	2	66.7	0	0	0	0	3	5.0
\$41 601 or more	2	6.7	0	0	0	0	0	0	0	0	2	3.3
TOTAL	30	100.0	17	100.0	3	100.0	4	100.0	6	100.0	60	100.0

Note: Percentages may not add to 100 due to rounding.
Source: Survey Data, 1988.

In terms of day-time activity, we see again wide disparities between the members of the impairment categories. Respondents with a physical or sensory impairment were much more likely to be in open employment, or to be engaged in some sort of vocational training than were those with an intellectual impairment or psychiatric illness. This is unlikely to be merely a reflection of the relative youthfulness of the people in our sample given that those with intellectual impairments were all above the age of 20. It is much more likely to be associated with availability. There is a good deal of anecdotal evidence to suggest that people with intellectual impairments or psychiatric illness have great difficulty in finding employment, particularly open employment. The small numbers in our sample do not provide us with conclusive supporting evidence, however.

In respect both of their positions in the occupational structure and of their incomes there are also marked differences. As we have noted, those with intellectual impairments and even many of those with psychiatric illness are unlikely to have been in open employment since the onset of their disability, and therefore cannot be located on any conventional occupational scale. Those with physical and sensory impairments, on the other hand, are quite widely distributed occupationally. However, if we exclude those who work in sheltered workshops, we find that as many as 79 per cent of the people in our sample who have ever worked are, or have been, in white collar occupations. This rises to 88 per cent of those with a physical impairment. Although strict comparisons are difficult to make, the equivalent figure for the employed population in Australia is in the region of 60 per cent (ABS, 1988: Table 30, p. 34). This is not surprising; we would expect that those with a paralysis or a problem with mobility to be over-represented in white collar occupations. It does re-emphasise the need to retrain those who have been in blue collar occupations, in skills which are not physically demanding.

The occupational positions of respondents tend naturally to be reflected in their incomes. People with intellectual impairments or psychiatric illness generally have far lower incomes than those with physical impairments because of their much greater dependence on social security benefits which is often their main and usually their sole source of income. We shall later be considering how income affects the ways in which the needs of these two groups of people are met.

Table 2 compares the incomes and earnings of sample members with those of the population at large. In looking at these tables it is important to bear in mind that the populations to which they refer have somewhat different characteristics, which may well affect incomes. One of the most important of these is the age distribution of the two populations. The sample population is generally younger.

The mean and median incomes of the members of our sample are below those of the population generally (see Table 2). Though the married couples in the sample are no more likely than couples in the population generally to be below the poverty line, the single people and lone parents with disabilities are so, much more often.

In terms of their incomes and wages, the members of the sample differed from the general population in important ways. A much larger proportion relied on a combined income of wages and social security benefits than was the case for the employed population generally, whose wages are likely to be their sole source of income.

Within the sample population only 17 people (28%) were solely dependent upon earned income. A little over half (36 people) received income from earnings but of these 15 (42%) relied primarily upon Social Security payments for their income. The range of wages earned by all members of income units varied between a low of \$500 (a single person) and a high of \$55,000 (a couple both working with no children). Wages earned by members of income units tended to be at the lower end of the scale. Thirteen people received less than \$5,000 over the last financial year from wages and eight received less than \$2,000 last year.

We can posit a number of explanations for these relatively low wages. First, a number of the respondents were employed at very low wages in sheltered workshops and Activity Therapy Centres (ATCs), possibly in order to ensure that their eligibility to Invalid Pension was unaffected. This was also the explanation offered for the low wages earned by some people employed by charitable organisations. Second, some members of the sample, on account of their disabilities, had been able to work only part of the financial year. Third, the employment of some wives had been disrupted during the financial year on account of the needs of their disabled spouses. Fourth, some people chose to work part-time because they felt unable, because of their disability, to work full-time.

TABLE 2: THE INCOME OF THE SAMPLE COMPARED WITH THE INCOME OF THE AUSTRALIAN POPULATION 1987/88

Income Unit	Mean Annual Income				Median Annual Income		Percentage Below the Poverty Line	
	Survey All Sources \$	Australia: All Sources ¹ \$	Survey Wage & Salary ² \$	Australia: Wage & Salary ³ \$	Survey \$	Australia ¹ \$	Survey 1987/88 ⁴ %	Australia 1985/86 ⁵ %
Married Couple no dependants	31,832	41,445	27,245	42,745	29,004	40,195	0	6
Married Couple with dependants	22,433	32,264	19,854	38,226	22,729	32,773	10	10
Single Persons	11,052	16,627	- 6	18,436	8,000	12,242	45	16
Single Parents	9,241	13,706	11,473	23,028	8,521	9,798	75	47
TOTAL	15,181	24,090	14,728	29,845	8,792	19,078	36	13

- Notes:**
1. Based upon the annual income from all sources Married couples without dependants and single persons are based upon people within the age ranges of 15-44 years only. All figures have been updated from 1985/86 to 1987/88 using Average Weekly Earnings figures.
 2. Based upon income received from wages and salaries among survey respondents. Within the sample 33 respondents received part or most of their income from earnings. The remainder were totally dependent upon income from a government pension or benefit.
 3. Based upon the annual income from wages and salaries. Married couples without dependants and single persons are based upon people within the age ranges of 15-44 years only. All figures have been updated from 1985/86 to 1987/88 using Average Weekly Earnings figures.
 4. The poverty line for the June quarter of 1988 has been adjusted using the Household Disposable Income in order to calculate the average poverty line for the 1987/88 financial year. Simple poverty line calculations have been used. In all cases except where a person or their spouse was neither in the paid workforce nor in education or training for at least part of the year the 'Head in Workforce' poverty line has now been used.
 5. Percentage of people in poverty for married couples without dependants is based upon those income units where the head is aged less than 65 years. For single person income units the percentage in poverty is for those aged between 25 and 64 years.
 6. Within the survey group no single parent receives income from a wage or salary.

Source: ABS 1986 Income Distribution Survey, Australia Preliminary Results, Cat. No. 6545.0.
 ABS Average Weekly Earnings, August 1988, May 1988, February 1988, November 1987, Cat. No. 6302.0.
 IAESR Poverty Lines: Australia June Quarter 1988.
 Survey Data 1988.

The overall picture of the two impairment groups that emerges is one of sharp contrast. The circumstances of respondents with intellectual impairments and psychiatric illnesses seem much bleaker than do those of people with physical or sensory impairments. In our interviews we were particularly struck by the social impoverishment of the people with psychiatric illness. Typically, they were poor, living alone and out of work.

THE AGGREGATE PICTURE: PERSONAL CHARACTERISTICS, SOCIAL CIRCUMSTANCES AND THE INFLUENCE OF LEVEL OF DEPENDENCY

One factor which, on the face of it, seems likely to affect the extent of additional expenditure is the severity of the disability, defined in terms of the limitations it imposes on a person's ability to function. The survey questionnaire examined this in relation to three broad areas; physical capacities, behavioural problems and competence in personal or self-care.

The first area included the following capacities; walking, the use of arms and hands, the control of bowels and bladder (continence), sight, hearing, speech and communication. The area of behavioural problems covered depression and anxiety, aggression and self-abuse or -injury. 'Personal care' embraced such matters as dressing, eating, washing, cleaning teeth and bathing, going to the toilet, and preparing meals. In this connection, account was taken of the length of time people could safely be left by themselves, and of whether nursing care was required at home.

It was hoped that it would be possible to devise a scale of disability that would combine these three areas. For each item in each area the respondents were given a score of 0, 1 or 2, where 0 indicated no problem or, in the case of personal care, no need for assistance, 1 a moderate problem and the need for some assistance with personal care and 2 a severe problem or a need for full assistance with personal care.

In devising this scale the first step was to examine whether and how the various components of disability were related to each other both within and between each of the three areas. If scores in all three areas had shown a high degree of correlation their development into a single scale could have been considered. An examination indicated only slight association between scores within the physical and behavioural areas. People who were unable to walk, for example, tended not to have problems with sight and those suffering from depression were unlikely also to be prone to aggression. However, in the area of personal care people who had difficulties with one aspect of self-care, for example with dressing, were very likely to need help with others, for example with bathing and the preparation of their meals. Taking each of the three areas as a whole, there was a fairly strong tendency for people who had physical incapacities to have difficulties in the area of self-care as well. However, people with behavioural problems were unlikely to have problems in either of the other two areas. This suggests that the questionnaire may not adequately have tapped information on other sorts of conditions which cause people who have behavioural difficulties to be defined as 'disabled'.

As a result of the test of correlation (see Appendix II) and also of some testing of sensitivity, it was decided to restrict the composite scale of disability to the area of personal care. People with a maximum score of 2 on any of the 8 aspects of personal care have been classified as having high disability/dependency, those with a score of 1 as having medium disability/dependency, those with a score of 0 as having no or minimal or no disability/dependency in any of the areas of personal care.

In view of our decision to base the scale on the amount of assistance needed in the various aspects of personal care, this will henceforth be referred to as a 'scale of dependency'.

It would have been possible, of course, to have developed a scale of disability determined by the highest severity in any of the areas we considered: physical capacities, behaviour problems or self-care. However, had we done this, all but four members of the sample would have been designated as having a high level of severity. The scale would therefore have lacked discriminatory power. We therefore considered it preferable to focus on the area of personal care. This is not to suggest that problems with mobility and continence are not also of great importance in determining levels of expenditure. We shall consider, later in the report, the combined effect of severe problems of mobility and incontinence on expenditure.

In the event we would not have wished to have included behaviour problems in our scale, because we were not satisfied that our questionnaire explored this complex area in adequate detail.

Whilst type of impairment serves as a clear discriminator in respect of the personal characteristics and social circumstances of the members of our sample, this is not the case for level of dependency.

As one can observe from Table 3 there is no really consistent relationship between level of dependency and personal and social circumstances, amongst any of the five variables that we considered. People with high dependency enjoy less favourable circumstances (for example, they have lower incomes and are less likely to be in paid employment) and are less likely to be living in conventional domestic arrangements (for example, with their own families rather than with their parents), but by no means all of them were excluded from these advantages.

THE RELATIONSHIP BETWEEN IMPAIRMENT AND LEVEL OF DEPENDENCY

Table 3 suggests that the level of dependency alone is unlikely to explain the circumstances of people in our study. However Table 4, read in conjunction with Table 1, indicates that all but one person with an intellectual impairment have high dependency and restricted social circumstances, whereas people with psychiatric illness, though they have in general relatively low dependency using our scale are also in restricted social circumstances. People with physical impairments on the other hand display a range of levels of dependency and a range of circumstances at each of these levels.

Of course we can look for other explanations in the inter-relationship of circumstances, impairment and dependency. We have already noted that those with intellectual impairments were, on the whole, younger than those with physical disabilities. The age at onset of a problem, whether from birth, in adolescence or adulthood, will also play an important part in current social and personal circumstances.

We have devoted considerable attention to the description of our sample because, as we shall show, the personal and social characteristics of our respondents had an important bearing on their expenditure. Later in the report we shall be exploring the interplay of these factors in more detail.

TABLE 3: THE AGGREGATE PICTURE: THE CHARACTERISTICS OF THE SAMPLE ACCORDING TO THE LEVEL OF DEPENDENCY

Social Characteristics	Level of Dependency							
	None/Minimal		Medium		High		Total	
	No.	%	No.	%	No.	%	No.	%
Age:								
20 - 29 years	5	25.0	1	11.1	17	54.8	23	38.3
30 - 39 years	10	50.0	5	55.5	4	12.9	19	31.7
40 - 49 years	4	20.0	3	33.3	9	29.0	16	26.7
50 years and over	1	5.0	0	0	1	3.2	2	3.3
TOTAL	20	100.0	9	100.0	31	100.0	60	100.0
Household Type:								
Nuclear family with children	6	30.0	0	0	5	16.1	11	18.3
Nuclear family without children	1	5.0	4	44.4	1	3.2	6	10.0
Lives with parents	4	20.0	1	11.1	12	38.7	17	28.3
Sole parent	3	15.8	2	22.2	0	0	5	8.3
Lives alone	4	20.0	0	0	0	0	4	6.7
Lives with friends	1	10.0	1	11.1	2	6.5	5	8.3
Hostel/group home	0	0	1	11.1	7	22.5	8	13.3
Family and hostel/group home	0	0	0	0	4	12.9	4	6.7
TOTAL	20	100.0	9	100.0	31	100.0	60	100.0
Employment Status:								
Employed, full-time	5	25.0	4	44.4	6	19.4	15	25.0
Employed, part-time	6	30.0	0	0	1	3.2	7	11.7
In education and training	2	10.0	0	0	1	3.2	3	5.0
Full-time parent	3	15.0	2	22.2	0	0	5	8.3
Sheltered workshop employee	0	0	1	11.1	5	16.1	6	10.0
Trainee at Activity Therapy Centre	0	0	0	0	14	45.2	14	23.3
Part-time work and part-time education and training	2	6.7	1	11.1	1	3.2	4	6.7
Full-time work and part-time education and training	1	3.3	1	11.1	1	3.2	3	5.0
Other	1	3.3	0	0	2	6.5	3	5.0
TOTAL	20	100.0	9	100.0	31	100.0	60	100.0
Current or Last Occupational Status:								
Never employed	1	5.0	2	22.2	16	51.6	18	30.0
Manager/administrator/professional/para-professional	4	20.0	1	11.1	4	12.9	9	15.0
Other white-collar	11	55.0	2	22.2	5	16.1	18	30.0
Semi-skilled blue-collar	1	5.0	0	0	1	3.2	2	3.3
Unskilled, blue-collar	1	5.0	3	33.3	0	0	4	6.7
Sheltered workshop employee	1	5.0	1	11.5	5	16.1	8	13.3
Other	1	5.0	0	0	0	0	1	1.7
TOTAL	20	100.0	9	100.0	31	100.0	60	100.0
Income Group of Income Unit:								
\$10 400 or less	8	40.0	2	20.2	20	64.5	30	50.0
\$10 401 to \$20 800	3	15.0	3	33.3	3	9.7	9	15.0
\$20 801 to \$31 200	8	26.7	3	33.3	5	16.1	16	26.7
\$31 201 to \$41 600	0	0	1	11.1	2	6.5	3	5.0
\$41 601 or more	1	5.0	0	0	1	3.2	2	3.3
TOTAL	20	100.0	9	100.0	31	100.0	60	100.0

Note: Percentages may not add to 100 due to rounding.

Source: Survey Data, 1988.

TABLE 4: THE IMPAIRMENT CATEGORY ACCORDING TO LEVEL OF DEPENDENCY

Impairment Category	Level of Dependency							
	None/Minimal		Medium		High		Total	
	No.	%	No.	%	No.	%	No.	%
Physical	14	46.7	4	13.3	12	40.0	30	100.0
Intellectual	0	0	1	5.9	16	94.1	17	100.0
Sensory	0	0	2	66.7	1	33.3	3	100.0
Psychiatric Illness	1	25.0	2	50.0	1	25.0	4	100.0
Other	5	83.3	0	0	1	16.7	6	100.0
TOTAL	20	33.3	9	15.0	31	51.7	60	100.0

Note: Percentages may not add to 100 due to rounding.

Source: Survey Data, 1988.

CHAPTER IV

THE COST OF PARTICIPATION

1. AN OVERVIEW OF EXPENDITURE

In the last chapter we presented an overview of the personal and social characteristics of the people in the sample. In this chapter, we begin with an overview of their annual expenditures. The amounts in Table 5 combine expenditures associated with general disability-related items and services and those specifically connected with participation in employment, or on education and training. Later, we shall be looking separately at these three different types of expenditure.

The table distinguishes recurrent and non-recurrent expenditure. Figures for recurrent expenditure relate to the year preceding the interview. Annual expenditure on non-recurrent items has been calculated by dividing the total amount spent by the respondent since the onset of his or her disability by the number of years elapsed. The amounts in this and other tables have been adjusted by the Consumer Price Index to December 1988.

The heading to Table 5 describes the amounts as 'estimates'. They are estimates in two senses. Firstly, they are based on respondents' recall of their expenditures rather than on documentary evidence; secondly, the annual figures have been arrived at indirectly either by averaging expenditures incurred over different time periods, as just indicated, or by extrapolation from reported weekly or monthly expenditures. In these senses, all the expenditure figures provided in this report are estimates but, to avoid clumsy repetition, we do not continue to use the term.

The amounts recorded in this and subsequent tables are almost certainly **underestimates**. In the first place we present no data for disability-related expenditure on items where the determination of an exact amount was not possible, as for example in the case of telephone, power, clothing, general transport and home maintenance costs. The fact that these amounts have been omitted should not be taken to imply that the sums were trivial but that, given the nature of our study, they simply could not be calculated. Secondly, we recorded no expenditure in all instances where respondents reported that they had incurred expense but could not recall the amount.

Table 5 shows the exceedingly wide range of expenditure amongst the 60 respondents, from \$0 to \$9,060. In nearly all cases recurrent expenditure represents the greater part of the total, but as Figure 1 indicates graphically, as total expenditure rises the non-recurrent share tends to increase, also.

In the concluding chapter, we shall be looking in more detail at this overall picture, in the light of some of the personal and social characteristics of the respondents. The purpose of this present overview is merely to set the scene for the detailed account of expenditure which follows in this and the next chapter.

2. EXTRA EXPENDITURE RESULTING FROM EMPLOYMENT

The main purpose of this study is to examine the extra expenditure incurred by people with disabilities when they participate in the workforce or in education and training. These two spheres have been treated separately because we found that the expenditure patterns associated with them tended to differ. We have nevertheless analysed the expenditures incurred in each in similar fashion.

We have classified expenditure in the first place as either recurrent or non-recurrent. Where recurrent expenditure is concerned we distinguish three categories: (a) travel; (b) personal assistance; and (c) other regular requirements. We first examine expenditure incurred in this way in relation to the sample as a whole. We then consider overall recurrent expenditure in relation to type of impairment. Similarly, we consider the distribution of non-recurrent expenditure according to type of impairment.

TABLE 5: TOTAL ESTIMATED ANNUAL EXPENDITURE OF MEMBERS OF THE SAMPLE - RANKED

Rank Order	Total Annual Recurrent & Non-Recurrent Expenditure ¹ \$	Total Annual Recurrent Expenditure \$	Total Annual Non-Recurrent Expenditure \$
1	0	0	0
2	0	0	0
3	10	10	0
4	20	20	0
5	40	40	0
6	60	60	0
7	90	90	0
8	140	110	30
9	150	90	60
10	190	190	0
11	220	220	0
12	230	230	0
13	270	210	60
14	270	270	0
15	400	400	0
16	580	580	0
17	600	600	0
18	700	400	300
19	720	700	20
20	730	730	0
21	760	750	10
22	870	860	10
23	970	880	90
24	1130	1110	20
25	1140	1140	0
26	1160	1160	0
27	1250	1250	0
28	1250	1010	240
29	1310	1300	10
30	1420	1400	20
31	1470	1350	120
32	1480	1490	0
33	1530	1170	360
34	1590	1590	0
35	1730	1670	60
36	1870	1870	0
37	1890	1270	620
38	2000	1810	190
39	2000	1970	30
40	2030	2020	10
41	2320	2300	10
42	2470	2420	60
43	2500	2150	360
44	2700	2690	10
45	2940	2910	30
46	3040	2930	110
47	3260	3200	60
48	3290	1520	1760
49	3290	2410	880
50	3410	3390	20
51	3590	3590	10
52	4550	3370	1170
53	5630	4020	1610
54	5700	5250	450
55	6110	5920	180
56	6150	4860	1290
57	6330	5280	1040
58	8180	2160	6020
59	8770	580	8190
60	9060	9060	10
Mean	\$2076	\$1700	\$425
Median	\$1445	\$1260	\$20
Range	\$0 - \$9060	\$0 - 9060	\$0 - 8190

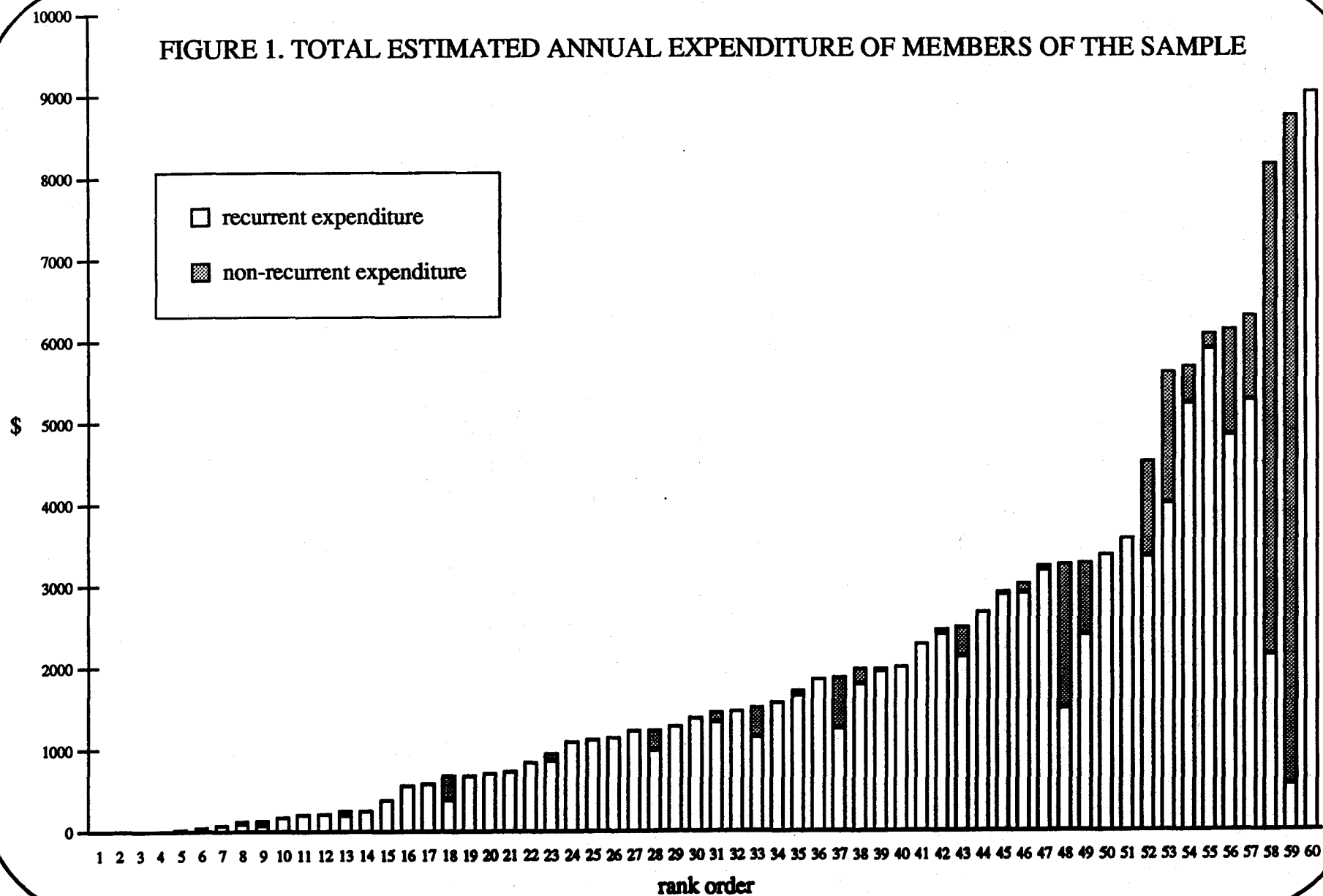
Note: 1. Includes all expenditure on items and services required for participation in employment, education or training and to meet other disability-related needs.

* For a breakdown of items/services included in the total refer to Appendix III and IV.

* Estimates of expenditure have been rounded.

Source: Survey Data, 1988

FIGURE 1. TOTAL ESTIMATED ANNUAL EXPENDITURE OF MEMBERS OF THE SAMPLE



The sample would appear to fall into two distinct, though by no means homogeneous groupings. One of these is comprised of people with either physical or sensory impairments who are typically employed and have relatively high incomes derived for the most part from their earnings. However, the income levels are not simply explained by the respondents' own earnings. As Table 1 indicated, it reflects the influence of marital status. People with physical and sensory impairments are more likely to be married or co-habiting. In 63 percent of these cases there were two earners in married couple income units. This contrasts with the second grouping of people with intellectual impairments, psychiatric illnesses and 'other impairments'. Typically such people are not in open employment, but either in sheltered workshops, or occupied in Activity Therapy Centres, or they are single parents. They have low incomes which are generally derived from social security payments, in some instances supplemented by extremely low 'wages' received from employment in sheltered workshops. The advocates of one respondent claimed that he actually has to pay to attend a sheltered workshop!

We present our findings from the perspective of impairment; but the relationship between impairment, employment and income is so strong that we might equally have begun the analysis with reference to either of the other two variables. However, as disability, which arises from impairment, is the focus of our study, the logic of our choice is clear enough.

Interpreting the expenditure tables

Tables 6 and 7 provide an overall picture of the expenditure pattern of people in employment. Whereas Table 6 provides information about expenditure incurred in connection with the current or last job of the 42 people who have been employed at any time since the onset of their disability, Table 7 considers only the expenditure of the 35 people currently in employment, and unlike Table 6, shows their expenditure according to their type of impairment. In this way it is possible to present information on current income and employment for the members of each impairment group, in the same table. This explanation for the way in which the tables in this chapter are organised, applies to the corresponding tables in the next chapter.

Tables 9 and 10 provide information on the expenditure of people in education and training; Table 9 looks at expenditure according to the class of item on which the expenditure was incurred and Table 10 according to the impairment of the person making the outlay.

Part A of Tables 6 and 9 in this chapter (and 11 and 14 in the next) describes the pattern of expenditure on various classes of items for people in employment and education and training respectively. Under each heading they show (a) the number of people who did not acquire an item either because they did not need it, or for some other reason did not obtain it; (b) the number who acquired the item at no cost to themselves or their income units; (c) the number who acquired the item at some expense, amount unknown; and, finally (d), the number who acquired the item on payment of a known sum. In these cases respondents themselves have paid either wholly or in part. We describe items as being 'of salience' if the respondent has obtained them; that is, if they are in categories (b), (c), or (d).

Part B of the same tables sets out the distribution of expenditure amongst the respondents in category (d) above, showing the range, mean and median expenditures for each item.

3. WORK-RELATED EXPENDITURE

3.1 Recurrent expenditure

3.1.1 Travel to work (Table 6)

The results of our questions on this subject (Col 1: Table 6) were less illuminating than we had hoped. Forty-three per cent of the sample for whom the questions were relevant could not provide information about their actual expenditure - they simply did not know how much they spent on travelling to work. Further scrutiny reveals that most of these 17 people were drivers who either had not worked out the running costs of their cars or were unable to separate the expenditure on their journey to work from expenditure on the other journeys they or members of their families made in the same cars. (The NRMA has devised a formula to determine the running cost of a car, but the

average motorist is unlikely to be au fait with its intricacies and the interview situation is not conducive to making the necessary detailed calculation.) Eighteen per cent of those in employment had incurred no expenditure on travel to work either because they walked to work or, more often, because they were driven by someone else who was not a member of their income unit, for example a parent. In these cases it appears that the cost was borne by that person and not by the one with the disability. On other occasions, travel costs were borne by the employers. For example, some people employed in sheltered workshops were transported to work in the organisations' buses, or by taxis provided for them. The outlays of the remaining 40 per cent who knew how much they spent ranged from \$240 to \$4,800 per annum (\$5 - \$100 per week)¹, with a median annual expenditure of \$1,185 and a mean of \$1,483. The person with very highest costs travelled a considerable distance to work by means of a taxi, her expenditure on which amounted to nearly one third of her gross earnings. People with disabilities are not always in a position to make purely rational economic choices where their jobs are concerned. Given her cerebral palsy, this respondent would probably have had very little choice of work, but her economic circumstances were unusual. A couple of years before the interview, she had been involved in a car accident, quite unrelated to her cerebral palsy, and had received a considerable amount in compensation. Undoubtedly this eased the economic constraints and provided her with much more freedom of choice. She could afford to go to work where she chose to.

3.1.2 Personal assistance needed to travel to and from work (Table 6)

Although as many as 32 per cent of the people in paid employment needed some assistance either to get ready for work, or to get in and out of vehicles, only one person paid cash for this help. In most cases it was provided by a parent or a spouse, often at some cost to that person, or by someone at the place of work, for example a colleague, a security guard, or in the case of employers whose primary purpose is the welfare of the people they employ, someone specifically employed to help people with disabilities. Taxi drivers provided another source of unpaid assistance, at least at a formal level, since sometimes they were tipped for this additional service. Often a person received personal assistance from several sources at different points of the working day and for a range of tasks. In the case of our sample, none of this assistance called for any expenditure.

3.1.3 Other recurrent expenses incurred as a result of participation in the workforce (Table 6)

Only six of the 41 people for whom this question was relevant had had other recurring expenses in the year preceding the interview, apart from those relating to travel. As Col 3 of Table 6 shows, the range in expenditure was immense (from \$75 to \$1,200 over the year) as was the variety of items it involved. These included regular excursions organised by the sheltered workshop, the replacement of mouthsticks used by a quadriplegic to operate a computer, and the maintenance costs of a guide dog. Two respondents received assistance at work which was provided by Home Care Service. However, they did not pay for this help.

3.1.4 The impact of impairment on work-related recurrent expenditure (Table 7)

As we can observe from Table 7, 31 or 89 per cent of the people currently in work incurred work-related expenditure. The mean annual expenditure of those who were able to provide information was \$1,481.

Four respondents incurred no recurrent work-related expenditure at all. They did not even have travel costs. They walked to work, or they were transported free of charge by the voluntary organisation for which they worked, or, being sight impaired, they travelled free on the train.

1. Annual figures have been divided by 48 not 52, to take into account 4 weeks annual leave from work.

TABLE 6: EXPENDITURE RELATED TO EMPLOYMENT¹

		Over Last Year				For The Duration of Current or Last Job			
		Travel to Work		Personal Assistance for Travel		Other Recurrent Expenditure		Non-Recurrent Expenditure	
		No.	%	No.	%	No.	%	No.	%
A PATTERN OF EXPENDITURE									
No Expenditure:									
a	Did not acquire	0	0	28	68.3	35	85.4	28	68.3
b	Item/service acquired but at no cost to respondent	7	17.5	12	29.3	0	0	9	22.0
Expenditure:									
c	Amount not known	17	42.5	1	2.4	1	2.4	1	2.4
d	Amount known	16	40.0	0	0	5	12.2	3	7.3
TOTAL		40 ⁺	100.0	41 ⁺	100.0	41 ⁺	100.0	41 ⁺	100.0
B AMOUNT OF EXPENDITURE									
	\$1 - \$250	1	6.3	-	-	1	20.0	0	0
	\$251 - \$500	1	6.3	-	-	0	0	0	0
	\$501 - \$750	2	12.5	-	-	1	20.0	0	0
	\$751 - \$1 000	3	18.8	-	-	2	40.0	0	0
	\$1 001 - \$1 250	1	6.3	-	-	1	20.0	0	0
	\$1 251 - \$1 500	4	25.0	-	-	0	0	0	0
	\$1 501 - \$1 750	0	0	-	-	0	0	0	0
	\$1 751 - \$2 000	1	6.3	-	-	0	0	0	0
	\$2 001 - \$3 000	1	6.3	-	-	0	0	0	0
	\$3 001 - \$4 000	1	6.3	-	-	0	0	1	33.3
	\$4 001 - \$5 000	1	6.3	-	-	0	0	0	0
	\$5 001 - \$7 500	0	0	-	-	0	0	0	0
	\$7 501 - \$10 000	0	0	-	-	0	0	0	0
	\$10 001 - \$15 000	0	0	-	-	0	0	1	33.3
	\$15 001 - \$20 000	0	0	-	-	0	0	0	0
	\$20 001 - \$30 000	0	0	-	-	0	0	1	33.3
TOTAL		16	100.0	-	-	5	100.0	3	100.0
Mean ²		\$1 483.00		-		\$741.00		\$15 004.00	
Median ²		\$1 185.00		-		\$816.00		16 296.00	
Range ²		\$240.00 -		-		\$75.00 -		\$3 574.00 -	
		\$4 800.00				\$1 200.00		\$25 141.00	

Note:

1. Relates to those who are currently working and also to those who are not currently working but who have been employed since the onset of disability.
2. Calculated on amounts given by those who had incurred expenditure for an item/service and who could recall its value.

⁺ Variation in total due to missing data in one case.
⁺ Variation in total due to missing data in two cases.
 Percentages may not add to 100 due to rounding.

Source: Survey Data, 1988.

TABLE 7: IMPAIRMENT CATEGORY BY DEPENDENCY, PRINCIPAL ACTIVITY, INCOME UNIT INCOME, INDIVIDUAL INCOME AND WORK-RELATED EXPENDITURE

		Impairment Category					
		Physical	Intellectual	Sensory	Psychiatric Illness	Other	Total
A. CHARACTERISTICS OF THE SAMPLE							
Impairment Category		30	17	3	4	6	60
Level of Dependency	None/minimal	14	0	0	1	5	20
	Moderate	4	1	2	2	0	9
	High	12	16	1	1	1	31
Principal Current Activity ¹	Employment	21	5	3	3	1	33
	Education/Training	6	12	0	0	1	19
	Other	3	0	0	1	4	8
Income Unit Income	Mean	\$20 234	\$7 895	\$31 407	\$8 897	\$9621	\$15 181
	Median	\$21 120	\$7 592	\$34 000	\$8 535	\$8 300	\$8 792
	Range	\$5 263	\$6812	\$23 454	\$7 029	\$6 242	\$5 263
		-\$55 000	-\$10 634	-\$36 767	-\$11 500	-\$14 960	-\$55 000
Individual Income	Mean	\$14 567	\$7 895	\$28 183	\$8 897	\$9 621	\$12 335
	Median	\$7 221	\$7 592	\$27 767	\$8 535	\$8 300	\$8 628
	Range	\$3 072	\$6 812	\$22 782	\$7 020	\$6 242	\$3 072
		-\$27 572	-\$10 634	-\$34 000	-\$11 500	-\$14 960	-\$34 000
B. WORK-RELATED EXPENDITURE²							
1.	Total number employed (including those in education)	22	5	3	3	2	35
2.	Recurrent expenditure (last year)						
2.1	No. incurring expenditure	21	3	3	2	2	31
2.2	No. incurring expenditure who recall amount	12	2	2	1	0	17
2.3	Mean recurrent expenditure (based on 2.2)	\$1 468	\$615	\$2 520	\$1 296	-	\$1 481
2.4	Median recurrent expenditure (based on 2.2)	\$1 156	\$615	\$2 520	-	-	\$1 112
2.5	Range of recurrent expenditure (based on 2.2)	\$528	\$240	\$624	-	-	\$240
		-\$4 800	-\$990	-\$4 416			-\$4 800
3.	Non-recurrent expenditure (current job)						
3.1	No. incurring expenditure	1	0	2	0	0	3
3.2	No. incurring expenditure who recall amount	0	-	2	-	-	2
3.3	Mean non-recurrent expenditure (based on 3.2)	-	-	\$20 719	-	-	\$20 719
3.4	Median non-recurrent expenditure (based on 3.2)	-	-	\$20 719	-	-	\$20 719
3.5	Range of non-recurrent expenditure (based on 3.2)	-	-	\$16 296	-	-	\$16 296
				-\$25 141			-\$25 141

- Note:**
- As demonstrated by Table 1 respondents may be participating in more than one activity. Hence totals in Part B differ from those in Part A of this Table.
 - Refer to Appendix III for a breakdown of the components of the total.
- * In all cases where a component of cost is missing or the respondent didn't know the amount spent on a particular item, the assumption has been made that nothing was spent on these items/services.

Source: Survey Data, 1988

As one might expect, people with physical or sensory impairment incur much higher work-related recurrent expenses than those with intellectual impairments or psychiatric illness. In any case, only two people in the latter group are in open employment. One has a psychiatric illness and works part-time as a librarian; the other has a mild intellectual impairment and works as a packer. All the other members of this grouping who are employed are in sheltered workshops.

By and large it is the difference in employment patterns which accounts for the differences in expenditure of people with different impairments. The costs of travel represent the most significant component of recurrent expenditure, and people with physical and sensory impairments had far higher travel costs than did those with intellectual impairment or psychiatric illness simply because they travel to open employment. They were much more likely to drive to work or to be driven by a spouse or carer. People with intellectual impairment or psychiatric illness tended to work closer to home and either walked to work, or more often were driven in a subsidized vehicle provided by the sheltered workshop or the organisation providing the residential accommodation. Normally the Mobility Allowance was used as payment for this transport. Whilst it is gratifying that people whose earnings are so very low effectively do not have to pay to travel to work, it is unfortunate that their mode of transport often tends to reinforce the isolation from the community which their sheltered employment already imposes.

Table 7 shows that average work-related recurrent expenditure of people with sensory impairments was particularly high. However, this value is strongly influenced by the very high expenditure of one person. This respondent, who had both sight and hearing impairments, travelled to work in a taxi. She explained that in other circumstances she would have used public transport, despite the difficulties it presented for her. However, taken together with the pressures of her present job and the unsociable hours it required, she found the strain of using public transport too great. Had she taken the train to work her transport costs would have been nil, as blind people travel free.

Over 90 per cent of the sample of people with physical impairments had work-related recurrent expenditure, and after people with sensory impairments, spent more on average than any of the other impairment groups. Once again this high expenditure is by and large incurred on travelling to work. One person, with travel costs of \$4,800 stands out. This person, to whom we have already referred, provides an excellent example of the complex interaction of employment, severity of disability and income as they affect expenditure. She used a taxi to travel to work as her disability was too great for her to drive herself to the city. She can usefully be compared with another respondent, with a disability somewhat less severe, who was able to drive herself to work. Although both travelled roughly the same distance, the journey by taxi was estimated to cost nine times more than the expense incurred by the person who drove herself. Two factors are operating: the severity of the disability and the ability to pay. The taxi user was more severely disabled and, though in a less well-paid job, had more additional financial resources than the car driver. Without these her choice of work, given the severity of her disability, would certainly have been much more limited. Though taxis, even with the UTA subsidy for people with disabilities, are a boon for short distances or for occasional and special use, for regular long distance use they are generally quite beyond the means of people with even middle income jobs. Indeed, only two people used a taxi to travel to work. Whilst a disability allowance of \$1,040 a year would more than cover our car driver's estimated annual travel-to-work costs of \$528, it would cover only a relatively small fraction of the taxi user's outlay, without which her present employment would be impossible.

The question of whether travel costs in their entirety should be regarded as an extra expense may perhaps be debated, given that they are incurred by everyone, disabled or not, but the examples above illustrate how costly it can be in this connection to meet the special needs that arise from disability.

Of course, we could consider not simply how much money our respondents spent on their journey to work, but how much less, or more, they spent than they would have done had they been able-bodied. This is not a question we could reasonably expect them to be able to answer however, though a high proportion of the sample (60%) thought that their transport costs generally were higher than they would have been had it not been for their disability. We attempted a comparison of the cost of the same journey to work or to education and training by different forms of transport. The results of this comparison are provided in Table 8. In nearly all cases the taxi, even with the subsidy for people with a disability, was by far the most expensive way to travel. Not surprisingly, very few used taxis for the journey to work. A comparison of the cost of the journey by private car or by public transport reveals no such clear cut answers. Sometimes the car is cheaper, sometimes public transport. In general, the longer the journey to work, the better an area is served by public transport, and the more days per week a person travels, the greater is the likelihood that public transport will be the cheaper option. However, the issue is largely academic. Most people with a severe impairment

TABLE 8: HYPOTHETICAL EXPENDITURE ON TRAVEL FROM HOME TO EMPLOYMENT AND EDUCATION OR TRAINING BY THREE MODES OF TRANSPORT: CAR, PUBLIC TRANSPORT AND SUBSIDISED TAXI

Mode of Transport	Expenditure on Travel							
	Most Expensive		Second Most Expensive		Least Expensive		Total	
	No	%	No	%	No	%	No	%
Car travel, (NRMA estimates)	0	0	22	42.3	30	57.7	52	100.0
Public Transport (Metro-trip estimates)	3	5.8	27	51.9	22	42.3	52	100.0
Subsidised Taxi	49	94.2	3	5.8	0	0	52	100.0

Notes:

- All calculations of expenditures are based on costings for January 1989. The estimates of cost are based on both the number of days travelled each week and the distance in kilometres.
- The cost of car travel was calculated by the NRMA and was based upon the average age and size of the vehicle used by survey respondents. Costings included depreciation, vehicle registration, insurance, NRMA membership, vehicle registration check fee, fuel, vehicle maintenance, minor and major servicing. Major repairs were excluded from the estimates, as was the initial outlay to purchase the vehicle.
- The cost of public transport was calculated by UTA Metro-trips for each respondent travelling to work and education or training.
- A number of cases were excluded from the table:
 - a) 3 people were excluded because the distance to their respective activities was less than 1 kilometre and therefore the cost of travel could not reasonably be calculated;
 - b) 1 person was excluded because that person worked from home;
 - c) 8 people were excluded because they are not currently in the paid workforce or in an education or training program.
- Five of the cases included people who both worked and attended an education or training program.
 - a) For 3 of these people both sets of expenditures have been included;
 - b) For 1 person who worked and attended two courses three calculations have been included;
 - c) For 1 person travel to work only has been included. Expenditure on travel to education or training was excluded because of the variety of venues which had to be travelled to, including one which was not in Sydney.
- Percentages may not add to 100 due to rounding.

Sources: NRMA unpublished data, 1989.
 UTA Metro-trips unpublished data, 1989.
 Survey Data, 1988.

have no choice as to their mode of transport. Unlike able-bodied people, they are not able to make an unfettered choice which simply takes expense into account. In fact, 75 per cent of our sample received a Mobility Allowance, for which a basic criterion of eligibility is that one cannot use public transport without substantial assistance. Most respondents who use a car do so because there is simply no alternative. They frequently point to the particular suitability of their cars for their special needs (for example, as being capable of accommodating a wheelchair or as having appropriate modifications). They also stress the absolute necessity for their cars to be roadworthy and reliable. Naturally this stems from an awareness of potential problems far more serious than the inconvenience and annoyance likely to be experienced by able-bodied people whose cars fail them.

Interviewer: *Do you think that you drive your car more or less because of your disability?*

Respondent: *Less, I think. Wouldn't I?*

Spouse: *Only because you don't go out as much ... It doesn't get used for shopping. We are frightened of getting it stolen ... The car is his legs.*

Respondent: *It takes over where this wheelchair leaves off.*

Several people mentioned their dread of mechanical breakdown. One woman with cerebral palsy vividly described her fear of this happening on her way home from work at night, and that she would be dragged defenceless from the car and left in the gutter unable to attract attention whilst the thieves drove off in her car. Another woman whose husband had quadriplegia had a similar fear. Since her husband's accident their social life had dwindled. The wife attributed this partly to her fear that their car would breakdown, that she would be attacked and that her husband would be unable to come to her defence. Such fears help to explain why people attach such importance to the reliability of their cars. One respondent deeply regretted that the purchase and running costs of a car telephone were beyond his reach. He thought that these telephones should be provided on some sort of concessional basis for car drivers with a mobility problem. Some of the more affluent respondents had taken advantage of the sales tax exemption concession available for the purchase of new cars, and had obviously found this a considerable help. Others, who could not afford new cars, expressed regret that no such concession was available to help them buy a more reliable secondhand car. Whilst the \$11 a week provided as a Mobility Allowance was not entirely disparaged, there is no doubt that many people thought that it only made a trivial contribution to their real extra travel costs. The sales tax exemption, on the other hand, was viewed very positively.

Only six respondents reported recurrent expenditure on items other than travel to work. Five of these were people with sensory or physical impairments giving rise to special needs. One person with quadriplegia spent \$75 on the replacement of mouthsticks used to operate a computer. Two others had to meet the annual maintenance costs of guide dogs, estimated by one respondent to be \$816 and by the other to be \$624, a disparity which illustrates the variability in reported costs of even reasonably well defined items. The fourth respondent's expenditure was for housecleaning. This person with multiple sclerosis was not strong enough to combine even a part-time job with housework. She placed such a high priority on going out to work that she paid \$1,200 a year for the cleaning of her part of a shared flat. The fifth respondent, who had an intellectual impairment paid \$990 a year to attend her sheltered workshop. The sixth respondent with quadriplegia could not recall his expenditure. He spent money on palmer bands, special aprons and bags to hang on his wheelchair in which he carried his tools of trade.

3.2 Non-recurrent expenditure (Tables 6 and 7)

We looked at work-related needs in terms of the special equipment or facilities or services respondents required to function effectively in their employment. From Table 6 (Col 4) it is evident that 28 of the 42 respondents who were either currently working or had worked since the onset of their disability had no apparent need for special equipment or facilities at work. The remaining 13 had acquired a range of items or services. In only four cases had these involved the respondents themselves in any expense. When we consider those currently in employment this number is reduced to 3 out of 35 people (Table 7).

We shall now describe the circumstances of the four people who have incurred some non-recurrent expenditure since the onset of their disability. One of these four respondents, who had a physical disability, could not recall the amount

he had spent on modifications of his car, which included the installation of hand controls, to enable him to drive to work. The NRMA had estimated that this work would have cost a minimum of \$600.

The expenditure of the other three ranged from \$3,574 to \$25,141. Two of them, both with sight impairments, were in professional occupations in the top income decile of the sample and had acquired a range of equipment, some of it costly, which they considered enabled them to perform their jobs more effectively. Their purchase of this equipment is fairly clearly related to their personal and social circumstances. In both instances household income comprised two professional salaries; in neither case were there dependent children to support. In both instances the income was enhanced by the non-means-tested blind pension. There may well have been other enabling factors which the questionnaire did not explore. These two cases have been considered together because their situations have certain parallels. This should not be taken to imply equivalence in the economic circumstances of the two people; this was certainly not the case. Although we have identified sensorily impaired people as relatively advantaged members of our sample (and in their relation to the social security system, vis-a-vis other people with disabilities, this is undoubtedly so) it would be quite incorrect to generalise from these two examples, either within the sample or to sight impaired people more generally. For example, the third respondent with a sensory impairment, had much more limited resources. His wife, a former teacher, was not earning. There were three dependent children in the family, and his job in a factory located at a considerable distance from his home was neither well paid nor secure. He found the journey to work and his job a daily ordeal, but no alternative work was available. This was partly a consequence of his lack of qualifications, but it should be noted that even the two respondents with professional qualification reported that their employment opportunities had been severely limited as a result of their disabilities.

The fourth respondent who had incurred some expenditure on a work-related item had a physical disability. He was temporarily out of work, on grounds of ill health. He had bought himself an electric shuttle and walking-frame to enhance his mobility at work.

In the last three cases of non-recurrent work-related expenditure, in addition to the amounts respondents themselves had spent, some help had been received from outside sources. For example, one of the sight-impaired respondents, who needed to be able to work at home, had purchased her own talking computer. She had also purchased a white cane, a blind person's tape recorder, a dictaphone, a special watch, and special hearing aids. The employer's contribution to this person's needs in the workplace was a talking computer and a telephone with augmented hearing. Guide Dogs for the Blind had provided her with a dog but this had involved the respondent in further recurrent expenditure (for example, dog food, shampoos and some medicines) and some non-recurrent expenditure, (for example, a dog bed, a fan and a lead). The second respondent had over his working life bought a number of aids for his impaired sight. One such aid had also been provided by a private donor and another donor had made some contribution to the purchase of yet another aid. The employer of the third respondent, who had purchased mobility equipment for work, had installed a hand rail for the toilet at work. In all of the three cases we have just described the value of the respondents' contributions considerably exceeded that of the donors.

The number of people who reported non-recurrent expenses is remarkably low, but this can hardly be taken as a reflection of the limited needs of people who are working. Rather, it is accounted for by the fact that a great many people had their requirements met by other agencies, public and private. In some cases, as we have noted, they made a partial contribution. In others, these sources of support provided in full for the needs in question.

Nine respondents had work-related needs which had been met entirely from external sources. The types of items mentioned included mobility aids, suitably designed office equipment and furniture, splints, specially designed computers and communication aids. In some cases it was the employer who had provided the item; in others, particularly in the case of wheelchairs, it had been the Program of Aids for Disabled People (PADP). Less often, support had come through the Commonwealth Rehabilitation Service (CRS). In several instances, support had come from a number of sources. In one example, a person with a high level of quadriplegia had been provided with a manually operated wheelchair by the PADP scheme. A group of his friends had purchased a second electric wheelchair solely for use at his workplace. His employer had adjusted his computer and had made special adjustments to his work area, including provision of a hands-free telephone and voice control equipment. His brother had given him a secondhand desk which his grandfather, in turn, had adapted so that he could use it in the workplace. Homecare had arranged to visit the workplace three times daily free of charge to provide personal care.

Aids and equipment provided through channels of formal support may not be sufficient to ensure full participation unless there is other support as well. This is illustrated in the contrasting case of another person with a similarly high

level of quadriplegia, who had also been provided with an electric wheelchair by PADP. However, once its batteries had run flat he could not afford to replace them and was forced to return the wheelchair. This respondent commented that whilst the electric wheelchair would undoubtedly have made his life easier, he was not in a position to maintain it and it had become a financial burden. From his point of view, the chair had not been worth the worry it had caused him while it was in his possession.

These examples demonstrate the importance of the resources that individuals themselves bring to their situation. Their knowledge of formal support networks and the social and economic resources of their informal networks are both clearly crucial to the satisfaction of their needs. Employers were sometimes a source of help for items that required a significant capital outlay. However, with two exceptions, all respondents who received help from their employers worked either for government or government-supported organisations. One of the private sector employees in question mentioned that he had received a considerable amount of support from his employer, however, including the promise of continued employment following his recovery from a traumatic accident.

3.3 Additional work-related requirements

Respondents were asked to describe items which given their disability would help them in their work, but which they lacked at present. The additional requirements identified in responses to this question were extremely modest. Only 7 of the 35 respondents who were employed at the time of the interview mentioned any such items. These were all people with physical impairments. Two people would have liked to have an electric wheelchair at work, but neither could afford one. Two people would have liked more comfortable, ergonomic chairs, but were also unable to meet the cost. Another respondent with cerebral palsy had asked for a special phone, but the request had been ignored by his employer. One person found the physical organisation of his office unsatisfactory. His job involved a good deal of walking from desk to desk, which he found very tiring. He thought that a reorganisation of the flow of work would have helped him, but it was not clear whether or not he had sought this. Another respondent with a high level quadriplegia who had had pneumonia on several occasions, would have liked additional heating and air-conditioning in his office. To alleviate this problem his employers were giving some consideration to the possibility of his working from home.

It is not clear whether the response to our question was a true reflection of the level of need or whether the response reflects a reluctance on the part of respondents to appear greedy either to their employers or to the interviewer. It is more than likely that people with disabilities will not wish to draw additional attention to these in their work situation. In one way or another, it is clear that people made do, or 'managed' with minimum demands, if any. One must also emphasise that people with many additional needs are less likely to be in the workforce and would not therefore have been selected for this study. It is important to note that quite a large proportion of the sample (62%) worked in the public sector or for organisations catering specifically for the needs of people with disabilities. It seems unlikely that people working for such organisations would have many additional unmet needs.

4. EDUCATION AND TRAINING RELATED EXPENDITURE

4.1 Recurrent expenditure

4.1.1 Travel to education and training (Table 9)

Thirty three per cent of people participating in education or training, (Col 1, Table 9) were not able to provide an estimate of their expenditure on travel. Sometimes they paid their Mobility Allowance direct to the organisation responsible for their training, which also provided their transport. In these circumstances people were often unable to say whether the Allowance entirely covered their travel costs, or whether the organisation provided an additional subsidy and, if so, how much this was. Thirty three per cent incurred no expenditure, either because they were being driven to their destinations by parents or other relatives or because they believed that the organisation which provided the training (usually an ATC) entirely met the travel cost. Amongst representatives of people with an intellectual impairment there was in general a good deal of uncertainty as to how travel expenses were being covered. Expenditure of the 8 respondents who were able to provide information ranged from \$480 to \$2,880 per annum (\$10 -

\$60 p.w.).² The median expenditure was \$840 and the mean \$1,122. On average, more was spent on journeys to place of work than on journeys to place of training or education. In addition to the factors mentioned above this difference will also be a reflection of the fact that, on average, the members of our sample travelled further to work than to their education or training.

4.1.2 Personal assistance required travelling to and from the place of education and training (Table 9)

Of those in education and training, a somewhat higher proportion needed assistance, but a proportion similar to that among those in employment, paid nothing for such help. As before, the parent or the training body, most commonly both, provided the help. Only two people found it necessary to pay for such assistance; one was a person with autism whose need for personal assistance was primarily for supervision while travelling. The other was a visually impaired person who needed help to participate in a Residential School.

In a small sample, detailed knowledge of a single case can often point in the direction of further fruitful investigation. In one instance parents paid 6 dollars per day for someone to accompany the respondent from home to the place where he could be picked up by bus. This enabled the parents themselves to go to work. On the return journey, one of the parents would pick up the respondent from the place at which he was dropped off by the bus. The organisational problems for these working parents were clearly quite substantial, and unavoidable, because there was no other closer source of day-time care prepared to accept anyone with so profound a disability as their son's. The parents told us that other people in the area with this level of disability spent all day at home with their parents because of the absence of day care facilities. The indirect costs, in these cases, must be considerable. It would be invidious to compare the costs of parents who are caring at home full-time for their adult offspring with the expenditure incurred by the parents of our respondent. Many might not be able to afford the extra \$30 they paid each week.

The complexity of the arrangements which sometimes have to be made in order to secure personal assistance was revealed by another member of our sample. This respondent had cerebral palsy and her condition was deteriorating. At the time of the interview she was studying for a degree by correspondence. Once a year she was required to attend a Residential School at a rural tertiary institution. Her mother accompanied her on these visits to provide the personal assistance she needed. The institution paid for her mother's board and lodging, but not for her fare. This year our respondent could no longer manage the journey by train as she had done in previous years, and had to go by plane. We see here, in a rapidly changing situation, a complex set of arrangements where expenditure is concerned. The institution provides a subsidy, the mother provides unpaid assistance, but the respondent's expenditure is increased to enable the mother to provide the unpaid assistance. It can be extraordinarily difficult, as this case illustrates, to quantify the cost of personal assistance and to determine its incidence.

4.1.3 Other recurrent expenses incurred as a result of participation in education and training (Table 9)

By comparison with respondents in the workforce, more of those participating in education and training had resultant recurrent expenditure. For the most part this consisted of fees. This was the case both for people in ATC's and for people in non-specialist further educational institutions. In the latter case, where students were receiving an Invalid Pension, the administrative charges (now, in any case, abandoned) were waived and only the annual student activity fees were required.

In the case of people with intellectual impairments, it was sometimes unclear who was actually meeting the expenditure. Parents usually acted as trustees of their offspring's social security payments or there was no clear demarcation between the resources of parents and offspring. Sometimes parents said that they thought they paid nothing or relatively little for their offspring over and above the Invalid Pension and the Mobility Allowance, but that

2. Annual figures have been divided by 48 not 52, to take into account 4 weeks annual leave from education and training.

TABLE 9: EXPENDITURE RELATED TO EDUCATION AND TRAINING¹

	Over Last Year				For The Duration of Education/Training			
	Travel to Education/Training		Personal Assistance for Travel		Other Recurrent Expenditure		Non-Recurrent Expenditure	
	No.	%	No.	%	No.	%	No.	%
A PATTERN OF EXPENDITURE								
No Expenditure:								
a Did not acquire	0	0	14	58.3	0	0	15	62.5
b Item/service acquired but at no cost to respondent	8	33.3	8	33.3	3	13.6	6	25.0
Expenditure:								
c Amount not known	8	33.3	1	4.2	2	9.5	0	0
d Amount known	8	33.3	1	4.2	17	77.2	3	12.5
TOTAL	24	100.0	24	100.0	22*	100.0	24	100.0
B AMOUNT OF EXPENDITURE								
\$1 - \$250	0	0	0	0	2	11.8	2	66.7
\$251 - \$500	2	25.0	1	100.0	1	5.9	0	0
\$501 - \$750	2	25.0	0	0	3	17.6	0	0
\$751 - \$1 000	1	12.5	0	0	1	5.9	0	0
\$1 001 - \$1 250	1	12.5	0	0	4	23.5	0	0
\$1 251 - \$1 500	0	0	0	0	0	0	0	0
\$1 501 - \$1 750	1	12.5	0	0	0	0	0	0
\$1 751 - \$2 000	0	0	0	0	0	0	1	33.3
\$2 001 - \$3 000	1	12.5	0	0	1	5.9	0	0
\$3 001 - \$4 000	0	0	0	0	4	17.6	0	0
\$4 001 - \$5 000	0	0	0	0	1	5.9	0	0
\$5 001 - \$7 500	0	0	0	0	0	0	0	0
\$7 501 - \$10 000	0	0	0	0	0	0	0	0
\$10 001 - \$15 000	0	0	0	0	0	0	0	0
\$15 001 - \$20 000	0	0	0	0	0	0	0	0
\$20 001 - \$30 000	0	0	0	0	0	0	0	0
TOTAL	8	100.0	2	100.0	17	100.0	4	100.0
Mean ²	\$1 122.00		\$250.00		\$1 633.00		\$745.00	
Median ²	\$840.00		-		\$1 128.00		\$120.00	
Range ²	\$480.00 - \$2 880.00		\$250.00 -		\$70.00 - \$5 000.00		\$115.00 - \$2 000.00	

- Notes: 1 Relates to those who are currently in an education or training program.
 2 Calculated on amounts given by those who had incurred expenditure for an item/service and who could recall its value.
 * Variation in total due to missing data in one case.
 Percentages may not add to 100 due to rounding.

Source: Survey Data, 1988.

they did not really know. At other times, particularly when their offspring came home for the weekend or on public holidays, it was clear to them that they incurred a considerable amount of additional expenditure, perhaps on a second set of clothes to be kept at home, on outings or other entertainment, or for the decoration and sometimes the furnishing of the bedroom at the hostel. (The replacement of clothing lost or spoilt at the ATC was another source of expense.) Although some parents said that the outings and excursions organised by the ATC were included in the course fees covered by the Invalid Pension, other parents said they needed to subsidise their offspring.

There are other costs mentioned by parents of offspring with intellectual impairments. These do not fall neatly into a category of 'recurrent expenditure' since they do not occur on a formally regular basis. These were the costs associated with fund-raising. Some parents described in detail, how much time, energy and money they put into mobilising financial support, in addition to that provided by government, for the voluntary organisations with which their offspring were associated. Their lives often seemed dominated by the needs of their, now adult, offspring. Perhaps most worrying was the anxiety some parents felt about possible implications for the future well-being of their offspring should they no longer feel willing or able to continue contributing to the work of fund-raising.

4.1.4 The impact of impairment upon education and training related recurrent expenditure (Table 10)

The pattern of expenses incurred as a result of participation in education and training differs from the pattern of work-related expenditure described above. Everyone who received education or training incurred some recurrent expenditure. Overall, education and training-related expenditure was slightly higher than work-related expenditure, averaging \$1,616 per annum as against \$1,481. People with intellectual impairments tended to pay more than those with physical or sensory impairments. In the case of education and training, tuition and other course-related costs dominated recurrent expenditure, rather than travel costs as in the case of employment.

People with intellectual impairments typically attended an Activity Therapy Centre on a full time basis. The cost of attendance ranged from \$228 to \$3,120 per annum, depending on the organisation providing the training. Not only was there very considerable variation in the cost of attending an ATC, but also considerable variation in charges for transport to and from the ATC. Sometimes hostels provided transport and personal attendance for their residents' daily journey, and in these cases did not appear to charge anything more than the Mobility Allowance. In some instances the charge for attending the ATC also covered transport to and fro. One respondent, however, was required to pay \$1,632 a year for transport to her ATC, an amount considerably in excess of the Mobility Allowance.

Receipts shown to the interviewer revealed that in at least 4 cases over 90 per cent of the respondents' social security payments were being consumed by hostel and ATC charges. These took up a very high proportion of benefit in all other cases, leaving little for everyday expenses such as toiletries, clothes, shoe repairs and entertainment. Many parents had to find the money to meet these additional needs. One wonders about the quality of life of those who had no parents to look after their interests and supplement social security payments. One parent calculated that he contributed at least \$1800 a year for extra pocket money, weekly excursions and an annual camp. This did not include the cost of a second set of clothes for his son to wear when he came from the hostel each weekend. It is not surprising that some parents were sceptical about the value of an increase in social security payments. This, they believed, would be completely absorbed by higher hostel and ATC fees.

Respondents with physical or sensory impairments spent more on transport to their courses but less on the courses themselves than did people with intellectual impairments. The average cost of their courses was \$297 per annum compared with \$1,707 for people with intellectual disabilities attending an ATC. In general, the cost of attendance at educational institutions was limited to students' union fees. On transport people with a physical impairment spent on average \$1,332 per annum compared with the \$1,056 spent by those with intellectual impairments. This latter average, based on only two cases, must obviously be regarded with caution however. People with intellectual impairments were generally unable to specify the amount they spent on travel because it was included in other comprehensive charges. The average travel costs of people with physical impairments has also been somewhat inflated by the very high expenditure incurred by one person, which amounted to \$2,880 last year. He travelled a considerable distance to his ATC by subsidized taxi, the only means of transport available to him.

TABLE 10: IMPAIRMENT CATEGORY BY DEPENDENCY, PRINCIPAL ACTIVITY, INCOME UNIT INCOME, INDIVIDUAL INCOME AND EDUCATION AND TRAINING-RELATED EXPENDITURE

		Impairment Category					
		Physical	Intellectual	Sensory	Psychiatric Illness	Other	Total
A. CHARACTERISTICS OF THE SAMPLE							
Impairment Category		30	17	3	4	6	60
Level of Dependency	None/minimal	14	0	0	1	5	20
	Moderate	4	1	2	2	0	9
	High	12	16	1	1	1	31
Principal Current Activity ¹	Employment	21	5	3	3	1	33
	Education/Training	6	12	0	0	1	19
	Other	3	0	0	1	4	8
Income Unit Income	Mean	\$20 234	\$7 895	\$31 407	\$8 897	\$9 621	\$15 181
	Median	\$21 120	\$7 592	\$34 000	\$8 535	\$8 300	\$8 792
	Range	\$5 263	\$6 812	\$23 454	\$7 029	\$6 242	\$5 263
		-\$55 000	-\$10 634	-\$36 767	-\$11 500	-\$14 960	-\$55 000
Individual Income	Mean	\$14 567	\$7 895	\$28 183	\$8 897	\$9 621	\$12 335
	Median	\$7 221	\$7 592	\$27 767	\$8 535	\$8 300	\$8 628
	Range	\$3 072	\$6 812	\$22 782	\$7 020	\$6 242	\$3 072
		-\$27 572	-\$10 634	-\$34 000	-\$11 500	-\$14 960	-\$34 000
B. EDUCATION/TRAINING RELATED EXPENDITURE²							
1.	Total number in education/training (including those in employment)	8	13	1	1	1	24
2.	Recurrent expenditure (last year)						
2.1	No. incurring expenditure	7	11	1	1	1	21
2.2	No. incurring expenditure who recall amount	7	11	1	1	1	21
2.3	Mean recurrent expenditure (based on 2.2)	\$995	\$2 138	\$2 050	\$576	\$1 107	\$1 616
2.4	Median recurrent expenditure (based on 2.2)	\$580	\$1 632	-	-	-	\$1 224
2.5	Range of recurrent expenditure (based on 2.2)	\$70	\$228	-	-	-	\$70
		-\$2 880	-\$5 000				-\$5 000
3.	Non-recurrent expenditure (current job)						
3.1	No. incurring expenditure	1	1	1	0	1	4
3.2	No. incurring expenditure who recall amount	1	1	1	-	1	4
3.3	Mean non-recurrent expenditure (based on 3.2)	\$120	\$3296	\$2 000	-	\$115	\$1383
3.4	Median non-recurrent expenditure (based on 3.2)	-	-	-	-	-	\$1 060
3.5	Range of non-recurrent expenditure (based on 3.2)	-	-	-	-	-	\$120
							-\$3 296

Notes: 1. As demonstrated by Table 1 respondents may be participating in more than one activity. Hence totals in Part B differ from those in Part A.

2. Refer to Appendix III for a breakdown of the components of the total.

* In all cases where a component of cost is missing or the respondent didn't know the amount spent on a particular item the assumption has been made that nothing was spent on these items/services.

Source: Survey Data, 1988.

We have noted that almost all the people with intellectual impairments who were undergoing education or training were attending an ATC. In the interview we asked why people were involved in their training. Almost without exception the caregivers of people attending an ATC viewed this question as absurd. 'What else is there for them to do?' they said. The one person not attending an ATC had a mild intellectual impairment and was attending an evening class to learn basic written English. His long term goal was to obtain a driver's licence so that he could cease to be a packer and become a lorry driver.

In contrast to the people with intellectual impairments, respondents with physical or sensory impairments were taking a wide range of courses, both academic and vocational. Two people were pursuing postgraduate degrees, three undergraduate degrees, (one by correspondence), and one was undertaking a postgraduate diploma course by correspondence. The remainder were pursuing vocational courses at TAFE colleges. In almost all cases their objective was to improve their position in the labour market. Some people recognised that this might be a vain hope because the problem of job acquisition was compounded by disability. One middle aged woman with cerebral palsy, who was taking a university degree by correspondence in the hope of becoming a teacher, felt that the contraction in the number of available teaching posts was making it unlikely that she would ever achieve this goal. In a competitive situation, she believed her age and her disability, which inevitably limited her mobility, would both count against her.

People with intellectual impairments are more likely than people with physical impairments to need personal assistance. Nearly everyone attending an ATC needed some personal assistance in order to make the journey. In all cases except one this was provided jointly by carers or a member of the hostel staff at the home end of the journey, and by a care attendant or a bus driver at the other end. In only one case was a cash outlay required; personal attendance was normally included in the ATC or hostel charge. In the exceptional case, already mentioned, the trainee required paid assistance to get to the place where the ATC bus could be picked up, at an annual cost of \$1,440.

Some people with physical or sensory impairments needed personal assistance to attend their courses, given the nature and severity of their disabilities. It was rare, however, for there to be a charge for this. Sometimes the driver was relied upon to help the student in and out of the taxi. Sometimes the educational institution arranged for its employees to help the student get from place to place on the campus, or this help was given by a fellow student. The two students who were taking a degree by correspondence both needed assistance to attend the annual residential school. In one case the university made no charge for the attendant's board and lodging. In the other case it made a charge of \$250. Of course, these two students also needed assistance with the journey to the residential school. In one case this involved an additional airfare. In the other, the journey was made by car so there was no additional cost. Though we are only discussing financial costs in this report, it needs to be emphasised that the setting up of arrangements for attendant care often requires considerable effort, even, or perhaps especially, when they appear to cost no money.

4.2 Non-recurrent expenditure related to education and training (Tables 9 and 10)

Nine of the 24 people in our sample mentioned items which either they or others had purchased to enable or at least to help them to participate in education or training. Three respondents had incurred expenditure on this account. Two of these people, who were studying at university, had purchased cassette players to record their lectures. These represented relatively small capital outlays but did involve appreciable recurrent expense on tapes and batteries, given that the respondents' sole source of income was the Invalid Pension. One person with a sensory disability incurred expenditure on a computer valued at \$2,000. Six people acquired items but at no cost to themselves. Two parents incurred expenditure on behalf of offspring with intellectual disabilities. In one case this was for a pair of 'safety shoes', costing around \$60 - \$70, and in the other it was for a very expensive travel chair (costing \$3,296) to enable the respondent to sit in a car. In both cases it would appear that the parents bore the cost entirely. In a further four cases respondents' needs had been met without drawing on their own resources. CRS had provided various items of equipment for two people, PADP for a third and the university had provided adapted furniture to enable a student with paraplegia to work in a laboratory.

On the whole the information on non-recurrent expenditure is unreliable, especially as it concerns people with intellectual impairments. We found it impossible to obtain either precise amounts or to ascertain who was actually bearing the expense. Despite this, it should not be assumed that the amounts involved are necessarily small. In the case of people with intellectual disabilities, expenditure is likely to be incurred for such items as excursions, outings and camps organised by the ATC, for which there is sometimes an additional charge. When such a charge was made,

parents often reported that they themselves had found it necessary to pay because it had not been possible to stretch the pension to include this expense once the charges for hostel accommodation and ATC had been deducted.

Respondents with physical impairments had a similar difficulty in assessing their additional non-recurrent expenditure. Because they found it difficult to get to libraries, they needed to do a great deal of photocopying. They might purchase more books than they would otherwise have done. They phoned around a great deal for books to check that they were available, before making the journey to the library. A couple of students who found difficulty in writing mentioned that they had bought tape recorders. One blind student had bought a computer so that a relative could type his books for transcription into braille. Whilst she provided this help free of charge, he nevertheless had to buy the word processor and the books, and to pay the costs of braille transcription from the computer disks. He estimated that apart from the cost of the word processor, transcription of each book cost about \$100. He required 16 books for his course, none of which was available in braille. Another student who had quadriplegia, referred to a more obscure but nonetheless real extra cost. His difficulty in writing and in manoeuvring a page so that he could write on the reverse side meant that he used much more paper than he would have done had he not had these difficulties.

Many of the examples that we have provided indicate that there is considerable dependence on others, and that services are often provided free or at low cost to people with additional needs. Whilst one would not wish to thwart the altruistic impulses to which our examples bear witness, it is pertinent to ask about the situations of people who do not have these supports. How do they manage? How far are people's activities constrained by an absence of unpaid help when their resources are too limited to pay for services they need? Indeed, this is the very situation in which the blind person referred to above fears he may shortly find himself. It is possible that the relative who types his books may soon no longer be available. If this valuable service ceases, he believes he may have to give up his course.

4.3 Additional education and training related requirements

Five of the 24 people identified items that they would have found helpful in their education or training. Two were parents of people with intellectual impairments. They wished that the ATC placed more emphasis on education and provided more useful training for independent living. One of these parents specifically mentioned more and better travel training. Another mentioned the need for training in living, social and leisure skills. There was also a plea for more speech therapists. The inadequacy of government funding for such services was noted by one parent.

Respondents with physical disabilities were also modest in their additional requirements. Had their resources permitted, three people would have liked a computer. One thought a personal computer which could be linked to the University's mainframe would have been particularly helpful. One other person who was receiving a grant through the Commonwealth Rehabilitation Service (CRS) thought that the allowance of \$100 for books was too low.

In this section of the report we have considered several sources of expenditure incurred both because the respondents are participating in the workforce or in education and training and also have impairments. A number of people reported additional needs arising in these circumstances but in many cases had them met at little or no extra cost to themselves. That, at any rate is what the quantitative picture suggests. However, there is a sense in which quantification distorts actual experience. We have tried to divide the data into meaningful categories of need and expenditure: travel, personal assistance, recurrent, non-recurrent; but this method of looking at the data can provide only limited insight into the cumulative effect on individuals. We have therefore looked a little closer by drawing on more detailed case material. This is the approach we develop in Chapter VI where we deal with disability-related expenditure more generally.

CHAPTER V

THE INDIRECT COSTS OF PARTICIPATION

Although actual expenditure or outlay was not a significant factor for many in our sample, a large proportion of those who were either currently in employment, or who had been at some time since the onset of their impairment, felt that their earnings, chances of promotion and work-related benefits had been affected by their disabilities. Altogether 86 per cent of respondents felt that their earnings or chances of promotion had been affected, 9 per cent thought that they had not been and 5 per cent were not able to say. When it came to the effect of their disability on fringe benefits, exactly 50 per cent thought that there had been an effect, 43 per cent thought that there had not and 7 per cent were unable to say. In many cases where respondents thought they had been disadvantaged their views were backed up by compelling concrete illustrations.

5.1 The effect of disability on job accessibility, earnings and promotion

Although the main focus of this study is on expenditure directly associated with participation in the workforce, any study dealing with the financial implications of participation would be seriously lacking if it ignored obstacles to the fulfilment of potential in the workforce. Occupational role is, after all, a major determinant of an individual's social position and an important means of self realisation.

But there is another reason for including a discussion of this issue in a study of participation. Some of the factors which affect job opportunities are also likely to affect expenditure. For example if jobs which are suitable and accessible to people with disabilities are not available locally, it is likely that either travel costs or housing costs will increase. As we have seen, a large proportion of our sample worked in the public sector or voluntary organisations. While respondents employed in the public sector certainly testified to problems of accommodation and advancement, our data indicate that these organisations bear many of the costs of employing people with disabilities. Although we have no direct evidence one way or another, it is obvious that private sector organisations which of necessity are concerned with profitability have every commercial reason for preferring not to incur the additional expenditure sometimes necessary to accommodate employees with disabilities. Presumably their willingness to employ people with disabilities is likely to depend on the numbers of people at the appropriate levels of skill available to fill their job vacancies.

Those who believed they were disadvantaged in the workforce saw this either as a consequence of the impairment itself limiting their capacity to perform in the same way as an able-bodied person could or from an early educational disadvantage resulting from their disability, or from problems of access severely limiting their work options, or from discrimination. In the majority of cases, as we shall see from the examples below, interplay between the impairment and the environment seemed to be the principal constraint.

Some of those who believed they had been affected detrimentally saw this as arising from early disability-related disadvantage. Their disabilities had prevented them from receiving as complete an education as they might have done. In some cases the education of respondents had been interrupted on account of their disability or associated ill health. Sometimes their impairments had led to a misjudgement of their educational potential. Some had even been judged to be 'retarded'. Three respondents, one with a hearing impairment and two with cerebral palsy, spoke about this. In two of these cases people believed that their early educational disadvantage had restricted their subsequent access to the labour market.

Some respondents thought that their particular disabilities limited their capacity to perform in the same way as able-bodied people. Answers to our question about the effect of disabilities on earnings were typically couched in terms of lost opportunities. In this context it is important to recognise that it was peoples' perceptions that we were soliciting. In real life we are looking at a continuum from ability to disability. All of us, whether able-bodied or disabled, perform some tasks better than others. Many of the people we spoke to, however, saw themselves first and foremost as disabled. Their view reflects a widespread community attitude.

Nevertheless, peoples' own explanations for their occupational disadvantage are important. 'My disability limits what I can do' or 'You need to be mobile and flexible to get promotion in my job, and I'm not' or 'I can only work part-

time'. The point raised above was illustrated by another person who took the problem of only being able to work part-time further. 'Its so limited, what I can do and the debilitating nature of my illness is such that I can't work more than two days. I have to work on weekends because I can't get a part-time job around here except at the times that no-one else wants to work' and 'Because they look on me as a telephonist. I could have worked in the pay office if I was able to work full-time'. It is the poor fit between particular job requirements and the available opportunities which affects the job choices of these people in much the same way as it does in the case of mothers who are restricted as to the hours they can offer.

Interviewer: *Are there any things associated with your disability which you don't have but which would help you in your job?*

Respondent: *Umm. Not really. No. The only thing that would help me at the moment is promotion (laugh). Actually this is important. I think really important Well, people with disabilities like me can't do the hack work and I'm at the moment at the level of doing the hack work. And so the next level of promotion which involves ... being a manager. I could do that on my head because its non-physical. The manager comes in every morning, sits at his desk, he answers his phone a lot, writes some things and its typed for him. It's non-physical. But if you're a disabled person it's very hard to get to the level where you are above the physical work because the assumption is that because you have a disability you can't do it which is really silly, because it's the other way around. You can't do the hack work if you have a disability.*

A number of respondents vividly described the daily effort expended by people with disabilities, and their helpers, in getting ready for work. Every task concerned with personal care can involve more or less of a struggle; getting out of bed, attending to personal hygiene, washing, dressing, shaving and the preparation and eating of breakfast prior to leaving the house for work. In the case of many forms of physical and intellectual impairment this will certainly involve the help of others, whether members of the family, or paid or volunteer attendants, or both. The scope for domestic friction in situations involving such dependency is clearly immense. It would hardly be an exaggeration to suggest that some people with disabilities (and in many cases their helpers too) have already undertaken a day's work before leaving their homes. The disability-related obstacles to participation are immense. One respondent described his predicament in this way:

Respondent: *Its useless going to a position where it takes a day to get there. See I can't. Homecare has to come at a certain time. By the time they're finished we never leave here by 9.00 am. So if you had a job at North Sydney you wouldn't be there until 10.00 am ... Because you're in a wheelchair you are limited.*

This daily struggle to accomplish anything has been vividly described by Robert Murphy, an anthropologist with quadriplegia, in his book *The Body Silent* (1987).

The journey to work also represented a hurdle for many people with disabilities. One blind respondent described the daily fear he felt; that he would walk into an obstacle and injure himself; or be run over as he attempted to cross the road unaided; or that he would fall on the train track. In fact, two years ago exactly this had happened and it had proved both physically and psychologically damaging. He had subsequently acquired a guide dog but they had not at first been able to establish the necessary rapport. This further damaged his already low self-esteem. Another respondent described his journey to work as follows:

Interviewer: *How long have you been in you present job?*

Respondent: *I was working in town before I got this transfer. I've been at ... for two years.*

Interviewer: *What did you do about parking in town?*

Respondent: *I didn't drive.*

Interviewer: *You went by taxi?*

Respondent: *No.*

Interviewer: *How did you get in?*

Respondent: *I caught a train.*

Interviewer: *With your chair?*

Respondent: *Yes.*

Interviewer: *How did you do that?*

Respondent: *Umm. What I did was I drove to Strathfield Station - 'cause at my local station one side had a ramp and the other side didn't ... So of a morning it was alright because there were ramps but of an afternoon there was seven stairs which meant I had to wait until everyone got off the train, then down the platform to the ticket collectors to help me down the stairs. And that's when I started to lobby with the Commissioner of the State Rail Authority to construct a ramp at ... on the other side. They said 'No'. I got the local Member of Parliament involved. Anyway, there's a ramp there now. So what I did was drive to Strathfield because of that. I used to catch a train from Strathfield to Town Hall. Get out at Town Hall and cross the platform and catch an Eastern suburbs train to Martin Place. Then up and down seven escalators.*

Interviewer: *How did you manage that on an escalator. Could you stand?*

Respondent: *No. In a wheelchair ... Easy. Just put your front wheels on the step as its forming and hold on.*

Interviewer: *I'd be petrified!*

Respondent: *Yes, a lot of people are. But if you want to get anywhere in society, especially if you are disabled you have to do these things. Otherwise I'd be unemployed today because the only opening the public service could offer me was in the City and I'd hung out for two years without employment because I didn't fancy going into the City. But I got to the stage where I thought 'Oh well, I'll give it a go anyway'. They... the Department I work for is a fantastic Department and they did offer me a car park in the building. But when I added it all up ... costs, petrol costs, maintenance, I wouldn't have been able to make a living out of it. The City has an intricate pedestrian network which meant because Martin Place is underground I had to go up and down seven escalators before I got to street level. And then it was a ten minute hike to the building where I worked and I did that for three and a half years ... If it rains I can't hold an umbrella and push a chair and its not exactly easy to just put on a raincoat. So once I did get out on street level and hike up that ten minute wheel to work, I'd be drenched.*

The interplay between participation and residential circumstances was another important factor. Just over half the respondents said that their disability had been a factor in the choice of their home, and over a quarter of these said that their place of work, education or training been the key factor in their choice. These respondents told us how important it was for them to live in places that were accessible to their work or to public transport. In some cases respondents told us that they had to pay more to buy or rent conveniently located accommodation. But location was not, of course, the only factor. Choice of accommodation was again limited by problems of accessibility. These constraints sometimes meant that people had had to spend more on their accommodation than they could really afford. The issue of accommodation not only has financial implications for respondents but also limits their choice of jobs and their job mobility. It is not unlikely that moving place of work will involve a change of residence as well, or vice versa. For some, such changes may be too difficult to even contemplate.

One person with severe cerebral palsy described the obstacles to his promotion. To obtain promotion in his job he had to demonstrate an all-round ability. One requirement which he could not fulfil was an ability to handle small instruments. He had worked for his current employer for many years and was aware of the difficulties he would encounter in trying to obtain a better job elsewhere. It can be difficult enough merely to transfer from one place to another without advancement. It can take many years for a person with a disability, especially a disability which is not generally understood to gain acceptance at work; to have to begin that process all over again can be a frightening prospect which many would not be prepared to countenance even for the sake of advancement.

A person with legal qualifications described the multiple disadvantages in the labour market that she suffered on account of her hearing and sight impairments. For example, had she been able to argue in court, she would have been able to specialise in a branch of law that would have been far more lucrative than her present job as an administrator. A car would normally have come with the job, a fringe benefit of which she could not take advantage because of her poor sight; (this was the complaint of another professional person whose salary took into account a company car which, because of her disability, she was not able to drive). She could not without a great deal of difficulty and/or disruption fulfil the requirements of the job and undertake those activities that would have helped her to advance in it. For example, she could not attend courses or even perform her job if country or inter-state trips were involved because she needed someone to accompany her and that meant two people out of the office instead of just one. Her job involved a certain amount of public and social contact. She found this difficult because it was harrowing for her to assimilate sound when it came not from a single source but from all directions.

The range of jobs available to people with a particular disability, sometimes even more limited because of educational disadvantage, was another factor and this took several forms. People often seemed to find themselves in a 'no win' situation.

Yes, my disability has had an effect. It cost me jobs that I went for in a milk bar and as a kitchen hand. My appearance put them off. Then I went for gardening work. They didn't think I'd be able to cope. Its true, I couldn't do gardening work because of the plastic surgery I've had done to my hands. The skin isn't strong enough to hold the tools. It's like tissue paper.

A large number of people saw their disadvantage in the workforce as arising from problems of access, which severely limited their work options. One woman, a chartered accountant, had tried to work in her local suburb but had found that all the chartered accountant firms were in older buildings without lifts. Even though it would have been easier for her to find a job in the city where she would have been able to earn more money, this was not an option for her. She would have had to get up very early because it takes her so long to get ready. One of her parents would have had to take her to the city but they were both elderly and no longer able to face the task. This respondent had put in an immense effort to obtain qualifications only to find herself severely restricted in her job options on grounds of accessibility.

Another person, a young man who, on account of his accessibility, had deliberately selected a public sector job from among a number of job offers, was now, seven years later, unable to stay with the job because the office had moved to another building which was not accessible to him. The severity of his disability, exacerbated by increasingly poor health, put him in a very poor position to find alternative work. His personnel officer was trying to find him another job in his old building. Another suggestion was that he might work at home at a more routinised job which would at least provide him with some day-time activity. He found it hard to contemplate sitting idle and useless.

Accessibility also affected advancement in the labour force. Three people in our sample had not been able to accept a promotion in the public service because it would have involved a move to a new office which was not wheelchair accessible. A number of respondents, even in our small sample, told us of how they had fulfilled every requirement for promotion, except that of being able-bodied. One person described how, having successfully applied for a job at a higher level, he was unable to take it up because the location was not wheelchair accessible. So instead of the job he was offered a portion of the salary but not the enhanced rank. Subsequently, a further possibility for promotion arose, but only for people of the rank he would have held had he achieved formal promotion in the first instance. These lost opportunities do not simply result in lower than deserved status and lower associated earnings but also have the longer term disadvantage of lower superannuation entitlement.

Interviewer: *You said that your disability had affected your chances of promotion?*

Respondent: *Well on two occasions, in '87 and '88, I received a promotion through a job selection committee under the normal public service conditions ... And I got a grade one in '87 and it was at Parramatta Branch but this had no access for wheelchairs into the building and they decided to give me an allowance to grade one. Then in 1988 I got a grade three/four at the same branch and once again I was told there was no access for wheelchairs ...*

Mother: *He was capable of doing the job ...*

Interviewer: *But there just wasn't access?*

Respondent: *Thats right and that was the only reason I didnt get it.*

Interviewer: *So they promoted you?*

Respondent: *Yes, the boss rang me up and said you've got the job if you can get in, and I said 'that's not much good for me. I can't!'*

One person, working in the public service, described how he had moved to the outer suburbs so that he could buy a house. However, he discovered that he was now not able to manage the journey to his office in the city. He was fortunate enough to be able to arrange a transfer to a local office but in the process he had lost the promotion for which he was due at his City office. Moreover, his promotion prospects in the new office had, in his view, greatly diminished because he was now competing with people who had been in this office much longer than he had.

The multiple disadvantages that arise from the interplay between the impairment and the environment which is undoubtedly the principal constraint to full participation is illustrated by the following example. This respondent with a mobility problem spoke at length, and with some bitterness, of his experiences in the workplace. After leaving school he had lived with his parents for about ten years, subsisting with their help on the Invalid Pension. He then decided that despite his slim prospects of employment, he would nevertheless try to find work. Having sought employment in a number of towns in New South Wales, after seven years he found a job as a process worker in Sydney, thanks to the efforts of a relative. Fifteen years later he was still in the same job. He has not been promoted despite his efforts to improve his work skills by undertaking appropriate courses. He feels that his lack of promotion is the result of thinly disguised discrimination on the part of management who view him as 'slow', both physically and intellectually. In addition to this, he has been unable to supplement his wages with overtime earnings. First, the jobs requiring overtime work are in general too physically demanding for him. Second, when overtime work which he could manage becomes available, preference is given to the regular overtime workers, who are obviously his able-bodied colleagues. The respondent spoke of the resentment he feels when he sees his friends, men who, he says, are no more intelligent than himself, earning twice his income and as a result being able to support their families at a standard he could never hope to achieve. He sees the cause of this not just his own physical limitation but also the limitations imputed to him by other people because of their perceptions of his disability.

The impact of a traumatic injury or progressive illness can mean that a person's work skills are no longer of use. This was felt most forcefully by those who had been in manual employment before their accident or illness. The consequences of this are manifold.

Interviewer: *Has your disability had any effect upon your earnings or chances of promotion?*

Respondent: *(laughs)*

Spouse: *(cynical laugh) I reckon ...*

Respondent: *I was a ganger with the DMR at the time when I had my accident ...*

Spouse: *We lost our home (pause)*

Interviewer: *You were buying your home?*

Respondent: *Yeah. We had. We were (blurred) the holding deposit was to go through on the Tuesday because it was Australia Day on the Monday and the holding deposit went to the bank manager on the Friday and ... everything was like he said. That was it. The final signing up of the papers and everything. Once the papers had crossed, that's it. It was only a matter of time for them to get out and that was it (accident happened on the weekend).*

Spouse: *But we couldn't go through with it. The house had ten steps at the back and front ...*

Respondent: *They bent over backwards, the bank. They wanted us to buy it and they were building other houses at ... and they wanted us to purchase one. They said they'd make it so we could pay it off on a pension.*

Spouse: *But you could see ... We had three little kids and all we had in front of us was a pension.*

Respondent: *It just frightened us at the time.*

Spouse: *You've got Council rates, and water rates and maintenance. We just couldn't do it. Not and stop sane. It was impossible for me to work and at the time, when he broke his neck, I was working full-time. See, we lost two incomes. (pause)*

Respondent: *I was working a lot of overtime ... I'd been banking all my money and we'd just been living off Pam's money.*

Spouse: *And I was doubling my money with bonuses. If you're prepared to work, you've got the money.*

Respondent: *I was in the retirement fund when it happened and ... (spouse interrupts)*

Spouse: *That must have cost us \$100 000.*

Respondent: *Even though they gave me back all the money that I'd paid in and the bonuses that went with it ... and they kept me employed for six months until the accident clause came into it ...*

Spouse: *We were working so we wouldn't have to go on the pension and it back-fired, somewhere.*

Respondent: *I've never drawn the dole in my life. I've been to the dole office to get a job but ... Jeez.*

Spouse: *Frank was the youngest of eight children and his mum and dad went on an Invalid Pension when he was six weeks ...*

Respondent: *I've never drawn the dole in my life. I've always looked ... for anything.*

Another respondent indicated a multiplicity of factors affecting his job situation. There was accessibility, which he saw in physical, geographical and social terms. There was the sheer problem of 'getting a job you can do'. Then there was the fact that retraining had delayed his access to the workforce and earnings. He also thought that the incentive to come off the Invalid Pension was low and had delayed his re-entry to the workforce. He felt there were certainly extra costs in looking for work, including the extra costs of transport to the interviews to check whether the workplace was accessible.

We have dealt at some length with the issue of accessibility because it emerged as a major factor affecting job, earnings and promotion opportunities for people with disabilities. It cannot as a rule be addressed by any individual action. The proposed disability allowance can, of course, do nothing to solve the problem. It is nevertheless worth highlighting because it is an undoubted source of extraneous limitation on the earning capacity of some people with disabilities. It is a restriction quite unrelated to their skills, imposed by virtue of collective indifference to their needs. The question is what long term collective action can be taken to redress the situation, and what can be done for the time being to affect some of the injustice which obviously flows from this source.

Most of the examples we have are of people with physical difficulties who were in open employment. But others with either an intellectual impairment or a psychiatric illness also experienced considerable difficulties. Parents of people with intellectual impairments complained about the lack of opportunities for their children. 'He'll never earn a wage because he can't get a normal job. He gets \$10 a week in a Workshop'. Several parents were very unhappy about their childrens' limited opportunities and the poor wages associated with 'employment' in a sheltered workshop.

Three of the four people with psychiatric illnesses felt that their condition had affected their earnings and opportunities for promotion. Two were working in sheltered workshops. However, the explanations they gave for their disadvantaged position were quite different from those of people with physical disabilities. They saw themselves as

people who were poor copers and lacked the ability to take the strain of a job. They saw themselves as victims of their own incompetence.

5.2 The effect of disability on access to fringe benefits

Our question on this topic elicited complaints of several kinds, most relating to superannuation. The main theme of these was that restricted employment or promotion opportunities had the effect of limiting or eliminating entitlement to superannuation benefits. Those able only to work in sheltered employment were entirely excluded from superannuation. Those in part-time employment have at best a limited entitlement and quite possibly none at all. Those unable to find employment at the level which, but for their disability, they might have expected, naturally not only suffer a loss of present income but also a reduced entitlement to superannuation. Similarly those whose chances of promotion are spoiled by disability also suffer consequent restriction of retirement income. The existence or onset of the impairment itself can also have a direct impact on eligibility for benefits. As a 'pre-existing condition' the impairment may automatically disqualify its owner from joining a superannuation scheme; and traumatic accident or progressive illness leading to premature termination of employment is likely to result in more or less seriously curtailed benefits from a superannuation scheme, depending on the age and length of service of the person concerned.

Unrelated to superannuation, but also illustrating the ramifying disadvantages of impairment, is the complaint that fringe benefits which cannot be taken up because of disability, for example the use of a company car, are simply forgone without compensation.

There is no doubt that in their context these disadvantages are real enough. It is also clear, though, that they are of a kind most likely to be felt by people in white collar and professional occupations. A substantial part of the able-bodied working population has not until very recent years had any possibility of access to occupational superannuation. This is simply another reflection of the white collar bias of the sample, to which we drew attention earlier, not in order to discredit these claims of disadvantage, but in order to signal the absence of a representative group of manual workers. A better understanding of the reasons for their absence would contribute a good deal to the basic objectives of this research.

CHAPTER VI

GENERAL DISABILITY-RELATED EXPENDITURE

Although the main focus of this study is on the extra expenditure associated with participation in specific areas of social life, that participation depends upon preconditions which themselves can involve extra expenditure for a person with an impairment. Of course, the basic preconditions of participation for people with impairments are no different from those affecting able-bodied people. It is simply that it may cost people with disabilities more to satisfy these preconditions.

Our questionnaire asked about specific items of expenditure which we thought were likely to help to enable people with disabilities to function sufficiently well to allow participation in everyday social life. We also gave respondents the opportunity to describe other items of expenditure which we had not separately identified, but which they themselves considered important. Although some people did mention other items (these are listed in Appendix V) we gained the impression that our questionnaire had tapped the most important areas actually recognised by people with disabilities.

For many items we attempted to determine the actual amount of expenditure over a given period (see Appendix III). In other cases, where people have incurred extra expense because of their disabilities, but have done so on items which cannot be regarded as disability-specific, there is a difficulty. It would hardly be satisfactory to ascribe some arbitrary fraction of the expenditure to the disability per se and identify it as 'extra'. Such items as clothing, special food and diets, telephone charges, fuel, transport, home maintenance and decorating all pose this difficulty. For these items we simply asked respondents to tell us whether or not they spent extra on that item on account of their disability. The replies we received were very well documented, and supported by compelling anecdotal evidence; but they are, of course, inescapably subjective.

In this section we first examine recurrent expenditure in the year prior to the interview. We then look at items bought on an occasional or non-recurrent basis. We shall be looking at first at expenditure for the sample as a whole, treating people in work and those in education and training without distinction. Later in the chapter we shall consider some of the ways in which expenditure patterns are affected by the personal and social circumstances of respondents, their types of impairment and their levels of dependence.

1. GENERAL DISABILITY-RELATED EXPENDITURE

1.1 Recurrent expenditure

1.1.1 Recurrent expenditure last year on specific items (Table 11)

Table 11 indicates expenditure last year on a number of disability-related items. Information on the amount of expenditure was collected in relation to items needed by people who are incontinent, and to a range of medical and paramedical needs including private medical insurance, homecare and personal care needs and the need for special footwear.

From Table 11 we can observe that there was considerable variation in the meaning or salience of different items. Incontinence equipment, being a hospital in-patient, homecare, personal care and health insurance were salient to less than one third of the sample. Travel costs to a hospital out-patient department, prescription and non-prescription medicines and treatment, and special footwear affected less than two-thirds but more than one-third of the sample. GP and medical or paramedical specialist consultations affected at least two thirds of the sample.

As the table shows, items of high salience did not necessarily involve people in a great deal of expenditure. Very few people paid to see their GP and a relatively low proportion paid to see a specialist. This was either because their GP bulk-billed or because they were holders of a Pensioner Health Benefit Card or a Health Care Card.

TABLE 11: LAST YEARS RECURRENT EXPENDITURE ON ITEMS ASSOCIATED WITH DISABILITY

ITEMS OF EXPENDITURE																									
Incontinence Items ¹		GP Consultations		Journey to Hospital out-patients		Hospital in-patients		Specialist Fees ¹		Powders creams etc ¹		Prescription medicines		Non-prescription medicines ¹		Health Insurance ³		Home-care		Personal Care		Special Footwear			
No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%		
A PATTERN OF EXPENDITURE																									
No Expenditure:																									
a	Did not purchase	47	78.3	17	28.3	36	60.0	45	75.0	15	25.0	29	48.3	22	36.7	26	43.3	34	90.0	48	80.0	57	95.0	36	60.0
b	Item/service acquired but at no cost to respondent	4	6.7	39	65.0	4	6.7	6	10.0	29	48.3	1	1.7	14	23.3	2	3.3	0	0	1	1.7	1	1.7	3	5.0
Expenditure:																									
c	Amount not known	0	0	0	0	2	3.3	0	0	1	1.7	5	8.3	1	1.7	2	3.3	1	1.7	1	1.7	0	0	2	3.3
d	Amount known	9	15.0	4	6.7	18	30.0	9	15.0	15	25.0	25	41.7	23	38.3	30	50.0	5	8.3	10	16.7	2	3.3	19	31.7
TOTAL		60	100.0	60	100.0	60	100.0	60	100.0	60	100.0	60	100.0	60	100.0	60	100.0	60	100.0	60	100.0	60	100.0	60	100.0
B AMOUNT OF EXPENDITURE																									
\$1 -	\$100	4	44.4	3	75.0	16	88.9	6	66.7	7	46.7	13	52.0	16	69.6	18	60.0	0	0	2	20.0	1	50.0	7	36.8
\$101 -	\$200	2	22.2	1	25.0	1	5.6	1	11.1	0	0	2	8.0	2	8.7	6	20.0	0	0	2	20.0	0	0	3	15.8
\$201 -	\$400	1	11.1	0	0	1	5.6	1	11.1	3	20.0	6	24.0	5	21.7	3	10.0	2	40.0	2	20.0	0	0	7	36.8
\$401 -	\$600	0	0	0	0	0	0	0	0	1	6.7	3	12.0	0	0	2	6.7	1	20.0	0	0	0	0	0	0
\$601 -	\$800	0	0	0	0	0	0	1	11.1	0	0	0	0	0	0	0	0	1	20.0	1	10.0	0	0	2	10.5
\$801 -	\$1 000	1	11.1	0	0	0	0	0	0	0	0	0	0	0	0	1	3.3	1	20.0	0	0	1	50.0	0	0
\$1 001 -	\$2 000	1	11.1	0	0	0	0	0	0	2	13.3	1	4.0	0	0	0	0	0	0	3	30.0	0	0	0	0
\$2 001 -	\$5 000	0	0	0	0	0	0	0	0	2	13.3	0	0	0	0	0	0	0	0	0	0	0	0	0	0
TOTAL		9	100.0	4	100.0	18	100.0	9	100.0	15	100.0	25	100.0	23	100.0	30	100.0	5	100.0	10	100.0	2	100.0	19	100.0
Mean ²		\$352.00		\$58.00		\$31.00		\$147.00		\$696.00		\$254.00		\$109.00		\$150.00		\$587.00		\$610.00		\$419.00		\$224.00	
Median ²		\$180.00		\$33.00		\$12.00		\$33.00		\$220.00		\$100.00		\$80.00		\$63.00		\$567.00		\$234.00		\$419.00		\$195.00	
Range ²		\$39.00 - \$1 440.00		\$16.00 - \$150.00		\$1.00 - \$236.00		\$14.00 - \$652.00		\$20.00 - \$2 500.00		\$7.00 - \$2 000.00		\$6.00 - \$328.00		\$5.00 - \$980.00		\$360.00 - \$1 960.00		\$22.00 - \$1 560.00		\$5.00 - \$832.00		\$50.00 - \$700.00	

Note: 1. For a list of items included in these categories of expenditure see Appendix III and IV.
 2. Calculated on amounts given by those who had incurred expenditure on an item/service and who could recall its value.
 3. Refers to those who would not have purchased health insurance, had it not been for their disability.
 Percentages may not add to 100 due to rounding.

Source: Survey Data, 1988.

The table indicates the very wide range in the expenditure for most items. Given our limited sample size these expenditures provide little basis for extensive comment. The table nevertheless raises a number of interesting questions. Why, in a sample of people with disabilities do so many items have a relatively low salience? In certain cases, for example incontinence items and special footwear, this merely reflects the distribution of disabilities in the sample. In other cases the answer is less clear cut. Why, in a sample consisting of people who have a high level of dependence, is personal care of such low salience? The answer almost certainly lies in the fact that the concept of salience says nothing about how needs are met or left unmet. For example, it does not say anything about the care provided by spouses and parents without charge, which, as a 'labour of love', was generally not perceived by the respondents as personal care. Indeed, even those respondents who received formally-provided personal care generally also had a spouse or parent who gave additional support. As one respondent commented, he preferred his wife to shower him, leaving some of the heavier and 'messier' work for the personal care worker. His wife added a wry comment about the unrecognised value of her care. She had left her job when her husband had become quadriplegic, in order to care for him. Though the employment of personal care workers had made her life easier, she was still 'on call' 24 hours a day, 7 days a week. For this she received \$21 a week in the shape of the Domiciliary Nursing Care Benefit. Another mother whose offspring had an intellectual disability commented, when asked about her son's need for personal care, that he didn't need these services because 'he had her'.

We know that spouses and parents provided most of the care for the heavily dependent members of our sample, often with little resort to outside help. In a number of instances this had severely limited the opportunities of caregivers, some of whom had given up work to assume their role. The cost in these instances is generally considerable, not only in terms of lost income but also in terms of lost social contacts at the workplace. One parent, whose adult child had an intellectual disability, reported that when his wife had become too ill to care for the offspring, he had left the workforce, before the normal age of retirement. As a result, he lost nearly half his expected superannuation payment. Because he was too young to receive the Age Pension, he and his wife were forced to live on Special Benefit for a number of years. In many other instances this role had severely limited the caregiver's opportunities for self-realisation and incidentally deprived the wider community of his or her contribution.

The impact of caregiving (Table 12)

We divert our attention for the moment to consider in more detail the impact of the 'informal' caregiving role, focusing our attention on the impact of this role on patterns of work and earnings. In interpreting the findings it will be important to bear in mind that where possible we undertook joint interviews with respondents and their spouses, or, where respondents were living with them, parents. The question of what impact living with and possibly also caring for a dependent adult has had on their working lives is, of course, very sensitive. In the circumstances in which we undertook our interviews, it seems very likely that spouses and parents will have tended to understate rather than exaggerate this impact.

In this section of the report we have called the spouse or parent, whatever the respondent's level of dependency, a 'caregiver'. This term is used merely by way of shorthand. In instances of high dependency, the caregiver will almost certainly have an important part to play in attending to the personal care needs of the respondent but may have a much less significant role when the respondent has only a medium or minimal dependency.

We expected that the impact would be greatest when the level of dependency of the person for whom the caregiver was responsible was highest. We therefore considered separately caregivers of people with a high dependency on the one hand and those of medium or minimal dependency on the other. The findings are summarised in Table 12. We must once again emphasise that because of the small numbers the findings should be treated with great caution.

We found some differences between the two groups. People with high dependency were more likely than people with medium or minimal dependency to be living with a spouse or parent. Those with high dependency who did not live with either spouse or parent lived in a hostel or group home. On the other hand, people with lower dependency who did not live with their spouse or a parent tended to live alone or with a friend. Some were single parents. High dependency, that is to say, was reflected in residential arrangements.

TABLE 12: THE RELATIONSHIP BETWEEN RESPONDENTS' LEVEL OF DEPENDENCY AND EMPLOYMENT OF CO-RESIDENTIAL SPOUSES AND PARENTS

		Respondents' Dependency			
		No.	High %	Medium or None/Minimal No.	%
A.	Respondent lives with spouse	6	19	11	38
	Respondent lives with parent(s)	16	52	5	17
	Respondents: Other living arrangements	9	29	12	45
	<i>TOTAL RESPONDENTS</i>	<i>31</i>	<i>100</i>	<i>29</i>	<i>100</i>
Employment of Co-Residential Spouse/Parent		No.	%	No.	%
B.	Working spouse/parent	3	14	6	38
	Non-working spouse/parent	15	68	6	38
	Not Relevant	4	18	4	25
	<i>TOTAL LIVING WITH SPOUSE/PARENT</i>	<i>22</i>	<i>100</i>	<i>16</i>	<i>100</i>
C.	Spouse/parent not working but would like to	6	40	2	33
	<i>TOTAL NON-WORKING SPOUSE/PARENT</i>	<i>15</i>	<i>100</i>	<i>6</i>	<i>100</i>
D.	Spouse/parent work affected by respondents' needs	3	100	1	25
	<i>TOTAL WORKING SPOUSE/PARENT</i>	<i>3</i>	<i>100</i>	<i>4</i>	<i>100</i>

Note: Percentages may not add to 100 due to rounding.

Source: Survey Data 1988

When the respondent had a high dependency the caregiver was less likely to be working than when the respondent was less dependent. Furthermore, when the respondent was highly dependent, a higher proportion of non-working caregivers would have liked to work but felt unable to do so because of their caregiving role than was the case with caregivers of less dependent respondents. These latter seemed more often simply to be exercising a personal preference.

The impact of working and caring for a highly dependent person on various aspects of their working lives was much greater than it was on the working lives of those who were both working and caring for a less dependent person. For the former, this meant, in all cases that the caregiver had to take time off work from time to time to attend to the needs of the respondent (although this did not usually affect their earnings). In all but one case caregivers had felt obliged to choose their workplace carefully with regard to the convenience of its location. Half these working caregivers also said that caregiving had affected the times at which they could work. In contrast, when the respondent's dependency was lower, the work behaviour of caregivers was generally unaffected. In fact, only one such working caregiver, a spouse, said that her husband's disability had had a significant effect on her working life. This woman, who had a professional qualification, was married to a man with severe cerebral palsy. They had a child of 6 years. The wife was extremely concerned that the relationship between the child and the father should be firmly bonded. She felt it was very important that the child should not pick up or internalise negative community attitudes to the father's disability. She believed that this would only be achieved if the family made a conscious effort to work at it together. To this end, the mother deliberately chose a job that would maximise the social and emotional rather than material gain. She did not use her qualification as a teacher, but worked in a rather less stressful clerical job, part-time and close to home. In this way she felt best able to foster the relationship between father and son. Although this case was unique in our small study, we mention it because it illustrates one way of performing the caregiving role. In a larger sample we would undoubtedly have come across other, similar examples.

The numbers in our sample are too small for detailed analysis but the differences we have noted between the effects of caring for high and low dependency people, do appear to confirm our commonsense judgement. They also suggest that when high dependency is involved, the caregiving role, through its effect on work behaviour, may significantly affect family income. We are not in this study concerned with any of the many other social and emotional effects of caregiving, but there is every reason to believe that these are substantial. It will be interesting to see whether our findings are confirmed by those of the recent ABS Disabled and Aged Persons Survey, 1988.

Returning now to the issue of disability-related recurrent expenditure, a further surprise is the relatively low apparent salience of prescription medicines. However, if we take the three 'healing' items together (creams and lotions and powders, prescription medicines and non-prescription medicines), we find that only 5 people in the sample had not acquired any of these over the last year. This is indicative of the wide range of treatments and management techniques used by people with disabilities.

Another question raised by Table 11 concerns people whose needs, in so far as they were articulated, appeared to be met at no cost to themselves. How are these needs being met and how are these sources of help accessed? What are the selective processes at work? Whilst we know that, in general, people who receive help from PADP will be among the less affluent, is this always the case, or are there other, non-economic criteria used to select the people who receive help? This raises the further question: Why do some people have all their needs met while others pay either all or part of the cost themselves? For example, what differences can we detect between the four people whose incontinence items are entirely free and the nine people who meet some of the cost of their incontinence items themselves? Does it reflect on the scale of the need? Is it that poorer people are more likely to receive help? Or better off people? Or does it turn on the nature or severity of the disability? We have some preliminary evidence that people who incur relatively low expenditure on incontinence items and who also have quite limited needs for these items are people with an intellectual impairment. Those with considerable need for these items are people with quadriplegia who tend to obtain the items they need for their incontinence through one of the quadriplegic organisations. Later in this chapter we shall be dealing in a little more detail with the question of how needs are met.

Yet another question raised by Table 11 has already been touched on: it relates to the wide range of expenditure for some items. Why do some people have particularly high expenditures? Is it a reflection of their need or of their resources? Two respondents had particularly high travel costs to a hospital outpatient clinic. One of them, who had very serious back problems, travelled a long distance very frequently; facilities were apparently not available closer to home. The other person made monthly visits to outpatients, travelling by subsidized taxi, each journey costing \$20 - \$25. Another example of particularly high expenditure stands out in the table: an outlay in the range \$1,001 to \$2,000

on 'creams and lotions'. This was in fact an annual expenditure of \$2,000 dollars on bandages (a non-prescription item) for a respondent with an intellectual disability, whose condition required the continual treatment of very bad sores. We were surprised by this figure but on further enquiry were assured that it was correct. The parent had applied to PADP for help, but had been told that such items were not available through the PADP scheme.

Considerable use was also made of medical specialists. Many people were not charged for their services, but others were. The study revealed a considerable use of paramedical and fringe medical treatments, for example those provided by naturopaths.

1.1.2 Overall recurrent expenditure (Table 13)

A rather more detailed consideration of the expenditure of selected members of the sample provides some clues to the questions posed in the previous section.

Three of the 60 respondents had incurred no extra recurrent expenditure on their disability, and as we can see from the range in Table 13, even amongst other members, these expenditures can be quite modest.

An account of the personal and social circumstances of these three people may help to explain why they had incurred no expenditure. The first was a man aged 20 who had an intellectual impairment and a high level of dependency. In addition to the considerable assistance he needed with his personal care he had additional disabilities. His fine motor movement was poor, reflected in his need for assistance with personal care, and he could not speak at all. He lived in a group home and attended an ATC. His income fell into the lowest category, consisting only of the Invalid Pension and the Mobility Allowance. All his daily and personal care needs were met by the staff of the group home in which he lived. Over the past year he had received medical and dental assessment and treatment as an outpatient. He had seen a psychologist, a social worker, a speech therapist and a physiotherapist. There had been no charge for any of these services. That this respondent did not incur any expense in order to obtain this treatment is a reflection of his income. That he received such a range of treatments is a reflection of the particularly high level of service provision in the area where he lives. The costs of caring for this highly dependent person were entirely met by the community or by relatives whom he visited on occasion.

The second person who had incurred no expenditure over the last year was a man aged 28. He had a psychiatric illness with a diagnosis of schizophrenia. He lived in a hostel and worked in a sheltered workshop. His income fell into the lowest category, being limited to the Invalid Pension, rent assistance, and \$15 - \$20 a week earned in the sheltered workshop. According to our scale this respondent had a minimal level of dependency as far as assistance with personal care was concerned, and he had no additional disabilities. He attended hospital as an outpatient and needed medication. All his personal care needs were met by the hostel, including his transport to hospital. He did not have to pay for his prescription medicines because he was receiving an Invalid Pension. Once again, the disability-related expenses have all been assumed by the community.

The third person with no disability-related expenses was a single mother aged 35 with an 18 month old child. This respondent had not been diagnosed as having a psychiatric illness, but suffered from severe depression, lack of confidence, agoraphobia, and arthritis in her legs. Her main physical disability resulted from her arthritis. Despite this, she lives in a fourth floor Housing Commission flat. She had no employment and her income was in the lowest category, consisting of the Invalid Pension, Mothers/Guardians Allowance, Additional Pension for Children and Family Allowance. She has had no medical treatment, nor has she incurred any other disability-related expenses over the last year. The circumstances in which this person lives are quite unhelpful to her disability. Her living arrangements impose a social isolation on her. Her arthritis makes the climb up to the flat, which is in a block largely populated by elderly people, very difficult. Her poverty isolates her even more; she claims to be able to afford virtually no social life. While we are not suggesting that her economic circumstances and her housing arrangements are the cause of her problems they are hardly conducive to her improvement.

Despite the fact that the three respondents whose circumstances we have described incurred no expenditure on their disability over the last year, there is no evidence that their disability-related needs were being neglected. Nevertheless, in the cases of the last two of these respondents, the barren and constricted nature of their impoverished lives is striking.

TABLE 13: IMPAIRMENT CATEGORY BY DEPENDENCY, PRINCIPAL ACTIVITY, INCOME UNIT INCOME, INDIVIDUAL INCOME AND GENERAL DISABILITY-RELATED EXPENDITURE

		Impairment Category					
		Physical	Intellectual	Sensory	Psychiatric Illness	Other	Total

A. CHARACTERISTICS OF THE SAMPLE							
Impairment Category		30	17	3	4	6	60
Level of Dependency	None/minimal	14	0	0	1	5	20
	Moderate	4	1	2	2	0	9
	High	12	16	1	1	1	31
Principal Current Activity	Employment	21	5	3	3	1	33
	Education/Training	6	12	0	0	1	19
	Other	3	0	0	1	4	8
Income Unit Income	Mean	\$20 234	\$7 895	\$31 407	\$8 897	\$9621	\$15 181
	Median	\$21 120	\$7 592	\$34 000	\$8 535	\$8 300	\$8 792
	Range	\$5 263	\$6812	\$23 454	\$7 029	\$6 292	\$5 263
		-\$55 000	-\$10 634	-\$36 767	-\$11 500	-\$14 960	-\$55 000
Individual Income	Mean	\$14 567	\$7 895	\$28 183	\$8 897	\$9 621	\$12 335
	Median	\$7 221	\$7 592	\$27 767	\$8 535	\$8 300	\$8 628
	Range	\$3 072	\$6 812	\$22 782	\$7 020	\$6 242	\$3 072
		-\$27 572	-\$10 634	-\$34 000	-\$11 500	-\$14 960	-\$34 000

B. OTHER DISABILITY RELATED EXPENDITURE ¹							
1.	Recurrent expenditure (last year)						
1.1	No. incurring expenditure	30	16	3	3	5	57
2.2	No. incurring expenditure who recall amount	30	16	3	2	5	56
1.3	Mean recurrent expenditure (based on 1.2)	\$980	\$571	\$488	\$597	\$339	\$760
1.4	Median recurrent expenditure (based on 1.2)	\$611	\$266	\$363	\$597	\$192	\$393
1.5	Range of recurrent expenditure (based on 1.2)	\$1	\$10	\$234	\$36	\$5	\$1
		-\$4 255	-\$2 500	-\$868	-\$1 158	-\$1 194	-\$4 255
2.	Non-recurrent expenditure (since onset of disability)						
2.1	No. incurring expenditure	27	11	3	0	1	42
2.2	No. incurring expenditure who recall amount	27	11	3	-	1	42
2.3	Mean non-recurrent expenditure (based on 2.2)	\$12 212	\$1 398	\$6 171	-	\$797	\$8 676
2.4	Median non-recurrent expenditure (based on 2.2)	\$3 492	\$459	\$436	-	-	\$1 220
2.5	Range of non-recurrent expenditure (based on 2.2)	\$30	\$50	\$6	-	-	\$6
		-\$108 395	-\$9 423	-\$18 070			-\$108 395

- Note:
- As demonstrated by Table 1 respondents may be participating in more than one activity. Hence totals in Part B differ from those in Part A of this Table.
 - Refer to Appendix III for a breakdown of the components of the total.
- * In all cases where a component of cost is missing or the respondent didn't know the amount spent on a particular item, the assumption has been made that nothing was spent on these items/services.

Source: Survey Data, 1988

Fifty seven of the 60 members of our sample spent some money on their disabilities last year; that is, money they would not have spent but for their disabilities. The mean expenditure of the sample members was \$760 (about \$15 a week). However, as the median value in the table indicates, half the sample spent less than \$393 (or about \$8 a week) last year. People with physical impairments had the highest average expenditure but one can observe they include the highest and lowest of the spenders in the sample. We now look in more detail at the expenditure of these two people for they exemplify completely contrasting situations, not just as far as their expenditure is concerned, but also in terms of their personal and social circumstances.

Marjory Ridley, the highest spender, spent \$4,255 last year on disability-related items.¹ Mrs Ridley is aged 41, married, without children. She works full-time as a telephonist. At the time of the interview her husband was unemployed. Her earnings were about \$15,000 last year. The total family income was about \$21,000, including the Mobility Allowance, which Mrs Ridley receives. Both Mrs Ridley and her husband have cerebral palsy. On our scale, Mrs Ridley has a moderate level of dependency. She has a problem with one arm which makes it difficult for her to cut up food, for example. She also has a serious problem walking. The money she spends because of her disability is clearly related to the areas in which she has the greatest difficulty. Last year Mrs Ridley spent nearly two and a half thousand dollars on treatments from a chiropractor and chiropodist. She spent \$195 on special shoes which she obtained at half price from the Crippled Children's Society, and she spent over \$1,500 on a housecleaner. Mrs Ridley's expenditure does not seem at all unreasonable, given the nature and severity of her disability. It is nevertheless surprising that she is able to spend this amount when the family income is only \$21,000 a year. We do not know all the circumstances of the family, but it would appear that a large lump sum compensation payment recently received, arising from a car accident a few years ago, unrelated to Mrs Ridley's disability, has enabled her to meet her needs in the way that we have described. Mrs Ridley is also mentioned earlier in this report as having spent a substantial amount on taxis to get her to her place of work. It is very important to her quality of life that her resources remain undepleted. Her life would be radically altered were her money to run out.

In this context it is perhaps worth commenting on the apparent advantages of lump sum payments. In fact, we came across one case of a man with quadriplegia who had obtained a fair amount of money from insurance as a result of a car accident. He spent a large portion of it on modifications to his parents' house, in which he subsequently decided not to live, as the house was in the country and his treatment was in Sydney. Financial counselling would perhaps have been helpful in this instance and may have delayed an expensive decision that, it would appear, he had not been ready to make. This example provides a salutary reminder that apparently large lump sum payments can be quite rapidly depleted.

Let us now turn to the lowest spender, who spent a mere dollar last year on his general-disability related needs within the categories of expenditure identified in the questionnaire. This person, whom we shall call Michael Hutchison, is 39. He is married with a dependent child. Mr Hutchison works full-time as an office worker; his wife is not employed. Mr Hutchison earns just over \$5,000 a year, but after receiving the Invalid Pension, the Mobility Allowance, Family Allowance and Austudy the family income is brought up to about \$19,000 a year. Mr Hutchison has quadriplegia C5/6 resulting from a car accident nearly 17 years ago. On our scale, Mr Hutchison has a high dependency on others for his personal care. At home Mrs Hutchison provides most of the help needed although his child also has an important role. When asked why she was not in employment Mrs Hutchison said that she was not sure which of several factors was the most important: her husband's dependency which was very demanding and tiring, her responsibilities as a mother, or the fact that her husband would lose his entitlement to Invalid Pension were she to start earning. It is relevant to add that her husband's health is extremely good, and this Mr and Mrs Hutchison, attributes this to the tremendous attention that they both pay to Mr Hutchison's personal care.

The Invalid Pension was extremely important to Mr Hutchison and certainly accounts for his low expenditure, despite his high dependency and health care needs. The expenditure of \$1 was a token amount estimated to be the cost of the petrol used to visit the local GP. Mr Hutchison's Pensioner Health Benefits card, which he holds by virtue of his Invalid Pension, entitles him to free medical treatment and prescription medicines on the 'free list'. His low income entitles him to a range of aids obtainable through the PADP. Items needed to manage his incontinence are provided through a consumer organisation. These were worth over \$1000. Mr Hutchison works for an organisation, which caters well for his special needs at work. For the purposes of this research, one of the most interesting features of what

1. Fictional names are used in this chapter.

we have described are Mr Hutchison's low earnings, given that he is working full-time. It is clearly mutually advantageous to the organisation and Mr Hutchison that he should be paid at this level. The organisation's salary bill is kept low; Mr Hutchison retains his entitlement to the Invalid Pension and its associated fringe benefits. However, there is clearly room to question a policy which constrains not just Mr Hutchison's earnings, but those of Mrs Hutchison, too.

Both Mrs Ridley and Mr Hutchison had physical disabilities. As Table 13 indicates, people with physical impairments spent considerably more on average than any other impairment group. This is not so much because they obtain more items, though they do, but because the items they acquire are on the whole more expensive. Some indication of this can be gained by examining the outlays on specific items by the different impairment groups. The commonest form of high expenditure incurred by people with physical impairments is specialists' fees. People with intellectual impairments also received specialist treatment, but in no case did any of them have to pay for this. It looks as though it is not so much the amount of need but the cost of meeting different types of needs that differs between impairment groups, at least as far as recurrent expenditure is concerned. These costs, as they affect the individual respondent, are strongly influenced by how needs are met. It is very important to examine the social context in which needs arise and are met. The two following examples illustrate this.

Adam Booker is 30. He is married, without children. He works full-time as a programmer and his wife works part-time. Their joint income last year was about \$22,000, including the Mobility Allowance and a Domiciliary Nursing Allowance. This income was in a state of flux, however, as there had been a change in the Booker's circumstances in the middle of the previous financial year. In the first part of the year he was still receiving training as a programmer. At that time he was receiving the Invalid Pension. Mrs Booker had only returned to work four months before our survey.

Adam Booker has a very high level of quadriplegia which is a result of an accident he sustained four years ago whilst playing football. He is highly dependent on others for his personal care and although he receives attendant care eight hours a week, most of the help needed is provided by Mrs Booker who, at 27 and without children, one might have expected to have a full-time job. The Bookers would ideally like more help, particularly with the housework which is difficult for Mrs Booker to combine with being a virtually full-time carer for a physically dependent adult and with a part-time job.

Amongst the people with physical impairments, Mr Booker was one of those who spent most on his disability. He had substantial incontinence costs and also high costs in areas of non-prescription medicines and treatments. In fact, his costs could have been higher, but for sporting friends who had set up a trust which partly covered his incontinence costs, and his father who, being a pharmacist could supply him cheaply with non-prescription medicines and treatments. In order to illustrate the importance of the social network providing help, it is worth considering some of Mr Booker's other non-recurrent needs and how these are met. Undoubtedly these would have been much greater without the help he received from a variety of sources. Indeed, without this help, it is likely that his quality of life would have been drastically reduced. For example, his car was purchased by the people he had worked with. The hoist for the car was bought by friends. His home computer was donated by a computer company, the total computer package being valued at \$10,000. Mobility equipment valued at over \$8,000 was paid for by the trust established by friends. Other equipment, for example, his shower chair, hoists, etc had been purchased by friends or donated by the Queen Elizabeth II Rehabilitation Centre (QEII). His family had bought special furniture for his use at home. In addition, insurance money collected after his accident had allowed him to purchase his home outright (\$90,000) and to cover the cost of modifications amounting to \$50,000.

Contrast Mr Booker's situation with that of another high spender on disability-related items. This is Sharon Harding, who is 28 years of age. Ms Harding works in a sheltered workshop. She receives the Invalid Pension and a Mobility Allowance. Her annual income is about \$7,900. Ms Harding lives at home with her mother, who is a pensioner, and her slightly younger brother, who has a mild intellectual disability and works only part-time. Ms Harding herself has a severe intellectual disability. She is highly dependent for nearly all aspects of her personal care, which is provided by her mother. Ms Harding is obese and respite arrangements have proved unsuccessful because careworkers did not satisfactorily attend to the control of Ms Harding's food intake. Ms Harding also has behavioural problems. On account of these she is sometimes sent home from the sheltered workshop because the staff cannot manage her. Another of Ms Harding's problems is that she mutilates herself, as a result of which she was obliged last year to spend \$2,000 on bandages. The annual expenditure which she incurs on account of her disability is \$2,415.

The point of presenting these starkly contrasting examples is certainly not to make any invidious comparisons as to their gravity or resulting pain. It is rather to draw attention, amongst all the other differences between the circumstances of these two people, to the consequences of the fact that Mr Booker is part of a social network, whereas Ms Harding and her family live in relative isolation. Ms Harding is part of a poor family, and has had her disability since birth. Her mother has always had to cope with her manifold problems by herself. Mr Booker, on the other hand, sustained a traumatic injury in adulthood when he had a well established social network which has proved to be exceptionally supportive.

1.2 Non-recurrent or occasional disability related expenditure (Tables 13 and 14)

Table 14 sets out details of non-recurrent expenditure over two time periods: last year, and since the onset of disability (including last year). The difference between the number of people who incurred expenditure last year and the total reporting expenditure over the entire period of their disability indicates that one risks serious underestimation of the importance of these occasional items by enquiring only about recent expenditure, particularly in a sample as small as ours.

The issues raised by Table 14 are similar to those which emerge in our discussion of recurrent expenditure. Once again, it is clear that different types of items have different levels of salience. Two types of expenditure have particularly high salience: mobility aids and heating and house modifications.

There are, of course, considerable difficulties in determining the expenditures that people have incurred on items, including services, acquired since the onset of their disability. The most obvious of these is the fallibility of memory. People may simply be unable to recall accurately either the actual items they have acquired, or whether, and if so, how much they paid for them. Small items, the cumulative cost of which can be considerable, are easily forgotten. People may confuse the present-day prices of items with the amounts paid at the time they were actually acquired. Had our sample been much larger and more representative of the population with disabilities, we could merely have obtained expenditure over the last year and felt able with reasonable confidence to estimate life time expenditures for the population.

Another difficulty arises in the determination of the lifetime expenditure of people who have had their disability since childhood and are still living in the parental home. In these cases, many of the most costly and necessary items will have been bought when the respondent was a child or adolescent. The cost in these cases will clearly not have been borne by the person with the disability, but by his or her parents. Though the present exercise calls for an assessment of how expenditure is distributed, this is no easy matter, especially as the person with the disability grows older but remains dependent. The apportionment of estimated expenditure as between the person with the disability and other family members will inevitably be somewhat arbitrary. Two examples serve to illustrate the point. The first is the case of a man, now aged 27, who has muscular dystrophy. The family moved to their present house about eleven years ago so that the respondent would be closer to his school. The house needed major external modifications to make it accessible to the respondent, and his parents naturally paid for them. They now represent part of his adult domestic environment. As his disability progresses, this respondent is developing additional needs. Some of these are in the area of personal care, which is becoming increasingly difficult for his parents to provide as they grow older. Other needs have to do with the replacement of various items of equipment previously acquired which have become unserviceable, obsolete or no longer appropriate. There is a need for further modification of the house, which is not the respondent's property but his parents'. In addition, over the years, there has been some wear and tear resulting from the use of a wheelchair in the house. While the original modifications were paid for by the parents, now that the respondent is an earning adult, still living in the family home, the issue of responsibility becomes rather blurred.

A similar case concerns a woman of 40. She has a serious physical impairment, and needs considerable personal care. She, too, lives with her parents. They have recently moved to a different house, because of an improvement in the respondent's condition. Her parents had always wanted a two-storey house, and with some improvement in her mobility the respondent can now manage stairs, albeit with some difficulty. The move has been made taking into account both the respondent's needs and her parents' preferences. The expense has been considerable, involving not just the cost of relocation but also the purchase of new furniture and certain adaptations to the house to meet the respondent's special needs. Every move made by the family, including this most recent one, has been prompted by the

TABLE 14: NON-RECURRENT EXPENDITURE ON ITEMS ASSOCIATED WITH DISABILITY

ITEMS OF EXPENDITURE ¹																					
LAST YEAR											SINCE THE ONSET OF THE DISABILITY ²										
Communication Aids		Heating and Home Modifications		Mobility Aids		Special Equipment		Special Furniture		Communication Aids		Heating and Home Modifications		Mobility Aids		Special Equipment		Special Furniture			
No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
A PATTERN OF EXPENDITURE																					
No Expenditure:																					
a Did not purchase	49	81.7	46	76.7	50	83.3	53	88.3	53	88.3	43	71.7	29	48.3	30	50.0	38	63.3	42	70.0	
b Item acquired but at no cost to respondent	2	3.3	1	1.7	3	5.0	0	0	0	0	5	8.3	3	5.0	9	15.0	7	11.7	2	3.3	
Expenditure:																					
c Amount not known	0	0	0	0	0	0	0	0	0	0	0	1	1.7	0	0	0	0	2	3.3		
d Amount known	9	15.0	13	21.7	7	11.7	7	11.7	7	11.7	12	20.0	27	45.0	21	35.0	15	25.0	14	23.3	
TOTAL	60	100.0	60	100.0	60	100.0	60	100.0	60	100.0	60	100.0	60	100.0	60	100.0	60	100.0	60	100.0	
B AMOUNT OF EXPENDITURE																					
\$1 - \$500	9	100.0	9	69.2	6	85.7	6	85.7	4	57.1	9	75.0	10	37.0	14	66.7	12	80.0	7	50.0	
\$501 - \$1 000	0	0	0	0	1	14.3	1	14.3	2	28.6	0	0	1	3.7	2	9.5	2	13.3	1	7.1	
\$1 001 - \$2 000	0	0	1	7.7	0	0	0	0	1	14.3	3	25.0	2	7.4	2	9.5	1	6.7	6	42.9	
\$2 001 - \$4 000	0	0	1	7.7	0	0	0	0	0	0	0	0	2	7.4	1	4.8	0	0	0	0	
\$4 001 - \$8 000	0	0	1	7.7	0	0	0	0	0	0	0	0	3	11.1	1	4.8	0	0	0	0	
\$8 001 - \$10 000	0	0	0	0	0	0	0	0	0	0	0	0	2	7.4	0	0	0	0	0	0	
\$10 001 - \$15 000	0	0	0	0	0	0	0	0	0	0	0	0	2	7.4	0	0	0	0	0	0	
\$15 001 - \$20 000	0	0	1	7.7	0	0	0	0	0	0	0	0	2	7.4	0	0	0	0	0	0	
\$20 001 - \$30 000	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	4.8	0	0	0	0	
\$30 001 - \$40 000	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	
\$40 001 - \$60 000	0	0	0	0	0	0	0	0	0	0	0	0	2	7.4	0	0	0	0	0	0	
\$60 001 - \$100 000	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	
\$100 000 or more	0	0	0	0	0	0	0	0	0	0	0	0	1	3.7	0	0	0	0	0	0	
TOTAL	9	100.0	13	100.0	7	100.0	7	100.0	7	100.0	12	100.0	27	100.0	21	100.0	15	100.0	14	100.0	
Mean ³	\$258.00		\$2 205.00		\$216.00		\$118.00		\$492.00		\$533.00		\$11 275.00		\$1 872.00		\$25.00		\$686.00		
Median ³	\$330.00		\$165.00		\$115.00		\$65.00		\$400.00		\$339.00		\$33.00		\$305.00		\$100.00		\$599.00		
Range ³	\$58.00 -		\$10.00 -		\$30.00 -		\$10.00 -		\$14.00 -		\$58.00 -		\$10.00 -		\$6.00 -		\$100.00 -		\$14.00 -		
	\$399.00		\$18 018.00		\$780.00		\$530.00		\$1 300.00		\$1 533.00		\$102 226.00		\$21 749.00		\$1 012.00		\$1 392.00		

- Note: 1 For a list of items included in these categories of expenditure see Appendix IV.
2 Adjusted by the CPI to December 1988 dollars.
3 Calculated on amounts given by those who had incurred expenditure for an item and who could recall its value.
Percentages may not add to 100 due to rounding.

Source: Survey Data, 1988

changing needs of the respondent since the onset of her disability at the age of about 20. Relocation costs have always been met by the parents, as have the cost of modifications. Now that the respondent, though still very disabled, is a high-earning member of the workforce, she is contributing to the cost of her special, disability-related requirements in the new home. However, allocating the various expenditures has proved to be an almost impossible task because of the embedded question of responsibility. Whose responsibility has this or that expenditure been?

It is with these methodological and conceptual problems in mind that we now look at expenditure on non-recurrent items (Tables 13 and 14). The mean lifetime expenditure, adjusted by the Consumer Price Index to December, 1988, was \$8,676. However, median expenditure was very much lower (\$1,220), and it is clear that the mean has been strongly influenced by a small number of very high spenders. As Table 13 indicates, high spenders are most numerous among those with physical impairments. In fact, of the ten people in the sample who spent more than the mean, eight had physical impairments. No expenditure on this scale was incurred by people with psychiatric illness, and very low expenditure overall was incurred by people in the 'other' impairment category. In fact only one such person reported any expenditure of this type.

When one considers the items embraced by the broad category of non-recurrent expenditure, namely communication aids, mobility aids, special furniture, equipment to aid independence, home modifications and additions to heating, it is hardly surprising that these types of expenditures fall most heavily on people with physical or sensory impairments. Of course, people with intellectual impairments also often have physical disabilities and problems in communication as well. In fact, eleven such respondents reported some non-recurrent expenditure but compared to people with physical impairments their mean expenditure on these items was low. There are several possible explanations. One is that only half the respondents with intellectual impairments lived at home. The needs of the other half are catered for in their hostels or group homes. Another is that though all but one of these respondents had some problem with mobility or speech, or both, these are now problems of long standing, and the likelihood increases that parents will come to feel that the condition is not amenable to further improvement. They may have come to feel that they have already done everything possible.

In the case of the high spenders with physical impairments, the expenditure was incurred almost exclusively to modify living accommodation to make it wheelchair accessible, or to make daily living manageable from a wheelchair. People spent amounts on home modifications ranging from \$10 to \$102,000. In most cases, these sums represent only part of the cost of the modification. In three cases relatives had contributed a considerable amount, either in the form of cash or by way of labour. In one further case, the modifications had involved the use of the respondent's own resources, some labouring help from a relative to lay a new floor, and help provided by the CRS in carrying out a range of modifications to bathroom and kitchen. In yet another case, the modifications were undertaken with the help of a Trust fund set up with contributions from friends and relatives, and with money paid in compensation for accidental injury. In three cases modifications were paid for solely by the respondent using money received by way of insurance or compensation payments. None of the respondents in our survey would have had sufficient resources of their own to undertake the modifications they had made.

We have provided a good deal of anecdotal evidence that the means by which the need for a modification is met will largely be determined by the social and economic circumstances of the individual, the supports he or she is able to call upon, and factors associated with the disability itself. The examples below provide some indication of the way these expenses may be met. People whose disability arises as the result of an accident will often, though by no means always, receive a lump sum by way of insurance, compensation or damages which will pay for all or some of the modifications. The payment may be topped up by a relative or by the respondent. People who have had their disability from birth are likely to have had some or all of the modifications paid for by their families, especially if they are living in the parental home. Of course, the resources of the family will be a limiting factor here.

Three members of the sample with physical impairments had their modifications undertaken without cost to themselves. These were people living in Housing Commission properties of which the Commission itself had undertaken the necessary modifications.

One person with a sensory impairment had incurred above average expenditure on the modification of her home. She had multiple disabilities, which included poor sight, poor hearing and a very serious allergic condition which necessitated a dust-free environment. The modifications entailed building an extra room as a study, required because, being almost blind, much of her work was done orally. Because of her hearing impairment, extreme quiet was also necessary. The study was particularly expensive because it included allergy-free flooring. Other modifications

included an indoor rail, secure fencing around the house for the guide dog, an outside ramp and the removal of outside steps. The cost of these modifications was almost \$40,000 at December 1988 prices, an amount found jointly by the respondent and her co-resident friend.

It is hardly surprising that, after home modifications, the next largest amounts were spent, again by people with physical impairments, on aids to mobility. Altogether 34 members of the sample had acquired a mobility aid since the onset of their disability. Thirteen had incurred no expenditure and three others had incurred some. Sources of assistance included PADP, the Muscular Dystrophy Society, Crippled Children's Society, Guide Dogs for the Blind or a friend or relative. Eighteen respondents bore the total cost of their mobility aids. One respondent with muscular degeneration had received no assistance with the purchase of his mobility aids. He had spent nearly \$22,000 over the past twelve years on a number of wheelchairs. This did not include the cost of maintenance. These costs, though often substantial, were generally difficult to quantify. However, they can easily amount to as much as \$500 a year, depending on the age of the chair and the amount of use it receives. Most of our respondents who used wheelchairs had more than one.

The way needs are met

In this section of the report we have been examining the needs that arise as a result of a disability. The specific needs that people have arise from the nature of their disabilities. They are likely to be both material and social. People need catheters, wheelchairs, mouthsticks, medicines and so forth. They also need people: for simple sociability, for professional advice, to ensure that the needs which they cannot provide for themselves are adequately met.

There is no such thing as an 'average' level of need, but there do appear to be characteristic clusters of need that arise from the nature of particular disabilities. For example, people with incontinence need particular materials and facilities to enable them to manage their condition. People who cannot walk need aids to mobility. People who cannot feed or dress themselves need attendants to help them. This is elementary, it might seem. Needs are not absolute, however. They are in part a function of how people wish or have the opportunity to live in society. The needs of a person who has incontinence and mobility problems will become different and more demanding if he or she ceases simply to stay at home and goes out to work, or to an ATC. The greater the level of participation, the greater will be the need for social and community support, and the greater the cost of meeting these needs. Needs are not static; they enlarge as horizons enlarge. Just as people have a range of needs arising from the complex interaction of the nature of their disability and their level of social participation, they will meet those needs to varying degrees and by various means. In this chapter we have begun to show how the individual, the family and the community interact to meet needs. We shall now try to look at this question a little more systematically.

It is clear both from the tables included in the report and from anecdotal evidence that many respondents received support from outside sources in meeting their needs. That this help plays a significant part is demonstrated in Table 15 below. Thirty nine per cent of all the items (that is, goods or services) that our respondents needed in order to participate in the workforce were fully provided by some other person or agency. Similarly 32 per cent of such items needed for participation in education and training were provided by an outside agency, as were 44 per cent of general-disability related items. Our sample consisted of people with relatively low incomes and earnings, as Table 2 shows. Many of the people with low incomes were solely dependent on social security benefits. Nobody in the sample showed evidence of substantial or even moderate surplus income or savings. For all but two, their disabilities entailed additional expenditure (Table 5). Although the range in estimated expenditures amongst sample members was wide, both mean and median values were high (\$2,076 and \$1,445 respectively). These are not insubstantial amounts for people with relatively low incomes and it is hardly surprising that outside sources have played such an important role in meeting disability-related needs. The absence of this support might well have meant that disability-related needs would have remained unmet or that it would have become necessary for respondents' resources to be diverted from other uses to the detriment of the respondent's standard of living. Given the significance of these outside sources of help it is important to identify them more exactly. The reliability and quality of this help clearly matters to respondents as does the equity with which it is dispensed. Although there will always be certain element of discretion in the provision of help it is important in the formal sector at least that this should be done in accordance with well defined limits.

**TABLE 15: ITEMS & SERVICES ACQUIRED BY RESPONDENTS SINCE THE ONSET OF DISABILITY
ACCORDING TO WHETHER THEY INVOLVED ANY EXPENDITURE BY RESPONDENT**

	Work-Related Items/Service		Education/Training Related Items/Service		General Disability Related Items/Service	
	No.	%	No.	%	No.	%
Items/Services acquired involving expenditure by respondent	44	61	42	68	164	56
Items/Services acquired involving no expenditure by respondent	28	39	20	32	130	44
<i>Total Acquired Items/Services</i>	<i>72</i>	<i>100</i>	<i>62</i>	<i>100</i>	<i>294</i>	<i>100</i>

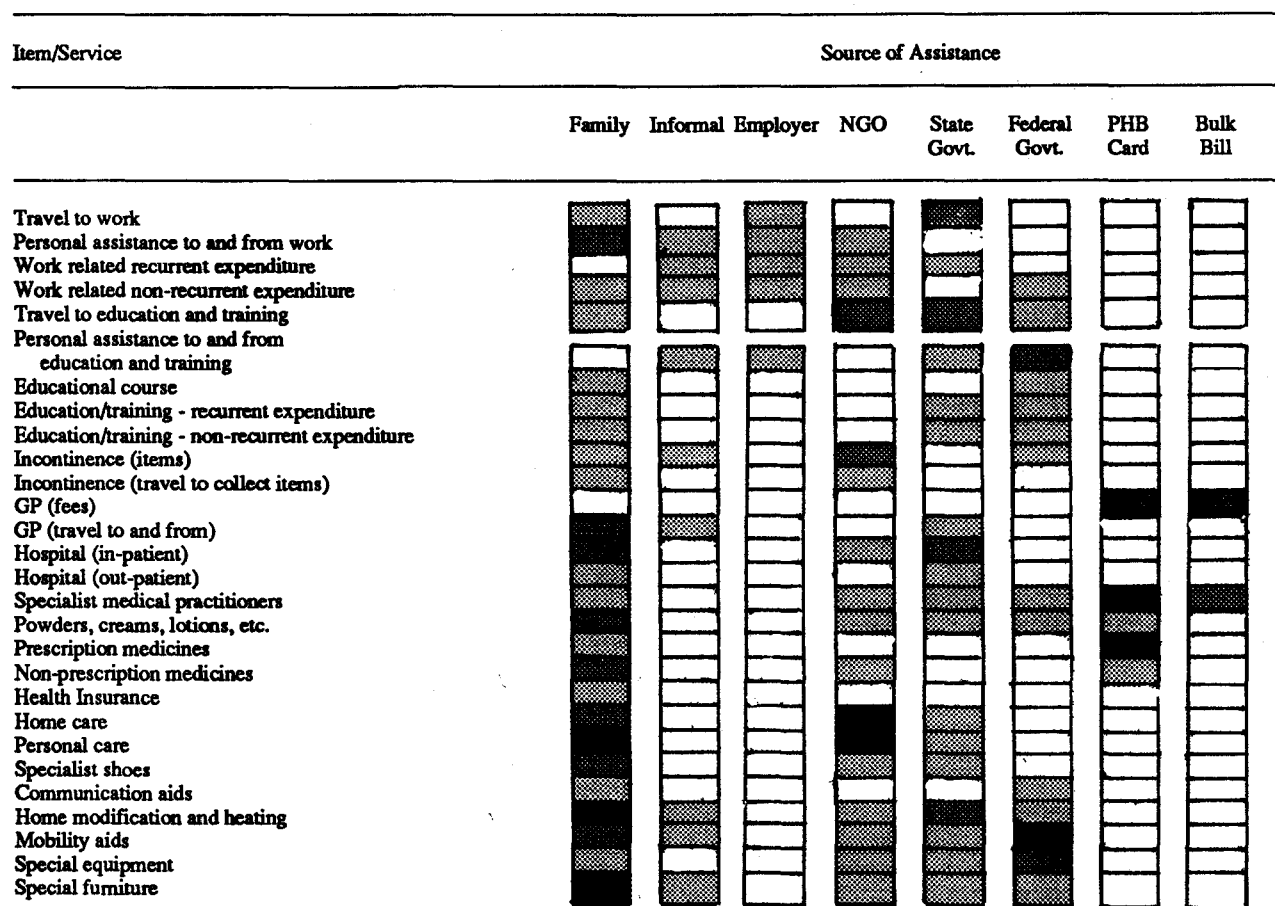
Source: Survey Data, 1988.

Figure 2 summarises the information we obtained on sources of support. One of the most significant findings it shows is that needs in most areas are being met from a wide range of sources. Our figure does not even provide the complete picture. Within each of the broad categories of sources of help there will be a multiplicity of agencies. In order to participate on an equal footing with an able-bodied person, the person with a disability must therefore call on considerable knowledge, powers of negotiation, effort and ingenuity to seek out and marshal support from this wide range of possible sources. Alternatively people will have to rely on the competence or goodwill of others; family members, advocates, professionals or officials to act on their behalf.

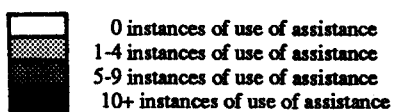
On the whole the goods and services for which an outside source of help was particularly important were: first, medical care; second, the larger consumer durables, for example, heating and air-conditioning, home modifications, mobility aids, equipment to aid independence and special furniture; and third, personal assistance. The most usual source of help for medical care was the Federal Government through the Pension Health Benefits Card and bulk billing. The most important source of help for the large consumer items was the respondent's family and the Federal Government largely through the PADP (Scheme) and the CRS. Personal care was most frequently provided by the family and non-government agencies. Of course, such care was also frequently given by spouses but this is not listed here as only sources of help outside the income unit are included in this part of the analysis.

A second fact to emerge is that the single most important source of outside support is the family and kin. This includes both the family with whom the respondent still lives and the family of whom he now lives independently, or it may be more distantly related members of the extended family. As we are concerned with expenditure incurred since the onset of disability, some of the needs referred to in Figure 2 may well have been met by the family whilst the respondent was still a dependent member. Although, taking all its forms together, support financed from the public purse is more frequently used than that provided by the family, members of the family are important not just as the most frequent providers of personal care and transport to doctors and hospitals, but also for the purchase of items of furniture and home modifications. We should perhaps question a state of affairs in which adults are so dependent for such a variety of goods and services on their extended families. How do people for whom there is no such source of support manage? There are also questions of equity. How much support a family can provide will depend on its own resources. Without seeking to thwart the desire of parents to support their offspring one could argue that the availability of essential items for people with disabilities should not depend on the family's ability to provide. This will not only result in inequity amongst dependent people but amongst supporting families as well.

FIGURE 2: SOURCE OF ASSISTANCE ACCORDING TO FREQUENCY OF USE



Key



Notes:

- Family:** Includes parents and other members of the nuclear and extended family, but excludes members of the respondent's income unit.
- Informal:** Includes help received from friends and work colleagues.
- Employer:** Includes sheltered workshops.
- NGO:** Non-government Organisation. Includes all agencies managed by a community based or charitable institution. Includes ACT's, the Home Care Service of NSW (which, at the time of the study, was not managed by the Department of Family and Community Services) and other organisations which assist particular disability groups such as Paraquad, AQA, the Challenge Foundation, and the Autistic Association.
- State Government:** This includes State Government bodies and statutory authorities such as the Housing Commission, Area Health Services, or Community Health Centres.
- Federal Government:** Assistance received from the Federal Government includes the PADP Scheme, the Commonwealth Rehabilitation Scheme, and all tertiary institutions.
- PHB Card:** This refers to benefits received by people holding Pensioner Health Benefit cards.
- Bulk Bill:** This refers to general practitioners, medical specialists and other health professionals who bulk-bill.

CHAPTER VII

CONCLUSIONS

PART 1 - SUMMARY OF FINDINGS

The purpose of the study described in this report was to describe the extra expenditure incurred by people with disabilities when they participate in employment or education and training. Since, in order for people to participate in these activities, other disability-related needs will also to be met, we have included an examination of these in our study as well.

THE SAMPLE

We interviewed 60 people. They were selected randomly from lists of recipients of the Mobility Allowance and the Invalid Pension held by the Department of Social Security. Our aim was to determine the level of disability-related expenditure of these 60 people and to examine whether and, if so, how this was related to their personal and social circumstances. We considered 5 variables: type of impairment, level of dependency, family composition, employment status and income.

Two broad clusterings seemed to emerge. One consisted of 33 people with physical and sensory impairments and the other of 21 people who were intellectually impaired or who had a psychiatric illness. Six people, whose impairment was such that they could not confidently be placed in either of these groupings, remained.

Although people with physical or sensory impairments were, according to our scale, less often highly dependent than those with an intellectual impairment (but not than those who either had a psychiatric illness or were in the 'other' category), they were relatively more likely to have a severe difficulty with mobility and to be incontinent. People with physical or sensory impairments were more likely than people with intellectual impairments or a psychiatric illness to be married and to be in open employment. They also had higher incomes. No person with an intellectual impairment or a psychiatric illness was currently living in a stable union, and only two were in open employment.

People with physical and sensory impairments were more likely than people with intellectual disabilities and psychiatric illness to be high spenders on their disability and less likely to be among the low spenders. Only two of the 10 lowest spenders were people with physical or sensory impairments. On the other hand, seven of the top 10 spenders in the sample were people with physical or sensory impairments (see Appendix VI). This is probably related to their higher incomes, associated with their greater propensity to work in open employment, and to the needs that arise from the nature of their disabilities. We are unable to say from our study which of these factors had the greater effect on level of expenditure.

OVERALL EXPENDITURE

There was a very considerable variation in respondents' annual expenditure. Two respondents spent no money at all on their disability. At the top of the scale three respondents had an annual expenditure of over \$8,000. The mean expenditure of the sample was \$2,076 and the median \$1,445. For reasons associated with our methodology, as we have noted, these amounts are likely to be underestimates.

For most respondents the largest proportion of their total expenditure was for items purchased regularly, for example, personal assistance, educational course fees, medicines and items needed to manage incontinence. In only 3 cases was non-recurrent expenditure higher than recurrent. In each of these cases expenditure was incurred on home modifications and the installation of heating and/or air-conditioning by people with physical disabilities.

If we look at the top 50 per cent (that is, people who spend above the median) we find that in terms of their conditions and their social characteristics they are a very heterogeneous group. However, within this group, we find a small over-representation of people with physical and intellectual impairments and a fairly high over-representation of

people with sensory impairments. People who have a psychiatric illness or who are in the 'other' impairment group, are considerably under-represented. There is a large over-representation of highly dependent people and of people who combine a serious mobility problem with incontinence. There is a small over-representation of people who are in employment and a high over-representation of people who have a high income. These findings are summarised in the table in Appendix VI.

PARTICIPATORY EXPENDITURE

Thirty five respondents were currently in full- or part-time employment. Thirty one of these had incurred some recurrent expenditure in connection with this activity. The range of expenditure in this group was considerable. The lowest recurrent expenditure was \$240 and the highest \$4,800. The mean value was \$1,481 and the median \$1,112. The main element of recurrent expenditure was most often the cost of the respondent's journey to work.

The mean and median recurrent expenditure of the 24 people who were receiving either full- or part-time education or training was higher than for those in employment (\$1,616 and \$1,224 respectively). In a majority of cases this expenditure is accounted for by the high cost of educational or training courses. People with intellectual impairments paid a particularly large amount for these. In general the expenditure incurred on travel to education and training was lower than that on travel to work, because it was frequently subsidized or included in the cost of training.

Relatively few people either employed or receiving further education or training incurred significant occasional expenditure on account of these activities. The largest amounts were spent by two of the three people who had sensory impairments. They both acquired expensive equipment to help them in their job or their studies.

GENERAL DISABILITY-RELATED EXPENDITURE

All but three people had incurred expenditure last year on items or services that they required regularly on account of their disabilities. Once again the range in expenditure was very great - from \$1 to \$4,255. The mean and median expenditures for the sample as a whole were \$760 and \$393 respectively. Expenditures tended to be particularly high on private health insurance (only people who said they would not have had this but for their disability were included in the calculation), homecare (when the respondent paid the full commercial rate), specialists' fees, (particularly specialists who were not in mainstream medicine) and items required to manage incontinence. Average expenditure on personal or attendant care was also high but involved too few people for the amount to have any meaning.

Over two thirds of the sample had incurred expenditure on items bought on an occasional basis since the onset of their disabilities. Mean expenditure was \$8,676 but this was considerably influenced by certain very large outlays on home modifications and the installation of additional heating and air conditioning. In general these modifications were undertaken by people with physical rather than other impairments.

NEEDS MET WITHOUT FINANCIAL OUTLAY BY RESPONDENTS

Expenditure incurred to meet disability-related needs, whether to enable participation or to meet general needs, would have been much greater but for the support provided by other persons or agencies. Altogether, 39 per cent of all items acquired by respondents for the purposes of their employment were provided without the need for any outlay on their part. For education and training this figure was 32 per cent, and for items required to meet other general needs arising from disability the proportion rose to 44 per cent. Assistance on disability-related items came from a number of sources. Most frequently assistance was provided by family members outside the respondent's own income unit. However, non-government organisations, funded by State and or Federal Government as well as by private contributions, were also an important source of support. State and Federal Government support were also significant, the latter often in the form of fringe benefits obtained by virtue of eligibility for the Invalid Pension. The study only considered support provided directly to individuals and not shared facilities or services, for example, ramps, toilets and so on.

INDIRECT COSTS OF PARTICIPATING IN EMPLOYMENT

Many of the respondents in employment said that their earnings, chances of promotion and fringe benefits had been affected by their disability. Most usually it was the inflexibility of the social and physical environment which accounted for these disadvantages. In many instances job choice had been very severely limited by problems of physical access. Promotion prospects were also frequently affected for the same reason. In a number of cases the employment possibilities of either spouses or parents were also adversely affected by their caregiving responsibilities.

A great deal of the evidence from this study points to the fact that enabling people to participate as full citizens in the ordinary life of the community involves considerable expense. Whilst some people with disabilities may be able to afford to meet their own needs the evidence suggests that most people are clearly not able to do so and rely heavily on outside support. In addition, individuals cannot be expected to provide the communal facilities which will be required if participation is to be anything more than an ideal. It is a discussion of this that now follows.

PART 2 - DISCUSSION

THE ROLE OF A DISABILITY ALLOWANCE IN RECOGNISING THE EXTRA EXPENDITURE INVOLVED IN PARTICIPATION

It is now necessary to recall the purpose of this study. It was to inform discussion of a proposed disability allowance, the intention behind which is to recognise the extra costs incurred by people with disabilities when they participate in community activities. It is also intended to be part of a package that would both enable and provide the incentive for people with disabilities to participate.

The suggestion was that the disability allowance would initially be set at \$20 a week or \$1,040 per annum, which is below both the mean and median participatory expenditure incurred by respondents involved in either of the areas of activity. The annual mean and median recurrent expenditure for those in employment were \$1,481 and \$1,112 respectively. Seventeen people could recall recurrent expenditure. For eight of these the amounts were below that suggested for the allowance and for nine they were above. The annual mean and median recurrent expenditures for people in education and training were \$1,616 and \$1,224 respectively. Twenty one people incurred some recurrent expenditure; for eight of these the amount of expenditure was below that suggested for the Allowance and for thirteen it was above. Employment expenditure was dominated by travel costs and training expenditure by the cost of educational and training courses. Expenditure would have been much higher had it not been for the support provided by other people and agencies. This support was most commonly provided by family members though we are unable to say whether in terms of monetary value family support was greater or less than that provided from other sources. It certainly costs the community less. The reader will recall that expenditure figures provided in this report are considerably deflated because they assume that people who were not able to specify the amounts actually paid for particular goods or services did not spend anything for them. This was particularly common in the case of travel costs.

We have already hinted that there is some room for debate as to whether travel costs should be counted as 'extra' since they are also incurred by people who are able-bodied. We have argued that their inclusion is appropriate for several reasons. First, they are costs usually incurred without a choice as to means of transport. People with disabilities are typically not free to choose the cheapest or otherwise most convenient means of travel to work. Our survey has shown that travel costs can be inordinately high, particularly for people who have to take taxis or who need expensive modifications to their cars. People with disabilities who drive cars need them to be particularly reliable if they are to be effective workers or students, because they do not usually have alternative means of travel. The most compelling evidence perhaps is the number of respondents who were driven to work by a spouse or parent. However willingly this may have been done, it certainly involved a cost. Though hidden, and not easily compensated for, it could be argued that some recognition is due.

In fact there is already a recognition of these travel costs in the form of a Mobility Allowance presently set at \$572 a year. About half the respondents had costs that were twice this amount. Equally important, even excluding the use of

taxis, respondents' average travel costs were quite considerably higher, using the means forced on them by their disabilities than the average cost of travelling to work by car or by public transport.

We have been looking so far at the contribution a disability allowance, hypothetically set at \$1,040, would make to the actual outlays on participation reported by the respondents in our survey. In fact, 24 of the 35 working respondents would have had their work-related expenditure covered by an allowance of this order. It is perhaps worth pointing out that for all types of family unit it has been estimated that where the head is in the workforce the poverty line for December 1988 should be set at a figure \$30 above that for families whose head is not in the workforce. That is to say, for the population in general, the estimated cost of being in the workforce is in the region of \$30 a week, that is, \$10 a week more than the suggested amount for a disability allowance (Social Policy Research Unit, April 1989).

We have argued in this report that it is not reasonable to differentiate between the expenditure incurred exclusively on account of participation and other expenditure incurred to meet more general needs arising on account of disability. Thus although much of the data assembled in this report relates separately to participatory and other expenditure, we would prefer now to look at the overall expenditure of respondents. This is described in Table 5. These findings enable us to make some judgement as to what order of recognition the proposed disability allowance would constitute in relation to the expenditure respondents actually incurred in meeting their needs. From this table we can infer that were an allowance to be set at \$1,040 a year it would cover all the disability related expenditure of 38 per cent of the sample; a half or more of the expenditure of 67 percent of the sample; less than a half of 33 per cent of the sample; less than a quarter of about 15 per cent of the sample.

A disability allowance set at the level suggested would certainly provide a recognition of the extra expenditure incurred as a result of disability and also of participatory expenditure. In some cases this would be considerable; in some others less so, and in others again, more of a token. For those with low expenses and low incomes it would probably appear generous; for those with low to medium expenses and low to medium incomes it should seem at least worthwhile. But as expenses rise in relation to income, an allowance of this order could appear quite meagre. Remember that relatively few respondents have incomes approaching the Australian average. For those rare people with high incomes \$20 a week would have rather less meaning, probably constituting too low a proportion of total income to be very significant.

Clearly, in the end, the determination of what represents a reasonable amount at which to set an allowance must be political decision, which we hope would be informed by the best available knowledge of actual expenditures. But considerations which relate to the criteria for eligibility are not solely political. What should be the cut off point for a disability allowance? To administer an allowance where entitlement was related to the actual amount spent on the disability, would be very difficult administratively. Indeed the Handicapped Child's Allowance attempted to do just this; and many of the appeals relating to the Allowance were associated with eligibility criteria, including expenditure. Our study has pointed to the enormous difficulties of obtaining accurate information even when people were interviewed at length and in great detail. Much of the expenditure associated with disability is simply not quantifiable. It would seem reasonable and cheaper administratively to pay the allowance, at whatever level it is decided to set it, to anyone who satisfies the clinical and social eligibility criteria.

Up to now, we have discussed this allowance as a recognition of expenditure. Since any amount of disability allowance would constitute some level of recognition it does seem more sensible to tackle the issue at the level of incentive. It is not easy to separate the notion of recognition from that of incentive. Though the stated objective of the allowance is recognition, the notion of incentive is also clearly built in. The allowance is, after all, intended to help people. But to help people do what? Is it to help meet their costs? By definition the allowance will do this in some degree at whatever level it is set, and whatever people's expenses are. Is it to help people to participate in activities more easily? If this is the case, one has to consider an allowance in relation to other factors which might help or inhibit participation. We have already noted that people receive assistance from a variety of sources. The proposed allowance would simply provide another source of help. In relation to their expenditure this would in some cases be considerable and in others, more slender.

THE ROLE OF A DISABILITY ALLOWANCE IN ENABLING PARTICIPATION

Given the goal of normalisation, one aspect of which must surely be participation in the ordinary life of the community, an important concern is the sorts of policies that might help or hinder participation. This is perhaps a more important, though admittedly no more tangible an issue than that of recognition. Participation hinges on an immensely complex web of factors. Our evidence suggests that these pertain to the level and nature of people's disabilities, to their social and domestic circumstances and support networks, to financial considerations, to the availability of work that they are equipped to do, and to the capacity of the social and physical environment to accommodate people with disabilities. One of the real difficulties of this study, given its objectives, is that it is not able to explain why people are not working. Until we know this, it is very difficult to say whether, how far and in what circumstances a disability allowance would play an enabling role. One can only assume that its efficacy would be related first to the strength of financial considerations vis a vis the others we have mentioned, and the level at which the allowance was set. Although our study does not offer a great deal of information about the factors which inhibit people who are not currently participating from doing so, we are able to identify a number of factors which appear to have enabled and which might encourage participation.

OBSTACLES TO PARTICIPATION

In this section of the discussion we look at the circumstances that appear to help and hinder participation. In order to assist us to assess the possible enabling role of a disability allowance and to highlight some of the issues involved we shall be considering the importance of expenditure in relation to some of the other factors which appear to affect participation amongst groups and individuals in the sample.

It is perhaps worth looking first at the characteristics of the 23 people whose expenditure would be covered by an allowance of \$1,040 and to consider the enabling effects of an allowance on some members of this group of 'low spenders'. The low spenders are by no means homogeneous in respect of any of the variables that we have considered, but as a group they can be characterised in certain ways. Although the group includes people both with physical and with intellectual impairments it also contains half the people with psychiatric illnesses and all but one of the people who are in the 'other' impairment category. People who are classified, according to our scale, as having high dependency are somewhat under-represented and people with lower dependency somewhat over-represented. It includes only one of the seven people in the sample with severe problems in the areas of mobility and incontinence. It contains all but two of the single parents and a half of the hostel dwellers. It contains all but two of the people who work in sheltered workshops. All but three of these low spenders earn less than \$20,000 a year and just over half are entirely dependent on social security payments. This group is manifestly made up of the poorest people in the sample. It contains a number of people who could be termed socially deprived and who would undoubtedly both be helped by and welcome an extra \$20 a week. It would contribute to an improvement in their standard of living, though their problems are, of course, unlikely to be entirely solved by this payment. We recall the example of a single parent with arthritis who lives with her child in a fourth floor apartment of a Housing Commission block. This respondent has a multiplicity of inter-related problems. Her arthritis makes it difficult for her to climb the four flights of stairs to her flat, especially with the load of the child and the shopping. The effort involved makes the whole exercise seem hardly worthwhile. So she leads a very isolated and depressed life. Her problems are exacerbated by financial circumstances which further trap her in her isolation. She is a good example of someone who would benefit from additional money, but her situation also needs to be dealt with much more holistically. This respondent is a long way from participation, and not just on account of shortage of funds.

Amongst the 'low spenders' described above there were five people who worked in a sheltered workshop or ATC during the day and went home to a hostel at night. Two of these people had psychiatric illnesses and three intellectual impairments. Their style of life could hardly be described as participatory. Certainly their low spending may be explained by their very low earnings which were negligible in all cases. But the real issue here is not the supplementation of incomes by an allowance, but rather policies to address the underlying problem. It is not the role of this report to suggest what these should be, but to point to a lack of jobs, either in open employment or in sheltered workshops, at appropriate skill levels, for which workers would receive a recognised working wage and enjoy normal work-related conditions and benefits.

When we consider the role of expenditure in participation we are not dealing with a situation which can be removed from its historical and social context. As we move up the scale of spending there is a tendency, evident in our research, for an increasing proportion of total expenditure to be spent on large consumer items, home modifications, mobility aids, special furniture and equipment. Table 5 shows an average annual expenditure on these items since the onset of disability. However, the table omits the expenditure incurred by others for those people whose condition existed from birth or developed whilst still in the parental home where they may remain. In these cases early and sometimes present needs have been met by parents, often with assistance from government and other agencies. It has often been this early expenditure which enables current participation.

We have referred earlier to the case of a young man with muscular dystrophy, still living with his parents who had moved to their present house in order to be near a special school for him. To be made wheelchair accessible, the house required extensive modifications. As this man's condition has progressed, other internal modifications have been needed. Though he is contributing to the current modifications, because he is now earning, it is clear that his parents have also made a very substantial contribution to his capacity to participate. They continue to do so. They provide for all his personal care needs and take him to and from his job. The lifetime current cost of his participation is extremely difficult to quantify but has clearly been very considerable. The parents may well feel that it has all been worthwhile; they are certainly proud of his achievements. The young man has done extremely well, first at his studies and now at his job. It is to be regretted that his promotion has been frustrated by the inaccessibility of the building in which the job at a higher grade would have been located.

The lesson from this example is that participation involves a collaboration of the individual, the family and the community and that the relative contributions of these, as we shall see when we explore this person's circumstances a little further, tend to remain in a state of flux.

In terms of the objectives of this study the findings have pointed to the extremely important role of the lifetime experience of people with disabilities. Those whose disability occurred at birth or developed in childhood will experience both the expenditure and the obstacles to participation in ways quite different from those whose disabilities arose as a result of a traumatic accident or from those whose condition first manifested itself in adulthood. In our view the sorts of expenditures incurred and the way they are met are only in part attributable to the condition or impairment itself. They are also a function of the highly variable circumstances of people's lives. Our study has provided a number of examples of the close interaction of these two forces, as they pertain to expenditure.

Above we have given the example of a man whose physical disability manifested itself when he was still a child. His life and that of his family has been dominated by the need to adapt to the progressive nature of his condition. Much expenditure, past and current, has been associated with the need to enhance his mobility. As we saw, his parents contributed a great deal, but in the provision of mobility aids, such as wheelchairs, they were assisted by PADP. The respondent, now a working adult, has considerable wheelchair maintenance costs to pay. It is perhaps worth noting that he dwelt at some length and with some anger on the fact that this expenditure was not tax deductible. Now he is working he will have to purchase his own wheelchair, which will involve a considerable outlay if he is to obtain a power-driven model. As he has been earning and has also lived at home at low cost, his resources may well extend to this. However, he and his family are conscious that his other expenses will increase. As his parents age they will become progressively less able to attend to his personal care. They will probably have to pay for help, which will stretch their resources considerably; though the fact that they can even contemplate this is a reflection of their relative affluence.

Contrast this person's position with that of someone who has had a traumatic accident. The domestic circumstances of such people at the time of the accident vary considerably and are likely to affect their decisions about where and how to live after their release from hospital. Of course this will not be the sole consideration; the location of their treatment, for example, will be another. Some people will return to their pre-accident domestic circumstances, whether with their parents, their spouse, their friends, or simply alone. They may subsequently move on again. Perhaps their earlier circumstances become untenable for one or more of the participants. In such a case there will be a constantly changing interplay between the individual's own resources, those he or she is able to call upon, and the demands made upon these resources. In understanding the role of expenditure in participation, it cannot be divorced from its social context.

One of our respondents returned to his marital home on his release from hospital after a traumatic accident. He and his wife paid for the home modifications required. The respondent's father and father-in-law also made a considerable

contribution towards these expenses. Two major changes subsequently occurred in this man's life. First his marriage broke up; secondly he decided to return to his studies to gain a further tertiary qualification, in the hope that this would enhance his chances in the labour market. He now lives in accommodation provided for students on a university campus. His current outgoings are modest, partly because of his low rental and partly because he receives the Invalid Pension. Much of his ongoing disability-related needs are provided for without cost because of his entitlement to the Invalid Pension's fringe benefits, and he hopes soon to procure a wheelchair through the PADP Scheme. Although confined to a wheelchair he is able to manage his own personal care. He finds house cleaning difficult, however, and he receives subsidised help with his housecleaning through Home Care Services.

This respondent looks forward with some trepidation to the end of his studies and his re-entry to the workforce. He will have to find new accommodation and pay a commercial rent. This may well be high because there will probably be few places which are both suitably located and wheelchair accessible. He could, of course, consider buying his own home; but this time, he is perhaps less likely to receive a parental contribution towards the cost of undertaking any modifications to his home that may be required. He would have to rely on his own resources for these. Clearly the decision as to whether to re-enter the workforce and thereby lose his Invalid Pension will be a difficult one. He will need to earn a good salary to compensate for the loss of the benefits associated with the Invalid Pension. A disability allowance of twenty dollars a week would help this man. It would pay for housecleaning services, for example, though it would barely pay for the upkeep of his wheelchair (which last year cost him \$700), let alone the high medical expenses and costs of managing his incontinence which he will have to meet if he is to participate in the workforce; or in any activity at all outside the home. It is clear that were this man still to be married, his circumstances would be very different. The advantages of two pooled middle incomes would more than tip the balance in favour of his working.

This dilemma was experienced by several respondents whose circumstances, though different in detail from those we have just described, were in principle the same. In the body of the report we have provided examples from respondents' own experiences of the constraints that arise from the earnings and income rules governing eligibility for the Invalid Pension and associated fringe benefits. We saw some examples of earnings being kept artificially low in order to retain the fringe benefits. We also saw how that affected not just the earnings of the person with the disability, but also the earnings of other members of the income unit. Our example of the respondent who had substantial disability-related requirements, but whose annual recurrent expenditure thanks to fringe benefits of the Invalid Pension was only \$1, illustrated this point well. Others whose expenses are lower would stand to lose less by relinquishing the pension than he did.

Interviewer: *Has your disability had any impact upon your earnings or chances of promotion?*

Respondent: *Oh yes! I mean I'm limited, very limited in what I can earn cause its going to knock the hell out of my pension. Right now I'm at that sort of stage where I'm not earning enough to go off the pension cause of the added expenses, like medicine. They're huge expenses that I have to face. I'd loose all my benefits from ... all my medical supplies ...*

We cannot tell from our study how far the fringe benefits of the Invalid Pension constitute a disincentive to participation. We have tried to illustrate with a few examples the rather obvious point that there is no single answer to that question.

Our respondents had, for the time being at least, overcome all disincentives, for they were participating. But this does not mean to say that they were satisfied with the conditions of their participation - far from it. Parents and advocates of people with intellectual impairments expressed great dissatisfaction with the opportunities available to their children. We have already alluded to the lack of opportunities in open employment and the dismayingly poor working and employment conditions of those whose only taste of the labour market is represented by the sheltered workshop. We found only one example of movement from a sheltered to an open work situation. There was no case of such movement amongst people with intellectual impairments.

We have written at length in this report of the disadvantages that people with physical and sensory impairments experienced. They indicated how their access to employment had been limited, as had their chances of achieving their true potential, and many suffered anxieties about long term economic security. The people we interviewed had, by dint of individual effort, overcome substantial obstacles to their participation in the workforce; whether they are able to attain their rightful place in it will clearly depend on the nature and extent of public support.

PART 3 - RESEARCH ISSUES

At various points in the course of this report, we have advised the reader to treat the findings of our study with caution. We have emphasised that the study is exploratory. It is always tempting, if the results of a study seem credible, as we believe ours to be, to treat them as conclusive. In the case of this study there are three main reasons for resisting the temptation. The study is too small in scale, it is not adequately representative of people with disabilities and the response rate is low.

The scale of the study: the sample is not large enough to provide a basis for generalisation. The small numbers mean that the people in the sample are hardly likely to be representative of the population as a whole. For example, the three people with sensory impairments whom we interviewed could not possibly represent the range of disability or of personal and social circumstances of all such people in Australia. As we saw, compared with other impairment groups in the sample the people with sensory impairments had relatively high incomes and were relatively high spenders; but we cannot with any confidence infer from the three people included in our study that Australians with sensory impairments tend to have high incomes or to be high spenders. From our study we can say, however, that it is possible for people with sensory impairments to have highly responsible professional jobs and that when they do so they may well spend quite a lot of money on technical aids to help them in their work.

The representativeness of the sample: The members of the sample were selected from particular populations which do not represent the full spectrum of Australian social experience. The spending pattern of people with different characteristics from the members of our sample may well be different. For example, all the members of our sample lived in the Sydney Metropolitan Area and the expenditures we describe which form the core of this study have no doubt been affected by this. A study in a small town or rural area might have yielded both different types and levels of expenditure. For example, travel costs may have been higher had we undertaken the study in a country area because of the greater distances to be covered in order to access jobs and services. On the other hand, travel costs may in other places have been lower because of an absence of accessible jobs and services. The level of service provision might have been different in another area, either higher or lower, and as we have shown, expenditure is very much affected by service use. In another way, too, the sample was unrepresentative. It was drawn almost entirely from recipients of the Mobility Allowance, and there is no reason to suppose that these people are representative of the disabled population generally, especially as such a high proportion of them are people with intellectual impairments.

The response rate: Only about 22 per cent of the people whom the Department of Social Security invited to participate in this study agreed to do so. We have no means of knowing whether the people who agreed to participate differed from those who did not in ways which might affect their expenditure.

However, the aim of this study was not to produce definitive findings. It was intended to be exploratory and it did achieve its principal objective, which was to explore the issues raised by the proposal for a disability allowance. From this emerged some indication of the sorts of considerations that might guide the design of further research. It is to these that we now turn:

1. A study whose purpose is to investigate the extra expenditure associated with disability should comprise both disabled and able-bodied people. This is particularly important in trying to identify the extra expenditure associated with disability on items which are not specific to the disability but which, nonetheless, may be affected by it: telephone, power, clothing, transport costs and entertainment, for example.
2. A study which purports to look both at obstacles and at conditions which might facilitate participation should, in our view, compare the circumstances of people who are participating in the relevant activities with the circumstances of those who are not. Questions which invite non-participants to conjecture about the sorts of circumstances which might entice them into the workforce have limited validity, but a thoroughgoing analysis of the disabilities and participation histories of participants and non-participants should bring to light evidence of the factors, including the expenditure involved, which encourage and inhibit participation. One concern we had about the composition of our sample was its apparent bias towards people with physical and sensory impairments who were in white collar occupations. The study included, for example, no blue collar worker who had sustained an industrial accident. Is this because blue collar workers find it difficult to re-enter the workforce, perhaps because they do not have the skills required for the sorts of jobs that people with severe physical disabilities are able to perform? Is it because the expenditure involved in participation is too great? Is

it because, for whatever reason, they did not volunteer to participate in our study? Or is it simply a reflection of the size of our sample?

3. A study concerned with expenditure should rely as little as possible on unsubstantiated recall. Information is far more likely to be accurate if it is contemporaneous and collected, as in the case with the Household Expenditure Survey, by means of expenditure diaries. We recognise that this is an expensive and complex procedure both for respondents and for those conducting the research. Problems will almost certainly occur in the completion of expenditure diaries. It is reasonable to assume that these will be greater on the whole for a disabled than for a non-disabled population, whatever the type of impairment. Extensive pilot work will be required first to ascertain, in cases where the respondents themselves are not able to complete the diary, who in the household would be the most appropriate substitute. This will be particularly important in cases where the respondent is living in a hostel or other group living arrangement or when the respondent is living alone. In these cases the respondent may need daily assistance from either a care worker or an interviewer, which is very likely to increase the cost of the investigation.
4. One of the most difficult tasks in a study of expenditure is to identify the effective unit of consumption. In our study we used the 'income unit' as our unit of analysis. In some cases this seemed quite appropriate, in others it proved not to be so. When the respondent lived either alone or with a partner the 'income unit' proved an appropriate basis for analysis. In other cases, where respondents were still part of their parental households, there was a difficulty. In some such cases we found that resources were pooled and respondents had neither effective control of their incomes nor any say in how they were spent. In these cases it proved extraordinarily difficult to tease out whose resources were being used to pay for what items; that is, who actually bore the expense. This was usually so in the case of people with intellectual impairments, whose carers sometimes lodged respondents' social security payments in their own bank accounts, for example. The situation is similar, in principle, when a person lives in a group home, hostel or other such residential facility. In both of these domestic situations people with an intellectual impairment have little or no control over the larger part of their resources and therefore over their expenditure. In the case of married couple households, though choice may be limited by the level of resources, it nonetheless remains intact.
5. In cases where a person still lives in the parental home but where resources are not pooled the issue is rather different. In these cases it becomes important to determine the respondent's contribution, if any, towards the expenses of the family. This will have an impact on the respondent's disposable income, which is likely in turn to influence expenditure. In these cases, some disability-related expenses will be met by co-residential parents, some by the respondent, while yet others may be shared. For example, a wheelchair may cause a great deal of damage to the interior decoration of a house. Who pays for house maintenance and redecoration? Parents may take their offspring to work. Who pays for the car and for its running costs? People who live alone or with partners may appear to have higher expenses than those who live with their parents. This is not necessarily because they have more disability-related needs but because they more often have the responsibility of meeting all of them. There is no one solution to this problem. But it is important to remain aware of it and to pay very careful attention to the distribution of resources in the family and to obtain full information as to whose money is paying for what items and to document cases carefully where it is not possible to assign expenditure to a particular individual. One approach is to treat different types of domestic units separately at this stage of analysis. This was not possible in our study because of its size.
6. A separate but related issue concerns the timing of expenditure. Our study took account of non-recurrent expenditure since the onset of disability. This was done because we were conscious that expenditure at earlier periods in a person's life could have an important persisting effect on their current circumstances. However, not only did this raise problems of recall, but we also found that we were in danger of attaching the same meaning to expenditure, regardless of the time at which it was incurred, or by whom. At the stage of analysis it is important to distinguish expenditure incurred whilst the respondent was still a dependant from expenditure subsequently incurred.
7. We did not pay sufficiently careful attention to some important areas of expenditure. Areas that require special mention were housing costs as related to location and accessibility of the dwelling, house maintenance, car maintenance and car modifications.

8. We do not doubt our decision to include people with all kinds of disabilities, regardless of their impairment, in our study. There is presumably no intention of excluding any group from an allowance because of the nature of their impairment or the source of their disability. Nevertheless, we remain in some doubt as to whether the conceptualisation and framework for the study has been entirely appropriate for people with intellectual impairments. In the case of all other respondents we were questioning people who within obvious limits were making autonomous decisions, and as far as their consumption was concerned were exercising some independent choice. For the most part this was not the case for respondents with an intellectual impairment. With very few exceptions, these were people who appeared to have a moderate or severe level of impairment. They tended to have a high degree of dependency. Whilst the subject of the research was the person with the intellectual impairment, the effective respondent in these cases was invariably the caregiver. The nominal respondent made no autonomous decisions and exercised no choice as to how his or her resources were dispensed. Although the expenditure has been treated as though it has the same meaning for all members of the sample, it clearly did not. Nor did 'participation'. For the most part the people in our sample were obtaining some training with the aim of enhancing their position in the labour market. This was not the case for people with intellectual impairments. They were not attending an ATC because they chose to; but because it is virtually the only day-time activity available for them. Their training has no determinate goal such as a marketable qualification. It will not lead to enhanced status or employment opportunities. This is not to argue that the training has no value but it is to question the implicit assumption that education and training have had the same meaning and function for all members of the sample. It is possibly not in the design of the study but in the interpretation of the findings that this point needs to be acknowledged.
9. We have developed a scale of dependency for this study, but we are aware that much more attention needs to be paid to this task. For example, in our terms, the psychiatrically ill emerge as a group with low dependency which is clearly a dubious result. It is more likely that our scale simply does not tap the particular areas in which people with a psychiatric illness are dependent, or all those areas which might influence their expenditure patterns or their use of services. The input of many professional groups would be required in the development of a more adequate scale. Medical, paramedical and social work practitioners must be incorporated.

With hindsight, we have concluded that our dependency scale pays too little direct attention to everyday adult living skills; for example, the ability to drive a car, to cook, to shave, to change the washer on a tap or alternatively to telephone a plumber, to apply a bandage to oneself, to deposit or withdraw money from a bank or to complete an official form such as an application for social security benefits. The capacity to do some of these things may certainly be inferred from answers to other questions, but we now believe that we should have paid more explicit attention to them.

10. The problem of low response is of a different order but does require some comment. The sample was selected from amongst people who have received a social security allowance. To receive this allowance they have provided the Department of Social Security with information about themselves which is intended to have one use only, that is, to calculate their entitlement to the allowance. Quite correctly, the Department of Social Security respects the confidentiality of its clients, as to their names and any other information it may have about them. Consequently it will not disclose the names of benefit recipients to research workers or to anyone else. If a research worker wishes to interview any of its clients and the Department considers that the research is of sufficient value, it will write to its clients asking them whether they agree to be interviewed and if so, to reply to this effect directly to the research worker. In this way the identity of clients, until they themselves have revealed it, remains unknown to the research worker. Correspondingly, the identity of the clients who have agreed to be interviewed is unknown to the Department. This procedure has the great merit of respecting the confidentiality of clients. Unfortunately it usually results in a level of agreement on the part of the clients so low as to endanger the purpose for which it was intended. It is interesting, however, that almost all who do reply do so positively. When their reply is negative it is rarely expressed with ill will either towards the Department or the research. One can only speculate about the reasons for which people fail to reply to the Department's letter of invitation. It may be based on hostility towards the Department or towards the purposes of the research. The letter may not arrive at its intended destination, or the client may have moved to another address. If the letter does arrive, the recipient may not open it until the deadline date for a reply has passed. It may be that people were unable to read or understand the letter, or realise that they were being requested to reply to it. For a variety of reasons they may not be able to reply. We do not know which of these or other

possible reasons operate, but it does seem likely that the people who reply will be those with the greatest capacity and motivation to do so.

We have dwelt at some length on this matter because it does raise important questions about government-commissioned research. In this case the Department commissioned a study in accordance with rules which rendered it much less useful than it might otherwise have been. We accept entirely the Department's reasons for respecting its clients' confidentiality, but we believe that with other procedures a higher response may be possible. In Britain, when Departmental clients are invited to participate in research, the Department writes to its clients indicating that if the client does not wish to be interviewed he or she may reply to the Department to this effect, either by reverse charge phone call or by using a prepaid envelope. The client is told in the Departmental letter that if no reply is received by a particular date it will be assumed that he or she does not mind being approached. The client's name will then be given to the research worker. However, if the client does not wish to be interviewed when visited by the research worker, he or she can simply refuse and this refusal will be accepted as final. In this way, people who do not mind participating in a research project but who, for whatever reason, did not positively indicate their agreement, can be included. We do not suggest that the British approach is the best or that it should necessarily be adopted, but we certainly think that it should be considered. It represents one way of enhancing the credibility of research results which government clearly wants.

CONCLUDING REMARKS

It is to be hoped that future research will benefit from the lessons learnt in this study. In the meantime, our study represents a preliminary attempt to describe the extra expenditure involved in participating in the workforce, education and training for a small group of people with disabilities. It has considered the role that a disability allowance might play in recognising this expenditure. It has suggested that other factors besides expenditure can severely constrain participation and that these may affect people with different impairments and disabilities in different ways. It concludes that for many people a disability allowance will make some contribution but the effective promotion of participation will involve support of many different kinds.

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**APPENDIX I: THE IMPAIRMENTS OF THE MEMBERS OF
THE 'OTHER' CATEGORY**

- * Minor paralysis on the right side of body, deafness in the right ear, and an ulcerated right eye. These impairments resulted from a brain tumour.
- * Agoraphobia and neurotic depression.
- * Multiple ailments including arthritis in the legs, incisional hernias, a fallen tendon in one foot, dermatitis, diverticulitis and high cholesterol levels.
- * Severe headaches.
- * Epilepsy and back problems.
- * Scleroderma.

**APPENDIX II: TABLE OF CORRELATION FOR
THE SCALE OF DEPENDENCY**

A1	A1																	
A2	*	A2																
A3			A3															
A4			**	A4														
A5					A5													
A6					**	A6												
A11	**	**			*	*	A11											
A12	**	**			**	**	**	A12										
A13					**	**	**	**	A13									
A14	**	**			**	**	**	**	**	A14								
A15	*	*			**	**	**	**	**	**	A15							
A16	**	**			*		**	**	**	**	**	A16						
A17					**	**	**	**	**	**	**	**	A17					
A18	*						**	*		*		**	*	A18				
A19	**						*		*	*		**		**	A19			

Note:

- A1: Walking
- A2: Use of arms/hands
- A3: Sight
- A4: Hearing
- A5: Speech
- A6: Communication
- A11: Dressing
- A12: Eating
- A13: Meal preparation
- A14: Bathing/showering
- A15: Washing hands, face and teeth
- A16: Toilet
- A17: Supervision
- A18: Nursing care
- A19: Incontinence

* indicates that the two variables were correlated at the 99% significance level.

** indicates that the two variables were correlated at the 99.9% significance level.

Variables A7 (learning difficulties), A8 (depression/anxiety), A9 (aggression), A10 (self-injury) have been excluded from the table because they were not correlated with any other listed variables.

Source: Survey data, 1988.

**APPENDIX III: TIME PERIODS FOR ESTIMATING THE EXPENDITURE ON SELECTED ITEMS
PURCHASED ON A RECURRENT BASIS**

1. Work Related Items (Table 6)

Item of Expenditure	Time Period
Return journey to work	Daily and weekly
Personal Assistance with travel	Weekly
Other Recurrent expenditure	Determined by respondent's own purchasing pattern

2. Education and Training Related Items (Table 9)

Item of Expenditure	Time Period
Return journey to course	Weekly
Personal Assistance with travel	Weekly
Other Recurrent expenditure:	
Cost of Course	Annual
Other	Determined by respondent's own purchasing pattern.

3. Other Items (Table 11)

Items of Expenditure	Time Period
Incontinence items	Past month
Consultation with GP	Past month
Return journey to out-patients	Last journey during past year
Hospital in-patients	Last over-night stay during past year
Other specialist treatments and consultations	Past year
Powders, lotions, bandages etc	Past year
Prescription medicines	Past year
Non-prescription medicines	Past year
Health insurance	Each month
Home-care	Average week
Personal care	Average week
Special footwear	Each year

APPENDIX IV: LIST OF ITEMS INCLUDED IN EXPENDITURE CATEGORIES IN TABLES 11 AND 14

Incontinence Items

Catheters, ileostomy, and abstomy bags
 Incontinence pads
 Waterproof underwear
 Deodorants or air fresheners
 Rubber sheets, mattress covers, disposable draw sheets or other protective bedding
 Others? (specify)

Other Specialist Treatments and Consultations

Any doctor, surgeon or other specialist
 Physio therapist
 Occupational therapist
 Speech therapist
 Chiropodist
 Counsellor
 Dietician
 Naturopath
 Osteopath
 Other? (specify)

Powders, Lotions, Bandages etc

Talcum powder/other powder
 Lotion/oil/skin cream of any sort/vaseline
 Disinfectant/antiseptic/liquids or creams
 Bandages/dressings/elastoplast/surgical tape
 Cotton wool
 Kitchen roll/toilet paper or paper tissues
 Other? (specify)

Non-prescription Medicines

Tonics, vitamins or cod liver oil
 Cough medicines or cough sweets
 Laxatives or kaolin mixture
 Aspirin or other pain killers
 Eye drops or lotions
 Other? (specify)

Communication Aids

Environmental Control Unit
 Equipment Control Unit
 Braille machine
 Special Adaptations to electronic equipment
 Portable writing system
 Computer
 Special typewriter
 Tape recorder
 Artificial voice system
 Talking communication

Electronic communication aid

Teletext

Hearing Aid

Paging System e.g. Vitacall

Intercom

Other? (specify)

Heating and Home Modifications

Indoor rails

Indoor ramps

Widened doors and passages

Extra bathroom or toilet

Other extra room

Adaptations to bathroom

Handshower

Kitchen adaptations

Lift/stairlift

Special flooring/fitted carpets

Alterations for security

Special electrical fittings

Outside rails

Outside ramps

Pool

Other indoor adaptations? (specify)

Other outdoor adaptations? (specify)

Heater

Air conditioner

Mobility Aids

A wheelchair

A second wheelchair

A power-driven wheelchair

A walking aid

Calipers

Environmental Control Unit

Other? (specify)

Special Equipment

Hoists

Commode

Shower Chair

Bathroom/toilet equipment

Other? (specify)

Special Furniture

Special chair

Special table

Special bed or bed equipment

Non-slide matting

Other? (specify)

APPENDIX V: OTHER EXTRA COSTS OF DISABILITY AS EXPERIENCED BY RESPONDENT OR PRIMARY CAREGIVER

ENTERTAINMENT/SOCIALIZING

- | | | |
|------|--|-----------------------|
| 1.1 | Can't afford much of a social life. | No. of Respondents: 5 |
| 1.2 | Special items for recreational use including:
a puppy
colouring books
computer games
tapes & tape recorder - (they're interesting to pull apart)
marihuana - it makes life interesting. | No. of Respondents: 5 |
| 1.3 | Parents unable to socialize because of the special needs of their disabled offspring. | No. of Respondents: 4 |
| 1.4 | Can't afford expensive entertainment such as the theatre. | No. of Respondents: 3 |
| 1.5 | Planning entertainment - not everywhere is accessible. This also means that you can't always do the things you would enjoy or like to do. | No. of Respondents: 2 |
| 1.6 | Family can't afford entertainment activities such as the movies, restaurants, Wonderland etc. | No. of Respondents: 1 |
| 1.7 | Can't afford a car. | No. of Respondents: 1 |
| 1.8 | Nature of disability restricts social life. | No. of Respondents: 1 |
| 1.9 | Cost of membership of social clubs for people with special social needs. | No. of Respondents: 1 |
| 1.10 | Had to buy an expensive CD player. Its the only way that the music could be heard because of a hearing impairment | No. of Respondents: 1 |
| 1.11 | Parents employ a person who is in the same age group as their disabled son to be 'a friend' to him during the holidays; that is, to talk with him, take him out and to help him with games e.g. dot-to-dots. | No. of Respondents: 1 |

HOLIDAYS

- 2.1 Can't afford a holiday.
No. of Respondents: 13
- 2.2 Can't manage cheap holidays because of personal care needs and also problems of access and mobility.
No. of Respondents: 5
- 2.3 Parents are unable to have holidays by themselves because of the special needs of their disabled offspring.
No. of Respondents: 2
- 2.4 A lot of time is spent planning and researching holidays and entertainment activities.
No. of Respondents: 1
- 2.5 Would have liked to travel but consequences of disability mean this will never be possible.
No. of Respondents: 1

GENERAL WORRIES ABOUT MONEY

- 3.1 Financial worries; penny pinching.
No. of Respondents: 5
- 3.2 Can't afford food luxuries e.g. ice cream, alcohol etc.
No. of Respondents: 5
- 3.3 Parents can't spend money they have saved on consumer items they may enjoy because they fear for the future of their disabled offspring. Money is saved for their future security.
No. of Respondents: 4
- 3.4 Can't afford the medicines which are needed for medical conditions which arise from impairment - and they are not on the free list.
No. of Respondents: 1
- 3.5 Envious of mates who earn a lot more money and can provide better things for their families - but they don't have a disability
No. of Respondents: 1

PERSONAL RELATIONS

- 4.1 Marriage breakdown.
No. of Respondents: 3
- 4.2 The impact of an intellectual disability means one respondent is unable to marry his girlfriend. Also he is not allowed to sleep in the same room as her. This makes him sad and he cries about this.
No. of Respondents: 1

EMOTIONS

- 5.1 Future fears for disabled offspring.
No. of Respondents: 6
- 5.2 Loneliness; no friends.
No. of Respondents: 2
- 5.3 Fear of being alone. 'While I can manage to be alone I am nervous about this. I once fell when my husband was at work. I had undressed to shower. I lay naked from 12.00 until my husband got home at 6.00 pm. This was in the winter'. Another respondent had a similar experience.
No. of Respondents: 2
- 5.4 Physical fear - wife fears that she will be attacked if she is out of a night because her husband who has a high level of quadriplegia is unable to protect her. In addition his own physical vulnerability might attract an attacker. This fear has arisen since disability.
No. of Respondents: 1
- 5.5 Hope - saving money in the hope of a cure.
No. of Respondents: 1
- 5.6 'Loss of dignity' because of dependence upon a pension.
No. of Respondents: 1
- 5.7 Sadness - 'he cries often because he can't do what other 20 year old men usually do'.
No. of Respondents: 1
- 5.8 Embarrassment plus financial costs when disabled offspring damages other peoples' property.
No. of Respondents: 1
- 5.9 Unfulfilled dreams - disability means a low income and in turn this means the dream of owning a house, not a flat can never be achieved.
No. of Respondents: 1
- 5.10 Boredom because disability prevents full-time work.
No. of Respondents: 1
- 5.11 Bought a dog in order to feel secure. 'When I feel insecure I hear "voices" more often.'
No. of Respondents: 1

INVOLVEMENT IN ORGANISATIONS FOR PEOPLE WITH DISABILITIES

- 6.1 Fund-raising for organisation. This involves time and money
No. of Respondents: 6
- 6.2 Membership fees for organisations.
No. of Respondents: 5

LIMITATION OF CHOICE

- 7.1 Can't get to garage sales because of mobility problems - this means you can't get bargains.
No. of Respondents: 1
- 7.2 Lack of house choice, you have to consider access, geography etc when choosing.
No. of Respondents: 1

DOMESTIC COMFORT & PERSONAL GROOMING

- 8.1 Cost of respite care.
No. of Respondents: 7
- 8.2 Buying special cleaners to clean wheelchair tyre marks in house.
No. of Respondents: 1
- 8.3 Creams to soften callouses that you get on your hands from pushing a wheelchair.
No. of Respondents: 1
- 8.4 Extra soap - 'I'm always washing my hands - you've no idea the dirt and things you pick up from the wheels of a wheelchair'.
No. of Respondents: 1
- 8.5 A sewing machine - so shirts can be altered to body shape.
No. of Respondents: 1
- 8.6 Can't both work and keep a house well run therefore has to pay for someone to keep house clean. Usually people can manage both.
No. of Respondents: 1
- 8.7 'I am eternally frustrated by my inability to earn enough in order to pay someone else to clean up where I can't.'
No. of Respondents: 1

TIME

- 9.1 Time to communicate with people. (This respondent uses a spelling board to aid communication. It takes 7 hours for him to type a A4 page of paper).
No. of Respondents: 1
- 9.2 Time waiting to see doctors.
No. of Respondents: 1

LOSS OF ASSETS

- 10.1 'The Tuesday after the accident we were due to exchange contracts on our first home. Obviously we couldn't go ahead with this.'
No. of Respondents: 1
- 10.2 Because respondent can not work full-time he and his family don't have enough money to finish building their house.
No. of Respondents: 1

TIME SAVING

- 11.1 Buys food which is easy to prepare - this usually costs more.
No. of Respondents: 2

CONFLICTING CHOICES

- 12.1 'The demanding nature of the job combined with my disability means that I have to pay extra for things which my colleagues don't need to pay for in order to perform my job adequately.'
No. of Respondents: 1
- 12.2 While the quality of life can be improved with special equipment this is very expensive. Hence other areas of quality of life suffer.
No. of Respondents: 1

EXPLOITATION/DISCRIMINATION

- 13.1 Unscrupulous taxi drivers have not given change from taxi fare. (This respondent has both a physical and intellectual impairment)
No. of Respondents: 1
- 13.2 Disability is misunderstood - respondent with cerebral palsy has problems of social acceptance and discrimination.
No. of Respondents: 1

OTHER

- 14.1 Extra clothes for offspring with intellectual disability - its important for him/her to look as 'normal' as possible.
No. of Respondents: 4
- 14.2 Difficulties in finding parking close to where you're visiting.
No. of Respondents: 3
- 14.3 Purchasing extra books because libraries are not organised for people with disabilities. Respondents complained libraries were inaccessible and don't stock books in Braille.
No. of Respondents: 2
- 14.4 Constantly repairing body of car because wheelchair damages body as it is taken in and out of car.
No. of Respondents: 2
- 14.5 Weight lifting gloves - physical exercise helps body adapt to impairment.
No. of Respondents: 1
- 14.6 Can't work hard without feeling a lot of pain.
No. of Respondents: 1
- 14.7 Unable to control cigarette and coffee intake because of psychosis - the cost of this adds up over a year.
No. of Respondents: 1

APPENDIX VI: TOTAL ESTIMATED ANNUAL EXPENDITURE OF THE MEMBERS OF THE SAMPLE

Rank Order	TAR + NR \$	TAR \$	TANR \$	IM	D	M&I	IUI	EMP	DU
1	0	0	0	PI	1	No	1	SW	H
2	0	0	0	O	0	No	1	SP	SP
3	10	10	0	O	0	No	1	E	A
4	20	20	0	P	0	No	1	E	M
5	40	40	0	PI	2	No	2	SW	H
6	60	60	0	I	2	No	1	SW	H
7	90	90	0	I	1	No	2	E/T	P
8	140	110	30	P	2	No	1	T	F
9	150	90	60	O	0	No	1	SP	SP
10	190	190	0	O	0	No	2	SP	SP
11	220	220	0	O	2	No	2	O	M
12	230	230	0	I	2	No	1	ATC	H
13	270	210	60	P	2	No	DK	E	P
14	270	270	0	I	2	No	1	SW	H
15	400	400	0	P	0	No	3	E	H
16	580	580	0	I	2	No	1	ATC	P
17	600	600	0	P	0	No	2	E	M
18	700	400	300	P	2	No	DK	E	F
19	720	700	20	I	2	No	1	ATC	P
20	730	730	0	P	0	No	1	O	P
21	760	750	10	P	1	No	3	E/T	M
22	870	860	10	S	1	No	3	E	M
23	970	880	90	P	0	Yes	1	T	A
24	1130	1110	20	P	0	No	3	E	M
25	1140	1140	0	I	2	No	1	ATC	P
26	1160	1160	0	PI	1	No	1	SP	SP
27	1250	1250	0	P	0	No	3	E	M
28	1250	1010	240	P	0	No	3	E	M
29	1310	1300	10	P	0	No	1	T	P
30	1420	1400	20	P	0	No	DK	E	M
31	1470	1350	120	P	1	No	3	E	M
32	1480	1490	0	I	2	No	1	ATC	M
33	1530	1170	360	P	2	No	2	E	M
34	1590	1590	0	I	2	No	1	SW	P
35	1730	1670	60	P	0	No	3	E	P
36	1870	1870	0	PI	0	No	1	E/T	F
37	1890	1270	620	P	2	No	3	E	P
38	2000	1810	190	P	2	No	2	O	P
39	2000	1970	30	I	2	No	1	ATC	P
40	2030	2020	10	I	2	No	1	ATC	P
41	2320	2300	10	O	0	No	1	E/T	A
42	2470	2420	60	I	2	No	1	SW	P
43	2500	2150	360	P	2	Yes	5	E	M
44	2700	2690	10	P	0	No	3	E	F
45	2940	2910	30	P	2	No	1	ATC	P
46	3040	2930	110	P	2	Yes	1	E/T	H
47	3260	3200	60	I	2	No	1	ATC	H/H
48	3290	1520	1760	P	1	No	DK	SP	SP
49	3290	2410	880	S	2	No	4	E/T	M
50	3410	3390	20	I	2	No	1	ATC	H/H
51	3590	3590	10	I	2	No	1	ATC	H/H
52	4550	3370	1170	P	0	No	3	E/T	P
53	5630	4020	1610	P	0	No	4	E	M
54	5700	5250	450	I	2	No	1	ATC	H/H
55	6110	5920	180	I	2	Yes	1	ATC	P
56	6150	4860	1290	P	2	Yes	3	E	M
57	6330	5280	1040	S	1	No	4	E	F
58	8180	2160	6020	P	2	Yes	3	E	M
59	8770	580	8190	P	2	Yes	1	ATC	H
60	9060	9060	10	P	1	No	3	E	M

Key:

TAR+NR

Total Annual Recurrent and Non-recurrent Expenditure

TAR

Total Annual Recurrent Expenditure

TANR

Total Annual Non-recurrent Expenditure

IM

Impairment Category (P = Physical; S = Sensory; I = Intellectual; PI = Psychiatric Illness; O = Other)

D

Dependency (0 = minimal; 1 = medium; 2 = high)

M&I

Mobility and Incontinence

IUI

Income Unit Income (1 = \$10,400 or less; 2 = \$10,401 to \$20,800; 3 = \$20,801 to \$31,200; 4 = \$31,201 to \$41,600; 5 = \$41,601 or more; DK = Don't Know)

EMP

Employment Status (SW = sheltered workshop; SP = single parent; E = Employed; T = Training; E/T = Employed and Training;

ATC = Activity Therapy Centre; O = Other)

DU

Domestic Unit (H = hostel; SP = single parent/s; P = parent; M = married couple; F = friend/s; A = alone; H/H = family and hostel)

Note:

Estimates of expenditure have been rounded separately therefore TAR + NR may not exactly equal total of TAR + TANR.

Source:

Survey Data 1988.

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