

SHORT CHANGED BY DISABILITY

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DIG The Disablement Income Group

Published by The Disablement Income Group

Millmead Business Centre, Millmead Road, London N17 9QU

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First published 1990

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Typeset by Avril Hogarth

Cover design by Beverly Levy

Printed by Direct Printers, Poole, Dorset

ISBN 0-905179-11-0

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ACKNOWLEDGEMENTS

This research is the result of a cooperative effort. It has been executed in a short space of time - 5 months - to ensure that its findings can be considered by everyone who has an interest in the financial consequences of disability before the Government's decisions about the future of disability benefits are finalised. My colleagues involved in the project have worked swiftly and efficiently and I am grateful for the support I have received from them.

John Curtice, Head of the Social Statistics Laboratory at Strathclyde University, gave me enormous help by collating and analysing the data and offered valuable advice as I drafted the report. Sarinder Hunjan did a remarkable job of transferring the data from the questionnaires into the Laboratory computer.

Margaret Lavery, DIG's Advisory Officer, brought her considerable knowledge of the social security system to the study and prepared the income and extra costs sheets. My Assistant, Avril Hogarth, patiently deciphered my manuscript and typeset the whole. Jean Macqueen gave me the benefit of her editorial skills. Peter Large, DIG's Parliamentary Adviser and Mavis Maclean, DIG's Research chairman helpfully commented on my drafts. Anne Ward provided valuable administrative back-up to the whole project at Head Office. Trevor Chapman at the ILF drew the sample of the Fund's beneficiaries and made the necessary contacts. Our twenty experienced interviewers revealed a great deal of enthusiasm for their task.

We were all, I think, inspired to work hard and give of our best to this project because we knew from the beginning that we were engaged in something important. I warmly acknowledge all these endeavours and thank everyone for their help.

But the research could not have been done at all without the assistance of the 87 disabled men and women who took part in the interviews and who spoke so frankly about their circumstances. I am grateful to them all and it is to them I dedicate this report.

Pauline Thompson

February 1990

NOTES

To preserve confidentiality it has been necessary to change the names of the disabled people whose circumstances are described in this report.

Where no source is given, the statistics are derived from the research by The Disablement Income Group.

As is often the case with surveys about income and expenditure there were some questions for which no information was recorded for certain respondents, generally because the respondent was unable to provide the information required. In these instances we have followed the procedure used by the OPCS and have imputed amounts for the missing data at the level of the individual items based on the average amount for people who had answered the question.

The Disablement Income Group holds the complete set of data for this research.

SUMMARY

The sub-headings in this summary correspond to the chapter headings.

The need for a study of the costs of disability

We describe the background to this research. We explain why we felt the OPCS survey published in 1988 had seriously underestimated the financial consequences of disability and we suggest three reasons why our brief 1988 study, undertaken in response, obtained different and higher results. We express concern about the importance of the OPCS findings on Government policy planning and we indicate the need for more indepth research.

Design of the study

We describe how we selected the sample and decided to include both people with lower severity ratings than in our 1988 study and very severely disabled people receiving help from the Independent Living Fund (ILF). We reveal some of the characteristics of the sample and discover that we had a very different sample from that of the OPCS, with many more non-pensioners than pensioners.

Sources and levels of income

We examine the income of the sample and compare its derivation with the OPCS findings. We find we had a highly benefit-dependent sample. We also discuss the anomalies in the OPCS severity ratings which in our sample do not relate to likely extra costs.

The extra costs of disability

We identify capital costs and ongoing extra costs. We show how spending on weekly extra costs generally rises with severity of disability. Our overall findings are significantly higher than those of the OPCS - eight times higher for the most severely disabled group in our sample.

People's perceptions of their problems

We confirm that non-pensioners in our sample were more likely to have negative perceptions of their standard of living than pensioners. Our benefit-dependent sample does tend to be in financial difficulties.

Selected case studies

We describe the circumstances of ten people in our sample. Their income and extra costs are recorded in Appendix 1.

Conclusions

We summarise our main findings and the reasons for the difference between our results and those of OPCS. We explain why we do not believe the OPCS report should be used by the Government as the basis for making policy decisions on disability benefits.

Chapter 1

THE NEED FOR A STUDY OF THE EXTRA COSTS OF DISABILITY

A major Government survey of disabled people was announced in April 1984. On 2 April that year, after referring to the Government's review of supplementary benefit and the reviews of child benefits and retirement pensions, Mr Norman Fowler, then Secretary of State for Social Services, spoke to the House of Commons about disability benefits:

"The largest remaining area within the social security programme is that of providing disablement benefits. Here I propose a somewhat different approach. With the ending of the invalidity trap, the introduction of war pensioners' mobility supplement and our proposals for a severe disablement allowance, we are making useful progress towards our declared objective of a more coherent system. We shall continue to look for further practical steps in this direction.

But it is clear that in the longer term development of our policy would be helped by more reliable information about the numbers of disabled people, their circumstances and their needs. There has been no comprehensive study of the extent of disablement in the population for 15 years, and even that excluded some important groups. I therefore intend to take steps to fill this gap in our knowledge by undertaking a full-scale survey. A feasibility study on this is already under way." (Source: Hansard, 2 April 1984, Vol 57, Col 653.)

More detail about the aim of this survey appeared in the 1985 White Paper on the reform of social security, which said that the Office of Population Censuses and Surveys (OPCS) would carry out a survey

"to enable estimates to be made of the national incidence of physical and mental disability, by age and degree of severity. It may also yield some estimates of the incidence of the more common causes of disability. In addition the survey has been designed to yield substantial information about the financial circumstances of those interviewed - standard of living, the extra costs attributable to disability, and income including receipt of benefits.

The full results of the survey are expected to be published in 1988, and will provide the evidence needed for a review of provision for sick and disabled people." (Source: Reform of Social Security - Programme for Action, Cmnd. 9691, December 1985.)

In the period between the announcement of the surveys and the publications of the results, that is to say between 1984 and 1988, the range of benefits available to disabled people was radically changed by the introduction of the income

support scheme and the social fund in place of supplementary benefits. Thus as regards providing evidence for a review of provision for sick and disabled people, unfortunately a significant amount of the financial information from the OPCS surveys was obsolete by the time the results were published.

Even more importantly, the published results of the OPCS survey, including the now well-rehearsed finding that the average extra costs of disability amount to only £6.10 per week, contrasted sharply with the experience of the disabled people with whom The Disablement Income Group (DIG) is in contact. OPCS appeared seriously to underestimate the extent of need among disabled people. Since the Government had awaited the results of this survey before embarking on a major review of benefits it was immediately obvious that a study should be undertaken to examine the reasons underlying the OPCS findings.

In November 1988 DIG carried out what might best be described as a small preliminary study of severely disabled people (NOT the OPCS survey: being disabled costs more than they said Thompson, Buckle and Lavery) and uncovered significantly higher extra costs of living due to disablement than the OPCS had reported. We therefore recommended that further, in-depth research should be carried out. In the summer of 1989 we resolved to carry out that further research ourselves. This report is the result of the study.

The history of surveys of disabled people

The first OPCS survey (Harris, Cox and Smith 1971; Buckle 1971) was carried out almost two decades ago. Since then there have been several important developments in social security for disabled people. In 1971 a long term benefit to replace earnings was introduced (invalidity benefit or IVB) and this was followed in 1975 by its counterpart for people who had not paid enough national insurance contributions to qualify for IVB (severe disablement allowance or SDA). In 1970, 1973 and 1976, respectively, higher and lower rate attendance allowances and mobility allowance were introduced. These last two benefits were designed to cover some of the expenses to which disability gives rise. The higher rate of attendance allowance is currently paid at the rate of £32.95 per week, lower rate attendance allowance at £23.30 per week and mobility allowance at £24.40 per week. While the aim of mobility allowance is to help disabled people get out and about, replacing the provisions of the invalid vehicle service, the purpose of attendance allowance has been less clear. It was generally intended to help with the extra costs of disablement, equating greater need with a decreasing ability to look after oneself.

The first OPCS survey (Harris et al 1971) made no attempt to quantify the extra costs of disability. It did, however, establish that disability gives rise to extra

costs. The survey showed that just over 3 million people (3,071,000) aged 16 or over and living in private households were suffering from some physical, mental or sensory impairment.

In this survey the sample included people with a limb or part of a limb missing; people who were bedfast or housebound; people who needed a lot of help with using a toilet or with personal care or dressing; people who had difficulty walking without help, kneeling, bending or going up and downstairs; people who had difficulty in feeding themselves or gripping or holding things; people who suffered from some permanent disability, including blindness, which stopped or limited their working or getting about or taking care of themselves. It dealt with physical impairments that limited the lives of disabled people in some way. One of the main purposes of this first study was to estimate the number of people who might qualify for attendance allowance, which was just being legislated for, so the scale used to measure a degree of disability was based on ability for self-care. Eight categories of "handicap" were identified. Those in categories 1 to 6 were described as handicapped, while those in categories 7 and 8 were described as impaired but not handicapped.

It was estimated that there were 1,942,000 people who were impaired but not handicapped, and 1,130,000 who were handicapped.

The second OPCS study (Martin, Meltzer and Elliot 1988; Martin and White 1988) was a large scale survey and set out to identify the prevalence of disability and then to look at the financial circumstances of disabled adults. One hundred thousand addresses were screened to identify people with some form of disability and 10,000 disabled people were interviewed at the second stage. The fieldwork was carried out in 1985. The OPCS researchers estimated that there were 6.2 million adults in Great Britain with one or more disabilities. Of these, 5,780,000 live in private households and the remaining 422,000 live in communal establishments.

The researchers acknowledge that their estimate is much higher than the estimate obtained by the first OPCS survey. The second survey was much wider in scope than the first.

It covered all kinds of disability, whatever the origin, and used a very low threshold of disability that obviously, as the report itself stated, "leads to high prevalence". The survey distinguished 13 different types of disability: locomotion, reaching and stretching, dexterity, personal care, continence, seeing, hearing, communication, behaviour, intellectual functioning, consciousness, eating (including drinking and digestion) and disfigurement. The severity of disability within each of these 13 categories was established and then the three highest of the 13 scores combined according to the following formula: worst plus 0.4 (second worst) plus 0.3 (third worst). This gave "an overall score from which people were allocated to one of ten overall severity categories (category 1 least severe, category 10 most severe)".

Table 1.1

Estimates of the number of disabled people in private households

Severity category	No of disabled people in private households
1 (least severe)	1,186,000
2	824,000
3	732,000
4	676,000
5	679,000
6	511,000
7	447,000
8	338,000
9	285,000
10 (highest)	102,000
Total	5,780,000

Source: Table 3.1, Martin and White 1988

Thus the largest numbers are in the least severe categories and the smallest numbers in the most severe. Someone who has difficulty following conversation against background noise or someone who cannot see well enough to recognise a friend across the street is defined as disabled and as in category 1. In category 2 would be someone who cannot walk 200 yards without stopping or severe discomfort and category 3 includes someone with high-tone deafness in both ears or someone who has difficulty putting either hand behind the back to put a jacket on or tuck a shirt in and who has difficulty getting in and out of bed.

Because it is hard to believe that in less than two decades the incidence of disability among the adult population has doubled, it is worth considering whether the threshold of disability used by OPCS in 1988 was too low. Certainly in categories 1 to 3 there are disabled people who might be considered as having an impairment but whose daily living activities are not severely restricted. Of the disabled adults in Great Britain identified by OPCS, 2,742,000 are in the least severe categories. However, there are 3,038,000 disabled adults in categories 4 and over living in private households - a figure that is very close to the estimate of 3,071,000 made by the first OPCS survey. It should be borne in mind that there has been an increase in the size of the total population since 1971.

Nevertheless, the level of disability threshold is important, because any study of the financial circumstances of disabled people which includes people who would not even consider themselves to be disabled is liable to distort the picture of need amongst significantly disabled people once averages are taken. This distortion almost certainly contributed to the low estimate of extra weekly expenditure by disabled people (rising from £3.20 for people in category 1 to £11.70 for category 10 with an average of £6.10). The distortion probably also contributed to the very high proportion of the sample (70%) who were quoted in the second report of the OPCS study as saying they were satisfied with their standing of living (Martin and White 1988).

The surprisingly low average extra costs that were reported require examination. The inclusion of a large number of people not traditionally perceived as disabled was one factor in producing such low responses. But there is another, equally significant, factor. As already indicated, attendance allowance and mobility allowance had been introduced to help significantly disabled people with some of the costs arising from their disability. But only 13% of the sample received a benefit paid to help meet these extra costs: 8% received attendance allowance and 7% received mobility allowance. Only 2% of the sample were sufficiently disabled to receive both benefits. Receipt of these two key disability benefits is related to severity of disability but only amongst those in the two highest severity categories were more than half receiving any disability cost benefit. Indeed, as many as 26% of those in category 10 were not receiving attendance allowance. The significance of, having either of these two benefits as financial resources should not be underestimated. Expenditure on extra costs is, to a large extent, dependent on available income. You cannot spend what you do not have. But for 87% of the OPCS sample there was no such income available.

DIG's decision very soon after the publication of the second OPCS report, to undertake its own small study of people with severe disabilities was encouraged by the statement in the OPCS report that the proportion of disabled people

claiming to have extra expenditure is sensitive to the interview techniques used. "In general it has been found that small-scale studies using semi-structured interviews, often carried out by the researchers, find higher proportions than large-scale studies using structured interviews carried out by professional interviewers."

Previous DIG studies

Indeed, DIG's experience over 15 years of research into the financial consequences of disability, and its day-to-day contact with disabled people through its Advisory Service, had already revealed a very different picture from that drawn by the OPCS.

DIG has made a speciality of studying the extra costs of disability. Hyman (1977) found that the extra costs of wheelchair users amounted to £14.13 per week. Stowell and Day (1983) found that shopping cost disabled people an extra £3.36 per week. A study of mentally handicapped living (Buckle, 1984) showed that the average weekly expenditure resulting from mental handicap amounted to £19.50 per week. This last figure, which was calculated at 1981-82 prices, was in itself more than three times the average weekly extra expenditure of disabled people found by the OPCS survey.

DIG's 1988 study

We wanted, therefore, to ascertain if and how the responses of the OPCS structured standardised questionnaire would vary from those of a DIG semi-structured unstandardised questionnaire used typically in small-scale in-depth studies. The results of this work are reported in NOT the OPCS Survey: being disabled costs more than they said Thompson, Buckle and Lavery 1988). The DIG study, carried out three years after the OPCS one, concentrated on a small sample of 13 people from our Advisory Service case-files who would have been in categories 9 and 10 of the OPCS scale (and perhaps in even higher categories had they existed) and who were all receiving attendance allowance and/or mobility allowance.

We looked at the main areas of extra costs examined by the OPCS survey (home services, unprescribed medication, laundry, clothing and bedding, food, fuel and travel). Using an interview schedule based on the OPCS questionnaire we

found the extra costs incurred to be 4.5 times higher than OPCS' own survey reported for people in disability categories 9 and 10 (£41.81 compared with £9.50). Using a questionnaire based on DIG's schedule we found the costs to be nearly 7 times higher (£65.92 compared with £9.50).

We suggest there were three particular reasons why our findings differed so much from those of the OPCS study.

*We only interviewed people with significant disabilities.

*Our sample were very aware of their financial situations. We were not attempting to provide national estimates of representative disabled people, but rather the true costs of disability to the individual. Our sample, all well known to the DIG Advisory Service, were in a particularly strong position to talk about their financial situation because they were not under-claiming benefits, understood the system and were thus likely to give us more accurate information.

*We took much longer to carry out individual interviews than OPCS did. Whilst there can be no dispute that the OPCS survey attempted to gain a full picture of the extra costs of disability, the questions on the extra cost of disability were only one part of an interview schedule the whole of which, we understand, took on average one and a half hours to complete. Our own experience is that to get a complete picture of costs much more lengthy and detailed questioning is required; this of course is why the small-scale, in-depth study can produce the higher findings. What is interesting is that we found the OPCS questionnaire was capable of eliciting useful information from people with more serious disabilities.

In short, we had confirmed OPCS' own suggestion that findings of research studies of this type are sensitive to the interviewing techniques used.

We went on to argue that it would be inappropriate, therefore, to use the OPCS findings on their own as the basis for making policy decisions about benefits designed to meet extra costs. We said that they must be supplemented by other information about the high extra costs of disability and that what was needed was an in-depth study of disabled people, using the research techniques we had shown to work and concentrating on a sample of disabled people with disabilities causing significant extra costs, and that probably meant from OPCS category 4 upwards.

The urgent need for a new, in-depth study was further amply emphasised by responses from Government Ministers to the OPCS findings they were to use for their review of benefits. "Now that we can look at them [OPCS reports] we find that in terms of financial circumstances, about 70 per cent are satisfied with their standard of living, few are in financial difficulties and the allowances paid for the extra costs of disability, such as attendance allowance and mobility allowance, more than cover the extra cost incurred." (Source: Hansard, House of Commons, 23 October 1989, OA, col 464.)

For an organisation that has had the need for a national disability income, including a disablement costs allowance, at the heart of its campaign for over 20 years, the message was clear. Unless more accurate information about the extra costs of disability could be gathered the chances of real improvements in disabled people's standards of living would be slight indeed.

We decided to carry out this new study ourselves and the results are reported here.

Chapter 2

DESIGN OF THE STUDY

Preparation for the study and the selection of the sample began in September 1989. Because the earlier DIG study (1988) had concentrated wholly on disabled people who would have been in categories 9 and 10 of the OPCS survey we decided, this time, to interview a somewhat larger sample and identify the extra costs incurred by less severely disabled people. In addition, we wanted to look at the extra costs incurred by people whose severity rating would have been higher than 10, had such a rating existed. So we included very severely disabled people receiving help from the Independent Living Fund (ILF) in the sample.

The most severely disabled people in the sample were selected by the staff of the Independent Living Fund itself, which contacted beneficiaries directly and sent an outline of our proposed study. The others were selected by DIG's Advisory Service and the advisory service of DIG (Scotland).

Factors affecting the sample

We decided at the outset that we would try to obtain our sample from various parts of Great Britain. We also wanted to interview people living in different locations - for example, inner cities, urban areas and rural areas. Our first - decision, therefore, was to choose West and South Yorkshire, East Anglia, London, southern England, West Wales and Edinburgh and the Lothians as the areas of the country in which we would do our interviewing.

We could not, of course, select a random sample. But we felt that, where possible, we should interview people who had had only slight contact with us. In the London office of DIG we selected people living in England from a list of names and addresses of people who had been in touch with us following a television programme which had featured DIG. Whilst this group had shown some initiative in contacting us they had not otherwise shown particular interest in, or knowledge of, their financial situation. Indeed, we knew very little about them except that at the time the new income support scheme was to be introduced they were concerned about possible rights to supplementary benefit, and we had sent an information pack.

The Welsh sample was chosen with the assistance of our DIG Llanelli-Dyfed branch, who were asked to locate disabled people who were unlikely to be receiving either of the two disability costs benefits. And in Scotland the sample was selected from the files of DIG Scotland's Advisory Service, again selecting people who were unlikely to be receiving these benefits.

The ILF was asked to select disabled people who were its regular beneficiaries and living in the areas prescribed.

The total number of people interviewed was 87. Interviews took place in November 1989 and lasted 1 hour 45 mins on average. Appointments were made before the interviews. Respondents showed a high degree of commitment to the lengthy and detailed interview and many were at pains to ensure the correctness of the information that was recorded. A few of the questionnaires were not fully completed during the interview (for example, information was not to hand at that time), but in most of these cases further verification was sought directly by the researchers and any gaps subsequently filled.

It is fair to say that because our sample either had had earlier contact with DIG, although not necessarily sustained, or were beneficiaries of the ILF on a regular basis, that they could have had a greater awareness than most people of their financial situation, budgeting and unmet needs. This is likely to be in contrast with the sample used by OPCS, who chose from a completely random group who may not have had similar levels of awareness. Whilst we recognised early on in choosing the sample that this might be a possibility we felt, nevertheless, that it could have a positive effect and be more likely to lead to correct perceptions of disability-related expenditure and the overall financial consequences of disability, as we had already shown in our 1988 study.

The design of the questionnaire

The questionnaire was based on the one used by OPCS. However, it was augmented by "prompting" questions and questions designed to elicit explanations for certain responses, a procedure which DIG has used in previous research studies. Although this was essentially to be a quantitative study, there was scope for qualitative responses to be recorded. A copy of the questionnaire we used is reproduced at Appendix 3.

Age and sex of the sample

The total sample consisted of 36 males and 51 females, ranging in age from 19 to 92.

Table 2.1

Age distribution of the sample

Age group	No in sample	%
16-24	3	4
25-34	14	16
35-44	15	17
45-54	22	26
55-59	9	11
60-64	8	9
65-74	9	9
75+	7	8
Base	87	100

74% of the sample were of working age. This is in sharp contrast with the sample used by OPCS of whom 69% were aged 60 or over.

Marital status of the sample

Table 2.2 shows that just over half the sample were married.

Table 2.2

Marital status of the sample

Marital status	No in sample	%
Married	49	56
Not married	38	44
Base	87	100

Household tenure

As Table 2.3 shows, 49% of the sample lived in owner occupied accommodation. In the OPCS survey this figure was 46%. Certainly people in our sample were less likely to own their own homes than in the general population, of whom about 68% are owner-occupiers.

Table 2.3
Household tenure

Household tenure	No in sample	£
Owner with mortgage	34	39
Own outright	9	10
Rent from council	29	33
Rent from housing association	7	8
Rent from private landlord	4	5
Rent and rates free	1	1
Other	3	4
Base	87	100

Household situation

We have used the same family-type classification as OPCS. This was based on the status of the head of household.

As Table 2.4 shows, only 21% of the families in our sample were headed by a pensioner. This contrasts sharply with the OPCS study in which 62% of the families in the sample were headed by a pensioner. However, the internal distribution of our sample within the non-pensioner groups is similar to OPCS [cf OPCS Table 2.6].

Table 2.4
Family type

Status	No in sample	%
Non-pensioner unmarried no children	20	23
Non-pensioner unmarried with children	3	3
Non-pensioner married no children	32	37
Non-pensioner married with children	14	16
Pensioner unmarried	12	14
Pensioner married	6	7
Base	87	100

The fact that we had far fewer pensioner households in our sample will prove to be significant when we look in detail at our findings.

Disability of other household member

In 29% of the sample households there was at least one other member suffering from a disability or longstanding illness. In 20 households (23%) these conditions were serious enough to limit activities in some way.

Working status

Table 2.5 describes the working status of the disabled person. The OPCS survey had shown that disabled adults under pension age were less likely to be in paid work than adults in the general population. 31% of the OPCS sample of non-pensioner disabled adults were working and this proportion, they found, fell with increasing severity of disability. However, only 7% of the DIG sample was working.

Table 2.5
Work status of disabled people

Status	Below pension age	Above pension age
Full time	3	-
Part time	4	-
Unemployed, seeking work	3	-
Unemployed, not seeking work	22	-
Sick	47	5
Retired	9	95
Other	12	-
Base	69	18

Table 2.6 describes the working status of the head of the household, who may not necessarily, of course, be the disabled person (the disabled person was head of household in only 40% of the sample).

Table 2.6
Work status of head of household

Status	No in sample	%
Full time	24	28
Part time	3	4
Unemployed, seeking work	1	1
Unemployed, not seeking work	7	8
Sick	14	16
Retired	22	25
Other	16	18
Base	87	100

Total income of household

Table 2.7 shows the total weekly income of the sample households in bands of £50 up to £250 and thereafter in £100 bands. It can be seen that almost half of the sample (46%) had net income of between £100 and £200. This figure excludes housing benefit.

Table 2.7

Total income of household

Income £ per week	No in sample	%
Less than 50	4	5
50-100	13	15
100-150	22	25
150-200	18	21
200-250	13	15
250-300	7	8
300-400	8	9
400+		2
Base	87	100

Socio-economic grouping

The Registrar General's classification of socio-economic groups provided the reference point for the classification of our sample:

- A Employers and managers
- B Professional workers
- C Lower non-manual
- D Skilled manual
- E Semi-skilled manual
- F Unskilled manual.

Table 2.8
Socio-economic group of head of household

Table 2.8

Socio-economic group of head of household

Socio-economic group	No in sample	%
O	8	9
A	6	7
B	3	3
C	28	32
D	24	28
E	15	17
F	2	2
Base	87	100

As Table 2.8 shows, the sample contained a very small proportion (10%) of people in the higher socio-economic groups, as compared with 16% in the adult population as a whole (1987 British Social Attitudes Survey).

9% of the sample are not classified. This is because either they did not give adequate information, or they did not have a classifiable occupation, or they had never worked.

Severity of disability

The severity ratings were assigned in accordance with the OPCS method and the interviews with the sample included the same questions posed by the OPCS in its first survey to establish the severity of disability, as described in chapter 1. The sample used by the OPCS for its study of the financial circumstances of disabled adults contained large numbers of disabled people in the lower severity categories, as Table 2.9 shows.

Table 2.9

Numbers of disabled people in OPCS study according to severity category

Category		No in OPCS sample
1	(lowest)	2,025
2		1,437
3		1,284
4		1,167
5		1,169
6		880
7		783
8		569
9		508
10	(highest)	157
Total		9,979

Source: Table 4.11, Martin and White 1988

The DIG sample proved to be completely different in its nature, with no-one in a category lower than 3 and a majority falling into the higher OPCS categories as in Table 2.10.

Table 2.10

Severity ratings for sample

Category	No in sample	%
3	2	2
4	6	7
5	6	7
6	13	15
7	12	14
8	13	15
9	19	22
10	16	18
Base	87	100

Summary

Two important points distinguish our sample from that of OPCS. The first is that in our sample we had many more non-pensioners than pensioners, whereas the ratio was the other way round in the OPCS study. The second is that the people in our sample were more severely disabled than those in the OPCS study. Both these factors were to prove to be important.

Chapter 3

SOURCES AND LEVELS OF INCOME

In this chapter the income of the sample is examined, including its sources. We collected information about cash income only and did not assess the monetary value to the individual of either services or help provided in kind. Information was collected about net income - but not about housing costs or housing benefit, which are usually treated separately when entitlement to social security benefits is considered.

We have used the same definitions of family unit as OPCS: non-pensioners and pensioners. These are defined according to whether the head of household is over retirement age.

Income from earnings and other sources

Table 3.1

Number of earners in the family unit and average net income from earnings by family type

Number of earners	Family type						
	Non-pensioners		Pensioners		All adults		
	Unmarried no children	Unmarried with children	Married no children	Married with children	Unmarried	Married	
No earners	90	(33)	59	21	100	(100)	68
One earner	10	(67)	31	79	-	-	29
Two earners	-	-	9	-	-	-	3
Total	100	(100)	100	100	100	(100)	100
Average net weekly income from							
	£11.00	£45.23	£79.00	£95.64	-	-	£48.53
Base	20	(3)	32	14	12	(6)	87

Only 7% of disabled people living in non-pensioner family units were working. Like the OPCS survey, our study suggests that disability adversely affects the chances of disabled people working. Table 3.1 shows the number of earners in different types of family and the average net weekly income from earnings. Altogether only 32% of disabled adults lived in non-pensioner family units in which at least one person was working. In the OPCS survey 52% of disabled adults lived in a non-pensioner family unit where at least one person was working [OPCS, Table 3.3]. (All references in square brackets are to tables in OPCS 1988.)

Table 3.2

Proportion of disabled adults and families receiving income from earnings and other sources: non-pensioner and pensioner family units

Source of income	Non-pensioner family unit	Pensioner family unit	All family units
Proportion receiving income from each source:			
Earnings from employment	9	-	7
Earnings from self employment	2	-	
Income from lettings	-	-	-
Income from maintenance	5	-	3
Income from trust fund	1	-	1
Income from Government training allowance	1	-	1
Occupational pension	10	5	9
Private pension	1	10	3
Spouse earnings from employment	28	-	22
Spouse earnings from self employment	8	-	6
Spouse income from lettings	1	-	1
Spouse income from maintenance	3	-	2
Spouse income from trust fund	-	-	-
Spouse income from Government training allowance	-	-	-
Spouse occupational pension	6	15	8
Spouse private pension			
Base	67	20	87

Table 3.2 shows the proportion of income from earnings and other sources for non-pensioner and pensioner family units. In 28% of non-pensioner family units the spouse was working. The most common other source of income was an occupational pension from a former employer.

Income from benefits

The majority of the sample (68%) lived in family units where there was no earner. In the OPCS study this figure was 78%. Inevitably the main source of income for these families was state benefits.

Since the OPCS carried out its survey the social security system has been radically changed. Supplementary benefit was replaced in April 1988 by income support, with fixed payments for specific groups of disabled people. For example, in addition to a weekly flat rate of benefit a disability premium is paid to people receiving attendance or mobility allowance or severe disablement allowance. Family credit has also replaced family income supplement. We found it easier, therefore, than OPCS did, to identify precise types of income. Some of the sample were still unsure, however, which benefits they were receiving and how much each was worth. Benefit order books do not show these benefits separately and so further verification and checking were necessary after the interviews in some instances.

As with the OPCS survey, the majority of the family units in our sample were receiving at least one benefit. Most of the family units in the OPCS survey were receiving retirement pension. Table 3.3 shows that in our survey, with our lower proportion of pensioners, the proportion of family units receiving retirement pension was 20% [OPCS Table 3.4]. In Table 3.3 the receipt of benefit from the Independent Living Fund (ILF) is also indicated as a benefit for the costs of disability (in the case of the ILF for personal care and domestic assistance). The ILF was not in existence when the OPCS collected its data.

Nearly all the pensioner family units (95%) received a general income maintenance benefit (mainly retirement pension) which was supplemented in 65% of cases with income support. 67% of disabled adults in non-pensioner family units were receiving a disability-related income maintenance benefit (mainly invalidity benefit or severe disablement allowance). These last two benefits are paid to disabled people who are unable to work. This contrasts with the OPCS finding that only 35% of such family units were receiving a disability-related benefit [OPCS Table 3.4].

Table 3.3 shows that 82% of our disabled adults were receiving at least one of the disability costs allowances.

Table 3.3

Proportion of disabled adults and families receiving each benefit: non-pensioner and pensioner family units

State benefit	Non-pensioner %	Pensioner %	All family units %
Proportion receiving each benefit:			
Child benefit	22	-	17
One parent benefit	2	-	1
<u>Any child benefit</u>	22	-	17
Family credit	-	-	-
Income support	40	65	46
Retirement pension	5	70	20
Unemployment benefit	-	-	-
Sickness benefit	-	-	-
Invalid care allowance	10	-	8
Other	3	5	3
<u>Any general income maintenance benefit</u>	42	95	60
Invalidity benefit	24	10	35
Severe disablement allowance	22	30	25
Industrial disablement pension	5	-	3
War disablement pension	2	-	1
<u>Any disability-related income maintenance benefit paid to disabled adults</u>	67	40	61
Disability-related income maintenance benefit paid to spouse only	5	5	5
Attendance allowance	37	75	46
Mobility allowance	73	40	66
Independent Living Fund	25	45	30
<u>Any disability costs allowance paid to disabled adults</u>	84	75	82
Disability costs allowance Paid to spouse only	-	-	-
Base	67	20	87

Mobility allowance cannot be claimed after the age of 65, although it can be received until the age of 80, and so more respondents in non-pensioner family units were receiving it than respondents in pensioner family units (73% compared with 40%). Such regulations do not exist in respect of attendance allowance so the proportions are different (37% compared with 75%).

Anomalies in OPCS severity ratings

In Table 3.4 we show receipt of attendance allowance and mobility allowance by OPCS severity category. Because receipt of these benefits is generally an indication of greater severity of disability it is not surprising that a large majority of disabled people in severity category 10 (88%) were receiving attendance allowance and 68% receiving mobility allowance.

It is more unexpected, however, that some respondents in categories 3 and 4 were receiving mobility allowance, especially as receipt of this allowance is one of the passporting benefits to severe disablement allowance which otherwise requires a severity rating of 80% disability on the loss of faculty scale. The case in severity category 3 receiving mobility allowance was a man with heart disease and diabetes who cannot walk farther than 50 yards without stopping or severe discomfort. One case in category 4 was a woman with Ehlers-Danlos syndrome, thrombocytopenia and scoliosis who cannot walk 200 yards without stopping and who needs to hold onto something to keep balance. A second case in category 4 was a man with severe coronary heart disease, angina, osteoarthritis, ulcerative colitis and hyper-tension. He cannot walk more than 50 yards and has problems with continence and digestion. A third case in category 4 was a man with ankylosing spondylitis and chronic renal failure who always needs to hold onto something to keep balance and cannot walk more than 200 yards without stopping or severe discomfort and who also has problems with dexterity and digestion.

Also interesting is the case in severity category 5 who was receiving the higher rate of attendance allowance. This is a man with chronic bronchitis and emphysema who needs to take oxygen for 15 hours per day. His walking is extremely limited and he needs to hold onto something to keep his balance. He has problems with reaching and stretching and cannot wash his hands and face, or dress and undress, without assistance.

Since attendance allowance is also considered as a passporting benefit to severe disablement allowance it is surprising that the severity rating here is also so low.

Table 3.4

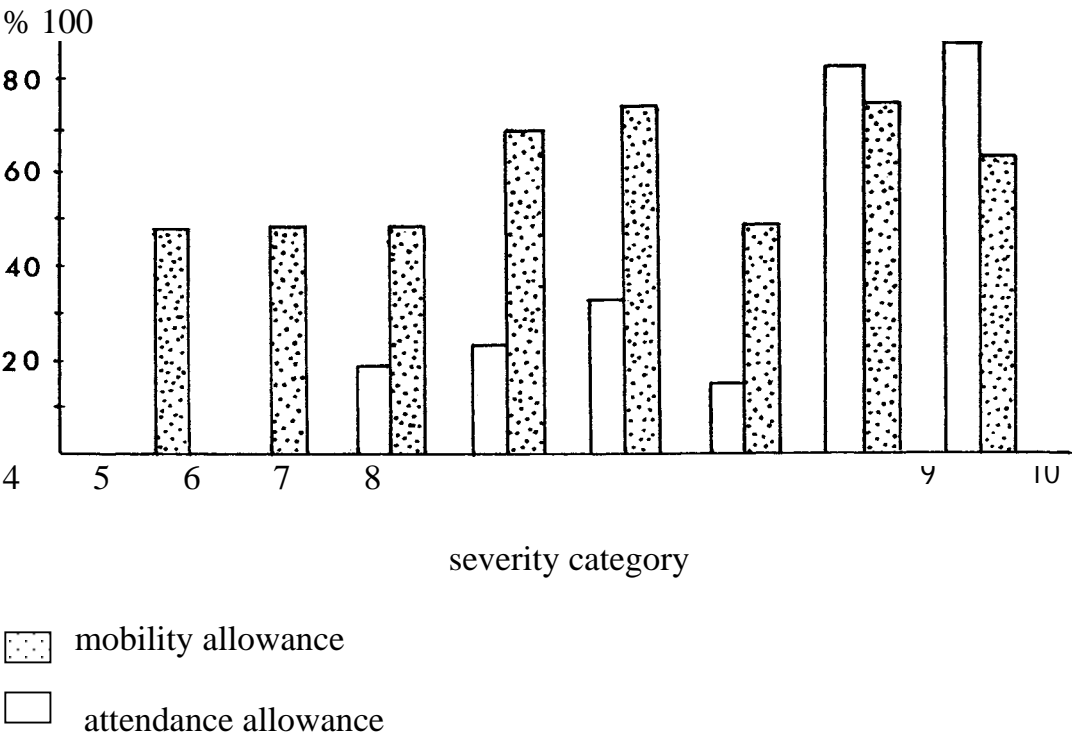
Receipt of attendance allowance (higher or lower rate) and/or mobility allowance by severity category and whether under/over pension age

Receipt of attendance allowance (AA) & mobility allowance (Mob A)	Severity category								All disabled adults
	3	4	5	6	7	8	9	10	
	%	%	%	%	%	%	%	%	
Proportion under pension age receiving:									
Higher rate AA	-	-	20	-	-	-	39	79	25
Lower rate AA	-	-	-	10	20	-	39	7	13
All receiving AA	-	-	20	10	20	-	77	86	38
All receiving Mob A	100	50	60	80	80	67	85	79	75
Base	1	6	5	10	10	9	13	14	68
Proportion over pension age receiving:									
Higher rate AA	-	-	-	-	-	-	50	100	26
Lower rate AA	-	-	-	67	100	50	50	-	47
All receiving AA	-	-	-	67	100	50	100	100	74
All receiving Mob A	-	-	-	33	50	25	50	-	32
Base	1	-	1	3	2	4	6	2	19
Proportion of all disabled adults receiving:									
Higher rate AA	-	-	17	-	-	-	42	81	25
Lower rate AA	-	-	-	23	33	15	42	6	21
All receiving AA	-	-	17	23	33	15	84	88	46
All receiving Mob A	50	50	50	69	75	54	74	68	66
Base	2	6	6	13	12	13	19	16	87

There could have been differences in the responses given to our interviewer from those given earlier to an examining medical officer in relation to the benefit application. It is also possible that the method used by the OPCS in assessing severity led to these inconsistencies. If this last point is the case then clearly a question arises over the nature of the OPCS assessments.

Figure 3.1

Proportion of disabled adults receiving attendance allowance and/or mobility allowance by severity category



One of the problems with an OPCS-style severity rating is that it does not relate to likely extra costs. People with locomotion problems but with few other difficulties score a very low severity figure yet they qualify for mobility allowance in respect of their extra costs. We would suggest that the OPCS severity ratings are not an adequate means of identifying disabilities that incur extra costs, nor can they reliably identify the proportion of people who have such disabilities.

Proportion of income from different sources

Table 3.5 shows the average amounts of income from each of the three main sources (earnings, benefits and other) by family type.

Average income for the whole sample was £182.32 per week. Since none of the pensioner families was working, all were dependent on benefits for their main income.

Table 3.5
Average weekly income from different sources by family type

Source of income	Family type						All disabled adults
	Non-pensioners		Pensioners				
	Unmarried no children	Unmarried with children	Married no children	Married with children	Unmarried	Married	
	£	£	£	£	£	£	
Earnings	11.00	45.23	79.00	95.64	-	-	48.53
Benefits	144.05	158.25	111.98	113.37	122.70	134.44	124.20
Other sources	10.55	28.30	10.44	2.37	7.92	12.78	9.59
Total income from all sources	166.61	231.78	201.42	211.38	130.62	147.22	182.32
Base	20	3	32	14	12	6	87

Benefit income generally increases with severity of disability. This is because the incomes of severely disabled people are likely to be increased by the receipt of attendance allowance, mobility allowance and ILF funding.

A comparison of this table with OPCS Table 3.15 shows that families in our sample were much more heavily dependent on benefits as their main source of income.

Summary

These findings confirm the importance of benefits as an income for disabled people. Clearly, we had a sample for whom benefits were a primary source of income. Even in the case of married non-pensioners with children in our sample there was a heavier reliance on benefits than in the same group in the OPCS study.

This dependence on benefits is in many respects unsurprising because the kind of people likely to be in touch with DIG are those for whom benefits are important. What is clear is that for this benefit-dependent sample any decisions the Government makes about benefits are going to be crucial.

Chapter 4

THE EXTRA COSTS OF DISABILITY

OPCS estimated that the average weekly costs of disability for all its sample were £6.10, ranging from £3.20 for people in category 1 to £11.70 for those in category 10. In this chapter we demonstrate what happened when we re-examined those findings with our sample. We show the results of our research in three separate stages: first, capital costs; second, ongoing weekly costs; third, unmet needs.

Capital costs include expenditure on the large and small items which were purchased infrequently. Some of the items were fairly specific to disability, while others were items of general household equipment. These general items are more of an essential than a luxury for many disabled people, however.

Certain respondents had difficulty giving a precise answer to some of the questions about the ongoing costs of disability. Although our use of semi-structured interviewing techniques helped to encourage clear thinking about individual items, nevertheless some respondents who said they incurred extra costs for a particular item were unable to specify the actual amount. OPCS had the same problem and we adopted a procedure similar to theirs. In these cases we imputed an average expenditure, based on the average of those who had answered the particular question fully and who were in the same combined severity groups.

Capital costs

OPCS collected the information on lump sum purchases only where they had been made during the previous twelve months. However, because of the relatively small size of our sample and the fact that some purchases are highly infrequent, we thought it was not practical for us to collect information on capital costs incurred only in the past year. The information we collected about capital expenditure thus related to a period within memory, and we have not revalued the cost. The information does indicate, however, the extent of need among disabled people to purchase equipment and gadgets for themselves.

The main items in this category were as follows:

vision aids
communication aids
equipment and daily living aids
adaptations to car
central heating

This list does not exactly coincide with that used by OPCS but reflects the understanding of DIG's Advisory Service of the more usual capital costs incurred by a generality of disabled people. Although OPCS attempted to collect information about capital purchases for items non-disabled people might also use, they did not report on this. We felt that such purchases might be significant and so our definition of "equipment and daily living aids" includes:

environmental controls	microwave oven
stairlift	washing machine
rails	freezer telephone
hoist	gadgets
special mattress	
special chair	

However, we did not include surgical aids or powered indoor or outdoor wheelchairs as OPCS did, because in our experience very few disabled people can afford to buy such expensive items.

Table 4.1 shows the proportion of people with expenditure on equipment and aids by severity category. It shows a large majority of people purchasing equipment and daily living aids, with the average total paid for all capital purchases closely related to the severity rating.

The average amount spent by our sample was £748, with the least spent £20 and the most £2205.

In addition to these costs, 54% of the whole sample owned a car because of their disability. For people receiving one or more of the disability costs benefits the proportion rose to 61%, with 19% of these purchasing a car through Motability, a voluntary organisation set up on the initiative of the Government and designed to help people with disabilities use their mobility allowance to buy or hire a car. What is clearly revealed by this part of the study is the very high percentage of the whole sample who were incurring capital expenditure on items which might be seen as luxuries for non-disabled people but which are necessities for people with disabilities. For example, 34% of the sample had bought a microwave

oven; 67% a washing machine; 65% a freezer; and 22% other gadgets, mainly for the kitchen. It appears that this class of significant expenditure might usefully have been included in the OPCS report.

Table 4.1

Proportion of people with expenditure on equipment and aids by severity category

Source of income	Severity category				All disabled adults
	Family type				
	3-4	5-6	7-8	9-10	
	Proportion incurring expenditure:				
	%	%	%	%	%
Vision aids	-	16	12	23	16
Communication aids	-	5	12	6	7
Equipment and daily living aids	100	84	92	96	92
Adaptations to car	-	11	8	20	13
Central heating	-	27	8	20	17
Average total paid for equipment and aids	£397	£589	£726	£925	£748
Base	8	19	25	35	87

This need is amply illustrated by the case of a married woman with a child under 16. She is disabled as a result of polio and has spent £1070 on equipment and daily living aids. She is paralysed down her left side and in order to run the home she needed to purchase some items to help her: a food mixer, an electric knife and can-opener and a tumble drier. This family reported that they were in some financial difficulty but because these items were essential other things were foregone, such as holidays and going out, which she said would be her personal luxury.

Ongoing extra costs

The calculation of extra expenditure attributable to disability was totally dependent on the information given by respondents on how much they spent on various services and items and on their estimate of how much of this was "extra", that is expenditure over and above that which they would have incurred

without their disability. Those people in receipt of ILF funding were very aware of their expenditure. This was not unexpected, since application to the Fund itself had arisen directly from inadequate resources to pay for care and part of the Fund's application procedure had involved a financial assessment.

We decided to show ongoing extra costs both with and without income from the Independent Living Fund. This Fund makes regular cash payments to severely disabled people which are used purely for the purchase of personal care and/or domestic assistance. In that sense it is a wholly committed benefit, which is not used in respect of other extra costs of disability. However, it is important to show ILF funding as a resource, and receipt of this funding contributes to the high level of expenditure on home services. 29% of the sample were receiving help from the ILF, with payments ranging from £11 to £181.50 per week. Most of these people were in severity categories 9 and 10.

The questions we asked were largely based on the OPCS schedule and covered the following items of expenditure. The question numbers are published alongside these items, and the full questionnaire can be seen in Appendix 3.

Q22 home treatment i.e. help from the health services

Q23 home services e.g. help from social services

Q24 informal assistance e.g. help from relatives and friends

Q26 prescriptions

Q27 chemist items including unprescribed medication

Q28 laundry

Q29 clothing and bedding

Q30 wear and tear/waste and destruction

Q31 diet and food

Q32 fuel and heating

Q33 transport and travel

Q38 other costs e.g. telephone, buying presents for helpers, insurance

As we have already noted, OPCS estimated that the ongoing costs of disability varied between £3.20 per week for those in severity category 1 to £11.70 per week for those in severity category 10.

Table 4.2 shows what we found when we asked our sample about their extra costs [OPCS Table 4.11]. We found the average extra costs for each severity category to be substantially higher than in the OPCS survey.

The average costs for the people in our sample without 'ILF-funded expenditure being taken into account were £49.86 per week, and with ILF-funded expenditure £69.94 per week. It should be borne in mind, however, that these figures cannot be compared directly with the OPCS overall average figure of

£6.10 per week, for theirs was an average across all the severity categories. What is important is to compare the findings for individual categories. Our findings are consistently higher than the OPCS figures, but particularly striking are the results for categories 9 and 10.

Table 4.2

Total average weekly ongoing costs by severity category, excluding and including ILF-funded costs

	Severity category								All disabled adults
With/without ILF	3	4	5	6	7	8	9	10	
	£	£	£	£	£	£	£	£	£
Average excluding ILF	28.25	20.05	34.23	39.49	29.78	42.04	60.54	86.73	49.86
Average including ILF	28.25	20.05	34.23	42.57	35.79	47.39	92.63	146.47	69.94
Base	2	6	6	13	12	13	19	16	87

Average extra disability-related expenditure for category 9 in the OPCS study was £11.10 per week. In our study it is £60.54 per week (excluding ILF) - over five times higher -and £92.63 (including ILF).

Weekly extra costs for category 10 in the OPCS study were £11.70. In-our study they were found to be £86.73 (excluding ILF) - almost eight times higher - and £146.47 (including ILF).

In Table 4.3 we have combined the OPCS severity categories. We have included this table as it is the basis for further comparisons with other OPCS tables in the remainder of this chapter.

Looking at Tables 4.2 and 4.3 together we can see an overall trend, with costs generally rising with severity. This is in line with the OPCS findings. What is remarkable is the quantitative difference in the results of the two investigations.

Table 4.3

Total average weekly ongoing costs by collapsed severity category, excluding and including ILF-funded costs

With/without ILF	Severity category				All disabled adults
	3-4	5-6	7-8	9-10	
	£	£	£	£	£
Average excluding ILF	22.10	37.83	36.16	72.51	49.86
Standard deviation	14.47	19.41	18.97	57.91	43.47
Average including ILF	22.10	39.94	41.82	117.25	69.94
Standard deviation	14.47	22.38	22.16	70.94	61.66
Base	8	19	25	35	87

Table 4.4 shows weekly ongoing costs by weekly net income [OPCS Table 4.18]. As might be expected this shows a relationship between total income and amount of expenditure on disability.

Table 4.4

Total weekly ongoing costs by weekly net income, excluding and including ILF-funded costs

With/without ILF	Net income per week								All disabled adults
	£ 0-50	£ 50-100	£ 100-150	£ 150-200	£ 200-250	£ 250-300	£ 300-400	£ 400+	
Average excluding ILF	14.48	27.29	40.64	54.45	51.85	62.72	101.62	55.44	49.86
Average including ILF	14.48	29.12	44.10	65.83	102.41	110.86	157.45	55.44	69.94
Base	4	12	23	18	13	7	8	2	87

Table 4.5 shows the relationship of ongoing costs to family type. It reveals that non-pensioner families spend more on disability-related expenditure than pensioner families do. This finding was also made by OPCS. The average weekly ongoing expenditure for non-pensioners in our sample was £72.00, compared with £62.55 for pensioners.

Table 4.5

Total weekly ongoing costs by family type, excluding and including ILF-funded costs

With/without ILF	Family type						All disabled adults
	Non-pensioners		Pensioners				
	Unmarried no children	Unmarried with children	Married no children	Married with children	Unmarried	Married	
	£	£	£	£	£	£	
Average excluding ILF	68.11	73.76	45.95	50.25	24.94	46.77	49.86
Average including ILF	104.47	134.26	55.85	50.25	65.50	52.60	69.94
Base	20	3	32	14	12	6	87

There are several possible explanations for this. Pensioners in our sample generally have less disposable income than non-pensioners. They also generally appear to have lower expectations, as will be seen later in chapter 5.

Weekly expenditure for our sample increased with receipt of one of the disability costs benefits. People receiving attendance allowance, mobility allowance or ILF funding spent proportionately higher amounts. For example, people in severity categories 5-6 receiving at least one of these benefits were spending on average 46.93 per week while those not receiving any were spending £28.40; people in categories 7-8 receiving one or more of the three benefits were spending £45.34 while those not receiving any were spending £31.72; and for people in categories 9 and 10 the amounts were £121.55 and £53.57 respectively.

The results of this part of the study suggest that spending on weekly ongoing

costs increases with severity of disability and also relates to receipt of one of the disability costs benefits. It also suggests that spending is related to income. These findings do not conflict with those of OPCS. What does sharply contrast, however, is the amount that people in our sample state they are spending as a result of their disability. We have already suggested reasons for this difference in chapter 1. In our concluding chapter we will discuss the implications of these findings.

Patterns of expenditure

We found a considerable amount of variation around the average levels of expenditure (see the standard deviations in Table 4.3), as did OPCS. Because of these variations averages are not necessarily the best way of comparing extra costs. However, since this was the device used by OPCS and

Table 4.6
Average weekly ongoing costs on different items by severity category

Source of expenditure	Severity category				All disabled adults
	3-4 £	5-6 £	7-8 £	9-10 £	£
Average expenditure per week:					
Home treatment	0.00	0.00	0.00	1.20	0.49
Home services	0.51	5.98	7.45	59.81	27.55
Informal assistance	3.00	4.05	2.64	12.35	6.89
Prescriptions	0.38	0.34	0.29	0.08	0.22
Chemist items	2.60	2.27	2.12	4.49	3.14
Laundry	0.59	0.58	1.82	3.80	2.23
Clothing	0.98	1.61	2.26	3.54	2.51
Wear & tear/waste & destruction	0.01	2.10	1.94	5.29	3.14
Food	5.63	7.47	5.98	7.63	6.93
Heating	2.96	3.46	4.10	4.34	3.95
Travel	2.48	7.93	9.03	9.11	8.22
Telephone	1.67	3.54	3.05	3.99	3.41
Helper's presents	0.87	0.50	0.16	0.75	0.54
Insurance	0.51	0.11	.98	0.87	0.70
Total expenditure	22.10	39.94	41.82	117.25	69.94
Base	8	19	25	35	87

we are comparing our findings with theirs we have chosen to publish averages also. A better idea of how individual people make individual choices and have different patterns of spending can be seen in the following tables, in chapter 6 on selected case studies and in the income and extra costs sheets for those cases in Appendix 1.

Table 4.6 shows the amounts of additional expenditure on each item for all adults in the sample [OPCS Table 4.12]. It includes expenditure resulting from ILF income. Again this table is in striking contrast with the OPCS findings. For example, in the OPCS study the average extra cost of fuel for categories 5 and 6 was stated to be £1.30 per week. In our study it is £3.46 per week. OPCS found the extra costs of laundry for categories 7 and 8 to be 30 pence per

Table 4.7

Average weekly ongoing costs on different items by severity category: all adults with expenditure on the relevant items

Source of expenditure	Severity category				All disabled adults
	3-4	5-6	7-8	9-10	
	£	£	£	£	
Average expenditure per week:					
Home treatment	0.00	0.00	0.00	10.51	10.51
Home services	4.10	14.20	26.61	83.73	58.47
Informal assistance	8.00	8.56	8.25	20.58	14.62
Prescriptions	1.00	0.82	1.17	1.40	1.01
Chemist items	2.85	2.39	2.51	4.52	3.36
Laundry	1.19	1.33	3.25	4.29	3.40
Clothing	1.57	2.03	2.68	3.75	2.95
Wear & tear/waste & destruction	-	4.96	4.00	12.90	7.89
Food	9.00	11.83	7.87	12.14	10.41
Heating	3.94	3.86	4.46	4.47	4.30
Travel	1.77	8.26	14.53	20.23	15.14
Telephone	2.68	5.61	4.49	7.35	5.56
Helper's presents	3.50	2.37	0.82	2.61	2.22
Insurance	2.04	1.00	3.06	4.33	3.14
Minimum base	5	12	17	18	52

week. In our study it is £1.82 per week. We found the average costs of wear and tear/waste and destruction to be £3.14 per week over our whole sample; OPCS did not examine this cost, nor the costs of informal assistance. We consistently record higher amounts both for individual items and higher costs overall.

Table 4.7 shows the amounts of additional costs for each item for all adults actually incurring expenditure on that item [OPCS Table 4.9]. This table shows which are the items that can prove to be major expenses to those disabled people who need to incur them. The contrast with Table 4.6 is particularly striking in the higher severity categories. OPCS reported that although expenditure on most items in their table went up as severity increased this was not to a very marked extent. However, as can be clearly seen in Table 4.7, costs for our sample do increase substantially in the higher severity categories and most noticeably in categories 9 and 10.

Table 4.8 shows the percentage of income spent on ongoing extra costs by severity of disability. OPCS did not publish a similar table.

Table 4.8

Percentage of income spent on ongoing extra costs by severity category excluding and including ILF-funded costs

	Severity category				All disabled adults
With/without ILF	3-4	5-6	7-8	9-10	
	%	%	%	%	%
Percentage on ongoing costs excluding ILF	22	28	26	35	30
Percentage on ongoing costs including ILF	22	29	30	53	38
Base	8	19	25	35	87

This table clearly shows that a very large proportion of disabled people's disposable income is being spent on the ongoing costs of their disability. In categories 9 and 10 this is especially the case, with 35% of income (excluding ILF) being spent on extra costs.

The following paragraphs describe the extra costs of disability in more detail, together with details of those services the respondents did not have to pay for. Home treatment: Since most of the treatment at home is provided without charge by health authorities, it was not surprising that the majority of the sample (95%) did not pay anything towards this; 55% were receiving such help, however, mainly for chiropody and physiotherapy. Four people were paying for home treatment and the average cost incurred by them was £10.51 per week. Disabled people in categories 9 and 10 were more likely to see a district nurse (66% of these) but only in 17% of these cases did the district nurse call once a day or more.

Home services: This general heading mainly covered services provided by the social services department or voluntary organisations, such as home helps and social workers. It also covered private domestic and nursing help. In categories 9 and 10 57% of disabled adults had not had a home help and only in 34% of the cases receiving this help was the service provided more than once a week. The average weekly cost to respondents with a home help was £2.68. Of the whole sample, 62% had not had a home help in the past year. A night sitting service was used by only one person in the sample (a woman in category 10 who was paying for it at a cost of £175 per week.) Only 24% of the sample saw a social worker.

Our findings show the importance of specialised care and support services for disabled people, for 29% of the sample were paying for private domestic help at an average cost of £42.00 per week and 15% for private nursing help at an average of £94.00 per week. Most of these cases were receiving funding from the ILF to purchase care.

Informal assistance: Just over half the sample (54%) were receiving help from their family and in 93% of cases it was given without charge. 46% received help from relatives and only in 24% of these cases was any payment made. These findings identify family and relatives as important sources of free help. Our survey also showed the difficulties that disabled people have in maintaining their homes. Reliance on help with maintenance was evident in the 30% of the sample who needed help with odd jobs, with 66% of these paying for such assistance.

Prescriptions: Three-quarters of the sample were exempt from prescription

charges. This was an important source of assistance, because 85% said they had to take drugs because of their disability.

Chemist items: A very high proportion of the sample (92%) said they needed to spend extra on unprescribed medication and chemist items. They were buying powder and creams, vitamins, dressings, supports and disinfectants. They were unable to obtain any of these items on prescriptions although they were, in many cases, important medical needs.

Laundry: Extra costs on laundry were incurred by 61% of the sample. People with this expenditure indicated a number of reasons for the additional costs, which included incontinence (42%); the use of special creams and medications (30%); and because they sweat a lot (34%).

Clothing and bedding: A large proportion of the sample said they spent extra on clothing and bedding. The most frequently mentioned items of clothing purchased were underwear (by 47%), and pyjamas and nightdresses (by 48%).

Wear and tear/waste and destruction: Over half our sample (58%) were spending extra because of the need to repair or replace items. Of these 19% paid for repair of broken equipment, 17% for replacing broken crockery, and 16% for making good damaged decorations.

Diet and food: Special diets were taken by 45% of the sample and in 38% of those cases they had been prescribed by a doctor. Only one person in the sample got food on prescription. Two-thirds of the sample said they spent more on food because of their disability, for a variety of reasons: the need for a special diet (35%), the need to buy convenience food (15%) and because they could not shop around (11%). These findings bear out those of an earlier DIG study (Stowell and Day 1983) which showed that the extra costs of shopping added an average of 15% to a household weekly shopping bill. However, 30% of the sample said they had to go without food from time to time because they could not afford it.

Fuel and heating: About two-thirds of the sample (69%) had central heating. In about half the cases where central heating was not installed it was said to be needed. This form of heating is the most easily handled and controllable form for disabled people. The control of the system and the all-over warmth require no physical effort. Of those respondents who said they were spending extra, 83% said this was because they were at home more than would be the case if they were not disabled; 79% said they needed higher temperatures because they felt the cold more. Worrying about fuel bills was a problem for 67% of the respondents and just over half (52%) said they sometimes felt the cold because

they attempted to economise by not putting on their heating.

Transport and travel: Over two-thirds of the sample (67%) owned or had use of a car. Of these 55% said they had to have one because of their disability and 47% said it cost extra to run it. 53% of the sample said they had other travel costs, including hiring taxis.

Other costs: We asked about other specific costs, including telephone, buying presents for helpers and insurance. The telephone is the only means of contact with the outside world for many disabled people and so it was not surprising that 76% of the sample said they spent extra on this item. One-third incurred costs on buying presents for helpers and 27% spent more on insurance because of their disability, generally because of higher premiums.

Unmet needs

We have shown that disabled people have very considerable extra expenditure because of their disabilities. We have also shown that families with higher incomes tend to spend more than families with lower incomes and that people receiving a disability costs benefit spend more than those who do not receive such assistance.

Table 4.9

The proportion of disabled people who thought they needed to spend more on specific items but who could not afford to by severity category

Item	Severity category				All disabled adults
	3-4	5-6	7-8	9-10	
	%	%	%	%	
Home treatment	25	39	48	47	43
Home services	25	11	30	24	23
Informal assistance	-	5	46	31	27
Chemist items	14	24	20	28	24
Laundry	29	12	32	30	27
Clothing	80	62	65	49	58
Wear & tear/waste & destruction	100	42	78	69	68
Food	75	47	56	63	59
Heating *	63	42	72	40	52
Base		19	25	35	87

* We asked if respondents ever felt the cold because they did not put the heating on.

Expenditure on disability is thus constrained by income. In order to get a full picture of the financial consequences of disability we also asked whether our sample thought they needed to spend more on certain items because of their disabilities but could not afford to do so (whether they had already incurred expenditure on these items or not).

Table 4.9 shows the proportion of disabled people who thought they needed to spend more by severity category. A high proportion of the sample (68%) said they needed to spend more because of wear and tear and waste and destruction but could not afford to do so.

This meant that they thought they needed to, but could not, replace worn out or damaged furnishings and equipment. Of all the possible extra costs this was the one most likely to be shelved because it would have least direct effect on health and well-being.

43% of those who felt they needed to spend more would have bought more home treatment, for example physiotherapy. 58% needed to spend more on clothing and 59% on food.

Interestingly a high proportion of respondents in categories 3-4 said they needed to spend more on basic items such as clothing, food and heating. People in categories 3 and 4 had the lowest average weekly income.

Table 4.10

The extra weekly amount that disabled people with the need thought they should be spending by severity category

Item	Severity category				All disabled adults
	3-4	5-6	7-8	9-10	
	£	£	£	£	£
Home treatment	10.00	21.50	9.50	43.50	30.12
Home services	10.00	27.50	27.00	61.03	52.08
Informal assistance	3.00	11.67	14.19	13.27	12.90
Laundry	10.00	10.00	4.50	12.25	9.44
Clothing	2.11	2.91	2.87	4.16	3.34
Wear & tear/waste & destruction	29.16	6.88	6.34	15.09	12.13
Food	9.12	11.67	9.50	8.45	11.21
Total	73.39	92.13	73.90	163.21	132.15
Minimum base	1	2	1	14	18

Table 4.10 shows the actual amount the respondents felt they should be spending on each item. Although the answers to this question were necessarily subjective they do, nevertheless, reveal a high degree of perceived unmet need. Particularly prominent amongst categories 9-10 is the need to spend more on home services (£61.03), for example domestic assistance. Also interesting is the high average amount people generally said they needed to be spending on food. Although it is difficult to quantify unmet needs with the same degree of accuracy as actual expenditure incurred, these findings do serve as an indication of how far the incomes of disabled people fail to meet their real needs.

Summary

In this chapter we have shown that the OPCS survey seriously underestimated the costs of disability for many disabled people - for the most severely disabled group in our sample, by a factor of eight. We have shown that spending on weekly ongoing costs rises with severity of disability; that it is related to available income; and that it is related to receipt of one or more of the disability costs benefits. We have also shown that spending on certain important items is constrained by income. In our concluding chapter we shall offer our explanation for the difference in our results and identify some concerns arising from this.

Chapter 5

PEOPLE'S PERCEPTIONS OF THEIR PROBLEMS

In collecting information about disabled people's financial situation and standard of living we used the same two approaches as the 'OPCS: asking people's opinions of their situation, and asking questions about savings, debts and arrears. The answers to both these questions can act as indicators of financial difficulty.

Subjective opinions of financial situation

On this topic, we asked two questions also asked by OPCS, but we adapted the first part of one of them to establish people's views of their financial situation by adding three extra responses, to give respondents greater choice. The first of these questions was:

"Thinking about how you are managing on your money at the moment would you say you are

managing quite well
just getting by
scraping by (new)
getting into difficulties
permanently in debt (new)
other?" (new)

and the second was:

"The things people can buy and do - their housing, furniture, food, leisure activities, etc - make up their standard of living. How satisfied do you feel with your standard of living at present:

very satisfied
fairly satisfied
neither satisfied or dissatisfied
very dissatisfied
don't know?"

Table 5.1 shows the subjective perceptions of financial situation and standard of living by family type. In this table we have not excluded non-householders. In the comparable OPCS Table 6.2 they were excluded. OPCS found

Table 5.1

Subjective perceptions of financial situation and standard of living by family type

Subjective views of financial situation	Family type						All disabled adults
	Non-pensioners		Pensioners				
	Unmarried no children	Unmarried with children	Married no children	Married with children	Unmarried	Married	
	%	%	%	%	%	%	
Permanently in debt	20	-	9	29	-	-	13
Getting into difficulties	15	-	9	28	-	(33)	14
Scraping by	20	(67)	28	29	33	(50)	30
Just getting by	30	-	35	7	42	(17)	27
Managing quite well	5	(33)	19	-	25	-	15
Other	-	-	-	7	-	-	1
Total	100	(100)	100	100	100	(100)	100
Satisfaction with standard of living:	%	%	%	%	%	%	%
Very dissatisfied	45	(33)	22	36	17	(20)	29
Fairly dissatisfied	25	(34)	19	14	17	(20)	20
Neither satisfied or dissatisfied	10	-	19	14	8	(20)	14
Fairly satisfied	20	-	25	29	33	(40)	26
Very satisfied	-	(33)	6	-	25	-	6
Don't know	-	-	9	7	-	-	5
Total	100	(100)	100	100	100	(100)	100
Base	20	3	32	14	12	6	87

that non-householders were more likely to say they were managing quite well financially and satisfied with their standard of living. Because we included non-householders the levels of dissatisfaction in our findings are likely to have been reduced, for this group are much less likely to be dissatisfied. Nevertheless, compared with the OPCS we found much higher overall levels of dissatisfaction. Whereas OPCS report that 70% of disabled householders were fairly satisfied or very satisfied with their standard of living, the corresponding figure in our sample is only 32%. Among the non-pensioners the unmarried expressed more dissatisfaction than the married (a finding reflecting that of OPCS), with 20% of unmarried non-pensioners without children saying they were permanently in debt and 15% getting into difficulties, and 70% of this group expressing dissatisfaction with their standard of living. Pensioners were more likely to be satisfied with their overall situation.

OPCS did not publish figures for subjective perceptions according to severity of disability, but we felt this information might be useful. However, as Table 5.2 shows there appears to be no clear relationship between severity rating and perceptions (perhaps because, as we have noted, the OPCS severity rating is not a good indicator of the need to incur extra costs).

Table 5.2

Subjective perceptions of financial situation and standard of living by severity category: all adults

Subjective views of financial situation	Severity category				All disabled adults
	3-4	5-6	7-8	9-10	
	%	%	%	%	%
Permanently in debt	13	11	20	9	13
Getting into difficulties	12	10	12	17	14
Scraping by	38	11	36	34	30
Just getting by	25	37	24	26	28
Managing quite well	12	26	8	14	14
Other	-	5	-	-	1
Total	100	100	100	100	100
Satisfaction with standard of living					
Very dissatisfied	38	21	32	29	29
Fairly dissatisfied	12	26	28	12	20
Neither satisfied nor dissatisfied	13	6	12	21	14
Fairly satisfied	25	26	16	32	25
Very satisfied	12	16	4	3	7
Don't know		5	8	3	5
Total	100	100	100	100	100
Base	9	19	25	35	87

Table 5.3 is perhaps a better indicator. It shows that people in receipt of attendance allowance, mobility allowance or ILF support were more likely to be dissatisfied

Table 5.3

Subjective perceptions of financial situation and standard of living by receipt of attendance allowance, mobility allowance, Independent Living Fund payments

Subjective views of financial situation	Receipt of AA, Mob A, ILF		
	Receiving %	Not receiving %	disabled adults %
Permanently in debt	14	6	13
Getting into difficulties	14	13	14
Scraping by	29	37	30
Just getting by	28	25	27
Managing quite well	14	19	15
Other	1		1
Total	100	100	100
Satisfaction with standard of living:			
Very dissatisfied	33	13	29
Fairly dissatisfied	19	25	20
Neither satisfied nor dissatisfied	14	12	14
Fairly satisfied	24	31	25
Very satisfied	6	13	7
Don't know	4	6	5
Total	100	100	100
Base	71	16	87

with their standard of living (52%) than people who were not receiving this help (38%). They were also somewhat more likely to be in financial difficulties (28%) than those not receiving (19%). Since, as has been noted earlier, receipt of these disability costs benefits is generally related to severity of disability, these findings suggest that the most severely disabled people feel they need more financial assistance than they are currently receiving. As we have already seen in chapter 4, this was the group that was spending the highest amounts on ongoing extra costs.

Financial problems

We then asked the same questions as the OPCS to measure financial difficulty more objectively:

"During the past 12 months have you ever:

- i Had to use any money you had in savings
- ii Had to borrow money from anyone for some big expenses
- iii Had to borrow money from anyone when you were short, just to make ends meet
- iv Fallen behind with your rent, mortgage or any other regular payments
- v Had a big bill that you could not afford to pay on time?"

We also asked:

"Are you behind with any payments at present?"

Table 5.4 shows the proportion of the sample with different problems by family type. It can be compared with OPCS Table 6.6, although our table does not exclude non-householders. As already indicated, this means that the overall levels of dissatisfaction in our sample are, if anything, likely to have been reduced.

Use of savings was the answer most frequently given, a finding which accords with that of the OPCS. They suggested that use of savings is not an indication of financial problems, since many people save for their retirement or for items of equipment and expect to use these savings. This could, of course, be an oversimplification in many cases: the repeated dipping into savings can lead to premature run-down of resources to a level inadequate compared with earlier expectations. However, we excluded this item from further analyses in order to compare our findings with theirs.

Our sample had a higher incidence of financial problems than the OPCS sample.

It is worth remembering, again, that ours

Table 5.4
Proportion of sample with different financial problems by family type

Financial problems	Family type						All disabled adults
	Non-pensioners		Pensioners				
	Unmarried no children	Unmarried with children	Married no children	Married with children	Unmarried	Married	
	%	%	%	%	%	%	
	Proportion with each problem:						
Used savings	50	(67)	67	46	50	(83)	59
Borrowed for big expense	47	(33)	50	86	17	(33)	49
Borrowed to make ends meet	42	(50)	19	71	25	-	33
Fallen behind with regular payments	40	-	19	50	8	-	26
Couldn't pay bill on time	45	(33)	34	64	17	-	37
Currently behind with payments	40	(33)	28	64	-	-	31
Average number of financial problems excluding savings	2.1	(1.3)	1.5	3.4	0.6	(0.3)	1.7
Base	20	3	32	14	12	6	87

was a much more benefit-dependent sample than the OPCS one. Married respondents with children had the largest number of financial problems (3.4). Pensioners were less likely than non-pensioners to have any of the financial problems.

Examination of Table 5.5 is interesting because it seems to bear out the point made earlier, that receipt of attendance allowance, mobility allowance or Independent Living Fund funding does not necessarily reduce financial difficulty.

Indeed, as can be seen in Table 5.5, people receiving one or more of these benefits were much more likely to have financial problems than people not receiving them. We suggest that severity of disability, and its consequent high costs, is a contributory factor in this finding.

Table 5.5

Proportion of sample with different financial problems by receipt of attendance allowance, mobility allowance, Independent Living Fund payments

Financial problems	Receipt AA, Mob A, ILF		
	Receiving	Not receiving	All disabled adults
	Proportion with each problem:		
Used savings	61	50	59
Borrowed for big expenses	50	44	49
Borrowed to make ends meet	34	31	33
Fallen behind with regular payments	27	19	25
Couldn't pay bill on time	39	25	37
Currently behind with payments	32	25	31
Average no of financial problems excluding used savings	1.8	1.4	1.7
Base	71	16	87

We also asked how respondents would spend a £10 a week increase in benefit. Although 27% said they would spend it on food and 7% said on care, answers were otherwise very varied. These included paying debts, clothing, decorating the house, telephone, social activities and the general observation that it would "make life easier and there would be less worry".

We then asked how respondents would spend a windfall of £200. 14% said they would save it but 31% said they would use it to pay off debts and 21% would use it to buy things for the home.

When we asked how respondents would cope if they were to have a reduction in benefit of £10 per week, 34% said they would cut down on heating and 9% on getting about. 41% gave a variety of responses, many non-specific but indicating a serious level of concern were that situation to happen.

"Hopeless, I couldn't live"

"I'd be in real trouble"

"I'd go begging"

"There is not a lot we can do without, so I don't know".

And when we asked them to consider how they would manage faced with a bill of £200 very few were able to specify an item they could go without. Instead they gave answers which indicate the precarious nature of some of their financial situations:

"I'd have no means of paying" "I'd panic"

"I couldn't cope"

"I would be ill with worry".

Summary

As with the OPCS survey non-pensioners in our sample were much more likely to have negative perceptions of their standard of living than pensioners. People receiving one of the disability costs benefits were more likely to have financial problems. There was no clear relationship between OPCS severity ratings and perceptions of need, but, as we have already said, these severity ratings do not necessarily reflect the dependence on extra costs benefits or likely extra costs. However, a benefit-dependent population does tend to be in financial difficulties and that is apparent here.

Chapter 6

SELECTED CASE STUDIES

In this chapter ten people are examined in detail in order to see more clearly how their disability impacts on their financial situation. Names of individuals and certain details have been changed to ensure confidentiality. The income and extra costs sheets of each person are included in Appendix 1.

Clare Bell is 38 years of age. She has a spinal cord lesion at TS8 and a less advanced lesion in her cervical spine. She uses a wheelchair. Her condition has deteriorated over the past six months and she has suffered a great deal of pain.

There are two adults in the household and three boys, one of whom is her partner's son. The home is described as "warm and busy", not unexpectedly with three children, and Clare works from home as a training coordinator. Her partner is a nurse. The home is a house which they are buying with a mortgage.

In addition to her spinal condition she suffers from painful colitis and incontinence, which results in a lot of washing. She cannot go to and use the toilet without help. She has a severity rating of 10.

She pays for home services and has a domestic help, private nursing help and a personal carer. She also pays friends and relatives to assist her. She spends £160.25 on home services and £75 on relatives and friends.

As might be expected she is a heavy user of unprescribed medication and chemist items (£16.12 per week). She particularly buys extra amounts of tissues/toilet paper and kitchen rolls, and vitamins, massage oils and pain killers. She says she would like to buy more, particularly royal jelly and homeopathic preparations, but she cannot afford them.

To prevent infections her clothes are washed frequently and she estimates the extra cost to be £7 a week. She spent over £600 in the previous year on clothing and bedding. Clare is particularly heavy user of trousers and cycling gloves, which she wears out manipulating her wheelchair. She buys replacement bedding twice a year. However, she lacks a sheepskin for her bed but she cannot afford to buy one. She says she needs an extra £40 a month to clothe herself properly.

Clare says "everything in this house needs replacing at least two years earlier than any other house." She particularly needs, but cannot afford, a special washable carpet that sticks to the floor and will not ride up with the wheelchair.

She replaces damaged fittings and crockery regularly and said she had spent £150 since Easter on making good decorations.

Clare's special diet has been recommended by her doctor. Because of this need and the fact that she buys convenience foods and cannot shop around she spends on average £20 a week extra on food.

Fuel bills are £160 higher per year than they might otherwise be because Clare feels the cold, uses extra hot water for washing, has more frequent baths and has the heating on at night, in addition to being at home more and therefore using the heating more often and for longer during the year. Sometimes, in order to conserve fuel she remains in one small room. She worries about her heating bills.

Clare spends about £850 a year on extra transport and travel costs. She paid £1,000 for adaptations to her car which she says she needs because of her disability.

Within memory she had spent over £2,000 on equipment and daily living aids. These included kitchen gadgets, a washing machine and a tumble drier, an intercom, a shower and a stairlift. However, she cannot afford to buy a comfortable chair or a special bed which would enable her to sit supported.

Clare describes herself as "scraping by" and says her priorities are food and heating, but she sometimes finds it necessary to cut back on buying all the clothing she needs. She has used money she had in savings and has sometimes needed to borrow money and been faced with a bill she could not pay on time.

Total weekly household income was £554. However, the extra weekly ongoing costs due to disability were £342.69, accounting for 61% of this income.

Linda Rice is 58 and lives with her husband in a house they are buying with a mortgage. Her husband is an accountant and Linda is self-employed, breeding Cavalier King Charles spaniels. Linda suffers from multiple sclerosis and spondylitis.

Her arms are especially weak and when her condition is at its worst she cannot walk 50 yards without stopping or severe discomfort or feed herself without assistance. She has a severity score of 5.

She spends £20 a week on private domestic help and £10 a week for gardening and odd jobs. Chemist items and unprescribed medications cost £2 a week and she eats whole foods without additives (a diet recommended to her) which adds

a further £15 to her food bill.

Over £1,000 has been spent on the purchase of equipment for the house including a special combination microwave oven, a washing machine and a freezer.

Linda says she is "managing quite well". Total household income is £445 per week with ongoing extra costs due to disability totalling £49.88, 11% of their income. However, there is no benefit income in this household.

Alan Hardy, a former salesman but now unable to work, is 58 years of age and married with no children. He suffers from arthritis and also has an ulcerated leg. He and his wife live in a house rented from the council.

Alan can only walk a few steps without stopping or severe discomfort. He has problems reaching and stretching, washing and dressing, with which he needs assistance. He loses control of his bladder occasionally. His severity rating is 7.

He spends an extra £3.11 per week on chemist items, particularly disinfectants and bleach. £7.50 is spent on extra laundry costs, incurred mainly for frequent washing of clothes and bed linen due to occasional incontinence and use of creams and medications.

Alan spends £2.88 per week extra on clothing and bedding but says he needs to spend twice this amount to clothe himself properly. Because he needs a special diet, which has been recommended by his doctor, he estimates he spends an extra £5 a week on food. He owns a car and spends £5.00 a week extra on running costs because of his disability.

He purchased a reclining chair which cost £425 and a washing machine and freezer which cost £450.

Alan says he is "just getting by" but he has had to borrow money in the past for some big expenses. His total weekly income is £112.56 of which £34.41 - 31% - is spent on ongoing extra costs due to disability.

Anna Taylor suffers from multiple osteo-arthritis with the added difficulties of angina and bronchiectasis. She is 66 years of age, divorced and living alone in a small bungalow which she rents from the council. She used to work as a research interviewer.

She cannot walk more than a couple of yards and is said to be housebound

unless she uses a car. Any exertion renders her breathless. She has difficulty picking up and pouring from a full kettle and cannot get in and of bed without help. She loses control of her bladder at least once every twenty-four hours. Her severity rating is 8.

She pays for private domestic assistance at a cost of £62.00 per week but she would pay for more if she could afford it -she estimates an extra £27 would buy 9 hours of help. Anna spends £7.02 per week on chemist items. She particularly buys evening primrose oil and a large quantity of tissues because her condition means that excesses of phlegm have to be removed regularly. She buys most of her clothes from Oxfam shops and cannot afford to replace special shoes so she wears slippers when she goes out.

She needs to replace carpeting in her kitchen/diner because her wheelchair has worn it out, but she cannot afford to do so. Since she cannot shop around she estimates she spends an extra £5.00 a week on food.

Her heating costs are extra £4.80 per week. This is because she needs the heating on at night; she worries about her bill, however, and sometimes does not put the heating on to economise - but then she feels cold. She uses her car for very short journeys and estimates that it costs her an extra £5 a week. Occasionally when her car breaks down she uses taxis. Telephone bills are high and she estimates ongoing costs to be £12.50 per week.

She purchased a washing machine, a special mattress, a freezer and a special chair which together amounted to £670.

Anna says she is "scraping by". She has had to borrow money and could not survive financially if a close relative did not occasionally send her gifts of money. "I dry one day's tissues to re-use the next day," she told our interviewer. Total weekly income is £145.50 of which £97.28 (67%) is spent on ongoing extra costs due to disability.

Adam Ferguson is a single man aged 54. He lives, with a co-tenant, in a flat rented from a private landlord. He was a medical analyst before he became disabled with a life-threatening hormone deficiency disease. This condition means that he cannot exert himself at all; he has fainted and fallen and cannot walk 400 yards without stopping. He loses control of his bladder two or three times a week. He has a severity rating of 4.

He spends £3 a week extra on chemist items, including cotton wool, dressings and elastoplast, disinfectant and bleach. However, he says he restricts use of these items because of the cost.

He has extra laundry because of incontinence but he says he does this at home by hand to economise. He cannot afford to buy all the clothes he needs. He should wear good quality natural fibres since maintaining a very stable body temperature is imperative. Because he needs a special diet he estimates the weekly extra cost of food to be £12 but says he should probably be spending an extra £8.50 on top of this.

Because Adam is at home more than would be the case if he were able-bodied, because the heating is on at night and because he feels the cold, he estimates he spends an additional £2.88 on heating each week; but he worries a lot about his bills however, and does not use all the rooms in the flat because he cannot afford to heat them.

He says he is "getting into difficulties" financially - his total income is £48.60 per week, of which half is spent on the ongoing costs of his disability.

Julie Irving is disabled through polio and has partial paralysis of her left arm and leg. She is 33 and lives with her husband and 4 year old son in a house they are buying with a mortgage. Her husband is a driver but sometimes needs to stay at home to help his wife, so earnings are rather erratic.

Julie cannot walk more than 50 yards without stopping or severe discomfort and she cannot use her left arm and hand. Her food has to be cut up for her and she needs help with dressing. She has a severity rating of 6.

She "pays" neighbours and friends for assistance by giving presents which cost her about £5 a week. She spends £4.51 extra on clothing, chiefly on thermal underwear, coats and jackets and gloves. She needs to keep warm at all times and in order to afford thermal underwear she does without something else. Nevertheless she estimates she needs to spend about £2.50 a week more on such items.

Because of difficulty in preparing foods Julie reckons she spends an extra £20 a week on convenience foods. Fuel costs are £5.57 per week as a result of more frequent use during the day and the heating is also on at night and all year round. Julie feels the cold and the house has to be hotter than it would otherwise be. She says she worries about her heating bills.

She spends £28.84 per week on travel and transport costs, chiefly through running a car which she has because of her disability.

Julie spent £340 on the purchase of gadgets for the kitchen including a food mixer, an electric knife and an electric can opener. She also bought a microwave

oven, washing machine and freezer. Total capital purchases within memory were £1,070. In order to finance these essentials she cuts back on other things. For example, the family have not had a holiday for 10 years and do not go out socially.

Julie says she is "scraping by". She has had to borrow to make ends meet and has had to convert payments for electricity and gas to coin-operated meters because of the problems of funding the cash to pay quarterly.

Total weekly income for this household is £200 and the ongoing costs of disability of £81.65 per week represent 40% of income.

Michael West is 41 and married, without children. Michael's disability is tunnel vision, night blindness and partial deafness and he has a gastric ulcer. He has a severity rating of 7. He lives in a ground floor flat in a small complex rented from the council. He makes furniture at a sheltered workshop for disabled people. His wife is registered blind and suffers from arthritis.

He is on a high fibre diet recommended by his doctor on which he spends an extra £6 a week, although he reckons that part of this extra amount is attributable to being unable to shop around. He does not own a car but spends an extra £3.84 a week on transport costs due to using taxis to get about.

Capital purchases on vision and communication aids within memory have included braille equipment, a writing frame and a typewriter, totalling £87 altogether. Michael has spent £645 on a washing machine, freezer, telephone and tumble drier, all items of equipment necessary because of his disability and his wife's condition also. He says he is "scraping by" and if his income was to increase his priority would be to buy better food.

Total weekly household income is £121.20 of which £18.13 -15% - is spent on the ongoing costs of disability.

Alice Campbell is 78 years of age and lives with her 81 year old husband who is said to have a chest condition. She is disabled as a result of a cerebral vascular accident affecting her right side and she has had cancer. They live in a flat rented from the council.

Her mobility is extremely limited and she has problems reaching and stretching. She cannot go to and use the toilet without assistance and loses control of her bladder at least once a week. She has a severity rating of 8.

She spends extra on chemist items, particularly on tissues and toilet paper,

disinfectant and bleach amounting to £4.50 per week.

During the previous year she had spent an extra £2.30 per week on clothing and bedding, especially on underwear, nightdresses and shoes. These items wear out quickly because of frequent laundering and she says she is particularly heavy on her shoes. She says she needs to spend more on bedding but cannot afford to.

Alice spends an extra £9.61 per week on replacing items which have worn out or been damaged, especially crockery and equipment. Although she does not have to have a special diet, because she needs to buy convenience foods and cannot shop around she spends an extra £15 per week on food. £260 extra per year (£5 a week) is spent on fuel bills. She feels the cold, needs extra hot water and electricity for washing, uses electric blankets a lot and needs the heating on most of the year.

Alice spent £75 on the purchase of a special mattress and £300 on a special chair. She has used savings and describes herself as "scraping by". Total weekly household income for this couple is £76.91 of which £40.04 - 52% - is spent on regular ongoing extra costs of disability.

May Francis is 54 and lives alone in a flat rented from the council. She developed multiple sclerosis in 1978. She used to work as a store detective. May cannot walk at all. She cannot hold either arm out in front of her nor pick up a mug of coffee with either hand. She cannot feed herself without help and loses control of her bladder at least once every twenty four hours. She has a severity rating of 10.

She spends £175 a week on home services (a night sitter). She is a heavy user of chemist items and unprescribed medications especially vitamins, oil of evening primrose and royal jelly. Nevertheless, she needs to spend more but cannot afford to and she would particularly like to afford to pay for a regular massage and for physiotherapy.

She does not spend extra on replacing worn out or damaged equipment but told our interviewer she "desperately needs to". She needs a specially adapted chair, a hoist and a standing frame, but these would cost her about £920 and she cannot afford them.

May is on a low fat diet, which was recommended by a dietician. She says she goes without all luxury items and will buy less or cheaper foods if she is faced with a big bill. She eats baked potatoes most days because they are very cheap. In winter she eats less because that is when the bills are highest. She describes her situation as "robbing Peter to pay Paul". Some of the £11 extra she pays for

food goes on feeding her carers.

May economises on fuel costs but feels the cold when she does not put the heating on. She spends an extra £3.36 a week on heating, chiefly because she is at home more than would otherwise be the case.

The telephone is her only means of contact with the outside world and her family live a long distance away. Extra phone costs amount to £2.69 a week. She spent £549 on capital purchases including an ioniser, a bed raise and a microwave oven. She says she needs to buy a washing machine and a hoist but cannot afford to. She is faced with making difficult choices - were any of her equipment to need repairing she would probably cut back on heating to pay for it.

She describes herself as "scraping by" but adds that life is "very difficult" and she feels she has to beg for basic rights. May's total weekly income is £280.50 and her ongoing costs due to disability are £210.95 - 75% of her income.

Colm Cook is 42 and lives with his wife and two children aged 15 and 9 in a house rented from the council. A former manager of a major retail chain, he has multiple sclerosis and suffers intermittent pain between his shoulders. He also has eczema, which means he has to be careful with clothes and washing powder. He cannot walk more than 50 yards without stopping or severe discomfort and has problems reaching behind his back to put a jacket on or tuck a shirt in. He cannot pick up small objects with either hand and occasionally loses control of his bowels. He has a severity rating of 7.

His wife suffers from sciatica and diverticulitis which are stated to limit her-activities.

Because he sweats a great deal Colm creates extra laundry and estimates he spends an extra £2.50 a week on this. He is on a specially recommended diet which costs him an extra £10 per week, although he says ideally he should be spending £15 but he cannot afford to.

His heating bills are especially high. Total costs over a year are in excess of £1,100. He says that £488 of this amount is attributable to his disability, for he feels the cold, uses extra hot water for washing and baths and is at home most of the time. He worries about his heating bills.

His travel and transport costs are £33.24 a week. He is buying his car which he needs because of his disability through the Motability scheme, so his mobility allowance is wholly committed, and he pays an extra £8.84 a week on top of

this to run the car.

Colm has made £488 worth of capital purchases in recent times including a microwave oven and a freezer. He says that social activities are restricted because of the need to economise. He describes himself as "permanently in debt" and has had to borrow to meet large expenses and has fallen behind with regular payments.

Asked how he would spend a £10 a week increase in his income he responded that the present benefit system would mean he would not see it for his housing benefit would be adjusted. He said he would be compelled to go to a charity for help if he were faced unexpectedly with a bill for £200. As things stand at the moment he feels the likelihood of his situation improving is remote.

Totals weekly household income is £176.11 of which £63.79 -36% - is spent on the ongoing costs of disability.

Chapter 7

CONCLUSIONS

At the beginning of this report we said that we had been concerned by the findings of the OPCS study of the financial circumstances of disabled adults and, in particular, the results of their enquiry into the extra costs incurred by disabled people as a result of their disabilities. The low average extra costs they had identified did not accord with the experience of the disabled people with whom we were in contact. We explained how our swift response to the OPCS study in December 1988 had revealed that disabled people in the highest severity categories were spending significantly more - almost seven times more - than the OPCS reported. At that time we said we did not believe that the OPCS findings could be used on their own as the basis for making policy decisions about extra costs benefits and so we argued that a further, more searching enquiry was needed.

This report has described how we carried out that further research ourselves. As a result of our study we are now even more convinced that the OPCS report does not provide a reliable basis for the Government to make long-term decisions on disability benefits.

We have two reasons for saying this. The first is that we have shown how extraordinarily sensitive this area is to the way research is conducted. The second is the findings themselves.

The style of our research

We accept that our small sample was different in composition from that of OPCS. We had a much larger percentage of more seriously disabled people. We also had proportionately more non-pensioners. And the people in our sample inevitably were more aware of their financial situation. Nevertheless, we would argue strongly that these are exactly the kind of people who should be interviewed about their financial circumstances, for they are more likely to give accurate and complete information.

Although we used a questionnaire based on the OPCS schedule, it was augmented by the questions we know from experience in our previous research are likely to produce responses.

Our style of interviewing was therefore less formal than OPCS', and we took longer over the interviews.

Our findings

We saw the importance of benefits as an income for disabled people. We found we had a heavily benefit-dependent sample.

We found that a very large proportion of our sample were incurring capital expenditure on items which were essential to them, but which might be considered as luxuries by the non-disabled population. This expenditure was not included in the capital costs reported by OPCS.

And we found a very wide difference in reported extra costs from those identified by OPCS. Our absolute levels are very high indeed.

We found that the amount spent is related to available income, and that it rises with severity. We found that spending on important items such as food and heating is constrained by income.

We also found that the most severely disabled people receiving one or more of the disability costs benefits needed more financial assistance than they are currently receiving. And we found that this group were more likely than the rest to have financial problems.

Our research also showed the crucial importance of payments from the Independent Living Fund in helping severely disabled people pay for their care costs. Where care costs enter into the overall costs the figures are really significant. The small amount of background material we collected on the services provided to this group from the statutory services suggests strongly that people are spending far more privately than the generality of local authorities are providing.

It is clear that most disabled people in all the severity categories studied need more money to help with their ongoing costs.

Not the way ahead

Since our study was carried out the Government has published its plans following its internal review of benefits ("The Way Ahead" Cmnd. 917, 1989). This was the Government's response to the OPCS reports. In relation to the extra costs of disability the Government said:

"Among those surveyed by OPCS receiving Mob A and AA, the value of those benefits exceeded the average extra costs arising from their disabilities. But there are some disabled people under pension age who need more help with the

extra costs that arise from their disability. The survey evidence shows that the people in most need of help are some with moderate-to-severe disabilities and corresponding costs, but who fail to qualify for AA or Mob A". (Source: "The Way Ahead".)

The Government has, therefore, decided to create what is called a "new disability allowance" for people of working age and below by means of incorporating the existing payments made through the attendance allowance and the mobility allowance within one administration and introducing new, lower rates for people with care and mobility needs further down the severity scale.

There was no suggestion of any new help with the general extra costs of disability. Extra costs other than those of care and mobility were not even acknowledged.

We believe that enough has been revealed by our survey to call into question these underlying principles of "The Way Ahead".

It is clear from our research, because we found so much variation, that we need a highly sensitive, needs-tested system that enables disabled people to make individual choices about their expenditure. This suggests that the Government's proposals to help only with care needs and mobility are extremely limited. But they have based their assumptions on the OPCS report and therefore we should not be surprised by the conclusion they reached.

On the other hand, we have shown that disabled people need significantly higher incomes in order to cope with the very high levels of expenditure they incur, or need to incur, on a whole range of services and items because of their disabilities. Unless there is a real attempt to provide extra cash to help meet these needs then disabled people are destined to remain short changed by disability.

Appendix 1 Household income and extra costs sheets

STATUS	Non-pensioner, unmarried, 2 children	Age 38
NAME	Clare Bell	
DISABILITY	Spinal cord lesion at TS.8	
RATING	10	
HOUSEHOLD	Two adults joint heads of household, 3 children under 16	
COMPOSITION		
TENURE	House owner-occupier with mortgage	
INCOME	Earnings, child benefit, one parent benefit, industrial injury benefit, attendance allowance, mobility allowance, Independent Living Fund	

SUMMARY OF INCOME AND EXPENDITURE	£	ONGOING EXTRA COSTS	£ WEEKLY
Total weekly household income	554.45	Home services	160.25
		Informal assistance	75.00
Total weekly ongoing extra costs of disability	342.69	Prescriptions	1.11
		Chemist items/	
Capital costs	3,862.00	unprescribed medication	16.12
Social security benefits		Laundry	7.00
(inc. ILF) as % of income	56%	Clothing/bedding	11.70
Weekly extra costs as		Wear & tear,	
% of income	61%	waste/destruction	15.00
		Food/diet	20.00
		Fuel	3.07
		Transport	16.34
		Other, phone	17.10
		TOTAL	342.36

WEEKLY HOUSEHOLD INCOME	£
One parent benefit	5.20
Child benefit	7.25
Industrial injuries benefit	59.00
Attendance allowance	34.90
Mobility allowance	24.40
Independent Living Fund	181.50
Earnings	80.70
Joint head household's earnings	161.50
Total	554.45

CAPTIAL COSTS		£
Equipment, daily living aids		2,039.00
Car adaptations		1,000.00
Vision aids		123.00
Central heating		700.00
	Total	3,862.00

STATUS	Non-pensioner, married, no children	Age 58
NAME	Linda Rice	
DISABILITY	Multiple sclerosis	
RATING	5	
HOUSEHOLD		
COMPOSITION	Subject and husband	
TENURE	House owner-occupier with mortgage	
INCOME	Earnings from self-employment	

SUMMARY OF INCOME AND EXPENDITURE	£	ONGOING EXTRA COSTS	£ WEEKLY
Total weekly household income	445.00	Home services	20.00
		Informal assistance	10.00
Total weekly ongoing extra costs of disability	49.88	Prescriptions	.20
Capital costs	1,015.00	Chemist items/ unprescribed medication	2.00
Social security benefits		Wear & tear, waste/destruction	.76
(inc. ILF) as % of income	-	Food/diet	15.00
Weekly extra costs as % of income	11%	Transport	1.92
		TOTAL	49.88

WEEKLY HOUSEHOLD INCOME	£
Earnings	45.00
Spouse's earnings	400.00
Total	445.00

CAPTIAL COSTS	£
Equipment, daily living aids	1,015.00

STATUS	Non-pensioner, married, no children	Age 58
NAME	Alan Hardy	
DISABILITY	Arthritis, ulcerated leg	
RATING	7	
HOUSEHOLD	Subject and wife	
COMPOSITON		
TENURE	House rented from council	
INCOME	Income support, invalidity benefit, mobility allowance	

SUMMARY OF INCOME AND EXPENDITURE	£	ONGOING EXTRA COSTS	£ WEEKLY
Total weekly household income	112.06	Informal assistance	2.00
Total weekly ongoing extra costs of disability	34.41	Unprescribed medication/chemist items	3.11
Capital costs	875.00	Laundry	7.50
Social security benefits as % of income	100%	Clothing/bedding	2.88
Weekly extra costs as % of income	61%	Wear & tear, waste/destruction	11.70
		Food/diet	5.00
		Fuel	1.92
		Travel	5.00
		Other, phone, presents for helpers	2.00
		TOTAL	34.41

WEEKLY HOUSEHOLD INCOME	£
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Income support	14.96
Invalidity benefit	72.70
Mobility allowance	24.40
Total	112.06



CAPTIAL COSTS		£
Equipment, daily living aids		875.00
	Total	875.00

STATUS	Pensioner, unmarried, no children	Age 66
NAME	Anna Taylor	
DISABILITY	Multiple osteo-arthritis, bronchiectasis, angina	
RATING	8	
HOUSEHOLD	Lives alone	
COMPOSITION		
TENURE	Flat rented from council	
INCOME	Retirement pension, income support, attendance allowance, mobility allowance, Independent Living Fund	

SUMMARY OF INCOME AND EXPENDITURE	£	ONGOING EXTRA COSTS	£ WEEKLY
Total weekly household income	145.50	Home services	62.00
Total weekly ongoing extra costs of disability	97.28	Chemist items/ unprescribed medication	7.02
Capital costs	670.00		16.12
Social security benefits		Food/diet	5.00
(inc. ILF) as % of income	100%	Fuel	4.80
Weekly extra costs as		Transport	5.96
% of income	67%	Other, phone	12.50
		TOTAL	97.28

WEEKLY HOUSEHOLD INCOME	£
Retirement pension	43.60
Income support	33.70
Attendance allowance	23.30
Mobility allowance	24.40
Independent Living Fund	20.50

Total	145.50
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CAPTIAL COSTS

£

Equipment, daily living aids

670.00

STATUS	Non-pensioner, unmarried, no children	Age 54
NAME	Adam Ferguson	
DISABILITY	Addison's disease	
RATING	4	
HOUSEHOLD COMPOSITION	With co-tenant	
TENURE	Flat rented from private landlord	
INCOME	Invalidity benefit, income support	

SUMMARY OF INCOME AND EXPENDITURE	£	ONGOING EXTRA COSTS	£ WEEKLY
Total weekly household income	48.60	Chemist items/unprescribed medication	3.00
Total weekly ongoing extra costs of disability	24.53	Laundry	1.00
Capital costs	-	Clothing/bedding	.65
Social security benefits (inc. ILF) as % of income	100%	Food/diet	12.00
Weekly extra costs as % of income	50%	Fuel	2.88
		Other, phone	5.00
		TOTAL	24.53

WEEKLY HOUSEHOLD INCOME	£
Invalidity benefit	46.50
Income support	2.10
Total	48.60

CAPTIAL COSTS

STATUS	Non-pensioner, unmarried, with children	Age 33
NAME	Julie Irving	
DISABILITY	Polio, left arm and leg partial paralysis	
RATING	6	
HOUSEHOLD	Subject, husband and child under 16	
COMPOSITION		
TENURE	House owner-occupier with mortgage	
INCOME	Husband's earnings, invalidity benefit, mobility allowance	

SUMMARY OF INCOME AND EXPENDITURE	£	ONGOING EXTRA COSTS	£ WEEKLY
Total weekly household income	200.00	Informal assistance	5.00
		Prescriptions	.30
Total weekly ongoing extra costs of disability	81.65	Chemist items/ unprescribed medication	1.60
Capital costs	1214.00	Clothing/bedding	4.51
Social security benefits		Wear & tear/waste & destruction	1.53
as % of income	42%	Food/diet	20.00
Weekly extra costs as		Fuel	5.57
% of income	40%	Travel	28.84
		Other, phone, present/helpers	14.30
		TOTAL	81.65

WEEKLY HOUSEHOLD INCOME	£
Child benefit	7.25
Invalidity benefit	52.80
Mobility allowance	24.40

Spouse's earnings	115.55
Total	200.00

CAPTIAL COSTS	£
Car adaptations	144.00
Equipment, daily living aids	1,070.00
Total	1,214.00

STATUS	Non-pensioner, unmarried, no children	Age 41
NAME	Michael West	
DISABILITY	Tunnel vision, night blindness, partial deafness, gastric ulcer	
RATING	7	
HOUSEHOLD	Subject and wife (also disabled)	
COMPOSITION		
TENURE	Flat rented from council	
INCOME	Earnings from employment, wife's severe disablement allowance	

SUMMARY OF INCOME AND EXPENDITURE	£	ONGOING EXTRA COSTS	£ WEEKLY
Total weekly household income	121.20	Informal assistance	3.00
Total weekly ongoing extra costs of disability	18.13	Chemist items/ unprescribed medication	1.25
Capital costs	779.00	Clothing/bedding	.28
Social security benefits		Food/diet	6.00
as % of income	22%	Fuel	.76
Weekly extra costs as % of income	15%	Transport	3.84
		Other, presents/helpers, insurance	3.00
		TOTAL	18.13

WEEKLY HOUSEHOLD INCOME	£
Earnings net	95.00
Spouse's SDA	26.20
Total	121.20

CAPTIAL COSTS	£
Central heating (extra radiator)	53.00
Vision aids	21.00
Communication aids	60.00
Equipment/daily living aids	645.00
Total	749.00

STATUS	Non-pensioner, unmarried, no children	Age 78
NAME	Alice Campbell	
DISABILITY	Loss of use of right side following cerebral vascular accident	
RATING	8	
HOUSEHOLD	Subject and husband, both retired	
COMPOSITION		
TENURE	Flat rented from council	
INCOME	Retirement pension	

SUMMARY OF INCOME AND EXPENDITURE	£	ONGOING EXTRA COSTS	£ WEEKLY
Total weekly household income	76.91	Chemist items/ unprescribed medication	4.50
		Laundry	.87
Total weekly ongoing extra costs of disability	40.04	Clothing/bedding	2.30
		Wear & tear	9.61
Capital costs	487.00	Food/diet	15.00
Social security benefits as % of income	100%	Fuel	5.00
		Transport	.76
Weekly extra costs as % of income	52%	Other, phone	2.00
		TOTAL	40.00

WEEKLY HOUSEHOLD INCOME	£
Retirement pension	27.58
Spouse's retirement pension	49.33
Total	76.91

STATUS	Non-pensioner, unmarried, no children	Age 58
NAME	May Francis	
DISABILITY	Multiple sclerosis	
RATING	10	
HOUSEHOLD COMPOSITION	Lives alone	
TENURE	Flat rented from council	
INCOME	Income support, invalidity benefit, attendance allowance, mobility allowance, Independent Living Fund, maintenance	

SUMMARY OF INCOME AND EXPENDITURE	£	ONGOING EXTRA COSTS	£ WEEKLY
Total weekly household income	280.00	Home treatment	2.50
		Home services	175.00
Total weekly ongoing extra costs of disability	210.95	Chemist items/unprescribed medication	11.14
Capital costs	549.00	Laundry	1.25
Social security benefits (inc ILF) as % of income	98%	Clothing/bedding	1.00
Weekly extra costs as % of income	75%	Food/diet	11.00
		Fuel	3.36
		Transport	2.00
		Other, phone, presents/helpers	3.69
		TOTAL	210.94

WEEKLY HOUSEHOLD INCOME	£
Income support	12.40
Invalidity benefit	52.80
Attendance allowance	34.90

Mobility allowance	24.40
Independent Living Fund	150.00
Maintenance	6.00
Total	280.50

CAPTIAL COSTS	£
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Equipment/daily living aids	549.00
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STATUS	Non-pensioner, married, with children	Age 42
NAME	Colm Cook	
DISABILITY	Multiple sclerosis	
RATING	7	
HOUSEHOLD	Subject, wife and children under 16	
COMPOSITION		
TENURE	House rented from council	
INCOME	Child benefit, invalidity benefit, mobility allowance, spouses earnings, maintenance payment	

SUMMARY OF INCOME AND EXPENDITURE	£	ONGOING EXTRA COSTS	£ WEEKLY
Total weekly household income	176.11	Prescriptions	1.93
		Chemist items/unprescribed medication	1.00
Total weekly ongoing extra costs of disability	63.79	Laundry	2.50
		Clothing/bedding	.57
Capital costs	488.00	Wear & tear, waste/destruction	1.15
Social security benefits as % of income	78%	Food/diet	10.00
		Fuel	9.40
Weekly extra costs as % of income	36%	Transport	4.00
		Other, phone, presents/helpers, insurance	
		TOTAL	63.79

WEEKLY HOUSEHOLD INCOME	£
Child benefit	14.50
Invalidity benefit	98.51

Mobility allowance	24.40
Spouse's earnings	31.80
Maintenance	6.90
Total	176.11

CAPTIAL COSTS	£
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Equipment/daily living aids	488.00
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Appendix 2 Explanatory notes on benefits

Child benefit £7.25	tax free, flat rate benefit for each child if under 16, or under 19 and still in full time non-advanced education
One parent benefit £5.20	tax free, flat rate allowance payable for one child to a person with sole responsibility for bringing up the child
Family credit	payable to families with children where one or both parents work 24+ hours a week and income is less than the set limit for that family. They must have savings of less than £6,000
NI Retirement pension or old age pension	payable on retirement to men at 65 and women at 60. Depends on contribution record
Income support	means-tested. If you have little or no money, are not working 24+ hours a week and have savings of less than £6,000, you can claim income support to top up your income.
Sickness benefit	flat rate benefit normally payable after 3 days incapacity for work for up to 28 weeks. Based on NI contributions unless industrially injured

Unemployment benefit	payable for up to a year if available for and capable of work. Depends on NI contributions
Invalidity benefit £43.60	payable after 28 weeks of sickness benefit or SSP, depends on NI contributions or industrial injury. Age allowance paid on top.
Severe disablement allowance £26.20	for those unable to qualify for sickness or invalidity benefit. Must be incapable of work and have been so for 28 weeks. Some people may have to prove they are 80% disabled.
Industrial injury benefit	varying rates of benefits payable to those who have suffered an industrial injury/accident at work.
War disablement pension	varying rates of benefits payable to people whose disability is due to or was aggravated by military service.
Attendance allowance Lower £23.30 Higher £34.90	tax-free, non-means-tested benefit payable at two rates for people who need a lot of looking after or continual supervision
Mobility allowance £24.40	tax-free non-means-tested benefit paid to people who are unable or virtually unable to walk.

Invalid care allowance £26.20	paid to people who are spending 35 hours a week caring for someone who gets attendance allowance.
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Independent Living Fund (Government funded charity)	means-tested, payable to those in receipt of attendance allowance who need to buy in personal care and/or domestic assistance
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THE DISABLEMENT INCOME GROUP

Millmead Business Centre, Millmead Road, London N17 9QU

The extra costs of disability, 1989

Confidential Questionnaire

Serial Number Date of Interview Day Month Time Interview began

Person interviewed

Disabled person 1

Parent 2

Other 3

OFFICE
USE ONLY
CARD NO 1
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8

IntroductionRead out

The Disablement Income Group is concerned that the Government's survey of disabled people may have seriously underestimated the extra costs incurred by disabled people. It is important, therefore, that we should provide the Government the fullest possible information about these extra costs so that it can be taken into account when the Government reviews disability benefits. Any details you give us will be strictly confidential and will not be passed to anyone outside DIG.

Typeset and Layout by Profile Design Systems Poole (0202) 675830

COMPOSITION OF HOUSEHOLD

1. First I'd like to ask a few questions about who lives in your household.

Person No.	Status	Age	Sex M F	Marital status specify	Work status Show card A
1	Disabled person relationship to above				
2 HOH					
3					
4					
5					
6					
7					

Office use	No of persons	23
	Household	24
	Work status of HOH	25

Show card B

2. Could you tell me which of the statements on this card applies to your accommodation.

Owner occupier, with mortgage	1
Owner occupier, own outright	2
Rent from employer	3
Rent from council/corporation	4
Rent from housing association	5
Rent from private landlord or company	6
Live rent free by pay rates	7
Live rent and rates free	8
Other (SPECIFY)	9

3. What kind of property is the accommodation?

House	1
Bungalow	2
Flat	3
Bedsit	4

4. How many rooms do you and your household occupy?

(Exclude kitchen [unless eaten in] and bathroom)

No. of rooms CARD NO 1
COL

9-22

26

27

28

Interviewers observations on condition of home
Write In

5. For the head of household and the disabled person who are in employment enter the following details. If unemployed or retired enter details of last job.

(a) Person no. (from Qn.1)	(b) Name of job	(c) Description of activity	(d) Industry/business/ profession of employer and No. persons employed at workplace (under or over 25)

6. (a) Apart from yourself does anyone else in this household suffer from any disability, infirmity or long-standing illness?

YES 1
NO 2

IF YES

- (b) Who is that? (Enter person no.(s) from household grid (Q.1) and ASK (c) and (d) of each person mentioned.)
- (c) Does disability mentioned at (a) limit(other disabled person's) activities in any way compared with most people of that age?
- (d) What is the medical diagnosis ofs disability?
(What does the doctor call it?)

(b) Person No.	(c) Activities		(d) Description of disability
	Limited	Not Limited	
	8	9	
	8	9	

CARD NO 1
COL

29 - 30
31 - 32

33

34
35

COF
CYSD NO 1
USE ONE A
OFFICE

ABOUT YOUR DISABILITY

7. Now I want to talk to you about your disability.

- (a) What is the diagnosis for your main condition?

- (b) When did it begin?

Year

- (c) Do you suffer from any other conditions?

Yes 1
No 2

If yes, specify

- (d) Are any of these problems causing you real difficulty?

Yes 3
No 4

If yes, specify how

- (e) Have you been admitted to hospital since Easter?

Yes 5
No 6

If yes, specify reason

- (f) SEVERITY RATINGS

OPCS Classification
Loss of faculty (i.i.)

			%
--	--	--	---

CARD NO 1
COL

36 - 37

38

38

38

39
40-42

Now I want to talk to you about how your disability affects you.

CARD NO 1
COL

I am going to read out a list of difficulties you may experience and I want you to tell me which of these apply to you.

8. LOCOMOTION

Ring answer - ask all	Severity Score
(a) Cannot walk at all	11.5
(b) Can only walk a few steps without stopping or severe discomfort/ Cannot walk up and down one step	9.5
(c) Has fallen 12 or more times in the last year	7.5
(d) Always needs to hold on to something to keep balance	7.0
(e) Cannot walk up and down a flight of 12 stairs	6.5
(f) Cannot walk 50 yards without stopping or severe discomfort	5.5
(g) Cannot bend down far enough to touch knees and straighten up again	4.5
(h) Cannot bend down and pick something up from the floor and straighten up again	4.0
(i) Cannot walk 200 yards without stopping or severe discomfort/ Can only walk up and down a flight of 12 stairs if holds on and takes a rest/ Often needs to hold on to something to keep balance/ Has fallen 3 or more times in the last year	3.0
(j) Can only walk up and down a flight of 12 stairs if holds on (doesn't need a rest)	2.5
(k) Cannot bend down to sweep up something from the floor and straighten up again	2.0
(l) Can only walk up and down a flight of stairs if goes sideways or one step at a time	1.5
(m) Cannot walk 400 yards without stopping or severe discomfort	0.5

9. REACHING AND STRETCHING

Ring answer - ask all	Severity Score
(a) Cannot hold out either arm in front to shake hands	9.5
(b) Cannot put either arm up to head to put a hat on	9.0
(c) Cannot put either hand behind back to put jacket on or tuck shirt in	8.0
(d) Cannot raise either arm above head to reach for something	7.0
(e) Has difficulty holding either arm in front to shake hands with someone	6.5
(f) Has difficulty putting either arm up to head to put a hat on	5.5
(g) Has difficulty putting either hand behind back to put jacket on or tuck shirt in	4.5
(h) Has difficulty raising either arm above head to reach for something	3.5
(i) Cannot hold one arm out in front or up to head (but can with other arm)	2.5
(j) Cannot put one arm behind back to put on jacket or tuck shirt in (but can with other arm)/ Has difficulty putting one arm behind back to put jacket on or tuck shirt in, or putting one arm out in front or up to head (but no difficulty with other arm)	1.0

10. DEXTERITY

Ring answer - Ask all

Severity Score

(a) Cannot pick up and hold a mug of coffee with either hand	10.5
(b) Cannot turn a tap or control knobs on a cooker with either hand	9.5
(c) Cannot pick up and carry a pint of milk or squeeze the water from a sponge with either hand	8.0
(d) Cannot pick up a small object such as a safety pin with either hand	7.0
(e) Has difficulty picking up and pouring from a full kettle or serving food from a pan using a spoon or ladle	6.5
(f) Has difficulty unscrewing the lid of a coffee jar or using a pen or pencil	5.5
(g) Cannot pick up and carry a 5lb bag of potatoes with either hand	4.0
(h) Has difficulty wringing out tight washing or using a pair of scissors	3.0
(i) Can pick up and hold a mug of tea or coffee with one hand but not with the other	2.0
(j) Can turn a tap or control knob with one hand but not with the other/ Can squeeze the water from a sponge with one hand but not the other	1.5
(k) Can pick up a small object such as a safety pin with one hand but not with the other/ Can pick up and carry a pint of milk with one hand but not the other/ Has difficulty tying a bow in laces or strings	0.5

11. PERSONAL CARE

Ring answer. Ask all until a positive response is given

Severity Score

(a) Cannot feed self without help/ Cannot go to and use the toilet without help	11.0
(b) Cannot get into and out of bed without help/ Cannot get into and out of chair without help	9.5
(c) Cannot wash hands and face without help/ Cannot dress and undress without help	7.0
(d) Cannot wash all over without help	4.5
(e) Has difficulty feeding self/ Has difficulty getting to and using the toilet	4.5
(f) Has difficulty getting in and out of bed/ Has difficulty getting in and out of a chair	2.5

12. CONTINENCE

Ring answer. Ask all until a positive response is given

Severity Score

(a) No voluntary control over bowels	11.5
(b) No voluntary control over bladder	10.5
(c) Loses control of bowels at least once every 24 hours	10.0
(d) Loses control of bladder at least once every 24 hours	8.0
(e) Loses control of bowels at least once a week	8.0
(f) Loses control of bowels at least twice a month	6.5
(g) Loses control of bladder at least once a week	5.5
(h) Loses control of bowels at least once a month	5.0
(i) Loses control of bladder at least twice a month/ Loses control of bowels occasionally	4.0
(j) Loses control of bladder at least once a month	2.5
(k) Loses control of bladder occasionally/ Uses a device to control bowels or bladder	1.0

13. SEEING		CARD NO 1 COL
Ring answer. Ask all until a positive response is given	Severity Score	
(a) Cannot tell by the light where the windows are	12.0	
(b) Cannot see the shapes of furniture in a room	11.0	
(c) Cannot see well enough to recognise a friend if close to his face	10.0	
(d) Cannot see well enough to recognise a friend who is an arm's length away	8.0	
(e) Cannot see well enough to read a newspaper headline	5.5	
(f) Cannot see well enough to read a large print book	5.0	
(g) Cannot see well enough to recognise a friend across a room	4.5	
(h) Cannot see well enough to recognise a friend across a road	1.5	
(i) Has difficulty seeing to read ordinary newspaper print	0.5	
14. HEARING		
Ring answer. Ask all until a positive response is given	Severity Score	
(a) Cannot hear sounds at all	11.0	
(b) Cannot follow a TV programme with the volume turned up	8.5	
(c) Has difficulty hearing someone talking in a loud voice in a quiet room	6.0	
(d) Cannot hear a doorbell, alarm clock or telephone bell	5.5	
(e) Cannot use the telephone	4.0	
(f) Cannot follow a TV programme at a volume others find acceptable	2.0	
(g) Difficulty hearing someone talking in a normal voice in a quiet room	1.5	
(h) Difficulty following a conversation against a background noise	0.5	
15. COMMUNICATION		
Do not ask. Interviewers judgement only - Ring answer	Severity Score	
(a) Is impossible for people who know him/her well to understand/Finds it impossible to understand people who know him/her well	12.0	
(b) Is impossible for strangers to understand/Is very difficult for people who know him/her well to understand/Finds it impossible to understand strangers/Finds it very difficult to understand people who know him/her well	8.5	
(c) Is very difficult for strangers to understand/Is quite difficult for people who know him/her well to understand/Finds it difficult to understand strangers/Finds it quite difficult to understand people who know him/her well	5.5	
(d) Is quite difficult for strangers to understand/Finds it quite difficult to understand strangers	2.0	
(e) Other people have some difficulty understanding him/her/Has some difficulty understanding what other people say or what they mean	1.0	
16. BEHAVIOUR		
Interviewer's judgement: Ask only where appropriate	Severity Score	
(a) Gets so upset that hits other people or injures him/herself	10.5	
(b) Gets so upset that breaks or rips up things	7.5	
(c) Feels the need to have someone present all the time	7.0	
(d) Finds relationships with members of the family very difficult	6.0	
(e) Often has outbursts of temper at other people with very little cause	4.0	
(f) Finds relationships with people outside the family very difficult	2.5	
(g) Sometimes sits for hours doing nothing	1.5	
(h) Finds it difficult to stir him/herself to do things/Often feels aggressive or hostile towards other people	0.5	

17. INTELLECTUAL FUNCTIONING		CARD NO 1 COL	
Interviewer's judgement: Another person may answer if present			
Severity Score	No of Problems	Number of problems from the following:	
(a) 13.0	11	Often forgets what was supposed to be doing in the middle of something	
(b) 12.0	10	Often loses track of what is being said in the middle of a conversation	
(c) 10.5	9	Thoughts tend to be muddled or slow	
(d) 9.5	8	Often gets confused about what time of day it is	
(e) 8.0	7	Cannot watch a half hour TV programme all the way through and tell someone what it was about	
(f) 7.0	6	Cannot remember and pass on a message correctly	
(g) 6.0	5	Often forgets to turn things off such as fires, cookers or taps	
(h) 4.5	4	Often forgets the name of people in the family or friends seen regularly	
(i) 3.5	3	Cannot read a short article in newspaper	
(j) 2.0	2	Cannot write a short letter to someone without help	
(k) 1.0	1	Cannot count well enough to handle money	
18. CONSCIOUSNESS			
Severity Score	Score	Add the scores for the following items:	
(a) 12.5	13.8	Has fits:	
(b) 11.5	12.8 - 13.0	Less than one year	0
(c) 10.5	11.8	Once a year but less than 4 times a year	1
(d) 10.0	10.8	4 times a year but less than once a month	2
(e) 9.0	9.8 - 10.0	Once a month but less than once a week	3
(f) 8.0	8.8 - 9.0	Once a week but less than every day	4
(g) 7.0	7.8 - 8.0	Every day	5
(h) 6.0	6.8 - 7.0	Only has fits during the night	1
(i) 5.0	5.8 - 6.0	Only has fits at the night or on awakening	3.8
(j) 4.0	4.8 - 5.0	Only has fits at the night on awakening or in the evening	5.8
(k) 3.0	4.0	Has fits during the daytime	6.8
(l) 2.0	3.0	Always has a warning before a fit	0
(m) 1.0	2.0	Has fits without warning	1
(n) 0.5	1.0	Loses consciousness during a fit	1
		Does not lose consciousness	0
19. EATING, DRINKING AND DIGESTION			
(a) Suffers from problems with eating, drinking or digestion which severely affects ability to lead a normal life	Severity Score	0.5	
20. DISFIGUREMENT (Scars, blemishes and deformities)			
(a) Suffers from a scar, blemish or deformity which severely affects ability to lead a normal life	Severity Score	0.5	
21. PAIN			
(a) Suffers from constant, intractable pain	1		
(b) Suffers from intermittent pain	2		
(c) Suffers from occasional pain	3		
(d) Pain is severe and restricts activities	4		
(e) Pain is moderate and has some effect on lifestyle	5		
(f) Pain is mild and generally controlled	6		

22. SERVICES AND PERSONAL ASSISTANCE

Now I want to talk to you about the support and services you receive

A Here is a list of some of the people from the public services who come to the home to help people with disabilities

(a) Have any of these people visited you in the past year?

Yes 1
No 2

43

Show card C

District nurse 1
Nursing auxiliary (eg bath attendant) 2
Community psychiatric nurse 3
Community mental handicap nurse 5
Health visitor 6
Speech therapist 4
Physiotherapist 7
Occupational therapist 8
Chiropodist 9

IF YES TO ANY, RING NUMBER AT TOP OF COLUMN AND COMPLETE (b) - (d) FOR EACH PERSON WHO COMES

	1	2	3	4	5	6	7	8	9
(b) NAME OF PERSON									
(c) How often do they come?									
Every day or nearly	1	1	1	1	1	1	1	1	1
2 or 3 times a week	2	2	2	2	2	2	2	2	2
Once a week	3	3	3	3	3	3	3	3	3
Less than once a week	4	4	4	4	4	4	4	4	4
IF CODED 07-09 AT (a)									
(d) Do you pay anything for the? Yes	6	6	6	6	6	6	6	6	6
No	7	7	7	7	7	7	7	7	7
IF YES	£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p
(i) How much do you pay per week?									
Total									
	1	2	3	4	5	6	7	8	9
How much would you pay per week in total	£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p
Total									

23 A. Here is a list of services which can help people with disabilities and their families

(a) Have you had any of these services in the past year?

Yes 1
No 2

64

Show card D

Local authority home help 1
Meals on wheels 2
Laundry service 3
Incontinence service 4
Night sitting service 5
Mobility/technical officer for the blind 6
Social Worker 7
Voluntary worker 8
Visiting service 9
Private domestic help 10
Private nursing help 11
Other (please Describe) 12

53-57

IF YES TO ANY, RING NUMBER AT TOP OF COLUMN AND COMPLETE (b) - (e) FOR EACH SERVICE

	1	2	3	4	5	6	7	8	9	10	11	12
(b) NAME/DESCRIPTION OF SERVICE												
(c) How often do they come?												
Every day or nearly	1	1	1	1	1	1	1	1	1	1	1	1
2 or 3 times a week	2	2	2	2	2	2	2	2	2	2	2	2
Once a week	3	3	3	3	3	3	3	3	3	3	3	3
Less than once a week	4	4	4	4	4	4	4	4	4	4	4	4
(d) Do you pay anything for the? Yes	5	5	5	5	5	5	5	5	5	5	5	5
No	6	6	6	6	6	6	6	6	6	6	6	6
IF YES	£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p
(i) How much do you pay per week												
AMOUNT												

B. Would you have any more of the services you already have (if you could afford it?)

Yes 3
No 4

70

IF YES RING NUMBER AT TOP OF COLUMN

1	2	3	4	5	6	7	8	9	10	11	12
£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p

How much would you pay in total per week

Total

70 - 75

C. Would you buy any of those services which you do not have at the moment if you could afford it?

Yes 5
No 6

IF YES RING NUMBER AT TOP OF COLUMN

1	2	3	4	5	6	7	8	9	10	11	12
£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p

How much would you pay in total per week

Total

76 - 80

24. A Here is a list of informal assistance that disabled people may receive

(a) Have you had any of this help in the past year?

Yes 1
No 2

1 - 3

Show card E

Family in household	1
Relatives not in household	2
Neighbours	3
Friends	4
Hairdresser	5
Gardener	6
Odd jobs/decorating/repairs	7

4

5 - 11

IF YES TO ANY, RING NUMBER AT TOP OF COLUMN AND COMPLETE (b)-(d) FOR EACH SERVICE

	1	2	3	4	5	6	7				
(b) NAME/DESCRIPTION OF HELP											
(c) How often does the come?											
Every day or nearly	1	1	1	1	1	1	1				
2 or 3 times a week	2	2	2	2	2	2	2				
Once a week	3	3	3	3	3	3	3				
Less than once a week	4	4	4	4	4	4	4				
(d) Do you pay anything for the?											
Yes	5	5	5	5	5	5	5				
No	6	6	6	6	6	6	6				
IF YES											
(i) How much do you pay per week?	£ p	£ p	£ p	£ p	£ p	£ p	£ p				
AMOUNT											
Total	<input type="text"/>										
1	2	3	4	5	6	7	8	9	10	11	12
£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p
1	2	3	4	5	6	7	8	9	10	11	12
£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p

ATTENDANCE AT SCHOOL/CENTRE

25. Do you regularly go anywhere for education, training or social activities, such as to the place listed on this card?

Yes 1
No 2

Show card F

School	1
Day centre	2
Adult training centre	3
Club for the disabled	4
Other social club	5
Adult education centre	6
Other (SPECIFY)	7

IF YES TO ANY, RING NUMBER AT TOP OF COLUMN AND COMPLETE (b) - (d) FOR EACH PLACE

	1	2	3	4	5	6	7
(b) Description							
(c) Is this..... specially for people with disabilities, or can other people go there?	1	1	1	1	1	1	1
For disabled people	2	2	2	2	2	2	2
For others							
(d) How often do you usually go to the.....?							
Every day or nearly	3	3	3	3	3	3	3
2 or 3 times a week	4	4	4	4	4	4	4
Once a week	5	5	5	5	5	5	5
Less than once a week	6	6	6	6	6	6	6
(e) How long do you usually stay there?							
1 or 2 hours	7	7	7	7	7	7	7
Half a day	8	8	8	8	8	8	8
Most of the day	9	9	9	9	9	9	9

EXTRAPERSONAL COSTS

26. I want to talk to you about prescription costs.

A. Because of your disability do you regularly take or use any medicines, drugs, tablets or anything else, which you obtain on a doctor's prescription?

Yes 1
No 2

B. Are you.....

RUNNING PROMPT

exempt from prescription charges	3
claiming back payments for prescriptions	4
paying for each prescription	5
or paying with a season ticket	6

(a) How many months does your season ticket cover?

4 months 7
12 months 8

C. How much have you spent on prescriptions in the past six months because of your disability?

TOTAL D/K

123

CARD NO 3
COL

29

30 - 36

37

38 - 42

27
A

(a) Can you look at this list and tell me whether you regularly spend extra on any of these items because of your disability.

Yes 1
No 2

Show card G

Tissues/toilet paper/kitchen roll	1
Cotton wool/dressings/elastoplast	2
Elastic bandages/supports	3
Talcum powder/ antiseptic or soothing creams	4
Vitamins/pain-killers and other medicines not on prescription	5
Disinfectant/bleach	6
Other medical supplies	7

(PLEASE DESCRIBE)

IF YES, RING NUMBER AT TOP OF COLUMN AND COMPLETE (b) - (c)

	1	2	3	4	5	6	7
(b) Description							
(c) About how much extra did you spend in the last 4 weeks on.....?	£ p	£ p	£ p	£ p	£ p	£ p	£ p
Total							

B. Are there any items on this list which you need to spend more on but can't afford to?

Yes 1
No 2

Item no 1-7

Description

28. Now I want to talk to you about extra laundry costs.

A. Does your disability mean that you have extra laundry because

(a) of incontinence

Yes 1
No 2

(b) you use special creams/medications

Yes 1
No 2

(c) you sweat a lot

Yes 1
No 2

(d) other (Specify)

Yes 1
No 2

CARD NO 3
COL

43

44 - 71

72 - 78

CARD NO 4
COL

4 - 7

B. Does your disability mean that you spend extra on		CARD NO 4 COL 8 - 10
INDIVIDUAL PROMPT		
Washing clothes or bed linen	Yes 1 No 2	
Dry cleaning	Yes 1 No 2	
Sending things to the laundry	Yes 1 No 2	
C. How much extra in total have you spent in the past 4 weeks because of washing/dry cleaning/laundry because of your disability?		
INDIVIDUAL PROMPT		
extra hot water	£	
extra soap powder	£	
extra fabric conditioners/softeners	£	
more frequent servicing machines	£	
TOTAL		£ <input type="text"/> <input type="text"/>
		11 - 14
D. Do you think that you need to spend more on washing, dry cleaning or laundry, because of your disability but can't afford to?		
	Yes 1 No 2	15 - 18
If yes, how much?		£ <input type="text"/> <input type="text"/>

29. (a) Does your disability mean that you spend extra on clothing or bedding, for example any of the things on this list?		CARD NO 4 COL 20 - 31
	Yes 1 No 2	
Show Card H		
Thermal underwear	1	
Other underwear (except incontinence pants)	2	
Pyjamas/nightdresses	3	
Trousers/shirts/dresses	4	
Shirt/blouse	5	
Socks/tights/stockings	6	
Cardigans/jumpers	7	
Coats/jackets	8	
Gloves	9	
Shoes	10	
Bedding (not protective coverings)	11	
Other (PLEASE DESCRIBE)	12	
(b) During the past year, about how much extra have you spent on clothing/bedding because of your disability?		32 - 36
TOTAL		£ <input type="text"/> <input type="text"/>
Why is this?		
INDIVIDUAL PROMPT		
frequent laundering	1	
need items specially made	2	
can only wear certain materials	3	
items wear out quickly	4	
some other reason (SPECIFY)	5	
B. Are there any items on the list which you need because of your disability but can't afford?		37 - 41
	Yes 1 No 2	
Item no 1-12	Description	
C. How much extra do you think you would need to clothe yourself properly?		
TOTAL		£ <input type="text"/> <input type="text"/>
D. Can you always afford to replace items of clothing/footwear?		
	Yes 1 No 2	

30. Now I want to talk to you about wear and tear and waste and destruction.

A. Do you think you spend extra because of wear and tear or waste and destruction?

Yes 1
No 2

42

Show card I

43 - 49

Furniture	1
Carpets	2
Decorations	3
Fittings	4
Crackery	5
Windows	6
Equipment	7

IF YES TO ANY, RING NUMBER AT TOP OF COLUMN AND COMPLETE (b) FOR EACH ITEM

1	2	3	4	5	6	7
£ p	£ p	£ p	£ p	£ p	£ p	£ p

(b) COST OF REPLACEMENT SINCE EASTER

Total

50 - 54

B. Are there any items on the list which you need to replace but have been unable to afford?

Yes 1
No 2

Item no 1-7

Description

How much would you need to spend?

TOTAL

55 - 59

31. Now I want to talk to you about diet and food

A. Does your disability mean that you have a special diet?

Yes 2
No 3

60

(a) Has this diet been recommended by a doctor or dietician?

Yes 1
No 2

(b) Do you get any food on prescription

Yes 1
No 2

61

B. At present, about how much do you/does your family spend on food each week?

EXCLUDE : CLEANING MATERIALS, PET FOOD, CIGARETTES
ALCOHOL, SWEETS

TOTAL

62 - 66

INCLUDE: COST OF SCHOOL/CANTEEN MEALS, TAKE AWAYS

C. Does your disability mean that you spend more on food than you would if you had no disability?

Yes 1
No 2

67

(a) Why do you need to spend more on food?
(Main reason)

Require special diet	1
Buy convenience foods	2
Cannot shop around	3
Medication increases hunger	4
Other	5
None	6

D. Of the money spent on you food each week how much is extra because of your disability?

TOTAL

68 - 71

E. Do you think you should be spending extra on food because of your disability but can't afford to?

Yes 1
No 2

72 - 75

How much? WRITE IN

F. Do you ever have to go without meals/items of food

Yes 1
No 2

76

32. Now I want to talk to you about fuel and heating		CARD NO 5
A. How do you heat your house?		COL
Show card J		1 - 3
WRITE IN MAIN (M)		4 - 5
AND ONE SUPPLEMENTARY (S)	Gas central heating 1 Electric central heating 2 Oil central heating 3 Storage heaters 4 Gas fires 5 Electric fires 6 Coal fires 7 Oil heaters 8 Bottled gas 9	
IF HAS CENTRAL HEATING		
(a) Have you had central heating installed or was it already in the house?		6
	Central heating installed Already in the house 1	
(b) Did you have the heating installed because of your disability or would you have had it put in anyway?		
	Installed because of disability 2 Would have had anyway 3	
(c) How much did this cost you and when was this?		
	WRITE IN £ <input type="text"/> <input type="text"/> 19	7 - 11 12 - 13
IF NO CENTRAL HEATING		
(d) Do you need central heating because of your disability?		
	Yes 4 No	
B How much did you pay for gas, electricity, coal and oil over the last 12 months? (to nearest £10)		
	Gas £ <input type="text"/> Electricity £ <input type="text"/> Coal £ <input type="text"/> Oil/paraffin/bottled gas £ <input type="text"/>	
	TOTAL £ <input type="text"/> <input type="text"/>	14 - 15

C. (a) Do you have additional fuel costs because		CARD NO 5	
		COL	
		16 - 22	
READ OUT	(i) You are at home more than would otherwise be the case and the heating is on more	Yes 1 No 2	
	(ii) heating is on at night	1 2	
	(iii) you feel the cold and the house has to be hotter than would otherwise be	1 2	
	(iv) of extra hot water for washing clothes	1 2	
	(v) of extra consumption of electricity for washing machine and tumble dryer	1 2	
	(vi) extra baths	1 2	
	(vii) you use electric blankets a lot	1 2	
IF NO, CODE 2 TO ALL (i) - (vii) ABOVE, SKIP TO (c)			
OTHERS ASK (b)			
(b) How much extra does it cost over a year in fuel bills because of your disability			
TOTAL £ <input type="text"/> <input type="text"/>			23 - 27
(c) Do you not use any rooms in your home because you cannot afford to heat them?			28
		Yes 1 No 2	
(d) Do you worry about your heating bills?			29
		Yes 1 No 2	
(e) Do you need the heating on all year round?			30
		Yes 1 No 2	
(f) Do you ever feel the cold because you don't put the heating on?			31
		Yes 1 No 2	

33. The next questions are about transport and travel costs

CARD NO 5 COL

A. Do you (or a member of your household) own or have use of a car?

Yes 0

No 4

32

B. (a) Do you have a car because of your disability?

Yes 2

No 0

33 - 37

IF YES

How much did the car cost?

WRITE IN

£

33 - 37

Are you purchasing through Motability?

Yes 1

No 2

38

IF NO

(b) Would you have had one anyway?

Yes 1

No 2

43

C. Is your car specially adapted?

Yes 1

No 2

43

If Yes Did you pay for these adaptations?

Yes 1

No 2

39 - 42

How much did it cost

£

39 - 42

Do you drive yourself?

Yes 1

No 2

44

D. (a) Does it cost any extra to run your car because of your disability?

Yes 1

No 2

44

INCLUDE, WHERE APPLICABLE, COST OF RUNNING A CAR/SECOND CAR BECAUSE OF DISABILITY, EXTRA PETROL COSTS BECAUSE OF EXTRA JOURNEYS - TO HOSPITAL, DOCTORS ETC.

(b) How much do you estimate it costs over a year (to nearest £10)

WRITE IN

£

45 - 47

E. (a) Apart from the extra costs of running a car are there any other extra transport costs?

Yes 1

No 2

48

(b) If yes, what are these extra costs?

INDIVIDUAL PROMPT

taxis 1

dial a ride 2

payment to friends 3

other 4

49 - 51

(c) How much do they amount to over a year (to nearest £10)

£

49 - 51

34. Next I want to talk to you about holidays

CARD NO 5 COL

A (a) During the past year have you been away on holiday?

Yes 1

No 2

52

(b) If no, when is the last time you had a holiday

WRITE IN 19

53

B. Apart from holidays, in the past year have you been to stay somewhere else or a break or convalescence (or to give the person looking after you a break).

Yes 1

No 2

53

EXCLUDE TREATMENT IN HOSPITAL

C. IF YES TO EITHER A(a) OR B

What sort of place did you stay at on your last holiday

Show card K

Ordinary holiday accommodation (hotel, villa, caravan, B&B) 1

With family or friends 2

Hospital 3

Nursing home 4

Convalescent home 5

Hostel for disabled people 6

Local Authority home 7

Home run by voluntary organisation 8

Private family 9

Other (SPECIFY) 10

54

D. Is the reason you have not had a holiday because you did not want one or for some other reasons? (SPECIFY)

MAIN REASON

Did not want to go 1

Financial reasons 2

Health/disability 3

Other (SPECIFY) 4

55

E. Did it cost you more to go on holiday because of your disability

Yes 1

No 2

55

IF YES, Why was this, SPECIFY

(IF SIGHT PROBLEM)

35. Now I want to talk to you about vision aids.

A. Do you use any vision aids such as those listed on this card?

Show card L

Magnifying glass	1
Low vision aid	2
Braille equipment	3
Writing frame	4
Frame for telephone	5
Talking book machine	6
Cassette recorder	7
Audible/tactile measuring device	8
Other (SPECIFY)	9

IF YES, RING NUMBER AT TOP OF COLUMN AND COMPLETE (b) - (d)

1	2	3	4	5	6	7	8	9
Yes 1	Yes 1	Yes 1	Yes 1	Yes 1	Yes 1	Yes 1	Yes 1	Yes 1
No 2	No 2	No 2	No 2	No 2	No 2	No 2	No 2	No 2
£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p

(b) DESCRIPTION

(c) DID YOU BUY IT

(d) HOW MUCH DID IT COST

Total

(IF COMMUNICATION PROBLEM)

36. Now I want to talk to you about communication aids.

A. Do you use any aids for hearing or speech difficulties listed on this card?

Show card M

Hearing aid	1
Adaptor or telephone	2
Adaptor for TV	3
Adaptor for radio	4
Flashing light for telephone	5
Flashing light for door	6
Flashing alarm clock	7
Pointer/board	8
Typewriter	9
Other (SPECIFY)	10

IF YES, RING NUMBER AT TOP OF COLUMN AND COMPLETE (b) - (d)

1	2	3	4	5	6	7	8	9	10
Yes 1	Yes 1	Yes 1	Yes 1	Yes 1	Yes 1	Yes 1	Yes 1	Yes 1	Yes 1
No 2	No 2	No 2	No 2	No 2	No 2	No 2	No 2	No 2	No 2
£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p

(b) DESCRIPTION

(c) DID YOU BUY IT

(d) HOW MUCH DID IT COST

Total

CARD NO 5
COL

56 - 64

65 - 69

70 - 79

CARD NO 6
COL

1 - 3

4 - 8

37. And now I'd like to talk to you about equipment and daily living aids.

A. Do you use any pieces of equipment or daily living aids such as those listed on this card?

Show card N

Environmental controls	1
Stairlift	2
Rails	3
Holst	4
Special mattress	5
Special chair	6
Microwave	7
Washing machine	8
Freezer	9
Shower	10
Telephone	11
Other gadgets (SPECIFY)	12

(a) IF YES, RING NUMBER AT TOP OF COLUMN AND COMPLETE (b) - (d)

1	2	3	4	5	6	7	8	9	10	11	12
Yes 1	Yes 1	Yes 1	Yes 1	Yes 1	Yes 1	Yes 1	Yes 1	Yes 1	Yes 1	Yes 1	Yes 1
No 2	No 2	No 2	No 2	No 2	No 2	No 2	No 2	No 2	No 2	No 2	No 2
£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p	£ p

(b) DESCRIPTION

(c) DID YOU BUY IT

(d) HOW MUCH DID IT COST

Total

B. Are there any items on this list or anything else that you have not mentioned that you need to spend extra on but cannot afford to?

Yes 1
No 2

Item No

Description

C. Are there any items mentioned here or earlier that you cut back on or do without in order to afford others?

Yes 1
No 2

Description

CARD NO 6
COL

9 - 20

21

22

38. And finally in this section - other extra costs.

A. We have talked about the areas where extra costs are incurred because of your disability. Are there any other things, such as those listed on this card, or anything else you haven't mentioned that you spend extra on

Yes 1
No 2

23 - 28

Show card O

Telephone	1
Paying for child care/babysitting	2
Buying presents for helpers	3
Paying for membership of clubs	4
Insurance	5
Other (SPECIFY)	6

(a) IF YES, RING NUMBER AT THE TOP OF THE COLUMN AND COMPLETE (b) - (d)

1	2	3	4	5	6
£ p	£ p	£ p	£ p	£ p	£ p
Total					1

29 - 33

39. Now I'd like to talk to you about your financial situation

A. Thinking about how you are managing on your money at the moment, would you say you are

RUNNING PROMPT - Code most serious

NOW		LAST YEAR
managing quite well	1	1
just getting by	2	2
scraping by	3	3
getting into difficulties	4	4
permanently in debt	5	5
Other (SPECIFY)	6	6

34 - 35

(a) And thinking about this time last year, how were you managing on your money then, were you:

B. (a) During the past 12 months have you ever:

	Yes	No	
i) Had to use any money that you had in savings?	1	2	36
ii) Had to borrow money from anyone to pay for some big expenses.....	1	2	37
iii) Had to borrow money from anyone when you were short, just to make ends meet?.....	1	2	38
iv) Fallen behind with your rent, mortgage or any other regular payments?	1	2	39
v) Had a big bill that you couldn't pay on time?	1	2	40

(b) Are you behind with any payments at present?

Yes 1
No 2

(i) About how much are you behind with at present?

<£50	1
£50-<£200	2
£200-<£1,000	3
£1,000-<	4
No	5

(ii) Were you behind with any payments this time last year?

Yes 1
No 2

RUNNING PROMPT

More	1
Less	2
About the same	3

41

C. The things people can buy and do - their housing furniture, food, leisure activities, etc - make up their standard of living. How satisfied do you feel with your standard of living at present?

Can you choose an answer from this card.

Show card P

Very satisfied	1
Fairly satisfied	2
Neither satisfied nor dissatisfied	3
Fairly dissatisfied	4
Very dissatisfied	5
DK/no opinion	6

42

D. (a) If your weekly income was to increase by £10 a week what would you spend it on?

WRITE IN _____

(FIRST MENTIONED) _____

(b) If your weekly income was to fall by £10 a week what would you do without?

WRITE IN _____

(FIRST MENTIONED) _____

(c) If you were suddenly faced with a bill of £200 how would you manage

WRITE IN _____

(d) If you received an unexpected windfall of £200 what would you be most likely to spend it on/save it towards

Show card Q

Paying debts/bills	1
Holidays	2
Things for the home	3
Entertainment	4
Clothes	5
Food	6
Presents	7
Save it	8
Other (SPECIFY)	9

43

44

45

46

A. At present are you (and your spouse) receiving any of the following state benefits?

A. At present are you (and your spouse) receiving any of the following state benefits?

	SUBJECT				SPOUSE			
			WEEKLY AMOUNT				WEEKLY AMOUNT	
			£	p			£	p
	Yes	No	£	p	Yes	No	£	p
1. Child benefit	1	2			1	2		
2. One parent benefit	1	2			1	2		
3. Family credit	1	2			1	2		
4. NI Retirement Pension or Old Age Pension	1	2			1	2		
5. Income Support	1	2			1	2		
6. Sickness benefit	1	2			1	2		
7. Unemployment benefit	1	2			1	2		
8. Invalidity benefit, pension or allowance	1	2			1	2		
9. Severe Disablement Allowance	1	2			1	2		
10. Industrial Injury Disablement benefit	1	2			1	2		
11. War Disablement Pension	1	2			1	2		
12. Attendance Allowance	1	2			1	2		
14. Mobility Allowance	1	2			1	2		
15. Invalid Care Allowance	1	2			1	2		
16. Widow's pension or allowance or other widow's benefit	1	2			1	2		
17. Any other state benefit or allowance (SPECIFY) EXCEPT HOUSING BENEFIT	1	2			1	2		
18. Independent Living Fund	1	2			1	2		
INCLUDE 'CONSTANT ATTENDANCE ALLOWANCE' UNDER 10 OR 11								

INCLUDE 'CONSTANT ATTENDANCE ALLOWANCE' UNDER 10 OR 11

47.

CARD NO 7
COL
- 77

1-80

		SUBJECT				SPOUSE			
				WEEKLY AMOUNT				WEEKLY AMOUNT	
		Yes	No	£	p	Yes	No	£	p
1.	Earnings from employment	1	2			1	2		
2.	Earnings from self-employment	1	2			1	2		
3.	Income from lettings	1	2			1	2		
4.	Income from maintenance	1	2			1	2		
5.	Income from trust fund or charity	1	2			1	2		
6.	Government training allowance	1	1			1	2		
7.	Occupational pension	1	2			1	2		
8.	Private pension	1	2			1	2		

C. Show card R

What is your total weekly household income

Total

Thank you very much for answering all the questions

Name of interviewer _____

Time interview finished

Length of interview _____

[FOR INTERVIEWER ONLY]

If there is anything especially significant about this interview that you would like to record, please do so here. This is for your personal use and will serve (if completed) as a background note for the individual case history.

CARD NO	COL
1	1
2	1
3	1
4	1
5	1
6	1
7	1
8	1
9	1
10	1
11	1
12	1
13	1
14	1
15	1
16	1
17	1
18	1
19	1
20	1
21	1
22	1
23	1
24	1
25	1
26	1
27	1
28	1
29	1
30	1
31	1
32	1
33	1
34	1
35	1
36	1
37	1
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41	1
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94	1
95	1
96	1
97	1
98	1
99	1
100	1

