

NOT

The OPCS survey

Being disabled costs more than they said

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with
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I am grateful to my colleagues and to our interviewees for helping to bring this report to fruition.

Pauline Thompson

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INTRODUCTION

The Disablement Income Group was astonished by the recent Office of Population Censuses and Surveys (OPCS) report on the financial circumstances of disabled adults living in private households, which found that disabled people spend on average £6.10 per week extra because of their disability.

This finding contrasts sharply with the experience of the disabled people who seek the help of our Advisory Service and with the findings of our ten-year research programme on the extra costs of disability.

Why do our findings differ so dramatically? We suggest that there are two reasons:

The OPCS survey studied 10,000 people, of whom only 13% were receiving one of the main disability related allowances i.e. who were the kind of people that DIG would consider to be disabled in that their condition would give rise to extra costs.

The OPCS study was a large scale survey covering all aspects of disability in an interview of one and a half hours. The time available to cover the financial aspects was limited and could not yield the detailed information which DIG's small-scale in-depth research is able to produce.

The OPCS study makes a useful contribution to our understanding of disability and impairment in the 1980s, but because most of the cases interviewed had disabilities that do not give rise to significant extra costs it would be inappropriate to use it as the basis for making policy decisions about disability benefits.

We have therefore prepared this brief account of the experience of a sample of our Advisory Service clients to give a fuller picture of the kinds of problems experienced. In addition we have demonstrated the difference in the results produced by using different interview schedules and different interviewing techniques.

Using a schedule based on the OPCS questionnaire, we found the average extra costs of disability to be 241.84 per week. Using our own questionnaire with the same sample, we found the extra costs to be 265.94 per week.

We believe the results speak for themselves.

CHAPTER ONE THE OPCS SURVEY

According to a recent OPCS survey of disabled people in Great Britain (Martin and White 1988), disabled adults are spending only an extra £6.10 per week because of their disability. We all know that £6.10 does not buy a great deal extra; we all know too that disability can be very expensive. How then can a survey which has taken four years to report its findings arrive at such an astonishingly low figure? And can it really be true, as the survey reports, that 70% of disabled adults are satisfied with their standard of living?

Since the first OPCS survey (Harris, Cox and Smith, 1971; Buckle 1971) was carried out almost two decades ago, two benefits have been introduced to cover some of the expenses to which disability gives rise. These benefits are attendance allowance and mobility allowance: higher rate attendance allowance is currently paid at the rate of £32.95 per week, lower-rate attendance allowance at £22.00 per week and mobility allowance at £23.05 per week. While the aim of mobility allowance is to help disabled people get out and about, the purpose of attendance allowance has been less clear, although it is probably intended to help with the costs of disablement in the widest sense. One would therefore expect the second survey to find some correlation between the amount spent on the extra expenses of disability and the amount received from the extra cost benefits, assuming that the former figure includes all the extra costs to which disability gives rise.

Earlier studies

Before attempting to understand how the OPCS survey could have found that disability costs only £6.10 per week it will be helpful to examine the findings of previous research studies. The first OPCS study made no attempt to quantify the extra costs of disability: it simply established that disability does give rise to extra costs.

The Disablement Income Group has made the study of the extra costs of disability its specialty. Hyman (1977) found that the extra costs of wheelchair users amounted to £14.13 per week Stowell and Day (1983) found that shopping costs 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 figure (calculated at 1981/1982 prices) is more than three times the average weekly extra expenditure of disability found by the OPCS survey.

The sample

The DIG surveys were in-depth studies based on relatively small samples. The OPCS studies was a large scale survey. Originally 100,000 addresses were screened to identify people with some form of disability, and 10,000 disabled people were interviewed in the second stage. The OPCS researchers estimated that there are almost 6 million adults (5,780,000) in Great Britain with one or more disabilities, and acknowledge that this is considerably higher than the estimate that was obtained by the first survey of the disabled which took place in 1969 (Harris, Cox and Smith. 1971). The first OPCS survey showed that just over 3 million people (3,071,000) aged 16 or over living in private households were suffering from some physical, mental or sensory impairment.

It is hard to believe that in less than 20 years the incidence of disability among the adult population has almost doubled. Medical science has certainly advanced in the last two decades but hardly to such an extent. The answer must lie in the definitions employed. The first national survey refers to impairment, and the most recent survey to disability.

In the first OPCS survey (Harris et al, 1971) the sample included those 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 w.c., personal toilet or dressing; people who had difficulty walking without help, kneeling, bending or going up and downstairs; people who had difficulty with washing, dressing, performing their toilet, feeding themselves, or gripping or holding things; or who suffered from some permanent disability (including blindness) which stopped or limited their working, or getting about or taking care of themselves. In other words it dealt only with physical impairments that limited their lives in some way. As one of the main purposes of the first survey was to estimate the number of people who might qualify for attendance allowance, the scale used to measure degree of handicap 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 was almost 2 million people (1,942,000) who were impaired but not handicapped, and 1,130,000 who were handicapped.

The new second disability survey is much more far reaching than was the first. It attempted to cover all types of disability, whatever their origin, and used a low threshold of disability which as the report states "leads to high prevalence estimates". The survey distinguished 13 different types of disability: locomotion, reaching and stretching, dexterity, personal care, continence, seeing, hearing, communication, behaviour, intellectual functioning, consciousness, eating, drinking and digestion, 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 + 0.4 (second worst) + 0.3 (third worst) "to give an overall score from which people are allocated to one of 10 overall severity categories (category 1 least severe, category 10 most severe)".

The estimates of the number of disabled people in each of the severity categories as follows:

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 (most severe)	102,000

Source: Table 3.1 Martin and White (1988)

We see that the largest numbers are in the least severe categories and the lowest numbers are in the most severe categories. It is most interesting to find out the kind of people who are in the different categories. For example, 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 by the survey, categorised as the least severely disabled. In category 2 would be someone who cannot walk 200 yards without stopping or severe discomfort, and in category 3 someone with high tone deafness in both ears or someone who has difficulty putting either hand behind back to put a jacket on or tuck a shirt in and who has difficulty getting in and out of bed.

In other words, in categories 1 to 3 are those disabled people who have traditionally been considered as impaired, i.e. their daily living activities are not severely restricted. A total of 2,742,000 of the disabled adults in Great Britain are in fact in the least severely disabled categories. But there are 3,038,000 disabled adults in categories 4 and over (i.e. those with a significant disability) living in private households, which incidentally is very close to the, estimate of 3,071,000 obtained by Amelia Harris.

The benefits

Perhaps the most unexpected finding of the OPCS survey is that only 13% of the sample receive a benefit paid to meet the extra costs of disability - 8% receive attendance allowance and 7% mobility allowance - and only 20% of this small group are sufficiently disabled to receive both. While the receipt of these two key disability benefits is related to severity of disability, "only among those in the two highest severity categories are more than half receiving any disability costs benefit". It is most surprising to find that as many as 26% of those in category 10 (the most severely disabled) are not in receipt of attendance allowance.

Since attendance allowance and mobility allowance were introduced the numbers in receipt of them have steadily risen. In March 1986 as many as 585,000 people (including children) in Great Britain were in receipt of attendance allowance and by April 1987 a total of 474,000 people were in receipt of mobility allowance. It is known that the take-up of attendance allowance and mobility allowance is less than 100 per cent (Buckle 1988), although the OPCS survey does not address itself to this problem.

The findings

The OPCS survey's low estimate of extra expenditure by disabled people arises from a combination of factors.

Firstly, the threshold of disability has been defined at a level so low that large numbers of people not traditionally perceived as disabled have been included in the sample, thus drastically lowering the average extra costs of disability of the whole group. Only 1.6% of the sample were in the most severely disabled category (category 10); details of their extra costs, which can be expected to be the highest of the sample, are inevitably lost among the mass of data concerning the minimally disabled. Moreover, 69% of disabled people are aged 60 or over (compared with 26% of adults in the general population); experience has shown that older people are unlikely to perceive themselves as incurring any extra costs of disability, even though careful questioning may well elicit a quite contrary

picture.

In addition, as the OPCS survey states, the proportion claiming to have such extra expenditure is sensitive to the interviewing 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".

The distortion of the statistics by the inclusion of many relatively lightly disabled people, together with the lack of a really searching questionnaire, have almost certainly contributed to the high proportion of the sample - 70% -that profess themselves satisfied with their standard of living. In this respect it is perhaps surprising that the OPCS survey states this proportion as an average of the entire sample and does not analyse the levels of satisfaction expressed by people with different degrees of disability. We may speculate that the level is very much less than 70% among the comparatively small groups having severe disability and relatively heavy costs, but although the OPCS undoubtedly holds this data it has chosen not to publish it here.

There can be no dispute that the OPCS survey attempted to gain a full picture of the extra costs of disability. The survey sought to collect information on four kinds of cost: extra capital expenditure on items required solely as a consequence of disability; capital payments for items which non-disabled people might require; regular payments for that component of a normal item of expenditure which can be attributed to disability. But the questions on the extra costs made up just one area covered in an interview that lasted one hour thirty minutes on average. DIG's experience is that in order to get a full and complete picture of the extra costs of disabled living requires much more lengthy and detailed questioning than was capable of being carried out in the OPCS survey. DIG has frequently carried out extra cost interviews lasting two, three, four or even five hours for completion.

While the OPCS survey of disabled people makes a useful contribution to our understanding of disability in the 1980's, because of the definitions used we have in effect a survey about many people who are not very disabled. It is therefore not surprising that average extra costs are calculated as amounting to only £6.10 per week.

It is perhaps the most surprising aspect of this survey that no attempt was made to analyse the extra costs by severity of disability. The case histories in Chapter 2 document the extra costs of a group of disabled people who are severely disabled.

CHAPTER TWO

DIG'S 1988 STUDY

Our aim

The authors of the OPCS report had already indicated that the results of surveys are generally affected by the kind of questionnaires and the interviewing techniques used. We, therefore, wanted to ascertain if and how the responses to the OPCS structured standardised questionnaire would vary from those of a DIG semi-structured unstandardised questionnaire used typically in small-scale in-depth studies. We aimed to ensure that we covered fully the main extra costs of disability.

Our research strategy

We selected seven levels of extra costs used in the OPCS survey: home services, unprescribed medication, laundry, clothing and bedding, food, fuel and transport. We also selected two questions about perceptions of individual financial circumstances. We then prepared two questionnaires. Questionnaire 1 used the OPCS questions and Questionnaire 2 used DIG questions on the same topics in the form that DIG prefers, with running prompts and additional questions designed to extract as much detail as possible from the interview. This meant that we would be able to compare the answers given.

Due to time constraints we were unable to cover all the likely extra costs of disability, but selected those that were perceived by OPCS and DIG as the most important. The two questionnaires used are reproduced at appendices 1 and 2. The benefit income analysis sheet used to record information about benefits received is included as appendix 3.

The sample was selected from the DIG Advisory Service case files to give a cross-section of disabled people, all of whom were receiving at least one of the two main disability-related allowances, namely attendance and mobility allowance. All of them were significantly disabled and would, on the basis of the OPCS scale of severity, be representative of categories 9 and 10 and even higher than this (although the OPCS scale stopped at 10) and would have been included in the 13% of the OPCS sample who were receiving one of these benefits. We deliberately did not select the most severe cases from our files.

The disabilities of the interviewees were respectively as follows:

- A. Vascular disease with circulatory problems and right leg below-knee amputation
- B. Meniere's disease, tinnitus and diabetes
- C. Spondylosis, osteo-arthritis and oedema
- D. Spinal injury resulting in quadriplegia
- E. Arthritis and back injury as result of accident
- F. Multiple sclerosis
- G. Crushed vertebrae, osteo-arthritis, curvature of the spine and sciatica
- H. Massive cardiac arrest, major stomach surgery, foot deformity and peroneal muscular atrophy
- I. Paraplegia
- J. Polyarteritis nodosa, cervical spondylosis, transient ischaemic attacks, bronchitis and myopathic atrophy
- K. Polio with paralysis of arms and legs
- L. Spinal injury with total blindness and partial deafness
- M. Arthritis in lower body, lymphoedema, mastectomy and partial removal of bladder.

Eleven of the sample were under 65 years of age, two were over 65 but had been disabled for 20 and 40 years respectively.

The practicalities of collecting the data swiftly and accurately ruled out all methods other than telephone interviewing. This method proved successful. Interviewing was carried out over a period of four days, with at least 24 hours between each interview. The OPCS questions were asked first and these interviews took 20 minutes each to complete. The DIG questionnaire required an average of one hour. One interviewer used the OPCS questions and the other the DIG questions, analysing and comparing responses only after all interviewing had been completed.

CHAPTER THREE

THE EXTRA COSTS OF DISABLED LIVING

The aim of this study was to establish what certain extra costs of living really are for people with significant disabilities and to compare the findings of our OPCS-based questions with those of the DIG questionnaire and the whole with the recent OPCS results.

The findings

We were successful in identifying the high level of extra costs incurred by our sample using both interview schedules. The first survey based on the OPCS questions was carried out conscientiously by our researcher but the more thorough questioning of the second (DIG) survey elicited an average extra costs figure over our whole sample that was 58% higher.

Table 1 shows seven weekly extra cost items for each person in the sample (real names have not been used) and compares the results of the two interviews.

The weekly extra costs of disability based on the OPCS-style interviews were found on average to be 241.84 whereas in response to the DIG questionnaire they were found to be £65.94.

Several people interviewed found difficulty in answering the OPCS-based questions. In these cases "don't know" was recorded and included in Table 1. All, however, responded positively to the prompting and additional questions in the DIG interview. As a result "don't know" was not recorded at all during the interview using the DIG questionnaire.

But in both interviews there were items for which extra costs were not perceived by interviewees, even after prompting. These responses are also included in Table 1.

TABLE 1 Weekly extra costs described in response to I OPCS based Questionnaire 1 and ii DIG Questionnaire 2 (£)

NAMES		HOME SERVICES	UNPRESCR MEDIC	LAUNDRY	CLOTHING BEDDING	FOOD	FUEL	TRAVEL	TOTAL COSTS	
A										
FRANK	i	-	0.80	3.00	0.57	4.00	D/K	20.00	28.37	i
WATSON	ii	-	2.12	3.50	2.81	5.70	3.75	29.05	46.93	ii
B										
GLEN	i	44.50	1.00	0.75	5.76	2.50	2.19	1.25	57.95	i
KELLY	ii	44.50	5.60	1.27	7.40	12.50	2.52	8.00	81.52	ii
C										
VIOLET	i	1.25	1.25	-	3.04	-	4.80	D/K	10.34	i
EVANS	ii	1.25	1.97	-	3.55	10.00	6.00	0.60	23.37	ii
D										
ERIC	i	-	2.00	1.24	D/K	5.00	4.80	D/K	13.04	i
PULLEN	ii	-	3.29	2.27	5.71	5.00	5.76	25.00	47.03	ii
E										
DAN	i	-	3.75	1.25	2.88	2.50	2.69	20.00	33.07	i
EAST		-	3.64	3.22	3.12	9.25	9.75	30.78	59.76	ii
F										
ROB	i	-	3.25	1.25	2.40	35.00	5.76	17.07	64.73	i
BROWN	ii	-	7.20	1.37	3.53	35.00	6.50	32.65	86.25	ii
G										
ROGER		73.45	10.00	5.00	9.61	15.00	9.61	10.00	132.67	i
SHARP		73.45	13.08	4.83	10.14	15.00	11.08	12.50	140.08	ii

- denotes no perceived extra costs

TABLE 1 (cont'd)

NAMES		HOME SERVICES	UNPRESCR MEDIC	LAUNDRY	CLOTHING BEDDING	FOOD	FUEL	TRAVEL	TOTAL COSTS	
H										
CARL	i	-	1.25	D/K	3.84	2.50	6.92	D/K	14.51	i
DYER	ii	-	6.69	.65	4.94	11.50	7.75	29.27	60.80	ii
I										
NORA	i	44.50	10.00	2.25	2.88	6.00	8.65	7.50	92.28	i
COOMBS	ii	44.50	10.00	4.72	8.94	10.00	8.65	11.15	108.46	ii
J										
MARY	i	1.25	2.50	1.50	D/K	D/K	D/K	5.00	17.45	i
WEBB	ii	1.25	4.84	3.51	5.01	13.00	-	6.82	46.63	ii
K										
ANN	i	-	1.50	-	1.34	-	5.76	-	49.10	i
CURRY	ii	-	3.69	0.17	4.02	7.00	9.16	2.65	67.19	ii
L										
ANDY	i	-	2.50	2.00	-	-	1.92	D/K	6.42	i
SMITH		-	3.78	4.22	2.28	10.84	1.75	16.07	38.94	ii
M										
JENNY	i	-	3.00	2.00	8.65	6.00	0.28	D/K	23.93	i
READ	ii	-	10.00	2.40	10.01	20.00	0.65	3.50	50.56	ii

Average extra costs of disability:

According to OPCS questionnaire £41.84

According to DIG questionnaire £65.94

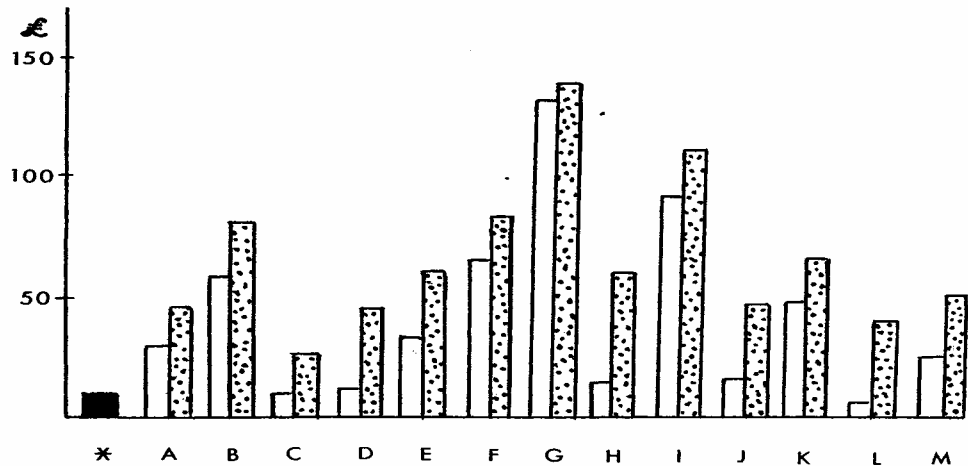
Tables 2 and 3 compare our findings in this survey with these of the main OPCS study for all adults and for severity categories 9 and 10.

In Table 2 we compare average extra expenditure for all individuals with actual expenditure on these items. This table shows the difference in stated expenditure on extra costs. Even our interviewing schedule based on the OPCS questionnaire shows a significant increase on the findings of the OPCS survey itself - £66.97 compared with £21.50 for all adults and £30.20 for severity categories 9/10.

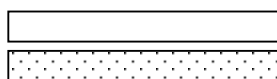
However, the most revealing findings result from the interviews based on the DIG questionnaire. The average weekly extra costs of disability for people actually incurring expenditure on these items was found to be £81.90.

Table 3 shows the weekly extra costs expenditure averaged across all the sample and compares our two sets of findings with the OPCS survey findings for all adults and severity categories 9/10. Compared with the OPCS all-adults figure of £4.60 and the categories 9/10 figure of £9.50 the weekly extra costs found by the OPCS-style interview were £41.81 per week and by the DIG questionnaire £65.92 per week.

FIGURE 1: Comparison of weekly costs obtained by the two questionnaires with different interviewing techniques for the same sample



Key



Weekly costs obtained using OPCS-style Questionnaire 1
 weekly costs obtained using DIG Questionnaire 2

The asterisked column refers to the OPCS survey's results for all respondents in categories 9 and 10

TABLE 2

Comparison of average extra expenditure: all individuals with actual expenditure on these items (£)

	OPCS SURVEY		DIG 1988 SURVEY	
	All adults	Categories 9/10	OPCS-based questionnaire 1	DIG questionnaire 2
Home Service	5.20	11.30	32.45	33.16
Unprescr. medication	1.10	1.60	3.29	5.83
Laundry	1.40	1.50	2.02	2.67
Clothing, bedding	0.80	1.10	4.10	5.49
Food	6.20	7.00	8.72	12.67
Fuel	2.50	2.80	4.85	6.08
Travel	4.30	4.90	11.54	16.00
Total	21.50	30.20	66.97	81.90

TABLE 3

Comparison of average extra expenditure: all sample (£)

	OPCS SURVEY		DIG 1988 SURVEY	
	All adults	Categories 9/10	OPCS-based questionnaire 1	DIG questionnaire 2
Home Service	0.60	2.20	17.47	17.85
Unprescr. medication	0.40	1.00	3.29	5.83
Laundry	0.20	0.70	1.55	2.47
Clothing, bedding	0.20	0.50	3.15	5.49
Food	1.10	2.10	6.03	12.67
Fuel	1.30	2.20	4.11	5.61
Travel	0.80	0.80	6.21	16.00
Total	4.60	9.50	41.81	65.92

The techniques used

Our findings are dramatically different from the main OPCS survey. We show higher expenditure on all items and more overall. We suggest there are two reasons for this.

First, we interviewed only people with significant disabilities who were incurring extra costs because of this. Second, the interviewees were more responsive to the DIG style of interviewing with its running prompts and additional questions.

That is not to say that Questionnaire 2, the interview schedule based on the OPCS survey, was not valuable. In itself it was capable of eliciting useful information from people with significant disabilities. It can be concluded in this respect that the main OPCS survey questionnaire might well have produced higher levels of extra costs if the original OPCS research had been used on people who were disabled rather than impaired.

Several people in our sample commented on the difference in the two interviews we carried out. They found the DIG method of prompting helped them to think through the questions and break down their extra costs into individual components. This enabled some of them to give a more definite response compared with the OPCS questions, to which some interviewees had struggled to find an answer and some failed to reply at all.

But the most significant point to arise from the DIG survey must surely be the massive amount of weekly extra costs incurred by our sample compared with the figure obtained by the OPCS survey. It is worth noting at this point that we did not attempt to cover all the extra cost items included by OPCS, nor did we look at capital expenditure or loss of earnings.

We were able to identify some areas of unmet need, where interviewees felt they needed to spend more on certain items but could not afford to do so. Everyone in our sample said they needed to spend more on at least one item, compared with 24% in the original OPCS survey who thought they needed to spend more.

In the next chapter we look at individual responses to the DIG questionnaire, which tell us more about their circumstances, the main areas of their extra costs and their perceptions of their unmet needs.

CHAPTER FOUR

CASE STUDIES

In this chapter we look in more detail at the circumstances of the individual people in our survey; here, and throughout the report, the names of the people have been changed to preserve confidentiality. The extra costs of each person are included in Appendix 1.

A. Frank Watson

Frank is 59 and suffers from vascular disease with circulatory problems and right leg below-knee amputation. He also has a history of kidney failure. He uses a wheelchair. He is not employed and lives alone. He sees a social worker only occasionally and receives home help three times a week for 1.75 hours each visit.

Although he said he was not spending extra on home services he indicated that if he could afford it he would buy in help for two hours a day. He says his need for extra fuel arises from his being mainly at home, keeping the heating on at night and his immobility, which means he feels the cold more. He worries about his fuel bills and he needs to budget carefully for them. He finds it too expensive to run an additional electric fire for extra warmth.

His extra laundry costs arise principally because of discharge from his ulcerated left leg which soils sheets and socks. His home help takes the washing to the laundry. Shoes and trousers need replacing more often because of soiling and wear and tear from his artificial leg, and he buys flannelette bedclothes for extra warmth, even in summer. His bed-cradle tears his sheets. But he cannot always afford to replace worn out items and relies on friends and relatives for some of his clothes. He buys second-hand things. Frank says he could "do with £10 a week more just to have sufficient" of these items.

He lives on a high-protein diet with lots of meat, fish and cheese. He buys more frozen, canned and prepared foods because of difficulties with cooking, and uses a microwave in preference to a cooker. If he had some domestic help, he told us it would be much easier. He "cannot envisage" life without his car and is totally dependent on it to go out.

He is just scraping by and is dissatisfied with his standard of living. He is short of domestic appliances such as a washing machine and a fridge-freezer. He has little spare cash to enhance the quality of his life. He doesn't buy books and his treasured typewriter is "falling to pieces".

Glen Kelly

Glen is 59 and lives alone in a flat specially adapted for disabled people. He suffers from Meniere's disease, tinnitus and diabetes, he is not employed. He has a weekly visit from a district nurse, receives meals on wheels five days a week and pays for a private carer for 15 hours a week. He would buy in more private help if he could afford it.

Glen says he needs to be clean and spends on laundry what he requires. He has extra laundry because of "accidents" and because he is unable to get to the toilet when he has a spasm. He "would do without food to be clean". Most of the time he wears mostly good-quality tracksuits which need replacing frequently, but he cannot always afford to replace worn-out items, and borrows money to buy clothes. He feels he needs between £200 and £300 extra per year for clothing and bedding to take the pressure off him.

As a diabetic he finds the weekly cost of food shopping very expensive. He would particularly like to eat seafood but cannot afford it. He needs about £8-£10 extra each week for food to get the quality he wants.

He says he is scraping by and is fairly dissatisfied with his standard of living, being faced often with a choice between adequate food and adequate heating.

Violet Evans

Violet is 55 years old and suffers from spondylosis, osteo-arthritis and oedema. She lives alone and does not work. She has a local authority home help two mornings a week for a total of three hours. She would like to be able to afford to buy in her own private help.

Her clothing wears out, and does so more quickly because of wear and tear. She has a badly twisted foot and wears out her shoes quickly. footwear. But she cannot always afford to replace these items and she is given clothing and footwear by friends and relatives. She reckons she needs about £100 a year extra to meet the costs of these items.

She is supposed to be on a special diet but cannot afford to stick to it. She does, however, buy a lot of convenience foods which are easier for her to prepare. If she had another £6 a week available for shopping, she says, she would buy "more fruit and meat".

Violet cannot afford to heat all the rooms in her house and worries about her fuel bills. She has shivered in the winter because she has turned the temperature down simply because she cannot afford the consequences of high bills. She estimates she needs a further £3 extra per week to pay for the heating she needs.

She is scraping by and only just keeping her head above water. She is very dissatisfied with her standard of living.

D. Eric Pullen

Eric is 40 and has been disabled for 21 years. A spinal injury has left him paralysed from the shoulders down. He lives alone and is not employed. A home help visits on three days a week but he finds this level of service inadequate and if he could afford it he would pay for private help. A social worker and occupational therapist visit infrequently.

He has significant extra laundry costs chiefly because he sweats a great deal and has the washing machine on every day. A consequence of this is that his machine needs frequent servicing and this adds to the expense. Were he to have sufficient money he would buy softeners for the wash and he would have his items of good clothing dry-cleaned. His washing machine recently "blew up" and needed repairing.

His clothes and shoes wear out more quickly because of wear and tear and extra washing. He is particularly heavy on trousers and tee-shirts and he says he "murders" his gloves. He buys items through a club. "I need £200 to set myself up with warm clothes," he tells us.

Eric is on a high-fibre diet eating a lot of brown bread, cereals, beans, white meat and fish. He is hungrier in the winter when he needs more warm food and would spend £5 more a week if he could afford to.

He heats his home "with a great deal of difficulty", using electric storage heaters and a fan heater. He has additional fuel costs because he is at home more, runs the heating through the night, feels the cold, uses extra hot water for washing and consumes extra electricity on a washing machine. He worries about his fuel bills: "I only use two out of five radiators and the fan heater". He has been cold in winter because he could not afford the fuel required to keep him warm. Over half Eric's extra expenditure is incurred by his transport costs and he worries about his car in case there is a major repair bill.

He is scraping by, but says he is neither satisfied nor dissatisfied with his standard of living.

E. Dan East

Aged 39, Dan suffers from arthritis and a back injury following an accident. He is married with two small children, and is not employed.

He incurs no extra expenditure on home services, though he would find it helpful for the whole family if he could afford four or five hours of private help each week. A social worker visits infrequently.

Dan spends extra on chemist's items not on prescription including deep heat sprays, vitamins, elastic supports and analgesics but he finds spending on these "a tight squeeze" and he would like to try some homeopathic remedies which he cannot presently afford.

He creates extra laundry because he uses special creams, he sweats a lot and he uses a spinal corset; he has extra dry cleaning costs on jackets and trousers because of sweating. His weight fluctuates during the year and he needs to buy different sizes of trousers but often he cannot afford to replace worn-out items of clothing and he relies on friends for hand-downs or goes to WRVS jumble sales. He buys second hand clothes "more often than new ones". His heaviest wear and tear is on vests, shirts, shoes and slippers. 2100 extra a year would make all the difference to his ability to clothe himself properly.

The family's bedrooms are chilly and extra bedding is essential, but Dan cannot afford the amount they need. "We've only got one decent pair of sheets". He needs extra blankets.

Dan is on a high fibre diet but often goes without so that the other members of the family can eat adequately. He tries to eat as much brown bread and bran as possible, supplemented by apples. He reckons he needs to spend a further £20 a week for an adequate diet.

The home is difficult to heat. There is a coal fire in the living room only. Electric fires and oil heaters are rarely used because of lack of money. Dan sometimes has to sit at home in fingerless gloves to keep his hands warm. He worries about his fuel bills, especially as he needs heating on all the time because of his condition and he uses more fuel because of twice-daily baths and frequent laundry and also because he is at home more than would otherwise be the case.

He says he is getting into financial difficulties "Last year was difficult, this year it's a nightmare," he told us. He is very dissatisfied with his standard of living.

F. Rob Brown

Rob is 42 and is married with five children. Multiple sclerosis was diagnosed about 10 years ago.

He presently incurs no extra costs on home services but indicated that he would if he could afford to do so for the periods when his wife goes out. The help needed would be "a mixture of nursing and domestic help". He spends a significant amount on unprescribed medication, particularly on vitamins and talcum powder, and would buy evening primrose oil but it is "too expensive". Rob creates extra laundry because of incontinence, spilling things and using special creams and medication. He estimates that five machine-loads weekly result solely from his disability. He recently had to buy a new washing machine because the previous one was beyond repair.

Special wide-seat, elasticated trousers are a necessity and result in extra expenditure being incurred. He replaces underwear very frequently. His mother buys jumpers for him for birthdays and Christmas and his wife looks out for second-hand clothes for him. Rob cannot always afford to replace worn-out items of clothing. "I could do with some shoes. I only have an old pair of trainers." Two pairs of trousers need replacing. "I need a complete refurbishment of my wardrobe."

The costs of Rob's diet are particularly high. Recommended by a dietician, the diet consists of fresh salads, liver, fish, wholemeal bread and fruit. He invariably eats different food from the rest of the family, but sometimes in order to ensure that his children eat well he makes do with soup and bread.

Extra fuel costs are incurred because he is at home most of the time and needs a constant temperature. He takes a daily shower. He does not normally turn the heating on at night because he would worry about the consequences. Asked if there were items he would spend more money on if he could, he told us that his phone bills are very high because he tends to use it a lot more than he would if he could get out and about.

He spends extra on transport costs and finds that the mobility allowance is insufficient to meet his weekly needs.

Rob describes his financial situation as "permanently in debt". He is fairly dissatisfied with his standard of living.

G. Roger Sharp

Roger is 34 and suffers from crushed vertebrae, osteoarthritis, curvature of the spine and sciatica. He does not work but his wife is employed.

He pays for 20 hours of domestic help and personal assistance at a cost of £70 per week. If he could afford it he would buy in physiotherapy and massage services. His extra costs of unprescribed medication and chemist's items are high and include purchases of extra toilet rolls, essential oils and cotton wool'.

Roger incurs extra laundry costs because of incontinence, spilling things and using special creams and medication. He has to purchase extra clothing because he feels the cold and particularly buys jumpers, warm trousers and sweatshirts. His clothing wears out quickly, since he wears a spinal corset, but he cannot always afford to replace worn-out items of clothing. He often buys second-hand clothes and reckons he needs an extra £500 per year to clothe himself properly.

He is on a special diet of whole foods and organic foods but cannot always afford to stick to his diet. His medication makes him dehydrated and he needs to drink a lot. Sometimes he does without meals because no-one is there to prepare them. If he had more money he would buy better-quality food.

The fuel costs are high because he is at home more, the heating is on at night, he feels the cold and he takes lots of extra baths. To cut down on outgoings he does not use all the rooms in the house. But he worries about fuel bills and sometimes has been cold because he chose not to put the heating on to keep costs down.

Roger indicates that his extra telephone costs are also significant at about £5 a week. Some of this he puts down to bureaucratic reasons - interminable negotiations over the phone with the DHSS about his benefits.

He says he is getting into difficulties and is very dissatisfied with his standard of living. He tries to balance his outgoings using credit cards, but he has been in a great deal of debt because of this.

H. Carl Dyer

Carl is 62 and has been disabled all his life with a foot deformity and peroneal muscular atrophy. Latterly he had a massive cardiac arrest and major stomach surgery. Carl is married, and is not employed.

Because of his disability Carl has to have trousers specially made to fit over his shoes, and buys extra woollens because he feels the cold. He uses a surgical collar and wears out the necklines of shirts quickly. Yet he cannot always afford to replace worn out items of clothing and relies on friends and relatives for some things. He often buys second hand shirts and says that he needs about £400 a year extra to clothe himself properly.

Whilst not recommended to have a special diet Carl was advised by his surgeon to eat well since one third of his stomach has been removed. He eats "little and often" (about every three/four hours) and bread and spreads alone for "snacks" cost £6.50 per week.

He spends more on fuel because he is at home and he has the heating on at night. He also feels the cold and has the heating on all year round. He also-pays £29.25 per quarter for an alarm phone.

He is leasing a car on the Motability scheme and estimates transport costs as an extra £29.27 a week due to his disability. If he could afford it he would go out more. He supplements his benefit income with earnings from his hobby which brings in about £3 a week.

Carl says he is scraping by and that he is dissatisfied with his standard of living.

I. Nora Coombs

Nora is 67 years old and suffers from complete lesion paraplegia due to an abscess on her spine 40 years ago. She lives alone and uses a wheelchair. She spends £55 per week on home services, buying in private domestic help and occasional physiotherapy. She feels she may need assistance for a further seven hours a week. In addition she also pays someone to shop for her.

Her monthly chemist's bills cover items such as cotton wool, soothing creams, vitamins, disinfectants and cod liver oil but sometimes she cannot afford certain items. If she could afford it she would try herbal remedies and she occasionally buys royal jelly.

She has extra laundry costs due to incontinence and catheter changing whilst in bed and because she uses special creams and medication. Although she has a washing machine at home, when she is unwell she sends large items such as bed linen to the laundry.

Nora buys more warm clothes because she feels the cold. She has long skirts specially made, and wears wool. Her underwear, skirts and slacks need replacing frequently due to wear and tear but she cannot always afford to purchase new items. She used to rely on a friend for some of her clothes and occasionally buys second-hand ones. To clothe herself properly she needs about £500 per year extra.

The bed-cradle she uses results in wear of the bed linen and Nora needs extra sheets and blankets because of the cold and because of deterioration due to frequent washing. She says she needs to replace all her towels at the moment. Nora is on a special diet, necessary because she has suffered from an ulcer and has been advised to be careful. She drinks a lot of spring water and fruit juices and eats fish, chicken, yoghurts beans and brown bread. She also tends to buy expensive convenience foods because they involve less work in preparation. She would like to be able to spend a further £5 a week on food: "It would be nice to order without thinking". To balance her budget she occasionally goes without: "If a lot has been spent one week, I cut down the next".

But she tells us she'd rather be hungry than cold. That is because she needs to incur high expenditure on fuel in order to keep warm. Besides being at home more and feeling the cold because of immobility, she runs the heating at night, consumes extra power to run her washing machine and tumble drier, uses electric blankets a lot and has the lights on during the night. She needs to heat all the rooms in her house, except the hall. She finds her fuel bills "a bit shattering when they arrive". Telephone bills are also a problem, working out at about £80 a quarter.

Nora says she is only just getting by through cutting back on other things. She is very dissatisfied with her standard of living.

J. Mary Webb

Mary is 69 and suffers from polyarteritis nodosa, cervical spondylosis, transient ischaemic attacks, bronchitis and myopathic atrophy. She lives alone. She pays for home services, including private domestic help for two hours a week and a local authority home help. She also pays occasional carers with gifts. An occupational therapist calls regularly. If she could afford it she would buy in an additional two hours of private help each week.

She purchases a variety of chemist's items and unprescribed medications, including some homeopathic remedies, and is a heavy user of tissues, toilet paper and kitchen rolls. Mary would like to take royal jelly but cannot afford it.

Extra laundry costs result from incontinence and soiling things and most weeks she send her towels and sheets out to be washed.

Mary needs clothes and shoes specially made to fit, particularly shoes and trousers. Due to spells as a hospital in-patient she needs extra underwear and nightdresses. She buys extra cardigans because she feels the cold and buys a lot of socks, but she cannot wear nylon. Her feet swell and she has to purchase extra slippers, bootees and slip-ons. She cannot always afford to replace worn-out items of clothing. An extra £100 a year would help her to clothe herself properly.

Mary follows a high protein-diet but with minimal dairy food. She eats a good deal of fish, bran biscuits, brown bread and drinks herbal teas because she avoids milk in tea. Because of her disability she also buys a lot of convenience foods. She considers food "a priority" and aims never to go without.

She cannot identify extra fuel costs chiefly because the cost is included in the service charge for her accommodation.

The telephone is important to Mary. Asked if there were any items she would spend more on if she could afford it she said that her phone bill is about £80 a quarter. She is permanently in debt but she tries not to worry; she is, however, fairly dissatisfied with her standard of living.

K. Ann Curry

Ann is 37 and lives with her adult daughter, who is working. She had polio at the age of two and is paralysed in the arms and legs as a result. She uses a wheelchair. Ann is not employed.

She purchases home services in the form of private domestic help five days a week at a cost of £40.50, but says she needs more help with personal things and getting meals and assistance at weekends. A voluntary worker assists with odd jobs.

Ann uses a number of items not on prescription including vitamins, garlic capsules, homeopathic remedies, cod liver oil and baby lotion for her dry skin. She would like to be able to spend more on these items and particularly on homeopathic medicines.

She feels the cold and needs light weight but warm clothes. She needs special light soft shoes without a heel, which are difficult to replace: "I cannot afford to get them made." She wears cotton next to her skin, and has to have her sheets specially made from a smooth, slippery fabric so that she can turn herself in bed. Her mother helps with providing clothes.

Although she is not on a special diet she does pay extra for her food through buying frozen and prepared foods, which involve less work in cooking. A major item of expenditure is fuel, for her flat is hard to heat. She also has extra costs directly attributable to her disability. She is at home more, she feels the cold, she runs the heating at night in the winter and she uses electricity to charge up her wheelchair. She worries about her bills and is often cold in winter because she cannot afford to turn the temperature up. She uses a fan heater to supplement the heating.

She says she is "scraping by" and is fairly dissatisfied with her standard of living. Until 1988 she had not had a holiday for 11 years. She has high phone bills and there are odd jobs around the house that need doing, like decorating and gardening, but she cannot afford to buy in the help she needs.

L. Andy Smith

Andy is 27 and as a result of a road traffic accident nine years ago is totally blind and partially deaf, has bladder problems and facial injuries. He lives with his wife and two children. His wife was the interviewee.

He spends extra on unprescribed medications and other items including vitamins, eye patches and talcum powder but they do find it difficult to afford every item they need.

Due to bladder damage - he has "dribbling incontinence" -and spilling things extra laundry costs are incurred and the washing machine is serviced twice a year. But it is not possible to afford softener for the wash, and repair and dry-cleaning costs are significant at £9.50 each month.

Andy sits around the house a lot and feels the cold more as a result. His wife buys warm sweatshirts rather than shirts and these tend to work out as more expensive. Frequent washing and heavy wear and tear mean that many items need replacing regularly and Andy scuffs his shoes and slippers. Replacement of worn- out items cannot always be afforded. Andy needs about £200 extra each year to clothe himself properly.

Due to his facial injuries Andy needs a soft diet. He eats a lot of bananas, yoghurt, eggs and braising meat. He does not always stick to this diet because he tires of it. If he had more money his wife would buy more cheese and other items.

Andy's guide dog costs extra. Although the Guide Dogs for the Blind Association provide £12 per month towards its food Andy has to find an extra £2 a week.

Without the car "life would be intolerable". It was left to them by Andy's father-in-law but is now quite old. They only use the phone for emergencies. Since Andy can no longer do odd jobs about the house, "even getting a shelf put up is very, very expensive". And they would like to be able to buy more tapes and more music.

They describe their situation as "getting into difficulties", and are very dissatisfied with their standard of living.

N. Jenny Read

Jenny is 55 and has arthritis in her lower body and lymphoedema. She has had a mastectomy and partial removal of her bladder.

Whilst she is not currently spending on home services - she used to have a home help but stopped it "because of all the aggravation involved" - she would buy in private help to assist her with some of the heavier jobs if she could afford to.

Jenny buys unprescribed medication, particularly vitamins, calcium pills, TCP and Vaseline liquid. This amounts to about £10 a week altogether but Jenny would buy more items if she could.

She buys support tights regularly and she needs to buy a special brassiere that costs £15 but presently cannot afford to do so. Her weight fluctuates dramatically during a year and she has to buy clothes varying from size 20 to size 24. As a result she spends about £300 a year on her wardrobe. She cannot always afford to replace worn-out items of clothing and relies on relatives for some of her clothing. She often buys second-hand clothing. She has sufficient bedding at the moment "because an aunt gave me some things".

Jenny is on a high-fibre, low-cholesterol, low-sugar diet. She does not know how long she can afford to keep it up, for it costs her about £20 extra per week. She says she is "always hungry" and at times she has gone without fish and meat.

Asked about areas where other extra costs are incurred Jenny said that her phone bills are £100 per quarter.

She is getting into difficulties and finds "it's getting harder". She said she was neither satisfied nor dissatisfied with her standard of living.

CHAPTER FIVE

CONCLUSION

This brief study has revealed the truth of what we suspected when we first saw the results of the OPCS report on the financial circumstances of disabled adults living in private households: that the sample they interviewed and the interview schedule and techniques they used had given rise to a much lower figure for the average extra weekly costs of disability than would have been the case if more significantly disabled people had been interviewed and if a more detailed questionnaire had been used.

Interestingly, in correspondence with the DHSS at the time when the draft OPCS questionnaire was being piloted, DIG expressed its concern that some of the questions were insufficiently detailed. For example, we said that it would be difficult for respondents to estimate the value of extra fuel costs, and further comparisons were needed. We advised, too, that more might be spent on all shopping, not just that related to a special diet. We said that we thought that costs covered by the questionnaire should have included those arising from a disabled person's being unable to shop around for bargains, having to buy small amounts, buying convenience foods and paying others to do the shopping. We knew too that disabled people often meet some of their needs at the expense of others, for example fuel may be paid for by sacrificing holidays, and we thought this information should be recorded. We also felt that there would be extra costs not indicated in the questionnaire which should be mentioned by the interviewers, not just left to chance, such as the extra costs of needing to be accompanied when going out, extra costs of holidays, extra costs of paying more generally for all shopping and so on.

Yet even if the interview schedule had been more detailed, it is unlikely that it would have revealed the true extra costs of disability because, as we have already stated, only a small percentage of the sample interviewed (6.65%) were in categories 9 and 10, the most severe; indeed, only 13% of people interviewed were receiving one or other of the two main disability-related allowances - attendance allowance and mobility allowance.

Our findings amply illustrate this point. Using an interview schedule based on the OPCS questionnaire we still found the extra costs to be 440% higher than the OPCS' own survey of people in disability categories 9 and 10, to which categories our respondents belong (£41.81 compared with £9.50) and 222% higher if we consider only people actually incurring a specific cost (£66.97 is against £30.20).

This demonstrates clearly the point made in Chapter 1: that because of the inclusion in the sample of so many people who are only mildly disabled and the consequent "bunching" in categories 9 and 10 of everyone above category 8 (whereas the severity categories could theoretically rise to a maximum of 17 to include all the possible levels of disability), even in categories 9 and 10 there are still substantial numbers of people who are not sufficiently heavily disabled to incur high extra costs.

Comparing the findings of the two questionnaires used by us, we see a 58% difference in the figures for average weekly expenditure elicited by the OPCS style questionnaire 1 and the DIG questionnaire 2 (£41.84 and £65.92 respectively) which may be directly attributable to the interview schedule and the interviewing techniques used.

But the most astonishing figure of all is the difference between the findings-of the DIG questionnaire 2 and those of the original OPCS study - 271% higher where expenditure is actually being incurred (£81.90 compared with £30.20) for people in categories 9 and 10) and 694% higher for all the sample (£65.92 compared with £9.50).

Overall in our sample 47% of an individual's total weekly income is spent on the extra costs of disability (this excludes Case G whose wife's earnings make it possible for him to spend almost his whole personal income on the extra costs of his disability). This figure compares interestingly with Mavis Hyman's 1977 study of disabled people in wheelchairs which showed that her sample spent on average 24% of their weekly income on meeting the extra costs of disablement.

We have concentrated on the main areas of extra costs and shown what these actually are for some people with severe disabilities, though we deliberately avoided interviewing people whose disabilities are quite exceptionally severe. And we have demonstrated the difference in results produced by different interviewing schedules and techniques. But, like the OPCS survey, we have not attempted to cover unmet needs in any detail, nor to cover opportunity costs and loss of earnings. But these are also major factors in the financial deprivation of disabled people so our survey cannot be considered to be complete.

The Government has been awaiting the results of the OPCS surveys in order to embark on a major review of disability benefits. We believe we have shown that the results in the OPCS second report cannot be used as the basis for making policy decisions about extra costs. They must be supplemented by other information about the high extra costs of disability. What is needed now is an in-depth study of disabled people using the techniques we have shown

to work and concentrating on a sample of people with disabilities that cause significant extra costs. If this study could report within a year to 18 months it should still be possible to influence social security policy development.

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APPENDIX ONE

Extra costs sheets

The detailed extra costs sheets are presented here. They follow the order of the listings in Table 1.

The benefits received by each person are recorded as follows: invalidity benefit (IVB), severe disablement allowance (SDA), income support (IS), attendance allowance (AA), mobility allowance (Mob A), payments from the Independent Living Fund (ILF) and child benefit.

At the foot of each sheet we record the interviewee's subjective views of his/her financial situation and standard of living.

The data in the column headed "OPCS" was elicited using Questionnaire 1 in appendix 2, and that in the column headed "DIG" by Questionnaire 2 in appendix 3.

DISABILITY Vascular disease with circulatory problems and right leg below-knee amputation

HOUSEHOLD COMPOSITION Lives alone

INCOME £102.65 comprising IVB £46.45 Mob A £23.05 AA £32.95

EXTRA WEEKLY COSTS (£)	OPCS	DIG
1 Home services	-	-
2 Unprescribed medication	0.80	2.12
3 Laundry	3.00	3.50
4 Clothing & bedding	0.57	2.81
5 Food	4.00	5.70
6 Fuel	D/K	3.75
7 Transport	20.00	29.05
TOTAL	28.37	46.93

PERSONAL VIEW OF FINANCIAL SITUATION

Scraping by

SATISFACTION WITH STANDARD OF LIVING

Very dissatisfied - "I lead such a frugal life"

B. NAME Glen Kelly

Age 59

DISABILITY

Meniere's disease, tinnitus, diabetes

HOUSEHOLD COMPOSITION

Lives alone

INCOME £104.27 comprising IVB £52.22 Occupational pension £29 per week Mob A
£23.05

EXTRA WEEKLY COSTS (£)

OPCS

DIG

1 Home services

44.50

44.50

2 Unprescribed medication

1.00

5.60

3 Laundry

0.75

1.27

4 Clothing & bedding

5.76

7.40

5 Food

2.50

12.50

6 Fuel

2.19

2.25

7 Transport

1.25

8.00

TOTAL

57.95

81.52

PERSONAL VIEW OF FINANCIAL SITUATION

Scraping by - "it's a choice between food and fuel"

SATISFACTION WITH STANDARD OF LIVING

Fairly dissatisfied - "I'm robbing Peter to pay Paul. I have to sell things like books and china to afford big items"

C. NAME Violet Evans

Age 55

DISABILITY

Spondylosis, osteo-arthritis, oedema

HOUSEHOLD COMPOSITION

Lives alone

INCOME

£74.09 comprising Widow's pension £22.10 IS £28.94 Mob A £23.05

EXTRA WEEKLY COSTS (£)

OPCS

DIG

1 Home services

1.25

1.25

2 Unprescribed medication

1.25

1.97

3 Laundry

-

-

4 Clothing & bedding

3.04

3.55

-

5 Food

10.00

6 Fuel

4.80

6.00

7 Transport

D/K

0.60

TOTAL

10.34

23.37

PERSONAL VIEW OF FINANCIAL SITUATION

Scraping by - "I'm just keeping my head above water"

SATISFACTION WITH STANDARD OF LIVING

Very dissatisfied

D. NAME Eric Pullen Age /40

DISABILITY Spinal injury resulting in quadraplegia

HOUSEHOLD COMPOSITION Lives alone

INCOME £127.20 comprising IS £71.20 Mob A £23.05 AA £32.95

EXTRA WEEKLY COSTS (£)	OPCS	DIG
1 Home services	-	-
2 Unprescribed medication	2.00	3.29
3 Laundry	1.24	2.27
4 Clothing & bedding	D/K	5.71
5 Food	5.00	5.00
6 Fuel	4.80	5.76
7 Transport	D/K	25.00
TOTAL	31.04	25.00

PERSONAL VIEW OF FINANCIAL SITUATION

Scraping by

SATISFACTION WITH STANDARD OF LIVING

Neither satisfied nor dissatisfied

E. NAME Dan East Age 39

DISABILITY Arthritis, back injury following accident

HOUSEHOLD COMPOSITION Wife and two children

INCOME £128.54 comprising IVB £91.34 Child benefit £14.15 Mob A £23.05

EXTRA WEEKLY COSTS (£)	OPCS	DIG
1 Home services	3.75	3.64 3.22 3.12 9.25
2 Unprescribed medication	1.25	9.75 10.78
3 Laundry	2.88	59.76
4 Clothing & bedding	2.50	
5 Food	2.69	
6 Fuel	20.00	
7 Transport	33.07	

TOTAL

PERSONAL VIEW OF FINANCIAL SITUATION

Getting into difficulties - "Last year was difficult, this year it's a nightmare"

SATISFACTION WITH STANDARD OF LIVING

Very dissatisfied

F. NAME Rob Brown Age 42
DISABILITY Multiple sclerosis diagnosed 10 years ago

HOUSEHOLD COMPOSITION Wife and five children

INCOME £252.25 comprising IVB & IS £160.00 Child benefit £36.25 Mob A £23.05

EXTRA WEEKLY COSTS (£)	OPCS	DIG
1 Home services	-	-
2 Unprescribed medication	3.25	7.20
3 Laundry	1.25	1.37
4 Clothing & bedding	2.40	3.53
5 Food	35.00	35.00
6 Fuel	17.07	32.65
TOTAL	64.73	86.25

PERSONAL VIEW OF FINANCIAL SITUATION

Permanently in debt

SATISFACTION WITH STANDARD OF LIVING

Fairly dissatisfied

G. NAME Roger Sharp Age 34

DISABILITY Crushed vertabrae, oster-arthritis, curvature of the spine, sciatica

HOUSEHOLD COMPOSITION Living with wife who is employed

INCOME £150.75 comprising SDA £24.75 AA £32.95 Mob A £23.05 ILF £70.00

EXTRA WEEKLY COSTS (£)	OPCS	DIG
1 Home services	73.45	73.45 13.08
2 Unprescribed medication	10.00	4.83 10.14 15.00 11.08
3 Laundry	5.00	12.50
4 Clothing & bedding	9.61	
5 Food	15.00	140.08
6 Fuel	9.61	
7 Transport	10.00	
TOTAL	132.67	

PERSONAL VIEW OF FINANCIAL SITUATION

Getting into difficulties

SATISFACTION WITH STANDARD OF LIVING

Very dissatisfied - "We balance our outgoings by using credit cards"

H. NAME Carl Dyer Age 62

DISABILITY Massive cardiac arrest, major stomach surgery, foot deformity and peroneal muscular atrophy

HOUSEHOLD COMPOSITION Living with wife

INCOME £134.53 comprising IVB & IS £78.58 AA £32.5 Mob A £23.05

EXTRA WEEKLY COSTS (£)	OPCS	DIG
1 Home services	-	-
2 Unprescribed medication	1.25	6.69
3 Laundry	D/K	0.65
4 Clothing & bedding	3.84	4.94
5 Food	2.50	11.50
6 Fuel	6.92	7.75
7 Transport	D/K	29.27
TOTAL	14.51	60.80

PERSONAL VIEW OF FINANCIAL SITUATION

Scraping by

SATISFACTION WITH STANDARD OF LIVING

Fairly dissatisfied

I. NAME Nora Coombs Age 67

DISABILITY Complete lesion paraplegic (T6 + T7) due to abscess on spine 40 years ago

HOUSEHOLD COMPOSITION Living alone

INCOME £175.95 comprising SDA & IS £69.95 AA £32.95 Mob A £23.05 ILF £50.00

EXTRA WEEKLY COSTS (£)	OPCS	DIG
1 Home services	55.00	55.00
2 Unprescribed medication	10.00	10.00
3 Laundry	2.25	4.72
4 Clothing & bedding	2.88	8.94
5 Food	6.00	10.00
6 Fuel	8.65	8.65
7 Transport	7.50	11.15
TOTAL	92.28	108.46

PERSONAL VIEW OF FINANCIAL SITUATION

Just getting by only through cutting back on other things - "I'd rather be hungry than cold"

SATISFACTION WITH STANDARD OF LIVING

Very dissatisfied - "it's the usual drag"

J. NAME Mary Webb

Age 69

DISABILITY Polyarteritis nodosa, cervical spondylosis, transient ischaemic attacks, bronchitis, myopathic atrophy

HOUSEHOLD COMPOSITION Living alone

INCOME £106.38 comprising Retirement pension £43.62 Occupational pension £39.71 Mob A £23.05

EXTRA WEEKLY COSTS (£)	OPCS	DIG
1 Home services	8.45	13.45
2 Unprescribed medication	2.50	4.84
3 Laundry	1.50	3.51
4 Clothing & bedding.	D/K	5.01
5 Food	D/K	13.00
6 Fuel	D/K	-
7 Transport	5.00	6.82
TOTAL	17.45	46.63

PERSONAL VIEW OF FINANCIAL SITUATION

Permanently in debt "but I try not to worry"

SATISFACTION WITH STANDARD OF LIVING

Fairly dissatisfied

K. NAME Ann Curry Age 37

DISABILITY Polio with paralysis of arms and legs

HOUSEHOLD COMPOSITION Lives with adult daughter

INCOME £1414.53 comprising SDA & IS £88.53 AA £32.95 Mob A £23.05

EXTRA WEEKLY COSTS (£)	OPCS	DIG
1 Home services	40.50	40.50
2 Unprescribed medication	1.50	3.69
3 Laundry	-	0.17
4 Clothing & bedding	1.34	4.02
5 Food	-	7.00
6 Fuel	5.76	9.16
7 Transport	-	2,65
TOTAL	49.10	67.19

PERSONAL VIEW OF FINANCIAL SITUATION

Scraping by

SATISFACTION WITH STANDARD OF LIVING

Fairly dissatisfied

L. NAME Andy Smith Age 27

DISABILITY Totally blind and partially deaf, suffered road traffic accident, bladder problems and facial injuries

HOUSEHOLD COMPOSITION Wife and two children

INCOME £171.75 comprising IVB £91.35 Child benefit £14.50 AA £32.95

EXTRA WEEKLY COSTS (£)	OPCS	DIG
1 Home services	-	-
2 Unprescribed medication	2.50	3.78
3 Laundry	2.00	4.22
4 Clothing & bedding.	-	2.28
5 Food	-	10.84
6 Fuel	1.92	1.75
7 Transport	D/K	16.07
TOTAL	6.42	38.94

PERSONAL VIEW OF FINANCIAL SITUATION

Getting into difficulties

SATISFACTION WITH STANDARD OF LIVING

Very dissatisfied

M. NAME Jenny Read Age 55

DISABILITY Arthritis in lower
body,
lymphoedema,
mastectomy and
partial removal of
bladder

HOUSEHOLD COMPOSITION Lives
alone

INCOME £74.61 comprising IVB &
IS £51.56 Mob A £23.05

EXTRA WEEKLY COSTS £

	OPCS	DIG
1 Home services	4.00	4.00
2 Unprescribed medication	3.00	10.00
3 Laundry	2.00	2.40
4 Clothing & bedding	8.65	10.01
5 Food	6.00	20.00
6 Fuel	0.28	0.65
7 Transport D/K		3.50
TOTAL	23.93	50.56

PERSONAL VIEW OF FINANCIAL
SITUATION

Getting into difficulties - "it's getting
harder"

SATISFACTION WITH STANDARD OF
LIVING

Neither satisfied nor dissatisfied

APPENDIX TWO QUESTIONNAIRE
1, BASED ON THE OPCS STUDY

Home Services

1. Have you had any of these services in the past year Yes/No

Local authority home help	01
Meals on wheels	02
Laundry service	03
Incontinence service	04
Night sitting service	05
Mobility/technical officer for the blind	06
Social worker	07
Voluntary worker	08
Visiting service	09
Private domestic help	10
Private nursing help	11
Other (please describe)	12

- (a) Ring no of service
(b) Name/description of service
(c) How often does the Come?
Every day or nearly
2 or 3 times a week
Once a week
Less than once a week

(d) Do you pay anything for the Yes/No

If yes
(i) How much do you pay £ p
Amount

If has a LA home help

(e) How many hours a week do you have a home help for ?
Hours

If varies give average

Extra Personal Costs

2. Because of your health problem/disability do you regularly take or use any medicines, drugs tablets or anything else which you obtain on a doctor's prescription?
Yes/No

Are you exempt from prescription charges
Yes/No

3. Can you tell me whether you regularly spend extra on any of these items because of your health problem/disability?

Tissues/toilet paper/kitchen roll	01
Cotton wool	02
Dressings/elastoplast	03
Elastic bandages/supports	04
Talcum powder	05
Antiseptic or soothing creams	06
Vitamins	07
Painkillers and other medicines not on prescription	08
Disinfectant/bleach	09
Other medical supplies	10

Description

Do you (or your Spouse) pay for this yourself
Yes/No

About how much extra did you spend in the last 4 weeks on?
£

Are there any items on this list which you need to spend more on but can't afford to?
Yes/No

If yes enter number from list and describe item

Description Item No

4. Does your health problem/disability mean that you spend extra on

Yes/No

washing clothes or bed linen?.....
dry cleaning?
sending things to the laundry?

How much extra have you spent in the past 4 weeks on washing/dry cleaning/laundry, because of your health problem/disability?

£ p D/K

Do you think that you need to spend more on washing, dry cleaning or laundry because of your health problem/disability, but can't afford to? Yes/No

5. Does your health problem/disability mean that you spend extra on clothing or bedding, for example any of the things on this list?

Yes/No

- Thermal underwear 01
- Other underwear (except incontinence pants) 02
- Pyjamas/nightdresses 03
- Trousers/skirts/dresses 04
- Shirt/blouse 05
- Socks/tights/stockings 06
- Cardigans/jumpers 07
- Coats/jackets 08
- Gloves 09
- Shoes 10
- Bedding (not protective coverings) 11
- Other 12

Do you (or your partner) pay for the extra cost of clothing/bedding yourself?

Yes/No

During the past year, about how much extra have you spent on clothing/bedding because of your health problem/disability?

£ p D/K

Are there any items on the list which you need because of your health problem/disability but can't afford?

Yes/No

a) If yes enter item number from list and describe item.

6. Does your health problem/disability mean that you have to have a special diet?

Yes/No

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

Yes/No

(b) Do you get any food on prescription or any allowance from the DSS for your diet?

Yes/No

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

£ p

Exclude: cleaning materials, pet food, cigarettes, alcohol, sweets

Include: cost of school/canteen meals/takeaways

Does your health problem/disability mean that you spend more on food than you would if you had no health problem/disability? Yes/No

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

Require special diet Yes/No

Other (specify)

Of the money spent on your food each week, how much is extra because of your health problem/disability? £ p

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

Yes/No

7. Fuel

Some people with a health problem or disability spend less on fuel than other people because they are confined to one room and only have to heat that one; others spend more because they are indoors more or need to keep warmer or need to use more hot water.

APPENDIX THREE

QUESTIONNAIRE 2, BASED ON DIG EXTRA COSTS INTERVIEWS

Home Services

1. I will read to you a list of services. Have you had any help from any of these services in the past year?

- Local authority home help 01
- Meals on wheels 02
- Laundry service 03
- Incontinence service 04
- Night sitting services 05
- Mobility/technical officer for the blind 06
- Social worker 07
- Voluntary worker 08
- Visiting service 09
- Private domestic help 10
- Private nursing help 11
- Other 12

Name of service
 How frequent
 Do you pay?
 How much?

Would you have more of any service (if you could afford it?)
 Which service?
 How much?

Would you buy in any of those services which you do not have at the moment if you could afford it?
 Which service?
 How many hours?

Prescriptions

2. Do you regularly take any kind of prescribed medication? Yes/No

How often is this? Specify

How much do the prescriptions cost over a year? £ p

Is there any expense involved in getting prescriptions? Yes/No

If Yes How much?
 How often?

Have you to make a special journey to pick up prescriptions? Yes/No

If Yes How much?
 How often?

Do you pay someone to collect them for you? Yes/No

If Yes How often?
 How much?

Unprescribed medication/chemist items

3. Do you need to buy extra amounts of the following because of your disability?

- Tissues/toilet paper/kitchen roll 01
- Cotton wool 02
- Wet wipes 03
- Dressings/elastoplast 04
- Elastic bandages/supports 05
- Talcum powder 06
- Antiseptic or soothing creams 07
- Vitamins 08
- Painkillers and other medicines not on prescription 09
- Disinfectant/bleach 10
- Other medical supplies 11

Which?
 How often?
 How much?

Are you able to get every item you need? Yes/No

If No Why not?

Would you get more items if you were able to afford them? Yes/No

4. Extra laundry costs

Do you have Extra laundry costs because of incontinence? Yes/No

Extra laundry costs because you use special creams/medication or you sweat a lot Yes/No

How much extra soap powder do you need?
Cost How often

How much extra fabric softener/other?
Item Cost How often

Do you need your washing machine serviced more often?
How often Last bill

Is your laundry (or part of it) sent out?
How often How much

Do you have any extra dry cleaning costs as result of your disability Yes/No
If yes How often How much

Do you need to spend more on laundry/dry cleaning but can't afford to? Yes/No

If Yes How much do you think you need to spend per week?

5. Clothing & Bedding

Do you have any extra costs for clothing or footwear because of your disability?
Because

You need clothes or shoes made to fit specially (use list for prompt)

Which item How much

Do you need more clothes because you feel the cold?

- | | |
|---|----|
| Thermal underwear | 01 |
| Other underwear (except incontinence pants) | 02 |
| Pyjamas/nightdresses | 03 |
| Trousers/skirts/dresses | 04 |
| Shirt/blouse | 05 |
| Socks/tights/stockings | 06 |
| Cardigans/jumpers | 07 |
| Coats/jackets | 08 |
| Gloves | 09 |
| Shoes | 10 |
| Bedding (not protective coverings) | 11 |
| Other | 12 |

Which items How much How often

Can you only wear certain materials (because of skin complaint or allergy)?

Which items How much How often

Do clothes or shoes wear out more quickly because of the following:

Wear and tear Extra washing Incontinence

If one of the above please say why

Reason Which item How often How much

Can you always afford to replace worn-out items of clothing or footwear?

Do you buy second hand clothes often?

How much extra do you think you would need to clothe yourself properly?

Do you need to spend extra on bedding?

If yes Why
Which item How much How often

Do you have sufficient bedding at the moment? Yes/No

If no Which items Why

6. Diet

Does your condition mean you need a special diet? Yes/No

What is the diet? Do you have to eat special foods? i.e.

What items How much How often

Do you eat the same food as the rest of the family or do you have to prepare something different?

Same food Eats different food

What items How often How much

Because of your disability, do you buy more expensive foods, e.g. frozen, canned or prepared foods which involve less work in cooking?

Yes/No

How often How much

Do you not always stick to your diet
Yes/No

If no Why

Do you incur any extra costs for food because medication makes you very hungry?
Yes/No

How often How much

Would you spend more on your diet if you had more money?
Yes/No

Would you spend more on food generally if you could afford to?
Yes/No
If Yes How much

Do you ever go without meals/certain items of food
Yes/No
If Yes Why How often

7. Fuel

How do you heat your house?

Gas central heating	01
Electric central heating	02
Oil central heating	03
Storage heaters	04
Gas fires	05
Electric fires	06
Coal fires	07
Oil heaters	08
Bottled gas	09

If has central heating

Have you had central heating installed or was it already in the house?

Central heating installed already in

Did you have the heating installed because of your disability or would you have had it put in anyway?

Central heating installed because of disability

Would have had heating installed anyway

How much did this cost you and when was this?
£ 19.....

If no central heating

(d) Do you need central heating because of your disability
Yes/No

(e) How much would it cost of have installed?
£

Extra fuel costs

A. How much did you pay for gas, electricity, coal and oil over the last 13 months?

B. Could you estimate how much was due to your extra costs?
A B

Gas
Electricity
Coal
Oil/paraffin/bottled gas

Do you have additional fuel costs because

1. you are at home more than would otherwise by the case and the heating is on more
2. heating is on at night
3. you feel cold and the house has to be hotter than would otherwise be
4. you need extra hot water for washing clothes
5. of extra consumption of electricity for washing machine and tumble dryer
6. extra baths
7. you have the lights on at night
8. you use electric blankets a lot

Number How often

Do you heat all the rooms in your home at you use?
Yes/No

Do you not use any rooms in your home because you cannot afford to heath them?
Yes/No

Do you worry about your heating bills?
Yes/No

Do you need the heating on all day all year round?
Yes/No
If yes Why?

Do you remain cold because you don't put the heating on?
Yes/No
If Yes Why?

8. Transport & Travel Costs

Do you (or members of your household) own or have the use of a car? Yes/No

Do you have a car because of you disability or would you anyway?

Because of disability
Would have anyway

Do you drive? Yes/No
Does it cost any extra to run your car because of your disability over the year? Yes/No

Include, where applicable cost of running a car/second car because of _____
Extra petrol costs because of
Extra journeys – to hospital, doctors etc

If yes – how much extra do you estimate it costs over a year? £

Apart from the extra costs of running a car are there any other extra transport costs
Yes/No

If yes – what are these extra costs and how much do they amount to over a year?
E.g. Taxis

What costs? How often? How much?

Would you go out more often if you could afford it?

9. Your financial situation

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 getting by
In difficulty permanently in debt
Other

We have talked about all the areas where extra costs are incurred because of _____ Are there any items you would spend more on if there was extra money, but are unable to afford to?

Do you have any financial worries or problems at present? Yes/No

Is there anything else that you would like to discuss with me that we haven't covered?

APPENDIX FOUR BENEFIT INCOME ANALYSIS USED IN CONJUNCTION WITH BOTH
QUESTIONNAIRES

At present are you receiving any of the following state benefits?

	Yes	No	Weekly Amount
1. Child benefit			
2. Family credit			
3. NI retirement pension or old age pension			
4. Income support			
5. NI sickness benefit (not Employer's SSP)			
6. Unemployment benefit			
7. Invalidity benefit, pension or allowance			
8. Sever disablement allowance or NCIP or HNCIP			
9. Industrial injury disablement benefit			
10. War disablement benefit			
11. Attendance allowance (higher rate)			
12. Attendance allowance (lower rate)			
13. Mobility allowance			
14. Invalid care allowance			
15. Widow's pension or allowance or other widow's benefit			
16. Any other state benefit or allowance (specify) except housing benefit			

Include constant attendance allowance under 10 or 11.