

# Handicapped by Numbers

A critique of the  
OPCS Disability Surveys

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# HANDICAPPED BY NUMBERS -

## A Critique of the OPCS Disability Surveys

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### ABSTRACT

This paper consists of an exposition and critique of the first two reports of the OPCS surveys of disability in England, Scotland and Wales.

Inadequacies of theoretical perspective and of methods are identified, and implications drawn for disabled people and for welfare providers.

### THE SIGNIFICANCE OF THE OPCS DISABILITY SURVEYS

The recent White Paper on care in the community (1) voices the expectation that there will be 900,000 severely disabled adults living on the community by 2001, whilst the bewildering succession of short-term occupants of the post of 'minister for the disabled' have repeatedly insisted that provision for disabled people will be reviewed on the basis of the OPCS survey data. It is therefore important that social workers working with disabled people have some understanding of this data, both for what it can tell us about the situation of disabled people, to which question 1 will argue the answer is "not much", and for how it can illuminate the processes by which government continues to sell disabled people short through the utilisation of so-called objective evidence, Official Statistics.

Like Max Bygraves, I would like to start off by telling a story. In Greek mythology, the robber Procrustes would invite travellers to spend the night in his wonderful bed, that fitted everyone. If they were too short for the structure he would stretch them, if too tall, cut off those portions of their anatomy that were deemed excessive; they rarely survived the ordeal, but in this way the reputation of his sleeping arrangements was preserved. In addition to this, and most significantly, he was now able to make off with the property of his overnight guests. Whilst some disabled people may see shades of Procrustes in some of the activities of

rehabilitative medicine, another area where his practices have found favour is amongst the compilers of Official Statistics. Indeed it is my contention that they more thoroughly reflect the Procrustean project, since the consequence of their statistical mutilations of the experience of disability is to enable the State to justify its failure to provide disabled people with the necessary resources to exercise our human rights, in a word, robbery. When confronted with the products of the Office of Population Censuses and Surveys, often referred to as Official Statistics it is then as important to consider the implications of their being Official as to analyse their significance as Statistics.

As far as disabled people are concerned, Stone (2) has indicated how the legitimacy or otherwise of claims about disability has been a matter of state concern since the concomitant development of the earliest stages of industrial capitalism and the most rudimentary elements of state welfare. The simple distinction between those unable and those unwilling to work, the deserving and the undeserving poor has, with increased sophistication in the division of labour, similarly become more refined, with new definitions, based on clinical or functional criteria, being employed.

Thus the new survey is presented as superior to others in part because its 10 point classificatory scheme is subtler than the 4 categories of its immediate predecessor. The thing it shares with previous studies, however, which far outweighs any differences, is that disability is seen as essentially a property of individuals rather than a consequence of particular social systems. As Oliver points out (3), a comparison of two different sets of questions on the same subjects, the first from an individual perspective as employed in the OPCS research. the second from a social one, makes this distinction apparent-

- 1) What complaint causes your difficulty in holding, gripping or turning things?
- 2) Do you have a scar, blemish or deformity which limits your daily activities?
- 3) Have you attended a special school because of a long term health problem or disability?
- 4) Does your health problem/disability affect your work in any way at present?

could be reformulated as:

- 1a) What defects in the design of everyday equipment like jars, bottles and lids causes you difficulty in holding, gripping or turning them?
- 2a) Do other people's reactions to any scar, blemish or deformity you may have, limit your daily activities?
- 3a) Have you attended a special school because of your education authority's policy of sending people with your long-term health problem or disability to such places?
- 4a) Do you have problems at work as a result of the physical environment or the attitudes of others?

It is a political decision, conscious or otherwise, to employ questions of the first type rather than the second. Since state researchers, whatever party is in power, have consistently asked individualising rather than socialising questions on a whole range of subjects it should come as no surprise that they do this on disability, which is as political a subject as any other.

Even for someone who finds this a contentious point, the notion that functional limitation can be investigated without regard to the different social and environmental contexts of people's lives, as the standardised OPCS questions attempt to do, is a dubious one. Any response about difficulties with an activity of daily living, e.g. using the lavatory, getting dressed, eating or drinking, only has its meaning in the context of the facilities available to that individual to carry out the task -an individual able to use the Euro-American pedestal may report severe difficulties east of Suez. An inability to use the right hand for eating will have more severe social consequences for someone from a Muslim than from a Roman Catholic background, for whom in turn the prohibitions of Leviticus will have implications for any aspirations for the priesthood. Gender and age are also important variables to be taken into account in assessing the significance of particular disabilities, whilst class in both financial and cultural aspects, also has obvious effects on people's experience of disability. There are then, these inevitable limitations to any understanding which fails to relate functional limitation to its social context, even in this limited sense of the word. Functional definitions are essentially State definitions, in that they relate to the major concerns of the state; as regards production, capacity to work, as regards welfare, demands that have to be met from revenue if they cannot be offloaded on some other party; they ignore any consideration of the role of the State in the construction and perpetuation of disability.

To say this is to say no more nor less than one would say of any other set of Government inspired statistics; that they reflect the interests of Government (4) .

One question often begged in the discussion of data is 'should it be gathered at all? Leaving aside the awkward question of whether money spent on research could more usefully be employed in meeting needs which are already quite apparent, there is, for example, an ongoing debate over the very gathering by the State of data on ethnic origin (5). Certainly most would agree that data gathering in Nazi Germany was not unconnected with the state's project of genocide. In a less extreme situation, registration as a disabled person is seen as of little if any value in Britain today and it is unlikely that Topliss's (6 P49) explanation of the mere 1/2 million names on the 1978 Disabled Person's Employment Register as 'undoubtedly due to the different definitions of disability employed' is a feasible one. Rather, any possible benefit that might result from registration accrues to the employer, in terms of his meeting his quota under the albeit unenforced Disabled Persons (Employment) Acts. The 'problem' with the figures is then more likely to result from a political source (the disabled persons recognition of the pointlessness to him/herself of registering) than to the 'technical' problem hypothesised by Topliss.

Whilst the proponents of Action Research can adduce some evidence for the beneficial effects of the active involvement of the subjects of their researches in the investigation and transformation of their own situation, the subjects of Official Statistics are invariably the passive objects of the researcher's investigations. Oakley (7) has argued that this is an inherently oppressive process, in that it not only does nothing to aid the transformation of the subjects' lives, but may also confirm and reinforce sentiments of ignorance and passivity in those interviewed. Likewise, the spurious objectivity of published findings upon which welfare agencies often rely for evidence, can reinforce for the whole range of people to whom the research is supposed to apply, oppressive definitions of their reality.. Both these aspects deserve consideration as regards the OPCS surveys of Disability. The very process of isolated disabled people being asked this kind of individualised question by someone in authority can serve to disempower them, since it reproduces and reinforces, as it ostensibly asks 'neutral' questions, a personal tragedy view of disablement. Similarly, the published findings, which claim to tell us the average cost of particular degrees of disability, or that a disfigurement which 'severely affects one's ability to lead a normal life' has a 'severity

score' of only 0.5, must, unless challenged, have their effects on the lives of disabled people.

As Hindess has pointed out (8 p12) there are two kinds of instruments employed in the gathering of Official Statistics, "instruments of the social survey and 'conceptual' instruments, the system of concepts and categories governing the assignment of cases into classes". In this paper I argue that the OPCS surveys are deficient with respect to both these aspects, that both the kinds of things enquired about are inappropriate and that the way in which the researchers go about trying to find out the answers to these inappropriate questions leaves much to be desired. But, given that a body of data has been gathered, whatever one thinks of the propriety or mode of its accumulation, what also needs consideration is whether, and if so in what ways, such data can be utilised in the interests of the objects of such investigations, in this case disabled people. I thus also try to indicate where I think the OPCS surveys do yield significant information about the situation of disabled people, and how it might be utilised.

## The Reports

The OPCS surveys of disability in Great Britain were commissioned by what was then the DHSS in 1984. The stated objective was to provide up-to-date information about the number of disabled people in Great Britain with different levels of severity and their circumstances, for the purposes of planning benefits and services. Four separate surveys were carried out between 1985 and 1988, covering adults in private households, children in private households, adults in communal establishments and children in communal establishments, and the results published in six reports. This paper will examine the first two reports, which are of the most general significance.

Previous investigations by the OPCS on behalf of the Ministry of Health nearly twenty years ago had culminated in a study of almost 250,000 households, of which 8,538 were followed up and interviewed in depth (9, 10). Degree of disability was operationalised in terms of a series of questions concerning capacity for self-care.

The responses to these questions resulted in total adult population projections, in terms of a division into four categories.

	Approx number
1) very severely handicapped	157,000

2)	severely handicapped	356,000
3)	appreciably handicapped	616,000
4)	impaired	1,942,000
	Total	3,071,000

Approximately 7.8% of total population

Since one of the main purposes of the survey was to estimate the number of people who might qualify for attendance allowance, impairment, in this survey, is distinguished from handicap, in terms of self-care needs, the former term implying nil or minimal need.

The most obvious feature of the new survey is that it results in the upward revision of estimates of the number of disabled adults in England, Scotland and Wales from just over three to nearly six million adults. The North of Ireland, for no obvious theoretical reason, but possibly because it was feared that high rates of injury associated with English occupation would become apparent, possibly because of similarly associated difficulties in carrying out research, was excluded from the investigation. What accounts for this discrepancy? Has life become that much more dangerous so that nearly three million more people have been irreversibly injured, or some hitherto unperceived plague maimed them? Has medicine advanced so far it has kept that many more people from dying, albeit with reduced physical capacities? The answer is far more prosaic, and to do with definitions; the 1971 survey was concerned with physical impairments that severely limited activities, the new survey with a much wider definition.

We should thus not look for an answer to the question 'what is the true number of disabled people?' Rather we should recognise, as Oliver has pointed out in relation to disability (II) and other writers have argued in more general and wide ranging ways (4,8) that all statistics are constructed by particular people in particular social and historical contexts for particular purposes, and can only be understood as such.

The first report (12) describes the main concepts and methods common to all the surveys and presents the prevalence estimates from the two surveys of disabled adults.

This disability survey attempts to be more wide ranging than the previous one, trying to cover all types of disability whatever their origin, and setting a lower 'disability threshold'. The survey distinguishes

thirteen different types of disability and produces a formula to establish severity categories.

This procedure gives rise to the following projections for the population as a whole.

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.	477,000
8.	338,000
9.	285,000
10.	102,000
Total	5,780,000
Living in establishments	422,000
Grand Total	6,202,000

(Adapted from Table 3.1 Martin & White 13)

Examples of who fall into categories 1-3 indicate that these individuals, whose daily activities are restricted, but not severely so, may not have been eligible for inclusion in the least severe 1971 survey category of 'impairment'. If we were to subtract these individuals from our total, the estimated total proportion of the population who are 'disabled' would roughly correspond with the 1971 figure.

However a third source, the 1985 GHS estimates, based on the answers to two questions (12 p20), gives an overall figure which is considerably higher in total, and for younger (less than 70) age groups. The OPCS surveys makes no significant attempt to establish the geographical distribution of disabled people, nor is this failure justifiable by methodological difficulties, since the 1971 survey (9) did precisely this. This omission seriously weakens the explanatory and policy-making potential of the data. Whilst the ten point severity scale is ostensibly a more sensitive measure than previous systems, the procedure used to judge severity is a complex one, which at base rests on the subjective judgements of a panel, an unspecified number of whose members were

themselves disabled, on the importance of a somewhat arbitrarily selected subset of incapacities. Essentially, despite protestations of the researchers to the contrary, judges were being asked, in a general way, and thus with no regard to individual situation or social contexts, to judge which conditions are 'worse'. In so far as the results of such procedures mean anything, they merely reflect a cruder version of any pre-existing cultural consensus in the groups from which the panel of judges is culled, cruder since most common beliefs about disability are more sophisticated than to attempt to provide an answer to questions of the 'is it worse to be blind or deaf' kind. The spurious objectivity implied by complex quantification's and ten- point scales should not fool anyone into believing that 'severity' is identified by the OPCS surveys in anything more than the most general of ways . (See 14 for a fuller discussion).

### AGE

The report is to be commended for separating ageing from disability. It shows that whilst the vast majority (69%) of disabled people are over pension age, a similar proportion of pensioners (355 per thousand) are NOT disabled. Only amongst those of 85 or more are disabled people in the majority.

### RACE

As far as race is concerned the treatment is woefully inadequate. One question yields the information that disability rates for 'Asians' and 'West Indians' are 12.6 and 15.1 per cent respectively (after adjustment for age distribution) compared to an equivalent figure for 'Whites' of 13.7%. The rest of the data is not systematically discussed in race terms, nor is this justified, for example in terms of small sample size, leading to the conclusion that the survey does not take race seriously. Some recent work, (15) indicates that the experience of disability for individuals from minorities already oppressed by racism requires separate and detailed analysis. Through its failure to systematically employ a 'race' variable, the OPCS survey has passed up the chance of gathering some general data which could have been of importance to those working in this area.

### SEX

The survey (table 3.6) indicates that there are considerably more disabled women than men except in the lowest severity levels, with 3.6 million disabled women compared to 2.5 million disabled men in the country as a whole. This excess is judged by the authors to be significant only in older people (75+) and may in large part be accounted for by greater female longevity. The increased prevalence of a number of functionally defined 'disabling' conditions in ageing, also contributes to

the increased 'disability' of ANY more elderly population. Since women generally live longer than men, they will be disproportionately included within this population.

However, it is also the case that the survey found (12 p22 Table 3.7) an increased prevalence rate (54 male 63 female per 1,000 in private households) in the 16-59 age group, a difference the authors of the report deem insignificant.

This apparently contrasts to the 1971 survey, where rates for males of working age with some impairment were rather higher (9 p5) and numbers greater (ibid p4). This led Oliver to argue (II p40) "up to the age of 50 both in sheer numbers and prevalence more men are likely to be defined as disabled than women. Two possible reasons are:

- i) many more men work and risk disablement through accidents and work induced illnesses and
- ii) many more young men partake in dangerous sports and leisure activities. ..consequently these figures reflect sexual divisions within society whereby certain activities, both work and leisure. are dominated by males' . .

OPCS 2 does not present its data in a form which allows direct comparison, employing a blanket 16-59 age band; one would not expect them to have done so however if there had been significant differences within it. So what accounts for this apparent turn around in the sexual distribution of disability in people of working age over the last twenty years? It cannot be explained through the inclusion of 'less disabled' individuals in the later survey, since the figures indicate differences at all levels of severity. It does then seem to indicate either

a) a 'real' change

or

b) significantly different methods of measurement between the two surveys. such that they could arrive at reversed rates for sex prevalence.

Whichever of these explanations is correct. the implications are of significance and it is unfortunate that the report does at least not mention

the matter. As a growing body of literature shows, (16, 17. 18) the mode and extent of oppression experienced by disabled women is different in important respects from that of disabled men, and a chance to provide a quantitative dimension to what has up to now been largely. of necessity, a qualitative argument has been missed by the OPCS researchers.

## THE QUESTIONS

Any introductory textbook on social research enjoins the reader to address notions of reliability and validity when examining the tools employed in a piece of research. Reliability in a question employed to elicit information in a questionnaire or on an interview schedule refers to whether we have reason to believe that the question is consistently understood in the same way by the interviewee, and is thus measuring the same thing in different respondents. Validity refers to whether there is reason to believe the question is understood in the same way by the researcher and the respondent, and is thus measuring what the researcher thinks it is and not something else. An examination of the questionnaires and interview schedule employed by the OPCS researchers reveals some significant problems as regards validity and reliability.

Repeatedly the notion of 'difficulty' and 'great difficulty' is employed, both in the postal screening questionnaire and interview schedule.

For example

4) Does anyone in your household have...

- |  |        |
|--|--------|
| a) Difficulty walking for a quarter of a mile on the level | Yes/No |
| b) Great difficulty walking up or down steps or stairs     | Yes/No |

To ask if someone has difficulty is to ask them to make a comparison, which a disabled person is in a particularly unsuitable position to do. For example, the literature informs me, (19 p12) following an explanation in physiological terms, that 'polio survivors work abnormally hard...to accomplish the same activity'. In this sense everything I accomplish with affected parts of my body is 'difficult'. But, having survived polio some 35 years I am in no position to make this judgement experientially, for I have no 'normal' baseline to measure my effort against. Again, by the use of tricks, like wheelies used to get wheelchairs over obstacles, and devices, disabled people survive in hostile environments. If you have a trick to get round the problem, do you still have a 'difficulty?' For people with longstanding disability then, who constitute the vast majority of respondents in the OPCS survey, 'difficulty' is quintessentially a

subjective construct, bearing little relation to 'normal' difficulty or to 'difficulties' confronted by someone with a dissimilar disability. As such it is a singularly inappropriate measuring tool for a supposedly objective assessment, and likely to result in systematic underestimation of the problems confronted, and often successfully dealt with, by disabled people.

## FINANCIAL CIRCUMSTANCES

The second report (13) examines the financial circumstances of disabled adults living in private households. It is based on data from a survey carried out in 1985, and so does not take into account changes, particularly those affecting social security benefits, that have taken place since that time. Various writers have argued that these changes have had the effect of worsening, in a variety of ways, the financial situation of disabled people.

Three specific aims are identified by the researchers:

- 1) to examine the extent to which disability affects people's income ;
- 2) to establish whether extra expenditure is incurred as a result of disability and to estimate the magnitude of that expenditure;
- 3) to evaluate the overall impact of disability on the standard of living and financial circumstances of disabled adults and their families.

## Employment

Disabled adults under pension age were found to be less likely to be in paid work than adults in the general population, allowing for differences in age, sex and marital status. Only 31% of non-pensioner disabled adults were working, this proportion falling from 48% in category one to 2% in category 10 (13 fig-Z.4). No attempt is made to relate these findings to the growing body of literature on unemployment and health (20, 21). Unmarried disabled adults were less likely to be working than married in each age, sex and severity group. as were those over, as opposed to under, 50. (13 table 2.18). Thus marriage and youth seem to be factors associated with likelihood of employment. as well as the more obvious factor of being in a lower severity category. A number of recent small scale studies (22, 23) have indicated the discrimination, direct and indirect. experienced by disabled people in obtaining and keeping jobs, and again it is a pity that the OPCS study did not take the opportunity to explore this further.

## Income

As far as earnings from work were concerned, both men and women disabled full time employees earned less than full-time employees in the general population, which could not be accounted for by differences in hours worked (13 table 3.1). Some evidence of a decrease in earnings was found with higher severity categories for men, but not for women. In discussing a similar pattern in relation to race Smith (24 p 169) suggests that 'part of the explanation for the similarity in the overall levels of wages among white and black women was that the enormous disparity between men and women in this respect left little scope for racial disadvantage to have a further, additive effect'. Whether these facts indicate that low pay follows from disability (discrimination, lower qualifications and thus job levels etc) or that those in low paid occupations are more likely to become disabled (a higher likelihood of impairment in lower social classes) is not determinable via this data. The probability is that the explanation is a combination of the two, that class inequalities and discrimination combine to produce general patterns of disadvantage. For the majority of married disabled adults under pension age at least one member of the family 'was earning, but only 22% of the total of disabled adults lived in such a unit.

The majority of disabled adults (78% of total, 54% of those under pension age) lived in family units containing earners and thus the significance of state benefits was great. Although half of all disabled adults had another source of income besides earnings and benefits, the most common of these were pensions or redundancy payments from a former employer or income from savings and investments, and were thus most likely to be received by older respondents.

Comparisons with the equivalent incomes of families in the general population showed that disabled non-pensioner families had significantly lower incomes than non-pensioners in general: on average 72%. Whilst much of this is due to disabled adults being less likely to have earned income, families with one or more earners still had lower than average incomes than comparable families in the general population.

Disabled pensioners, however were not readily distinguishable in income terms from non-disabled, and this again probably related to the general lower average income of pensioners than non-pensioners, which produces a 'flattening' effect on the figures. In 1983 64% of pensioners were living in poverty or on its margins, compared with 24% under pensionable age (24).

Expenditure

It was found that for all severity-categories there was some extra expenditure involved because of disability. This was divided into 3 types, lump sum expenditure on special items, regular expenditure on special items and regular expenditure on items required by most people but on which disabled people need to spend more.

#### Occasional costs.

Type one, lump sum expenditure, on special items of equipment like special furniture in the year previous to the survey was incurred by only 16% of the sample, spending £78 on average, but with considerable variation between individuals. The average for all disabled adults works out at £12.50 a year. Because of the limited time span the OPCS researchers admit this is likely to be a low estimate of true costs.

#### Regular Costs

Regular expenditure on items required solely because of disability, like prescriptions, costs associated with hospital visits, private domestic help, were incurred by 60% of disabled adults. Amounts and proportions increased with severity-category, with average expenditure for those incurring it being £2.20 a week, or £1.30 for each disabled adult.

The third type of expenditure, 'ordinary' items on which disabled people need to spend more e.g. fuel, clothing, food, travel, home maintenance, was reported by 71% of disabled adults, with an average cost to those incurring it of £6.70, or £4.80 for all disabled adults. Again the proportion of adults with expenditure of this kind and the amount they spent rose with severity.

Adding these two together, the average extra expenditure entailed by disability for all disabled adults amounted to £6.10 a week, or, including the lump sum average, £329.70 a year. This is only an arithmetical average, however and there were considerable variations in actual expenditure, both within and between severity categories.

As well as rising with severity, average extra expenditure rose with income within severity categories, indicating that people may well have spent more if it were available. Altogether 24% of disabled adults thought they needed to spend more because of their disability but could not afford to do so.

An effect of having to spend a proportion of income on items associated with disability is to reduce disposable income. The report examines this in terms of 'equivalent resources', which is arrived at by calculating the

income remaining after disability related expenditure has been subtracted and using equivalence scales to adjust the remaining income for differences in family composition. This is expressed in terms of £=.

On average net equivalent resources were 92% of net equivalent income, that is 8% of income was spent on disability-related expenses. Although the average amount of such expenditure was lower for those on lower incomes, they spent a higher proportion of their income on disability-related expenses. Proportion also rose with severity: those in severity category 10 were spending on average 15%, compared with 4% for category 1.

The average equivalent resources of disabled non-pensioners were £=91.70 per week, compared to £=136.70 for the non-pensioner general population. 41% of disabled non-pensioners had equivalent resources of less than half this amount, compared to 23% of the general population.

The difference between disabled and non-disabled pensioners was not so marked, probably for reasons mentioned above. The use of the notion of equivalent income in making these calculations, whatever reservations one may have about the calculations themselves, is to be welcomed. It makes clear that there are calculable costs of disability which, given the political will, government has the ability to offset, employing a number of alternative or complementary mechanisms, some of which are more attractive to disabled people than others.

### Financial Problems

Altogether 8% of disabled householders thought they were getting into financial difficulties, but there were significant differences between household types, with 36% of the albeit small group of single parents, 23% of single childless householders, but only 3% of pensioners reporting difficulties. Objective calculations tended to confirm subjective views, and both related financial difficulties strongly to equivalent resources.

### Standard of Living

Measures of standards of living are habitually constructed in terms of the lack of named items or activities, which are deemed to be 'basic' e.g. a warm winter coat, meat or fish every other day or 'consumer durables' e.g., washing machine, telephone. In terms of 'relative deprivation' some consumer durables are judged luxuries e.g. videorecorder, whilst others considered 'normal' items of living at a given point in time e.g. refrigerators today, but not in the 1950s. The selection and significance

of these items is involved in the ongoing debate about 'absolute' and 'relative' poverty, and the report assiduously avoids employing these terms. A criticism raised of previous studies, for example Townsend (26) was that they failed to distinguish between not possessing a consumer durable or basic item because you could not afford it, which would be a reasonable indicator of economic deprivation, and not having it because you did not want it, which would not. This study allows for that, and found a proportion of both 'luxuries' and 'basic items' lacking from choice. However, it found a relationship, strongest when calculated in terms of equivalent resources, between disability and inability to afford desired items.

## RESPONSES

It is evidence of the growing strength of organisations for and increasingly of disabled people that a number of detailed responses to the reports, particularly report two, were speedily forthcoming. In particular, the Disability Alliance and the Disablement Income Group produced documents (27, 28) which, whilst welcoming the reports' highlighting of the link between disability and poverty were critical of the methods employed, which, they argued, resulted in systematic and significant underestimations of the 'true cost' of disability, which OPCS quantified at an average of £6.10 a week. These reports largely take the individualistic methodology of OPCS for granted, but argue that their methods results in them getting the 'wrong' answers to what are tacitly assumed to be the 'right' questions.

Whilst this approach does not address the more profound methodological issues raised in the earlier parts of this paper, these are perhaps not of such a great significance in relation to the attempt to quantify the costs of disablement, and their contributions are certainly of significance in the immediate social policy debate. A number of factors, the critiques argue, combine together to produce systematic underestimation of the costs of disability.

- 1) The survey was conducted before the benefit changes of April 1988, which resulted in reduced benefits for an estimated one million disabled people. The survey was thus seriously out of date even before the publication of results.
- 2) One-off items, such as costs of a car, housing adaptations, electrical wheelchairs etc are grossly underestimated as a result of the OPCS decision to ask only about items bought in the last 12 months although from their own figures (13 p37) whilst 68% of

people surveyed had made at least one 'lump sum purchase' only 16% had done so during the relevant twelve month period.

- 3) Not enough severely disabled people were surveyed. OPCS employ 10 categories of disability, of which 1-3 are those whose 'daily living activities are not severely restricted' (DIG would argue these should not be included at all). OPCS respondents are mostly in the lower categories, with only 1.6% of those surveyed in the highest category (10). Using other likely indicators of severity of disability in the sample, only 13% received disability benefit, 8% attendance allowance, 7% mobility allowance and only a fifth of this 13% received two benefits. The suggestion is then that the sampling technique was skewed in a way that made the more severely disabled, and thus those most likely to incur greatest additional expenditure, less likely to be included.
- 4) The form of question, interviewing method and the time taken over interviews. The OPCS interviews lasted about 1~ hours, only a part of this time being devoted to questions about the costs of disability. No prompting or clarification by interviewers was permitted, resulting in a significant number of D/K responses, since, by the researchers own admission (13 p35) "not surprisingly people found it very difficult to estimate what proportion of the total cost of say heating was incurred because of their disability". DIG and DA argue that more time needs to be spent on interviews, with clarification and illustration to help people work out the answers. When DIG replicated the OPCS survey with a more lengthy and explanatory interviewing technique they reduced the 'Don't know' category to zero. In the OPCS survey there was at least one item of information missing in at least 40% of responses, which led them to "decide to impute an average expenditure for them based on the estimates of those who were able to give an estimate" (13 p36). Disability Alliance argue "It is impossible to calculate the effect that this will have on the overall accuracy of the results" (27 p22).
- 5) Need and expenditure  
The OPCS data indicated 71% of their sample of disabled people were spending extra as a result of their disability. 24% -1,387,000- said they needed to spend more than they did but could not afford to. The items most often cited were basics such as fuel, clothing and food. Shocking though these figures are, DA argue that these figures are likely to systematically underestimate real levels of

need. Accurate responses in this area are notoriously difficult to achieve. Coates and Silburn have commented (29) on the unrealistically low estimates provided by their respondents of the level of extra income they would require to be 'comfortable'. West (30) describes how female tobacco workers would describe themselves as working for 'pinmoney' when a detailed survey of household income and expenditure revealed the essential nature of their contribution to family economy. A high proportion of the respondents were elderly, amongst whom discrepancies between their own estimates and those of professionals have habitually been noted. All this suggests that we should pay particular attention to the apparent contradiction between 70% of disabled people having an income substantially lower than the general population and a similar percentage expressing 'satisfaction' with their standards of living.

## WHAT DIG DID

The Disablement Income Group has made the study of the extra costs of disability its speciality, with work by Hyman (31) Stowell and Day (32) and Buckle (33) all producing considerably higher figures than the recent OPCS study. Whilst the OPCS used a large-scale survey technique, the DIG studies employ in-depth studies based on relatively small samples. To demonstrate what they regard as the inappropriate nature of the OPCS methodology in ascertaining the 'true cost' of disability, DIG followed a two-pronged strategy of

- 1) administering an OPCS type questionnaire
- 2) administering a semi-structured unstandardised questionnaire of a type used in small-scale in-depth studies with running prompts and additional questions to the same subjects, and comparing the results from the two. DIG, who, unlike some other sections of the Disabled Peoples Movement regard a high degree of restriction of activity as definitional of disablement, employed a sample culled from their Advisory Service case files which represented a range of conditions, but all of whom would fall into the two highest (9 and 10) OPCS categories, and were receiving at least one of the two main disability-related allowances. However, they say they deliberately avoided selecting the most severe cases from their files. Their sample was also significantly younger, on average, than the OPCS group, and the only 2 respondents over 65 had been disabled for 20 and 40 years respectively.

Employing the OPCS style survey, an average extra weekly expenditure of £41.84 was reported whereas the response of the same subjects to the DIG schedule produced an average of £65.94, a difference of 58% between the two methods.

DIG argue that these results support their view of the OPCS survey: "that the sample they interviewed and the interview schedule and techniques they used have given rise to a much lower figure for the average 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" .(28 p28)

Avoiding any discussion of the DIG view that some of those included in the OPCS survey aren't 'really disabled', the discrepancy between the results obtained employing the two main types of interview support DIG's more general conclusion -"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". (27 p29).

## CONCLUSION

For disabled people and for social workers attempting to work appropriately with us, the significance of the OPCS surveys lies in their occurrence and the chance for discussion of disability that they provide, rather than their contents

Whilst the first report highlights the systematic underestimation of the prevalence of disability which was enshrined in previous government research, and upon which social policies were putatively based, it should by no means be interpreted as providing the 'true' figure. Such a project is an impossible one, since 'disability' is a social construct, and definitions inevitably in contention. They depend upon the interests, intentions and unexamined presuppositions of those with the power to define, and the ability of those so defined to resist inappropriate conceptions of their reality. As far as the severity scales are concerned, the danger is that the spurious objectivity implied by calculations and an elaborate system of judgement panels seduces the social worker into concluding that degrees of disadvantage and suffering are amenable to statistical representation in this way, and that appropriate welfare

provision and resource allocation may be determined on the basis of it. In other areas, particularly those related to the growing concern amongst disabled people and their allies to explore the relationship between disability and other dimensions of oppression, such as racism and sexism (34), the report is disappointingly, but predictably, silent. It largely fails to seek information in these areas, and where it does, gathers and presents it in a form which is not amenable to its contributing to current debate.

The second report, on financial circumstances, does provide official recognition that disability causes poverty, although, mindful of the sensibilities of their paymasters, the word itself is avoided by the researchers. Because of the research methods employed, however, they fail to even approach an adequate quantification of the financial disadvantages experienced by disabled people. (Since this paper was first written, further research by the Disablement Income Group (35) puts the extra costs of severe disability at £86.73 per week, almost eight times the figure produced by the OPCS). The danger here is that the figures presented, in the absence of any others and as part of a general strategy of reducing public expenditure, form the basis of Government policy towards disabled people, and will be accepted by social workers in their day-to-day work as realistic.

The OPCS surveys constitute a missed opportunity. A rare chance to carry out a large scale study which could provide evidence to support or refute aspects of a growing body of micro-level studies existed. The resources of time, money and technical expertise available to OPCS, despite repeated cuts in the funding of state research since the Rayner review of 1981, dwarf those of individual researchers and organisations of disabled people. But this review also made clear that information should not be collected primarily for publication. It should be collected primarily because government needs it for its own business. That this is the course that has been adopted has become increasingly apparent, with senior government functionaries up to Sir John Boreham, former head of the Government Statistical Services, as well as the more usual critics, expressing their disquiet at the constraint and abuse of the statistical services for political purposes. It is to be expected that the questions asked and the information arrived at should reflect even more directly than before the concerns of the State rather than those of disabled people and social workers attempting to provide appropriate services.

Given this, a critical understanding of the deficiencies of the OPCS surveys, both in terms of overall approach and of method, can provide a salutary example of how not to research issues of disability. Attempts to depoliticise the unavoidably political, to examine the complex and subtle through crude and simplistic measures, indicate by negative example some of the things that good research in this area, and indeed any other, requires. Disability must be recognised as a political matter, with ramifications in our understanding of work, sexuality, literature, design, humour and all other areas of human life, and discussions of the more obvious and immediate sphere of social policy cannot take place in isolation from a recognition of this. This is not to say that a single piece of research must deal with all these aspects, but rather that it should be designed with and interpret its results in the light of, such an awareness. Disabled people, in this country and elsewhere, are increasingly conceptualising their lives in political terms and acting accordingly rejecting the dominant 'personal tragedy' model of our situation. In this context, no conceptualisation of or questions about disability can be seen as 'neutral'.

As with other oppressed groups, for the social worker to operate in a non-oppressive manner, a preliminary requirement is that she develop some knowledge of the nature, extent and mechanisms of that oppression. Part of what that involves is the critique of oppressive practices and 'knowledge'. A critical reading of one of the most recent examples of oppressively structured 'knowledge' of disabled people, the OPCS surveys, is quite a good place to start. And what about following this up by talking to disabled people themselves, after all there are now six and a quarter million of us to choose from - and that's official!

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