

A critique of the OPCS Disability Surveys

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When confronted with the products of the Office of Population Censuses and Surveys, often referred to as Official Statistics, it is 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 (1984) 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.

In line with this, the new survey is presented as superior to others in part because its 10 point classificatory schema 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 (1990 p7-8), 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 you 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 cause 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. This will depend on both the general arrangements for performing certain activities in a society and the specific aids available to an individual. Thus, depending on personal and social circumstances, an individual with a particular kind or degree of impairment may be more or less restricted in her activity to a widely variable degree.

Gender, age and culture are also important variables to be taken into account in assessing the significance of particular impairments, whilst class, in both financial and cultural aspects, also has its effects on people's experience of disability. There are then, 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 off-loaded on some other party. They ignore any consideration of the role of the State in the construction and perpetuation of disability.

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 (Leech 1989). The gathering of data on disabled people in Nazi Germany was inextricably connected 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 (1979 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 meeting their 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 her/himself 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 research 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 (1981) 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 (1973 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, both that 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.

The Reports

The most publicly noted feature of the 1988 OPCS Disability surveys was

their upward revision of the estimated number of disabled people in Britain from three and a half to six million. Previous surveys (Harris 1971) had resulted in the following estimates:

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.

The OPCS survey (Martin, Meltzer and Elliot 1988) attempts to be more wideranging, trying to cover all types of disability whatever their origin, and setting a lower 'disability threshold'. The survey distinguishes 13 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	447,000
8	338,000
9	285,000
10	102,000
Total in private households	5,780,000
Living in establishments	422,000
Grand Total	6,202,000

(Adapted from Table 3.1 Martin & White 1988)

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 2 questions (Martin, Meltzer and Elliot 1988 p20), gives an overall figure which is considerably higher in total, and for younger age groups.

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 (Oliver 1983) and other writers have argued in more general and wideranging ways (Irvine, Miles and Evans 1979, Hindess 1973) that all statistics are constructed by particular people in particular social and historical contexts for particular purposes, and can only be understood as such.

Severity scale

Whilst the ten point severity scale is ostensibly a more sensitive measure than previous systems, the procedure used to judge severity 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 quantifications 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 Disability Alliance 1988 (a) for a fuller discussion).

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

4) Does any-one 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 (Laurie 1984 p12) 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 37 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 and devices disabled people survive in hostile environments. If you've a trick to get round the problem, do you still have a 'difficulty'? For people with long-standing 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 impairment. 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.

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 (645 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 (Confederation of Indian Organisations UK n.d.) indicates that the experience of disability for individuals from minority ethnic groups additionally oppressed by racism requires separate and detailed analysis.

Sex

The survey (table 3.6) indicates that there are considerably more disabled women than men, 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 (Martin, Meltzer and Elliot 1988 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 (Harris 1971 p5) and numbers greater (ibid p4). This led Oliver to argue (1983 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".

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 not at least mention the matter. As a growing body of literature shows, (Deegan and Brooks 1985, Campling 1981, Morris 1989 and 1991) 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.

Financial circumstances

The second report (Martin and White 1988) examines the financial circumstances of disabled adults living in private households, commented on in the following sections.

Employment

Disabled adults under pension age were found to be much less likely to be in paid work than adults in the general population, allowing for differences in age, sex and marital status. A number of recent small scale studies (Fry

1986, French 1988) 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 (Martin and White 1988 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 (Smith D 1974 p169) 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.'

The majority of disabled adults (78% of total, 54% of those under pension age) lived in family units containing no earners and thus the significance of State benefits was great.

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: under 3/4 of average income. 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.

Expenditure

Expenditure was calculated by adding together occasional costs, regular expenditure on items associated with disability and extra expenditure on ordinary items.

Occasional costs of special items of equipment like special furniture in the year previous to the survey was incurred by only 16% of the sample. But because only items purchased in the last year were allowable, OPCS researchers admit this is likely to be a low estimate of true costs. Adding the three 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. 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 a quarter 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 £=.

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 use of the notion of equivalent resources 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.

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 the second report, were speedily forthcoming. In particular, the Disability Alliance and the Disablement Income Group produced documents (Disability Alliance 1988, Thompson with Buckle and Lavery 1988) 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 responses largely take the individualist methodology of OPCS for granted, but argue that their methods result in them getting the 'wrong answers to what are tacitly assumed to be the 'right' questions.

Whilst this approach does not address the more wideranging 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 (Martin and White 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 those most likely to incur greatest additional expenditure, less likely to be included.

4) The form of questions, interviewing method and the time taken over interviews. The OPCS interviews lasted about 1 1/2 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 Don't Know responses, since, by the researchers own admission (Martin and White 1988 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" (Martin and White 1988 p36). Disability Alliance argue "It is impossible to calculate the effect that this will have on the overall accuracy of the results" (Disability Alliance 1988(b) p22)

5) Need and expenditure. The OPCS data indicated seven out of ten of their sample of disabled people were spending extra as a result of their disability, and that one in four 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 they are likely to systematically underestimate real levels of need. Accurate responses in

this area are notoriously difficult to achieve. Coates and Silburn have commented (1970) on the unrealistically low estimates provided by their respondents of the level of extra income they would require to be 'comfortable'. 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% percent of disabled people having an income substantially lower than the general population and a similar percentage expressing 'satisfaction' with their standard of living.

What the Disablement Income Group did

The Disablement Income Group has made the study of the extra costs of disability its speciality, with work by Hyman (1977) Stowell and Day (1983) and Buckle (1984) 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 techniques 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." (Thompson P with Buckle and Lavery 1988 p28).

Subsequently, a more methodologically sophisticated study (Thompson P with Lavery M and Curtice J 1990) for DIG established an even greater discrepancy between their findings and the OPCS surveys.

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 types of interview support D.A.'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." (Disability Alliance 1988(b) p29)

Conclusion

For disabled people and for those 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 are contested. 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 reader 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.

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. In a situation where research by the Disablement Income Group (Thompson P 1990) puts the extra costs of severe disability at £86.73 per week, almost eight times the figure produced by the OPCS, the consequences of such calculations forming the basis of Government policy towards disabled people will be disastrous.

Whilst there are ways in which we may utilize OPCS data, we must not in doing so lose sight of its fundamental flaws. Information gathered on the basis of an oppressive theory, unless handled with circumspection, is itself one of the mechanisms of oppression.

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