

# Truth or Manipulation? The Politics of Government-funded Disability Research

JOHN STEWART, JENNIFER HARRIS<sup>1</sup> & BOB SAPEY<sup>1</sup>

*Department of Applied Social Science, Lancaster University, Lancaster LA1 4YL, and*

*<sup>1</sup>Department of Social Work, University of Central Lancashire, Preston PR1 2HE, UK*

In the debate about independent research conducted in this journal both Barnes and Bury have expressed concern regarding the constraints placed on researchers by government departments funding their studies (Barnes, 1996; Bury, 1996). Barnes points out that the main principle behind this control according to the Department of Health's own documents is that 'the customer says what he wants, the contractor does it, if he can and the customer pays', whilst Bury suggests that such an over simplified description is exacerbated by the influence of politicians; an example of which was Margaret Thatcher's view that research should serve specific interests. Others may have concluded with more sagacity that the last Conservative administrations would rather have seen their policies implemented than researched.

In this article, we will show how research commissioned by the Department of the Environment might well have met the requirements of the paying 'customer', but fell far short of academically acceptable professional research standards and had nothing whatsoever to do with the interests, needs, aspirations or wishes of the service users—disabled people.

For the past year we have been conducting a secondary analysis of various data-sets relating to the need for and provision of wheelchair accessible, social sector housing. The literature search inevitably led us to a report called *Living Independently* (McCafferty, 1995) which was funded by the Department of the Environment. The study sought to estimate the need in England for specialist housing for older people and disabled people, which of course would include wheelchair accessible housing. While earlier estimates of the need for wheelchair housing had varied from about 60,000 to 330,000, *Living Independently* suggests that there is a shortfall of 12,988 wheelchair units in England. Viscount Ullswater on behalf of the government gave four separate defences of this estimate in a reply to a question from Lord Swinfen (House of Lords Debates, 1995, cols 35–36). The government and, hence, the Department of the Environment, accept the figure which remains even now the basis for planning in this area.

On close examination of *Living Independently* we discovered some fundamental methodological flaws which not only resulted in a gross underestimation of need,

but also causes us to question what 'need' was actually being measured, hence laying open to question the effectiveness of the commissioning process.

The first flaw is a mathematical one. The study produces an estimate of the proportion of disabled people who need social sector wheelchair dwellings which, quite rightly, does not include those already occupying such properties. However, when this figure is used to calculate the actual shortfall in current housing stock, the stock of suitable properties in England is deducted. These dwellings are of course already occupied and given the report's assumption that they are both accessible and habitable, their occupants have already been excluded from the calculation of need. By first counting out a group of people as being in need because they are suitably housed and then deducting the very resource that prevents them from being in need, *Living Independently* produces a gross underestimation of need. While we shall say more about the mathematics in a moment, what is also of methodological concern is the use of medicalised concepts to estimate housing need.

The subject in contention in wheelchair housing is the design of dwellings, and their accessibility, physically, socially and economically, by wheelchair users. Even if the focus is narrowed to the physical, the relationship between the spatial needs that arise from using a wheelchair and the design of housing is both simple and well known. However, in search of that methodological reliability which is sacrosanct to positivist research, the report rejects the social model of analysis, in which housing design is a cause of disablement, and instead opts for a measure of individual dependency, in order to validate the estimation of spatial need. In *Living Independently* the Townsend Clackmannan scale of dependency which is utilised is described as having been developed by Bond and Carstairs who, 'took the original sixteen-point Townsend index, which is the basis of all recent dependency measures, and developed a uni-dimensional scale for functional criteria. The chosen scale was based on Guttman logic, from work by Sainsbury (1973) and inter-item correlations' (McCafferty, 1995, p. 26)—clearly not a social model analysis of the problem, but a means of individualising dependency. This description continues in the same vein, but what has it got to do with a wheelchair user's need for housing? The claim is that in some way this leads to an objective measure (and one might ask, of what?), but in fact, as seasoned disability rights campaigners will know, such an approach actually serves to counter an expressed need by disabled people.

In *Living Independently* it is considered important to take into account the aspirations of disabled people (McCafferty, 1995, p. 156). However, this is achieved by discounting from the estimate of need for wheelchair housing those people who would prefer to be owner occupiers rather than tenants. This presumes of course that the private sector can meet the expressed need for wheelchair housing at a price disabled people can afford and in reality is simply a device to reduce need. Furthermore, the 'allocation model' constructed from these different criteria was developed as the result of a one day seminar which involved 'twenty-five leading, housing, medical and social services practitioners and academics' (McCafferty, 1995, p. 157), but no representatives of the disabled people's movement.

While we have briefly explained the nature of the mathematical error in this study, it is also worth considering how this arises and whether it is a design to reduce

the need for government expenditure. The result of this expensive and lengthy, if somewhat pointless exercise is a series of twelve reports. The significant findings are presented in chapter 2 of the first (and main) report—i.e. the numbers of dwellings that are needed. However, it is not until chapter 8 that the description of the ‘allocation model’ used to estimate the proportion of the population of disabled people who are in need of wheelchair dwellings is explained. The model is complex and involves a number of stages in which there are approximately twenty basic needs assessment criteria. The first twelve of these apply only to the ‘elderly’ sample. The ‘non-elderly disabled people’ are put through what is described as a filter of eight assessment criteria. The criteria for wheelchair housing are that:

- (1) the household is not living in ground floor accommodation;
  - (2) the household is living in ground floor accommodation but the building is in a poor state of repair,
  - (3) if the household Clackmannan score is G (critical level—functional), a member of the household is bed-fast or chair-fast or uses a wheelchair to help them perform mobility or domestic tasks;
  - (4) wants to live in accommodation specially-designed for easy access, for example, by someone using a wheelchair.
- (Adapted from McCafferty, 1995, para. 8.19)

After applying these criteria to the sample, it is estimated that in:

... households containing non-elderly disabled adults, the allocation model would suggest that 2% of this group nationally have a need for wheelchair housing and just over 3% have a need for mobility housing/housing adapted for disabled people. These figures are, once again, quite low, but reflect the relatively small proportion of the sample that wished to move from their current accommodation or used a wheelchair on a regular basis. (McCafferty, 1995, p. 167.)

It is this figure of 2% which is used in chapter 2 (Table 2.22) to estimate the unmet need in relation to wheelchair dwellings. This was achieved by deducting the existing stock of wheelchair dwellings in the social housing sector from 2% of the estimated population of disabled people between the ages of 16 and 65 years. However, at this stage it was not explained that the 2% had already excluded those who were suitably housed.

The error occurs because the criteria for being considered in need of wheelchair accommodation is that the household does not live in ground floor accommodation or, if they do, that the building is in a poor state of repair. Therefore to deduct the current stock of social sector wheelchair dwellings is to double discount.

The effect of this error is to drastically reduce the estimate of need for all the categories of housing that are studied, as *Living Independently* employed the same method of discounting twice throughout. Using this methodology without error, we have calculated the level of need for wheelchair dwellings to be 40,658 which represents a 213% increase on the stated estimate of 12,988, and in terms of mobility dwellings we calculate that the need for England should be 69,104

dwellings, almost 63,000 more than is suggested. Although these are still considerably lower than previous estimates, they would have some statistical credibility if it were not for the individual dependency measures that are employed to deal with what is essentially a spatial issue.

The extent to which the errors in this research are deliberate in order to reduce the government's need to commit funds to the social housing sector can only be answered by its authors and funders, but the effect of publishing such a study, that can never be of any real benefit in terms of housing policy, is to reinforce the distrust of government research. It is rumoured that *Living Independently* cost in the region of £5 million and, while we cannot confirm this, it is clear that the amount was substantially in excess of the £1 million cost of the 1986 OPCS disability surveys. Leaving aside the issue of the best use of such substantial funds, the effect of publication is to establish a benchmark against which other research will be judged and the criteria against which the objective need for wheelchair housing will be established [1]. The credibility of the sponsors and the massive amount of funding has the effect of legitimating the findings, despite the shortfalls of the methodology.

Alongside its methodological failings, this study ignores the case for Lifetime Homes that has been put via research funded by the Joseph Rowntree Foundation, thus ignoring a solution that is widely held to be politically, socially, economically and physically credible. In terms of housing research, this could be seen as analogous to Churchill ignoring the Beveridge Report.

What also concerns us as researchers is that this is precisely the type of study which gives non-disabled researchers a bad name. We share Bury's belief that the integrity and independence afforded by academic institutions can help to overcome the worst practices in research and it should be noted that no such institution was involved in this study. What seems to us to be of most importance in this sorry tale is the warning it gives concerning the credibility of government funded research. It seems timely to call for some guidance to be issued in the commissioning of research and to argue for more participative frameworks to be given the recognition they deserve.

#### NOTE

- [1] *Living Independently* is recommended as further reading in a selected list of publications in the Department of the Environment and Department of Health's joint guidance document to directors of social services, directors of housing and chief executives of health authorities, *Housing and Community Care: Establishing a Strategic Framework*, January 1997.

#### REFERENCES

- BARNES, C. (1996) Disability and the Myth of the Independent Researcher, *Disability & Society*, 11, pp. 107–110.
- BURY, M. (1996) Disability and the Myth of the Independent Researcher: a reply, *Disability & Society*, 11, pp. 111–113.
- HOUSE OF LORDS DEBATES (1995) Volume 560, 'Wheelchair accommodation provision: reports', *written answers*, 17 January.
- MCCAFFERTY, P. (1995) *Living Independently: a study of housing needs of elderly and disabled people* (London, HMSO).