

Incapacity Benefit and Medical Sociology: A Missing Link?

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On July 4th 2001, Alistair Darling, the Work and Pensions Secretary, announced a crackdown on illegitimate claimants of incapacity benefit (IB), and suggested that some 70% of IB claimants could return to work. His statement, supported by the Prime Minister and Cabinet, but unsupported by evidence, evoked indignation amongst representatives of disability groups and a significant number of MPs. No comment, to my knowledge, was forthcoming from sociologists of health and illness - possibly because of their lack of awareness of the impact of benefit-related issues on the lives of the chronically sick. In this article, I suggest that there is a large Benefits Agency-shaped gap in medical sociology, which could profitably be filled¹.

First, a comment on the recent controversy: it is notable that both Darling's statement and the way in which it was initially reported were grossly misleading. Darling claimed that the new regulations were aimed at rectifying a situation in which people were able to claim IB, unchecked, for an indefinite period. Two days later, however, his department was forced to admit that IB claimants are currently subject to a regime of medical checks more, not less, frequent than the three-yearly tests he proposed for new claimants. It is inconceivable that Darling did not know this when he made his original announcement. It is also puzzling, given that IB has been the subject of repeated public debate in recent years, that the quality press should have followed his line so slavishly. The Times (Sherman 2001; Times 2001), the Telegraph (Sparrow 2001), and, more surprisingly, the Guardian (Wintour 2001) all referred to a situation in which people could claim IB, unchallenged, more or less indefinitely. That even the Guardian should swallow this inaccuracy wholesale is perhaps symptomatic of the suspicion which now bedevils anyone claiming state benefits on grounds of incapacity to work.

The basis on which IB is awarded, and the stresses involved in obtaining it, are probably unfamiliar to most readers. A brief account of these matters therefore follows.

Who receives Incapacity Benefit?

IB is payable to people who become incapable of work. There are three rates, the long-term rate (normally applicable after 52 weeks) being the highest - higher than jobseekers' allowance. Entitlement ceases at pension age: 65 for men; 60 for women. IB itself is contribution-related, but some of those lacking the necessary contributions receive other benefits, or national insurance credits, on the same basis, and are counted as IB claimants². In February 2001, there were 2.3 million claimants according to a broad definition (Department of Work and Pensions 2001a: 5; 23-24). Of these, almost 1.9 million had been claiming IB for over a year, and almost a million for over 5 years. Men over 50 constitute 35% of IB claimants (ibid.). The number of IB claimants has more than trebled since around 1980 (Beatty and Fothergill 1999: 8-10; White 2001). There are many possible reasons for this other than a collapse in the health of the nation. Most significantly, the Tory government encouraged the transfer of large numbers of redundant people - mainly men - to sickness-related benefits, to keep unemployment figures low (Beatty and Fothergill 1999; Toynbee 2001). Research points to high levels of hidden unemployment (claimants registered as sick, but, despite genuine health problems, able and willing to do at least some work) in traditional industrial areas where jobs are now scarce (Beatty and Fothergill 1999). (This research

suggests no deliberate abuse of benefits; and a recent survey by the Department for Work and Pensions (2001b: 3) found the incidence of fraud amongst IB claimants to be low.) If this is indeed the case, the government may find that a tougher stance on IB opens a new can of worms, exposing the extent of involuntary unemployment.

A further probable cause of the increase in IB claimants is the rationalisation of many workplaces, and the increasingly pressurised pace of work in all sectors of the economy (academia is just one example amongst many). Employees who lose the capacity to work at full tilt are less likely to be accommodated than they were 20 years ago. The deterioration of public transport may also play a part, as it becomes harder for people with limited mobility or strength to reach a potential workplace. All this shows that, for some people at least, (in)capacity for work is not a quality which inheres in the individual, but is a matter of interaction between individual and environment.

It may be older male claimants who, because of their numbers, are the government's main target. However, the difficulties of relying on the state have a profound effect on other sick and disabled claimant populations, such as the members of the M.E. group amongst whom I conducted my research (de Wolfe 1999). Most (although not all) of my research subjects were female, white and middle-class; most had been in the labour force before becoming ill, but now seemed unfit for work under any economic circumstances. Their experience brings to light many of the problems of establishing eligibility for IB.

Testing for incapacity

Anyone claiming IB for longer than 28 weeks is subject to the Personal Capability Assessment (PCA), formerly known as the All Work Test³. This assesses the claimant's capacity to carry out a range of functional activities: walking; manual dexterity; climbing stairs; lifting and carrying; sitting; rising; bending and kneeling; reaching; standing; speech; hearing; vision. The self-assessment questionnaire (IB50) issued to claimants also asks about incontinence problems and seizures. Within each broad functional area, there are specific activities to which points are allocated according to severity of impairment. (Mental illness and learning disability are assessed differently.) There is a space for additional comments at the end of the form, and the claimant's GP is also asked to supply information (Paterson 2001: 67-77). In - recently - some 50% to 70% of cases (Comptroller and Auditor General 2001: 22), the claimant will then be examined by a Benefits Agency doctor, or rather, a doctor employed by SEMA, the private agency to whom medical examinations are outsourced.

Undergoing the test for incapacity is gruelling for everyone, since livelihoods are at stake. Even people with disorders which fit well into the parameters of the questionnaire may have difficulty in proving the extent of their disability. Further, the test treats fitness for work as a property of the claimant, ignoring availability of suitable work. But for people with chronic illness, there is a further problem with the PCA: it makes no allowance for being ill. No points are available for feeling drained, unsteady, or even running a fever - or rather, points are available on these grounds only insofar as they affect capacity to perform the tasks specified above. Oddly - and this confirms the impression that the test is aimed at manual workers - there is no question which enables claimants to gain points on the grounds that they rapidly become too tired to think straight. M.E. is, of course, a contested condition, but organisations representing people with better legitimated diseases such as arthritis (Betteridge 2001) raise similar objections. Where sick people are subject to a test which accords no legitimacy to the symptoms of illness, the task of establishing incapacity for work assumes a Kafkaesque quality. It is, in the words of one harassed claimant, like trying to prove you have a soul.

The purpose of physical medical examinations is to confirm information supplied on the form. From claimants' accounts (Pearce 2001; personal communications), their content and quality seems immensely variable. They may consist purely of questioning about daily activities, or they may include a clinical examination. Tasks may be set: the doctor may throw a piece of paper on the floor and ask the examinee to pick it up (Pearce 2001). Some claimants report fair and polite treatment, others discourtesy: the largest single category of complaints about medicals concerns doctors' manner (Comptroller and Auditor General 2001: 36). Some examinees complain of entrapment: someone who, on their IB50, has pleaded inability to manage steps may, on arrival, be directed up a staircase; or someone who reported limited strength be pointed towards a heavy door. In a situation of great tension, it takes courage and presence of mind to request assistance rather than struggle to comply (ibid.; Earnshaw 1999). The process may be experienced as humiliating, and the outcome as inequitable. Trivial activities (in one case, reading a daily newspaper) may be pronounced to establish fitness for work. (This claimant's IB was reinstated on appeal.) SEMA doctors have immense power over examinees in this situation - and they may or may not turn out to act respectfully and reasonably. In fact, being a claimant entails an ongoing sense of helplessness and uncertainty.

If declared unfit for work, claimants have no idea when they might be retested. Contrary to Darling's statement, fewer than a quarter are permanently exempt from reassessment (Department of Work and Pensions 2001a: 11). Re-evaluations, supposedly conducted at intervals specified by the Benefits Agency, tend in practice to occur irregularly. People may be assessed twice within months, and then hear nothing for years. A virtually housebound patient may be retested more often than one who is less restricted. There also seems to be no consistency in the decision-making process which results in some claimants, but not others, being summoned to a medical following the completion of an IB50. Most importantly, people may be baffled as to why their account is not believed, and IB refused - about 20% of cases (Department of Social Security 2000).

The strain of the PCA is compounded by the delay in hearing appeals - at which over 40% of claimants disqualified after medical tests are said by disability groups to have their IB reinstated (White 2001). Waiting time has now been reduced to about three months, but could until recently be much longer. IB is withdrawn pending appeal, although other benefits are available (usually at a lower rate) in the interim.

These delays, understandably, cause intense anxiety. Some of the sickest or most disabled may also be claiming Disability Living Allowance, payable to those who need care and have mobility problems; this has its own rules and system of assessments, and is equally likely to be stopped or reduced, generating a further set of uncertainties, appeals and delays. If stress impairs health, being a claimant cannot be good for the chronically sick.

Sociology and Incapacity Benefit

What has all this to do with sociology? This becomes clearer if one examines aspects of the sociological literature. Research on the experience of chronic illness in the UK and USA, addresses, inter alia: disruption of normal life and expectations, and damage to sense of self (Bury 1982; Charmaz 1983); the balancing of tasks and goals in the face of unpredictability (Pinder 1988); the transformation of pre-existing concepts and experiences of body, self and society (S. Williams 1996); the (felt) stigmatisation of specific conditions (Scambler and Hopkins 1990). Recent sociological interest in narrative has led to an emphasis on sufferers' accounts as storied attempts at the restoration of order (see G. Williams 1996: 201-203; Bury 2001). The experience of claiming state benefits, however, barely features in this literature. Texts aimed at students (Nettleton 1995: 68-99; Locker 1997) discuss a range of

emotional and practical issues confronting the chronically sick, but are silent about being a claimant.

In the course of my own research, the subjects of which were nearly all claimants of sickness-related benefits, I found that fear of having these benefits withdrawn hung over people like a dark cloud. They complained of 'brown envelope syndrome': the panic which overwhelmed them at the sight of an official-looking letter lying on the doormat. Problems with and anxieties about welfare benefits were one of the dominant topics of conversation in the self-help group whose meetings I attended. Admittedly, by no means everyone reported difficulties with their claim; but everyone knew someone whose application for benefits had been apparently unreasonably disallowed. People are, therefore, haunted by worry, and also by resentment that this worry should be inflicted upon them, further impairing what are already spoiled lives.

There would be much in the conditions and experience of being a claimant for social scientists to study, from a range of theoretical stances. The suggested themes which follow emerge from my own research; investigation of the concerns and experiences of, for example, former industrial workers might produce a different set of proposals.

Sociologists with an interest in presentation of self and the social construction of subjectivity could note the effects of long-term dependence on social security, beyond ongoing financial uncertainty, and, for those with no other resources, poverty. Many IB claimants feel permanently under suspicion - a feeling fuelled by the repeated public attacks on their integrity. They therefore experience a constant niggling fear of being discovered in breach of (often ill-defined) limits, and, at worst, reported to the Benefits Agency. They also experience a sense of disjuncture. Those with some capacity for activity may feel obliged to conceal their status as 'normal' social actors (who may occasionally drive a car, go on an outing, or undertake light gardening) from anyone aware that they are claimants; and their status as claimants from those who witness them acting 'normally'. Media questioning of their legitimacy may even affect claimants' own perception of their bona fides. In particular, people with fluctuating conditions (MS, M.E., arthritis) may, when in partial remission, themselves come to question whether they are really unfit for work. (One claimant, in the grip of such self-doubt, telephoned an agency which helps disabled people into work, and was - politely - laughed out of court when she described her state of health.) Applications for benefits and medical examinations may themselves contribute to a sense of leading a double life, as - contrary to customary strategies of 'making the best of things', and concealing symptoms for social purposes - claimants are obliged to describe and present their symptoms in their full severity (Pearce 2001).

The notion of the biographical disruption caused by illness (Bury 1982) could also be extended in the light of dependency on the state. Becoming a claimant involves a kind of infantilisation: a loss of control over one's own financial affairs, and an inability to plan for the future. Further, the 'parent' on whom the claimant depends is perceived as wayward, unresponsive and miserly. For many, the unreliability (as well as the level) of welfare benefits increases dependency on partners and/or family - compounding the dependency which may already have arisen out of the physical depredations of the illness. This unforeseen financial dependency may give rise to a sense that moral, as well as physical competence has been lost. It may also cause tensions in, and contribute to breakdowns of, relationships.

Along different lines, there is scope for Foucauldian analyses. People who claim sickness-related benefits experience themselves as being subject to surveillance, but this particular form of surveillance is, again, notably absent from the literature (Shildrick and Price 1996 is

a rare exception). If IB claimants were to read Foucault, they might recognise in their situation a means through which the effects of power gain 'access to individuals..., to their bodies, their gestures and all their daily actions' (Foucault 1980: 151-152). Foucauldian claimants might also recognise the image of the Panopticon, rendering everyone a potential object of surveillance (Foucault 1977: 195-228). The omission of this line of enquiry is particularly striking when one considers the widespread theorisation of medicalisation as surveillance - and hence, implicitly, as oppressive. From the point of view of sick people, however, medicalisation has a lot going for it. It does, at least, promise - and occasionally deliver - relief from physical suffering. Medical examinations carried out for social security purposes, however, have no therapeutic aim. To be the recipient of Benefits Agency attention is to be scrutinised, not cured or cared for or comforted.

From both modernist and poststructuralist stances, government rhetoric on (supposedly unjustified) claims to IB could be studied for its constitution of long-term disabling illness as shameful or as non-existent, hence contributing to the marginalisation of the sick, whether or not they are claimants. This rhetoric is liable to magnify the sense of dislocation, already considerable, which besets people when they first become ill with an incurable disease - and when many first move from financial independence to dependency on the state. It is also interesting to speculate on the motivation behind government attacks on the legitimacy of the sick - on whether this is purely cost-led, or whether it is part of an ideological agenda, and whether the government believe, and are justified in believing, that their tough stance will play well with large sections of the electorate⁴.

Obstacles exist to the pursuit of some of these lines of enquiry. Anyone wishing to investigate the quality of medical examinations is unlikely to find that a welcome is extended to observers. The effect on public attitudes of government discourses on sickness-related benefits is diffuse, and hard to research empirically. As to the motives of those in power, ministers will not admit to any goals other than targeting benefits to those in real need and extending help to those eager to return to work.

It is also possible that some claimants might be reticent, fearing breaches of confidentiality. On the other hand, many of those long-term IB claimants who feel they are struggling against great odds, only to be subjected to inappropriate forms of testing and to aspersions of malingering, might be eager to tell their story to researchers. The voices of chronically sick people, especially those dependent on welfare benefits, carry little social weight, and they have little opportunity to make themselves heard. Unlike some of their disabled counterparts, few are able even to take part in demonstrations to put their case. It would be heartening if, in future, when a government minister makes an unsubstantiated statement about the capacity of IB claimants for work, sociologists of health and illness were able and willing to respond, documenting the profoundly detrimental effect which such pronouncements have on many claimants' lives.

Notes

1. The Benefits Agency is now an executive agency of the Department for Work and Pensions, which was formed in June 2001 from the former Department of Social Security and part of the former Department for Education and Employment.
2. Government statistics distinguish between 'claimants' in this sense, and the narrower category of 'beneficiaries'. The latter receive contribution-related IB and number 1.5 million, 44% of them men over 50 (Department of Work and Pensions 2001a: 5; 16).

3. The change of name in April 2000 signalled 'a new focus on ability rather than disability' (Department of Social Security 2000). The method of assessing entitlement to IB remains unchanged, but, in pilot areas, examining doctors now produce a second report, which focuses on the claimant's capabilities.

4. Perhaps ministers foresee a fall in IB claims, which can be presented as a vindication of their 'toughness': many IB claimants will have reach pension age before the next election, losing their entitlement to the benefit, and are unlikely to be replaced in similar numbers.

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References

- Beatty, C. and Fothergill, S. (1999). *Incapacity Benefit and Unemployment*. Sheffield: Sheffield Hallam University.
- Betteridge, N. (2001). Letter, *Guardian*, July 5th.
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health and Illness*, vol. 4, 167-182.
- Bury, M. (2001). Illness narratives: fact or fiction? *Sociology of Health and Illness*, vol.23, no.3, 263-285.
- Charmaz, K. (1983). Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of Health and Illness*, vol. 5, no. 2, 168-195.
- Comptroller and Auditor General (2001). *The Medical Assessment of Incapacity and Disability Benefits*. London: The Stationery Office.
http://www.nao.gov.uk/publications/nao_reports/00-01/0001280.pdf
- de Wolfe, P. J. (1999). 'I'm Really Ill, I've Got M.E.': Bodily Disorder and the Quest for Disease. PhD thesis, University of London.
- Department for Work and Pensions (2001a). *Incapacity Benefit and Severe Disablement Allowance: Quarterly Summary Statistics*. February 2001.
<http://www.dss.gov.uk/asd/ibsda.pdf>
- Department for Work and Pensions (2001b). *Fraud and Error in Claims to Incapacity Benefit: the Results of the Benefit Review of Incapacity Benefit*.
<http://www.dss.gov.uk/publications/dss/2001/incapacity/frerin.pdf>
- Department of Social Security (2000). Press Release 2000/061: Personal Capability Assessment - a New Focus on Ability Rather Than Disability.
<http://www.dss.gov.uk/mediacentre/pressreleases/2000/mar/00061.htm>
- Earnshaw, C. (1999). Diary of an incapacity benefit claimant: physical jerks. *Guardian*, August 4th.
- Foucault, M. (1977). *Discipline and Punish: The Birth of the Prison*, trans. Sheridan, A. London: Penguin Books.
- Foucault, M. (1980). *Power/Knowledge: Selected Interviews and Other Writings 1972-1977*, ed. Gordon, C. trans. Gordon, C., Marshall, L., Mepham, J. and Soper, K. Hemel Hempstead: Harvester.
- Locker, D. (1997). Living with chronic illness. In Scambler, Graham (ed.) *Sociology as Applied to Medicine*. 4th edition. London: W.B. Saunders, 77-88.

- Nettleton, S. (1995). *The Sociology of Health and Illness*. Cambridge: Polity Press.
- Paterson, J. (2001). *Disability Rights Handbook*. 26th edition. London: Disability Alliance.
- Pinder, R. (1988). Striking balances: living with Parkinson's disease. In Anderson, R. and Bury, M. (eds.) *Living with Chronic Illness: The Experience of Patients and their Families*. London: Unwin Hyman, 67-88.
- Pearce, H. (2001). The sick role - use it or lose it. *Auto/Biography*, vol. IX, nos. 1 & 2, 61-67.
- Scambler, G. and Hopkins, A. (1990). Generating a model of epileptic stigma: the role of qualitative analysis. *Social Science and Medicine*, vol. 30, no.11, 1187-1194.
- Sherman, J. (2001). Fury at 'MoT' benefit test for disabled. *Times*, July 4th.
- Schildrick, M. and Price, J. (1996). Breaking the boundaries of the broken body. *Body & Society*, vol. 2, no. 4, 93-113.
- Sparrow, A. (2001). Tougher checks on incapacity benefit claimants. *Telegraph*, July 4th.
- Times* (2001). Leading article: Greener Grasses. July 7th. Toynbee, P. (2001). No benefit to anybody. *Guardian*, July 6th.
- White, M. (2001). Blair defiant on benefit change as anger grows. *GuardianUnlimited*, July 5th. <http://uk.news.yahoo/010705/11/bxev8.html>
- Williams, G.(1996). Representing disability: some questions of phenomenology and politics. In Barnes, C. and Mercer, G. (eds.) *Exploring the Divide: Illness and Disability*. Leeds: The Disability Press, 194-212.
- Williams, S. J. (1996). The vicissitudes of embodiment across the chronic illness trajectory. *Body & Society*, vol. 2, no. 2, 23-47.
- Wintour, P. (2001). Anger at new test regime for incapacity benefit. *GuardianUnlimited*, July 4th. <http://uk.news.yahoo.com/010704/11/bx9wq.html>

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