

Chapter 5 (In 'Disabled People in Britain and Discrimination : A case for anti-discrimination legislation', Colin Barnes (1991))

THE DISABILITY BENEFITS SYSTEM

Benefits which are not carefully related to the struggle for integrated employment and active social participation will constantly be used to justify our dependence and exclusion from the mainstream of life - the very opposite of what is needed (UPIAS, 1976, p. 15).

Since at least the seventeenth century poverty has been an inevitable consequence of living with an impairment. This form of poverty is the direct result of the systematic exclusion of disabled people from the social processes which make employment possible. As a consequence disabled people are perceived as objects of pity dependent upon the charity of others. Since 1945 the overwhelming majority of disabled people have been supported by a state-sponsored charity or welfare benefits system which maintains that dependence.

This Chapter will show how the modern welfare benefits system is a major factor in the disabling process because it fails to provide disabled people with an adequate income, compounds their dependence upon professionals and professional organisations and, most important, does not facilitate their integration into mainstream employment. It is divided into two main sections. The first examines economic deprivation in relation to impairment-related expenditure, and the second focuses on the benefit system with particular emphasis on changes during the 1980s.

Economic Deprivation and the Additional Costs of Impairment

Economic Deprivation and Disabled People. Since at least the 1960s there has been growing concern over the financial circumstances of disabled people. A succession of studies has documented the extra financial costs incurred by impairment and the very low levels of income upon which the overwhelming majority of disabled people and their families have to rely (Baldwin, 1985; Buckle, 1984; Hyman, 1977; Stowell and Day, 1983; Townsend, 1979). This has been accompanied by repeated calls for a complete reappraisal of social security benefits for disabled people (DA, 1975, 1987; DIG, 1987).

Official Estimates of Economic Deprivation among Disabled People. In response to this long-standing concern the Government promised a comprehensive review of the benefits system. This was to be preceded by a national survey of disabled

people to provide an up-to-date basis for future planning. The previous Government - sponsored survey of disability (Harris, 1971), which had been conducted during the 1960s to provide data for the expansion of services for disabled people, was considered inaccurate and out of date. Although this research showed that impairment results in extra expenditure, no attempt was made to quantify that cost.

The Office of Population, Censuses and Surveys (OPCS) looked at disabled people's incomes in the report *The Financial Circumstances of Disabled Adults Living in Private Households* (Martin and White, 1988). This found that the majority of disabled adults, 78 per cent (54 per cent of those below retirement age), lived in households containing no wage-earners whatsoever. The significance of welfare benefits was correspondingly great. Although half of all disabled people interviewed had another source of income besides earnings or benefits, the most common of these were pension or redundancy payments from previous employers or income from savings or investments, and were thus more likely to be received by older disabled people.

Comparisons with the equivalent incomes of the general population showed that families with a disabled member below retirement age had significantly lower incomes than those without a disabled member - 72 per cent lower. Although this can be attributed to the high levels of unemployment among disabled adults, families with one or more wage-earners still had lower than average incomes than similar households with no disabled members. The incomes of disabled people over retirement age were not much different from those of their able-bodied peers (Martin and White, 1988). This is because most people's incomes are reduced radically after retirement. For example, in 1983 64 per cent of people above retirement age were living in poverty or on its margins, compared with only 24 per cent of those under retirement age (Abberley 1990, p. 13).

Impairment-Related Expenditure. The OPCS researchers, who only asked questions about items bought in the twelve months prior to the survey, found that impairment involved some additional financial cost regardless of the degree of severity. This was divided into three types, capital expenditure on lump-sum purchases, regular expenditure on items related specifically to impairment, and expenditure on items required by most people, but on which disabled people need to spend more. Lump-sum purchases were of items such as wheelchairs, special aids and equipment, special furniture and car adaptations, which are only bought occasionally. Expenses of this nature were only incurred by, 16 per cent of the sample, and amounted to an average of £78, although there was considerable variation among individuals. The average for all disabled adults worked out at £12.50 per year. Because of the limited timespan the OPCS researchers admit that this is likely to be a low estimate of this type of outlay.

Regular expenditure on impairment-related items such as hospital visits, personal and domestic assistance and prescriptions was incurred by 60 per cent of all disabled adults. This increased along with the degree of impairment. The average weekly cost for those who incurred these expenses was £2.20, or £1.20 for all disabled adults.

A higher level of expenditure than that incurred by able-bodied people on 'normal' items such as fuel, clothing, food, travel and home maintenance was reported by 71 per cent of those interviewed. This amounted to £6.70 per week for those incurring it, or £4.80 for all disabled adults. The estimated extra impairment-related expenses for all disabled adults amounted to £6.10 per week or £329 per annum.

Overall, however, there was considerable variation in actual expenditure according to the degree of impairment. As well as rising with severity, average extra costs also rose with income within categories of severity. This indicates that respondents would probably have spent more money had it been available. In all 24 per cent of all disabled adults thought they needed to spend more on impairment-related items but could not afford to do so (Martin and White, 1988, Chapter 4).

Having to spend a proportion of one's income on items associated with impairment reduces disposable income, which is normally the amount available for everyday living after tax, National Insurance contributions and housing costs have been met. The OPCS report examined this in terms of 'equivalent resources'. This was arrived at by calculating disposable income remaining after disability-related expenditure had been subtracted, and using equivalence scales to adjust the remaining income for differences in family composition. Disabled adults had, on average, lower equivalent incomes than families in the general population, so that when the extra financial costs of impairment were taken into account, disabled adults had lower equivalent resources available to spend on other things.

In general, impairment-related expenses amounted to 8 per cent of all disabled adults' disposable income. Although the average amount of such expenditure was lower for those on lower incomes, they spent a higher proportion of their resources on disability-related expenses. The proportion rose with severity of impairment; those considered the most severely impaired were spending an average of 15 per cent, compared with 4 per cent for those with the least impairment. Eight per cent of disabled householders said that they were getting into financial difficulties, and objective tests based on experience of debt and arrears confirmed this (Martin and White, 1988).

The standard of living of disabled people was judged to be generally lower than that of non-disabled people. Assessments of living standards are usually constructed in terms of the lack of named items or activities considered basic, such as a warm winter coat and consumer durables such as a refrigerator and a telephone. In terms of 'relative deprivation' some consumer items such as video recorders would be considered a luxury whilst others are deemed 'normal' at a given point in time. A washing machine, for example, is now considered an essential, whereas in the 1950s it was thought of as a luxury.

The significance of these items is central to the ongoing debate about what is considered 'absolute' and 'relative' deprivation. A criticism often levelled at studies of poverty is that they fail to distinguish whether or not a lack of resources or consumer choice explains the absence of basic items owned by a given population. The former would be an indicator of economic deprivation whilst the latter would not. The OPCS study took account of this problem and found a proportion of both luxuries and basic items absent from choice. There was, however, a definite relationship between impairment and the inability to afford desired items. This was most evident among unmarried disabled people below retirement age. These people generally lacked the greatest number of consumer durables and the most basic items (Martin and White, 1988).

Some Criticisms of Government Assessments from Disabled People and their Organisations. As Abberley (1990) has noted, it is evidence of the growing strength of disabled people and their organisations that a number of detailed responses to this report were quickly forthcoming. In particular, the Disablement Income Group (DIG) and the Disability Alliance (DA) produced reports which welcomed this official recognition of the connection between impairment and economic deprivation, but criticised the methods used by the OPCS researchers, which had yielded data that seriously underestimated the true financial cost of impairment (DA, 1988; Thompson *et al.*, 1989, 1990). Each of these documents takes the individualistic approach of the OPCS for granted but argues that its methods produce the wrong answers to what are 'tacitly assumed to be the right questions' (Abberley, 1990, p.17).

The inaccuracy of the findings of the OPCS survey is explained by a number of factors. First, the study was carried out before the major benefit changes of April 1988, which resulted in a reduction of income for over a million disabled people (see below). Secondly, major capital expenditure on single items such as a car, house adaptations and electrical wheelchairs were generally excluded from the OPCS survey because of the decision to ask questions only about items bought in the year prior to the interview. Thirdly, the sampling technique was biased in such a way as to exclude people with more severe impairments, i.e. those most likely to

incur the highest additional expenditure. The OPCS researchers designated ten categories of impairment of which categories 1-3 were people whose daily lives were not seriously restricted. Almost half the sample were defined thus; on this basis they estimated that 2,742,000 people were in these three categories. This left 3,038,000 disabled people in the remaining categories, a figure very close to the estimate of 3,071,000 made by the first OPCS survey (Harris, 1971), which excluded people with learning difficulties and non-visible impairments.

Fourthly, the form of questioning, interview technique and the time taken for the interviews limited the amount of data which could be collected. The OPCS survey was a large-scale study in which 10,000 people were interviewed. Each interview lasted approximately 90 minutes and only a portion of that time was devoted to questions of finance. As is common in this type of research, no prompting or clarification of the interviewees' responses was permitted. Inevitably there were a significant number of 'don't know' answers, particularly in relation to regular expenditure such as heating costs. Forty per cent of interviewees failed to answer all the questions asked (Martin and White, 1988, p.35).

Finally, it is likely that the OPCS findings seriously underestimated the real level of need. Although the survey showed that 71 per cent of respondents had impairment related expenses, only 24 per cent said that they needed to spend more but could not afford to. The items cited most were basics such as fuel, food and clothing. Abberley (1990) has rightly noted that accurate responses in this area are notoriously difficult to achieve, particularly from people over retirement age. Sixty-five per cent of the OPCS sample fell into this category (Martin and White, 1988).

In a society which places such a high premium upon individual self-sufficiency, need is frequently associated with financial incompetence, and because financial incompetence is a source of shame, need is often concealed. This casts serious doubt on the value of the OPCS study's conclusion that around 70 per cent of all disabled adults expressed 'satisfaction' with their standard of living (Abberley, 1990; DA, 1988; Thompson *et al.*, 1990).

There is a wealth of evidence to show that the OPCS findings concerning the financial costs of impairment are grossly inaccurate. For example, in the 1970s Hyman found that impairment expenditure for wheelchair-users amounted to £14.50 per week (Hyman, 1977). A study in the early 1980s showed that shopping cost disabled people an extra £3.36 per week (Stowell and Day, 1983). Apart from the costs of special diets, clothes etc, many shops are simply not accessible to disabled people. A study of people with learning difficulties found that their

impairment-related expenses were £19.50 per week (Buckle, 1984). Of course, the amounts quoted would be considerably higher today on account of inflation.

In response to the publication of the OPCS survey, the DIG has conducted research showing that among 'severely' disabled people impairment-related expenditure is much higher than Government estimates. To demonstrate the gross inaccuracy of the OPCS findings the DIG researchers used a questionnaire similar to that used for the OPCS study. They then compared the results with data from research which employed a semi-formal interview technique widely used in small-scale in-depth studies which dealt with the same subject, but allowed respondents to think about and clarify their answers. The sample used in the study, however, differed from that of the OPCS survey in size, severity of impairment and age. Thirteen people were interviewed, all described as 'significantly' impaired and only two over retirement age.

Using only the OPCS-type questions, an average extra weekly expenditure of £41.84 was recorded whereas the response of the same subjects to the DIG questionnaire yielded an average of £65.94, a difference of 58 per cent between the two methods (Thompson *et al.*, 1988). To verify these findings a second, larger study was undertaken using the same approach. It reported remarkably similar results. Eighty-seven people were interviewed, 74 per cent of working age. Although a number of the sample was less severely impaired than in the earlier study no one was considered below OPCS category 3. Their average weekly impairment-related expenses totalled £69.92 per week (see Table 5.1).

The DIG study made it clear that the financial cost of impairment increases dramatically with severity, is determined by available income, and is related to receipt of impairment-related benefits. It was also evident that spending on certain important items, such as food, is constrained by limited financial resources (Thompson *et al.*, 19CJO, Chapter 4).

Table 5.1 Average Weekly Impairment-related Expenditure on Selected Items

<i>Item</i>	<i>Amount</i>
Home treatment	0.49
Home services	27.55
Informal assistance	6.89
Prescriptions	0.22
Chemist items	3.14

Laundry	2.23
Clothing	2.51
Wear and tear description	3.14
Food	6.93
Heating	3.95
Travel	8.22
Telephone	3.41
Helper's presents	0.54
Insurance	0.70
Total	£69.92

Source: Adapted from Table 4.6, Thompson et al., 1990, p.33

The Government's Response. The Government's review of benefits for people with impairments, titled *The Way Ahead*, was published in January 1990 (DSS, 1990). In conjunction with a number of measures announced four months earlier, this review proposed a number of small extensions to existing benefits. These included the introduction of additional financial support for people who acquired impairments early in life. Three new measures were also introduced: the administration of the two main disability benefits was rationalised; a new lower-rate payment was introduced for less severely disabled people, and non-elderly people who require intermittent assistance; and a new social security benefit was to be paid to encourage disabled people into employment by supplementing earnings from low-paid or part-time work (Disability Benefits Consortium, 1990).

Despite repeated Government commitments to the contrary, the review which formulated these proposals did not consult with disabled people and their organisations. It has been described as a 'grubby public relations exercise' which will only help a small number of disabled people in a limited and piecemeal way. The new proposals will not eradicate the 'inadequacies and discrimination' which characterise the disability benefits system, or eliminate the economic deprivation faced by disabled people and their families every day of their lives (DA, 1990).

It is unlikely, therefore, that the economic circumstances of the overwhelming majority of disabled people will improve in the foreseeable future. This is a key feature of the discriminatory process, since access to adequate financial resources is crucial in a society in which conspicuous consumption is increasingly assumed to denote status and prestige. However, poverty alone does not separate disabled

people from the rest of the community. It is the disability benefits system itself which does that.

The Benefit System

The Organisation of the Benefit System for Disabled People. The organisation of the present benefit system for disabled people has developed in a largely unplanned and *ad hoc* manner since before the 1914-18 war. Until the 1970s, state-funded welfare payments were focused mainly on people who had acquired impairments due to war or industrial accident, and who had a qualifying record of National Insurance contributions (DSS, 1990).

War and industrial disablement schemes were set up to provide compensation benefits based on a percentage assessment of functional limitations arising from a war or industrial injury. As a result, people who acquire impairments in the armed forces or at work can sometimes receive a substantial war or industrial pension. In addition, specific payments are provided for attendance services, and for limited mobility in the case of the war pension scheme, as well as other special additions including payments for reduced earnings. Those eligible for these schemes are also entitled to claim other impairment-related benefits such as Invalidity Benefit (IVB) and Mobility Allowance (MA), provided that they qualify (see below).

People who acquire impairments because of an accident may also be eligible for large sums of money in compensation, if it can be proved that an individual's impairment is the result of someone else's negligence, as in a road traffic accident. Compensation of any sort, however, is only attainable for a minority. In a recent study of the experience of spinal cord injury, only 39 per cent of a representative sample of seventy-seven felt that there was any possibility of legal compensation for their injury. Of these only 63 per cent had their claim settled at the time of the accident, although this does not mean that they did not experience delays in payment. The remainder encountered major delays. The length of time waiting for settlement, or until the completion of the settlement, varied between less than one year and seven years (Oliver *et al.*, 1988).

These delays can have serious negative financial and psychological implications for disabled individuals and their families. While some people receive interim payments to alleviate financial hardship before the final settlement, many are kept in ignorance of the amount due or, indeed, of whether they will get anything at all. This financial uncertainty, coupled with the additional worry of protracted and complicated legal battles, can cause debilitating psychological distress. Further, since the size of the compensation is normally determined by the degree of impairment there is little incentive for claimants to overcome any impairment-

related problems which might ensue during the litigation process (Oliver *et al.*, 1988).

It has been suggested that some of these problems might be overcome with the introduction of a no-fault compensation system similar to that advocated by the Pearson Commission (1978) for motor vehicle injuries (Oliver *et al.*, 1988). Until fairly recently this idea has received little support from the insurance industry (see *CII Journal*, 1978) and indeed from successive governments. But the idea of no-fault compensation for 'small motor vehicle accidents' is being debated by the Lord Chancellor's Department and a statement was due to be produced in late 1991. Also the notion of no-fault compensation for injuries through treatment by the National Health Service is now supported by a variety of agencies, including the British Medical Association (BMA, 1990), and some politicians.

One of the factors which precipitated this interest is the public concern over the protracted legal battles for compensation paid to people with haemophilia who contracted human immunodeficiency virus (HIV) through blood products provided by the NHS. On 25 October 1990 the Labour MP Harriet Harman introduced under the ten-minute ruling a no-fault compensation for medical injuries bill (House of Commons Bill 208) (*Hansard*, 1990d). Although it was defeated, it has since been adopted by the Independent Social Democrat MP Rosie Barnes, who has extended it to include injuries through drugs and appliances prescribed through the NHS. Ms Barnes put the National Health Service (Compensation) Bill before the House on 1 February 1991. It was defeated on its second reading by 193-81, a majority of 112 against (*Hansard*, 1991).

Until the general expansion of benefits during the 1970s, disabled people who were not eligible for any form of compensatory benefit had to rely entirely upon means-tested assistance. In 1971 a long-term benefit to replace earnings was introduced, the Invalidity Benefit (IVB). This was followed in 1975 by its counterpart for people who had not paid enough National Insurance contributions to qualify for IVB. Originally known as the Non Contributory Invalidity Pension (NCIP) it is now referred to as the Severe Disablement Allowance (SDA) (DA, 1990).

In 1970, 1973 and 1976 respectively, higher and lower rate Attendance Allowance (AA) and Mobility Allowance (MA) were introduced. These last two benefits were specifically designed to cover some of the impairment-related expenses discussed above. Whilst the aim of the MA is to assist disabled people with the additional costs of transport, replacing the provision of the invalid vehicle service, the purpose of the AA is less clear. It was generally intended to provide funds to cover impairment-related expenses with the need for 'attendance' serving as a means of identifying the most 'severely' disabled people, those considered most in need.

However, although 'self-care' ability is used as a means of measuring need, AA was not introduced to pay for personal assistance (Large, 1990). In December 1990 the higher rate of AA was £37.55 per week, the lower rate £25.05 and MA £26.25 (Large, 1990).

In 1975 the Invalid Care Allowance (ICA), a benefit paid to people of working age who act as personal assistants (PAs) to disabled people in receipt of AA, was introduced. It was not, however, available to the vast majority of personal assistants, namely married women, until 1986 and it is not available to those people who act as PAs to disabled people not in receipt of AA. Invalid Care Allowance can be worth up to £45.05, but £28.20 of this is deducted from the benefits, in particular the severe disability premium, paid to the disabled person receiving the PA service (DA, 1990, p. 117). It is important to note how low this allowance is compared to the wages of other full-time workers. (One of the consequences of this exploitation of PAs is discussed in the following chapter.)

It will be evident that, in common with state benefits generally, allowances for impairment-related expenditure are allocated for a specified purpose and named accordingly. This bureaucratic regulation carries with it unmistakable assumptions of social incompetence which might prove unacceptable to other sections of the community. How many wage-earners, for example would tolerate their wages being divided up in this way? These assumptions are especially marked in the case of impairment-related benefits because of the use of explicitly disablist language which emphasises and reinforces difference and dependence. Of particular note is the term 'invalidity', the etymology of which is quite clear, namely in-valid. Moreover, assumptions of social incompetence are so clear in that the state is willing to pay PAs an ICA rather than giving the allowance to recipients of the service so that they can pay the PAs themselves.

The traditional divisions between disabled and non-disabled people are also enhanced by the number of allowances 'targeted' specifically at people with impairments. This perpetuates the wide-spread view that disabled people have their needs adequately catered for by the disability benefits system (Thomas, 1982) and are consequently better off financially than other sections of the poor. This is particularly important since financial hardship is increasingly common among non-disabled British citizens. A recent analysis, for example, found that between 1979 and 1987 the number of people with incomes below the 'benefit line', which is widely regarded as the 'official poverty line', rose by 18 per cent (IFS, 1990). Large sections of the community now find themselves wholly or partly reliant on state benefits as a major source of income. However, as was demonstrated clearly above, disproportionate economic deprivation is particularly acute among disabled people. The DIG study found severely disabled people (category 10 in the OPCS

scale) were spending £146.47 per week on impairment-related expenditure (Thompson *et al.*, 1990).

Besides emphasising differences between disabled people and non-disabled people, the organisation of the disability benefits system also creates significant economic and social divisions within the disabled population as a whole. Each of the benefit systems mentioned above has a different set of criteria for eligibility. Age at the onset of impairment, the cause of impairment, its severity, an individual's work record, National Insurance contributions, and even country of residence for the previous twenty years all have an important bearing on the amount which can be received. As a result people with similar impairments can be entitled to vastly differing sums of money. For example, someone considered to have 'severe' impairments on the war disablement scheme can receive up to £287 per week, whilst a similarly impaired individual who has not paid National Insurance contributions, and who has not lived in Britain for ten of the previous twenty years would only be eligible for AA and MA, which in 1990 amounted to a meagre £63.80 per week. People who have not been in Britain for ten out of the past twenty years cannot claim SDA (DA, 1990, p.2).

Recent Changes in the Benefit System. Contrary to official rhetoric throughout the 1980s, the value of impairment-related benefits has been reduced by successive Government attempts to cut public expenditure generally. Although the demand for benefits among the population as a whole has increased, social security expenditure has been singled out for particular attention in these cuts. As a result, between 1979 and 1989 around £11 million has been cut from the social security budget (Lister, 1989).

For example, before 1980 increases in long-term benefits such as IVB were linked to the rise of either wages or prices, whichever was the greater. Under the first 1980 Social Security Act, these benefits were pegged to prices only. The second 1980 Social Security Act reduced Invalidity Benefit by 5 per cent and abolished the earnings-related supplement to short-term benefits payable during the first six months of injury or sickness. This resulted in a loss of over £330 a year at 1983 prices for a family with a disabled member (Franey, 1983, p. 8).

Major changes to the social security system were introduced in 1988 following a series of Government policy reviews. The old Supplementary Benefit system was abolished and with it a range of additional payments hitherto available to large numbers of disabled people on the basis of individual need. These were replaced by a system of fixed premiums which provided extra benefit to people who fitted into particular categories, namely 'disabled' or 'severely disabled'. One of the ways in which claimants were slotted into one of these categories was by being in receipt

of AA or MA. Consequently, these benefits have become far more important, not only in themselves but also because they act as a passport to additional financial support (NACABx, 1990a, p. 5).

Changes were also announced in 1988 to the State Earnings-Related Pension Scheme (SERPS). Incentives were introduced to encourage workers into employers' or private personal pension schemes. Disabled workers are often at a disadvantage in occupational and private pension schemes and therefore rely heavily on SERPS. Hence, their future disability and retirement pensions will be adversely affected. Government figures suggest that some 80,000 sick or disabled people, along with 30,000 dependants, will be worse off as a result of these changes (*Hansard*, 1988), while independent estimates put the figure at well over 1 million (DA, 1987).

As well as the cuts in the SERPS and the incentives to join occupational and private pension schemes, responsibility for paying sick benefit during the first twenty-eight weeks of sickness has also been transferred from the state to employers. It is reported that 'early monitoring' of the new system has shown high error rates in Statutory Sick Pay (SSP) payments, widespread ignorance on the part of employees and employers regarding the new scheme, a lack of official supervision and enforcement, and that employees are being sacked or forced to become self-employed by employers who refuse to operate it. Shifting the responsibility for payment of SSP on to employers in this way can only add to the discriminatory practices within the workplace and make employees with real or imagined poor health records more vulnerable to discrimination (Baloo *et al.*, 1986; Glendinning 1990).

In order to achieve cost effectiveness within the social security system the Government used two main strategies: the targeting of impairment-related benefits at those people considered most in need through the use of economic means testing, and the replacement of statutory provision with discretionary grants from Government and quasi-charitable agencies (Glendinning 1990). Both of these approaches signify a dramatic strengthening of bureaucratic regulation and control, which can only emphasise difference and reinforce dependence - the first because it makes the claiming process even more difficult than it already is and the second because it marks a significant retreat from the idea of disabled people's rights and legal entitlement.

The Disability Benefits Claiming Process Economic means-testing is a process by which individuals have to provide information about their income and resources to state or the officials in order to receive welfare payments. Economic mean-tests were developed during the nineteenth century to separate the 'deserving' from the

'undeserving' poor. They are widely regarded as a humiliating and degrading process, which compounds the difficulties of living on welfare. Successive studies show that the stigma, ignorance and misunderstanding which surround economic means-testing prevents many people from claiming the benefits to which they are entitled (Glendinning, 1990; Young, 1987). To claim their welfare rights, however, disabled people are subjected to at least two means-tests -an economic one and a functional or medical one.

To some extent all impairment-related benefits are dependent upon medical evidence. Sometimes this may be provided by a claimant's own doctor, as with IVB. Department of Social Security (DSS) officials normally base decisions as to whether, or not an individual is to be described as incapable of work upon evidence from the claimant's own doctor. However, if the DSS doubts the validity of the doctor's report, it can insist on a second opinion. This means that the individual claiming benefit will be referred to a doctor in the Regional Medicaid Service of the Department of Health (DoH) (DA, 1990).

To become eligible for either of the two main impairment-related benefits, namely AA or MA, an individual must be examined by a doctor or doctors other than their own. A recent report from the National Association of Citizens Advice Bureau (NACABx) concluded that these medical assessments cause unnecessary 'humiliation and distress' (NACABx, 1990a, p. 3). Most of the doctors used by the DSS are men. In December 1988 there were 14,863 examining medical practitioners undertaking examinations for AA, of whom only 816 were women. Similarly, there is an absence of doctors of both sexes from ethnic minority backgrounds (NACABx, 1990a, p. 11). Consequently, if a disabled woman or someone from an ethnic minority wishes to be examined by a doctor of the same sex or cultural background then s/he must contact the DSS in advance. This can mean a delay in being examined and hence a delay in receipt of the benefit, or additional travel (DA, 1990, p. 3).

A major problem in the assessment process arises from what doctors are attempting to measure. To qualify for AA an individual must prove that s/he requires from another person 'frequent attention throughout the day', or night, in connection with her/his bodily functions, or 'continued supervision' throughout the day or night to avoid substantial danger to her/himself or others. In other words, people have to demonstrate that they cannot look after themselves. They are expected to go into detailed explanations about the difficulties they experience when doing such intimate things as washing, dressing, eating and using the toilet. Such interrogations are undoubtedly 'degrading and demeaning' (NACABx, 1990a, p.11).

To qualify for MA, claimants must prove that they are unable or 'virtually' unable to walk due to a physical cause which is likely to last for at least one year. They are asked to demonstrate in a short interview the difficulties they encounter in walking. The claimant's walking ability out of doors is considered with 'any aids that are used. Other factors taken into account are the distance which can be walked, the length of time that can be spent walking, the manner of walking, and any pain that may result from walking. Environmental or social circumstances, such as living at the top of a hill or on the fifteenth floor of a high-rise block of flats, are not considered (NACABx, 1990a, p.6).

Although claimants for both AA and MA are examined by doctors appointed by the DSS, claims are dealt with by two quite different adjudication processes. With AA, decisions on whether or not an applicant is eligible are taken by an AA Board which consists of a Chair and between four and nine other members. All but two of the Board's members must be medically qualified. In the majority of cases medical decisions are made by Delegated Medical Practitioners, who are themselves doctors employed by the DSS. They rarely examine the claimant in person but their decision is determined by the report of the examining doctor, who in most cases will only meet the claimant once for the examination. The decision on this aspect of the claim is then passed on to the Adjudicating Officer, who decides the non-medical aspects of the claim.

There is no right of appeal against the AA Board's decision on medical grounds, only a right of review within three months of the decision or in certain other circumstances. Applications for review are dealt with by a further medical examination and reconsiderations by the Delegated Medical Practitioners who will be asked for their 'opinion' as to whether the claimant fulfils the medical criteria for the allowance. The Adjudicating Officer then makes a decision on the claim.

The Adjudicating Officer can refer a claim to a Medical Board, consisting of two or more doctors, for decision on medical questions. A claimant who is refused on medical grounds may appeal within three months of the medical decision, and then be examined by a Medical Board if this has not already happened. An appeal against a negative decision would go to a Medical Appeals Tribunal consisting of a legally qualified Chair and two medically qualified members. They are independent of the DSS (NACABx, 1990a, p.8).

Medical criteria are often used to deny access to both AA and MA. Claimants may have to apply several times before allowances are awarded. With the AA, 300 appeals to the Social Security Appeal Tribunal on non-medical questions were cleared in 1988, whereas there were 56,000 requests for the AA Board to review its decisions. Over 30 per cent of initial claims were refused, but the percentage of

the reviews decided in the claimants favour when the reason for review was dissatisfaction with the original medical decision was 632 per cent. Figures published by the DSS for 1989 are not directly comparable, but as there were 318,380 initial claims, and 56,087 applications for review decided in 1988, questions arise over the proportion of claimants who are dissatisfied with the decision initially given on their claims, and over the decision-making process generally (NACABx, 1990a, p.10).

With the MA, 29 per cent of the decisions against the claimant were overturned by Medical Boards and a further 42 per cent at Medical Appeals Tribunals. The vast majority of queries arise over the medical conditions, with only 1,812 appeals on non-medical grounds cleared in 1988, compared to 6,547 decisions by Medical Appeal Tribunals and 20,980 by Medical Boards (NACABx, 1990a). Claimants who decide to ask for a review of a refusal or appeal against a negative decision are likely to have to undergo a further medical examination, either by a second doctor, or in the case of the MA by a Medical Board, or members of a Medical Appeals Tribunal (NACABx, 1990a, p. 10).

In line with the proposed merging of the AA and MA into a 'new' Disability Living Allowance (DLA) in 1992, it has been announced that the requirement for successive medical tests for access to benefits is to be abolished. They are to be replaced by 'a single claim' and 'a single medical examination' which has to be submitted to a new decision-making structure (DSS, 1990a). Under the new system decisions will be made by 'non-medical Adjudicating Officers' but medical staff will 'continue to assist and inform the adjudication process' (DSS, 1990a, p. 7).

With the new proposals claimants can opt for a medical assessment or complete a new 'rather more detailed claim form' designed to identify the level of 'disability in relation to both self-care and mobility'. This is because the DLA bundles together AA and MA, and does not acknowledge other impairment-related expenditure (Large, 1990). There are no plans to include environmental and social factors in the new assessments. Claimants, can, however, bolster their written claims by supplying supplementary evidence 'about their condition and the effect it has on their ability to perform normal functions' from 'whichever agency is 'in the best position to make that judgement'. This can include a general medical practitioner, hospital consultant, health visitor or a special school (DSS, 1990a, p.7). In addition, medical assessments will be carried out on a small number of claimants to act as an audit 'to check on the accuracy of the written statements received' (DSS, 1990a, p. 90).

Dissatisfied claimants will be able to have their claim reviewed by a different Adjudication Officer, who will also have access to 'expert medical advice'. But the

Government expects a medical examination to be necessary where the first-tier assessment has been made on the basis of written evidence alone Claimants still not satisfied with the outcome of the appeal will be able to apply to an 'independent appeals tribunal' comprising a 'a legally' qualified chairperson; a medically qualified member; and a third member who ideally will have practical experience of people with disabilities' (DSS, 1990a, p. 9).

Clearly, apart from the reduced number of medical tests disabled people will have to endure, little has changed. First, for a variety of reasons, not least the inadequacy of the special education system, many disabled people have difficulties with communication and literacy skills, and consequently the new detailed claim form will present them with a major problem. Secondly, in order to claim their rights disabled people will still have to answer detailed sensitive and intimate questions about their impairments and their functional abilities and be asked about their ability to 'perform key daily tasks' such as 'cooking a main meal' (Brindle, 1990) - a feat which a sizeable proportion of the adult British population may not be able to accomplish. Moreover, if claimants are unable to fill in the form themselves they will have to discuss these delicate subjects with someone else before that person can complete it on their behalf.

Thirdly, since both components of the new DLA are to be paid at very different rates, the AA is to be extended to include a third lower rate of £10 per week and the MA is set to include a second lower rate of a similar amount, claimants will therefore want their claim to carry as much weight as possible to avoid being awarded the lower rate. Additionally, by lowering the payout rates the new allowances will attract many new claimants and the introduction of 'self-assessments' gives Adjudicating Officers far more scope to 'short-change' new beneficiaries (Large, 1990, p. 19). Hence, many disabled people will feel compelled to support their claim with medical evidence.

While a clearly-defined review procedure is to be established, the increasing importance of medical criteria becomes apparent at each stage of the appeals process. Indeed, one of the appeal tribunal members is to be a doctor, one a lawyer and the other an 'expert' on 'people with disabilities'. Who that 'expert' will be, however, remains unclear. Based on past experience, it is unlikely to be a representative of an organisation of disabled people or someone who will be in a strong enough position seriously to challenge traditional wisdom in these matters. Hitherto most official bureaucracies have been particularly reluctant to support organisations of disabled people or their representatives (see Chapter 6).

Overall, disabled people still have to supply sensitive and intimate information to professional 'experts' in order to receive benefits, and it is those experts who will-

decide on the basis of that information whether benefits should be granted. In short, functional or medical means-testing will not disappear and the welfare bureaucracy will remain intact.

This process brings into full view one of the major problems of the disability benefit system as a whole, namely that it encourages rather than discourages dependence. To receive financial support, applicants are compelled to emphasise impairments and functional limitations as opposed to personal autonomy and skills. Indeed, to secure the maximum economic advantage from the benefit system disabled people are forced to present themselves in, the worst possible light (Oliver *et al.*, 1988). This has become even, more important in recent years because of the shift away from statutory entitlements to discretionary grants.

The Shift from Statutory to Discretionary Entitlement. Since 1988 the claiming process has become even more complex with the withdrawal of some of the hitherto available statutory payments to cover impairment related expenditure in favour of discretionary grants. Prior to 1988, a number of additional weekly payments were available to recipients of Supplementary Benefit. Ten of the fourteen allowances provided were specifically concerned with impairment or health-related expenditure. A significant number of these allowances had no maximum amounts fixed and therefore, taken together, they could 'virtually' cover the full financial cost of a disabled claimant's needs, including the cost of employing a full-time living-in P A for those who needed one. Claimants were also legally entitled to lump-sum awards to cover major items such as furnishing, clothing and household equipment. As noted above, these are particularly important to disabled people. Following the social security review of 1988 this support was removed (Glendinning, 1990).

It was replaced by two discretionary, cash-limited funds; the Social Fund and the Independent Living Fund. The Social Fund, which is administered by the DSS, is designed to provide single payment grants for specific items needed by the poorest disabled people, especially if they are at risk of being admitted to a residential home (Glendinning, 1990). The Independent Living Fund (ILF) is run by the DSS with the full cooperation of the DIG. The funding, headquarters and staff are supplied by the DSS and the trustees are chosen in equal numbers by the DSS and the DIG; The ILF was set. up to compensate for some of the financial losses incurred by people with severe impairments following the abolition of the Domestic Assistance Addition (DAA) to Supplementary Benefit in April 1988 (*Same Difference*, 1990a).

These developments signify a major shift in the allocation of resources for disabled people away from statutory provision with its commitment to 'demand-led

expenditure', in favour of a discretionary-based system with a limited budget controlled by 'quasi-independent organisations' which are publicly accountable only in part. In short, disabled people's rights and legal entitlements have been substantially eroded by Government efforts to control public spending and reduce the power of the welfare state. Under the new system there are no guarantees that even the most urgent needs will be met, no assurances that applicants in similar circumstances or with similar needs will be treated equally, and only very limited rights of appeal (Glendinning, 1990).

These criticisms certainly apply to the Social Fund. A recent report by the NACABx found that in a sample of 550 Social Fund applications only 20 per cent had their claims met in full. A staggering 55 per cent had been refused support altogether. Of those described as 'sick or disabled', 23 per cent had been refused a grant. Thus, as pressure on the annual budget increases, the major inadequacies of the system in meeting even the most basic needs become apparent. Applicants considered high-priority are refused simply because the local office budget is exhausted. It is, therefore, impossible for an applicant to predict whether s/he will receive a grant, a loan or a refusal. Applicants in the same circumstances will receive very different decisions, and there is no formal appeals procedure outside the DSS (NACABs 1990).

The report showed that people were very reluctant to apply to the Social Fund because in certain instances they were offered loans instead of grants and felt they would not be able to meet the repayments. People were also put off by the complexity of the claiming process. Moreover, because there are no clear criteria for payment, the onus is on the applicant to provide the appropriate information. This means that applicants with limited communication or literacy skills are at a 'particular disadvantage' (NACABx 1990, p.3). At present, the only way this problem can be overcome is by reliance on others. A recent study showed that Social Fund applicants who enlisted the help of a social worker were far more likely to receive payment than those who did not (Community Care and the Benefit Research Unit, 1990).

The Independent Living Fund came about as a result of the DIG's collaboration with the Government after the publication of the 1986 Social Security Act and the social security changes discussed above. The DIG's action was severely criticised by many disabled people because it effectively stifled the possibility of wider public debate on the purpose and practice of funding personal assistance. Moreover, when the ILF was set up there were a number of disabled people with considerable expertise in the process of gaining and using money to buy personal assistance. These experts were ignored when the trustees came to draw up their guidelines, although some – notably the Hampshire Coalition of Disabled People - did offer

their services (Mason, 1990). The ILF currently employs fifty-five staff, the majority of whom are on secondment from the DSS. Their wages are paid out of ILF funding (House of Commons Social Services Select Committee, 1990).

The ILF is a state-sponsored charity whose sole purpose is to keep disabled people out of institutions. While this is a worthy goal in itself, the ILF does not see disabled people as 'whole' people, but merely as 'eaters and sleepers' (Mason, 1990). It provides weekly payments to cover the cost of personal and domestic services as well as one-off payments for special equipment. In the assessment process the only task considered eligible for awards are those to do with personal and domestic needs; employment needs are not taken into account. The ILF is not intended to enable disabled people to achieve equal opportunities, and it therefore contributes to the discriminatory process. Moreover, as with all discretionary systems, ILF applicants have to submit to an economic means-test. Hence, any income above the DSS income support level is considered available to pay for essential services. Although the application process for ILF awards is fairly simple and straightforward, claimants are subjected to the indignity of assessment by a visiting social worker (VSW) who will require proof of income and expenditure (*Same Difference*, 1990a).

Originally the Government expected that the ILF would only be used by about 300 people, reflecting the small number receiving the DAA. But the availability of DAA was not widely publicised and like many DSS impairment-related benefits it was difficult to claim. The setting-up of the ILF, on the other hand, received a great deal of publicity and, largely through the efforts of the DIG, was providing financial support to 3,000 disabled people within its first year. In the event, the ILF's budget has risen from £5 million in 1988/9 to £62 million for 1991/92 (Large, 1990).

Many people experience problems with the IF. Long delays before decisions on claims are common. This causes great anxiety and cash flow problems to anyone involved. These are huge gaps between the VSW's assessment visit, confirmation of the award and when people actually start to receive the money - at present around three months (Mason, 1990).

The cash amounts and the way they are calculated are inadequate for what they are intended to pay for. They do not accommodate basic variables such as staff holidays, weekend pay, night attention and staff change-over, nor do they allow for any sudden irregularities or emergencies - though some of these sums can be recouped at a later date by reapplication. Independent Living Fund support does not allow for administrative and management costs which are regarded as normal by commercial and statutory agencies doing the same sort of work. It does not

cover, among other things, insuring staff, advertising, interviewing and training. Disabled people must meet these costs from their other over-stretched resources, which can cause severe cash problems. In addition, the grants paid to fund PAs' salaries are based on the lowest pay rates (Mason, 1990). The reliance upon cheap labour for personal and domestic assistance should not be a basis upon which to structure disabled people's lives.

The conditions under which awards are made do not allow people to employ family or friends as PAs, and the criteria for eligibility can rule out some people who require assistance. The ILF receives 1,800 applications every month, but only one in three is successful. Claimants are, however, entitled to a review if the award is turned down or considered too low. Again, claimants are urged to seek the assistance of a welfare rights worker to help with their claim (*Same Difference*, 1990a).

In 1990, a lack of resources forced the ILF to restrict awards still further. In its response to calls for extra funds by the ILF's trustees, the Government argued that the organisation was making awards to people for whom it was not intended; also, that it was set up as a temporary measure to fill the gap created by the 1988 social security review until the implementation of the social service reforms of 1991/3 (see Chapter 6), when local authorities will take over its responsibilities. 'This prospect is viewed with alarm by some disabled people because, despite its shortcomings, the ILF has given them direct control over their own personal and domestic support services. To relinquish that control to local authorities, social services departments signals a further denial of disabled people's right to autonomy. 'To replace charity by parish relief does nothing to further the rights of disabled people' (Witcher quoted in *Same Difference*, 1990a, p.2).

The Benefit System and Employment. As was shown in the previous Chapter, work is central to our society and disabled people are at a particular disadvantage within the British labour market. Current and proposed social security arrangements act as a major disincentive to their employment, despite Government declarations of intent to remedy the situation.

At present, income maintenance levels draw a sharp distinction between capacity and incapacity for work. Benefits awarded on grounds of incapacity for work, such as IVB or SDA, may be lost in full when an individual actively seeks work or receives employment training. Current social security arrangements particularly the complexity of the system, the humiliation of the claiming process, and the uncertainty of its outcome make it particularly difficult for disabled people to move between employment and unemployment. Those who take a job run the risk of losing their right to benefit should they become unemployed within a

remarkably short period of time. The risks are greatest for those under twenty, who, following a spell of paid employment, may never be able to re-establish entitlement to SDA. The period under which benefit entitlement is safeguarded is currently eight weeks (Hirst, 1990). Disabled people are forced to choose between competing for mainly low-paid, low-status jobs on unfavourable terms with non-disabled people, and thereby losing some of the impairment related benefits, or resigning themselves to long-term unemployment.

People on IVB or SDA are allowed to obtain employment, but only if they can prove that this work is medically certifiable as 'beneficial', or if it has 'therapeutic value'. This in itself is remarkable in a society where work is crucial to an individual's self-esteem and the debilitating physical and psychological consequences of unemployment are well known. Moreover, the amount which can be earned is subject to a 'Therapeutic Earnings Limit' of £35 per week. If an individual is able to earn more than this amount, then s/he is no longer considered incapable of work (SS, 1990, p. 32), regardless of the severity of impairment, and the type of work involved. As shown in Chapter 4, those people who choose employment are invariably penalised financially. Apart from MA and AA, the granting of which is put at some risk when an individual starts work (given the prevailing assumptions surrounding disabled people and employment, it is likely to be far more difficult to 'prove' functional incapacity if one is in work), the present benefit system does not accommodate impairment-related expenses for disabled people who are actually in employment. For example, there is no state-sponsored system for enabling disabled people to employ a PA for work. Some local authorities (a minority) will pay the full cost of employing PAs, while others will pay less, the ILF providing finance to cover the balance, but this is extremely limited in relation to the work likely to be required and is not consistent throughout the country. Moreover, in both cases the recipients of these services are subject to means-testing, and consequently any income above the level of income support is regarded as available to cover the cost of PAs.

In a minority of cases the employment of PAs can be funded by charities. For example, the Royal National Institute for the Blind (RNIB) can provide a personal reader service, but the readers are mainly paid for either by the employer or by the disabled worker. Since most employers have hitherto proved reluctant to provide any facilities whatsoever to enable disabled people to work (see Chapter 4), most workers who require a PA have to pay for one themselves. Hence, the disabled worker has to earn the equivalent of two people's wages or there is no financial incentive for her/him to work at all. Indeed, even where a disabled person has sufficient income to employ a PA/he is not allowed to offset that cost against tax liability. According to the Inland Revenue, 'a PA is a perk, a luxury, not a necessity and therefore its tax liability is increased, not decreased' (Mason, 1990, p.2).

The Government has acknowledged these problems in its recent review of social security benefits for disabled people, *The Way Ahead* (DSS, 1990). In consequence, a new benefit called the 'Disability Employment Credit', recently renamed 'Disability Working Allowance' (DWA), will be introduced in 1992. It will be paid to disabled people in receipt of the new DLA or to those assessed by a doctor as only partly capable of work who are getting IVB, SDA, or the Income Support or Housing Benefit premiums. It will also be available to some disabled people in work who were receiving specific benefits before they started work and who are on very low incomes. The new benefit is designed to top up low earnings and result in a higher income for some disabled people. Also, those receiving the new benefit who were receiving either IVB or SDA before starting work will, if they lose their jobs, be eligible for long-term 'incapacity benefits' without having to re-qualify (DSS, 1990). It is officially estimated that only about 50,000 disabled people will be eligible for the new scheme (Glendinging, 1990, p. 14).

There is a number of problems with these proposals. First, there are many disabled workers on extremely low wages who will not qualify for DLA because they have neither 'self-care needs' or mobility problems; only 8 per cent of all disabled adults receive AA and 7 per cent MA (Martin and White, 1988). The rest will not, therefore, benefit from these measures. Secondly, it is not clear how 'partial incapacity' for work will be assessed as there is no precedent for this within the existing benefit system. Originally the Government proposed that claimants must 'satisfy a doctor that they were only partially capable of work' and that since the new benefit is to be paid for six-month periods only, claims will be subject to 'periodic medical evidence of partial incapacity'. However, a recent House of Commons Social Services Select Committee which looked at these new proposals warned ministers about subjecting disabled workers on low pay to 'inappropriate medical assessments' (House of Commons Social Services Select Committee, 1990, p.29). It has subsequently been announced that self-assessment will be acceptable in order to claim DWA (Bindle, 1990). Claimants are likely, therefore, to have similar problems to those discussed above. Additionally, the question of periodic assessments of incapacity has yet to be resolved. Thirdly, the position of those termed 'partially capable' of work is not clear. At the moment they would not qualify for IVB but would be assessed as unemployed and so suffer a loss of income (Graham *et al.*, 1990).

Fourthly, it is not evident whether disabled people working part-time will be eligible for the new scheme or, if they are, at what point the Government will draw the line about the number of hours worked. Fifthly, the new benefit does not accommodate disabled people who lose their jobs for other reasons than incapacity for work, such as discrimination.

Finally, the new benefit, because it involves an economic means-test, does not address the major problem of low-take up. The House of Commons Social Services Select Committee mentioned above expressed fears that the new benefit would, like Family Credit, suffer from low take-up problems as well as a poverty-trap effect. The MPs stated:

We believe that fears that a claim for the new benefit combined with the existing barriers' faced by disabled people seeking entry to the labour market are likely to form a very strong disincentive for disabled people who are keen to work but who are understandably concerned not to jeopardise income in cash or in kind (House of Commons Social Services Select Committee 1990, p.29).

Conclusion

This chapter has demonstrated that the overwhelming majority of disabled people and their families are disproportionately reliant upon social security arrangements for their livelihood and experience extreme economic deprivation as a result. The evidence shows that for disabled people the price of living on welfare is a systematic erosion of personal autonomy and excessive bureaucratic regulation and control. It is also evident that this process intensified markedly in the 1980s.

There has been widespread concern over the financial circumstances of disabled people and their families since the 1960s, and repeated calls have been made for a comprehensive disability income. Government research shows that families with a disabled member have significantly lower incomes than those without. This was attributed to the high unemployment rate among disabled people (due to institutional discrimination within the labour market) and the extra financial costs of impairment. Using a more appropriate research methodology, data from the DIG show that although accurate in its conclusions, the Government study has seriously underestimated the true financial cost of impairment and the degree of economic deprivation suffered by most disabled people. The Government has largely ignored this evidence.

This is important because the lack of financial resources in an overtly materialist society such as that in Britain is a major factor in the discriminatory process. Economic deprivation alone, however, does not separate disabled people from the rest of the community. Like other benefit claimants they have the indignity of living on state welfare, which is then enhanced by the disability benefit system, reinforced by the degrading claiming procedures and compounded by its failure to integrate them into mainstream employment.

The disability benefits system in force at the time of writing is clearly an *ad hoc* hotchpotch of grossly inadequate measures which maintain the historical divisions between disabled and non-disabled people. It uses explicitly 'disablist' terminology that perpetuates the illusion of dependence and is characterised by a complexity which encourages the notion that disabled people's economic needs are well provided for. This complexity also creates significant economic and social differences within the disabled community as a whole.

The recent changes to the social security arrangements have made this situation far worse. The policy of targeting benefits at those considered 'most in need' through the use of economic means-tests and the shift away from statutory entitlement in favour of discretionary awards distributed by semi-independent organisations with limited budgets" signifies both an erosion of disabled people's rights and an intensification of bureaucratic regulation and control. The claiming process has become even more tortuous than before and disabled people are now subject to the indignity and humiliation of at least two means-tests, a functional or medical one and an economic one, the outcomes of which are never certain.

The present disability benefits system demands and rewards complete dependence and penalises individual autonomy. Disabled people are forced to elicit the aid of professionals in order to help them emphasise their individual impairments and beg for the allowances to which they are entitled. In addition, because the existing and proposed social security arrangements fail to compensate for the problems faced by disabled people within the context of the labour market, they will continue to be a major disincentive to employment in the foreseeable future. The overwhelming majority of disabled people will therefore remain dependent upon welfare, and their social inefficiency will be preserved. While the introduction of a national disability income might go some way towards making this disadvantaged position a little more palatable, it will certainly not change it.