

5. Paying for the Additional Costs of Disability

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What is meant by the additional costs of disability?

In explaining this it is essential to distinguish between the two financial effects of disability. On the one hand, disability can lead to a loss of earned income on the part of the disabled individual or his or her non-disabled partner or parent, either of which may be a partial or complete loss. On the other hand, disability invariably leads to additional costs whether or not there is loss of income.

In one sense any reduction in earned income brought on by disability is a 'cost' of disability. But it is not the sort of 'cost' being examined in this chapter. This paper deals exclusively with the additional costs of disability, the extra costs encountered in disabled daily living.

The additional costs of disability can be divided into two basic types: capital and revenue; both may be divided into disability-created costs and disability-enhanced costs.

Disability-created capital costs

First, there are the costs of essential or highly desirable items of equipment that are not available through the National Health Service or local authorities. Non-disabled people do not incur these costs.

Occupant-controlled powered indoor/outdoor wheelchairs are an example. These can easily cost £2,000-£3,000. They can be expected to last ten or more years but will involve fairly heavy maintenance costs, maybe £100 or more a year with replacement batteries costing £140. Lightweight, so-called sports, wheelchairs, which are far less difficult to hand-propel than standard issue wheelchairs, can cost

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£1,500 or more. They are needed by paraplegics who want to remain as active as possible. Special wheelchair cushions needed to avoid pressure sores can cost as much as £250 or £700 each.

None of this equipment is readily available through the National Health Service; much of it is unavailable. With responsibility for the artificial limb and appliance centres being fully in the hands of Regional Health Authorities in April 1993, securing such equipment may be even more difficult in future.

Indoor hoists, special beds and bedding— motorised beds, sheepskins and special mattresses and pads, for example — may all have to be bought by the individual.

Communication equipment for deaf or blind and partially sighted people — for reading printed matter or computer displays, for example — generally has to be paid for by the individual. It can be provided by the Department of Employment and grants of up to £3,000 in total for the duration of a course are now available for students, but non-students and those who are not employed have to buy the equipment themselves. Incidentally, any disabled student can receive a discretionary grant of up to £1,000 a year to cover disability costs in studying and up to £4,000 a year can be paid to a deaf or blind student for non-medical personal helpers. There is no such help for non-students.

Disability-enhanced capital costs

There are also extra costs involved in having a legitimate need for items of equipment on account of disability, items that might be thought of as luxuries for a non-disabled person. An electric can opener, electric carving knife, remote controls for radio, television and hi-fi, remotely controlled lights and door-answering system, an automatic potato peeler and food mixer are all examples.

Half-way between these two types of capital costs are the costs of adaptations and extensions to the home to make it suitable for a disabled person. Some add to the value of a property; many do not. Means-tested 'disabled facilities grants' are available towards these costs, but they are pitched at a very low level — ridiculously low when one considers the possibility of an existing mortgage. For example, a married couple, one of whom is disabled, would be expected to pay for the whole of the cost of adaptations costing £10,000 if they enjoyed an income of £308.72 a week (£16,129 a year); such a couple would

be expected to start contributing towards these adaptation costs as soon as their income exceeded £99.70 a week (£5,199 a year).

Disability-created revenue costs

Turning to the second area of extra cost – revenue costs – one again encounters several types. First, there are costs that are incurred entirely as a result of a disability, costs that non-disabled people do not incur. One obvious example is the cost of medicaments and medicines. Even the prescribed medicines cost money – £3.05 per prescription or £43.50 for a year's season ticket. Prescriptions are free only for pensioners, people on income support and those unable to get out of the home without assistance. A man with arthritis and other problems recently sought assistance from the Disablement Income Group (DIG) for £360 a year spent on prescriptions. Unfortunately, there is also the cost of medicaments that are not generally prescribed but are nevertheless needed. Vitamin C is an obvious example. Many paraplegics and tetraplegics take high quantities of vitamin C to avoid coughs and colds that could kill. Some take up to 4,500 mg a day in slow release tablets. A bottle of 30 x 1500 mg tablets now costs £3.95 – £144 a year.

Other examples of costs that can be avoided by non-disabled people are the costs of help in the home. As has been demonstrated by the Independent Living Fund (ILF), the cost of personal assistance – help to get up, washed, dressed and so forth, help to go to bed at night and help around the house – can cost more than £400 a week. Payments to some 6,000 people now average £74 a week. Home helps and meals on wheels, two very basic forms of local authority help, all have to be paid for by disabled people with an income just above income support levels.

Blind people's payments to readers constitute another example. Many cinemas, theatres and concert halls insist that a blind or wheelchair-using disabled person is accompanied by a non-disabled companion; some charge for the companion.

Other examples of this type of extra cost of living arise in travelling: you may need an escort if you have difficulty in getting on or off a bus or train or because you are partially sighted, blind or deaf. Some airlines insist that a severely disabled person is accompanied by a non-disabled companion. Airlines require payment for the extra seat. While Virgin and Britannia Airways allow guide dogs to travel

free of charge under an unoccupied seat, most airlines charge for this. If you are blind and have to be accompanied, British Rail will allow the escort free travel, but only if it is to a place of treatment or in connection with work. You may be so severely disabled as to be unable to use any form of public transport or unable to get to some isolated accessible public transport system. To get anywhere beyond the confines of your house or street, you would then have to resort to private transport.

Disability-enhanced revenue costs

A second type of extra cost is that which both disabled and non-disabled people incur but on which the disabled person's expenditure is greater as a direct result of disability.

Heating is an obvious example. If you are young and physically fit you will not feel the cold so much as many elderly and disabled people. And if you do, you can at least jump up and down to keep warm or put on extra clothing. If you break your back you will find that you need consistent and higher levels of heating compared with the average non-disabled person. Other severely disabled people may also need the same high levels of heating in order to keep wasting muscles as active as possible; wearing heavier clothing may simply further immobilise them. Compared with the non-disabled, these people need heating for longer periods during the day – some throughout the day and night – and over many more days in the year.

Holidays can cost more if you are in a wheelchair. You cannot go on the cheap. If you are in a wheelchair it is virtually impossible to stay at any bed and breakfast establishment.

Use of the telephone provides yet another example of higher costs for some disabled people. Leaving aside the need to keep in touch for anyone unable to get out of their home, telephone calls through British Telecom's National Telephone Relay Centre will involve higher costs because of the time taken to convert the spoken word into text.

Other examples include special diets costing more than ordinary diets, laundry and dry cleaning costs inflated by incontinence or lack of dexterity, the use of more convenience food because it is easier to prepare, clothing that wears out faster because of braces and callipers, and shoes that have to be replaced frequently because of a dragging foot.

Shopping in general costs more for many disabled people than for non-disabled people. This was highlighted in a report on shopping published by DIG in 1983 (Stowell and Day, 1983). This study in depth of 14 disabled people showed that the extra costs arose for a variety of reasons: travel and access problems and lack of lavatories reducing mobility, restricting choice and precluding shopping around for bargains; inability to buy in quantity through lack of money or inability to carry heavier loads; having to shop locally; and having to rely on others to do the shopping. Having goods delivered and mail-order shopping can both add to costs. The DIG study showed that, compared with the costs of comparable non-disabled individuals and families, the shopping costs of disabled people were higher by an average of 15 per cent, the extra cost varying from 7 to 33 per cent.

DIG research into additional costs

Over the years DIG has sponsored several studies of the extra costs of disabled living. One of the earliest, by Mavis Hyman in 1975, studied a sample of 56 wheelchair users, not necessarily wheelchair-bound, in the London Borough of Camden, aged between 17 and 65 (Hyman, 1977).

As a proportion of total household income, extra private expenditure arising through disability varied from less than 20 per cent to more than 60 per cent. Half the respondents with household incomes of up to £2,000 a year spent less than 20 per cent but three spent 60 per cent; of those with incomes from £2,100 to £3,000, three-quarters spent less than 20 per cent; of those with incomes from £3,100 to £4,000+, just under a half spent less than 29 per cent, and just over a half spent more than 40 per cent.

At that time – 1975 – there were special allowances under the supplementary benefit scheme covering heating, laundry, diet and clothing, but where these were payable – in only five cases because of means-testing – the allowances failed to cover the costs.

A few also incurred heavy extra costs in respect of help in the home. Payments per annum for help in the home, with local authority contributions in brackets, for a selection of respondents ranged from £750 (£364) to £42 (£75); one local authority paid £1,165.

In addition to all the types of extra costs incurred by other disabled people, families with mentally handicapped members incur the extra costs of wear and tear, waste and destruction of furniture and fittings

in the home. A study by Judith Buckle in 1984 showed that total extra costs for these families amounted to an average of 8.9 per cent of weekly family income, varying from £1.10 to £78.71, representing from 0.3 per cent to 47.6 per cent of weekly household income.

The study showed incidentally that the higher the income of a family, the more was spent on extra costs. In 1984 this expenditure varied from £11 a week for incomes of 50 per cent or less of the average non-disabled household of similar type, to £19 a week where income was between 75 and 99 per cent of the norm, and to almost £30 a week where the household income was 150 per cent or more of the norm, although the extra costs as a proportion of the various incomes dropped from roughly 12-15 per cent for the lowest incomes to 7-9 per cent for the highest (Buckle, 1984).

Mavis Hyman's study revealed that 21 out of 56 respondents had had to dip into savings to pay for additional costs of disability: 2 spent between £25 and £35; 13, between £100 and £300; 4, between £700 and £750; and 2 spent £1,000 or more.

An OPCS survey in 1975 on prolonged sickness and the return to work (Martin and Morgan, 1975) showed that the percentage of people who had had to use savings to manage during illness increased as the period of sickness increased: 35 per cent for 1 month; 41 per cent for 3 months; 51 per cent for 6 months; and 62 per cent for 12 months. The amounts of savings used varied from £10 in one month to over £200 over 12 months. Higher amounts correlated with longer periods off sick. The researchers noted 'We asked people how they had managed and found that they had cut down on luxuries such as entertainment and smoking, but many had also cut down their spending on food and clothes'.

Other DIG studies of the financial effects of disability have included: disabled housewives on Merseyside in 1973 (Earnshaw, 1973), disabled people on supplementary benefit in 1979 (Stowell, 1990), which showed heavy extra costs for heating, diets and laundering, and an assessment of the positions of disabled people on the new supplementary benefit scheme in 1981 (Robbins, 1981).

Savings

In her study of wheelchair users, Mavis Hyman briefly discussed savings arising from disability. Several users cited savings on

footwear. Savings on parking and haircuts were other examples. She concluded:

There may be some justification in arguing that there are savings as a result of disability, such expenses saved in not going out to work, not spending money on leisure activities which require mobility, etc, but the extent of measurable savings as a result of disability for the sample as a whole was very small indeed. (Hyman, 1977)

Obviously, there are great savings to be made if disability precludes a person doing something. Not going on holiday because it is too expensive on account of disability might be an example; not buying newspapers or magazines because of blindness and not using a telephone because of deafness might be others. In all these cases, however, given sufficient money, there is no reason for the enforced savings. Here, therefore, one moves too easily from savings into deprivation.

Principles of additional costs

From all this and other work on costs it is clear that there are a host of different extra costs of disability – too many to cover them all by individual distinct allowances – and that they are not all incurred by every disabled person. Many extra costs are incurred whether or not a disabled person works, although some may be increased while others are decreased and some may only be incurred in work.

Studies have indicated that for a given disability the costs tend to increase with increasing disability and, at least to some extent, that the cost increases in line with increasing disability generally. Several studies have also shown that the extra spent on disability increases as the amount a disabled person has to spend increases.

Referring to those disabled people with the lowest incomes and having lower extra dietary costs than others, Mavis Hyman observed: ‘These are examples where expenditure was indeed matched to income but the "cost" was deprivation.’

A corollary of these last two observations is the first law of the extra cost of disability: if you don’t have the income you can’t pay for the expense, and if you can’t pay for the expense, the cost is deprivation.

In the light of all this past research and of the first-hand experiences of so many of DIG’s disabled members, the results of the OPCS survey conducted in 1985 were remarkably disappointing.

OPCS and DIG additional costs figures

Announced in April 1984, the survey of the Office of Population Censuses and Surveys on disability in Great Britain produced its first results in September 1988, when Report 1, *The Prevalence of Disability among Adults* (Martin, Meltzer and Elliot, 1988) was published.

Adopting a very low threshold of disability, the survey defined as disabled some 5,780,000 adults in private households and 422,000 in communal establishments, a total of 6,202,000 – about 14.2 per cent of adults in Great Britain. Disabled people were divided into ten categories, category 1 being the least disabled and category 10 the most severely disabled: 2,038,000 were in categories 1 and 2, a further 2,707,000 in categories 3 to 6, leaving 882,000 in categories 7 and 8, and 575,000 in categories 9 and 10.

The threat of over 14 per cent of the adult population in Great Britain jumping onto the disablement costs bandwagon was frightening enough. Worse was to follow, however, when Report 2, *The Financial Circumstances of Disabled Adults Living in Private Households*, (Martin and White, 1988) was published in November 1988. This alleged that the average extra costs incurred by the 6.2 million disabled adults was £6.10 a week. The average was £11.70 for category 10, and £3.20 for category 1, but with standard deviations of £12.40 and £5.30 respectively.

Reports 1 and 2 added up to bad news until it was recognised that the threshold of disability chosen had led to the inclusion of many people whom few could pretend were disabled, and that the selected disability categories had led to many in each category reporting no extra cost on account of disability.

Acting swiftly to get a truer message across, DIG undertook a survey and published a response in December 1988 (Thompson, Buckle and Lavery, 1988). In this survey, disabled people in receipt of attendance or mobility allowances, or both, were asked about extra expenditure in particular areas, using the OPCS questionnaire and a lengthier DIG questionnaire; the results were compared with those obtained by the OPCS. The OPCS results of extra weekly costs for all adults in categories 9 and 10 who reported an extra cost in the given areas was £30.25. This compared with £66.97 reported by DIG using the OPCS questionnaire, and £81.90 using the DIG questionnaire.

Later, DIG undertook a wider survey covering disabled people in categories 3 to 10 with some in category 10 receiving payments from the Independent Living Fund. The results of this broader survey were presented in a report published in February 1990 (Thompson, Lavery and Curtice, 1990).

It must be stressed that it was not a random sample. The total number of people interviewed was 87 and interviews took place in November 1989 and lasted 1 hour 45 minutes on average. As Pauline Thompson explained in an article in *DIG Progress* (Thompson, 1990), the questionnaire was again based on the one used by OPCS but 'was augmented by "prompting" questions and questions designed to elicit explanations for certain responses, a procedure which DIG has used in previous research studies.'

According to the OPCS survey, average weekly on-going disability-related extra costs ranged from £4.90 for category 3 to £11.70 for category 10. DIG figures ranged from £28.25 a week for category 3 to £86.73 for category 10 excluding ILF payments. Average weekly on-going costs including ILF payments ranged from £28.25 for category 3 to £146.47 for category 10.

Why the difference?

The reasons for the difference between the OPCS and DIG figures were examined by John Curtice, Director of the Social Statistics Laboratory, University of Strathclyde, in an article in *DIG Progress* (Curtice, 1990). He cites five major differences between the ways in which the two studies were conducted which explain the differences in the estimates of extra cost.

First, the obvious one. Considering the difference between the average weekly ongoing cost of disability found by the OPCS of £6.10 and that of the DIG survey of £49.86, it is quite obviously the result of the OPCS covering the whole spectrum of disability – from an exceptionally low threshold – whereas DIG covered only people in category 3 or higher, over two-thirds being in category 7 or higher.

The second reason is that members of the DIG sample were probably more aware of the costs of their disability. The sample came from people who received payments from the Independent Living Fund (one-third) and the remaining two-thirds from people who had responded to an offer of further information following a Channel 4 television programme on the rights of disabled people to

supplementary benefit. All of these people had shown an interest in disability benefits and were struggling to match their income with their expenditure.

The third reason is that the average income of the DIG sample was much higher than that of the OPCS survey: the average for DIG's sample being £182 (1988) whereas the average for the OPCS sample was £82 (1985). The difference is too great to be accounted for by inflation. Both surveys revealed, however, that those with higher incomes reported higher levels of disability extra costs, a fact that has already been noted in respect of Mavis Hyman's research.

A fourth reason was that the respondents in the DIG sample were on average far younger than those in the OPCS sample. In both samples, however, pensioners reported lower extra costs than non-pensioners. Reasons for this, according to John Curtice, may include the fact that retirement commonly brings with it a lowering both of an objective level of standard of living and of subjective expectations.

The fifth reason – possibly the most significant – is the difference between the OPCS and DIG interviewing methods. First, the OPCS interview covered many aspects of disabled living other than finance. DIG concentrated solely on the financial effects of disability. Second, the whole OPCS interview was accomplished in an average of one and a half hours. DIG's average interview lasted one and three-quarter hours. Third, as noted already by Richard Berthoud, there was a significant difference in the OPCS and DIG interviewing styles.

Taking heating and lighting as an example, one is bound to get different answers if, on the one hand, one blandly asks: 'Does your disability mean that you spend extra on fuel? If so, how much extra in the last 4 weeks?' compared with, on the other hand, more deeply probing questions: 'Does your disability mean that you need higher lighting levels? Higher levels of heating? Heating on for longer periods of the day? Heating during the night?'

As John Curtice observed, DIG adopted the 'more intensive interviewing techniques that are likely to elicit fuller information on the financial costs of disability'.

This constitutes the second law of extra costs: if you don't ask the right questions in the right way, you don't get the right answers.

What neither OPCS nor the two recent DIG surveys did was to assess the costs of paying for goods and services that a disabled person

with a sufficient income would invest in order to bring his or her standard of living back up to that of his or her non-disabled colleagues. Also unsurveyed were the extra costs that could be incurred in trying to compensate for disability; for example, the costs of some hobby to make up for activities that are no longer possible because of disability.

Existing benefits* for additional costs

Leaving the question of what extra costs are or should be incurred by disabled people, it is useful to examine what benefits are currently available to help offset the extra costs of disabled daily living.

The White Paper *The Way Ahead* (DSS, 1990) cites only three: attendance and mobility allowances (AA and MobA) and payments from the Independent Living Fund. AA is currently worth £41.65 at the higher rate, £27.80 at the lower rate; MobA is worth £29.10 a week; ILF payments average £74 a week over some 6,000 severely disabled people.

ILF payments are means-tested, and it could be argued that the disability and severe disability premiums payable with income support are other means-tested extra-costs payments. They are worth £16.65 and £31.25 a week respectively. A few people receive both.

There are several more benefits for extra costs that are not means-tested, which must not be forgotten when talking about the financial effects of disability.

First there are the constant attendance allowances of the industrial injury and so-called war pension schemes, 'so-called' because you do not have to be disabled in active combat; you can benefit – providing you do it in the right area at the right time – by breaking your back in a swimming pool. There are four rates of constant attendance allowance: exceptional rate £68.00 a week; intermediate rate £51.00; normal maximum rate £34.00; and a part-time rate of £17.00 a week. Those who qualify for the attendance allowance at more than the normal maximum may also qualify for an additional 'exceptionally severe disablement allowance' amounting to £34.00 a week.

In addition, for both the industrial injury and war pension schemes there is the very significant disablement benefit, graded according to degree of functional disability, varying from £84.90 a week for 100

* benefit rates quoted are those applicable from April 1991

per cent down to £16.98 for 20 per cent disablement. This, incidentally, was recently reclassified as a disablement pension and made age-related in so far as rates for people under 18 years are some 61 per cent of the rates for people over that age.

There are further additional allowances in the war pension scheme: comforts allowances of £14.60 or £7.30 a week; clothing allowances of £104 or £66 a year if clothes are worn out by the effects of disability; and an extra £3.25 a week for mobility over and above the general MobA.

Taking the most severely disabled as an example, and ignoring the comforts and clothing allowances and mobility supplement of the war disabled, the *extra* extra-costs allowances enjoyed by the industrially injured compared with ordinary, so-called 'civilian', disabled people can amount to £145.25 a week *more* for the person who breaks his or her back at work rather than at home; that is, for a married couple without children, £310.35 a week compared with £165.10.

It will no doubt be argued by some that the disablement benefit of the industrial injury and war pension schemes is not entirely an extra-costs allowance but also partly a compensation payment, 'compensation' in the sense of helping to make up to some degree for the pain and suffering associated with disablement. Let as much as one half be 'compensation' of this type, and we are still talking of a difference of £102.80 a week.

If the government is right in its White Paper in pinning its benefit fig leaves to the scrawny OPCS totem pole, as opposed to providing the more respectable covering advocated by DIG, one could ask why it does not abolish the disablement benefit of the industrial injury scheme and other preferences. Are we not otherwise squandering money unnecessarily on the industrially injured and war disabled pensioners?

The answer to this – 'Of course not' – calls into question the government's assessment.

The government's assessment of the present situation

The White Paper *The Way Ahead* was laid before Parliament on 10 January 1990. This gave the government's assessment of the situation and its proposals for changes in social security benefits for disabled people in response to the survey of their circumstances commissioned from the OPCS.

In the White Paper the government observed:

The OPCS surveys found that AA and MobA are well directed towards the most common of the more costly disabilities. Locomotion (most common of the adult disabilities) and self-care disabilities (third most common) are associated with relatively high disability-related expenditure....

The OPCS findings also showed that in most cases AA and MobA are more than sufficient to cover people's disability-related expenditure....

Both the existing and proposed arrangements therefore recognise that exceptionally severely disabled people may have special needs which are not met in full by the financial help provided by AA and MobA. The Government considers, and the OPCS findings confirm, that for the great majority of disabled people the rates of AA and MobA make generous allowance for variations around the averages identified by OPCS. (DSS, 1990, p.26,27)

While AA and MobA may be well directed towards two of the most common and more costly disabilities, the OPCS found other costly disabilities. Moreover, it should be noted that the AA was not introduced to pay for care costs; it was introduced as an allowance for the general costs of disability, self-care ability being used as a measure of need.

The OPCS survey found overall that the disabilities most strongly associated with higher than average additional expenditure were in the following order: locomotion; eating, drinking and digestion; personal care; reaching and stretching equally with disfigurement (which included amputations and deformities); dexterity; and continence (Martin and White, 1988, Table 4.14).

The order of degree of association of the different disabilities with extra expenditure, controlled for the presence of other disabilities and for severity, did not vary much between disabilities and differences in severity, income and family type. The resulting order was: digestion, locomotion, disfigurement, personal care, behaviour, continence, reaching and stretching, dexterity, consciousness, seeing, hearing, intellectual functioning, and communication (*ibid.*, p.54).

There are thus several more causes of higher extra cost besides the disabilities of locomotion and personal care.

It is also difficult to argue that for most recipients the AA and MobA were 'more than sufficient to cover (their) disability-related expenditure'. Recipients were so few and widely distributed that

average extra costs in the various categories were bound to be exceeded by the allowances. The OPCS found that of all disabled adults, only 8 per cent received AA, only 7 per cent received MobA, and only 2 per cent received both; 87 per cent were not receiving either. Moreover, people receiving MobA appeared in every OPCS category from 1 to 10; people receiving AA at higher or lower rate appeared in every category from 2 to 10 (*ibid.*, p.23).

Obviously, then, we would argue against at least two points in written Ministerial answers to MPs who had asked whether account would be taken of the DIG findings. They included the following:

We will consider them, but I must point out that the value of the independent OPCS survey lies in the fact that it was based on a properly drawn sample of 10,000 disabled people and was carried out in consultation with experts in the field of disability.*

The reports show that Attendance Allowance and Mobility Allowance are well targeted at the heaviest sources of extra expenditure incurred by disability. The OPCS data indicates that actual extra expenditure is generally far lower than the current level for these benefits.*

Dismissing a comprehensive disability income (including the disablement costs allowance), the Ministerial reply argued:

We have aimed to provide a more simple and coherent system of financial help. ... I am sure you will agree that the prime objective must be to provide a system which can get help quickly and effectively to those most in need.*

Do the proposals in the White Paper match this aim and what are DIG's views of those relating to the extra costs of disabled daily living?

The way ahead?

Only two changes are proposed in the White Paper *The Way Ahead* in relation to the extra cost of disability:

- an extension of AA to include a third and lowest rate of £10 a week for some 140,000 people 'who need help with self-care during the day but less frequently than those who currently qualify for AA'; and

* in letters to Tim Devlin MP, 15.10.90; Michael Jack MP, 8.11.90; and Jerry Hayes MP, 12.10.90.

- an extension of MobA to include a second and lower rate of £10 a week for some 150,000 people ‘who are not independently mobile’.

These two extensions to existing benefits will be available only for people who qualify before the age of 65, although payment will continue irrespective of age provided the criteria continue to be met. The two extensions and the existing allowances will all have common administrative and adjudication arrangements and a common qualifying period of three months (except for those classified as terminally ill for whom there will be no qualifying period at all).

Referring to the ILF, the White Paper optimistically expects local authorities to pick up the cost of care packages of all but a few of the Fund’s beneficiaries.

Considering only disability costs, the White Paper proposals are open to a number of criticisms. First, it is inappropriate to base the next decade’s benefit system for disabled people on research into the benefit system which has already been superseded – supplementary benefit was replaced by income support and the social fund.

Second, the proposals are unreliably based on the extra-costs data secured in the OPCS surveys. While not everyone may accept DIG’s figures, nobody who knows anything about disability would accept the OPCS figures as being nearer to reality.

It is certainly inappropriate to base the proposals on an interpretation of research into the extra costs of disability that judges the need for extra cash by reference to the extent to which the extra cash is spent. Clearly, this contravenes the first law of extra costs.

What is particularly distressing is that the government denies the existence of the generality of extra costs. The two modest extensions of MobA and AA acknowledge only mobility-related and care-related extra costs. Disabled people with other types of extra costs are left wanting.

It is also distressing to note that people must become disabled before reaching the age of 65 to benefit.

Finally, it is dismaying to realise that the White Paper offers nothing more for severely disabled people who receive both MobA and AA. And yet it is accepted that many of these severely disabled people do incur many other extra costs. ILF payments are indicative of some of them.

There are also, for example, a growing band of severely disabled people using their MobA to finance a Motability vehicle and spending their higher rate AA and most of what they earn merely to buy in personal assistance. MobA was designed for those unable or virtually unable to walk. It was intended to go towards the vehicle that was no longer being issued free of charge and to extend help to people who were too severely disabled to walk or drive. Extending this allowance to deaf/blind people, rather than introducing a disablement costs allowance, is illogical. Further extending it to 'people who are not independently mobile, for example those with a severe mental handicap or behavioural disturbance', as indicated in paragraph 4.7 of the White Paper, compounds the mistake. Like many deaf/blind people, many mentally handicapped people have care and other financial needs rather than mobility needs, and to pretend otherwise is to risk having every blind and every mentally handicapped person in the country claiming that they lack independent mobility.

Unfortunately, the two rates of benefit will attract a swarm of marginally unsuccessful claimants whose protestations could dominate future developments. The cacophony could drown the valid claims of disabled people who incur extra costs other than, or in addition to, those of mobility or care.

The Way Ahead thus promises to be little more than a cul-de-sac. Far from creating a more comprehensive and coherent system of disability benefits than ever before, it offers a complex and illogical mix of old and new benefits.

DIG has grave misgivings about the intention to treat the existing AA and MobA and their extensions as a 'New Disability Allowance' or 'Disability Living Allowance', as it is to be called. We can see no practical reason for this and, indeed, believe it will present many difficulties.

The bundling of the two benefits is already bemusing people. They cannot understand which parts will be available to them to claim after the age of 65, whether any parts will cease to be paid after 65, and why, if they can apply for one after 65, they cannot apply for the other.

Motability, the ILF and local authorities will all need to know who is receiving what part of MobA and AA. Motability can only finance contracts based on the existing MobA, eligibility for help from the ILF

requires a higher rate AA, and local authorities treat the two allowances differently in their means tests.

The non-medical entitlement rules for the existing mobility and attendance allowances differ – for very good reasons – and we would not like to see the difference eradicated. We would be very worried indeed, for example, if it was proposed to stop payment of MobA to people in residential care merely because the AA is not payable to them.

As regards the new collective name, there is only one reason for calling two existing separate benefits and two extensions to them a Disability Living Allowance. That reason is political: an attempt to put across the idea that a sort of disablement costs allowance is being introduced. We deplore this.

For disabled people, the bundling together of two entirely different allowances into a single ‘new’ allowance is likely to be a retrograde step. For the government, the ingenious packaging was a stroke of evil marketing genius.

Leaving this important issue aside, we welcome the emphasis on self-assessment and the simplification and co-ordination of the two current assessment and adjudication procedures, not least their partial de-medicalisation. We can also warmly welcome the allocation of some £62m to the ILF for the year 1991/92 – up from £42m in 1990/91 (and £5m only three years ago in 1988/89) – and the additional grant to Motability of £1m a year to enhance the assistance it can give with the expensive adaptation of cars used by severely disabled people.

As regards ‘a more simple and coherent system of financial help’, one can only observe that the three levels of AA and the two levels of MobA will involve eleven benefit combinations ranging from ineligibility for one to eligibility for both at the top rates. This would be relatively easy to accommodate if there were only one criterion with eleven levels or degrees. In fact, there are no fewer than nine different criteria: being unable or virtually unable to walk; being deaf/blind; being able to walk but being so severely disabled mentally or physically as to require guidance or supervision from another person most of the time; needing frequent attention during the day with bodily functions; needing continual supervision during the day to assure safety; needing prolonged or repeated attention at night in connection with bodily functions; needing someone to be awake at night for a prolonged period or at frequent intervals to assure safety; being unable

to prepare a cooked main meal even though having the ingredients; and being under or over the age of 65.

All this still leaves us looking for a non-taxable disablement costs allowance to help bridge the costs gap between the industrially injured and 'civilian' disabled people.

Unfortunately, the developments announced in the White Paper are likely to postpone, if not preclude, such an allowance. Disabled people may be forced to pursue special allowances for identifiable special extra costs, along the lines discarded when the precisely targeted supplementary benefit system was replaced by the imprecise Gattling-gun scheme of income support and disability premiums.

The DIG hopes not. It believes that the additional costs of disability – excluding the extra capital costs – should, in part at least, be offset by a flexible disablement costs allowance, assessed by reference to loss of relevant normal capacity through physical, sensory or mental malfunction. This should be payable by right of disability and regardless of cause of disability. It should be payable regardless of sex, marital or working status, to children, adults of working age and elderly people. And it should be payable in full in addition to any attendance or mobility allowance.

As indicated, the rationale behind such an allowance is not to compensate for the degree to which a disabled person is restricted from living a normal life, but to help offset the extra costs of daily living as a disabled person, those extra costs being not only the costs that disabled people actually incur but also the costs they need to incur to get themselves back to a basic average standard of living enjoyed by the majority of their non-disabled colleagues.

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