

## **8. Support for Informal Carers – the Role of Social Security**

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### **Introduction**

This chapter deals with a major aspect of how care or support is provided to disabled people – by relatives or friends on an informal basis. It is important to preface this discussion by acknowledging the relationship that exists between the level of support disabled people receive from the state and their need to rely on informal sources. It is also important to acknowledge that the language of ‘care’ is itself problematic. Many disabled people neither need nor want care and do not want to rely on informal carers (see the chapter by Richard Wood in this volume). They need statutory support to enable them to maximise their independence. Other disabled people do want and need help from informal carers. The population of disabled people is varied. It includes severely disabled children, elderly people suffering from dementia, adults with mental health problems and people with terminal illnesses as well as people with mainly physical or sensory conditions. It is clearly important to press for the development of policies and services that maximise the independence of disabled people. However, it is also important to recognise that, for reasons to do with the kinds of condition involved and with love and familial obligations as well as resource constraints, there will probably always be disabled people whose relatives and friends are involved in supporting them. These informal carers themselves need support.

The case for taking a hard look at the circumstances of carers and the objectives and structure of policies to support them is strong. Like

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disability, caring was not explicitly considered in the 1985 review of social security benefits. Neither is it addressed in the 1990 White Paper *The Way Ahead* (DSS, 1990). On the service side, by contrast, caring *has* received attention in the NHS and Community Care Act, 1990, though anxieties remain about the translation of good intentions into policies. The only place where the respective roles of cash and care in supporting carers have been fully and explicitly considered is in a recent report by the Social Services Committee (House of Commons, 1990).

What do we know, then, about the current pattern of support for people with disabilities and the extent to which carers substitute for statutory help? Hazel Qureshi's chapter in this book considers the pattern of statutory provision in detail. However, it can be amply demonstrated from a large body of research on disability and service provision that the support provided to people with disabilities is, in general, provided at a low level, variable in quality and coverage, poorly targeted and inflexible.

The OPCS disability survey report on service receipt (Martin, White and Meltzer, 1989), for example, found that just over half the people in severity categories 9 and 10 had seen a community nurse in the previous year (Table 4.12). The figures for services supplied by social services are even more striking. Thirty per cent of people over 75 and eight per cent of those aged 16 to 49, in severity categories 9 and 10, had received the services of a home help. These figures decreased sharply when the disabled person was living with someone else and particularly so when he or she was a child. These findings are borne out by the 1985 General Household Survey (GHS) carers' section which found that 69 per cent of disabled people living in the same house as their main carer had received no regular help from social or voluntary services in the previous year, as against 46 per cent of those whose carer lived in another household (Green, 1988).

This sketchy account can be supplemented by the exhaustive and detailed work carried out over the years by Davies and his colleagues (Davies and Challis, 1986), by the body of work on disabled children carried out at the Social Policy Research Unit (SPRU) at the University of York (summarised in Bradshaw, 1980), by the work of Keble (1979) and others on aids and adaptations, and by the Department of Health's own statistics on services to people with disabilities. More recently, work at SPRU on services to carers (Parker, 1989; Twigg and Atkin,

1990) has demonstrated the virtual non-existence of support delivered specifically *to* carers and the extremely limited extent of key services such as day and respite care, evening and night sitting.

It is fair to say, then, that widespread agreement exists about the paucity and ineffectiveness of services to support people with disabilities and their carers and help them to stay at home. In the words of the White Paper on community care (Department of Health, 1989):

the reality is that most care is provided by family, friends and neighbours. (para. 2.3)

The next section of this chapter looks at what research can tell us about the number of people involved and the intensity of their involvement.

### **The number of carers and hours of care they provide**

Surveys which try to establish the numbers of certain sub-groups in the population pose methodological problems. This is particularly so when, as with informal carers, perceived membership of the sub-group is largely determined by social rather than physical factors. In such cases the answer (i.e. the number revealed) will depend on how the question is formulated and who is asked it.

Until very recently, information on the likely number of informal carers in the United Kingdom had to be estimated from a variety of sources, none of them designed to provide it. These estimates converged around a figure of 1.3 to 1.5 million people acting as principal carers to adults and children with disabilities severe enough to warrant assistance in daily living (see Parker, 1985). Since then, both the OPCS disability survey and the 1985 GHS have given us nationally based estimates. Paradoxically, these surveys raise as many questions as they answer, not least of which is why there is a substantial difference in the number of carers identified by the two sources.

The 1985 GHS revealed that 14 per cent of adults (16+) in Great Britain were looking after, or providing some regular service for, someone who was 'sick, elderly or handicapped' (Green, 1988, p.6). Applied to the whole population, these figures suggested a total of around 6 million adults who were carers. However, the GHS identified a very wide range of caring activity. The published report suggested that 3.7 million adults had *main responsibility* for the care of someone else and that only 1.4 million of the total were spending at least 20 hours a week on providing help and supervision. Some 1.7

million people helped someone who lived in the same household; almost half of these (45 per cent) were providing 50 hours or more of help each week (Green, 1988).

By contrast, the OPCS disability survey, which questioned mainly disabled people themselves, identified an estimated 1 million ‘*main carers*’ of disabled adults from an estimated total of 3.9 million ‘*informal helpers*’. Including one main carer for each disabled child brings the estimated total of *main carers* revealed by the OPCS survey to 1.3 million. Among the main carers of adults in the same household 42 per cent were providing care all day and all night; 13 per cent were doing so all day. Among main carers who lived elsewhere, 25 per cent provided 20-49 hours of help a week and 12 per cent 50 hours or more. Comparable information for those caring for disabled children is not available.

At first sight these estimates seem very different, but given the differences in definitions used and in who was asked the relevant questions, this is not surprising. The definition of a main carer in the OPCS adult disability survey is *the person who gave the most help with self-care activities*. If we restrict the GHS analysis to main carers providing personal and/or physical help (i.e. the range of tasks which

**Table 8.1 Numbers of hours of care given by main carers helping with self-care activities by whether or not in same household as disabled person: population estimates of number of main carers for adults in each category (thousands)**

	GHS			OPCS		
	In house- hold	Out of household	Total	In house- hold	Out of household	Total
<b>No. of hours of care provided per week*</b>						
<5	71	206	277	} 205	26	} 249
5-9	60	240	300		18	
10-19	107	194	301	} 196	26	} 250
20-49	140	131	271		28	
50-99	164	16	180	116	} 13	} 503
100+	297	2	299	374		

\* OPCS in-household hours interpreted as: <10 for ‘less than a few hours per day’; 10-49 for ‘a few hours per day’; 50-99 for ‘all day time’; and 100+ for ‘all day and all night’.

encompasses the OPCS self-care activities) to adults, do the two sets of figures correspond any more closely?

Table 8.1 shows that, while the two sets of data still diverge as to the total number of carers in this category (around 1.6 million in the GHS compared with 1.0 million identified in the OPCS survey), at the top end of hours devoted to caring the estimates are much closer. The comparison is not exact because the OPCS survey gathered the hours data in different ways for main carers in the same household and those elsewhere. However, both sources give us around half a million main carers of adults providing help with *self-care activities* for 50 or more hours a week.

The GHS identified a total of 0.7 million carers providing this number of hours of care of all types (not just self-care), 8,000 of whom were looking after children under the age of 16. Given the correspondence between the two surveys at this level of caring involvement, we feel that the GHS figure of 0.7 million carers providing 50 hours or more of care, and another 0.5 million providing between 20 and 49 hours, is reasonably accurate. It is a better figure than the one derived from the OPCS survey because it covers all forms of caring activities and those who do not define themselves as main carers but who, nonetheless, provide a lot of care. It also covers care provided to disabled children under the age of 16.

We are thus fairly confident in talking in terms of a population of at least 1.2 million heavily involved informal carers – people giving 20 hours of care or more. A further 4.8 million are involved in less intense forms of care. We suspect from our re-analysis of the GHS data that women systematically under-report the number of hours they spend providing care (Parker and Lawton, 1990a). The actual figure may therefore be somewhat larger.

### ***Who are informal carers and what do they do for whom?***

The 1985 GHS showed that men and women were almost equally likely to be carers although, because of the larger number of women in the population as a whole, there were estimated to be more female carers than male (3.5 million and 2.5 million respectively). It also showed that the largest group of carers (59 per cent) were caring for parents or parents-in-law, followed by friends or neighbours (26 per cent), ‘other’ relatives (23 per cent), spouses (12 per cent), and children (7 per cent). About a third of all carers were assisting

someone who lived in the same household; 23 per cent did so without help from anyone else (sole carers). A further 30 per cent received help but spent more time caring than anyone else (main carers), while 11 per cent shared the main responsibility with someone else (joint main carers).

These figures, while interesting, are not of themselves very useful in helping us to think strategically about policies for carers and disabled people because the level of involvement in caring varies substantially across carers. Secondary analysis of the GHS data carried out at SPRU has used the information on the range of caring activities carers reported to identify six different *caring categories* (Table 8.2). This approach moves us away from previous research, which has categorised carers in terms of who they, or those they helped, were, and takes the analysis of caring activity away from its social or relational context. It also takes us nearer to what might be called a ‘service-shaped’ analysis. Given existing service provision, it seemed more helpful to think about what carers did than who they were. This is not to deny that the relationship between the carer and the person being helped may influence both perceived need for support and the way in which that support is delivered (Twigg *et al*, 1990). Rather, it acknowledges that knowing what carers actually *do* has a clear relevance for service provision.

**Table 8.2** Categories of caring

	% of cases	Population estimate (000s)
<b>Category</b>		
Personal and physical	12	734
Personal <i>not</i> physical	9	560
Physical <i>not</i> personal	8	477
Practical and ‘other’	50	2,960
Practical only	8	453
Other	14	815
<i>Base (100%)</i>	<i>3,032</i>	

We identified people involved in substantial levels of caring activity, providing *personal and/or physical* care for long hours and over relatively long periods of time. These carers were often quite elderly and most likely to be caring for close relatives who lived in the same household. We also identified substantial groups of people involved in activities which might more accurately be termed *informal helping*. These people provided practical help to friends, neighbours and less close relatives, who usually did not live in the same household. They did this for relatively few hours a week but might have been doing so over long periods. These ‘helpers’ seemed to fall into two main sub-groups. First, there were those who were the only or main source of assistance for the other individual. The second, and larger, group were those who appeared to be part of a network where others, presumably, were taking major responsibility.

Who the carer was and his/her characteristics varied substantially between the different caring categories. Women were far more involved in personal forms of care than men, who were more likely to provide physical and practical help. Providing informal care was predominantly an activity of those over the age of 45. However, carers over the age of 65 were more involved in providing the most intensive type of care (*personal and physical*).

Around 70 per cent of those providing only practical assistance or ‘other’ help gave under 5 hours of help a week. By contrast, 46 per cent of those providing *personal and physical* care and 25 per cent of those providing *personal* but not *physical* care gave 50 or more hours of care a week. When *personal* or *physical* assistance was being provided the carer was much more likely to be in the same household as the person being cared for. By contrast, most practical and ‘other’ help (over 80 per cent) was provided to individuals in other households.

### **Economic activity, earnings and income**

Paid employment can be an important determinant of the financial situation of a household and of individual well-being. In this section we look at the labour force participation of carers and of other household members, and at carers’ earnings. We also examine household income.

### ***Employment***

Examining how caring affects carers' labour market participation and earnings presents a number of methodological challenges. The most substantial is comparing carers with non-carers in a way which avoids the confounding effects of age, sex, marital status and other variables which, of themselves, influence labour market participation and earnings. This can be done either by using a control or comparison group or, if the data set is large enough, through *post-hoc* control of the relevant variables. The second methodological challenge is to generate samples which are large enough to deal with inherent variability, and representative samples which allow the findings to be extrapolated with some confidence.

A large number of studies in the past fifteen years or so have suggested that providing care has adverse effects on carers' labour market participation, particularly when the carer is female. However, with two notable exceptions (Baldwin, 1985; Joshi, 1987), these studies were not based on nationally representative samples and lacked a comparison or control group. More recent research – the 1985 GHS, a recent study of young adults with disabilities and, to a degree, the OPCS disability survey and a follow-up study of the Family Expenditure Survey (FES) – have gone some way to filling this gap.

These studies demonstrate two sorts of effects. First, carers *as a group* have depressed levels of labour market activity compared with their peers. Joshi's re-analysis of the national 1980 Women and Employment Survey showed that responsibility for someone needing care reduced the likelihood of a woman's being in paid work by around 9 percentage points, all else being equal. Informal caring responsibilities thus had a 'depressive' effect of 'the same order of magnitude as the effect of the average dependent child' (Joshi, 1987, p.120). Secondary analysis of the GHS (Parker and Lawton, 1990b) suggests a similar level of impact, although different techniques were used to control for intervening variables. Carers of working age were less likely than their peers to be in full-time paid work, though there was little difference in relation to part-time work. However, the impact on full-time work was somewhat greater among men (see Table 8.3).

The second sort of effect which the available data demonstrate is the differential impact of caring on sub-groups of carers. The most substantial effects are found among parents caring for disabled



**Table 8.3 Economic activity by sex and whether or not a carer (all under pensionable age)**

	Male		Female		All	
	Carer %	Non-carer %	Carer %	Non-carer %	Carer %	Non-carer %
<b>Economic activity</b>						
Full-time employment	70	79	25	31	44	52
Part-time employment	3	1	33	30	20	18
Seeking work	12	9	5	5	8	6
Permanently unable to work	5	4	3	1	4	3
Retired	5	4	1	2	3	3
Keeping house	2	<1	30	28	18	16
Student	2	1	2	2	2	2
Other inactive	1	1	1	<1	1	1
<i>Base (100%)</i>	<i>800</i>	<i>793</i>	<i>1,087</i>	<i>1,078</i>	<i>1,887</i>	<i>1,871</i>

children. Baldwin's work on families caring for a severely disabled child showed clearly that the labour market participation of mothers was considerably lower than that of mothers in a control group (33 per cent and 59 per cent respectively). Further, the control-group mothers worked longer hours and earned more. The differences increased with the age of the youngest child in the family, suggesting that women with disabled children were less likely to rejoin the labour market and to move into full-time employment as their children grew up. Baldwin also found differences between fathers' participation rates, particularly among unskilled manual workers, though fathers' employment was not as seriously affected as that of mothers. Similar but smaller effects on women's paid work were evident in the OPCS survey of children, which covered a much wider range of disability than Baldwin's study; the effects were largest in relation to full-time paid work (Smyth and Robus, 1989). Fathers of disabled children were also less likely to be in full-time employment than all fathers. Parents in paid work in both these studies identified a number of effects on their employment, most often restrictions in the number of hours they could work and the need to be away from work from time to time. Mothers were far more likely to report such effects than fathers.

Evidence from a study of young disabled people and a control group of non-disabled young adults demonstrates that effects of this sort persist well beyond early childhood (Hirst, 1990). Multivariate analysis showed that the mothers of disabled young adults in Hirst's study were about a third less likely than all mothers to be in paid work, after controlling for their age, family size and their partner's economic activity. Given the scarcity of independent living arrangements for disabled adults, these findings are not, perhaps, surprising. Hirst found that young adults who had been disabled since birth or childhood were far less likely than their peers to have left the parental home. They were also less likely to have some form of day-time occupation after leaving school, or to go out socially.

For older disabled adults the picture is less clear, not least because household composition may become more complex and the problem of identifying carers and effects on their employment harder. The recent follow-up of disabled adults in the FES (Matthews and Truscott, 1990) suggests that the number of earners in non-pensioner households with a disabled member is lower than in other households, and that this pattern is consistent across all household types. This effect may be due either to the depressed labour market activity of the disabled person, or of other members of his/her household, or both. These data therefore tell us nothing definitive about carers' employment *per se*.

The second OPCS survey report (Martin and White, 1988) provides economic activity information only for disabled people and their partners, not for other household members. It found that both male and female partners had reduced levels of paid work compared with the total population of working age. However, there is no way of knowing how much of this apparent effect is due to caring activity. We know that wives' labour market activity is in general depressed when their husbands are not in paid work. Given that disabled men were less likely to be in paid work than their peers, it may be this, rather than any 'caring effect', that explains female partners' patterns of employment. Small-scale research suggests that male spouse carers, because of their lack of access to part-time work, are more likely to experience a 'threshold' effect on their paid work, giving up completely rather than reducing their hours (Parker, forthcoming). Secondary analysis of the GHS (see Table 8.4 below) indicates that in general men caring for non-elderly adults (most of whom are spouses)

experience a greater effect on their labour market participation than other male carers.

A number of small-scale studies have suggested that caring for frail elderly people has substantial effects on paid work, again especially for women (Nissel and Bonnerjea, 1982; Wright, 1983; Levin *et al.*, 1983). However, among *all* carers of elderly people one might expect a smaller overall effect because so many carers for this group are themselves older. Some 62 per cent of those in the 1985 GHS who were caring for someone over 65 were themselves over 45, with 17 per cent over the age of 65. (By contrast 82 per cent of those looking after a child under 16 were 45 or under.)

Those helping elderly people in the GHS were more likely than any other group of carers to have retired. However, working-age carers of elderly people in the 1985 GHS were more likely than any other group of working-age carers to be in some form of paid employment (Table 8.4). Indeed female carers in this category had a similar labour market participation rate to all non-carers (age/sex matched). This analysis does not, however, show the proportions who were in part-time rather than full-time work.

The type of care provided (and therefore the intensity of caring activity) also has a differential effect on employment. Our analysis

**Table 8.4 Proportion of male and female carers of working age in paid work by age of cared-for person**

	% in paid work	
	Males	Females
<b>Age of cared-for person</b>		
0-15	68	31
16-45	57	44
45-65	64	54
66+	75	61
All	72	58
All non-carers (age/sex matched)	81	62

showed that providing personal care was particularly associated with reduced rates of labour market participation compared both with other carers and with matched non-carers. This was the case for both males and females.

### ***Carers' personal and household incomes***

In this section we consider how the labour market effects discussed above affect the personal earnings and incomes of carers and, to an extent, those of the household in which they live.

Information about carers' incomes comes from three different sorts of research and analysis. First, there is the re-analysis of general population surveys in an attempt to isolate the income effect of caring. Secondly, there are large-scale surveys of disabled people and of carers, notably the OPCS and the GHS surveys. Thirdly, there is research designed specifically to examine the financial impact of caring, both small-scale qualitative work and larger studies.

All three types of research provide convincing evidence of effects on carers' personal earnings. However, when we look at income, and particularly at household income, considerable methodological and interpretive problems arise in disentangling effects on the carer from those on the disabled person and others in the household. As McLaughlin has pointed out, social scientists have been increasingly engaged over the last few years with questions about how personal and household income should be thought about and measured, and how the relationship between them should be conceptualised. However, no easy answers have emerged (McLaughlin, 1991). Intra-household transfers and access to resources in complex households have received little attention (Glendinning, 1989). We know from the 1985 GHS that households containing carers are more likely than other households to be complex, so this represents a real hurdle to our understanding. In general, we are on safer ground in dealing with simpler household structures – families with dependent children, for example.

Personal income usually covers income from *all* sources, including benefits, savings and so on as well as earnings. This is complex enough for individuals but even more so for households; does household income mean all the income that individual members command or only that portion of it which is actually devoted to the household purse? Clearly, the latter definition may be more useful

when thinking about meeting costs but begs many questions about the relative responsibilities of different household members. The former definition is essential to understanding the impact of caring on other household members, but by itself is unhelpful in understanding the relationship between expenditure and resources. Ideally, then, we should have information on the personal incomes of all household members, as well as on the size of the household 'pot'. In addition, because income in households containing a disabled person often has to cover additional costs, some notion of net disposable income, after the additional costs have been met, would be useful. In fact, none of the studies reviewed here has all three types of information.

As in the previous section, we start by looking at research which examines the impact on carers as a group and then go on to look at different sorts of carers. Joshi's re-analysis of the Women and Employment Survey (Joshi, 1987) suggested that women giving up work to care for a disabled relative during later stages of the life-cycle would forgo earnings of around £8,500 per annum if childless and around £7,000 per annum if they had ever had children. Further, if women returned to work after caring, their 'subsequent pay might be reduced through loss of seniority' (p.129). Such effects are probably most serious when women give up paid work early in the life-cycle.

Our re-analysis of the 1985 GHS has also looked at earnings (Parker and Lawton, 1990b). Given carers' lower rate of paid employment (see above), it was not surprising to find that their personal earnings were lower than those of matched non-carers (Table 8.5).

The analysis suggested two main effects on carers' personal earnings. First, there is an overall depressive effect because carers are less likely than their non-carer peers to be in any paid work. Secondly, among those who are in paid work, average earnings are lower, often because some types of carer are more likely to be in part-time work than their peers. We cannot judge directly from this analysis whether or not carers are generally working for lower rates of pay.

Other sources of personal income not included in the table – e.g. social security benefits, income from savings or investments, payments from others in the household, occupational pensions – can all substitute for or supplement earnings from paid work. Hence, although very low, the average personal income of female carers was

**Table 8.5 Average personal net earnings of carers and a matched group of non-carers, by sex, type of care, and residence (£)**

	Total			Among those with any earnings		
	Carers	Non-carers		Carers	Non-carers	
All	43	51	***	86	96	***
Male	71	87	***	122	136	**
Female	24	28	**	55	62	**
Personal and physical	27	42	**	77	91	
Personal <i>not</i> physical	38	43		86	86	
Physical <i>not</i> personal	35	53	**	75	98	*
Other practical	40	48		80	95	
Practical only	48	54	*	90	99	*
Other	50	53		90	100	
In same household	31	46	***	82	102	**
In other household	47	53	*	87	95	*

One-way analysis of variance (F) significant at  
 0.05 level (\*)  
 0.01 level (\*\*)  
 0.001 level (\*\*\*)

little different from that of their peers. For male carers, however, there was a significant difference of £12 a week.

There were very few differences between the other sources of carers' and non-carers' personal incomes. Male carers were more likely to receive supplementary benefit and invalidity benefit while women (mothers of disabled children) were more likely to receive attendance allowance. Those providing the most intense forms of care and those looking after someone in the same household were substantially less likely than their non-carer peers to have income from savings. Given that age and sex are controlled for, this result cannot reflect life-cycle or gender differences in capital accumulation. It seems to reflect a real effect of caring. Years of depressed income must affect carers' ability to save, as must any pressure to spend more because of the cared-for person's disability (Baldwin, 1985; Glendinning, 1989).

Very few carers in the 1985 GHS received invalid care allowance (ICA). The survey was carried out before the extension of ICA to

married women but, even so, there is little evidence of its reaching other groups. This is not so surprising perhaps when, as an income-replacement benefit, ICA is available only to those under retirement age, when there are rules relating to earnings and hours spent caring, when overlapping benefit regulations mean that those without paid work who claim social security benefits are unlikely to gain financially from receipt of ICA, and also when receipt of ICA depends on the dependent person's receipt of attendance allowance (see McLaughlin, 1991, for a full exploration of this effect).

Using an equivalence scale to control for household size and composition, it is clear that carers' households have lower net incomes than matched non-carers' households. However, this is more obvious among those providing particular types of care and those caring in the same household (Table 8.6).

Regardless of their source of income, other household members fail to 'make up' shortfalls in carers' earnings and incomes in order to bring household income up to levels comparable with those of non-carer households. Further household income in the GHS is based

**Table 8.6 Carers' and non-carers' equivalent household incomes: by sex, type of care, and residence (£)**

	Carers	Non-carers	
All	84	88	*
Male	86	92	
Female	82	86	
Personal and physical	75	90	**
Personal <i>not</i> physical	84	83	
Physical <i>not</i> personal	75	90	**
Other practical	86	89	
Practical only	83	82	
Other	92	88	
In same household	72	86	***
In other household	88	89	
One way analysis of variance (F) sig at		0.05 level (*) 0.01 level (**) or 0.001 level (***)	

on the total income of all household members and thus probably overestimates the amount available for household expenditure.

So far we have looked at the overall impact of caring. What about carers looking after particular groups of disabled people? As with the section on labour market participation, it is easiest to disentangle 'caring effects' among parents caring for disabled children, and most of the soundest information comes from studies of this group.

One study found that employed women with a disabled child earned an average of £7.20 a week less than employed women in a control group (Baldwin *et al.*, 1983; Baldwin, 1985). This difference increased as the age of the youngest child in the family increased; by the time the youngest child was 11 years old, the average weekly earnings of employed women in the control group were £16.30 higher than those of the employed women with disabled children (all 1978 prices). Although Baldwin's evidence of the effect on men's earnings was less conclusive, it suggested some impact, especially on non-manual workers who earned an average £18.00 a week less than their control counterparts.

Disability benefits for children, although not designed as income replacement, are almost inevitably used as such. Yet in Baldwin's study benefits 'evened out earning losses for only one group of families - manual workers with a child under five. They had little impact on the earnings losses of non-manual workers with a disabled child and manual workers' families with older children' (Baldwin *et al.*, 1983). Life-cycle effects on total family income were also different between those with disabled children and the controls.

The OPCS survey of disabled children paints a similar picture. Average gross earnings for all people with children were 9 per cent higher for men, and 7 per cent higher for women in part-time employment, than those of parents of disabled children. This effect was most evident among parents of the most severely disabled children. The lower levels of earnings appeared to be accounted for, at least in part, by the disabled children's parents receiving lower hourly rates of pay (Smyth and Robus, 1989). The average earnings of married couples with only one earner were substantially higher than those of lone parents in paid work. This was because married couples were likely to have a full-time earner whilst lone parents were usually working part-time.



A comparison of average equivalent incomes (including benefit payments) in different types of households and with the general population of those with dependent children showed that all types of family containing a disabled child were disadvantaged relative to similar families, except for lone parents (Table 8.7).

**Table 8.7 Average net weekly equivalent incomes for different types of families with a disabled child and similar families in the general population (£)**

	Families with disabled children	General population with dependent children
<b>Type of family</b>		
Lone parent	79	78
Married, one child	116	126
Married, more than one child	90	107
Total	91	110

Source: Smyth and Robus, 1989, Table 3.17.

The apparent lack of effect on lone parents' family income is explained by the high proportion of lone parents in both the OPCS survey and the FES (which was used to provide the comparative figures) who were dependent upon benefit income. Families which contained other dependent children as well as the disabled child appeared to be particularly disadvantaged.

The OPCS survey also used the concept of net disposable resources, a figure calculated to take account of additional regular expenditure incurred because of the child's disability. Equivalence scales were then used to create a figure for 'equivalent resources'. This analysis showed that the average equivalent resources of all families with a disabled child were 78 per cent of average equivalent income for all families with children. Lone-parent families were the closest of all family types to their peers but had, on average, the lowest equivalent resources of *all* family types. We see here again the importance of having at least one family member 'free' to participate fully in the labour market.

Evidence about the effects of caring when the disabled person is an adult is much less conclusive. The OPCS adult disability survey generated a substantial amount of information about the financial circumstances of disabled people. However, the information about the earnings of others in the household is available only for their partners. Consequently, the relevant report is based only on 'family units': single adults or married couples, together with any dependent children. The report showed the importance of the presence of a partner who was not disabled and who was in paid work. Married adults were in households with the highest amounts of earned income 'mainly because there were more earners in the family unit, but also because when only one person was earning it was more likely to be the non-disabled partner with higher average earnings' (Martin and White, 1988, p.19). However, when real incomes were converted into equivalent incomes in order to compare households of different compositions, married couples with children had very low incomes, second only to lone parents. None of this allows us to disentangle the specific effects on *carers'* earnings. Indeed, not all the partners of disabled adults were necessarily carers.

The follow-up survey of disabled adults in the FES takes us a little further. This examined households, not just family units, finding that the 'average income from earnings of households with a disabled member is reduced primarily through the lower number of earners in these households' (Matthews and Truscott, 1990, p.13).

This study compared the earnings of disabled people, non-disabled people in the same household as a disabled person, and other non-disabled people. The earnings of non-disabled people were much nearer to those of disabled people when they shared a household with a disabled person than when they did not. Able-bodied men in households with a disabled person had lower rates of pay and worked slightly fewer hours than those in households without. Able-bodied women in a household with a disabled person also had lower rates of pay but worked fractionally longer. As Matthews and Truscott point out, we do not know in which direction causality lies here:

it could be either because disability is more common in households whose members have low-paying occupations, or because other household members are constrained to work fewer hours because of the need to care for the disabled person. (p.14)

The follow-up survey also showed that equivalent net income in households with a disabled person was lower than in other households. This indicates that the effects of taxation and benefit receipt fail to compensate for the lower average earnings of disabled people and those who live with them. Here again it is not possible to distinguish clearly effects on carers as opposed to disabled people.

Small-scale studies of the financial impact of caring for disabled adults get nearer to the perceived impact of caring on income, but because of their size and lack of comparison or control groups are less capable of generalisation. However, they do point to the nature of caring effects, if not their size, and most record lost earnings. Nissell and Bonnerjea's pilot study (1982) estimated that women caring for elderly parents and parents-in-law, who were not in paid work but would like to have been, lost an average of £87 per week or £4,500 a year. The opportunity cost of earnings foregone by women who were in less than full-time employment was £37.00 per week, or £1,900 a year (all at 1982 prices).

Hyman (cited by EOC, 1982), in her study of the extra costs of disablement, calculated that carers who had had to give up their own employment to care for adults with disabilities had an average loss of earnings of around £120 per week (at 1980 prices). More recently Glendinning (1989) found that, in a sample of 30 carers (caring for someone other than a spouse), only six had experienced no effects on their paid employment and, thereby, their earnings. Although these effects were not quantified they must have been substantial, particularly for the eight who had given up paid work completely. This research highlighted again the importance of the number of earners in a household. Two-adult households where one person was caring and the other disabled were particularly vulnerable financially.

Research on non-elderly married couples where one partner had become disabled since marriage has suggested that (over and above the nature or severity of the spouse's disability) cohort effects, life-cycle effects, and structural differences in male and female labour market participation all mediate the effect which caring has on carers' paid employment and earnings (Parker, forthcoming). Household income varied enormously, influenced by differential entitlement of male and female disabled partners to national insurance benefits and occupational pensions, the degree and type of the partner's disability (and therefore entitlement to disability-related benefits), the receipt of

compensation payments and industrial disablement benefit, and the non-disabled partner's participation in paid work. In combination, these factors meant that households where the wife had become disabled were most affected financially.

***Summary of the research evidence on carers' economic activity, earnings and income***

The research evidence reviewed here is deficient in two respects for establishing the economic impact of caring in a rigorous way. First, it was not, by and large, designed to do this. The 1985 GHS probably offers the best source for all carers but the OPCS disability survey and the FES follow-up are of limited value. Research which was designed to look at economic impact is either somewhat restricted in scope or difficult to generalise from.

Secondly, all the evidence is at least five years old. In the meantime ICA has been extended to married women and changes have occurred in the economic activity of the general population. The effects of caring on the economic situation of carers and their households may thus have altered in the interim. The extension of ICA will not, however, have affected the poorest households in the OPCS survey – those entirely dependent on benefit income. (See below for more detailed discussion of ICA's impact.)

What, then, can we conclude about the effect of caring activity on labour market participation, earnings, and income? Overall, caring is associated with depressed levels of labour market participation relative to non-carers. This effect appears to be most marked among women when they are caring for a disabled child or young adult (under 21); and among men when they are caring for a non-elderly adult. Effects on earnings tally with the effects on economic activity. Carers generally have lower earnings than non-carers. Both lower rates of pay and the fewer hours worked play a part. Because women generally have lower levels of earnings than men, the impact of caring is somewhat smaller on average for them than it is for men. However, there is a substantial effect on the earnings of younger women caring for disabled children. Carers' average personal incomes are also lower than those of similar non-carers but the differences are less striking overall. This suggests that benefits and other forms of income redress some, but not all, of the balance. Again, because of women's low incomes generally, the impact on female carers appears to be smaller.

Equivalent household incomes are lower in carers' households than non-carers' households, but the differences are smaller still. Other household members' incomes clearly help to bring carers' households nearer to their peers, although this begs the question of how much of their income actually finds its way into the household purse.

The number of adults in a household 'free' to take paid work is clearly crucial to economic well-being. This makes two-person households where one person is disabled and the other providing care particularly vulnerable.

Given the substantial variability of the caring 'effects' identified, it seems unhelpful just yet to think in terms of round figures which describe 'lost earnings' or some overall 'economic impact'. However, there is clear potential here in the secondary analysis which is currently under way at SPRU and other centres.

### **Benefits for carers**

Income maintenance for people who provide care on an informal basis currently comprises:

- Invalid care allowance (ICA);
- Income support (IS). Since April 1991 there is a carers' premium of £10.80 for carers on IS who receive ICA;
- Home responsibilities protection of retirement pension rights and exemption from the requirement to be available for work from carers claiming IS.

In all these cases provision is limited to those of working age caring for a person in receipt of the attendance allowance (AA).

ICA was introduced in November 1975 following the review of disability benefits announced in the 1974 White Paper, *Social Security Provision for Chronically Sick and Disabled People*. Originally restricted to men and single women, ICA was extended to distant kin and non-relative carers in June 1981 and, after a protracted campaign and a successful appeal to the European Court of Justice, to married women in June 1986.

ICA is a non-contributory benefit available to those caring at least 35 hours a week for someone receiving attendance allowance and not 'gainfully employed'. For the purpose of ICA this means that the claimant does not receive more than £30 a week net of work-related

expenses or is not in full-time education. Like the non-contributory invalidity pension (now the severe disablement allowance) introduced at the same time, its level was set at 60 per cent of the contributory invalidity pension (IVB). The 1991 rate is £31.25 a week, as against £52.00 for IVB. Additions can be claimed for a spouse who does not earn more than £16.85 per week and, in some circumstances, for dependent children. ICA is not means-tested and can thus be paid to carers whose spouse is in employment or who have savings in excess of £8,000. It is, however, fully taken into account in assessments for IS.

Carers receiving ICA can claim IS on the same basis as single people, except that they do not have to register for work. The basic rate of IS for a single person over 25 is currently £39.65, together with an 80 per cent rebate on the community charge and, for tenants, full rebate on rent. Only £5 of earnings is disregarded for ICA claimants as against £15 for other groups such as lone parents or people with disabilities. Since October 1990 carers have been eligible for a carers' premium, worth £10.80 a week from April 1991.

ICA is thus the only non-means-tested benefit specifically for carers. Its principal objective is the (partial) replacement of earnings lost by people whose caring work prevents them from continuing in or taking up paid employment. Subsidiary objectives include the creation of an independent source of income for carers, and thus the reduction of financial dependence on those they care for; recognition of the importance and value of caring work; and, to a degree, the encouragement of family caring.

A sustained critique of ICA since its inception has cast strong doubt on whether the first two objectives are being met. Among the criticisms made, four kinds of issues stand out:

- ICA's adequacy as an earnings replacement;
- its effectiveness in creating an independent income for carers;
- its place in the relationship between care-giving and paid work;
- the extent to which ICA in its current form meets the particular needs of carers.

### ***Adequacy as earnings replacement***

ICA is paid at only 60 per cent of IVB. It is, with the severe disablement allowance (SDA), the lowest benefit in the DSS portfolio.

The introduction of age-related additions to SDA will leave it as the lowest benefit of all. Its current level is well below both short-term national insurance benefits and the single person's rate of IS.

***Effectiveness in creating an independent source of income***

ICA cannot then, to any great extent, fulfil the key objective of providing an independent income for carers. Many carers will have to supplement their ICA by relying on someone else or claiming IS, which is means-tested. Dependence on friends and relatives can create tensions, and poverty when financial support is withheld. Reliance on IS – the last resort of the income maintenance system – carries strong connotations of dependence on the state. It can also be experienced as a harsher regime than the claiming of contributory benefits such as IVB.

Two further aspects of dependence are involved. First, the carer's entitlement to ICA depends on the cared-for person's receipt of attendance allowance. This removes the carer's independent access to a benefit; some disabled people are unwilling to claim attendance allowance. It also means that problems in the administration of AA – for example, delays in decision-making and a high proportion of initially 'wrong' decisions – are mirrored in respect of ICA. Secondly, overlapping benefit regulations mean that carers who satisfy the other criteria for ICA can find their access to it compromised by the benefit situation of someone else in the family – usually a spouse. As a maintenance benefit, ICA cannot be paid when another maintenance benefit is being received at the same or a higher level. So where other members of a family are claiming, the notion of an independent income for a carer is somewhat illusory. (When the decision is made to claim ICA rather than the other benefit there is no immediate cash advantage in doing so. The only advantage is the accrual of national insurance credits, which do not carry entitlement to short-term national insurance benefits for unemployment or sickness.)

***The relationship between care-giving and paid work***

The use of an income cut-off has been criticised for its apparent assumption that carers should detach themselves more or less completely from the labour market to qualify for benefit. It is argued that this does not reflect the importance of sustaining carers in

employment. Sustaining carers in the labour market does not appear to be a strong objective of policy at the moment.

Paid employment can be important to carers for a number of reasons: to increase their incomes, to reduce their dependence on relatives or the benefit system, to keep them in touch with the labour market and improve their chances of re-employment at a later stage, to maintain their contributions to pension schemes and to provide a break from caring and improve their social contacts. As noted in the Social Services Committee's report, there are parallel advantages to the state in encouraging part-time work among carers (House of Commons, 1990, para. 90).

It is also argued that an income cut-off does not reflect the gradual shift of many carers from full- to part-time work before giving up completely, or earnings lost in the move to part-time work. Nor does it reflect earnings lost because of lost time, lost promotion, inability to move away and so on.

The two-stage increase in the earnings limit for ICA from £12 to £30 could have a substantial effect on the work and earning power of some carers. However, it is possible, as discussed further below, that some kind of tapered earnings disregard or carers' credit on the lines of the new disability credit would have a better effect.

### ***ICA and the particular situation of carers***

It is argued that as an earnings-replacement benefit ICA fails in two ways to meet the particular situation of carers. First, it fails to deal with long-term losses in earnings and earning power and the translation of these into inadequate pensions and poverty in old age. ICA carries no entitlement to the state earnings related pension scheme, while long periods of caring work reduce the build-up of occupational pension rights. Second, there is virtually no provision for the end of caring. When the cared-for person dies or goes into residential care, ICA stops immediately and carries no credits which create rights to unemployment benefit.

More fundamentally, there is a view that an earnings-replacement benefit like ICA cannot deal with important aspects of caring, some of which have financial implications. First, it cannot compensate for the extra costs which, it is argued, care-giving can create. These may be costs arising from the disability and transferred to the carer when the cared-for person's income is low. They may also be costs created



for the carer by caring itself – the use of more expensive food or transport to save time, for example, or wear and tear to the carer's home. Carers over retirement age are particularly disadvantaged by these omissions, since they are not eligible for ICA nor, by extension, for the carers' premium on IS. Secondly, ICA cannot recognise the long hours, heavy labour and opportunity costs that caring can involve, or distinguish between the different amounts of care given. It is not *payment for caring*, simply recognition that the carer is not free to take paid work.

These arguments suggest the need for substantial change in ICA itself and possibly for an additional carers' benefit. This is discussed further below. Before that, however, we look at how the available research evidence can inform this critique of ICA and allow us to assess the validity of the arguments outlined above.

### ***Research and ICA***

Both the 1985 GHS and the OPCS disability surveys predate the extension of ICA to married women and are thus of very limited value in assessing the benefit as it now stands. A recently completed study, commissioned from SPRU by the DSS (McLaughlin, 1991), is thus of considerable value in this respect.

The scope of this study was limited to carers who had applied for – though not necessarily received – ICA. The study did not, therefore, provide evidence on the financial impact of caring for a representative sample of carers. Another effect was that the consequences of linking eligibility for ICA to receipt of attendance allowance could be addressed only through secondary analysis of available data sets and investigation of claimants' sources and level of knowledge of ICA. The study nevertheless provides extremely important information on ICA.

The design comprised three elements:

- secondary analysis of existing data sources, including administrative statistics and the 1985 GHS;
- an interview survey of 614 carers, broken down into three groups: current and past recipients of ICA and unsuccessful applicants;
- a separate qualitative study involving in-depth interviews with 37 carers from the three groups interviewed in the main survey.

It is not possible to do justice here to the findings of this major study. However, key findings include:

- the limited coverage of the benefit. Approximately 850,000 people in the United Kingdom provide 50 or more hours of care a week, but only 109,000 received ICA in December 1988. (Since the study, the number of recipients has risen to 134,000 in December 1990).
- the amount of care given. Most ICA recipients in the study provided considerably more than 35 hours of care and were caring for severely disabled people.
- the adverse effects of caring on carers' personal and household incomes – notwithstanding the introduction of ICA and its extension to married women. Both carers themselves and their households had incomes substantially lower than those of similar people in the population at large.

### *Carers' personal incomes*

The personal incomes of carers in the study were very low. Table 8.8 shows the value of ICA in raising carers' personal incomes; those who were unsuccessful in claiming the benefit had the lowest incomes of the three groups in the study. It also demonstrates its limited success

**Table 8.8 Mean personal weekly income, by employment status (1989 ICA Survey)**

	Not employed	Employed part-time	Employed full-time	All
Current ICA recipients	£55 (248)	£64 (10)	- -	£55 (258)
Ex-ICA recipients	£49 (17)	£71 (7)	£118 (7)	£64 (41)
Unsuccessful claimants	£32 (46)	£45 (10)	£61 (3)	£35 (59)

Source: McLaughlin, 1991.

Note: The sample size for each figure is shown in brackets.

in doing so. ICA recipients who had some work and, even more, carers who had taken sufficient work to disqualify them from the benefit had much higher personal incomes.

### ***Household incomes***

The household incomes of carers in this sample were considerably lower than those of non-retired households in the 1988 FES (the latest FES available at the time of analysis), £13 a week on average lower in the case of current ICA recipient households, £33 for past recipient households and £79 for unsuccessful claimant households. Taking account of household composition by calculating per capita income figures again brings out the relatively advantaged position of current and past recipient households over unsuccessful claimants. However, all three groups fall short of the income levels found in the general population (Table 8.9).

**Table 8.9 Comparison of household income and household size: ICA Survey and Family Expenditure Survey**

	Average household income	Average household size	Income per capita	As per cent of national average
<i>ICA survey, 1989</i>				
Current recipients	£219.92 (196)	4.01 (270)	£54.84	59%
Past recipients	£199.99 (33)	3.18 (44)	£62.89	68%
Unsuccessful claimants	£154.38 (40)	3.70 (62)	£41.72	45%
<i>Family Expenditure Survey, 1988</i>				
	£233.20	2.52	£92.54	100%

Source: *ibid.*

Note: The sample size for each figure is shown in brackets.

The low incomes of carer households were due to a number of factors:

- a low incidence of two-earner households;

- depressed levels of employment among carers, only partially off-set by ICA;
- lower employment rates and below-average earnings among partners;
- a high prevalence of no-earner households, predominantly spouse-carer households.

The particularly low incomes of unsuccessful claimant households, compared with those of current and past recipients of ICA, were due not only to the absence of ICA but to the associated absence of attendance allowance and to very low levels of earnings among employed partners. ICA, then, provided some protection against loss of earnings, but carers in receipt of other benefits or choosing to work part time instead of claiming ICA had higher personal incomes than ICA recipients.

The ICA study provides supporting evidence for two criticisms of ICA discussed earlier. First, the adverse effect on carers' incomes of the link to attendance allowance and overlapping benefit regulations. The extremely low personal and household incomes of carers whose dependants did not receive attendance allowances (a high proportion of the unsuccessful ICA claimants) suggests that the link between the two benefits may well disadvantage carers. The data also show the difficulty, within existing regulations, of improving the financial situation of carer households whose income comes entirely from benefits. The OPCS disability survey demonstrated the financial vulnerability of such households. They were invariably among the poorest in that sample. The extension of ICA to married women, which will have improved the situation of women with earning partners, will have done nothing at all for benefit households, including single parents who have disabled children. Both groups were identified in the OPCS survey as having very low 'net equivalent resources'.

Secondly, the ICA study confirms that employment continues to be affected and income lost when caring has finished. Some carers evidently found difficulty in re-entering the labour force. The loss of disability and carer benefits was not compensated for by alternative sources of income, reflecting the age and low levels of employment of past ICA recipients. The household incomes of all the non-retired ex-carers in this study were substantially lower than those of the

general population – by between £150 and £180 a week in different household types (McLaughlin, 1991).

### ***Recommendations for change***

The Social Services Committee's report concluded that ICA was not effective at present in even its 'relatively limited' objective of (partially) replacing earnings lost as a consequence of care-giving (House of Commons, 1990, paras. 106-7). While acknowledging the value of recent improvements (the extension to married women, the increase in the earnings limit and the new carers' premium), the Committee took the view that the question of how carers *should* be supported – financially and practically – needed more fundamental consideration. In terms of financial support, the Committee identified two long-term policy objectives: improved income maintenance, and improved opportunities to combine caring with paid work.

It recommended a two-stage programme of change, focusing on:

- the level of ICA. This should be raised immediately to the level of short-term insurance benefits or, alternatively, additions related to the duration of caring should be introduced. Ultimately ICA should be paid at the same rate as IVB and retirement pensions;
- carers' ability to combine caring with paid work. This could be improved by making further increases in the earnings limit; introducing a tapered disregard; increasing the IS disregard for carers; or disregarding all or part of ICA. Longer-term options include the introduction of a reduced rate of ICA for people who care for disabled people but stay in paid work – similar to the new disabled work allowance;
- independent access to ICA – via hours of care given rather than receipt of attendance allowance by the person cared for;
- provision for the end of caring – immediately by reinstating carers' rights to unemployment benefit, and ultimately by extending eligibility for ICA to the six-month period after caring ends;
- pension provision for carers who have spent significant periods out of paid work, and financial support for older carers.

These proposals meet many of the criticisms made of the financial support currently available to carers. In their current form they need further development; the Committee's proposals are more a 'shopping

list' of possible improvements than a fully coherent benefit package. Clearly, however, they have the potential to transform social security provision for informal carers, among other things removing the need for most carers to claim IS and dealing with the problem of overlapping benefits regulations. This process may already be under way. The government has decided to increase the earnings limit on ICA to £30 a week and to continue payment of the carers' premium for eight weeks after the end of caring.

The Committee's proposals were welcomed by carers' organisations – though outstanding problems are identified. The most serious concern:

- how to provide compensation for loss of pension rights;
- how to provide for shorter and longer periods of care-giving and different amounts of care given;
- compensation for the costs of caring;
- financial support for older carers.

*Compensation for loss of pension rights.* The Social Services Committee recognised both the effects of long periods of caring on pension levels and the difficulty of dealing with this within current pensions provision. One possibility is the introduction of a carers' 'occupational pension addition' to the state retirement pension – paid to people claiming ICA for a considerable period in their late 40s and 50s. Policies to keep carers in touch with the labour force would also help. Manifestly, however, caring is only one of many intractable factors shaping women's low incomes in retirement.

*Providing for different levels and periods of caring.* The question of how to recognise the different effects of caring for different lengths of time or providing different levels of care is also knotty. If entitlement to ICA is linked to the lower levels of the new disability living allowance, the appropriateness of a flat-rate carers' benefit will be difficult to defend. Yet paying ICA at different levels according to the number of hours spent caring could be seen as changing the benefit's purpose – away from earnings replacement and towards payment for care. This is very much not what carers' organisations want. One possibility would be to mirror short- and longer-term NI benefits, creating two levels of ICA:

- a lower level, set at the level of short-term NI benefits and paid to all carers for the first three months of caring, and thereafter to carers giving fewer hours of care;
- a higher level, set at the level of basic retirement pensions, available after three months to all carers giving greater levels of care.

*The costs of caring.* The problem with carers' costs is whether they should be dealt with via a benefit for carers or through benefits and services for the disabled person. Carers' organisations argue that carers incur costs which are separate from those of the disabled person and which should be met via a carer's allowance. Such costs are, however, difficult to separate empirically from the costs of disability and to measure with any precision (Glendinning, 1990). The Social Services Committee took the view that costs borne by or transferred to carers were best dealt with

- by improving benefits for disabled people;
- by changing ICA to help carers stay in paid work;
- by improving the level and quality of the support to disabled people and their carers: day and respite care, domiciliary and nursing help, aids and adaptations and so on.

The logic of this position is clear. However, it clearly requires an improvement on the current level of extra-costs benefits and their availability to disabled people over pension age. It also requires a somewhat heroic act of faith that statutory authorities will be willing and able to deliver appropriate adequate support.

*Older carers.* Carers over retirement age are not eligible for ICA or for the carers' premium on IS. A carers' costs allowance would help older carers. Probably a better solution is to link the carers' premium to hours of caring rather than ICA – and to ensure that older carers in particular are recognised as needing more support in the new arrangements for care management introduced by the NHS and Community Care Act.

To summarise, research evidence supports the strong case made by carers' organisations and the Social Services Committee for improving the level of benefits to carers and possibly restructuring them to reflect different periods and levels of care-giving. There is

general agreement that the role of social security should be confined to income maintenance – rather than paying for care. It is recognised that this leaves major gaps in support for disabled people and carers. However, the consensus seems to be that these are best filled by services – whether organised via health and social services authorities or via an agency like the Independent Living Fund. This immediately raises fundamental and contentious questions about how support services *should* be provided to disabled people unable to live in ‘the community’ without them. Crucially, it raises questions about the role disabled people and, where appropriate, carers can play in managing their own support and the role of directly provided services as opposed to cash or vouchers.

These are questions which have great importance in the development of the new structures for assessing needs and delivery services envisaged in the NHS and Community Care Act. They are also questions which go beyond the scope of this chapter – partly because of the lack of research evidence to illuminate the discussion and partly because they deserve separate analysis. Nevertheless three issues seem worth highlighting at this point.

The first concerns the role of social security in providing social protection in the form of long-term care. United Kingdom policy has moved decisively away from this with the abolition of residential care allowances. Other countries have taken a different stance (Norway, Germany, Australia and Israel among others). However, relying on social security rather than discretionary decisions by social workers has advantages for the claimant – in terms of clearer entitlements, greater equity and fairer appeals procedures, for example. The identification of the disabled person rather than the family or community as the focus of policy is also an advantage lost in the move away from social security. How will the new community care arrangements replace these advantages?

The second concerns the appropriateness of the models of care management currently being developed by social services authorities. Here the general point is that the dominant role they assign to professionals – as assessors of need and gatekeepers to resources – is at odds with what many disabled people and many carers want. Alternative approaches based on concepts of empowerment and independence seem both feasible and valued, though little research has yet been done to evaluate them. There is also a growing view that



disabled people or their carers should be given control of budgets to pay for their support. Preliminary evidence from the Independent Living Fund suggests that this will not necessarily be straightforward. Some disabled people and some carers found the Independent Living Fund ‘an unqualified blessing’; others found problems in funding and managing their own services (Kestenbaum, 1990). It is clear, nevertheless, that the direction in which most disabled people, and most carers, want to move is towards greater autonomy in arranging and managing their support.

Finally, there are questions about the charges now being levied on disabled people for care and the extent to which disability benefits are seen as available to pay for services. The OPCS and the 1985 GHS surveys have demonstrated the very low incomes of disabled people and of carers. Will they be further reduced by having to meet care costs? *Should* disabled people be expected to pay for basic care? Will charging create a disincentive to taking paid work? Will ability to pay influence the level of service available? Is this kind of inequity acceptable? The extent to which assessments are made and decisions taken on these matters by people with relatively little knowledge of the costs of disability or purposes of disability benefits must give cause for concern.

### **Conclusion**

There will clearly continue to be a role for social security within community care policy – both in the specialised areas discussed above and in the general context of the adequacy of benefits. The evidence discussed in this chapter suggests that serious thought should now be given to the objectives of social security policy for carers and its interaction with policies for disabled people, and to devising a benefit structure which takes better account of the financial impact of care-giving. Other chapters in this book make it clear that policy for disabled people should aim to maximise their independence and choice. It is important to recognise that better social security provision for carers need not subvert these goals.

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*Disability and social policy*

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