KF

Project Paper NUMBER 81

Value for caring

Recognising unpaid carers

BILL JORDAN

VALUE FOR CARING:
RECOGNISING UNPAID CARERS

VALUE FOR CARING:
RECOGNISING UNPAID CARERS

Bill Jordan

King Edward's Hospital Fund for London

Typeset by J&L Composition Ltd, Filey, North Yorkshire
Printed in England by GS Litho Ltd
Distributed by Bailey Distribution Ltd

ISBN 1 85551 050 2

Contents

Foreword

The care provided for ill or disabled people by their families and friends has attracted considerable interest and concern during the 1980s. Carers have been discovered, both in terms of the extent and variety of care they give and the disadvantage and hardship which many experience as they carry out the caring role. As we enter the 1990s, carers are no longer outside the realm of policy and politics. Many practical initiatives are evident throughout the country and carers now feature prominently in government plans for community care in the next decade and beyond.

The changes aimed at supporting carers represent tentative steps in forging a new relationship between formal and informal care systems. Whether or not these steps are in the right direction is a matter of some debate. *Value for Caring* contributes to that debate at a time when there is a great deal of uncertainty about the future of community care and when fears about the exploitation of carers are widespread.

Many of the issues raised by Bill Jordan began to emerge during research and consultation preceding the publication by the King's Fund Informal Carers' Support Unit of *A New Deal for Carers*. It was not possible to explore these issues in any detail in that book and, hence, *Value for Caring* was commissioned.

As the latest in a series of King's Fund publications about carers, *Value for Caring* airs ideas which are rarely considered by those who are caught up in the immediate practicalities of improving support for carers. By stepping back from those day-to-day problems, readers will, we hope, find food for thought which will help them decide for themselves how in the longer-term real freedom and choice can be made a reality for carers.

Janice Robinson
Programme Director
King's Fund Informal Carers' Support Unit

1. Introduction

In its white paper on care in the community, *Caring for People*, the government lists as one of its key objectives for service delivery 'to ensure that service providers make practical support for carers a high priority'.[1] Does this statement mark a real step forward in the recognition of unpaid carers and guarantee them against neglect and exploitation? This paper takes a longer-term look at the implications of measures to switch from institutional to community care, and at the future role for carers.

The title of this paper, *Value for Caring*, is deliberately ambiguous. The government's strategy in this field, as in the health service, is to introduce accounting and budgeting principles to ensure efficient management and prudent public spending. Its primary aim is 'value for money'. But at the same time the government aims to increase freedom and choice for those who need care and the people who care for them. In this sense it wants to revalue these groups by allowing them more control over their lives and by offering them better support. The link between these two aims is made in a short section on the contribution of carers: 'helping carers to maintain their valuable contribution to the spectrum of care is both right and a sound investment'.[2]

At first sight this sounds like an important step forward. At last more recognition and value is being given to the role and tasks of assisting people who need practical help in their daily lives. But I shall argue that these new developments fall short of including carers and those they care for as full and equal members of our society. Other changes – in income maintenance and in services – are needed before carers are valued in the way which is their due as citizens.

In many spheres of life, we indicate the value of a service given by paying for it. But in other spheres – family, friendship, community groups, churches – people care for themselves and each other without direct financial reward. Caring for children, old people, those with physical and mental handicaps, victims of chronic illnesses and accidents, is the largest part of this unpaid work, and women are the main workforce.

Yet paid and unpaid work are not entirely different kinds of activities. Rich people can afford to pay poor people to do many of these tasks for them; and poor people are sometimes so busy doing things for the rich that they do not have the time, energy or resources to care for themselves or each other. The more unequal the society, the clearer this division between kinds of people (rather than kinds of work) tends to be; in South Africa, for example, most white households have black domestic servants and gardeners, but in many black communities children suffer from malnutrition and preventable illness while parents are away working in white areas.

In response to similar divisions in British society in the Victorian era, our social services were developed as a way of giving paid care to people who could not afford it. Originally, state care was given in large institutions (workhouses, asylums and hospitals) to people who were destitute, or who were rejected by their families, or whose families could not afford to care for them. Later, with the creation of the National Health Service, provision became less uniformly institutional, less stigmatised, and available for all on the basis of need. But part of the old legacy remained. State care was not so much a supplement to family care as an alternative to it – for people who could no longer care for themselves or each other, and who had no available carer to provide the help they needed on an unpaid basis.

In the 1980s and 90s some important changes are taking place. As the elderly population increases, commercial care has grown, mainly supplied by small family businesses, financed partly out of private savings and pensions, but mainly out of state payments to people who qualify for income support. At the same time, policies for care in the community have gained momentum. The running down of large hospitals for people with mental illnesses and mental handicaps has accelerated, and local authority residential provision is also diminishing. So a smaller proportion of direct caring is being done by the state, which leaves more caring for more people to be done on an unpaid basis.

These changes provide the starting point for the white paper. But the framework in which they are considered is one of business administration – how to run state-funded care services in such a way as to provide clear accountability, performance standards, and the best value for taxpayers' money. In particular, the government is concerned about the fact that growing sums of income support are being spent on private residential care, without professional assessment of need. The aim is to reallocate the 'care element' in these payments to local authorities, requiring them to make detailed plans for each person in need of care, and to spend their budgets on purchasing a range of domiciliary, day, respite and residential services, from commercial, voluntary and cooperative services, as well as providing their own. In other words, the white paper is all about how to pay for care, and whom to pay; unpaid care is still there as the foundation of the whole edifice – acknowledged at least in several paragraphs, to be supported and buttressed by paid care, but still largely assumed and left unanalysed.

So the white paper leaves many fundamental questions unanswered. First, there is a range of issues about how paid service-providers can best support and recognise unpaid carers, how they can work together as partners, and how carers can be included in the planning of service provision. These issues are beginning to be addressed, particularly by carers' organisations. In March 1989, the King's Fund Informal Carers' Support Unit published *A New Deal for Carers*, by Ann Richardson, Judith Unell and Beverly Aston, which outlined carers' needs, and gave guidelines for policy and practice in the social services.[3] The first item on their list was 'recognising carers' contributions'. In other words, the first step towards greater cooperation and a 'new deal' in relations between paid and unpaid care, the state and the family, is a recognition of the value of caring and of carers.

But there are some even more basic questions about unpaid care and the role of carers in our society. These are issues of justice and citizenship. Is it fair on women that they should so often be seen as having the duty to care, when so many more of them now do paid work? Is it fair on anyone to expect them to be a full-time unpaid carer when the role is so demanding and so isolating? And why should unpaid care provide the foundation for a system of paid care, including extensive and growing opportunities for some family businesses to make profits from providing a range of services while other families do much the same for no payment?

None of these issues is addressed in the white paper, yet all are crucial for the long-term future of community care. Above all, how can the new aim of *valuing* unpaid care be sustained in a period when women of all ages will increasingly be in demand in the labour market and, therefore, the traditional providers of unpaid care will have improving opportunities for paid work? It is one thing for the white paper to say that carers should have more choice; it is quite another to say who will choose to be a carer and whether the choice will be a free and fair one.

This paper takes a step back from the immediate, practical issues and looks at the longer-term implications of change. Some people may find it annoyingly speculative and its perspective too lofty and distant. If so, then *A New Deal for Carers* will provide an immediate antidote, because it supplies detailed, practical suggestions about what can be done *now*. This paper should be seen as complementing it, by setting out some broader considerations about the future and asking some questions about how underlying issues over caring are to be tackled in the longer term. In particular, it addresses the problem of how an unpaid role can be given value in an increasingly commercial world.

2. Contracting and sharing

The first issues we need to consider are why unpaid work exists at all and what part caring plays in the system of unpaid work. If the simplest way of giving value to work is to pay for it, then why don't we base all our relationships on commercial contracts – agreements to exchange money for goods and services? Why not shop around for friends who will last us a day or two, like loaves of bread? Why not advertise for a contract sexual partner, or reach an agreement with someone (not necessarily the same person) to bring up a child together? Why not ring an agency for someone to care for us when we are old?

The first reason seems to be that we have a need to share important parts of our lives with others we have chosen and value because there is mutual liking between us. A person's life is not just a series of individual projects (getting a degree, running a marathon, setting up a business) whose success is measured in terms of solo performance. It also contains projects such as setting up a home, having a family, making friends, joining clubs and being a member of a community, the essence of which is that they involve sharing with others. It would be odd in any of these activities to start by marking out exclusive territory, defining what is ours alone and avoiding all contact with others. This is because the purpose of such shared projects is only partly captured in their material objectives; it also includes the act of sharing itself, and the enjoyment of each other's company, support and help. Our needs include a need to share parts of our lives in these ways.

This strongly influences the way we choose partners, friends and associates. We select them in rather intuitive and idiosyncratic ways, according to largely unspecifiable criteria, which include our feelings about them. We appear to put a premium on non-rational (or at least non-explicable) elements in these choices, and the emotional satisfaction we get when our liking for them is reciprocated. In other words, we put a high value on the fact that we feel good in their company and they in ours. So what we mean by value in these relationships is something quite personal, which cannot be bought or sold, because it only comes about by processes which are quite different from market ones.

The next reason is that everyday living, and especially the life of households, requires great flexibility and adaptability to rapidly changing situations. Ordinary life is chaotic and unstructured, and keeps being interrupted by all sorts of people and factors beyond our immediate control. It would be difficult to draw up a contract that would cover all the eventualities that arise in sharing a household. So the arrangements under which people share their lives are best kept flexible and negotiable, based on a rough understanding of roles and responsibilities, rather than closely defined rights and rules. The most common approach is one of give and take, with frequent adaptations to crises, illnesses, and emergencies, and no careful account of who owes a favour to whom, or when it should be repaid.

However, along with the stronger emotional ties between people who share their lives come far more difficult moral issues. If we are close to others for years or decades, the scope for misunderstanding, manipulation, mistrust and mystification is enormous. Because both physical and emotional dependence are characteristic of family relations in particular, there are many opportunities for cruelty, exploitation and cheating within these relationships.

Hence the commitments we make to others in shared projects rely on our moral qualities as well as on our emotions. Unlike contractual relations, they depend on empathy, patience, courage, forgiveness, enthusiasm, loyalty, humour, kindness, consideration – virtues which are not fully tested in the world of business and commerce. When a family member speaks of 'duty' to another, it is usually a complex set of feelings, related to a long history of experiences, rather than a precise obligation.

So I am suggesting that contracting and sharing are two quite different ways of meeting human needs, forming social relations and achieving cooperation. But they are not the only ways. Some of the same needs are met by state social services, in ways that seem to have some elements of contracting and some elements of sharing. How does this come about?

The state itself may be seen either as a contract between citizens to provide themselves with certain services (the 'social contract') or as a kind of club where members share in life together (the 'common good' or 'commonwealth'). On either analysis, the state provides certain services (such as settling disputes and keeping order) which would not otherwise be supplied but which benefit all.

It might also look after the interests of people who are unable to resist exploitation (such as adults with mental handicaps), or who have no one willing to care for them (like orphans or isolated elderly people). It might also act as a kind of giant insurance company, pooling risks in relation to certain needs (like health care) which are too unpredictable and expensive for most people to afford through private insurance.

But beyond this the two notions of the state could have very different implications. For instance, the 'contract' version might imply that the state does as little as possible, leaving citizens to meet almost all their needs through the market or shared arrangements. But the 'sharing' version might suggest that the state is itself a kind of community, whose citizens join together in a quality of life they prize. This would imply that state services try to share in the lives of the people, and that public facilities contribute to the meeting of a wide range of needs. These differences will be explored later.

The purpose of this chapter has been to analyse the different ways we meet out needs, with particular reference to how people's actions are valued within them. We have seen a sharp contrast between value measured quantitatively (in terms of precise sums of money) in the commercial system, and value measured qualitatively (in terms of emotional and moral bonds) within systems of sharing. Finally we have recognised that state social services may contain elements of both these systems: the state can be both a contractor for certain goods and services that the market will not supply and an association between citizens who share in a quality of life that they value.

3. Fairness and caring

Just as there are contrasting ways of valuing people and their actions in the systems described in Chapter 2, so there are differences in the ways that fairness is understood within them.

When we talk about a 'fair deal' in business, we mean a contract which has advantages for all the parties. In a free market, people are assumed to be able to choose the goods they want most at the price which is most favourable; so the process itself is fair, as long as the goods turn out to be as sound and wholesome as they look. But there is another sense in which such a deal may not be fair. Imagine that one of the parties is a property company that has just redeveloped a derelict building as sheltered flats, and the other is an old lady who is no longer able to go on living in her house alone. One party gains thousands of pounds from the deal; the other gains security in exchange for her life savings. But there are many other old people in rented accommodation, with an equal need for sheltered flats, who cannot even get into the market for them because they have no resources.

So another way of seeking fairness in commercial transactions is for the state to redistribute resources, so that everyone can get into the market to meet their needs. There is plenty of scope for political argument about how far this redistribution should go. For example, it is one thing to try to use a social security system to make sure that every citizen has enough to eat; quite another to try to redistribute resources in such a way that all handicapped people have the chance of a job.

In a group of friends, fairness is a matter of give and take. People help each other out in times of trouble – they lend an ear, or a lawnmower, or a pound of sugar, and do not reckon up how much support or practical assistance is owed to them. In families, the process of give and take has to cope with childbearing and with the period of dependency that we all go through as children, and most of us go through as old people. It also has to cope with occasional periods of acute need, like severe illnesses or accidents, and unpredictable long-term need, like disabilities and handicaps. Because so much of life is shared in families, and because relationships continue over the whole of members' lives, the system of exchange is organised around roles which have become relatively fixed, and are transmitted (often with only minor modifications) from one generation to the next.

By the beginning of this century, there were striking differences between the roles of men and women in British society. In addition to men's traditional hold on political power in every social organisation (including the family itself), men also expected to have 'full-time' employment outside the household and to earn a 'family wage', enough to provide for the other members. Married women were expected to be only occasional or secondary paid workers, and to devote most of their time to unpaid housework, child care and the care of any other adult family member who (for any reason) needed this. In other words, although families shared a home, possessions and income, men's and women's work was very different in nature and in reward, and these roles had become traditional and non-negotiable, with give and take over some of the daily details but little over the essential divisions between them.

Although there have been major changes in this century, particularly in employment patterns (60 per cent of married women now do paid work), the 'rules' governing relationships between family members have changed only in slow and piecemeal ways. And it is often only by the conscious organisation of women, people with handicaps or carers that these 'rules' are made explicit and questioned. It is far harder to identify issues of fairness over unpaid work, done as part of a network of mutual exchanges between family members, than it is to challenge the fairness of an employment contract with precise hourly pay and conditions.

Although we all live our family lives according to these 'rules', it has only been through recent research that we are learning to recognise exactly what they are, and to reflect on whether they are fair.[4] By talking to people about how they become carers, and why they continue caring, researchers have begun to chart how they apply to caring (though this work is not yet complete because it will still be necessary to talk to people about why they do *not* become carers).

The first 'rule' seems to be that able-bodied spouses should care for their disabled partners – this applies to men *who are* *retired* as well as to women of all ages. In fact, there appear to be almost as many elderly men caring for severely disabled spouses as there are women. Once people become carers, they tend to continue in that role, even if they themselves become very frail and in need of care.

The second 'rule' (once again concerning older people who become disabled and dependent), is that if there is no surviving spouse, or if he or she is not fit or suitable to care, then the role falls to a daughter or daughter-in-law. This responsibility seems to be given to women only; sons are seen as having some duties to *arrange* care for parents, but not as being candidates for the role of practical caregivers, unless they are unmarried and living in the same household. However, daughters-in-law seem to be almost on a par with daughters as potential carers, especially if no daughter is readily available for the role.

The third 'rule' allows some exceptions to the second, in that certain factors – such as geographical distance or having other important responsibilities – can exclude people from being candidates for caring. Having young children, a full-time job, or someone else to care for may also 'excuse' a woman from the role, and not being emotionally close may 'excuse' a daughter-in-law (but not a daughter).

The fourth 'rule' is much vaguer and may override the third: it is that whoever is 'closest' to the person who needs care (visits and is visited most frequently, has the stronger emotional bonds, was always the 'favourite' or lives closest) should become the carer, often in spite of the factors mentioned under the third rule.

The fifth 'rule' is that the mother is responsible for a child who is born with a handicap, or who later is recognised as needing a carer. Like all the other rules, this one has become so customary that it is seen as 'natural' that a mother should do this – it is part of what is meant by being a mother. These 'rules' are seldom discussed in families, and the person who becomes a carer does not feel as if she has a choice about taking the role (though she may be able to negotiate with relatives about the details and get some support from them).

It should be clear from this summary that the role of carer is not a special, unique one in families, but one that flows out of the customary responsibilities of family members to each other. When a husband or wife becomes a carer, it is like what they would do for each other during an illness – except that it is not time-limited as that would be, and it often involves much heavier work and a more stressful relationship. When a daughter becomes a carer for her mother, it is usually not a sudden decision, but something that grows gradually out of years of helping out in small ways as the mother grows older. When a mother becomes a carer for a handicapped child it is like caring for an able-bodied child, but the time and energy expended are much greater.

The fact that these 'rules' have become established, customary, even 'obvious' does not necessarily make them fair. We have inherited them from an age of large families, close links between generations, little geographical mobility and low female employment. Nowadays there are more people who need care, but they have fewer available relatives, and even fewer who are not in paid work. Society has changed, but the rules have only been slightly adapted. People do not have an equal chance of becoming carers; some are given the role with little choice, and others are never even candidates for it. So there are important issues of fairness over selection for the carer's role – between men and women, and between paid and unpaid workers.

4. The process of caring

I have argued that unpaid caring arises out of relationships between people who share parts of their lives (usually in families), in which they recognise moral bonds between them. Caring is a way of handling dependence within these relationships, which change over time. Often the person who becomes the carer has been physically dependent on the person cared for, either for a short time (during illness) or for the long period of childhood; often there is strong affection between them.

Caring and dependence involve both physical and emotional elements. Where the person cared for is unable to get out of bed or go to the toilet, carers have to do heavy lifting which can cause severe physical injury. Where he or she needs attention or supervision by day and by night, the work the carer does can take many more hours than a paid job and cause great physical stress.

But research suggests that it is the emotional aspects of caring which are the most stressful. This is sometimes because the character of the person cared for changes as a result of their condition; sometimes because of the distressing nature of that condition; sometimes because of the intimacy of the tasks with which help is needed; or for all these reasons. Dependence can alter the emotional quality and significance of the relationship.

All carers experience tiredness and anxiety, but whether or not they feel burdened and oppressed seems to be related to emotional elements more than to the physical demands or the seriousness of the condition of the person cared for. Some see the role of carer as rewarding and satisfying, feel personally fulfilled in it, and recognise that they benefit as well as give within the relationship. These carers have usually had a close, warm and affectionate relationship with the person they care for before dependence started, and this has been sustained by caring. But other carers describe the role as stressful, involving feelings of guilt, resentment and self-sacrifice. The background to these relationships was usually that they were not close or satisfying before dependence, or that they changed during dependence.

Since caring usually arises within family relationships and the role of carer often builds up slowly, starting with small acts of practical assistance (for example by a married daughter living close to her mother), carers often do not recognise that they are fulfilling a role other than that of a family member. Researchers investigating caring are frequently told things like: 'I'm not a carer, I'm a daughter'. Caring is seen as something quite different from a paid job, because of its different emotional and moral setting.

If we are to find ways of valuing carers, then it is important that we recognise the morality of caregiving and the values by which carers live. It seems to be a morality in which interdependence and mutual help form part of long-term patterns of relationships within a system of kinship (or occasionally of friendship). In this system, all members are to be included and assisted and valued for who they are rather than what they can do. When problems and conflicts arise, members try to resolve them by negotiation in such a way that friendly relations are maintained and emotional bonds remain intact.

Some psychologists have argued that this form of morality is characteristically feminine.[5] It contrasts with masculine morality, which is more concerned with individual autonomy and competition. Masculine values place a high premium on freedom and independence and establish rules about winning and losing which lead to hierarchies of esteem and success. Feminine values emphasise interdependence, mutuality and inclusion, with rules about helping and peacemaking.

It seems fairly obvious that these two kinds of morality correspond with the worlds of economic activity and the family respectively. In the male-dominated economy, relationships are by contract and value is measured by money, which give individuals the resources to pursue their own goals. In the more female-oriented family, relationships are by sharing, value is expressed in emotional terms and by mutual assistance, allowing members to handle dependency and conflicts of interest over a long time-span.

But for the purposes of seeking fairness for all, this raises formidable difficulties. It means that there are two sets of standards of fairness which are difficult to compare. Men and women participate in the economy and in the family, although men have an advantageous position in economic life, which gives them control over many resources and access to many facilities which women lack. They also have a customary role of decision-making power in families. Women have traditionally had major responsibility for unpaid work, and especially for caring. But although they have done most to maintain families, they are by custom subordinate within them – at least partly because they depend on men for money and because this dependence is greatest when their caring responsibilities are heaviest. A woman who is a carer for a very handicapped child, or a very frail parent, cannot do any paid work.

So the question is this: how in a world of two different kinds of value, and two different systems of morality, can we recognise the contribution of carers and ensure that they are fairly treated?

5. Rights and needs

So far we have seen that caring usually arises from family relationships, under 'rules' which are customary but not necessarily fair. Is there any way these rules could be changed to make them fairer? Other groups in society which face injustice have defined the changes they want, and organised to demand them. The idea of a 'charter for carers' which would be such a programme for action has been discussed for several years. In this way, carers could pursue the choices, opportunities and resources that are due to them. The authors of *A New Deal for Carers* had to decide whether to frame it as a charter expressing carers' demands.

The major issue for a carers' charter would be the language in which its claims were expressed. Most charters demand *rights*; they argue for formal entitlements, under rules. If someone has a right, then he or she can get something from another person, or stop another person doing something, or do something without being stopped. But rights such as these are characteristic of relationships which are contractual. In relationships based on sharing, where roles are flexible and negotiable, and responsibilities reciprocal, mutual and moral rather than formal and legal, the language of rights does not seem entirely appropriate. For example, it would be odd to talk of children having a right to be included in family meals, outings or holidays. This is because, as we noted earlier, when people share all or parts of their lives, they do not specify what they will do for each other, or count up exactly what they have done. Just as there is no written contract, so there are no formal entitlements. It is true that in the last resort people can appeal to rights in such a relationship, but they do so usually only when they want to refer to standards of fairness which apply outside the family or group.

Of course a charter for carers might state what rights someone in a carer's role should have – for instance, rights to assistance, to breaks, to holidays, and so on. But research suggests that many carers are rather resistant to this sort of language in making claims on their behalf. The notion of rights seems to apply to a far more formalised system of relations which many carers regard as contrary to the spirit in which they do their caring. (There are others especially parents caring for a severely mentally ill son or daughter who do think that they should have formal rights, especially to hospital treatment for the person they are caring for.)

Carers want what they do to be recognised, valued and supported, rather than taken for granted and ignored. They want the role they play to be enhanced, in the sense that it allows them to gain some self-esteem and some status in the eyes of society. But they want it to continue to be part of a system of relationships based on sharing.

So the authors of *A New Deal for Carers* decided not to express their claims in the form of a charter, but as a list of needs. The list was as follows:

Carers need:

1. recognition of their contribution and of their own needs;
2. services tailored to their individual circumstances;
3. services which reflect an awareness of differing racial, cultural and religious backgrounds;
4. opportunities for a break;
5. practical help;
6. someone to talk to about their own emotional needs;
7. information about benefits and services, and about the conditions of the person they care for;
8. an income which covers the costs of caring;
9. opportunities to explore alternatives to family care;
10. services designed through consultation with carers.

What this list says, in effect, is that carers do a valuable job on a shared, not a contractual basis; they ask the rest of society to recognise their needs, rather than demand a series of rights. This seems to be in tune with the nature of caring – family members respond to each other's needs in a flexible, individual and personal way, rather than buying and selling each other's services, or claiming rights from each other. But it has important implications for the relationship between carers and the people who provide state services, and between carers and other members of their families. Ultimately, as we shall see, it has important implications for the nature of our membership of society.

6. Citizenship

It is time to return to the topic of how all the people who make up a society relate to each other. So far we have looked at contracting and sharing as two major ways in which people cooperate to get things done. But we have also mentioned briefly the question of how we understand the part played by the state in organising society as a whole, and in providing certain services that individuals could not otherwise organise for themselves.

Here we have to recognise some very weighty and contentious issues. It is not just politicians who disagree about the fairest and most effective role for the state in these matters – economists, philosophers and experts on social policy also disagree fundamentally about it. And carers are really in the thick of the conflict, sometimes as protagonists, but more often caught in the crossfire. This is partly because community care has become a hotly debated political issue, and the pace of change in this sphere of policy has accelerated. But it is mainly because the issues we were considering in the last chapter – about rights and needs – are at the heart of disagreements over the proper role of state services.

It is argued that people in a prosperous, modern society can meet their own needs best by having the maximum choice over how to use their resources. So they should be left to organise their own lives as much as possible, in terms of how they decide to spend their money and whom they choose to share their lives with. But this freedom also entails responsibility. People have to stand by their choices, and look after themselves and each other in the marketplace and in the family. They have a moral duty to try to be self-sufficient, which includes a duty to care for members of their family who cannot cope without their assistance.

This view takes a restrictive attitude towards state services. It recognises that the state may have a part to play in meeting certain basic needs – for education and health, for example – but insists on getting value for money from these, much as in the marketplace. It also accepts that some individuals and families cannot be self-sufficient and independent, no matter how hard they try. For these it allows state services to be provided for needs that others would meet either by buying commercial services or through unpaid care. But it insists that officials must test whether people who ask for these services are in 'genuine need' so that they can be properly 'targeted'.

But it could be argued that this way of doing things leads to unfairness. Because of the very different rewards paid to various skills and abilities, some individuals are able to get large resources and some hardly any. There is, therefore, unfairness between rich and poor. Because of the different roles played by men and women in families, and because women often have low-paid jobs, responsibilities for housework and care are not equally shared and fall mainly on women. This is particularly unfair when there is a member of the family who needs full-time care and a woman has no choice about taking on the caring role.

This view is very critical of the attitude towards state services. It points out that rich people are able to buy private services to supplement or replace state ones; they can, for example, jump queues for health care or send their children to private schools. It argues that selective 'targeted' services which go only to poor or disturbed people carry stigma, are often avoided, and have the effect of dividing off these groups from the rest of society. It puts the case for more universal and generous state services which are economically valued and achieve social solidarity and fairness for all.

It is difficult to evaluate these two views objectively because they are closely aligned with the positions taken by the rival political parties in Britain. However, it appears at first sight that there are elements of both views in the account of caring which was given in the earlier chapters. On the one hand, carers see themselves as usually responsible for the person they care for and as trying to use their family resources to meet that person's need for care. This seems to reflect the first side of the argument. On the other hand, carers feel disadvantaged and undervalued, in relation to the economy (because they are often unable to do paid work they suffer financially), and in relation to those who do not have caring responsibilities. Carers, therefore, look to state services to help correct some of this unfairness, and to meet their needs and those of the person they care for. In these respects, they seem to reflect the second view.

Perhaps the least controversial way of stating an acceptable moral starting point for the discussion of these issues would be that both carers and the people they care for are citizens. By citizenship I mean full membership of society, with all the benefits and responsibilities of membership, opportunities to make contributions to the life of the community, and to have the worth of one's contributions properly recognised. In the past, neither carers nor people with handicaps have been treated as full citizens; both have been put in roles that excluded them from large parts of the life of wider society. Both have suffered from having their actual contributions undervalued, and their potential contributions unnecessarily blocked. So the aim of state policies and services should be to enable them to become full citizens.

In a society like Britain, part of this citizenship will indeed take the form of having the freedom and choice to plan their own lives, make their own decisions, have their own possessions, and take responsibility for their own actions. But another part will be the chance to share in the life of the whole community, rather than confine themselves to the private world of their household. In this sense, citizenship is about membership as well as about freedom, and carers and the people they look after will need state services which include them as members of society, by enabling and encouraging their participation in every aspect of communal life.

The rest of this paper is an exploration of how this can best be done. It assumes that the state wants to give its citizens the freedom to choose their own lifestyles and to allow them to share in common membership as equals. It looks at the long-term issues for carers and those they care for from this perspective and tries to think about the policy issues across a range of services.

Some of this will necessarily be speculative. *A New Deal for Carers* is a more immediate guide to policies and practices which can be implemented now, within the existing framework of services. This paper takes a longer and broader perspective, and asks questions about the directions in which policy is heading.

7. Carers as citizens

The framework I have suggested for considering the future of caring is a rather all encompassing one. To say that all citizens should be treated as of equal value, and have equal opportunities to participate in society, is to raise fundamental questions about all relationships in every sphere. For example, it raises the questions of whether rich people and poor people enjoy the same status of citizenship and, even more strongly, whether white people and black people are treated equally. But for the purposes of this paper the main focus will be on the value and opportunities given to people who do unpaid work compared with those who do paid work.

The ten needs identified in *A New Deal for Carers* are all for support for caring from state services. It is a particular sort of support which is required, given in a particular way, which will be discussed in later chapters. But the needs for income, practical help, breaks and alternatives all imply that the state gives resources to carers and the people they care for to improve their range of choices over how to live their lives and to allow them to play a fuller part in the community. The aim of this support would be to give a fairer deal to carers and those they care for and to improve their status as citizens.

It is easy to endorse all these changes as long-overdue improvements. For far too long, carers have been almost invisible – taken for granted by those who provide services, or patronised, or (worst of all) treated as 'part of the problem'. Carers have made sacrifices of money, energy and time, and have been left unsupported, right up to the point where their own health collapsed and they themselves needed care. Those they cared for have been seen as low priority compared with others who needed less help but who lived alone or in residential care; and they suffered from lack of planning, which meant their needs were only attended to in a crisis and then often inappropriately.

So immediate action is needed on all the ten points. *A New Deal for Carers* indicates changes in policy and practice which local and health authorities can implement straight away, which do not require enormous extra resources, and which would greatly improve the quality of life of carers and those they care for. All these measures could be taken simultaneously; indeed, some of them have been acted on in many areas, and the book provides a checklist for service providers to see which aspects they are already working on, and which need more attention.

But in the longer run these measures will need to be assessed, because they may prove to contain some contradictory tendencies. It is important that the view of carers as citizens which they promote is consistent and coherent, and does not shift the situation from one set of tensions and problems to another. To be fairer and give a better long-term status to caring, the changes must reflect principles which can be developed without damaging internal contradictions.

This means that the directions in which change is to take place must be clearly spelt out, and not left implicit and vague. For example, it should be clear whether the aim of policies and practices is to encourage people to become full-time carers, or to encourage them to share care so that no one person carries all the responsibilities of the role. While nothing should prevent a person from being a full-time carer if he or she wants to, there ought to be a clear direction of policy over whether the way benefits and services are provided is intended to encourage people to become and stay full-time carers, or whether it is to make the sharing of the carer's role more possible than it is at present.

This is a key area. As we have seen, certain family members, most of whom are women, are lined up for the role of carer by the 'rules' of family relationships. Once they take this role (often feeling that they have no choice about it), they then have no option but to continue as full-time carers until either their health breaks down or the person cared for dies. Even with much better support than exists at present, this system of 'choosing' the carer, and making the role an open-ended one, has very important consequences for fairness. It means that the measures taken to try to achieve greater fairness all take the form of improving the income and services available for carers, without regard for the effect this has on how responsibilities are divided up between carers and others.

There is a potential paradox in this. If benefits and services are concentrated on full-time carers at the expense of part-time carers (for instance, by making them available only to those who do more than a set number of hours of caring), then this will tend to increase the numbers of full-time carers and reduce the numbers of part-time carers. So the structure of state benefits and services will actually promote full-time caring at the expense of sharing the carer's role between members of the family. This may have wider implications for the role of women in society and for fairness between men and women.

In the next two chapters I discuss recent trends in policy in state benefits and services, and look at their long-term implications. I shall argue that carers' organisations, and those who campaign for greater fairness and equal citizenship for people who need care, should decide between two different sets of principles for their long-term needs. These two strategies will give very different results and produce different patterns of care for the next century. They will have important effects on the kinds of citizens that carers of the future will be.

8. Regulating caring

In Britain, North America, Western Europe and Australasia there has been a strong policy thrust towards community care. State policies in countries with contrasting political traditions, from the enterprise culture of individualism in the United States to the collectivist socialism of the Scandinavian countries, have promoted the reduction in institutional care and the closure of large, remote and impersonal hospitals and asylums. This has focused attention on unpaid caring, which had previously been largely ignored by policy-makers and service-providers, and made it the object of research, debate and changing practice. In this sense, carers' issues have become political issues and reached the forefront of the dialogue between politicians and professionals in the social services.

Unpaid care has, therefore, come to be seen as a resource and as a kind of labour. In this sense it is being revalued, but in a particular way. It is coming to be seen as a potentially more efficient way of caring for people with handicaps than the notoriously expensive systems of institutional care. Economists and social science researchers are conducting studies which compare the costs of residential and family care, and working out how much support can be given to unpaid carers, at what expense, which will enable them to care for more handicapped people than they have previously been able to manage.[6]

In this sense, the boundaries between paid and unpaid work are becoming more blurred. Instead of being a role purely related to kinship and the bonds of affection and duty between family members, the carer is becoming the focus of official policy. Instead of being entirely private, isolated and invisible, caring is becoming more public and scrutinised.

Researchers are even comparing the productivity of paid and unpaid carers – what tasks each can do in what time and what handicaps they can handle. They are using the language of work study, cost analysis and investment strategy where previously there were only emotional ties and sharing.

This suggests that one way in which carers' work could be given value is through the state's recognition that it is an efficient and effective way of enabling people who need care to live in the community. Indeed, something like this is happening already and both sides – policy-makers and carers' organisations – seem to be recognising and encouraging it. In this way the role of carer gets more attention and is seen as deserving public acknowledgement and public support. If this work is seen as socially productive, then it should receive resources (investment) to improve its productivity, and service providers should support and enhance it through their activities.

This implies that what carers get from the state is in exchange for what they do.[7] It is not pay for their work, but resources received because of their role. It includes specific allowances for carers (like the invalid care allowance in Britain) which are tied to conditions about the number of hours of caring done, whether paid work has been given up, earning only a very small sum outside the carer's role, as well as to conditions about the severity of the disability of the person cared for. It also includes breaks (respite care and time out), practical support, education and training for caring tasks (in Norway carers are allowed 'leave' to train for caring). Finally, in the Nordic countries there is an increasing trend for it to include provision of resources for parental work, not only maternity and paternity leave but also, in Finland, a choice for parents of children between one and four years of *either* free crêche facilities *or* a grant for the work they do in recognition of unpaid child care service.

In other words, one way of looking at all the changes that have been coming about in a piecemeal way in many different countries is that community care has led to a new relationship between the state and carers, in which something approaching rights to resources are being established. Caring is not paid, but it is not quite like traditional unpaid caring either. What the state gives carers is not so much related to their needs as to their work role, so that caring occupies a position somewhere between paid work and what ablebodied adult partners do for each other in a relationship. Dependence is thus managed by the state through the family, with the carer's role supported and resourced by the state's services.

But it is important to emphasise that this new role is also regulated by the state. Benefits and services are not unconditional: they are given under rather strict rules. Carers are only entitled to resources if they fulfil the state's requirements, in terms of how much care they give and how they do it. Carers carry out their task under the supervision of state officials who are expert in the needs of those they care for and who can monitor their performance and advise them on how to improve it. If they do not approve, they can withhold resources.

This development should perhaps be seen in the context of changes in the structure of paid work. This too is shifting away from large institutional structures (the giant firms of the 1950s and 1960s) towards smaller units, greater flexibility, more self-employment and more home-based work. Employers are less anxious to organise workers into large factories and offices, and more willing to recognise the advantages of subcontracting work to people who do tasks on their own premises and at their own pace. In all these respects, new structures of work are arising, and caring can take its place in a continuum stretching from formal full-time employment through self-employment, small family businesses, home-based flexible working, to voluntary work. But caring would no longer be a private arrangement between kin; it would be a form of regulated work, officially recognised, rewarded and supported by the state.

The change should also be seen as part of a new set of arrangements which include the growth of commercial care, and especially an increase in the number of small private residential homes, run on a 'family' basis and financed mainly out of the state benefits of residents. But the new white paper indicates a move towards greater official control over who gets these benefits, and over standards of care. So the state is more involved in paying for, monitoring and regulating commercial care and family care, more families are now caring for profit in this sector, and carers are receiving more state recognition, reward and resources.

In all these respects, community care policies fit in with changes in employment and economic structures and reflect a more varied and flexible continuum between paid and unpaid work. But how does this affect the citizenship of carers and those they care for, and will it lead to greater fairness between them and their fellow citizens in the long run?

9. Are the conditions fair?

We set two tests of fairness over citizenship in Chapter 7: do carers and the ones they care for have the freedom to choose from the same range of lifestyles as other citizens, and do they have the resources and opportunities to contribute to their communities in ways they value and are valued by others?

The measures discussed in the last chapter certainly do something to combat unfairness: they give carers resources which they can use to develop their own lifestyles from the range available in our society; they recognise the work done by carers in a way which gives it a value, similar to but not exactly the same as paid work; and some of them (for example, the provision of breaks and practical help) give carers some opportunities to participate in other activities in their communities.

However, I am going to argue that in the long run the conditions attached to these resources, this system of valuing and these opportunities are likely to prove unfairly limiting. This is because, in combination with the existing patterns of employment in paid work, they will tend to trap women in the role of full-time carer, which will still be a disadvantaged role and continue to deny them many of the opportunities enjoyed by non-carers.

We have to remember that the starting point for all these measures is that most of the paid work done by women is differently organised and worse paid than work done by men. Female employment is concentrated in certain occupations (clerical, hotel and catering, retail and social services) and almost half of married women's jobs are part-time. In Britain, women's hourly pay is about two-thirds that of men on average; in the Nordic countries it is almost equal, but even more women work part-time. The result is that most households depend on women's earnings to improve their standard of living but rely on men's for the bulk of their income. This means that when a need for unpaid caring arises, both the 'rules' of kinship and the economics of paid employment point to women as the ones for the role of carer (unless the need is for the care of a wife and the husband is retired).

The conditions attached to the new systems of rewarded and regulated caring do nothing to change this situation; they tend to reinforce the custom of 'selecting' a full-time carer rather than sharing the role between two or more family members. This is because, as we have already noted, the rewards (money, breaks, practical help) are offered to a person who can be identified as a carer because of the amount of work she does. This is most obvious in the case of the invalid care allowance, with its stipulated number of hours of care (35) to be done by one person.

So these arrangements tend to consolidate rather than challenge the division of labour in which women are regarded as the 'natural' carers and men do little to share the responsibilities of caring. It gives an official seal of approval to the customary system by setting up the role of full-time carer almost as a post approved by the state, supervised, rewarded and, ultimately, perhaps disciplined by the state's services. The benefits and support offered by the state are conditional in a way which traps women in this role.

This happens in a way which is a bit like the 'unemployment trap' which affects people claiming unemployment benefit. If carers receive benefits and services which are conditional on full-time care work in their own homes, the costs of doing any paid work become exorbitant. To get a paid job, carers have to lose their benefit *and* pay their travel costs to work. This is also what happens to single parents in the social security system: their child care, travel costs and their benefits have to be covered by their wages, and many cannot earn enough to achieve this, especially when they first start back to work. This explains why so many single parents are out of the labour market, even though they would like to do some paid work, and it would be good for their health, morale and status in the community. It is also what happens to other groups of unemployed people and their spouses, and explains why pockets of unemployment persist even when there are large numbers of job vacancies. The system of rewarding carers being developed is in danger of creating a 'household trap' much like the 'unemployment trap' which ensnares a growing number of women.

So we have identified two major and one minor possible sources of unfairness in the developing system for valuing carers. The major sources are: that the role of carer would become a full-time one for women and would tend not to be taken or shared by men, other than retired men, because of the terms and conditions surrounding it; and that it creates a 'household trap' for carers which has the effect of excluding them from paid employment. The minor source is that, although the role would be rewarded rather than paid (and hence carers would have a status somewhere between that of claimant and that of worker), it would be under the supervision, and to some extent control, of state officials and would, therefore, become something done on behalf of the state which would further reduce carers' autonomy.

But there are two other ways in which this system could prove unfair, not to full-time carers but to others. First, it could be unfair to people who need care. If benefits and services are given as rewards to full-time carers and not to part-time, it means that people who need care have to make a very all-or-nothing choice. Either they live with a full-time carer who qualifies for these rewards or they rely on paid care; and for many the amount of help they need means that the only alternative is residential care. But these choices are more restrictive than the ones other citizens have. A fairer system might give people who need care the chance to combine part-time unpaid care with part-time paid care, or to join with others who need care in a kind of cooperative living unit which employs its own paid carers. This would require a different system for rewarding carers, one which allowed a wider range of arrangements and choices for both parties.

Second, in giving rewards only to full-time carers, it creates a new kind of unfairness. It is not just that the system tends to trap people (usually women) in a full-time caring role; it also penalises those who share care or give care to others who need less than full-time assistance by not rewarding them. And it selects certain forms of care for reward while leaving others unrewarded. For example, the British system now rewards full-time care of people who qualify for attendance allowance but not the care of able-bodied children (even where a parent has several young children). The Nordic system rewards parental care of young children but not voluntary service given to the community or care given by friends. All this suggests that it is worth investigating whether another approach might give fairer outcomes and incentives. This will be the subject of the next chapter.

10. The basic income approach

It is becoming clear from the discussion so far that issues of fairness over valuing carers raise wide and complex problems about the relationship between paid and unpaid work. Piecemeal solutions probably create as many new unfairnesses as they remedy old ones, because the central difficulty – the existence of two entirely different kinds of work, organised around different relationships, roles and reciprocities – is not directly addressed.

The approach discussed in the last two chapters tries to tackle that difficulty by creating a new kind of rewarded care work, with new benefits and services for those who do it full-time. But another approach is to recognise that care is part of a much larger system of unpaid work which goes on in a wide range of relationships based on sharing – friendship networks, clubs, voluntary organisations, local politics, community groups, and so on, as well as families. There are good reasons for wanting to value all these unpaid activities and to encourage all citizens to take part in them.

This goes back to the idea that citizenship means membership of a community, and the way this is expressed is in sharing in forms of life together. The public life we live as neighbours, as users of local facilities, as participants in community affairs and the political life of our society, is an important element in the quality of our own lives and an essential element in the quality of social relations. In this sense, the aim of a state which is committed to fairness should be to encourage sharing on a community-wide basis not just in families. And we would not imagine that the way to do this would be to create a special role of full-time active citizen, rewarded by special benefits and services. Rather it would be to make sure that all have opportunities and incentives to participate in communal life.[8]

We can see this most clearly by looking at the example of people who need care. In the past, their lives in institutions excluded them from sharing in the life of the wider community. Hospitals and asylums were separate communities, usually in remote rural places, in which they often led routine and depersonalised existences. Community care seeks to give them the opportunity to lead 'an ordinary life' (to borrow the title of a King's Fund paper on people with learning difficulties). This does not just mean living in a house with a family, it also means having access to recreation, leisure, sport, culture, education, training, employment, and to the public life of a citizen (including representation on bodies which plan their services). All these same considerations should also apply to carers.

So we are looking for an approach which allows unpaid care and carers a share in the life of families, friendship networks, associations and communities. This means that it should be valued as part of those ways of doing things, and not as part of something else (a state system of car, for instance), and that the people involved (carers and cared for) should be treated as equal citizens rather than as being in a special category of their own. And it cannot be separated from issues about how we treat all the other people in our society who do no paid work – retired people, unemployed people, sick people, single parents and 'housewives' – who form the majority of citizens in our society. They deserve to be valued too, and whatever system is adopted to recognise carers' needs and reward their efforts must be consistent with equal respect for the citizenship of those they care for.

I have already argued that the present system of social security benefits traps people of working age in roles which exclude them from aspects of the life of the community. I used the examples of the 'unemployment trap' for people with low earning power and high travel to work costs, and the 'household trap' for single parents and increasingly also for carers. There is also something which might be described as the 'disability trap' under which people qualify for disability benefits at a slightly more generous rate than unemployment benefits as long as they declare themselves unfit for any form of paid work. Many people who would like to do part-time work are actively discouraged from registering as unemployed by a combination of these rules and pressure from the benefit authorites. And there is even something that might be called an 'ignorance trap' – claimants of income support are not allowed to take full-time educational courses at a non-advanced level.

There is also the 'poverty trap', which is slightly different. People in low-paid work who get means-tested benefits (family credit and housing benefit, for example) lose these as their earnings rise and also face income tax in the same range of earnings; hence they lose 90p or more in the pound on their extra earnings. If they also have additional travel or child care costs, they have no incentives to try to increase their earnings. This has the effect of excluding a large group from any opportunities to save (which would lead to further benefits loss) and, therefore, from access to owner-occupied housing, pensions, share ownership, and other valued aspects of life in our society.

Pensioners are in a rather different position. Until recently, a condition for receiving a retirement pension between the ages of 65 and 70 (for men) and 60–65 (for women) was that the claimant was retired (that is, did not hold the sort of job that was 'inconsistent with retirement') and earned less than a certain amount (around £70 per week) for any 'retirement job' he or she performed. But in 1989 this condition was abolished; pensions are now unconditional and those who receive them are able to be included in every aspect of the life of the community without penalty. Of course, the basic state pension and the state earnings related pension are tied to contributions made by people in paid work, so they are both work-related. Income support for people of retirement age also incorporates a 'pensioners' poverty trap' under which pensioners lose benefits if they have savings or occupational pensions. Finally, the system of child benefits (although the rates are very low and their real value is being allowed to fall) reflects the same principle as old age pensions – the benefit is unconditional and goes to the parents of all children, whatever their income or employment status. Receiving child benefit is therefore not conditional on doing a certain number of hours of parenting, or not having a paid job.

This is the principle which I believe should apply to all citizens and to the basic income allocated to every member of society. Instead of having tax allowances for people in paid work (the value of which for many high earners is greater than the amount we give to unemployed people or single parents) and benefits which create traps and exclusions for those who receive them, we should have a single system which guarantees a tax-free sum to each individual, irrespective of their marital status or whether they are in paid work or not. This then uses exactly the same mechanism for the state to show that it values the contributions of all its citizens – a guaranteed basic income – rather than one which gives opportunities and incentives to one group, and traps and stigma to another.

This is a controversial proposal (though one which is attracting increasing interest in Britain and elsewhere in Europe). In the next chapter I shall explain and try to justify it.

11. The costs of care

The idea behind the basic income principle is that all citizens should have their basic needs for income met by the state before they enter the world of paid work (the labour market), or the world of unpaid work (the family and community). This is a rather revolutionary idea; up to now, although some needs were met in this way (health, education, defence, environmental safety), income was provided either from earnings or from state benefits paid to those outside the labour market (with the exceptions mentioned in the last chapter).

A new principle as radical as this could not be introduced overnight. It would have to be gradually phased in while income tax allowances and social security benefits were being phased out. At first it would take the form of a small partial basic income for all citizens, which would be gradually increased until as many as possible of the old allowances and benefits had been eliminated.

One obvious problem for such a system is that people do not have the same basic living costs. For instance, housing costs vary enormously, from one part of the country to another and according to size of household. Another glaring example concerns the extra costs of living associated with disability. People with disability have higher expenses for items like heating, clothing, adaptations, mobility and food.

The aim of the scheme would be to treat all citizens fairly by making sure that the sum they received brought them all up to the same 'starting line' so that they all had the same opportunities and incentives for participation in the paid and unpaid aspects of social relations. It would, therefore, be fair to give more to people with disabilities to meet their extra living costs. They would receive a basic income supplement to take account of these.

But this does not take account of the care that some people need and others do not. It does not differentiate between people who can look after themselves and those who cannot, or take account of the lost opportunities for paid or unpaid activities which are associated with the need for care. And nor does it take account of the fact that some people are too handicapped to do paid work, or have greatly reduced earning capacity.

In seeking a way to deal fairly with these issues, the scheme must try to create the greatest number of possible options for the person who needs care, and for the people who provide it. It must aim to allow the same person to receive a number of different kinds of care which are most appropriate to a balanced life as a member of the community. And it must aim to allow care to be shared between a number of family members, or friends, or a cooperative of carers, if this gives them the best opportunities for living a full life and doing other things.

One advantage of the basic income approach is that, unlike existing forms of social security benefits (contributory or means-tested) it does not discourage part-time work, but treats it exactly the same as full-time work. This encourages job sharing and the sharing of unpaid work and care. So the existence of a basic income for every individual is fairer than having a benefit specifically for full-time carers because it does not trap people in that role. But it is unfair on its own, because people who have no caring responsibilities get exactly the same as people who give full-time unpaid care. Hence there must be a mechanism for assisting people who need care to meet its costs, which does not limit their choice over what form this care takes and which allows them to combine various forms of care according to their needs and preferences. In the long run, it is hard to see how this can be achieved without paying people who need care an allowance which varies according to the amount of help or supervision they need, and allowing this to be used as they choose. If they opt for paid care, then this would all go towards the costs of whatever mixture of residential or day or domiciliary care they elect to have. If they opt for unpaid care, then this can be shared between the carers who provide it, as part of the resources of the family, friendship group or cooperative. Most people would probably choose a mixture of paid and unpaid care (for example, living at home, receiving day care and occasional residential respite care, but with additional practical help and relief for the family carer). Hence the allowance would be divided up between the costs of the paid care and the amount shared within the household.

There are important differences between this proposal and the system for individual care plans, drawn up by a 'case manager' and paid for out of local budgets, described in the white paper, *Caring for People*. The basic income approach puts money, and hence choice, in the hands of those who need care. The white paper gives case managers the budget and, therefore, the power. In the last resort, they make the decisions about how resources are to be allocated.

In the white paper's proposals, the funding for this budget would be derived mainly from the present 'care element' in income support payments to people who enter residential care. But whereas at present anyone who qualifies for this after means-testing has the chance of entering residential care, in the future only those assessed as needing residential care will receive the 'care element' through the local authority. Choice, therefore, will diminish not increase. Above all, the new system will take no account of unpaid care. The approach I suggest would, however, allow part of the care allowance to be shared with the carer rather than spent on paid care.

The advantage of this approach could be that it would not attach funding for care costs to any particular kind of care, but could give those who need care the maximum control over what combinations to choose. Clearly in the case of people with severe mental illnesses or handicaps there would need to be a process of guidance and counselling from care planners, but the power and resources would lie with carer and cared for rather than with state officials. From the point of view of equal citizenship this seems the fairest arrangement.

We are obviously a long way from this system at present, but because of the changes in community care which are happening at present, it seems important to identify the directions in which policy should be moving. People who need care, with private savings, private pensions, or resources that they can realise (such as houses), are in a position to make arrangements very much in the way that I have just described. Some opt for residential care; some pay a housekeeper or nurse to live with them; some simply share their lives with a family carer; but most have some mixture of these. Nothing in the white paper's recommendations would limit the choices of these better-off citizens. But there is a strong emphasis in the white paper on preventing poorer people (who qualify for income support) from entering residential care if they do not (in the opinion of case managers) 'need' it. There is also much reliance on unpaid carers as the mainstay of community care yet they are to have little real power in decisions about care plans. A fairer system of allowances related to costs of care would reduce this imbalance.

However, before a basic income approach comes onto the political agenda (let alone implemented), we need to identify principles in relation to the provision of services to carers which are consistent with the ideas of fairness developed in this paper. I will turn to this in the next chapter.

12. Negotiation and partnership

In the scheme outlined in the last two chapters, each form of paid care (including state services) would have a price. The allowance for care costs would cover this price and any part of the allowance which was not spent on paid care would be shared with unpaid carers.

But, at present, most state services do not have a price. They are mostly free at the point of delivery to those who receive them, and paid for out of rates and taxes. They are allocated by service providers – social workers, nurses, occupational therapists, doctors, home care organisers, and so on – after various forms of professional assessment. The assumption behind this system is that resources like practical assistance, adaptations, transport, sitting services, day care, respite care and residential care are finite and limited, and that these professionals are able to be the best, most impartial assessors of need, and can allocate them in the fairest way.

Carers have been justifiably critical of this allocation process for a number of reasons:

1. Services have tended to be organised and developed in ways which suit the service-givers rather than the service-receivers. Clinical services are concentrated in hospitals which are often inaccessible. Domiciliary services are organised on a nine-to-five weekdays only basis, when practical support and assistance is needed most in the early mornings, in the evenings, and at weekends.

2. Services have reflected service-givers' assumptions which have not been checked against carers needs and requirements. For example, black and ethnic minority carers have seldom been consulted about their preferences and have often found the services offered unacceptable – for instance, meals which are unpalatable or insensitive to religious rules. Service-providers have made assumptions about the needs of people living alone having higher priority than those of people living with carers, and about male carers needing more assistance and support than

female carers. They have passed judgment on carers without trying to understand their values and motives.

3. Carers are not consulted about the quality of services offered or the details of the conditions under which those they care for are provided for (for instance in day or respite care). Again, black and ethnic minority carers' views are not canvassed over the kind of care they would find acceptable, so many do not take up services they see as being given by white people to white people. Carers who desperately need breaks do not ask for respite care if they see what is on offer as of low quality, or if they cannot ensure that the person they care for has the personal consideration and sensitivity which is due to them.

4. Carers are often allocated 'standard rations' of services (so many hours of home help a week; so many days of respite care a year). But these sometimes take no account of the variation in their needs, and particularly of times of crisis. Carers are often forced to give up caring because of the rigidity of allocation systems which cannot respond to extra need in an emergency, by giving additional help when it is most needed.

5. Services are frequently offered on a take-it-or-leave-it basis, without proper discussion. The emotional significance of asking for and receiving services is not properly considered, and nor are alternative arrangements fully explored. The carer's expectations of him or herself are not checked out and the balance between the needs of carer and cared for evaluated. In other words, allocation is made on a pseudo-scientific basis without exploring the emotional and ethical context of caring, and without involving the carer in the process and the choices to be made.

These criticisms have been forcefully made through carers' organisations, and many of the messages have been heard and taken seriously by policy-makers, managers and service providers. Among the new trends in community care services already discernible and acknowledged by the white paper are the following:

1. More flexible organisation of services, to include the capacity to give 24-hour and 7-day-a-week services, and to give extra domiciliary services at times when they are most needed. This

is often achieved by having special employment contracts for community care assistants or by employing 'bank' nurses or home helps. Services are being made more accessible to carers.

2. Greater sensitivity to carers' values and needs, including sensitivity to black and ethnic minority carers' views. This includes anti-racist and anti-sexist training for service providers, and more training in the values of caring (including training by carers).

3. Greater consultation with carers about acceptable standards of services and the special needs of those they care for. This includes awareness of the needs of black people in predominantly white environments, employment of black staff, and provision of services acceptable to black carers. It also includes involvement of carers in planning and in the details of running services.

4. More willingness and ability by service providers to formulate and review individual care arrangements and plans, to tailor them to the specific needs of the carer and the person cared for, and to give extra help when it is required. More responsiveness by service providers to crises and an approach which is more sensitive to the vulnerability of carers.

5. More emotional support for carers and recognition of the emotional stress of caring. Service providers are becoming more conscious of the need to explore alternatives, offer choices, and share information and expertise with carers. Hence assessment is becoming less of a rationing process and more of an investigation of individual needs; it recognises possible conflicts between carers' needs and those of the person cared for, and that the service provider can mediate between these.

These approaches require a fundamental change in the attitudes, practices and organisation of services. It is a shift from assuming that professionals know best, and are the guardians of the true interests of those who need care, towards a recognition of the value of carers and respect for what they do. Instead of seeing state services as a superior alternative to unpaid care, it sees carers as equal partners, who should be included, consulted, represented, listened to and supported. It also stops treating state services as belonging to service providers, and shares them with carers by making them more readily available and approachable.

But it should be emphasised that the new approach is not one of defining carers' entitlements to standard amounts of services. The weakness of trying to reach definitions of such rights would be that they would become standardised rations of units of services. Instead, it recognises something which might be called 'negotiation rights' in treating carers as equal partners with professionals. It accepts that carers, as valued people, are entitled to a personal, detailed and individualised negotiation about the appropriate quality and quantity of services that are due to them. In other words, it tries to start from the attitude of equality of respect that is characteristic of a relationship based on fairness, and then uses the methods of a system of sharing – negotiations – as the means of assessing and meeting needs and defining mutual responsibilities.

All this is still very new, and in the early stages of being developed in community care services. Progress in some areas has been much faster than in others. Because the changes are essentially ones of attitude, as well as organisation, they are fragile and depend on personal experiences and relationships. In the next chapter, I shall explore some of the factors which could consolidate or threaten them.

13. Professional power and carers' needs

State services were originally developed as alternatives to family care and paid (commercial) care which were given to people who were too destitute, disabled, desperate or disturbed to care for themselves, or whose families were lost or unable to care for them.

These original services (based in the Poor Law) caused a great deal of stigma and shame, and were feared by more respectable and self-reliant citizens who saved money so they would be able to afford to pay for care should they need it.

The post-war welfare state was intended to change this by making services available to all citizens on the basis of need. But, as we saw in the last chapter, need was defined by professionals who controlled access to these services and rationed allocations. It was focused on the medical condition of the person needing care in the health service, and on assessment for specific services in the personal social services. Because carers recognised other needs, and other forms of support they themselves required, those who could afford it still relied on paying for services of many kinds, to meet gaps in the state's provision or because state services were insensitive to their needs.

Community care policies are reducing the availability of one range of state services (hospitals and residential care) at a time when resources for all kinds of state services are being strictly limited by central government. In the face of economic constraints, there is inevitably an ethos of rationing in the management of organisational change, so the new approaches described in the last chapter are taking place under severe resource constraints. Unfortunately, there is something of an assumption in some government circles that community care is a cheaper option; and that it represents an opportunity to force families to take responsibility for care while allowing the state to reduce its provision.

This would clearly be a hopeless basis for trying to implement the fundamental changes discussed in the last chapter. If the overall availability of services is inadequate, service providers will not be able to allow carers to express their needs freely, or to treat them as partners and equals. They will be driven back into a defensive, rationing and restrictive position, and will tend to offer services only to crisis situations, when care is in danger of breaking down.

The two sources of official and professional power over people who need care and their carers are control over resources and the discretion that service providers have in allocating them. An adequate allowance for the costs of care would give those who need services a countervailing power in respect of the first source of power. An attitude of equal respect and partnership would make professional discretion acceptable. The power of experts should rest on their knowledge and skills, not their exclusive right to make decisions about the lives of others. Professionals need to exercise judgment and to be able to distinguish creatively between the needs of those who consult them. But they should use this expertise in a way which empowers service users, improves their understanding and control over their problems and shares responsibility and choice.

I have argued that the best way to provide long-term fairness and free choice over unpaid caring is to give benefits to those who need care. The corollary of this is that all services would have a price, including those provided by the public sector. The role of professionals and experts would then become an advising one, offering consultancy and counselling rather than assessment and regulation. But this change would take many years to implement. In the meantime, the white paper, while mentioning many of the innovations in attitudes and practices, especially in relation to carers' needs, adopts a different approach to the problem of decision making. It sees freedom and choice for carers and those in need of care mainly in terms of budget-holders being offered incentives to spend public money in the commercial, voluntary and cooperative sectors. Its main aim is to get 'value for money' – money which is still treated as belonging to the state, to be administered as efficiently as possible on behalf of taxpayers.

But if budgets are strictly limited, and all aspects of budget control are in the hands of a single authority, carers could find themselves with less rather than more choice. The danger is that central government sees money for community care as a kind of poor relief, to be targeted on those in 'genuine need' but withheld from people who should be able to provide for themselves out of their own resources. This takes services back to the spirit of the Poor Laws, and restores the ethos of rationing and control with the associations of stigma and shame. The white paper indicates that the government will issue a detailed code of guidance for local authorities on assessment.[9] The local authority agency administering the budget could be large, bureaucratic and cumbersome if it has to undertake financial assessments – in contrast with the more flexible, less hierarchical, less impersonal, small inter-disciplinary teams which have developed in some areas.

In many ways the white paper reflects the ideology and practice I tried to describe in Chapter 8 of a new form of *regulated* caring. New community care policies are constructing new categories of citizens, in new roles and with new rewards. The agency structure and accountability recommended would be ideal for regulating this kind of relationship between the family and the state. It would indeed place a new value on carers, but as full-time, supervised, monitored agents of the state system, isolated from each other and from the rest of society, and required to fit in with the standards laid down by officials. In other words, carers would not have the range of choices and opportunities of other citizens, and nor would those they care for. They would be answerable to the official system for the performance of their role in ways that others doing unpaid work are not. Side by side with this, others – perhaps even their neighbours – would be enabled to provide care for profit in small family businesses, financed out of public funds. None of this would be fair.

14. Conclusions

The discussion in this last chapter indicates that issues about carers and community care cannot be isolated from much broader issues – citizenship and fairness. For good or ill, the questions raised in this paper form part of a range of important decisions facing our society. They must be seen in this context.

Value for carers is part of the problem of how to give value to people who need care, to people who do other unpaid work (in the family or the community), to retired, unemployed and sick people, and to single parents. This in turn is part of the problem about how to achieve fairer and more equal relations between men and women. Giving acceptable services to black and ethnic minority carers and ensuring that they are not discriminated against is part of the wider issue of combating racism in society and that minorities are included as equal citizens. Balancing the power of state officials by real freedom and choice for carers is part of the problem of creating public facilities and services which encourage active citizenship, participation and sharing, rather than restricting options and imposing passivity or constraint.

This paper does not take sides in the argument between those who favour market solutions to these problems and those who favour state solutions. Both marketed and state services can provide acceptable levels of freedom and fairness if the parties to transactions are reasonably equal in terms of the assets they can command and the power they wield. The important thing is that, in a society which has both market and state systems for gaining access to resources and lifestyles, people who give care and people who receive it should not be excluded from either of these systems, and should be able to make the same range of choices as other citizens.

We should not see unpaid care and the sharing that takes place in families as unique. They are part of a much more extensive system of chosen and voluntary relationships in society, in which people organise themselves in small and large groups to get things done, to enjoy themselves, and to improve their quality of life. Indeed, I have argued a case for suggesting that society itself is essentially such a grouping, and that democratic citizenship is one way of making it work for all its members. The value of caring should be seen in this context, as part of a series of relationships that are valuable to us all. Carers are – or should be – also friends, associates, members of clubs, churches and electorates. We should not introduce a scheme for valuing caring which confines it to the home and hearth, isolating both the carer and the person cared for, and turning them and their environments into miniature embodiments of institutional care. They can enrich our wider shared community as fellow citizens.

References

1. Parliament. Caring for people: community care in the next decade and beyond. Cm 849. London, HMSO, 1989: p 5.

2. See 1 above: p 9.

3. Ann Richardson, Judith Unell and Beverly Aston. A new deal for carers. London, King's Fund. 1989.

4. See, for instance, Clare Ungerson. Policy is personal: sex, gender and informal care. London, Tavistock, 1987; *and* Janet Finch. Whose responsibility?: women and the future of family care. In: I Allen, M Wicks, J Finch and D Leat (editors). Informal care tomorrow. London, Policy Studies Institute, 1987.

5. Carol Gilligan. In a different voice. Harvard University Press, 1982.

6. David Challis and Bleddyn Davies. Long-term care for the elderly: the community care scheme. Discussion paper 386. Personal Social Services Research Unit, University of Kent, 1985; *and* K G Wright. The application of cost benefit analysis to the care of elderly people. University of York, 1986.

7. Adalbert Evers. The basic income and the redefinition of work beyond the boundaries of the market. Paper prepared for the IRES seminar on 'New rights of social citizenship'. Rome, 5–7 April, 1989.

8. Bill Jordan. The common good: citizenship, morality and self-interest. Oxford, Blackwell, 1989.

9. See 1 above: p 20.

£4.00

ISBN 1 85551 050 2