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Caring about carers: only half the picture?

Abstract

This article examines the government's Strategy for Carers and considers its significance for people in informal caring relationships. It argues that although it contains important and innovative measures, the impact of these is likely to be limited. In addition there are issues that are overlooked or given insufficient attention. Crucially, the strategy does not address adequately the complex nature of caring relationships nor does it take account of the perspectives of people who receive care. There is a danger, therefore, that the strategy will be divisive. However, the recognition that caring is a widespread activity in which we are all implicated is to be welcomed.

Key words: carer's organizations, caring relationships, innovation, service standards

Introduction

In February 1999 the government published *Caring about Carers: A National Strategy for Carers*. It is introduced as a 'new, substantial policy package' that marks 'a decisive change from what has gone before'. This article examines the strategy in the light of these claims and considers the extent to which it represents a new approach to unpaid caring. According to the government, caring about carers means:

[G]iving them more control over their lives and over the range, nature and timing of services which they need. It will offer real choices about the extent to which they provide care, remain in employment, receive information and are involved in the life of their community. (HM Government, 1999a: 62)

The strategy thus expresses the principles of choice, consumer control,

access to paid work and social inclusion, the hallmarks of the New Labour approach to welfare.

The National Strategy for Carers (launched in June 1998 under the leadership of Paul Boateng, then Minister at the Department of Health) was required to draw together existing government activities that have an impact on carers and to set out strategic aims for the future. In addition, the strategy was expected to take account of the emerging findings of the Royal Commission on Long Term Care and to identify gaps in provision as well as examples of good practice at the local level. There is therefore an integrative function in this strategy, in keeping with ideas on 'joined up government'. The process of consultation and fact-finding over an eight month period included a conference in November 1998.

Caring about Carers is, therefore, not a consultation document but the outcome of a consultative process. Carers' organizations were actively involved in this process and their influence is evident in the range of issues addressed and the strategic response proposed. According to Paul Boateng, the strategy 'gives carers a voice at the heart of Government' (DoH, 1998a), making them visible and validating their contribution. The Carers' National Association has given it a warm welcome and has declared its intent to continue campaigning for its implementation.

A summary of the strategy

The government identifies three elements to the strategy: information, support and care for carers. In addition, there is a chapter on carers and paid employment as well as one on young carers. The following is a brief summary of the main points of the strategy as presented.

Information about carers

The first section provides an outline of current information on carers, drawing on the 1995 General Household Survey. It identifies trends in caring that need to be taken into account in service development, including the ageing of the population, changes in marriage patterns and labour market trends. However, it also acknowledges the difficulty of predicting such trends in future. For example, preventive health strategies may reduce the incidence of strokes or osteoporosis and

therefore reduce levels of demand for care. However, there is an increase in the number of premature babies that survive but they may need long term care. The unpredictability of trends such as these poses a challenge for those who develop services.

The lack of reliable information about caring activities, particularly in relation to young carers and those from minority ethnic groups, is acknowledged and the intention is stated to address this by including a question on caring activities in the 2001 census.

Carers and employment

The strategy document places a high value on unpaid caring. Indeed it contains an acknowledgement that carers should be allowed to give up work altogether if they so wish. However, it also contains a clear indication that paid work is to be encouraged where possible. The chapter on employment discusses how carers can combine paid work with their caring responsibilities or return to employment after their caring responsibilities cease. The strategy is clearly embedded in the government's general principle that paid work is vital to ensuring financial independence and personal wellbeing and preventing social exclusion, as set out in the 'Fairness at Work' White Paper (DfEE, 1998).

A campaign is being organized to persuade employers of the benefits of carer-friendly employment policies. This is assumed to benefit not only carers but also businesses, on the grounds that good people-management is linked with profitability. The business case is that carer-friendly practices reduce the costs associated with staff turnover, sickness and absenteeism, improve morale among employees and promote more flexible working patterns. Awards for family-friendly employment practices are being considered as an incentive to employers. There is in the document a call for greater recognition by support services of employed carers' needs and more flexibility in service provision to take account of work commitments. In addition, the government is said to be looking at ways to facilitate carers' return to work when caring comes to an end, including an extension to the New Deal programme so that those who have not been registered unemployed for the previous two years can qualify for help.

There is a brief section on financial support for working carers. The government is to keep under review benefits for carers, including Invalid Care Allowance, and promises to introduce a tax allowance for working mothers with dependent children and incapacitated

husbands. The most radical financial proposal is to provide a second pension for carers who are not working or who have earnings below the current National Insurance Lower Earnings Limit *and* receive Invalid Care Allowance and care for someone receiving Attendance Allowance or Disability Living Allowance (HMG, 1999a: 35).

Information for carers

The section on information stresses the importance of involving carers in decision-making at two levels. First, carers should be informed and consulted about professional decision-making concerning those they care for. Second, carers' views should be taken into account when planning community care services. Information is seen as a two-way process in which carers' perspectives should be central to service planning and provision and information about services should be provided routinely to individual carers. The government intends to develop its own data bank by collecting information on 'Referrals, Assessments and Packages of Care' and publishing this to enable local authorities to evaluate their own performance against that of others.

The strategy emphasizes carers' rights to information about services, including costs involved. The role of voluntary organizations and government helplines in providing such information is acknowledged. An emphasis is placed on carers' needs for information on health care to improve their understanding of the medical conditions of the person for whom they care and to enable them to carry out a range of relatively complex tasks with greater skill and confidence. Where this raises ethical questions about confidentiality the advice given is that clinicians should generally gain the consent of the person being cared for and should review this regularly. However, in some circumstances (where the safety of the patient or the public is concerned) carers might be given information about the person being cared for without their consent.

Support for carers

The chapter on support for carers picks up and develops the issue of consultation and the involvement of carers in service planning and delivery, referring to a range of provision, including health, social services, housing and transport. There is a strong focus on housing, including recognition of carers' need for information and advice on

housing adaptations and flexibility in housing provision. Resources to fund adaptations are to be made available from the Disabled Facilities Grant funds (administered through both the DETR and local authorities), which will be increased from £60 million in 1998–99 to £75 million in 2001–2. The chapter also outlines action to increase flexibility in housing allocation and to streamline Housing Benefit services. The use of technology as a means of supporting carers is also encouraged. This includes devices that enable disabled people to communicate with others or to move around in their homes as well as devices that monitor and promote the safety of a disabled person.

There is also a specific focus on support for ‘parent carers’ of disabled children. This includes extending the Working Families Tax Credit scheme to parents of disabled children up to the age of 16, whereas previously there was an upper age limit of 12. Strategic planning for disabled children at the local level is included in the ‘Quality Protects’ programme, which should mean that the needs of disabled children are more thoroughly researched and assessed.

Care for carers

The focus in this chapter is on maintaining and promoting the health of carers. The strategy encourages health professionals to consider the health of carers as part of their responsibility. Similarly, the National Priorities Guidance for Health and Social Services (DoH, 1998b) requires GPs, primary care workers and social services staff to identify carers in their area by April 2000, as the first step towards providing them with appropriate services. Two important elements are outlined. The first concerns training and guidance for carers in how to prevent illness and injury that might be brought on by caring activities and the second is the provision of regular breaks from caring. An accompanying document (*A Real Break*) is published alongside the strategy (HMG, 1999b). This provides an outline of good practice for local authorities. New, ring-fenced funding is made available to local authorities to develop a range of services to give carers a break. The government is to put £140 million into this fund over the next three years, to cover English services. No new money was allocated for Scotland, Wales or Northern Ireland. It will be up to the Scottish Parliament and the Wales and Northern Ireland Assemblies to fund services from their own resources. The apparent aim is to make regular breaks from caring a normal part of carers’ experience. Thus, the term

'respite' is replaced by 'breaks' that should be more frequent and short term.

Another important element of the chapter on *Caring for Carers* is the emphasis on provision of services for carers in their own right. According to the strategy, the present system, which limits carers' entitlement to services, 'undervalues their role and needs, and their ability to have a proper say in the kind of provision which best suits them' (HMG, 1999a: 57). Changes in legislation necessary for developing services directly for carers are promised when 'Parliamentary time allows' (HMG, 1999a: 58).

Local care for carers

This section discusses the role of the voluntary sector in supporting carers and its relationship with the statutory sector. Local support for carers is, according to the strategy, best run and managed by the voluntary sector. Three main approaches can be identified. First, local authorities and health authorities should identify local carers' organizations and, where gaps exist, give priority to developing them. Second, carers' organizations should be the main spokespersons for carers in local consultation processes on planning and developing services. Third, carers' organizations should be invited to develop quality assurance schemes for local services for carers to ensure that they conform to accepted standards. The Carers' National Association, The Princess Royal Trust for Carers and Crossroads 'Caring for Carers' are to be responsible for developing the quality assurance scheme.

Young carers

Drawing on research by the Social Services Inspectorate (SSI/DoH, 1995), which identifies the disadvantageous effects on young people of caring, the strategy urges social services departments, schools and health professionals to develop a more comprehensive understanding of the needs of young carers and better ways of supporting them. Thus, the needs of young carers should feature in social services plans, personal, social and health education programmes and training schemes for health, social work and teaching professionals. In addition, local authorities are encouraged to develop young carers' schemes in their areas. The proposals for young carers can be seen to mirror those for adult carers in that they attempt to facilitate participation in school

as in work, to develop a more comprehensive data bank, and to promote voluntary and self-help groups that can advise and support.

The strategy in context

The strategy reflects the government's commitment to a reduced emphasis on the state and an increased emphasis on family care. Using a 'third way' approach, it is constructed to present a picture of government intervention that supports but does not take over family care. Moreover, the importance of intervening to support family care is stressed not only for those who give and receive care, but also for employers and business and for society at large. 'Caring forms a vital part of the **fabric and character** of Britain' (HMG, 1999a: 5) (original emphasis). The language of the strategy, including words like 'value', 'pride', 'worth' and 'unsung heroes', illustrates clearly the intention to raise the social status of unpaid care. In many ways, unpaid carers exemplify New Labour's emphasis on duty and responsibility as key elements of citizenship. In the government's view: 'caring should become something that people can **do with pride**' (HMG, 1999a: 6) (original emphasis).

The strategy aims to set the tone for an inclusive approach to meeting the needs of all carers. However, there are a number of specific elements that are out of step with this approach. For example, the proposed second pension for carers is to be paid only to those who meet qualifying conditions related to the number of hours spent caring and the receipt of other benefits. The targeting of benefits and services to those in greatest need contradicts the inclusive tone of its overall philosophy. Indeed, one of the reasons given for the reform of the housing benefit structure is that the existing system was failing to reach those in greatest need. The strategy therefore reinforces the principle of limiting entitlement and access to benefits and services.

The direction of relationships between central and local government under the Labour government can also be seen clearly in the strategy. Local authorities and health authorities are given a mixture of guidance, financial incentives and instructions on developing local services. Throughout the strategy, local carers' organizations are promoted as essential players in service planning, development and delivery while local statutory services are to be more closely monitored and scrutinized. For example, patchy, inconsistent and inadequate

implementation of the 1995 Carers (Recognition and Services) Act is to be addressed through the collection of more information from social services departments via the 'Referrals, Assessments and Packages of Care' data collection system. This will provide central government with more detailed information about local authorities' activities in relation to carers as well as service users. At the same time, the strategy refers to the proposed long term care charter that will provide carers with information about the nationally determined standards of care that they can expect from local authorities and health services as well as procedures for complaints if the statutory agencies fail to meet these. Similarly, the White Paper 'Modernising Social Services' (DoH, 1998c) promotes national standards in eligibility criteria and charging policies to overcome local variations.

The strategy also demonstrates the changing role of the voluntary sector in relation to both central and local government. In some senses carers' organizations may be regarded as the vehicle through which centrally determined strategies are put into operation at the local level, since they are to be involved at every stage from developing strategic plans to assessing service quality as consumers. Local authorities may experience this as an added pressure as they are squeezed between the demands of central government and carers' groups.

Is the strategy really innovative?

One of the innovative measures, identified by the Carers' National Association as 'the most important announcement of the strategy' (CNA, 1999), is the provision of new, ring-fenced funding for regular breaks for carers in England. This recognition of the need for regular breaks as opposed to 'respite', with its connotations of relief from suffering, is important. Local authorities and health authorities will be obliged to demonstrate that they are developing appropriate services for carers to take a break in order to get the money on offer. The questions that remain are whether the new funds will be sufficient to make regular breaks part of normal practice in caring and whether this will make a difference to a wide range of carers or only to those who conform to particular conditions.

Without adequate funds, the good practice guidelines will be of limited value. The Royal Commission on Long Term Care was split over the issue of whether to target resources for respite care at those in

greatest need or to provide it to all carers as a right (Royal Commission on Long Term Care, 1999). The strategy tends to fudge this issue by outlining a range of possible measures that give carers a break but no advice on priorities for allocating the money provided.

The strategy asserts the need for new legislation to enable the provision of services to carers in their own right, since the current legislative framework does not allow this. However, policies and legislation that could be used to promote the health and wellbeing of carers, including the provision of regular breaks, already exist. Clements (1996), for example, points out that there are provisions in the NHS Act 1977 and the Local Government Act 1972 that empower local authorities to provide a wide range of services that would be of benefit to carers. In particular, Schedule 8, para. 2(1) of the 1977 NHS Act could be used to provide services to prevent illness in carers but legislation such as this is not currently used. The explanation for this appears to lie in the over-riding imperative to keep within spending limits and to target service users in greatest need, a policy that has left many carers and those they care for outside the scope of provision (Royal Commission on Long Term Care, 1999).

The effectiveness of training for carers as a means of preventing injury is open to question. Evidence from research on occupational injury in nurses suggests that training in manual handling has not had a significant impact on levels of injuries (Ashton and Wright, 1995) and it is therefore likely that some carers will continue to suffer injury as a result of unsupported caring activities. Adaptations to homes and the provision of equipment would be more likely to have an impact on the health and wellbeing of carers. Paradoxically, the European regulations require local authorities to provide equipment to protect *paid* carers from injury and this has had a significant impact on the funds available for adaptations to homes. Moreover, there is no evidence to suggest that the increase in the Disabled Facilities Grant funds will be commensurate with the considerable increase in need and demand for adaptations (Heywood and Smart, 1996).

The provision of a second pension for carers is another example of new thinking and represents a significant gain for the Carers' National Association. As recognition of the financial cost of caring to some carers it has merits but these are limited because of the conditions on eligibility and because of the amount of money that will eventually be paid out. Similarly, the introduction of a tax allowance for all working mothers with dependent children and incapacitated husbands will also

benefit only a limited number of carers. The strategy pays very little attention to the financial position of carers in general and the promise to keep benefits under review is vague and unspecific. Research evidence on the links between caring and poverty is very strong (see, for example, Hancock and Jarvis, 1994; McLaughlin, 1994; Evandrou, 1996). The failure of the strategy to acknowledge and deal with this is a significant gap.

The emphasis on enabling carers to combine caring with paid employment also suggests an innovative approach and the proposals to develop carer-friendly employment practices are in line with the idea that caring should be seen as part of the normal social fabric. Research evidence points to the benefits of paid work for carers. For example, Salvage (1995) draws on evidence from 11 European countries to demonstrate that paid work can have a 'restorative' function for carers as well as providing a decent income. Drew (1995) argues that paid work can also help to combat isolation and enable carers to develop new skills. However, research also shows that in order for the benefits of paid work to be realized, conditions of work must be conducive to caring activities. The question, therefore, is how effective the government's strategy is likely to be in encouraging employers to be more carer-friendly?

The range of employment practices outlined as 'carer-friendly' are not specifically to meet carers' needs. For example, part-time working and job sharing may enable some carers to take up employment but are not designed with them in mind. Moreover, although the government makes claims for the business case for carer-friendly employment practices, it acknowledges the need for more research to assess their effectiveness. Employers are likely to require much stronger evidence before changing their current employment practices.

Services for carers in their own right

A significant step has been taken in this strategy towards reaffirming the principle that carers should receive services independently of the person for whom they care. The only service currently provided specifically for carers is an assessment of their needs under the Carers (Recognition and Services) Act, 1995. However, at present, carers cannot have their needs assessed if the person for whom they are caring has been offered and refused an assessment of their own needs. The

government promises new legislation 'when Parliamentary time allows' (HMG, 1999a: 58) to address this. In their response to the strategy, the Carers' National Association declared its intention to see this legislation enacted within the lifetime of this parliament.

The strategy is an example of the tensions that exist between those who maintain that carers' needs are best met through improved services for service users (Walker, 1995) and those who support the carers' campaign for services in their own right (Warner, 1995). The introduction to the strategy stresses the importance of the relationship of caring while at the same time emphasizing the need to recognize the individuality of each person in the relationship. The line taken in the strategy is that 'helping carers is one of the best ways of helping the people they care for' (HMG, 1999a: 12). The integration of carers as partners in the network of care provision is the means by which this principle is realized. Clearly, there is a danger in this approach that service users' perspectives will be obscured or overlooked. The strategy is portrayed as a way of achieving a better 'balance' between the rights of disabled people and carers although, apart from a reference to the proposed Disability Rights Commission (HMG, 1999a: 14), the strategy fails to engage with service user perspectives.

As Barnes (1997: 136) argues, 'the danger with current community care policies and practices is that, rather than giving appropriate support to families with a disabled or elderly member, they are making life more difficult by forcing people into separate and opposed camps'. Promoting carers as service providers exemplifies this, since it separates them from users of services. The role of carers' organizations in promoting carers' needs as separate from those of the person being cared for needs to be recognized. Bytheway and Johnson (1998) argue that to develop a perception of the distinctiveness of their experience was essential to the success of the carers' lobby. The strategy is strongly influenced by this perspective.

Added to this, there are contradictions in the strategy in the way the caring relationship is perceived. For example, the accompanying booklet, *A Real Break*, makes the point that the conventional distinction between users and carers 'can be unhelpful when applied to the provision of short breaks' (HMG, 1999b: 7). The emphasis is on the need for a variety of ways in which the ongoing routine of care at home can be supported to the benefit of both carer and service user. On the other hand, we have the statement: 'In providing or developing the provision of short breaks for carers, the empowerment of the carer should be a key aim' (HMG, 1999a: 62).

Significant by its absence is any mention of caring for carers on the death of the person for whom they care. With the exception of enabling carers to get back to paid employment 'when caring comes to an end', there is no reference to the need for care and support on bereavement. Similarly, there is no reference to changing circumstances, such as when a person being cared for in the family goes into a residential or nursing home. The Relatives and Residents Association has long campaigned for changes in the way families of people in residential care are treated by staff (White, 1996). Continuity in relationships is vital to wellbeing and the failure to pay attention to this is a serious flaw in the strategy. Indeed, it reveals an attitude towards caring that diminishes the relationship and its importance to both the carer and the person being cared for. Interdependence and mutuality of care remain unacknowledged.

A broader perception of caring?

The strategy stresses the widespread nature of caring: 'everyone feels the effect of caring' (HMG, 1999a: 11) and the diversity of caring relationships. Local authorities are expected to develop a range of services to respond to the diverse needs of carers and service users. Paradoxically, however, the strategy itself is likely to have the effect of reinforcing a relatively narrow perception of carers. For example, the new question in the 2001 census is intended to improve the quality of available information about caring. However, the question is to be focused only on the provision of personal care. This is significant because those who provide personal care are more likely to be women, related to and co-resident with the person for whom they care for more than 20 hours a week (Parker and Lawton, 1994), the grouping that represents the popular view of carers. It is therefore unlikely that information from the census will enhance knowledge about the breadth and diversity of caring.

Bytheway and Johnson (1998) make a similar point about the process of the 1995 Carers (Recognition and Services) Act, which moved from a relatively broad and inclusive perception of carers to focus on the 1.5 million who provide care for 20 hours a week or more. This focus on those who are at the 'heavy end' of caring is important in understanding the differential *effects* of caring on the health and wellbeing of the carer. A number of commentators have stressed the

importance of recognizing that the effects of being someone's main or sole carer are significantly greater than simply being part of a caring network (Hancock and Jarvis, 1994; Taylor et al., 1995; Evandrou, 1996). However, a focus on those in greatest need means that preventive services become less of a priority and the range of support and help available is reduced. In addition, people may be deterred from asking for help at all if services are regarded as available only to people in desperate need. The aim of the strategy to create a broader, more inclusive picture of caring will not be realized as long as the emphasis is on the 'heavy end'.

Conclusion

There is innovative and creative thinking in this strategy. It promotes the view of carers as a diverse and widespread group and emphasizes the point that we are all implicated in the way we care for each other. In addition, it reflects the government's line on 'joined up' thinking in that it draws on a wide range of policies and initiatives that have an impact on carers' lives. However, the more concrete proposals are directed at particular groups of carers rather than taking into account the diversity of their circumstances and needs. This is particularly so in relation to addressing the poverty experienced by a wide range of carers and those for whom they care.

The strategy is a major boost to carers' organizations whose position in the policy process is reinforced, expanded and increasingly influential. Not only are they to be consulted over broad strategic planning for health and social services, they are also to be used as experts in establishing quality criteria for local services. Their perspectives and activities will be highly influential in shaping future conditions for caring. However, they will need to take into account the potentially negative effects of this changed role on their relationships with local authorities who may feel increasingly resentful about the monitoring role of carers' groups.

Most importantly, what has happened to those who are cared for in all this? The strategy does pay lip service to disabled people's groups and to the need to 'balance' the rights of both people in the caring relationship. However, there is little evidence in the strategy of the perspectives of people who are cared for and in this respect it can be seen as divisive. Indeed, it runs the real risk of putting the interests of

carers above those of the people who are on the receiving end of care. For example, the consultative conference held in November 1998 was addressed by a wide range of speakers, but none that represented the interests or perspective of disabled people. In privileging the views of carers' organizations, the government has failed to grasp an opportunity to develop more inclusive and creative ideas about the nature of care and support.

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