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Rationed Care: Assessing the Support Needs of Informal Carers in English Social Services Authorities

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ABSTRACT

The passing of the Carers (Recognition and Services Act) 1995 was a step forward in trying to ensure that people who provide informal care to disabled, sick or elderly relatives or friends are properly recognised and properly supported. The Carers Act gave informal carers the right to an assessment of their own needs, and this article is based on a study into the impact of the legislation in four local authority social services departments. It is argued that the vision of supporters of the Carers Act, namely to achieve real benefits for many carers, has yet to be realised. The analysis draws on Klein *et al.*'s (1996) framework of service rationing strategies to demonstrate that decisions about priority setting and different forms of rationing of social care took place at three different levels: national government, local authority and front-line practitioner. Evidence is presented to show that some carers chose to impose rationing on themselves by reducing their demands. The article concludes with comments on the implications of rationing decisions for policy and practice.

INTRODUCTION

Prime Minister Tony Blair, in the foreword to the National Strategy for Carers (DH, 1999), described people who provide informal care to disabled, sick or elderly relatives or friends as among the 'unsung heroes of British life'. He was referring to the estimated 5.7 million people in Britain who are informal carers (ONS, 1998), 1.7 million of whom spend at least 20 hours a week caring. It has been suggested (DH, 1999) that in

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addition there are between 20,000 and 50,000 young carers (under 18). Informal carers provide more care than the combined efforts of the National Health Service and local social services. Their value to the economy is estimated to be in the region of £34 billion a year (Hirst, 1999). The provision of social care is becoming an important policy issue for governments worldwide, as countries face the challenge of responding to ageing populations (Nolan and Philp, 1999).

The Carers (Recognition and Services) Act 1995 came into force in England and Wales in April 1996. The Carers Act gave carers the legal right to a community care assessment, the results of which must be taken into account when making decisions about services for the care recipient. Although the Act was introduced at a time of increasing budgetary pressures, the Conservative government of the day did not allocate any additional central funding for implementation. Carers' new entitlements under the Act were modest, but even so it was seen as a major step forward: it gave carers legal status. Concerns have been expressed, however. The disability movement, in seeking to promote user empowerment and social justice, has argued that carers only need services because service users' rights to independent living are not upheld (Morris, 1997). Whilst tensions remain, the Act does not necessarily challenge the service user perspective. According to the policy guidance (DH, 1996) many local authorities already offered carers an assessment, so the legislation in effect enshrined existing good practice into statute. So how has the Carers Act been implemented and delivered? Has the legislation lived up to the vision of campaigners for carers' rights, or are local authorities having to restrict carers' access to social care because of the need to reconcile infinite need with finite resources?

Rationing and targeting of resources has featured in the delivery of health care and other public services for many years. Recently, media coverage of health care rationing has given rise to heightened public concern and emotions. Recall, for example, the controversial case of Jaymee Bowen, otherwise known as Child B, who suffered from leukaemia (Ham and Pickard, 1998). Jaymee became the subject of a legal action brought by her father against Cambridge Health Authority's decision not to spend £75,000 on further intensive treatment. Whilst there has been no such high-profile equivalent regarding the provision of social care, some disabled people have challenged local authorities' decisions to ration levels of service and support in the community. The House of Lords ruling in the Gloucestershire case (*R. v Gloucestershire County Council and the Secretary of State for Health ex parte Barry*, 20 March 1997) in favour of the Secretary of State and Gloucestershire County Council means that

local authorities can draw up eligibility criteria that balance the need for support with the resources available.

Research on priority setting and rationing in social care is limited. What little there is shows that local authorities are tightening eligibility criteria to determine who qualifies for an assessment (Ellis, 1993; Davis *et al.*, 1997; Phelps, 1997; DH, 1998; Janzon, 1998). Authorities employ initial screening processes – often undertaken by reception staff – to establish the level and type of assessment required, and the urgency of the need (Ellis, 1993; Lewis and Glennerster, 1996; Phelps, 1997). Limited time means that practitioners ration how long they spend on assessment visits (Ellis, 1993). Subsequent service provision is delayed, reduced or withdrawn leaving people to manage with inadequate levels of care, or even no care at all (Phelps, 1997). People in seemingly similar circumstances receive different levels and types of service provision (Lewis and Glennerster, 1996; SSI, 1998a). Decisions about care are service driven according to what is available, rather than tailored to individual needs (DH, 1998).

As far as implementation of the Carers Act was concerned, funding – or rather, the lack of funding – was a big issue for most local authorities (CNA/ADSW/ADSS, 1997). Evidence suggests that budget constraints encouraged a service-led approach to carer assessment and care planning rather than a needs-led approach (Seddon, 1999). Many carers do not know of their rights to assessment (CNA, 1997; SSI, 1998a). Services and support for carers, including young carers, appear to reflect geographical or resource differences rather than levels of need (Dearden and Becker, 1998; SSI, 1998a).

This paper uses evidence from a study into the impact of the Carers Act for local authorities and carers to illustrate how social services departments sought to implement the new legislation against a background of limited resources. The analysis draws on the conceptual framework of priority setting and rationing elaborated by Klein *et al.* (1996). Priority setting refers to the allocation of resources to particular services or programmes; rationing relates to the distribution of resources to individuals at the point of service delivery. Box 1 contains a list of service rationing strategies. These strategies are not exclusive, and a mix can be operated reflecting the policy environment, the specific setting and the particular services or programme being delivered. The present article concentrates on the most widely used strategies, and takes a global approach in efforts to shed light on decision-making at the national, local authority and front line delivery levels.

- *Rationing by denial.* Services are denied to specific individuals, or client groups. Particular forms of help may be excluded from the menu of services available
- *Rationing by selection.* Staff 'select in' those individuals thought to: have most to gain from the intervention; be deserving cases; or least likely to cause problems
- *Rationing by deterrence.* Access to services is made difficult, for instance receptionists are unhelpful, telephone messages are not passed on or answered; information leaflets are not freely available
- *Rationing by dilution.* Demand is diluted by reducing the quantity and quality of services provided: no-one is excluded, but instead everyone receives less
- *Rationing by delay.* Access is discouraged through delaying tactics: appointments are weeks ahead; correspondence is slow; waiting lists are in operation
- *Rationing by deflection.* Agencies protect resources by channelling prospective clients to a different programme, service or organisation
- *Rationing by substitution.* Cheaper services are offered
- *Rationing by termination.* Services are withdrawn; cases are closed
- *Rationing by charges.* Charging policies are developed, and service users contribute towards the costs of the services they receive

Source: Drawn from Klein *et al.* (1996)

BOX 1. Repertory of service rationing strategies

The article is organised as follows. The next section describes the research methods employed. The following three sections present the evidence relating to decision making about priority setting and rationing at the levels of national government, local authorities and front-line practitioners respectively. The findings are completed by outlining how carers imposed rationing on themselves by reducing requests for help. The

concluding section discusses the implications of the analysis in terms of theory, policy and practice.

THE STUDY

Four local authority social services departments in the north of England took part in the study. The research sites were chosen to reflect a cross-section of authorities; as well as varying in type, they differed in size, location, population mix and policy approach to carers. The carer population in two sites was 10 per cent of the total population, and 14 per cent in the other sites. The fieldwork period lasted for 12 months, commencing May 1998.¹

The study involved collecting data through a documentary review and interviews. Nationally, the Act itself, the accompanying policy guidance (DH, 1996) and the practice guide (SSI, 1996), and the record of the parliamentary debate at the Committee and Third Reading stage (*Hansard*, 1995) were examined. Documentation produced by the four local authorities that was reviewed included policy statements, official papers to social services committees and operational guidelines.

One senior manager responsible for policy formulation for the Carers Act was interviewed once in each local authority, together with four front-line practitioners whose duties included carrying out carer assessments. The discussions with senior managers yielded information on local policy on carers, implementing the Carers Act, assessment procedures and monitoring outcomes. The interviews with practitioners centred on local policy and practice on carers, access and eligibility to assessment, the carer assessment process, care planning and service provision, follow up and reviews. Both sets of interviews generated accounts of the tensions between meeting needs and keeping within limited budgets, strategies adopted to match supply and demand, and the difficulties of managing scarce resources.

The aim was to interview 60 carers across the four research sites. In the event, a final sample of 51 carers was obtained, 36 women and 15 men. Semi-structured interviews with carers were held at two points in time: as soon as possible after they had been assessed under the Carers Act (Time 1), and six months after the first interview (Time 2). The first interview focused on the process and form of the assessment, and any associated service provision. The second interview concentrated on changes during the six-month interval, and the perceived outcome of assessment for carers.

All the interviews were audio-recorded, with permission. Those with professionals were transcribed in full, as were nearly half the carer interviews at both Time 1 and Time 2. The choice of which carer interviews to

transcribe was made on the basis of relevance to the research questions, as well as ‘newness’, similarity and difference in terms of individuals’ experiences. Comprehensive notes were made of the remaining interviews. Analysis was aided by the use of the qualitative software data analysis package NUD.IST. For a more detailed account of the research methods used, see Arksey, Hepworth and Qureshi (2000).

Decision-making at the national level

This section draws on the documentary review to illustrate how decisions by national politicians and civil servants helped limit carers’ access to assessment under the Carers Act.

Priority setting and eligibility criteria

The Carers Act was a Private Members Bill introduced by Malcolm Wicks, MP. In the parliamentary debate at the Committee stage, Wicks was concerned that the Bill should ‘include *all* carers’ (emphasis added; *Hansard*, 1995a: col. 424), identifying three particular groups: adult carers of frail, elderly relatives; parent carers; and young carers. Initially, Wicks talked in terms of the ‘6.8 million carers throughout Great Britain’ (*Hansard*, 1995b: col. 426), but then focused on what he called the ‘caring army’ of 1.5 million people who provided care for 20 hours a week or more, a threshold probably informed by the work of Parker and Lawton (1994).² In the debate, Wicks stated ‘It is certainly the policy intention of the Bill to target that group of carers who carry the major burden’ (*Hansard*, 1995b: col. 426).

When the Carers Act became law, it defined a carer as someone who provided, or intended to provide, ‘a substantial amount of care on a regular basis’. Policy guidance issued by the Department of Health advised local authorities to interpret the terms ‘regular’ and ‘substantial’ ‘in their everyday sense’ (DH, 1996: 4), whilst the practice guide (SSI, 1996) suggested that practitioners take account of the type of tasks undertaken, the number of hours spent caring, the amount of supervision given and whether the care work was a continuing commitment. Beyond these indicators, it was left to the discretion of local authorities to reach their own interpretation of who did and did not qualify for a carer assessment although the policy guidance also pointed out that decisions should take into account the relative needs of carers in the area.

Eligibility was further restricted because the Act did not give carers a free-standing right to an assessment: carers could only have their needs assessed if the person they supported was being assessed or reassessed for community care. The Carers Act did not entitle carers to services, only

the right to be assessed; from this point of view, the Act was misnamed. Recognition costs little; services, however, are expensive to provide. In fact, as an opposition MP, Wicks negotiated support for the Bill from Conservative government ministers which led to a compromise about the issue of carers and service provision.

As a piece of legislation, the Carers Act reflected rationing by denial: at the very outset, it was exclusive in who it applied to, did not give carers any rights to services and there was no extra funding from the centre. The implication is that despite the rhetoric carers were still seen as a low priority. So how did the four research sites deal with the additional obligations the Carers Act placed on them?

DECISION MAKING AT THE LOCAL AUTHORITY LEVEL

This section draws on interview material from the four senior managers interviewed. All spoke about the benefits of the Carers Act. These included: raising the profile of carers; increasing the legitimacy of carers' issues amongst staff; promoting good practice; and using the Act as a tool around which to focus staff training. Achieving improvements in relation to work with carers was challenging, though, given that the authorities in the study were constrained by fixed global budgets. There is ample evidence (Baldwin and Lunt, 1996; Balloch, 1999) of local authorities levying charges, and not surprisingly the research sites were increasingly charging service users as an option to ease financial pressures:

I mean we've just upped our charges tremendously, about three hundred per cent recently . . . Just said 'We have to live with this to protect the budget' . . . Not that I wanted to put a major increase on the charging policy but we were faced with that alternative or a reduction in services. (Senior Manager, Site 4)

Three of the four authorities contained expenditure to implement the Carers Act within existing budgets; the remaining one made additional monies available for new staffing. Echoing the findings of other studies (CNA/ADSW/ADSS, 1997), the (in)adequacy of resources to meet increased demand greatly concerned managers and throughout their respective interviews, they spoke spontaneously of difficulties regarding finance, staff shortages and time pressures, 'There's a whole host of issues we've got to take on board, and are trying to in an under-resourced and overworked sort of way' (Senior Manager, Site 1). There were serious repercussions, for instance three managers made statements indicating that in their authorities community care assessments were service-led rather than needs-led, an approach which goes against recent government guidance (DH, 1998).

We openly acknowledge that in many areas the assessments we're doing are still service-led ... because under the pressure of work time and resources, it's much quicker to assess for services than it is to do an assessment of need and then a flexible package of services afterwards. (Senior Manager, Site 3)

Priority setting and eligibility criteria

From their interviews, it seemed that an important issue for managers was prioritising not only *amongst* carers but also *between* service users and carers. Historically, service users have been the main priority for social services departments. The senior managers (and front-line practitioners) confirmed that this emphasis remained, although they felt that a shift towards a more balanced approach was slowly under way.

With regard to priority setting amongst carers, this was not explicit in the sense that none of the four sites had formal systems for ranking carers. However, since under the Carers Act the right to an assessment was dependent on the service user being assessed, and in the four sites eligibility for assessment for users was prioritised on the basis of urgency, risk and (in)dependence, then by default there was a degree of prioritisation taking place. Further ranking might then take place, reflecting professional perceptions of the severity and/or fragility of the caring situation:

[If] you've got a carer's assessment that says 'The carer's at the end of their tether, this person's going to end up in residential care and the carer is going to end up freaking out if we don't help', then that beefs up, that pushes it up the priority ... it doesn't really give carers more choice but it means we're making better, we're prioritising the cases better. (Senior Manager, Site 2)

Local authorities in the shape of local politicians and social services officials had to decide for themselves what constituted 'regular' and 'substantial' when making priority decisions about who qualified for a carer assessment. Previous research (CNA/ADSW/ADSS, 1997; SSI, 1998a) shows that authorities developed a multitude of definitions, and evidence from the present study endorses this. Rather than offer an open-ended commitment to carers, the four sites drew up their own local guidelines based on the central guidance. Eligibility criteria were not prescriptive but instead comprised triggers or rough rules-of-thumb to help staff prioritise (see below for further details of how staff operated the criteria). Indicators related to the number of hours of spent caring, the type of tasks undertaken, the carer's age, and levels of supervision and responsibility for the person being supported. The four managers all emphasised a policy of inclusion. Ironically, one manager commented that the set of eligibility criteria developed in his authority was potentially more

restrictive than previously, but in some circumstances might well provide a valuable excuse:

Our definition [prior to the Carers Act] was quite broad anyway; we didn't need the definition to widen the number of people who we were assessing and who had the right to support. But it was useful to have the definition if somebody was running at us and demanding services. We said 'Really, you're way down on the list of priorities', so it was a defensive bit really. (Senior Manager, Site 3)

Rationing by deterrence

The analysis revealed evidence of rationing by deterrence. This form of rationing is experienced when obstacles and difficulties are placed in the way of people trying to get into the system and access services. There were examples of different mechanisms, some of which were applied by practitioners (see next section) and others that also related to organisational procedures: the provision of information, and self-assessment by carers.

The policy guidance to the Carers Act (DH, 1996) required local authorities to publish information telling carers about their right to assessment, eligibility criteria and how assessment procedures worked. Recent studies into the implementation of the Carers Act (CNA, 1997; CNA/ADSS/ADSW, 1997; Dearden and Becker, 1998; SSI, 1998a) suggest there is still a long way to go in informing carers about the Act. The four sites in the present study had information about the legislation, but the amount and quality provided varied considerably. Only one authority had a publication focusing exclusively on the Act.

Local carers' centres and groups were routinely used as principal sources of information about the Carers Act and support for carers, yet less than half the carers taking part in the study were in contact with such organisations. For many people, this may not be an effective way to make information available (Parker, 1993). Senior managers acknowledged there were difficulties in distributing information, and recognised that carers as a group were hard to reach:

The fundamental [difficulty in implementing the Act] has been information ... ensuring that carers are receiving the information sufficiently early in the process. Then when they get the information, that it's accurate; and so that's something about also being clear that professionals, including social workers, have the information and understand it, and understand the importance of it. (Senior Manager, Site 1)

Without adequate knowledge, carers will be deterred from asking to be assessed. But if practitioners wait for carers themselves to request an assessment (which is contrary to national and local policy guidance but

nonetheless is implied in the comment below) then it is not surprising that the number of carer assessments undertaken remains low (CNA, 1997; SSI, 1998a; Cheetham, 1999):

I think that even social workers wait still for an approach to be made from the carer ... I think there are plenty of instances where they're not thinking 'carer' and starting to talk to them about the possibility of a carer assessment. (Senior Manager, Site 1)

There was a second way in which social services systems potentially discouraged carers from having an assessment. All four sites used carer assessment forms to record information describing the circumstances and needs of carers, but how they collected this information differed. One authority employed self-assessment procedures, and although it was not recommended practice in the remaining three sites it still happened:

In the procedure it says 'The carer should always be offered a chance to talk to you in confidence and not with the service user present.' But whether that happens I've no idea. I think most of them are just 'Here's the form, please fill it in and sent it back to us.' (Senior Manager, Site 2)

However, it has been established that carers appreciate face-to-face contact (Warner, 1995), and when completing forms on their own tend to give superficial responses (SSI, 1998a). Many of the carers interviewed – particularly older carers – found completing assessment forms by themselves a struggle. They were not aware of the full range of services available and appropriate so could not easily answer questions such as 'What further help would you like?' Neither were carers keen to put in writing comments about the cared-for person's deteriorating abilities. Consequently, there is potential for carers not to complete and return their assessment form. From this viewpoint, self-assessment may be disempowering and may deter carers from seeing through the full assessment process.

Ironically, two managers acknowledged that rationing support to carers on the one hand whilst relying on them to underpin formal care provision on the other involved treading a very fine line:

A part of the skill of the assessment is picking up the sounds when the carers are saying 'I've had enough', and part of it is then trying to sustain them by putting resources in to keep them going a bit more. (Senior Manager, Site 1)

Ultimately, it is front line practitioners who are responsible for translating decisions at national and local levels (Lipsky, 1980; Lewis and Glennerster, 1996). Previous findings about 'street level bureaucrats' (Lipsky, 1980) illustrate the considerable discretion staff have for applying their own forms of rationing within the framework of national and

local guidelines. The next section shows the mix of rationing strategies employed by practitioners undertaking carer assessments.

DECISION-MAKING AT THE FRONT-LINE LEVEL

The front-line practitioners interviewed for the study had varied job titles: social worker, care manager, team leader, home care manager, monitoring and reviewing officer, carers' officer and social welfare officer. All but one person carried out carer assessments. When devising care packages and help for carers, staff had to work within established budgets. There were limits on the packages they could commission from eligible providers without authorisation from supervisors. Generally, staff could access support from in-house providers. In some research sites, if the resources were not obtainable in-house the option of buying them in from private or voluntary service providers was not available. Practitioners received new referrals at the same time as having to deal with their existing case load. Overall, it was in practitioners' own interests to limit rather than encourage demand. The following examples – taken from the practitioner interviews – illustrate how this could be accomplished.

Priority setting, eligibility criteria and undertaking carer assessments

Departmental guidelines about eligibility criteria, and the need to inform eligible carers of their right to request an assessment, were available in all four research sites. However, the evidence shows that in two sites none of the practitioners knew what their departmental guidelines contained, or where they were kept. In contrast, some practitioners in the other two authorities were familiar with their guidance.

Irrespective of whether staff were aware of local eligibility criteria, they made personal decisions based on what they believed was good practice. Like the senior manager interviewees, the majority of practitioners talked in terms of interpreting the criteria widely, using words such as 'liberally', 'leniently' and 'very broadly'. For many, the basis of decisions about eligibility was the time spent caring, although other indicators staff looked for included the health of the carer and whether s/he lived in the same household as the care recipient. In spite of managers' and practitioners' allegedly generous and inclusive approach, 49 of the 51 carers we interviewed cared for over 20 hours a week (47 for over 35 hours) suggesting that in reality carers with lower levels of involvement were not a priority for assessment. This result is supported by other work (CNA, 1997).

A common anxiety expressed prior to the introduction of the Carers Act was that social services would be inundated with requests from

carers to be assessed. The findings show, however, that any fears of a large increase in demand from carers for assessment have not been realised. In fact, only two of the fifty-one carers taking part in the study had themselves asked for an assessment, which suggests that decisions about whether to undertake an assessment are largely a matter for professionals. Most of the practitioners interviewed said they would routinely advise carers they could have an assessment but some admitted they were reluctant to push the issue:

I still offer an assessment to a carer but as things stand at the moment, like I say, I don't go back and say 'You can have an assessment in your own right.' I don't follow that through because time, pressure of work, etc., does not allow that. (Front-line Practitioner, Site 1)

Rationing by deterrence

The study found evidence of staff practising rationing by deterrence in relation to the method of assessment and follow up after assessment.

Guidance to the Carers Act (SSI, 1996) indicated that assessment would probably involve a face-to-face discussion, with the option that it took place in private and in that sense was 'separate'. Some practitioners found they did not have sufficient time to work in this way:

I think sometimes it's very difficult [to tap into a carer's needs] because ... you're actually usually doing the assessment with the service user there. And in order to truly give them enough time, I think you'd have to see them separately. And just of the nature of the work and the volume of referrals, it would be very difficult to do that, although I think that is really what is required. (Front-line Practitioner, Site 4)

As implied in the above observation, assessing care recipients and carers together has the potential to overlook the latter's needs. Given that the majority of practitioners agreed with senior managers in that ultimately their priority lay with service users rather than carers, then carers' needs are even more likely to be marginalised. Furthermore, unless the point is made explicitly, there is also the risk that carers might not even realise that they too are being assessed and so are deterred from asking for help on their own behalf. Practitioners' vagueness or informality on this issue may account for the fact that around half of all the carers taking part in the study were not aware they had been assessed, a phenomenon found elsewhere (CNA, 1997; SSI, 1998a).

As far as completion of carer assessment forms was concerned, social work practice varied amongst practitioners both within and between different local authorities. Some staff commented that it was part of their routine assessment practice to follow up forms that were not returned to

them in case carers needed help to fill them in. Others, in contrast, took no further action, putting the onus on carers to be proactive if they did want to proceed with the assessment.

A further example of rationing by deterrence related to the results of the assessment. Both national and local policy guidance said that carers should be provided with written confirmation of their assessment. In common with other research (CNA, 1997; SSI, 1998a), at least half the carers in the present study said they had not received anything in writing. But without the results of the assessment, carers could not assert their rights, question or complain about the outcome (CNA, 1997).

Rationing by dilution

Even though practitioners had to work within constrained budgets, there were examples of services being tailored to meet individual carers' needs, and practitioners developing comprehensive and flexible care packages that helped carers (and the person supported) achieve an improved quality of life. At the same time, staff had to make finite resources go further.

Rather than deny services altogether (which could happen: staff reported instances of telling carers they were unable to provide a particular service due to lack of resources even though they had identified a need), preferred strategies included: reducing the quality and quantity of services; offering alternative, more modest, forms of help; giving newly referred carers less; and volunteering information and advice, but no actual services or support. Like the senior managers, a small number of practitioners spoke about deploying a service-led approach. Consistent with previous work (SSI, 1998b), practitioners in one site identified this as a particular issue in so far as meeting the needs of carers from ethnic minorities were concerned:

We may try our damnest to think 'Right, what are the [cultural and religious] implications here?', but our resources at the minute are not vast ... so it is a bit frustrating that sometimes you do recognise people's needs but don't have the wherewithal to then meet them as best you can. (Front-line Practitioner, Site 1)

Practitioners prioritised practical support services which helped carers with the physical aspects of caring rather than help that potentially might have improved their quality of life, say in relation to emotional health or maintaining social relationships, outcomes that are known to be important to carers (Qureshi *et al.*, 1998). The following quote captures the rationing dilemmas that practitioners had to resolve:

I think the service really centres around bodily functions. ... For instance, it'd not be seen as the highest priority if a person, a carer, wanted to go for a round of golf which took four

hours but the person who's disabled couldn't be left alone. It'd be more difficult to argue the toss to get four hours care for that person, for somebody to sit with them, than it would be to argue the toss about somebody to get them washed, dressed, etc. (Front-line Practitioner, Site 1)

Rationing by delay

There is existing evidence pointing to the use of waiting lists for over subscribed services, equipment and adaptations (Scrivens, 1983; SSI, 1998a), and this is confirmed by the present study. As one practitioner said in relation to the twilight service operated by the home care section:

'It is restricted; there's only so many bodies and there's only so many people they can attend to in one night.' (Front-line Practitioner, Site 2)

Another practitioner reported that in his area the waiting list for sitting services was so large that, to quote, 'Unfortunately, they might have died by the time they're half way up.' Without any effective means of prioritising those on the list, practitioners might suggest alternative services or refer carers to private suppliers. Some staff said they might approach a supervisor for authorisation to purchase the service in question from independent providers if they felt early intervention might prevent a breakdown in the caring situation.

The discussion so far has concentrated on the scope for policy makers, managers and practitioners to restrict access to social care – but what about carers themselves? How do they fit into the picture?

Carers' self-imposed rationing

The analysis suggests that carers imposed their own limits on the amount of help they asked for, so in effect were imposing rationing on themselves. Carers gave varied reasons for self-rationing. Although all the fifty-one carers taking part in the study had been assessed, about seven or eight did not even ask for assistance. Some said this was because they had been told by their social worker that they could not do anything for them because of the resource situation. Other carers felt guilty about accepting outside help for their relatives, especially if they had experienced a short-term break and the person supported did not appear to have enjoyed their stay. Such carers continued to care with the minimum of help from social services even if this was at the expense of their own physical and emotional health. One care recipient refused to co-operate with home care staff; this was so distressing for the carer that for a time he struggled on his own, but eventually this particular caring situation broke down.

Some people cancelled formal services because they did not meet the needs of carers and/or the person supported. For instance, two carers from different sites commented that the home care workers involved with their respective relatives were 'noisy' and 'loud' and 'too gossipy'. Whilst the formal carers had 'only wanted to have a cup of tea and a chat', what the care recipients actually wanted was to be left in peace to read.

Charges for services were an issue for some carers, even though it was actually the service users who were assessed and charged according to their income. Three of the fifty-one carers cancelled some services during the six-month gap between their Time 1 and Time 2 interviews because of their cost, a finding documented in other recent research (Balloch, 1999). Other carers did not take up the option of support in the first place, even though they knew they stood to benefit:

We won't have the respite care 'cos the respite is going to cost money, which we haven't got. So in a way the respite's going to make my life easier because I have a bit of space but I then will not have any money to do anything with, and will then be worrying more about the finances because of the cost of the respite. (Carer, Site 3)

The experiences of senior managers and practitioners from all four sites supported the notion of self-rationing carers. Staff gave examples of carers who declined to be assessed for a variety of reasons. A common one was carers' belief that there were no resources available, so it was a waste of time. Another was that any official form filling would lead to assumptions about the formality and permanence of someone's involvement in the caring situation. A further reason related to anxiety about the potential for repercussions from the practitioner for the care recipient. One manager singled out the in-depth nature of assessment as a problem:

'[Carers] don't want a deep, probing, holistic assessment of all their psychological and personal circumstances to be able to get two hours of home care a week.' (Senior Manager, Site 4)

Practitioners also talked about carers who refused services, or trimmed their demands. As just indicated, this often related to charges and the fact that, to quote, 'a lot of people don't want to pay'. But it was equally the case that people were reluctant to identify themselves as 'carers', and instead saw themselves as spouses, sons or daughters whose care work reflected marriage vows, family obligations and duty. Many of these concerns have their roots in the complex interaction between carers and those they are looking after, and their different – sometimes conflicting – views on choice, independence, risk and options for the provision of care.

In two sites, the complexity of caring relations could be manifest as a problem, often in relation to minority ethnic carers:

'In a lot of instances extra help is also refused and I find this particularly with minority groups, ethnic groups like the Italians. ... You can offer [help] but you can't force them.' (Front-line Practitioner, Site 4)

Figure 1 draws together the previous examples to illustrate the constraints on the Carers Act at different stages of implementation. It shows how carers are filtered out of the assessment process in line with the imperative to remain within budget. Supporters of the Act, whose initial vision was that carers would experience real improvements, must be frustrated to read reports suggesting that the legislation has had minimal impact to date and led to few improved outcomes for carers (Seddon, 1999).

DISCUSSION

The government believes that carers need support because 'helping carers is one of the *best ways of helping* people they are caring for' (DH, 1999; original emphasis). The foregoing analysis has traced the decisions by government, through to local authorities and finally down to individual practitioners in efforts to discover how carers' rights under the Carers Act to request an assessment of their ability to care were conceptualised and managed.

Klein *et al.*'s (1996) conceptual framework on rationing was useful. As an analytical tool, it risks oversimplifying and obscuring the complexity of decision-making but in the event served effectively to illustrate the various ways in which priority setting and rationing of social care operate at national and local policy and practice levels. Looking beyond the main stakeholder groups, we can see that carers may also be 'agents' in the rationing process as they limit or withdraw their requests for support.

The 'goods' that practitioners rationed at the point of service delivery were of different forms: professional time and expertise; access to assessment, which acts as a gateway to services; and practical support itself. This is not an uncommon finding. Seddon (1999) reported that local authorities taking part in her study of carers of people with dementia admitted that eligibility for assessment varied according to the resources available. Staff were unwilling to undertake separate carer assessments because they were time consuming, added to the administrative workload and tended not to result in any tangible outcomes for carers.

Some forms of rationing were more visible than others. For instance, rationing by dilution – the stretching of limited resources such as home care or short-term breaks more thinly – was less perceptible than a

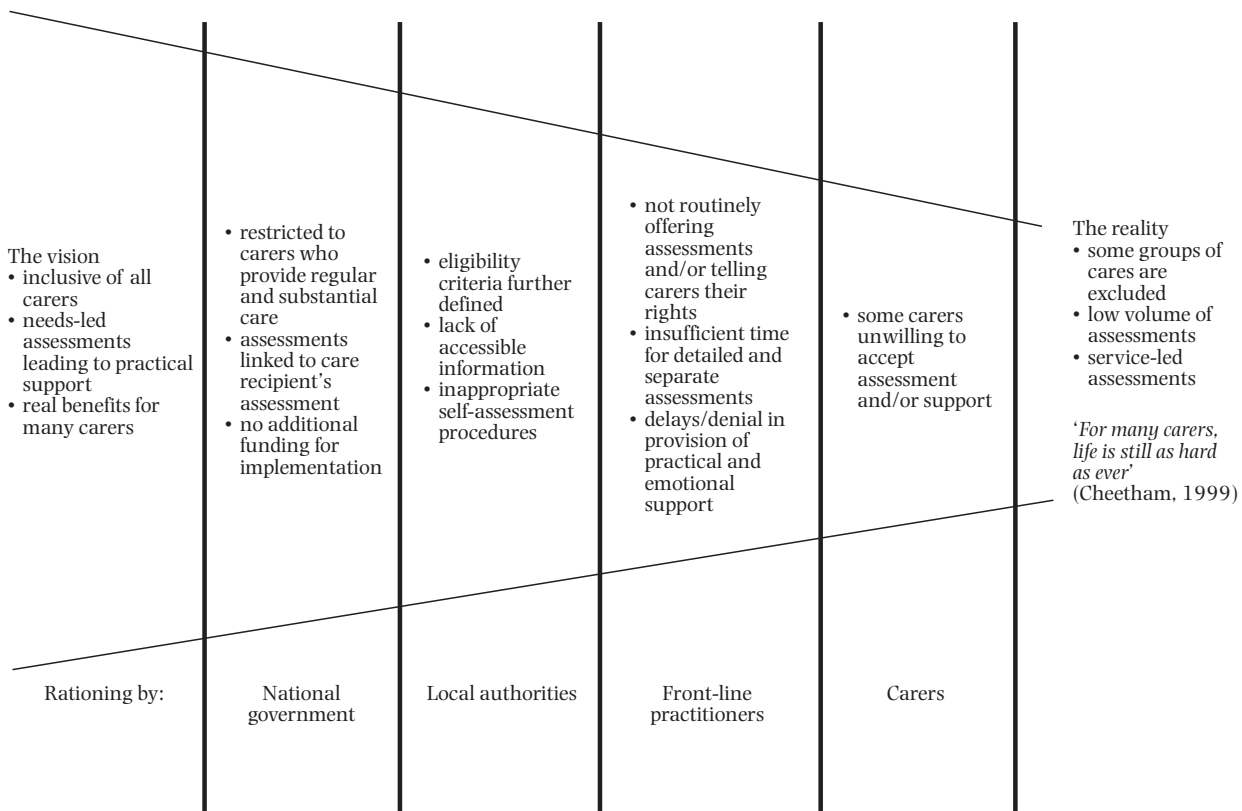


Figure 1. The process of rationing in implementing the Carers Act.

complete denial whereby carers went without such services altogether. Rationing by deterrence was also less noticeable. Furthermore, the tactics operated under this label tended to affect all carers and so were not especially likely to cause an outcry.

Responsibility for rationing decisions was shared by different professionals: national and local politicians, civil servants, social services officials and front-line practitioners. In principle, this meant there was more scope for allocating blame about unpopular decisions about who should get what. Moreover, formal methods to decide eligibility for assessment and support served to protect practitioners from taking all responsibility for decisions dictated by restricted resources (Lewis and Glennerster, 1996).

What were the implications of rationing decisions? Some carers might not receive an assessment even though they would be eligible; they were likely to be in receipt of limited levels of support, and often experienced delays before services were put in place. However, it is important that all carers have equal access to services (DH, 1998), and that services are allocated more systematically in relation to need. From this point of view, rationing is not necessarily bad or undesirable. One principle underlying priority setting and rationing decisions is that of 'equity-based-on-need' (Klein *et al.*, 1996), whereby people with equal need receive equal treatment, whilst those with greatest need are given top priority. In these circumstances, front-line practitioners play a critical role. For instance, Mechanic (1995), writing about equivalent situations in health care, argues that rationing should be left for doctors and patients to work out themselves. Doctors are the ones who are nearest to the population being served, and who have the relevant information with which to make informed decisions. Exercising professional discretion, for Mechanic, not only offers a more sensitive, flexible and individualised way to respond to differences in people's needs, preferences and situations but has the potential to lead to outcomes that are not discriminatory but in fact are more equitable.

It is a likely prospect that social care will continue to be rationed, and available selectively according to assessed need and ability to pay (Blackman, 1998). Common sense suggests that it is in the interests of organisations to help practitioners better manage supply and demand imbalances. The case is even stronger given that studies (Bradley and Sutherland, 1995; Balloch *et al.*, 1998) have shown that social workers cite problems related to resource issues, and not being able to give people the help they need, as particularly stressful. In the case of assessment under the Carers Act, some immediate issues to address in staff induc-

tion, on-going training and supervision include reinforcing the need for practitioners first to be consistent when determining who is eligible for assessment, and secondly to inform carers of their right to request an assessment as part of routine social work practice.

Recent governments have sought to demonstrate their commitment to carers, for example through the National Strategy for Carers (DH, 1999) and the new Carers and Disabled Children Act 2000. The latter piece of legislation aims to resolve some of the criticisms of the Carers Act, by entitling carers to be assessed in their own right and requiring local authorities to provide direct services to carers to meet their assessed needs. Such services could include home care, travel fares, mobile phones or pagers so carers can stay in touch with the care recipient. It is hoped that the linking of service provision to assessment will encourage more carers to request assessment.

In a similar way to the Carers Act, however, the Department of Health has indicated that any additional costs are expected to be contained within local authorities' existing allocation. Organisations such as the Association of Directors of Social Services are already voicing concerns that many of the benefits will be lost without extra central funding to meet the increased service demands the Act may generate. This analysis into the implementation of the Carers Act suggests that unless the fundamental issue of resourcing is addressed, government commitments to making sure that carers have practical help stand to be undermined.

NOTES

- 1 The research was undertaken by Hilary Arksey and David Hepworth from the Social Policy Research Unit at the University of York.
- 2 These figures quoted by Wicks were derived from the 1985 General Household Survey (Green, 1988), but have now been superseded by those cited in the Introduction which came from the 1995 General Household Survey.

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