

Public sector

National report

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**Better
Government**
FOR OLDER PEOPLE






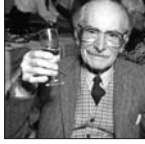


Support for carers of older people

Independence and well-being 5

The Audit Commission is an independent body responsible for ensuring that public money is spent economically, efficiently and effectively, to achieve high-quality local and national services for the public. Our work covers local government, housing, health, criminal justice and fire and rescue services.

As an independent watchdog, we provide important information on the quality of public services. As a driving force for improvement in those services, we provide practical recommendations and spread best practice. As an independent auditor, we monitor spending to ensure public services are good value for money.

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Introduction

Background to the study

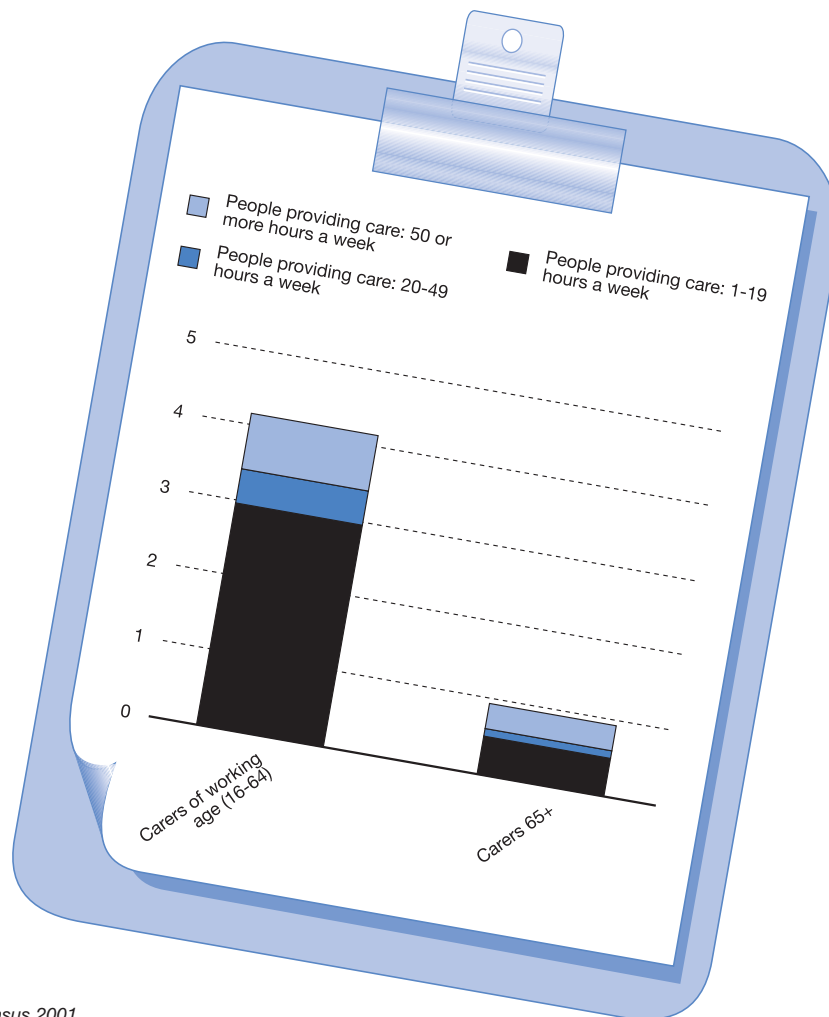
- 1 This is the fifth report in the Audit Commission's series looking at ways to promote the independence and well-being of older people, the previous reports have focused on:
 - what independence means for older people (**Ref. 1**);
 - what local authorities, working with other agencies, can do to promote independence and well-being for all of their older citizens (**Ref. 2**);
 - ways of doing this for older people who have become frail (**Ref. 3**); and
 - the role that assistive technology can play (**Ref. 4**).
- 2 Many frail older people rely on care provided by relatives or friends. This report looks at the nature and extent of help that is currently available to carers and makes suggestions about how it can be strengthened.
- 3 There are currently around five million people in England providing support to relatives or friends in need of care (**Ref. 5**), with approximately 70 per cent of them providing support for older people (**Ref. 6**). These carers are often older people's main source of support, as support from health and social services is necessarily limited.
- 4 The number of older people in the UK is increasing (**Ref. 7**) and in the future, their carers may need to provide even more support to ensure their continued well-being. But carers themselves need care.

Who are the carers?

- 5 Carers are a very diverse group, the majority of them are of working age, although one in six are older people themselves. Half of them live with the person they care for; one-fifth care for 50 or more hours a week; one-third for 20 or more hours a week, and over three-fifths for between 1 and 19 hours a week (**Exhibit 1**). Within this group, support must be flexible enough to adjust to people's individual needs. For example, there are huge differences between the needs of a 45 year old working woman who is providing, or is about to provide, significant care and a 95 year old man caring for his 90 year old wife.
- 6 There is a big turnover of carers of older people: each year, approximately two million people become carers in the UK, with another two million ceasing to be carers (**Ref. 8**). Information, advice and support must therefore be organised so that it is readily accessible to people new to the caring role.

Exhibit 1**Analysis of carers in England in 2001**

Most carers are of working age.



Source: Derived from National Census 2001

- 7 Demographic projections suggest that care could become a bigger issue in the future. Taking into account population changes, it is expected that need for support from carers could rise by 40 per cent in 35 to 40 years time (Ref. 9). At best, the population of carers will remain the same, with changes in lifestyle (for example, more women working) reducing the number who can provide regular care.

National policy and legislation

- 8 Over the last 20 years, successive governments have increasingly recognised the importance of carers, introducing legislation and guidance to support them. The UK is the only country covered by our literature review to give this kind of official recognition to carers (**Ref. 10 and Appendix 1**).
- 9 *The Disabled Persons (Services Consultation Representation) Act 1986* (**Ref. 11**) was the first legislation to acknowledge the existence of carers. It required local authorities to have regard for the carer's ability to provide, or continue to care when providing, services to the disabled person.
- 10 *Caring for People 1989* (**Ref. 12**), the cornerstone of the Government's community care reforms, recognised that 'helping carers to maintain their valuable contribution to the spectrum of care is both right and a sound investment'.
- 11 *The Carers (Recognition and Services) Act 1995* (**Ref. 13**) gave carers the right to ask for an assessment of their own circumstances and needs as part of the assessment of the person they care for. This was the first piece of legislation that gave specific rights to carers who provide substantial and regular care.
- 12 *The Carers and Disabled Children's Act 2000* (**Ref. 14**) gave carers the additional right to request an assessment of their own circumstances and needs, even when the person they were caring for had been offered but refused an assessment. It also gave councils the power to provide services specifically for carers, as well as the power to make direct payments to carers to meet their own assessed needs.
- 13 *The Community Care (Delayed Discharges etc) Act 2003* (**Ref. 15**) makes particular reference to carers in relation to hospital discharge arrangements. It states that, where the carer has asked for an assessment, the social services authority must assess and, after consultation with the NHS body, determine what services it will provide for a carer when the person they care for is ready for discharge.
- 14 The Government also published *Caring about Carers: A National Strategy for Carers 1999* (**Ref. 16**), which set out the Government's aims for carers. It had four main themes affecting carers of older people:
 - **information for carers**, to enable them to 'become real partners in the provision of care to the person they are looking after, with the means to provide that care...with wider and better sources of information about the help and services available';
 - **support for carers**, from 'the communities in which they live, in the planning and provision of the services that they and the person they are caring for use;

- **care for carers**, 'so that they can make real choices about the way they run their lives, so that they can maintain their health, exercise independence, and so that their role can be recognised by policymakers and the statutory services'; and
 - **carers and employment**, whereby carers are encouraged and enabled to remain in work, and 'those carers who are unable to, or do not want to, combine paid work with caring' are helped 'to return to work when their caring responsibilities cease'.
- 15 In March 2001, the Government made its policies in relation to carers of older people more explicit in the *National Service Framework for Older People* (Ref. 17). This set out more detailed requirements for informing, assessing and supporting people who care for older people. In contrast to the *National Service Framework for Mental Health* (Ref. 18), published in 1999, it did not include a separate standard for carers. This decision was based on the recommendations of the Carers External Reference Group who felt that both the integral role of carers play in supporting older people and their needs as carers should be shown throughout the document. The implementation of the *National Service Framework for Older People* (Ref. 17) is to be reviewed by the Commission for Health Audit and Inspection and the Commission for Social Care Inspection in 2004. This will provide an opportunity to identify the extent to which its requirements in relation to carers are being met.
- 16 *The Carers Grant* was introduced in 1999 as a ringfenced grant, mainly to finance breaks for carers. Its value has been increased each year since (Exhibit 2).

Exhibit 2

Value of carers grant

This has increased each year.

Year	Allocation
1999-2000	£20 million
2000-2001	£50 million
2001-2002	£70 million
2002-2003	£85 million
2003-2004	£100 million
2004-2005	£125 million
2005-2006	£185 million

Source: Department of Health

The grant is no longer ringfenced for three-star social services departments and excellent councils in 2003-2004 and will no longer be ringfenced for all councils from April 2004.

- 17 The government issued *Fair Access to Care* guidance (**Ref. 19**) to local authorities in 2002, and expected them to apply it from April 2003. It sets out a framework for local authorities to devise eligibility criteria for receipt of services. Carers' needs are not specifically included in this guidance, but it refers back to the guidance provided in the *Carers and Disabled Children's Act 2000* (**Ref. 14**). This sets out similar risk criteria, such as risks of losing employment, and should influence the way that local authorities approach service delivery for carers.

Given all this, what could carers expect?

- 18 Given the recent legislation and strategies, carers could rightly expect several courses of action to happen.

Identification

- 19 Carers could expect primary care staff to identify them as carers and make suitable reference in their notes (and that of the person they care for), saying that they are a 'carer'. They should also expect councils to identify them as carers when a referral has been made to them, from whatever source.

Information

- 20 They should be able to expect clear, concise, relevant information about their rights and the benefits and support they can get, without asking for it, or at the very least, to be able to find it without looking too hard – from both local and national sources.

Support and services

- 21 They might expect that, with the introduction of the Carers Grant, they would be provided with breaks. Carers who are working or who want to return to work should expect to receive some help.

Assessment

- 22 Carers should expect that any assessments of the person they care for would be done in consultation with them as the carer. They should then be offered an assessment of their needs on top of this. As a result, they could expect to 'become real partners in the provision of care to the person they are looking after...' as the national strategy clearly sets out.

- 23 As partners, carers should be able to expect that they are not only included in consultations with social services whenever any contact is made with the person they care for, but in consultations at the hospital discharge process and at the GP practice – provided the person they care for has given permission. This, they could assume, would lead to their views and needs being taken into account in any care plan for the person they care for, or for themselves. All in all, they should be able to feel that their point of view is critical to the care of the person they care for.

Methodology

- 24 This study has looked at the extent to which these carers' expectations are being realised. It has involved consultations with a range of national organisations, including Carers UK and the King's Fund, about issues currently facing carers and current policy developments.
- 25 It went on to look at the support and services for carers of older people in six different areas of England, covered by county councils, unitary authorities and inner and outer London boroughs. Our thanks go to the staff of these areas who gave so freely of their time.
- 26 Relevant information and data were collected before each visit, ranging from the local carers strategies to the numbers of staff given training relating to carers. A detailed carers survey, developed by the study team, was also sent to around 200 known carers of older people in each area, taken from either the council's or the main carers voluntary organisation's database. Around 40 per cent responded (an average of around 80 responses per site).
- 27 Interviews were held in each area with the social services carers lead officer and a sample of team leaders, care managers and social worker assistants with responsibilities for older people. Case vignettes were used to explore each council's approach to typical situations involving carers and to identify differences in the responses of staff within the same council. Interviews were also held with primary care trust (PCT) staff with carers remits and with strategic health authority staff when a brief for related issues could be identified.
- 28 Senior staff of voluntary organisations serving carers were also interviewed and a focus group was held with carers of older people in each area to explore their experiences and aspirations.
- 29 Towards the end of each visit, a sample of recently opened social services case files of older people with a known carer was examined. This was done to identify the extent to which the carer was recognised and involved, and whether this was affected by the implementation of the *Fair Access to Care* guidance (Ref. 19).

30 We commissioned literature reviews of:

- the effectiveness and cost-effectiveness of support for carers (**Ref. 20**);
- carers of older people and employment (**Ref. 21**); and
- some intranational and international comparisons (**Ref. 10**).

31 We also analysed the findings of joint reviews of social services carried out in England in 2002/03 concerning support for carers of older people.

32 We report on how far support for carers has progressed since the introduction of the national strategy. Our findings have been organised into six chapters:

- Progress with identification of carers.
- Progress with information available to carers.
- Progress with support and services available to carers.
- Progress with assessments of carers.
- Progress with management arrangements.
- The way forward.

1



Progress with identification of carers

The first step in providing carers with the support they need is for them to be identified. Carers benefit from early contact with statutory and voluntary services. The NHS, and particularly primary care, provide the first point of contact for many carers.

- 33 The first step in providing carers with the support they need is for them to be recognised.

Primary care

- 34 The NHS provides many first contact points according to *Caring about Carers: A National Strategy for Carers* (Ref. 16). Its staff have a key role in identifying people who are carers or who have a carer. This applies particularly to those in primary care, since most carers are likely to come into contact with them at some time. A study by Carers UK, carried out in 1998, found that nearly 40 per cent of carers were first told that they were carers by NHS staff (Ref. 22).
- 35 Research has shown that carers see GPs as having provided the best information, help and most practical support (Ref. 22). In other research, carers felt that, of the health professionals they saw, GPs also had the best understanding of their role. They felt that NHS consultants, specialists and other local staff had less understanding of it (Ref. 23). Even so, we found that GPs and primary care staff were generally not identifying carers or referring them on to social services. They were, however, often referring the people the carers were caring for.
- 36 The recent report *Primary Carers – Identifying and Providing Support to Carers in Primary Care* by the Princess Royal Trust for Carers (Ref. 24), concluded that the very process of introducing a system of carer identification and referral in primary care would raise awareness of carers issues among GPs and primary care staff.
- 37 Such identification does not need to be a complicated process. Again, as *Primary Carers* (Ref. 24) noted, normal consultations/home visits present obvious opportunities for primary care staff to identify a caring situation, as does the process of ordering and collecting prescriptions. Providing such consideration for carers prevents them from feeling ignored (which the Princess Royal Trust for Carers noted was a common complaint) and can have a great impact for little or no extra effort.
- 38 Among the six sites, only one PCT was giving GPs and primary care staff any guidance about how to identify or respond to carers of older people. It was also monitoring progress and providing protocols specifying when to refer carers on to social services for assessment or help. Others should be adopting a similar approach, although part of the problem with this lack of identification is that the Government has never published detailed advice to local practices and PCTs about how to identify carers and support them.
- 39 The new GP contract awards only three points for identifying and referring carers to social services, out of a maximum of 1,050 for quality of service. Clearly this is a step forward, but others, for example, a voluntary organisation in Hertfordshire, have taken this issue forward by developing a toolkit specifically to identify carers (Case study 1).

Case study 1

Primary care 'toolkit' to identify carers

National statistics suggest that, at any one time, around 120 out of every 1,000 people on a GP practice register will be carers. The new GP contract, which starts in April 2004, requires a protocol for referring carers to social services. Carers in Hertfordshire, a county-wide carers organisation, has put together a toolkit to help primary care teams to put systems in place to identify carers.

The toolkit includes:

- information about Carers in Hertfordshire and how it can help primary care teams and carers themselves;
- a list of 13 methods whereby primary care teams can identify carers;
- an outline letter, which can be sent by a GP to all their patients, that:
 - invites them to let the practice know if they are a carer;
 - includes a reply slip on which the carer can record their name and address and the name and address of the person they care for;
 - a section on the reply slip asking if they would like their name passed to Carers in Hertfordshire so that they can receive regular, useful information;
- a poster for display in surgeries inviting carers to ask at reception about how the surgery supports carers;
- a leaflet/reply slip to accompany repeat prescriptions, telling patients what Carers in Hertfordshire can provide and asking if they would like to receive a free copy of a quarterly carers newsletter and other carers information or have someone from Carers in Hertfordshire give them a call; and
- a referral 'prescription pad' for members of the primary care team to use to refer a carer to Carers in Hertfordshire and to identify whether or not the referral is urgent (such as the carer needs to be contacted within 48 hours).

To date, take-up of the toolkit has been patchy. Obstacles, such as extra administrative costs have been cited, but 'champions' have managed to overcome these. Carers in Hertfordshire's recent campaign 'Nothing Registered, Nothing Gained' has increased the toolkit's use. Experience indicates that it is best to customise the toolkit to fit each individual surgery's and PCT's requirements.

Source: Audit Commission

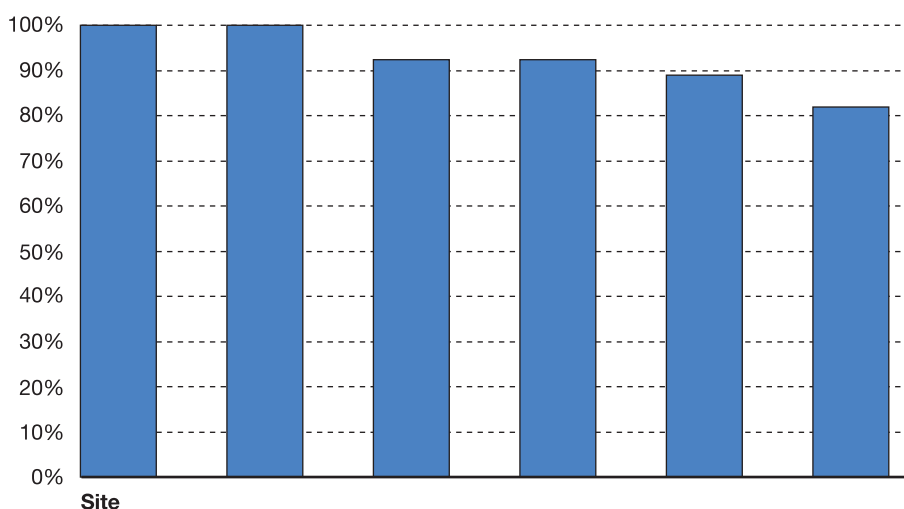
Social services

- 40 A study by the Princess Royal Trust for Carers reported that some carers, particularly those caring for someone with a mental illness, did not think that social services staff understood the carer’s role (Ref. 23). However, our review of a sample of case files revealed that most files did clearly state where there was a carer, indicating that social services are generally identifying when a carer is involved (Exhibit 3).

Exhibit 3

Percentage of case files in which it was clearly stated there was a carer

Case files were generally good at stating there was a carer.



Source: Audit Commission review of individual case files

- 41 However, few authorities were centrally recording carers to provide a count of the number of carers identified, as anticipated by the Government and recorded by the *Social Services Delivery and Improvement Statements (DIS) 2003-04* (Ref. 25). Three of the sites had zero counts while the other three had low counts in their DIS returns. The advantage of building up registers of carers, apart from looking better on Government returns, is the ability to provide a mailing list that allows regular, targeted communications to carers. The disadvantage lies in the fact that people are reluctant to be on registers, particularly those held by a local authority, and if resources are scarce such registers may be too expensive. If a mailing list is developed from the registers, then it need not be restricted to carers who provide substantial and regular care.

National initiatives

- 42 A number of innovative projects were being run by organisations in order to try to identify carers, such as Carers Rights Day. This is an annual event that is organised by Carers UK (who have a national helpline) in which over 250 local groups participate. The aim of this day is to identify and inform new and existing carers about their rights, benefits and entitlements. It was not possible to measure how many new carers were reached by these events.
- 43 Another example is Carers Week, which each year promotes a different theme. It involves over 2,000 local events linking national and local initiatives. Carers UK provide information, resources and a focus: local organisations then organise local events in response.

Self-identification

- 44 Imaginative initiatives and incentives to encourage people to identify themselves as carers can be developed without needing a lot of resources and can benefit both carers and the statutory agencies (**Case study 2**).

Case study 2

Registration and discount scheme

The London Borough of Tower Hamlets has developed a simple strategy to identify 'hidden' carers, by making a discount card scheme an attractive incentive for them to establish contact with social services.

The scheme offers a package of discounts (negotiated at no financial cost to the council) on a range of local goods and services, including discounts on chemists' goods, ironing, cleaning, reflexology, other alternative therapies, cinema and other leisure facilities and restaurants. Upon registration, the carer is also encouraged to have a carer assessment. The authority then has a record of the number of carers who accepted or declined a carer assessment.

The initial aim of the scheme was to increase the number of carer assessments within the borough, but the benefits to the carers and the council are numerous. Not only do carers 'save' money, but they feel less isolated, more appreciated and better placed to receive regular information, updates and newsletters on issues that affect them as carers. The council benefits by building up a register of carers, with information on the ethnicity, age and status of the carers, allowing them to gain an understanding of the possible demand for services or information.

Source: Audit Commission

Conclusion

- 45 Carers benefit from early identification and contact with statutory and voluntary services. Likewise, statutory agencies gain a better understanding of present and future needs and are able to better target information/support. The implications for reducing carer breakdown (and all that comes with this – increased residential/nursing home use, increased hospital admissions, potentially increased need for more intensive packages of care) can only be positive. But one of the keys to this process remains with primary care. If carers are not being identified early on, then they are not being referred to social services and the voluntary sector for support and guidance.
- 46 Once carers are provided with support by social services, case files showed that social services staff were identifying most instances where there was a carer involved – although few were recording significant numbers of carers centrally.
- 47 Nevertheless, all agencies need to build on the progress already made if carers are to be identified, or helped to identify themselves, as early as possible.

2



Progress with information available to carers

Carers need information and advice to help them fulfil their role. Councils and voluntary agencies between them appear to produce quite good-quality written information. However, its provision needs to be more systematic.

48 Once people have been identified as carers they need information and advice that helps them to fulfil their role. The information they need depends on their circumstances. There are a number of national sources of information, such as CarersLine, a telephone helpline, advising carers on their rights, benefits and entitlements.

Written information

49 Local agencies on the whole were producing quite good-quality written information about support and services for carers, as well as about allowances and benefits. The degree of coverage varied, and, while only one site directly provided comprehensive information booklets on all of the issues raised in the study, voluntary agencies often compensated at the other sites, meeting the shortfalls and sometimes acting on behalf of the authorities (**Exhibit 4**).

Exhibit 4

Content and quantity of local literature provided by statutory agencies

Only one site had comprehensive information booklets covering all of the issues raised in the study.

- Good coverage
- ◆ Superficial coverage
- No coverage

	Site					
Information up to date	□	□	–	–	–	–
Covers benefits	□	□	–	–	–	□
Covers assessments	□	◆	–	◆	◆	□
Covers other services	□	–	–	–	–	–
Legal framework	□	–	–	–	–	–
Signposts to other/ more information	□	□	–	◆	◆	□
Online information	□	–	–	□	◆	–
Available in large print/ on tape	□	◆	–	◆	□	–
Provides for different languages	□	–	□	◆	□	–
Lists contact details of key organisations	□	□	–	◆	◆	□

Voluntary sector leaflets collected on site visits

	Site					
Leaflets	3	5	9	5+	2	0
Booklets	1	0	5	1+	0	0

Source: Audit Commission literature and information review

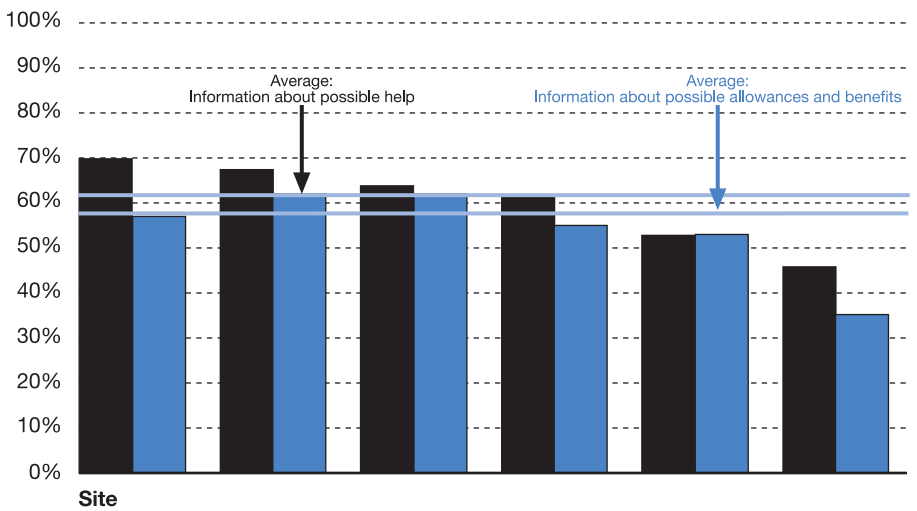
- 50 *The National Service Framework for Older People (Ref. 17)* Standard 2 milestones anticipated that the overall information provided would be reviewed in a systematic way in order to produce an action plan to correct shortcomings. However, this was not happening. Such reviews should be conducted, preferably with the help of carers themselves.
- 51 Most councils were making some good efforts to make this written information accessible to everyone living in their area, using translation services, Braille, various languages, large print, type-talk, audio and distribution through libraries and post offices in rural areas. Over 60 per cent of carers who responded to our survey said that they had received information about support and services, which means that nearly 40 per cent of these identified carers had not. Slightly less than 60 per cent said that they had seen leaflets or booklets that told them about allowances and benefits (Exhibit 5).

Exhibit 5

Percentage of carers who said they had seen some information about possible help and about allowances and benefits

The majority of carers said they had seen information about possible help, allowances and benefits.

- Information about possible help
- Information about possible allowances and benefits



n = 396 (for information about possible help)
 n = 385 (for information about possible allowances and benefits)

Source: Audit Commission survey of carers

- 52 One recent study found that most new carers (who had started caring in the previous two years) were being directed to sources of information and support. However, 20 per cent of carers participating in the study said that they had not been directed to any sources of information or support and more than 30 per cent said that they found sources of information difficult to use (Ref.23).

- 53 Comments by carers who came to our focus groups indicated that more still needs to be done in some areas to present the material more clearly:

GPs don't have any information for carers.

and even if they do, one carer noted:

Leaflets are not properly presented – stuffed in places, back to front, and no one has any responsibility [for them].

- 54 None of the areas were monitoring and reviewing the take-up of this information to any significant degree, nor were they involving carers or carers organisations in doing so. So while our survey indicated that information is getting through to most carers, agencies need to continue to look at ways to increase distribution.

Call centres and websites

- 55 All of the councils we visited had some form of call centre, but there was very little separate recording or analysis of contacts by carers. In fact, only two sites were recording the number of contacts by people over 65. Better monitoring would help authorities to keep track of who is contacting them.
- 56 Some councils are developing a dedicated section for carers on their websites (**Case study 3**), but this is a task for the future as far as some people are concerned. Coverage, though good, is inevitably partial as many people do not have access to the internet. During a focus group at one site, particularly proud of its website for carers, only one-third of the carers present had heard of the site, while none of them had used it. So while the development of websites should be encouraged as a means of providing all relevant information in one place – particularly useful for people who live in rural areas – it needs to be one approach among many.

Case study 3

Internet site for carers in Surrey

A website for carers in Surrey, www.carersnet.org.uk has been run for over three years through a partnership of carers organisations and Surrey County Council. The site provides comprehensive information to carers 24 hours a day and to professionals who support carers.

About 2,700 people visit the site each month (6,600 with repeat visits). The site is linked to the national website, www.carersonline.org.uk run by Carers UK. This is the hub of a network of websites for carers. Carersnet also hosts Care Radio, an internet radio service for carers.

Source: Audit Commission

57 Carers UK reports that councils also refer carers to national sources of information and benefits advice, such as CarersLine.

Word of mouth

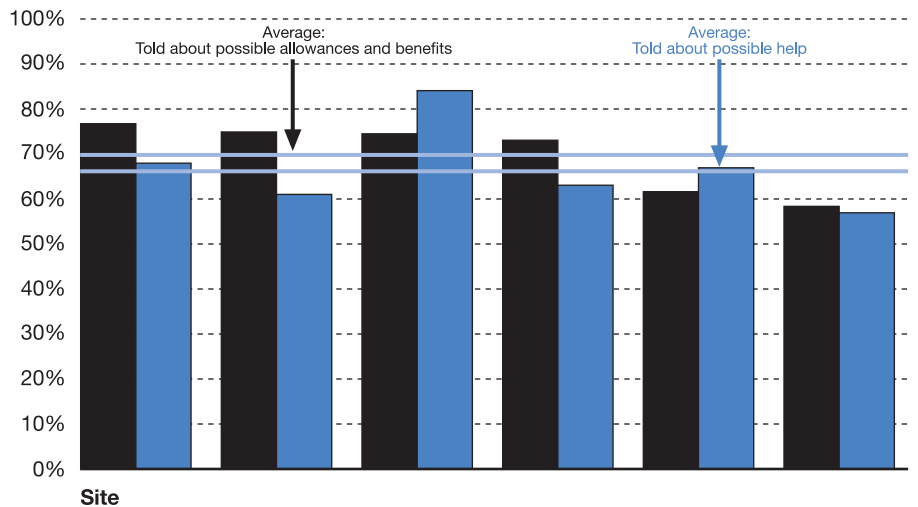
58 Rather more carers reported obtaining information by word of mouth. Information that is provided verbally and backed up with written information, is often preferred by carers. Over 70 per cent of carers said that someone had told them what help might be available, and 66 per cent said that someone told them about the allowances or benefits they might be able to claim (**Exhibit 6**).

Exhibit 6

Percentage of carers who said they had been told about possible help and about possible allowances and benefits

Most carers had been told about possible help.

- Told about possible allowances and benefits
- Told about possible help



n = 393

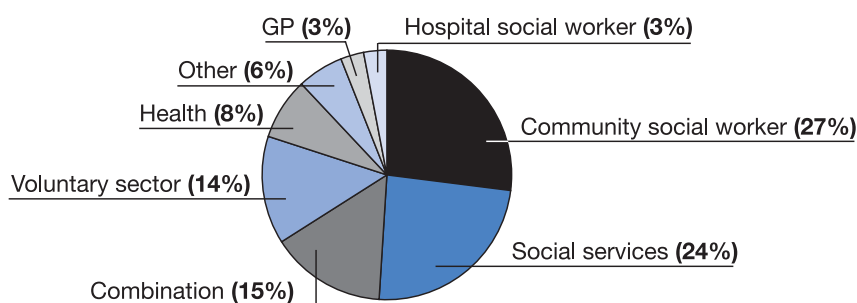
Source: Audit Commission survey of carers

59 This information came from a wide variety of sources. Over one-half of carers who received information verbally received it from social services (**Exhibit 7, overleaf**).

Exhibit 7

Who told the carers

Over one-half of carers who had received information verbally received it from social services.



n = 265

Source: Audit Commission survey of carers

60 Word of mouth is a particularly helpful way to provide information, as the person concerned is able to pass on the information that is relevant at the time, especially if it is backed up by leaflets. However, more needs to be done and care managers need to be kept up to date with the relevant information available. In one site, care managers were unaware of a particularly useful booklet on benefits (for carers) produced in-house. And, again, some of the carers on our focus groups were critical:

...it's piecemeal how you find out about anything.

Social services tell you to get in touch with so and so and it's the wrong information.

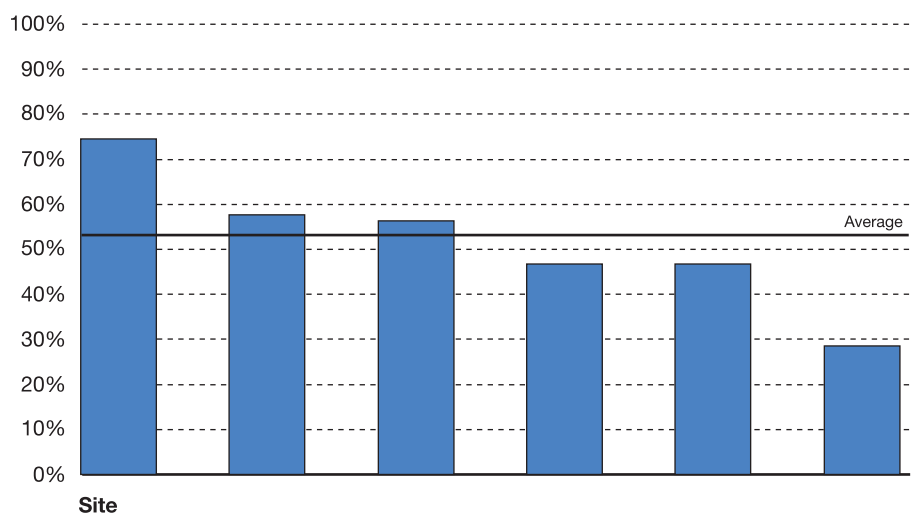
Emergency contacts

61 Only just over one-half of carers said that they had been told who to contact if they needed urgent help or advice with the care of the person they cared for; this generally seemed to be a health contact (**Exhibit 8**).

Exhibit 8

Percentage of carers who said they had been told who to contact if they needed urgent help

Just over one-half of carers knew who to contact if they needed urgent help.



n = 390

Source: Audit Commission survey of carers

- 62 Some reported very negative experiences when they tried to make contact with social services. What was said to be a typical response was given by one angry lady. She said that she rang the emergency social worker line at her **'wits-end'** saying she couldn't **'cope any longer'** and that the social worker had **'insensitively'** responded:

...you're letting us pick up the reins...

Similarly another gentleman simply stated:

There's nobody you can call...

A basic piece of information for all carers should be who to call in an emergency. Part of the assessment process should be the development of an emergency plan, specifying what the carer should do in an emergency and what social services should do if the carer is incapacitated.

Primary care

- 63 Nearly 80 per cent of carers responding to our survey reported that, when the person they cared for gave permission for their GP to share information with them, the GP was, on the whole, happy to do so (varying between 74 per cent and 86 per cent at different study sites).

- 64 In the study *Carers Speak Out* (Ref. 23) carers said that they did not have enough information about:
- the medication of the person they cared for (30 per cent of carers);
 - the side effects of the medication (more than 50 per cent);
 - medical procedures, for example, injections, catheters, dialysis (60 per cent); and
 - the diagnosis or prognosis of the illness or disability of the person they cared for (25 per cent).

Another study carried out in 1998 found that around two-thirds of carers had been given general information about the treatment and medication of the person being cared for, with around 70 per cent satisfied with the information given (Ref. 22). Staff in primary care and NHS trusts need to continue to look at ways to increase the distribution of information to carers.

- 65 When agencies do take the initiative, the impact can be very significant. GPs and primary care staff must be supported so that they can give accurate information to carers, or can refer them on to somewhere that is accessible to carers, such as a voluntary organisation (Case study 4).

Case study 4

GP-attached carers support worker service

In May 2001, the carers support worker service in Crawley was restructured to provide three half-time workers for the 16 GP practices. Each week they provide a regular half-day session for carers in each practice. They also run various groups, including 'keeping carers healthy' and a parent carer group, and attend other support groups to publicise their service. GPs and primary care staff can refer carers to the service and carers can make their own appointments.

Crawley Council for Voluntary Service administers the service. West Sussex Social Services initially supported it with £38,000 from its prevention grant, but now does so from its main budget. The service agreement between them outlines the aims of the service as:

- providing support for carers and preventing carer breakdown by timely intervention and support, via advice, accessible information and networking with appropriate organisations and agencies; and
- encouraging carers to recognise their role and to identify their need in relation to the planning and development of services.

By December 2002 the service had helped over 680 carers. Currently, 542 carers and about 70 former carers are in touch with it (former carers can be supported for up to a year after their caring responsibilities cease). It is anticipated that many more carers are unaware of the service.

A recent evaluation of the service involved questionnaires to GPs and practice managers, questionnaires to a sample of carers and interviews with key stakeholders. It found that:

- many carers do not see themselves as carers and ongoing publicity is needed about the service;
- more carers support workers are needed;
- the service can save GPs' time; and
- all carers were positive about the service because:
 - it reduced their stress;
 - it improved the quality of life of the person they cared for;
 - it gave them an independent person to talk to; and
 - it reassured them to know the service was there.

The groups were helpful in providing information and a place to meet others with similar problems, reducing isolation.

Source: Audit Commission

Voluntary bodies

- 66 Voluntary bodies, especially carers centres, were often a good source of information and support for carers, particularly for carers who had not had any contact with social services. Carers had access to this kind of independent advice and support in five of the six sites.

I would have had a breakdown if not for them [voluntary organisation] and she went on to say ...I can't complain about them...

Most information was from the carers centre. Someone has come along to the centre to talk about benefits.

Without the voluntary organisation you'd never be able to get in touch with social services.

- 67 In one area, the county-wide carers organisation has established a growing database of carers, which it uses for mailing both information and consultation documents and to provide up-to-date management information (**Case study 5, overleaf**).

Case study 5

Voluntary organisation's carer database

Carers in Hertfordshire, a carer voluntary organisation, has 3,491 carers on their database. The database's primary function is to keep records, provide the basis for information distribution and provide management information.

All enquiries from carers are mapped on to the *Carers Compass* (Ref. 26) so that carers needs are segregated into what affects them most. They are then mapped geographically onto PCT districts.

Carers are registered against 'activities' so that information is provided to suit individuals circumstances. All activity to support these registered carers is then logged. This includes:

- telephone calls;
- meetings;
- conferences attended;
- consultations; and
- information distributed.

From this information, Carers in Hertfordshire can improve the support that they offer carers in their present caring roles and can extract how efficiently and effectively they are supporting them. They can also highlight any potential 'gaps' in service.

They have just undertaken a six-monthly liaison report to the PCT and to Hertfordshire County Council Adult Care Services – providing aggregated and anonymous information to them about the numbers of carers in contact with them, a comparison with the number identified in the census and the nature of the contact and queries with them. PCTs have found this very helpful and it has demonstrated that many carers remain 'unidentified'. This subsequently helps PCTs to develop the identification process by GPs and primary care.

An annual accuracy check of records is due to begin in January 2004, which will involve writing to carers to verify all information held. They will be asked specific questions about the kind of service they receive from Carers in Hertfordshire and whether they wish to remain on the list.

Source: Audit Commission

- 68 In another area, the Princess Royal Trust carers centre has been given a major role in the provision of information and support to carers in the area, and has been resourced to do so (**Case study 6**).

Case study 6

Information and support from a voluntary organisation

Princess Royal Trust Carers Centre, covering Bristol and South Gloucestershire, provides a range of information and support services for local carers. These include:

- telephone support and information through the centres 'carersline'. The service provides for Urdu and Cantonese, as well as English speakers, and analysis has shown that 25 per cent of calls are from carers not previously known to the centre;
- one-to-one support/advocacy, including information and advice on entitlement to benefits as well as support services;
- out-of-hours support, which ensures that information is available to carers even on Saturdays and during evenings; and
- Carers News – a half-yearly newsletter circulated to all registered carers to update them on current issues/developments.

Additionally, the centre brings carers together in groups to give them information and support; 138 meetings around the area in one year. It has also organised 'one-off' events, including conferences and participation in national 'Carers Week' with the emphasis very much on providing information about available help and support.

In recognition of the success of these initiatives, and of the expertise of Carer Centre staff, South Gloucestershire Social Services and South Gloucestershire PCT have funded the Carers Centre to undertake a number of specific reviews around information and support for carers. These have included:

- a winter pressures project aimed at preventing hospital admissions of carers or the people being cared for. If an admission does become necessary, the project facilitates prompt and effective discharge from hospital by providing extra emotional and practical support to supplement existing packages for the carer;
- a joint project with the PCT on carers' health needs, which looked at identifying carers' health needs and providing information on care and accessible treatment;
- the Bristol Hospital Discharge Project, which provided relevant information and special short-term support to carers during the discharge from hospital of a family member/friend; and
- the 'Carers Count' project, which was undertaken jointly with the PCT to identify and inform/support carers within a specific area.

Source: Audit Commission

69 However, some voluntary agencies said that they had not been able to sustain their information and advice services at previous levels. They attributed this to reduced financial support from the statutory sector, particularly from PCTs, compared with the district health authorities that they replaced. Agencies need to review how best to use and support voluntary agencies.

Advice and training for carers

70 Many carers of older people would benefit from advice or training targeted at their particular circumstances. In one site, the council and PCTs worked with carers and carers organisations to develop training and advice for carers and to identify the kind of training and advice required. But resource constraints prevented it from being made available to all the carers of older people who stood to benefit.

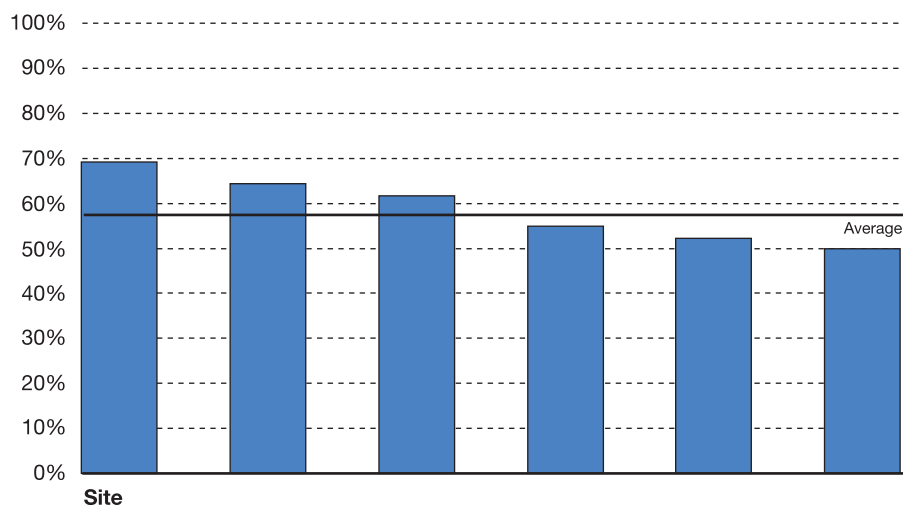
71 Nevertheless, 60 per cent of carers responding to our survey said that they had been given some information or advice to help them look after the person they cared for (Exhibit 9). And nearly one-half (48 per cent) said that they had seen some leaflets or booklets telling them about the availability of this advice (Exhibit 10).

72 The number of carers given any specific training was a very small proportion of the total. The most common form was provided by occupational therapists on moving and handling skills.

Exhibit 9

Percentage of carers who said that someone had given them information or advice to help them look after the person they cared for

Over one-half had received information.

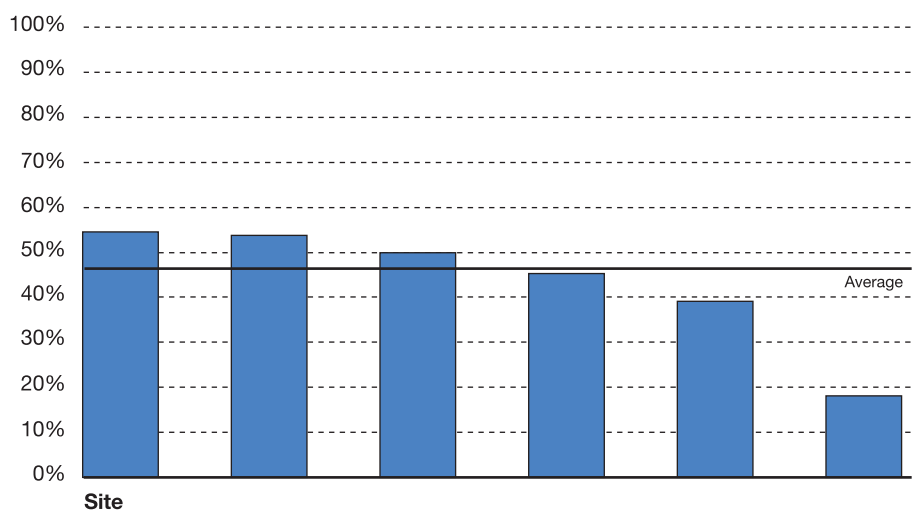


n = 394

Source: Audit Commission survey of carers

Exhibit 10**Percentage of carers who said that they had seen some leaflets or booklets telling them about this advice**

Nearly one-half (48 per cent) had seen some leaflets or booklets.



n = 380

Source: Audit Commission survey of carers

- 73 Councils can provide benefits advice to good effect, and such advice allows people to purchase their own services (**Case study 7**). Given limited resources, such extra help can be crucial. There may be other positive elements to providing this advice. One Carers UK study found that nearly 80 per cent of carers were worried about their finances and 60 per cent of carers said that this was affecting their health. There is also evidence to show that carers refuse services because of worries about how they will manage financially (**Ref. 27**).

Case study 7**Carers benefit take-up project**

Hertfordshire County Council's Money Advice Unit set-up a carers benefit take-up project to provide a targeted welfare benefits advice service to carers and the people they care for. Initially run as a pilot from 1 November 2001 to 31 March 2002, the project has now been included in mainstream funding.

The aims of the project are to:

- promote benefit take-up and income maximisation among carers of disabled people (especially those not receiving other council services);
- help carers to get the benefits information they need;
- raise the profile of carers and benefits among all social services staff; and
- explore opportunities for developing take-up work in partnership with appropriate voluntary organisations and PCTs.

One full-time adviser and one part-time interviewer provide benefits checks, advice and help to carers with claims, and training and information to people and groups working with carers.

The methods used include: housing benefit data matching; targeted distribution of the council's updated *Carers and Benefits* pamphlet; widespread distribution of a short flyer encouraging people to claim the carers' allowance; press releases to local papers; articles in local voluntary organisation publications, for example, Age Concern newspaper; briefing note for people who advise and assist carers; talks and training to carers groups and to relevant county council and health staff; and carers benefits information on the council's money advice unit web-channel.

The project has undertaken an average of 229 benefit checks for both carers and the people they care for each year. Initial assessments are carried out over the phone and advice is given; these are followed up by home visits, when help is given to complete claim forms. Such visits allow ongoing casework, representation and advocacy, where appropriate.

Since the project started in November 2001, carers have received an additional £246,671 in verified benefit gains, which equates with an average weekly increase of £46 per client. Many further potential benefit gains have still to be checked.

Source: Audit Commission

- 74 So while agencies have made good progress in providing advice to carers of various forms, they need to continue to develop ways of helping carers to fulfil their role.

Conclusion

- 75 Provision of good advice and information is crucially important to carers. There is a lot of activity to provide this. Generally, it needs to be more systematic, as envisaged by the national service framework milestones.
- 76 Word of mouth is the most widespread way of getting information across, so it is essential that everyone in contact with carers is properly briefed and supported by up-to-date information packs and leaflets. Wider consultation with carers and carers organisations would help agencies to identify the gaps. A common gap is a lack of clear points of contact for carers when they need urgent help or advice. Another is a shortage of training schemes to help carers to cope. Voluntary agencies have a key role to play, although this will vary in different areas, depending on local arrangements.

3



Progress with support and services available to carers

Support to carers is necessarily limited given their large numbers. Gaps occur at crucial times such as on discharge from hospital, and at night and weekends. The flexibilities of the new types of services can sometimes provide effective, but quite inexpensive, options for supporting carers.

- 77 In addition to information and advice for carers of older people, authorities also provide support in the form of services. This support essentially takes two forms:
- support for the older person(s) they care for; and
 - support for the carers themselves.

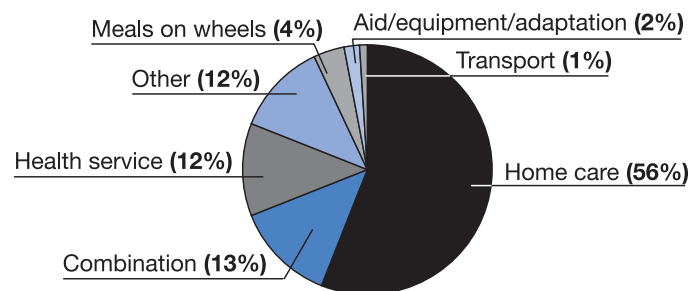
Support for the older person(s) they care for

- 78 Carers tend to benefit from any services provided for the person they care for. Most social services care managers clearly took notice of the fact that a carer was involved when arranging services. Indeed, between 39 and 55 per cent of carers responding to the survey said that they and the person they cared for were receiving services *together*. These were mainly different forms of community care services (**Exhibit 11**).

Exhibit 11

Different kinds of service received by carers and the person they cared for

Most services were home care.



n = 180

Source: Audit Commission survey of carers

Mobile hairdresser at home organised privately. Chiropodist visits at home. Meals on wheels are provided.

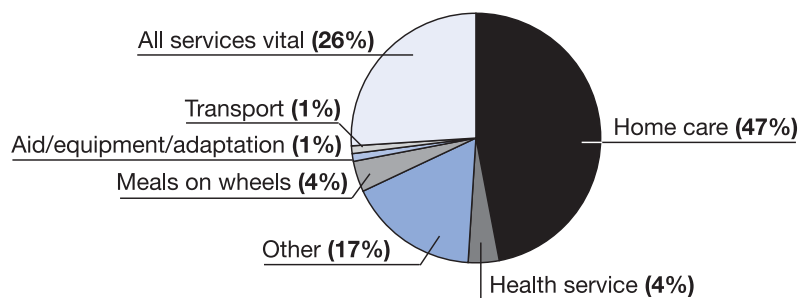
Caring Café on Saturdays run by Crossroads.

- 79 Carers indicated that the most important of these services to help them to continue caring were home care services, for example, washing and dressing the person they care for, helping to get them in and out of bed and helping to prepare meals (**Exhibit 12**).

Exhibit 12

Services that carers said were the most important to help them to continue caring

Home care was seen as the most important.



n = 145

Source: Audit Commission survey of carers

- 80 The responses from the survey also included help with showers, bathing, washing and cleaning as essential. The things that carers said would make these services work better for them were pretty unsurprising. They cited more home care, more personal care, better quality services (especially home care), reliable transport, more daycare and better or different equipment.

It would be better if I had the care assistants coming in every night and morning, but as we have to pay for this I am putting off that day.

- 81 Appropriate equipment, provided promptly, can be a big help to carers. Community equipment services provide the gateway to the independence, dignity and self-esteem of some 4 million older or disabled people and for 1.7 million carers (Ref. 28). The *Independence and Well being 5 – Assistive Technology* report (Ref. 4) highlights the potential of providing appropriate equipment.

Support for carers themselves

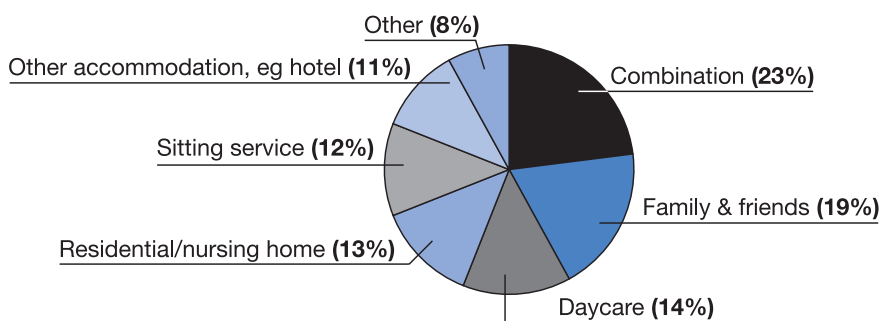
- 82 Analysis of the Census 2001 shows that carers who provide over 50 hours care per week are statistically twice as likely to suffer from poor health as other people (Ref. 5). Other research shows that carers who do not get a break are twice as likely to suffer from mental health problems as those who do (Ref. 29). The health of carers is also more likely to deteriorate over time compared with non-carers (Ref. 30). Carers, therefore, need care in their own right.
- 83 Most support specifically for carers takes the form of breaks. In all of the sites we visited between 58 and 68 per cent of carers responding to the survey said that they had had some kind of break in the last 12 months. These breaks took different forms (Exhibit 13, overleaf).

All you want is to have one day and not clock watch.

My husband went into a nursing home recently for two weeks and I went to panto and two live shows and it was a real tonic.

Exhibit 13 Different kinds of breaks had by carers in the last 12 months

The types of breaks varied.



n = 240

Source: Audit Commission survey of carers

84 However, of the people who had not received a break in the last 12 months, a further two-thirds said they felt they would like one. Some carers remain ambivalent about breaks, which require the person cared for to go into a day centre or institution.

85 Two-thirds of carers who responded to a survey and said that they would like a break wanted this to be day or residential care with one-third wanting a sitting service (Ref. 23). However, one-third said that they would need some financial help to take advantage of such services. The kinds of break that carers responding to our survey said they would like varied. A break in a hotel or similar accommodation was the most popular choice (Exhibit 14).

...breaks away from home – completely away so that I can switch off mentally.

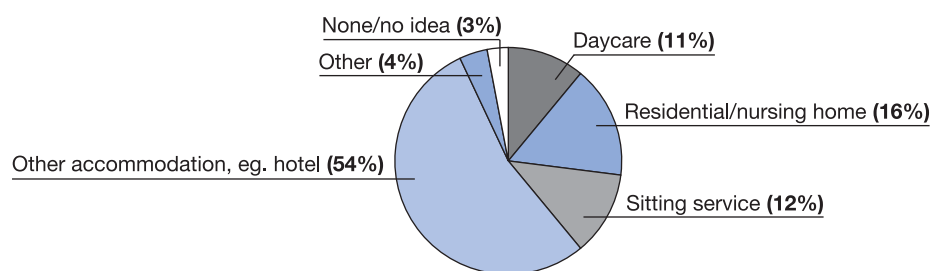
I would like a holiday where I could take my husband and know that he would be looked after if taken ill.

86 The literature review of effectiveness and cost-effectiveness of support for carers of older people carried out as part of this study (Ref. 20) found that daycare and breaks in an institutional setting can delay admission to residential and nursing home care of the person being cared for. However, breaks in an institutional setting can hasten admission where there are bad relations between the carer and the person being cared for, or where the person being cared for is more dependent. There is currently not enough evidence to say whether breaks at home are cost-effective, although both the people being cared for and their carers say that they particularly value them, as carers' mental health can suffer when they do not get a break of more than a few hours (Ref. 29).

Exhibit 14

The kinds of break that carers, who had not had one, would like

Most carers would prefer a break in a hotel or similar accommodation.



n = 140

Source: Audit Commission survey of carers

- 87 Carers also identified other help or services that would help them in their caring role. They were no doubt influenced by what they thought might be available. 'Proper' breaks, house cleaning, financial help, someone to listen and take notice and help with the garden were among the most commonly cited.

...someone to take over from this 'job': dealing with all the correspondence, attending meetings/ endless negotiations with health and... I'm doing all this for no charge!

- 88 Care managers, however, were briefed on the kind of support available in only one site. Authorities could perhaps do more to help their staff to locate appropriate help for carers.
- 89 Under the *Carers and Disabled Children's Act 2000 (Ref. 14)*, provision was made for carers to receive services other than breaks. It gave councils the power/legitimacy to provide non-community care services to carers, but relatively few carers were generally receiving them. However, at one study site the council had begun to make a difference to about 200 carers each year who are hard to help, with solutions that are low cost and flexible. We came across some very imaginative examples where staff had made rather unorthodox arrangements that helped carers in ways that were cheaper and more satisfying for all concerned, such as contributing to relatives' travel costs from Australia to give carers an extended break at less than the cost of a normal break.

Range of support

- 90 On the surface it appeared that all sites offered a range of services designed to support both the person being cared for and the carer. Indeed, many of the carers responding to our survey appeared to be receiving a reasonable service.

- 91 However, the case files that we reviewed highlighted that some sites tended to offer only limited packages of care to the 'unit' (carer and person cared for). For example, one site generally only provided daycare, while another only provided home care. This reflected what many of the carers at the focus groups reported – that in practice they received little help.
- 92 Evidence in one of the literature reviews (**Ref. 20**) suggests that home care can delay admission to residential and nursing home care of the person being cared for. There is also evidence that, as a consequence of targeting resources on those in most need, the community care reforms may have shifted resources away from older people who are being looked after by a carer. For instance, in 1998 an older person living alone was nearly ten times more likely to receive home care than an older person living with a spouse or partner.
- 93 The introduction of the Carers Grant has undoubtedly increased the number of breaks for carers, but it has not been designed to provide more home care. In one area, a voluntary agency has been asked to administer the Carers Grant in its entirety. This enables the voluntary sector to add value by securing additional resources. It also promotes greater consultation about the use of the Grant (**Case study 8**).

Case study 8

Management of the Carers Grant

London Borough of Richmond upon Thames (LBRuT) has delegated responsibility for the distribution of the Carers Grant to the local voluntary sector – Richmond upon Thames Council for Voluntary Service (RCVS).

The rationale behind LBRuT's decision to delegate the management of the Carers Grant was influenced by a number of local factors including:

- the potential for the voluntary sector to add value to the grant allocation by securing additional resources;
- acknowledgement of the RCVS's strong links with local carers and with local carers organisations;
- acceptance that the voluntary sector can offer a greater level of flexibility in agreeing grant distribution arrangements and potentially do this more efficiently than might otherwise be possible; and
- provision of clear management information and transparency as to how the Grant has been spent.

In preparing to administer the grant each year RCVS uses a three stage process:

- *Publicising the availability of the Grant* is carried out in RCVS Carers Briefings and in newsletters distributed by other local groups. Presentations about the grant are also made to minority ethnic and other marginalised groups. Detailed mailshots are also sent to other voluntary organisations that are likely to have an interest in the grant.

- *Consultation about the Grant* is undertaken in a questionnaire survey of all registered carers about the use to which the grant should be put. Carers groups are each invited to send carer representatives to a consultation event designed to further explore survey results and possible responses.
- *An invitation to submit proposals and awards of Grants* are circulated to provider groups from the voluntary, statutory and private sectors that have expressed interest in delivering services. A multi-agency panel, comprising the local branch of Carers UK, LBRuT Social Services, Richmond and Twickenham PCT and RCVS representatives, subsequently considers the bids received.

Thereafter, individual assessments are undertaken by the selected provider groups, while overall responsibility for the scheme, and day-to-day administration, rests with the RCVS, which is wholly accountable to LBRuT for all actions/expenditure.

Source: Audit Commission

- 94 In another area, the council has used the Carers Grant to commission a range of culturally sensitive support and services for its substantial and diverse black and minority ethnic population (**Case study 9**).

Case study 9

Use of Carers Grant in Tower Hamlets

There are currently 14 voluntary organisations in the borough providing services to carers, six of which support carers of older people. They provide a number of services, including rapid response (for carers needing an urgent break away), sitting services, daycare, night sitting services and information and advice on benefits, advocacy, liaison and relaxation events. Tower Hamlets Social Services funds a number of the voluntary organisations' projects. It uses £124,750 (14 per cent) of its Carers Grant to fund projects run by these six organisations that support carers of older people.

One of these is the Access to Respite Care project, which helps Asian (mainly Bangladeshi) carers of disabled adults and older people to get short breaks from caring, and advises them on other services available within Tower Hamlets. Short-term respite of up to eight weeks for carers (in the form of a day centre placement for the person being cared for), or help at home (for cleaning or personal care) can be arranged. The project is able to purchase this support on the basis of an assessment by one of the voluntary organisations within the area. GPs and care managers both refer to the project.

During 2002/03 it:

- assisted over 214 carers;
- arranged nearly 908 units of respite day centre placement and 1,282 hours of home help;
- ran a fortnightly carers group;
- empowered carers to get involved in Social Services' carers services review workshops;

- advocated and negotiated with care managers on behalf of individual carers; and
- represented Bangladeshi elders and their carers in an older people's partnership board.

Other voluntary organisations' projects, specifically for groups from black and minority ethnic communities, administer rapid response services for carers in need of a break and provide additional short-term support services to carers, including a flex-break scheme specifically for the Jewish community, a night sitting service and services for carers of people with mental health needs (including self-training and relaxation groups).

Approximately 450 carers of older people are supported directly with services from specialist voluntary organisations and a great many more receive care, support and information on a regular basis.

Source: Audit Commission

- 95 Analysis of the 32 joint review reports that referred to carers of older people provides additional evidence of the present situation. Only 11 (one-third) of the councils were reported as providing a good or adequate range of support services to carers. The other 21 (two-thirds) were not considered to be meeting carers needs **(Case study 10)**.

Case study 10

Need to support carer before crisis point

- Mrs A is a 75 year old woman with dementia, cared for by her husband. She was assessed by social services in 1999. A package of respite care was arranged.
- The case was not reviewed for two years, during which time Mrs A predictably deteriorated.
- 11 June 2001: Mr A was referred to social services for an assessment for further respite care by the local carers association. The district nurse separately referred Mr and Mrs A to social services.
- Social services placed their case on the 'A' waiting list. This meant that 'unless there is an urgent issue like breakdown of care, hospitalisation of the carer, sickness or a fall etc we leave it on the waiting list' (care manager).
- No further contact was made with Mr and Mrs A and no assessment took place.
- 19 September 2001: The district nurse referred them again, saying the situation was serious. A number of phone calls occurred between professionals.
- 3 October 2001: An assessment took place. Mrs A was moved immediately to emergency respite care for two weeks. A package of home care was arranged for her discharge.
- Following Mrs A's discharge home, the arrangements for home care were changed a number of times, culminating in Mr A declining further help and asking for long-term residential care for his wife.
- 28 November 2001: A carer assessment was completed on Mr A.

- 17 December 2001: Mrs A was admitted to residential care as an emergency. She is now in long-term residential care.

Source: Joint review report

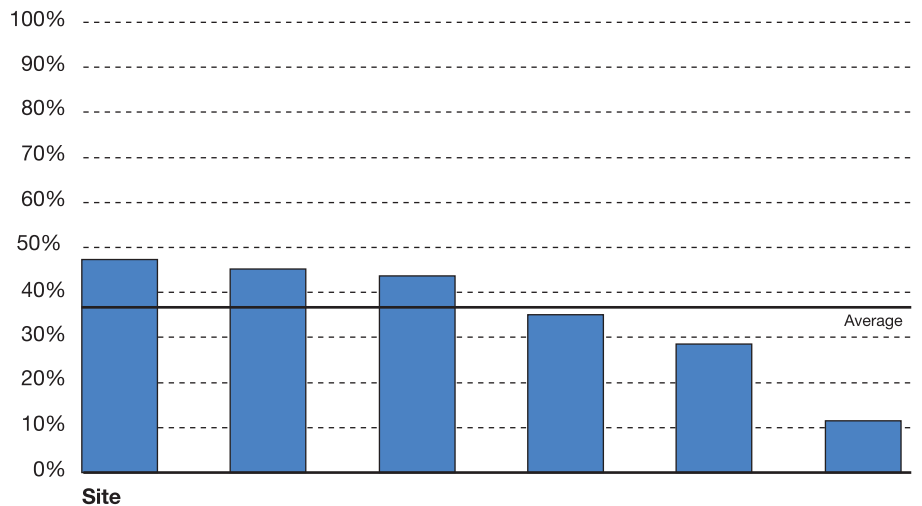
Support at crucial times

- 96 Carers may need additional help and support when the person they care for is discharged from hospital. Only 36 per cent of carers said that they received any extra help at this time (**Exhibit 15**) despite the requirements of the *Community Care (Delayed Discharges etc) Act 2003*. This accords with an earlier study into carers' experiences of hospital discharge that found that 43 per cent of carers said that they were not given sufficient help on returning home from hospital (**Ref. 31**).

Exhibit 15

Percentage of carers who received some extra help when the person they cared for first came home from hospital

Less than four in ten had extra help at discharge.



n = 281

Source: Audit Commission survey of carers

- 97 Yet supporting carers when the person they care for is being discharged from hospital can reduce delays and emergency re-admissions – a new social services Performance Assessment Framework (PAF) indicator for 2003/04. A recent scheme in Bristol and South Gloucestershire shows how (**Case study 11, overleaf**).

Case study 11

The Hospital Discharge/Avoidance of Admission Intensive Carers Support Scheme

This scheme was a partnership project between Bristol City Council, South Gloucestershire County Council and the Princess Royal Trust Carers Centre (PRTCC), which covers Bristol and South Gloucestershire. The project started in March 2002 with two half-time carer support workers and lasted for one year.

PRTCC had identified that the period around the time of discharge from hospital of an elderly or disabled person is extremely stressful for carers. This project involved the setting up of a specialist support scheme for carers of people leaving hospital. Funded through 'Cash for Change', the scheme provided intensive support for carers before, during and for a short while after discharge. The aim was to facilitate effective, stress-free discharge for the carer and older person, to help avoid delayed transfers of care for the statutory agencies and to reduce the number of emergency re-admissions.

The target group was carers of people over 60 years of age. One of the carer-support workers made contact with the carer, while the older person was still in hospital, and provided support throughout the hospital stay. Intensive support was then provided for up to 12 weeks after discharge. The nature of this support included:

- *emotional support* through hospital visits, home visits and telephone support – especially where the carer was taking on a caring role for the first time or where the caring role had changed significantly since admission to hospital;
- *advice, advocacy and signposting* to help the carer to make sense of what was going on around them, providing support at care meetings and advice on how to contact health professionals, what services were available and where to obtain further information; and
- *practical help* in the form of short-term sitting services, help completing forms, dealing with correspondence and assistance with the purchase of equipment using a small support budget.

In the 12 months of the project, there were 97 referrals – greatly exceeding the initial target of 50. Feedback and analysis from the project have shown that providing intensive, individual support to carers during a hospital admission, and in the weeks following discharge, has proved effective both in allaying the fears of carers and in helping them obtain the right information and services. The aim of helping reduce delayed transfers of care was also met, although this has not been quantified in terms of estimated savings.

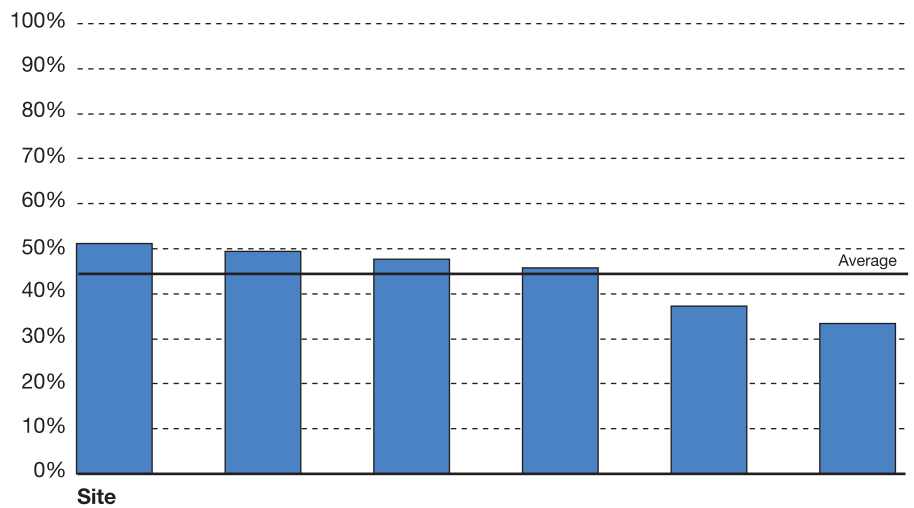
Source: Audit Commission

98 Carers may also need help out-of-hours, but only 43 per cent of carers who said they needed help actually received it. This was generally in the form of an ambulance rather than the most appropriate form of service. (Putting someone back into bed who has fallen out is hardly an appropriate use of an emergency service of trained paramedics, but is often the only service that people can call out-of-hours that will not refuse to attend) (Exhibit 16).

Exhibit 16

Percentage of carers who needed extra help in the evenings and/or weekends and who received it

Only a minority who needed extra help received it.



n = 365

Source: Audit Commission survey of carers

Other forms of support

99 Vouchers for different forms of support were available to carers of older people at two of the sites with direct payments available at three. However, for such schemes to work, a pre-condition is that services of the necessary variety, quality and quantity are available for carers to purchase. Effective market management and quality assurance by the statutory services are vital if direct payments are to provide realistic ways for carers to exercise choice.

100 Direct payments are starting to have an important impact on carers' lives, even though they are not widely used as yet (Ref. 32). Carers welcomed the flexibility that they brought. Agencies need to ensure that these methods of service delivery are better promoted.

- 101 A thriving supply of good-quality services is also needed by carers who wish to pay for support and services themselves. For this to work well, councils need to give market management and monitoring some priority. Given current budget constraints in the public sector, many carers will be in this position.
- 102 In five of the sites, the council and PCT(s) had worked with carers and carers organisations to identify and respond to gaps in services and support. As a result, there were plans at these five sites to introduce or develop further support and services for carers of older people (including a discount card scheme, hospital discharge projects and work with GPs to benefit carers). A mapping exercise to identify gaps in service was being completed at the sixth site. One site was systematically monitoring the impact of providing support or services to carers, for example, on carer breakdown and the quality of life of carers and the people they cared for.
- 103 Intermediate care services should also be a key tool in supporting carers as well as preventing admission to hospital and ensuring that people are properly supported when they leave hospital. One survey of carers providing substantial care found that in 1999, the proportion of people being readmitted into hospital after two months was 19 per cent. By 2001, this had risen to 43 per cent (**Ref. 32**). The proportion of carers who felt that this was due to the discharge being too early rose from 23 per cent in 1999 to 45 per cent in 2001.
- 104 The largest group of carers are of working age and they often need help to stay in employment. The council in one of the study sites was part of the national Action for Carers in Employment (ACE), a European funded project, that has worked with the government, British Telecommunications, the Confederation of British Industry and financial institutions to develop employment practice in the workplace to benefit carers, and shows what can be done. ACE publishes a range of useful information at www.acecarers.org.uk. The statutory agencies at another site had produced a booklet for working carers and employers, aimed at reducing the number of carers who leave employment. The council at a third site had developed a carer-friendly employment policy and hosted a major conference on carers in employment.

Conclusion

- 105 Most carers benefit from any services that are provided for the person they care for, if they are of good quality, flexible and responsive to both their needs. These services take different forms, although carers indicate that home care is the most important to them, and there is evidence to suggest that this can delay admission to residential and nursing home care. It is important that care managers acknowledge the value that carers put on practical help of this kind.

- 106 Support is not always available at crucial times, for example, at night or on weekends, or when the person they care for is being discharged from hospital. These shortcomings need to be addressed. Health services need to actively support carers at these times. Options such as pooled budgets for carers services could be considered. The Department of Health has published a hospital discharge workbook designed for both health and social care staff that makes reference to support for carers (Ref. 33).
- 107 Many of the carers completing our survey appeared to be receiving a reasonable service. However, many of the carers at focus groups reported receiving very little. There appears to be a two tier service. Some of those known to social services are receiving fairly good support, but many who are not known to social services are receiving little or none.
- 108 This is understandable as resources are tight. The Carers Grant provides substantial sums of money and mainstream services provide a lot more – especially when resources to users are taken into account – but given the number of carers, resources per head are still modest. Care managers find themselves gate-keeping very limited resources in the face of raised expectations from carers, given the legislation and national strategy. This places them in the unenviable position of constantly having to say ‘no’ to large numbers of hard-pressed people. This is not sustainable and a different approach is needed.
- 109 We need to strike a balance, ensuring that those with high needs are supported while still putting in place preventative services. The big turnover of carers of older people, combined with any additional resources (for instance from the next two years’ Carers Grant) provide an opportunity to redesign the forms of support provided for new carers. The aim should be to focus on activities that do not cost vast amounts of money but which nevertheless have a big impact, so that the allocated monies are spent in ways that help the majority of carers within the resource constraints. The flexibilities of the new types of services that are now possible can sometimes provide effective, but quite inexpensive, options for supporting carers. Assessment is crucial, as described in the next chapter.

4



Progress with assessments of carers

Effective carer assessments are the key to getting maximum value for money for carers from the resources available. The picture is confusing because of poor recording, both on individual case files and centrally.

110 The previous two chapters have summarised the kind of support provided to carers – in the form of advice and information or as services of one kind or another. As reported earlier, while the resources to fund this support are appreciable, so is the number of carers who need it. If we are to get maximum value for money for carers from these resources, they must be carefully matched to needs. This is why effective assessment is key. Focusing on risk, as set out in the practitioner’s guide to carer assessments (**Ref. 34**), is an important way to balance different carers’ needs.

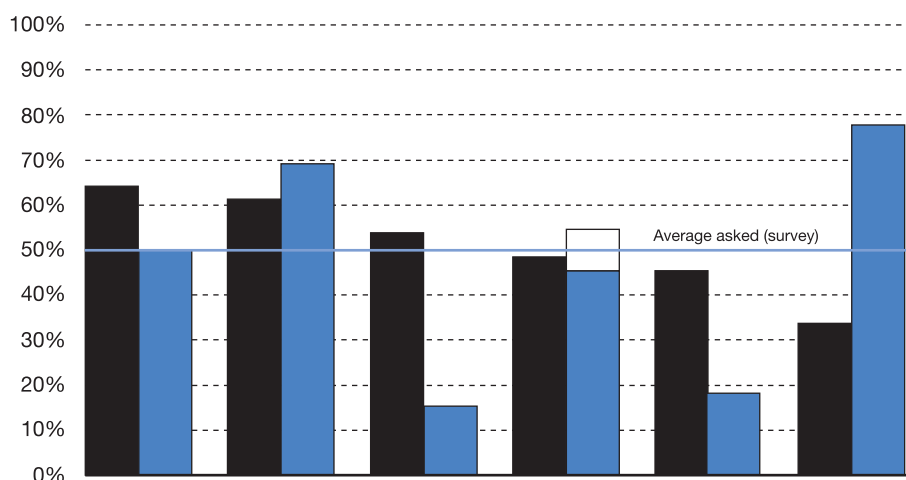
Number of carer assessments

- 111 All carers providing substantial and regular care have the right to an assessment, either jointly with the person they care for or separately if they prefer. But getting an accurate estimate of the number of assessments being offered and carried out proved difficult.
- 112 The percentage of user and carer assessments carried out in 2002/2003 that were reported as being carer assessments varied in the 6 sites from 6 to 54 per cent. These data were included in the sites’ *Social Services DIS 2003/04*, and were, at the same time, returned to government statisticians. They were published as social services PAF indicator D42 2002/2003. However, they did not match what carers responding to our survey reported or what we found in our reviews of case file.
- 113 On average, around half of the carers responding to our survey said that someone from social services or the NHS had asked if they needed any help as a carer. This was supported by our findings from our sample of case files, although the variance here was greater (**Exhibit 17, overleaf**). On the basis of our observations, the study suggests that the D42 indicator data, returned to the Department of Health and the Social Services Inspectorate, probably inaccurately reflect the level of carer assessments actually carried out in relation to the definitions in the guidance. Efforts to improve the external monitoring of the quality of the data from councils are, therefore, to be welcomed.

Exhibit 17 Percentage of carers provided with an assessment

The numbers of carers being offered help varied.

- Asked if they needed any help (survey)
- Case files that clearly recorded an assessment offered
- Case files that indicated an assessment probably offered



n = 385

Source: Audit Commission survey of carers and Audit Commission review of individual case files

114 Carers appreciated being offered an assessment:

Nice if someone asked if you need anything

but none of the sites maintained a record of how many carers of older people had been offered and refused an assessment (whether separately or jointly with the person they cared for), although one council said it could retrieve this from its electronic recording system. However, we did find this recorded in a few case files.

115 This lack of data may simply reflect partial recording rather than actual assessment practices. But the case file review and our survey of carers do indicate that carer assessments are by no means universal.

116 A recent survey of carers found that 32 per cent of carers had a carer assessment (Ref. 32). Only 4 of the 39 joint review reports we analysed (10 per cent) said that the councils concerned were making reasonable progress with carer assessments, whilst the rest (90 per cent) were criticised for not meeting the requirements regarding them. They indicated that carer assessments were not being widely promoted and that carers were often unaware that they were entitled to one (Case study 12).

Case study 12

Extracts from joint review report

The council has very weak performance in undertaking carer assessments – only 3 per cent of assessments undertaken were for carers.

A lot of people are still not aware that they can ask for a carer assessment, and social workers are not proactive in telling people...nor about the benefits allowed if a carer.

Few of the carers whom the joint review team spoke to were aware of carer assessments, and many staff seemed to feel that carers did not want assessments.

- 117 Carer assessments are vital if best use is to be made of resources and the right support provided for carers and the people they care for. Agencies need to increase their efforts to make sure that carer assessments are carried out. The introduction of the single assessment process (SAP) may provide an opportunity to strengthen current arrangements.

Quality of carer assessments

- 118 Estimating the quality of carer assessments, carried out either jointly with the person they care for, or separately, is even more difficult than estimating their number. A recent survey (**Ref. 23**) found out that 81 per cent of carers who were assessed and who had health problems said that the assessment involved health issues. It was reported by 46 per cent of carers who had decreased their working hours or given up work that their assessment covered employment. Both of these are positive indications, although of course they could be better. But only 28 per cent of assessments addressed contingency planning to deal with emergency situations.
- 119 It was usually not clear from the case files whether a carer assessment had followed the Government's practitioner's guide to carer assessments (**Ref. 34**) or not. And there was no recording of whether the carers involved had been given copies of the Government's carer's guide to a carer assessment (**Ref. 35**), or similar materials produced by other organisations, at any stage. Again, this may reflect poor recording practice, but care managers rarely appeared to have heard of either of these guides.
- 120 Very few case files indicated that the carer had been given any written information about the results of their assessment and fewer still contained a specific care plan for carers. In fact, we found a small number of these at one site only. However, Carers UK's research (**Ref. 32**) indicated that after 2001, 62 per cent of carers assessed were getting written summaries of their assessment, although this still meant that over one in three carers were not. If there is nothing on the file, it is difficult to see how the local authority can monitor the situation or ensure quality.

121 At two sites some carers were offered a carer self-assessment form. However, little or nothing appeared to be done with these forms after completion and return by the carer, other than to include them in the count of the number of carer assessments carried out.

122 In part, this reflects the ambivalence of care managers and others to carer assessments that 'aren't leading anywhere'.

One lady was told by a social worker that she was not going to get anything as a carer so *'...she shouldn't bother with the carer assessment...'*

123 This is indicative of a 'gatekeeping' approach to assessment. But in practice, during the process of carrying out a carer assessment, the assessor can potentially identify lots of ways of helping the carer at little or no cost – by providing some relevant contacts, a better understanding of the older person's medical condition, or some advice about local and national voluntary agencies who might provide further relevant information and/or peer support. If nothing else, the assessor can provide a sympathetic ear.

124 By gaining a better understanding of the carer's circumstances, worries and difficulties, care managers should be better able to assess any risks and to provide some reassurance. Agencies need to review how they can monitor and improve the quality of assessments, record them properly and pass written summaries to carers.

Involvement in assessments of the people they care for

125 In practice, care managers and primary care staff may be taking the carer into account when assessing the person being cared for – albeit in a less systematic way than anticipated by the legislation. A large majority of carers said that they had been involved when someone assessed the needs of the person they were caring for; this was again supported by evidence on case files at most sites (**Exhibit 18**).

Exhibit 18

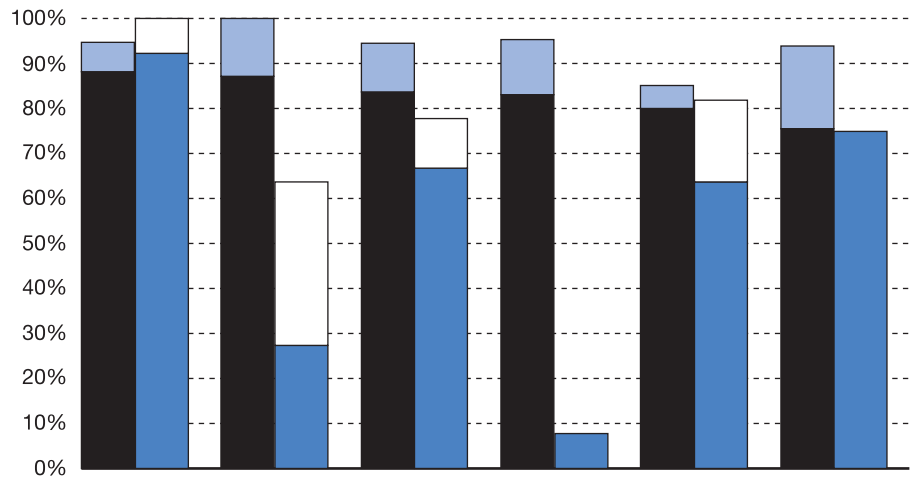
Percentage of carers who had been involved in the assessment of the person they cared for

Generally carers were involved in the assessment of the person they were caring for.

- Said someone involved them
- Said someone had partly involved them
- Case files that clearly indicated carers were consulted
- Case files that indicated carers were partly consulted

n = 296

Source: Audit Commission survey of carers and Audit Commission review of individual case files

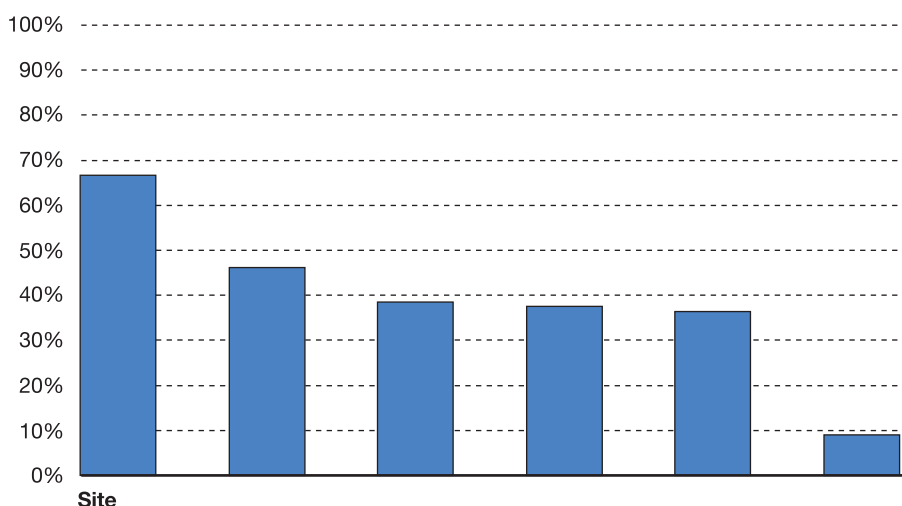


126 The case files indicated that only 38 per cent of carers were given any written information following their involvement in the assessment of the person they cared for (**Exhibit 19, overleaf**). Agencies should be providing written information to carers following assessments.

Exhibit 19

Percentage of case files in which carers had been given written information about the results of the assessment of the person they cared for

Thirty-eight per cent of carers were given any written information following the assessment.

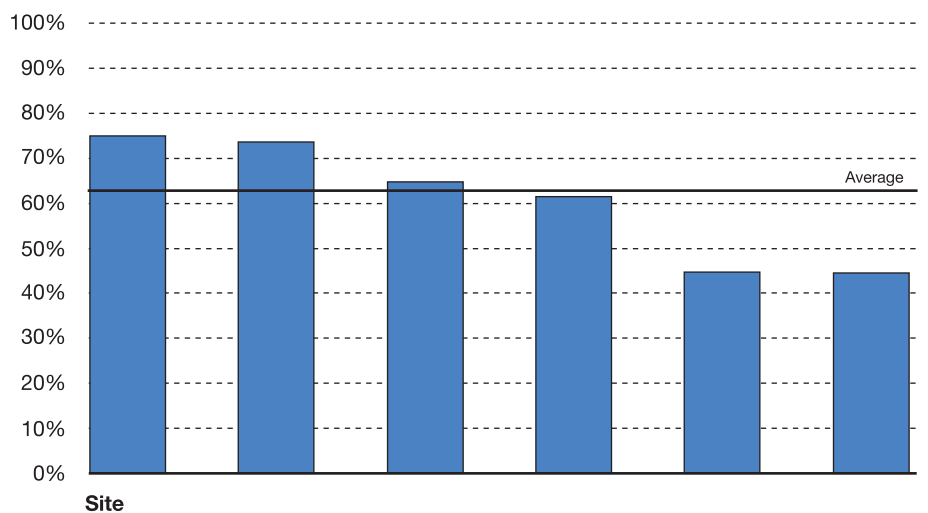


Source: Audit Commission review of individual case files

127 Both the national strategy and earlier guidance on carers legislation (Ref. 36) highlighted the importance of ensuring that carers are involved at the point of hospital discharge, to ensure the right support, reduce readmissions and protect carers' own health and well-being. In our survey, after the person they were caring for had been admitted to hospital, around 60 per cent of carers said that they had been involved in planning their discharge (Exhibit 20). This still left 40 per cent of carers who said that they had not been involved in a process that affects them fundamentally. These results concur with earlier studies on carers' experiences of hospital discharge and suggest that little has changed in the past few years (Ref. 31). NHS staff should routinely involve carers in discharge planning (Ref. 33).

Exhibit 20**Percentage of carers who said someone had involved them in planning the discharge from hospital of the person they cared for**

Around 60 per cent of carers had been consulted on hospital discharge.



n = 209

Source: Audit Commission survey of carers

- 128 Some social services team leaders said that the pressure to discharge patients from hospital as soon as possible makes it difficult to adequately consult and engage with carers. They felt that carers' involvement in discharge planning would continue to be piecemeal until this conflict was recognised and addressed.

There's always a tension between the consultants and us – it's an 'us and them' atmosphere...

And the focus groups included some very negative comments on discharge planning:

The discharge process was a shambles.

Conclusion

- 129 Getting the balance of support right, through good assessment, is not only crucial to carers and the people they are caring for, it also determines how cost effectively that scarce public funds are used. Carer assessments are crucial if we are to deliver value for money and give carers the information and advice that supports them in their role. But the picture that emerged was confusing.

- 130 It appears that many carers are not being assessed separately in their own right, although they are being included in the assessment of the person they care for. Given that the services they value are often the ones (like home care) that are provided to the person they care for, this inclusion is helpful. But there is much to be gained by providing separate assessments for carers in specific situations, for example, where there is a potential conflict of interest.
- 131 Those conducting carer assessments need to move away from a 'gatekeeping' approach and instead see assessments as an opportunity to engage with carers as real partners in the provision of care – mostly exploring with them what help and support they might access at little or no cost.
- 132 The picture is particularly confusing because of poor recording, both on individual case files and centrally to provide overall counts of activity, as required by the PAF. It would be very helpful if a more systematic approach to carer assessments could be matched by better recording – with care plans for carers and the people they care for drawn up and shared with them.
- 133 However, all of this takes time – a commodity in short supply, as described in the next chapter.

5



Progress with management arrangements

Sound management arrangements are needed if information, services and assessment are to be delivered more systematically. These should allow some support and recognition for many more carers.

Care managers

- 134 Information, services and assessment must all be co-ordinated and delivered in a systematic way, which requires sound management arrangements. Central to the support of carers are social services care managers, who provide most of the assessment and information, as well as co-ordinating services. But they are under considerable pressure.

- 135 The picture we gained from the views expressed by carers and care managers highlighted considerable tensions. Carers were frustrated and angry at some care managers' attitude and approaches to them. This contrasted rather starkly with their views about other professionals, such as district nurses and occupational therapists, for whom they had nothing but praise (especially for district nurses).

- 136 Some social services team leaders referred to the large caseloads of care managers. They suggested that this was the biggest factor determining how carer assessments were approached. Care manager resources had not been increased in any of the sites in recognition of the additional work associated with carrying out these carer assessments, though one site had invested in specialist workers to help with them.

We don't have time to do carer assessments as well...

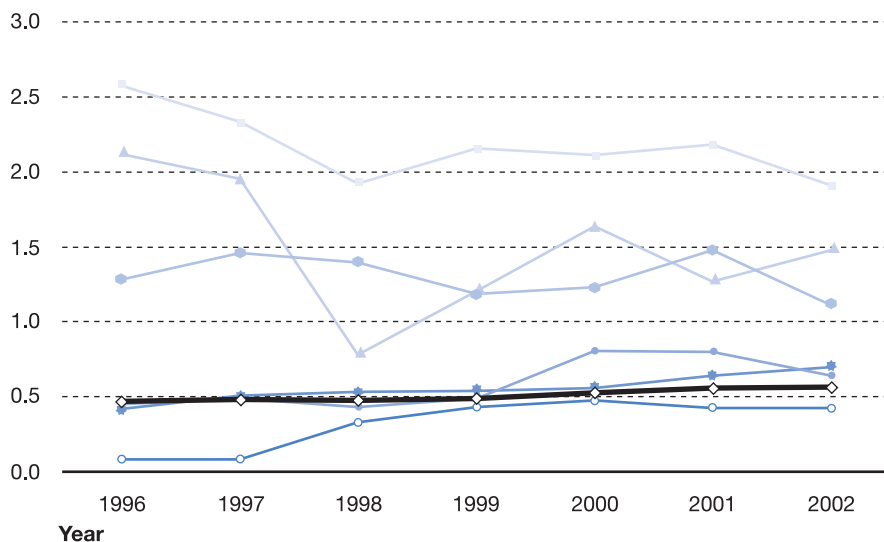
- 137 The number of care managers for older people varied quite considerably between sites. There was evidence of both increases and decreases in their numbers over recent years (**Exhibit 21**).

Exhibit 21

Social services care managers for older people per 1,000 65+ population

One site had five times as many care managers per head of population as another.

◇ England average



Source: Derived from Department of Health Referrals, Assessments and Packages of Care returns

- 138 This represents a significant difficulty, because if there are not enough care managers, then it is unlikely that effective assessments will be carried out. This, in turn, means that the potential gains in cost effectiveness reported in the previous chapter will be difficult to realise.
- 139 But it is not only numbers that count. Care managers and others also need the necessary skills and mindset to undertake carer assessments successfully. The gatekeeping approach has already been described and many care managers remain wedded to a service-led approach. If carers are to receive the support they need, new skills are required – including greater awareness of the needs of carers and how to approach carer assessments.

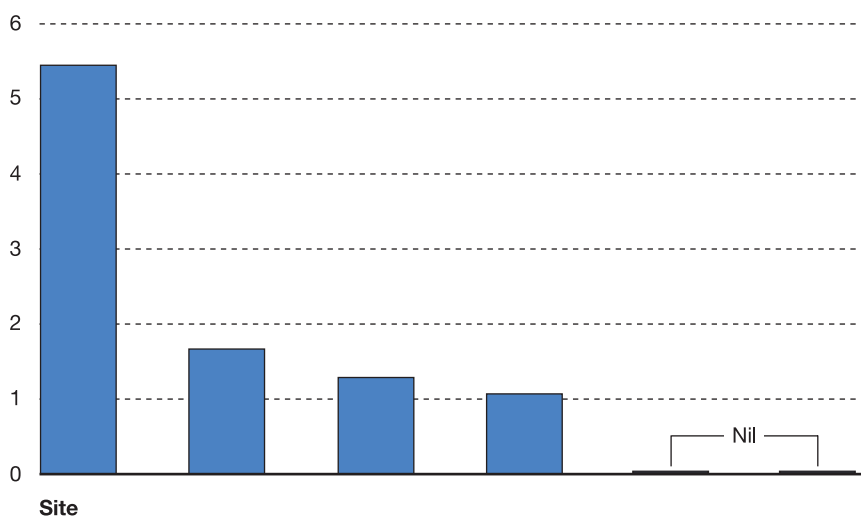
Carer awareness training

- 140 Only four of the six sites appeared to recognise the importance of raising awareness of carers and the problems they face to staff. But even within these sites, staff gave us different information about how long the course was (responses ranged from half a day to two days), whether it was regularly repeated, was actually taking place at the present time (several care managers at one site did not know about it – even though it was taking place) and seen as useful by staff themselves.
- 141 At one site, some care managers felt that the training insulted their professionalism and abilities as trained social workers, with one of them saying:
- We've been told it's no good anyway.*
- 142 The number of staff who had received carer awareness training last year varied greatly (**Exhibit 22, overleaf**).

Exhibit 22

Staff receiving carer awareness training in 2002/03 per 1,000 65+ population

Only four sites provided evidence of any carer awareness training.



Source: Audit Commission information request

143 Without such training, poor practice may persist. One carer wished the care manager:

...wouldn't come and review the situation of my wife [who has dementia] when I'm not there.

Another carer reported:

Social services rang me at home but spoke to my husband [whom she cared for]. He told them everything was okay. But I [as the carer] wasn't even spoken to...

144 These anecdotes point to the need for more carer awareness training, not only for care managers, but also for staff in primary care (including GP surgeries), managers and even board and council members. Provision of carer-awareness training within the professional training and continuing professional development of doctors, nurses and social workers would heighten awareness of carers' needs.

Carer assessment training

145 In general, councils recognised the importance of providing training for staff who carry out carer assessments, although some care managers did not see this as a priority, and again, referred to their professional training:

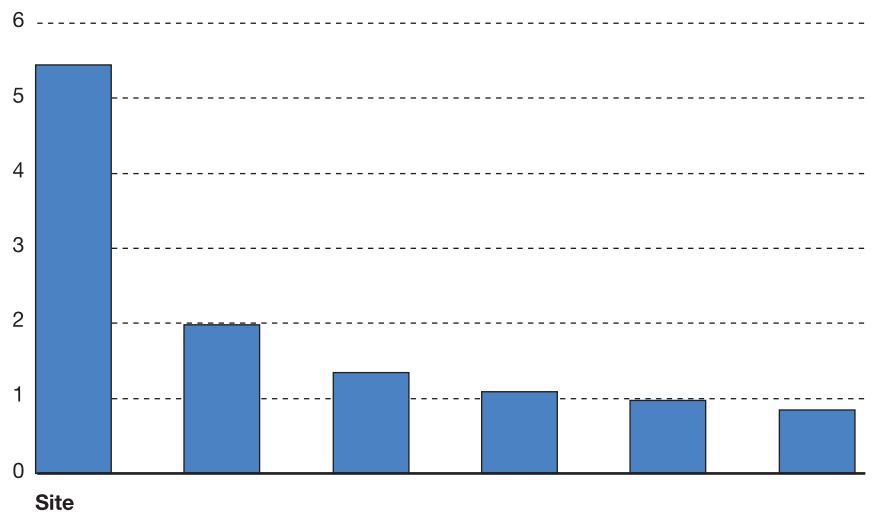
...but we're trained social workers, it doesn't apply to us...

- 146 The number of staff who received carer assessment training last year varied greatly (Exhibit 23).

Exhibit 23

Staff receiving carer assessment training lasting a minimum of one day in 2002/03 per 1,000 65+ population

All of the sites provided evidence of how many staff had received carer assessment training, but the number varied.



Source: Audit Commission information request

- 147 Most care managers (except at one site) acknowledged that they had not read the Government's practitioner's guide to carer assessments (Ref. 34) and/or were not aware of the carers' section in the hospital discharge guidance (Ref. 36).

...haven't seen it and don't need it...

Again, poor practice may be the consequence:

They assess the husband and make little reference to you.

- 148 If a care manager is ignorant of new rights and provisions for carers this can seriously disadvantage the carers with whom he/she has contact. This is not acceptable. Continuous professional development is the norm for other professions and needs to be the same for social workers.

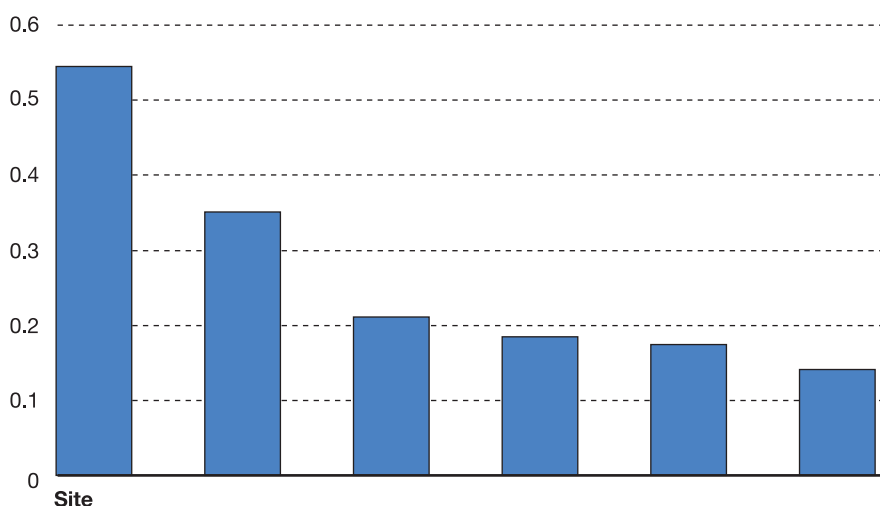
Specialist staff

149 All six sites have appointed specialist staff to lead the development of effective support for carers. They work with all carer groups, although carers of older people are by far the largest group. The number of staff specifically designated to work with carers varied between sites (**Exhibit 24**).

Exhibit 24

Professional social services staff working specifically on support and services for carers (per 10,000 65+ population)

The number of dedicated staff varied.



Source: Audit Commission information request

150 These specialist staff are playing a key role in leading and co-ordinating local agencies' approach to carers. They are the natural focus for development work with care managers and others, but they also help agencies to shape their overall strategy to carers, as described in the next section.

Local strategies

151 If support for carers is to improve, agencies need to set out their intentions clearly. All of the sites had some form of multi-agency carers strategy document, although the extent to which these documents addressed issues raised in the legislation and guidance varied widely (**Exhibit 25**). One study site emphasised that their strategy was not available in a single accessible document but was a series of strands of work which, together, constituted their strategy, and that the exhibit did not accurately represent their situation.

Exhibit 25**National policies reflected in local carers strategies**

All the sites had some form of multi-agency carers strategy document, though their age, structure and content varied enormously.

- Good coverage
 Superficial coverage
 – No coverage

	Site					
Information						
Provision of information	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	–	<input type="checkbox"/>
Housing support/advice	–	–	<input type="checkbox"/>	–	–	–
Training and support to care	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Financial security	<input checked="" type="checkbox"/>	–	<input type="checkbox"/>	–	–	<input type="checkbox"/>
Development of a communication strategy	<input checked="" type="checkbox"/>	–	–	–	–	–
Support and services						
Establishment of a range of services to give carers a break	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	–	<input type="checkbox"/>
Supporting carers through technology	–	<input checked="" type="checkbox"/>	–	–	–	<input checked="" type="checkbox"/>
Direct payments	–	–	–	–	<input type="checkbox"/>	<input type="checkbox"/>
Support for black and ethnic minority carers	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	–	–	<input checked="" type="checkbox"/>	–
Working carers	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	–	–	–	<input type="checkbox"/>
Emotional support	<input checked="" type="checkbox"/>	–	<input checked="" type="checkbox"/>	–	–	<input type="checkbox"/>
Involving carers in service planning/provision	<input checked="" type="checkbox"/>	–	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Assessment						
Ensuring carers are aware of their right to an assessment	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	–	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Carers health needs	–	<input checked="" type="checkbox"/>	–	–	–	<input type="checkbox"/>
Quality of life	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	–	–	<input type="checkbox"/>
Carer involvement in care planning	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	–	–	–	<input type="checkbox"/>
Carer involvement in discharge planning	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	–	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Management arrangements						
Performance monitoring to include regular surveys of carers	–	–	–	–	–	<input type="checkbox"/>

- 152 The implementation of these strategies needs to be monitored and reviewed. Only one site had managed a partial review to date.
- 153 Clearly, strategies need to be taken seriously. They are the foundation for the development of a comprehensive approach to carers and need to be multidimensional. They should also set out clearly how agencies are proposing to prevent carers from breaking down and being unable to care any longer. If successful, they should reduce the number of admissions to hospital and residential care and the associated expenditure.
- 154 The national quality standards for local carer support services (**Ref. 37**), developed as part of the implementation of the national carers strategy, can be used to help check local progress. The *Carers Compass* (**Ref. 26**), an audit and performance tool for statutory and voluntary agencies and *How Good is Your Service to Carers?* (**Ref. 38**), an implementation tool, may also be helpful.

Carers and employment

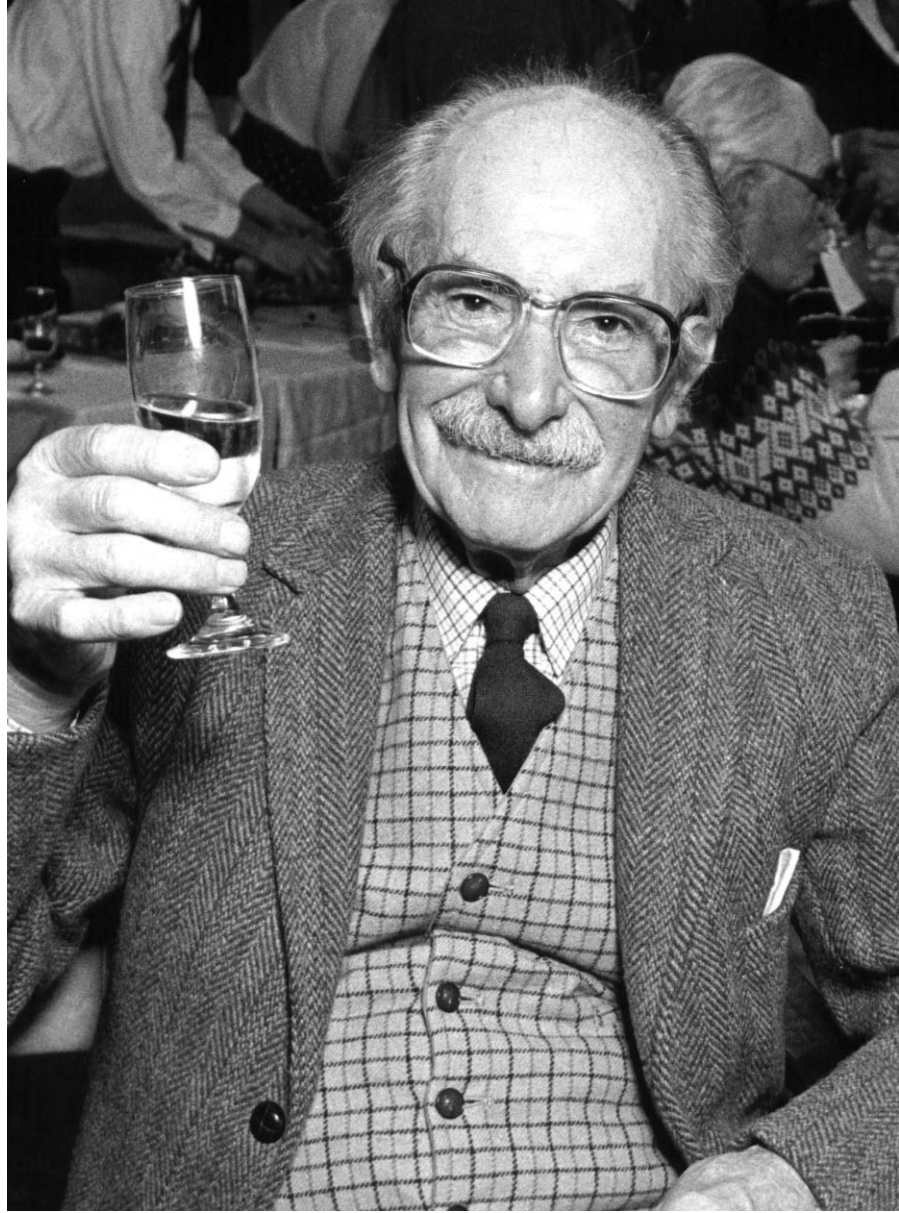
- 155 Local strategies also need to address the important area of carers of older people in employment. This section summarises the literature review on carers in employment undertaken by Linda Pickard of the Personal Social Services Research Unit at the London School of Economics (**Ref. 21**).
- 156 Although most carers work (around two-thirds of all carers), caring can have a negative effect on their employment, requiring them to work shorter hours or part-time, withdraw from the labour market or take early retirement. They may have to accept lower incomes, diminished career prospects and reduced occupational and personal pensions. Employers themselves can face lower production, increased absenteeism and high staff turnover from carers. But the costs of failing to support working carers can be high, and employers can gain if they make efforts to do so. A widely cited figure is that replacement and training costs can be as high as around one to one-and-a-half times an employee's annual salary.
- 157 However, there is still little evidence that many employers are aware of the specific needs of employees caring for elderly relatives. A number of measures can help them, particularly time off for emergencies, carer-friendly working arrangements (for example, flexible work hours) and working from home. But relatively few carers are working in a flexible manner. Flexible and part-time ways of working are often only possible for people who earn enough money or are supported by a partner who is working. And flexible working patterns can be a problem for small employers. Carers are usually only able to combine work and caring because they provide relatively low levels of care. Services are generally not flexible or reliable enough to support working carers who provide higher levels of care. The kind of services that these carers would like include home care, suitable daycare, alternative care services, meals on wheels, care assistants and sheltered housing.

- 158 The public sector appears to be ahead of industry and commerce in developing policies to support staff with caring responsibilities. Employers in the public sector are particularly concerned about the problems of recruiting and retaining their workforce. They face shortages of staff, especially trained staff, and recruitment and retention difficulties with lower-graded staff. Public sector organisations, therefore, have a particular interest in helping their workforce to reconcile caring and employment. Most councils have a number of forms of leave aimed at carers. They also have a variety of flexible forms of working. Workplace counselling is also widely available. However, not all arrangements in councils are available to all employees. Following the implementation of the NHS *Improving Working Lives* initiative (Ref. 39), all NHS organisations should now have policies for supporting staff who are carers.
- 159 The Government supports good practice in achieving an appropriate work/life balance. But for carers who are working, the effectiveness of current policies in local authorities and the NHS is reduced by:
- low take-up of measures intended to support carers, which are discretionary in nature and may label employees as in need of help;
 - the prevalence of a culture of long working hours in the public sector;
 - a move to part-time work, which can mean having to accept a demotion; and
 - long-term effects on pension rights of part-time work.
- 160 To improve the situation it is suggested that:
- existing arrangements should be regularly monitored and reviewed;
 - there should be a change of culture in the workplace to give greater recognition to the needs of employees with caring responsibilities;
 - a range of practical responses should be developed, for example, telephone helplines, putting people in touch with each other and introducing them to carers networks;
 - compassionate leave should be interpreted more flexibly;
 - a framework and ethos should be developed that allows more working from home where possible; and
 - there should be more access to counselling services.
- 161 The introduction of employment practices that are sensitive to carers' needs, especially in public sector organisations, is leading to people becoming more 'carer aware'.

Conclusion

- 162** The anger and frustration from the carers was worrying. On site visits the attitudes encountered from some of the care managers were surprising. There appeared to be some professional ambivalence toward training and use of guidance, tools or aids. This reflected some of what we had heard from the carers. The defensiveness and lack of sensitivity of some care managers was perhaps the most striking thing we encountered on our visits.
- 163** In part, this may be explained (if not excused) by the difficult position that care managers find themselves in. They have little time and resources to allocate to carers. Care managers' work loads and numbers of care managers need to be kept under close review. However, there is no excuse for not being up-to-date with new guidance, new legislation and developments in ways to support carers.
- 164** The statutory agencies also need to turn their approach around and focus on:
- 1.** Providing good advice, information, training, guidance and emotional support to carers;
 - 2.** Being sensitive to their needs, as well as to those of the older person, when providing packages of care using 'mainstream' services; and
 - 3.** Providing breaks selectively to carers in households at risk of breakdown, in a way that is sustainable, given the remaining funds after steps 1 and 2.
- 165** This hierarchy should allow some support and recognition for many more carers, and provide a less defensive role for care managers, as the gatekeeping of resources will no longer be their primary role. They become advisors and supporters first and gatekeepers as a last resort.
- 166** While the situation of carers in employment is improving in places, much still needs to be done. Councils and the NHS should pay particular attention to the needs of staff who are carers, providing a range of support for them which enables them to combine working and caring.

6



The way forward

The present situation is not satisfactory. A clearly articulated and co-ordinated approach is needed from all concerned if this is to change.

- 167 The present situation is not satisfactory. The government's aspirations for carers of older people are not being realised in practice for the majority of them. A clearly articulated and co-ordinated approach is needed from all concerned if this is to change. This must be deliverable within the resources available.
- 168 This approach must focus on:
- giving all carers access to information relevant to their circumstances;
 - ensuring that where mainstream services are provided for older people, they take account of carers' needs and preferences; and
 - giving a break to carers who are at serious risk of breakdown.
- 169 Key to this is:
- identifying carers, or helping them to identify themselves as carers, as early as possible;
 - fully involving carers who provide substantial and regular care in the assessment and plans for the people they care for; and
 - providing these same carers with relevant and tailored carer assessments which skilfully identify their circumstances and needs, sensitively exploring the future options available to them.

Identification

- 170 Statutory agencies should provide carer awareness training to all staff in a position to identify carers. It must emphasise that carers are real partners in the provision of care. It must also ensure that staff are conversant with key elements of new legislation, guidance and new practices in supporting carers. A carer or ex-carer should be a member of the training team. Carers UK have carried out work on training the trainers **(Ref. 40)**.
- 171 This training should be a priority for staff who have most contact with carers, including GPs and primary care staff who are often in the best position to identify carers early. This is recognised not only in the national strategy for carers, but also in the new GP contract. Ideally, training on carer issues should be part of doctors', nurses' and social workers' professional development. PCTs need to give guidance to GPs and primary care staff in the form of a protocol for identifying carers and a mechanism for referring them on to social services for assessment. They are likely to require a designated carers' lead officer for this activity.
- 172 Statutory agencies should develop and support imaginative initiatives and incentives to help carers identify themselves. These do not necessarily require a lot of resources. Carers benefit through early recognition and contact, and statutory agencies need to gain a better understanding of present and likely future needs.

- 173 Local registers can help to provide a measure of the numbers of carers in the area who are being identified and facilitate the provision of information, discussed below.

Information

- 174 The agencies in each area should develop a carer information strategy to provide information to all carers. This should be part of their action plan for providing comprehensive information to older people, as required by Standard 2 of the *National Service Framework for Older People (Ref. 17)*. It should be reviewed periodically with the help of carers.
- 175 There should be a wide range of material in various forms that take account of the needs of different local communities and groups. Agencies need to continue to look at increasing effective means for its distribution. The development of websites should be encouraged as one approach among many. Better monitoring would help agencies keep track of who is contacting them.
- 176 Care managers need to be kept up-to-date with the information available so that they can pass this on reliably. GPs and primary care staff must be supported so that they can give accurate information to carers or refer them on to somewhere that is accessible to them (for example, a voluntary organisation).
- 177 Agencies need to continue to review ways of providing advice to carers to build their capacity to fulfil their role. A basic piece of information for all carers should be whom to call in an emergency.
- 178 For many carers, and the people they care for, information and/or advice on financial issues and benefits is important. Staff with particular knowledge and skills are needed to give appropriate and targeted financial and benefits advice.
- 179 The local registers of carers can facilitate regular, targeted communications to all who would welcome this and should not be restricted to those who provide substantial and regular care. These registers and communications could be the responsibility of an appropriately resourced voluntary organisation. Indeed, agencies need to carefully review how best to use and support voluntary agencies.
- 180 Regardless of who has this responsibility, the provision of information must be monitored, reviewed and adjusted, preferably with the help of carers themselves, so that it reaches all who need it. This is an important task which needs proper resourcing.

Support and services

- 181 The introduction of the Carers Grant provided ringfenced money to give carers who are at serious risk of breakdown a break. Subsequent relaxation of the guidelines has meant that it could also be used to give a small number of carers other forms of support, for example, a specific carer's service under *The Carers and Disabled Children's Act 2000* (Ref. 14). Now the ringfencing has been lifted, there is the potential for greater flexibility, but also the potential that councils will divert some of the money to other areas of policy or service. Councils should therefore ensure that support for carers is embedded within all services based on local priorities.
- 182 In practice, carers' main source of support comes from mainstream services such as home care provided to the people the carers are caring for. It is therefore essential that their provision takes account of their needs and preferences. It was telling that, apart from breaks, the carers responding to our survey rated home care as the most valuable service they received. It is important that care managers acknowledge the value that carers put on help of this kind and factor it in when drawing up care plans.
- 183 The provision of appropriate equipment can also be of great assistance to carers. The full potential of equipment or 'assistive technology' is considerable, as described in a separate report in this series (Ref. 4).
- 184 When planning the discharge of an older person from hospital, serious consideration should be given to providing some short-term support to any carer involved. *The Community Care (Delayed Discharges etc) Act 2000* (Ref. 15) states that, where the carer has asked for an assessment, the social services authority must assess and, after consultation with the NHS body, determine what services it will provide for a carer when the person they care for is ready for discharge.
- 185 Carers of working age are the largest group of carers of older people. To date, services have not been geared to supporting them. The statutory agencies must give serious attention to the needs of this group of carers and identify a range of support and services to meet the needs of carers who wish to work. More widely, employers need to be more flexible in their treatment of employees who have caring responsibilities.
- 186 The statutory agencies should ensure that support and services for carers (and indeed for the person being cared for) are available in the necessary variety, quality and quantity. This market management and quality assurance is vital if carers, including working carers, are to obtain the support they need. Care managers should ensure that carers who wish to source support and services themselves have the necessary information, advice and help to do so.

Assessment

- 187 Assessment is crucial if resources are to be used in a cost-effective way and carers are to be given the support they need. Agencies need to increase their efforts to make sure that carer assessments are carried out. They also need to review how they can monitor and improve the quality of assessments. They should ensure that assessments are properly recorded and written summaries of assessments and resulting care plans are passed to carers. Ideally, all assessments should involve face-to-face contact.
- 188 The recording of numbers of assessments needs to be improved. The present PAF indicator D42 is neither an effective measure of present practice nor an incentive for improvement.
- 189 All carers who provide substantial and regular care should be fully involved in the assessment and plans for the people they care for, including planning their discharge from hospital. NHS staff should routinely involve carers in this. Carers' own circumstances and needs should be skilfully identified and the future options available to them should be sensitively explored, either during the assessment of the person they care for or on a separate occasion.
- 190 The statutory agencies must confirm that the introduction of the single assessment process in their area ensures that all carers who provide substantial and regular care are always fully involved on these occasions. They must also confirm that it ensures that carers' own circumstances and needs are identified and future options explored. Whenever possible, their needs, and those of the people they care for, should be looked at holistically, providing this suits them both.
- 191 The statutory agencies must also confirm that they have rigorous monitoring and recording systems in place to identify how many separate and joint user and carer assessments have taken place and to confirm that these have been carried out to an agreed standard.
- 192 All staff who carry out carer assessments, whether separately or jointly with the user, should receive specific training. Advice and guidance to carers from care managers should be considered a service in its own right. The potential for an accredited training scheme should be considered. The limited resources for carers may become less of an issue if care managers are seen to make a real difference to carers' lives through the quality of their advice and guidance.

Management arrangements

- 193 The statutory agencies should ensure that care managers have manageable caseloads, as well as receiving appropriate training and supervision in carer issues. Their high caseloads and restricted budgets perhaps explain some of their present approaches. Care managers at one site had caseloads of over 70, with team leaders, who were not supposed to have caseloads, with caseloads of over 40.
- 194 Carers need acknowledgement and inclusion. It should be the responsibility of care managers and team leaders to provide this. Even though it may not be possible to provide a tangible service to a particular carer, it is not helpful if a care manager or team leader adopts a defensive stance.
- 195 A clearly articulated, multi-agency, local carers strategy is essential if carers are to be recognised and supported. It must focus on building partnerships between, and within, organisations to address carer issues. Both councils and PCTs should have designated lead officers. All staff who are likely to come into contact with carers – whether from the council, PCT(s), primary care or voluntary organisation – and the carers groups themselves, should be familiar with the local strategy.
- 196 It must be translated into an agreed action plan which has achievable, time-limited objectives which have been adequately resourced. The implementation of strategy should be monitored and regularly reviewed.
- 197 The government should consider developing a set of relevant indicators, which are adequately 'policed' to help to promote better practice. It is not within the scope of this chapter to propose what form these indicators should take, but indicators that look at voluntary sector involvement and coverage (in an area), the distribution of information, the satisfaction of carers, the number of staff accredited on carer awareness and carer assessment training and the amount of preventable carer breakdown could be useful for monitoring progress and providing incentives for continuous improvement.
- 198 Councils and NHS trusts, as employers, should monitor and review their existing arrangements to support staff who are carers of older people and further develop the range of responses that they are able to offer.

Appendix 1 – Intranational and international comparisons

- 199 This is a summary of a literature review undertaken by Professor Caroline Glendinning at the National Primary Care Research and Development Centre at the University of Manchester. The complete review can be accessed on the Audit Commission's website (**Ref. 10**).
- 200 The literature review looked at a number of countries, these included: Wales, Scotland, Northern Ireland and the Republic of Ireland, Germany, Sweden, Netherlands and Australia.
- 201 There appears to be very little difference between the countries of the UK in their policies and patterns of support for carers, with each country broadly following the measures in the UK governments Carers Strategy. However, outside of the UK, patterns of support for carers are different.
- 202 The Republic of Ireland has a fairly unique context amongst these countries. Traditionally, the family has taken responsibility for the care of older people, and the state, church and voluntary organisations have played a subsidiary role to them, thus statutory welfare services remain poorly developed. Nevertheless, there has been a Carers Allowance since 1990 and the voluntary organisations have made several campaigns to highlight carers needs.
- 203 Germany, which uses a compulsory social insurance model covering long-term care needs, offers benefits as cash or benefits in kind (at twice the value) or a combination of the two. The cash benefit option ranges from £145 to £469 per month, depending on the level of care dependency.
- 204 Sweden, whose home help services are very extensive, offer 24-hour home-based care if necessary with support from family members regarded as voluntary, as well as cash benefits as part of the health insurance scheme. A working age relative who takes care of the ill person is entitled to 30 days loss of earnings in the lifetime of the cared for person. But family members can also become paid kin care-givers, where they are paid based on the number of hours of help needed by the cared for person at an hourly rate of regular home helps.
- 205 Netherlands, which, like Germany, is based on the social insurance system, but in determining the level of support, takes account of the carer in the assessment of the cared for person.

- 206 In Australia, carers have no entitlements to assessments or services in their own right, as these are provided to the older person, with community-based services being provided by local government, voluntary, religious and charitable organisations along with some commercial providers.
- 207 The measures to support carers that were identified in the report fall into five main categories:
- Traditional, formal, statutory services in kind that are primarily provided for the person receiving care and are accessed through assessments of his/her needs. These include home care, meals, personal care and home nursing. In Sweden, for example, relatively high levels of home care services for older people have traditionally reduced the levels of support expected from family carers.
 - Respite care, both home-based and in institutions. Recent new investment to stimulate the supply of 'breaks' for carers are common in many countries. Scotland's strategy has involved an investment of £10 million to be distributed by social services as grant aid to help stimulate carers' services including respite. Yet there is ambiguity about the benefits of respite care with some countries giving more emphasis to its role in giving carers a break, whilst in others, the person receiving care is regarded as the major beneficiary of respite care.
 - Payments that are broadly intended to acknowledge the costs and reward the work of care-giving. These are normally not wage-like (Sweden being the exception), are likely to be below the equivalent value of work and are accessed through an assessment of the service user. The Netherlands, however, is unusual in that the level of payment is equivalent to the 'market' costs of providing support to an older person through the formal home help and home nursing services.
 - Measures that recognise the tensions between care-giving and formal paid employment (for example, the Carers Grant in the UK countries and Republic of Ireland). These include social security benefits to replace lost income; quasi-employment as a paid care-giver; and protection from loss of employment-related social rights.
 - 'Soft' forms of support, such as information, advice and membership of support groups. These are often located within the voluntary sector with grant-aided and sometimes short-term funding. Australia, for instance, relies heavily on the voluntary sector provision.
- 208 A number of common issues can be identified. In most countries it is not clear whether carers are regarded as needing support in their own right or as resource in the care of older people. This blurring involves a wider lack of rights and entitlements by carers. The entitlement of carers in all the countries of the UK to an assessment of their own needs, independent of the needs of the older person receiving care, is unique in this respect. In many countries carers receipt of services and/or payments is dependent on an assessment of the cared for. This is most starkly illustrated by Germany where despite cash payments from an insurance system, carers have no independent entitlements of their own.

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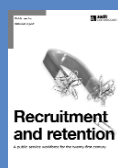
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