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Social Policy Research Unit

CARERS' NEEDS AND THE CARERS ACT: AN EVALUATION OF THE PROCESS AND OUTCOMES OF ASSESSMENT

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CARERS' NEEDS AND THE CARERS ACT

EXECUTIVE SUMMARY

Aims

To investigate the impacts of the Carers Act: first, in terms of changes in local policy and practice; and, second, from the perspective of a sample of carers who received an assessment under the Act.

Methods

Interviews with local senior managers and practitioners, and document analysis, in four local authority social services departments. Two interviews, six months apart, with 51 carers nominated by the research authorities as having been recently assessed.

Findings

National and local policy

- The introduction of the Carers Act did provide opportunities for reflection and consolidation in each authority, but changes in policy and practice towards carers were already underway. Specific effects of the Act are therefore hard to disentangle.

- The lack of accompanying resources was an expressed concern in all authorities at the time of implementation.

- It was strongly felt that the quality of support for carers was not a matter for social services alone. Health, housing and transport services among others all had important contributions to make.

- There was a variety of policy and organisational responses to dealing with equal opportunity issues such as the needs of ethnic minorities, with the different responses being influenced by local geography and demographic characteristics of the local populations.

Access

- Formally expressed criteria of eligibility for assessment remained fairly open-ended in local implementation, but in practice the majority of carers assessed (49 out of 51) provided more than 20 hours per week of care (47 for over 35 hours)

- Decisions to assess carers were largely made by professionals. Only two carers had themselves requested an assessment.

- Over half of carers assessed had been caring for some years, and were not new to social services.

- Finding out about services available took carers considerable time and persistence. Workers did not always know of all available local services to support carers.

- The most common route of first referral to social services had been through health service staff, although with hindsight some carers felt that their referral could valuably have been made earlier in their caring career.

The process of assessment
- Around half of all carers interviewed were not aware that they had undergone an assessment of their needs.

- Those who were aware of being assessed generally valued the opportunity for a discussion of their concerns and needs.

- Older carers were particularly unlikely to be aware that an assessment had taken place. They were more likely to be heavily involved, and to feel that professionals did not understand their needs. However they were as likely as other carers to express satisfaction with services received.

- Carers generally preferred face to face discussion to the use of self-assessment forms, although the latter could be valuable if used in conjunction with face to face contact.

- Preferences about whether the person cared for should be present were varied (but strongly held), and depended on the relationship, and the nature of the illness or impairment which occasioned the need for assistance.

- Carers valued continued contact with known and named staff following their assessment.

Services - shortfalls and impacts
- In many cases it was not possible to reliably decide whether particular services were the result of the carer assessment, the user assessment or would have been provided anyway.

- With some exceptions, carers generally expressed satisfaction with practical services such as home care, day care, sitting services and breaks. Two areas where carers would have like more help were:
  - Emotional support, for example opportunities to talk through difficulties and decisions. Carers who found the assessment process itself helpful in this respect could feel abandoned or let down if such opportunities subsequently seemed to be unavailable.
  - Financial matters: this included not only benefit advice but the ability to talk through the financial implications of decisions being considered, such as whether to return to work, or to use temporary or permanent residential services.

- Three of the 51 carers cancelled some services during the six month period because of their cost.

- There were examples of imaginative and extensive packages of services which, for example, enabled carers to pursue higher education or to work.

- Combining work and caring was almost always seen as a struggle, and employers were not necessarily able or willing to be supportive. Nor did carers always find services sufficiently reliable to enable them to work. About a quarter of carers had some employment.

- Carers showed very slight improvements in relation to their assessment of difficulties (CADI) scores relating to physical and emotional health over the six month period. People in their first year of caring accounted for positive health changes in terms of: the provision of services; being better informed; sharing responsibility with social services; increased peace of mind.

- The minority of carers who used carers' centres or support groups (whether provided from statutory or voluntary sources) valued their involvement highly. Men under pension age, while comparatively rare among carers assessed, were particularly likely to be involved.

- Where the cared for person died, or was admitted to residential services, carers reported experiencing isolation and lack of motivation. Carers appreciated continued support from social workers (if this was given) during the process of re-adjustment to a different life.

Recommendations
Central Government: Department of Health

1. Review or clarify the eligibility requirement restricting carer assessment to carers of people and disabled children already being assessed by the local authority, to ensure that carers are enabled to request a carer assessment directly.

2. Review or clarify the eligibility requirement restricting carer assessment to people who satisfy locally defined eligibility criteria based on providing, or intending to provide, 'a substantial amount of care on a regular basis', to ensure that entitlement is applied in a fair and consistent way.

3. Means should be found to reinforce the policy intention that carer assessment and support is not just a social services responsibility nor even dependent on a social services lead role.

4. Review or clarify the policy of service provision needing to be justified in terms of meeting the assessed community care needs of the care recipient, to enable services to be provided in direct support of carers.

5. Promote means of support from employers being recognised as important to enable carers to participate in the labour market.

Central Government: Social Services Inspectorate and Social Care Group

1. When advising and monitoring local authorities, to work toward supporting and building upon the recognition of the needs of carers in local policy statements and the management and practitioner 'good practice intentions' within social services.

2. Means should be found to reinforce the recognition and practice of allied services (health, housing, education and employment) that carer assessment and support is not just a social services responsibility.

Local Authority: Policy and Senior Management
1. The policy for the entitlement of carers to carer assessment and the eligibility criteria should be reviewed and clarified, with the emphasis on an inclusive rather than exclusive approach to entitlement.

2. The importance of a joint working element to policy formation and implementation in respect of carers should be maintained and developed further where possible, with a particular emphasis on effective joint working between health and social services.

3. The process of developing more effective information systems for monitoring and managing the operational response to policy intentions about carer assessments and reviews and outcomes should be maintained/continued.

4. The information and systems developed to support carers in participating in care planning in an informed way should be reviewed and strengthened where appropriate, including keeping the printed information and its dissemination under review.

5. The policy intention that staff should inform carers of their rights to carer assessment and participate in the care planning process should be reinforced through management supervision and support.

6. Effective liaison and collaboration should be maintained between mainstream services and carers' centres and support networks. In respect of work with carers' organisations:
   - It should be recognised that not all carers want to be involved with support organisations
   - It should be recognised that carers' attitudes toward support groups can vary over time and circumstances
   - Although some carers might normally resist attendance at meetings or other contacts with support groups as an added burden or imposition on their private time, there could be particular times and circumstances when they would benefit and respond to an accessible and flexible support contact.

7. In respect of staff induction, on-going training and preparation for duties under the Carers Act:
   - The policy about carers being informed of their rights and assisted to participate in a conscious and informed way should be reinforced and maintained
   - Means should be found of ensuring that practitioners who deal with carers are informed and up to date about carer support facilities and networks
   - Practitioners should be supported in giving recognition to carers' needs for emotional support and counselling, and not simply focusing on practical support and tangible care services
   - The policy intention that carers should receive written confirmation of the carer assessment and care plan should be reinforced through management supervision and support.

8.   A proportion of staff should be trained to give specialist help to carers who want to discuss the financial implications of any decisions they might make.

9.   Although most carers appeared to be generally satisfied with tangible services such as day care, home care, and respite care, they and service users should be regularly consulted in association with management reviews of the quality and appropriateness of these and allied services such as transport.

10.   The importance to carers and service users of continuity of contact with known and trusted staff should be acknowledged in the way service provision is allocated and maintained.

11.   As one aspect of the policy recognition of carers in their own right, the need of some carers for support when the care recipient moves into long term care or for some other reason is no longer in their care should be recognised.

12.   Steps should be taken to reach black and ethnic minority carers, and promote their access to carer assessment.

Local Authority: Care Managers and Assessment Staff

1.   In seeking to ensure that carers receive appropriate information and supportive guidance and encouragement to participate in the carer assessment process, special consideration should be given to older carers with heavier caring responsibilities.

2.   It should not be assumed that carers are aware that their needs are receiving a distinct focus within the assessment and planning for the needs of the care recipient; practitioners should make their right to assessment and the carer assessment arrangements explicit.

3.   The arrangements for the assessment, including the issue of separate interviews and whether the carer wishes to be accompanied, should be a matter of discussion and agreement.

4.   Self-assessment forms should be used selectively and as an aid and preparation for the carer assessment, not as a separate assessment option.

5.   Carers should be given the opportunity to discuss their financial circumstances as well as the financial implications of the care plan and support services.

6.   Carers should be given the opportunity to discuss health issues in relation to their own health as well as that of the care recipient.

7.   Carers who are in employment, or who want to work, should have the opportunity to discuss and seek advice on the implications of this during the carer assessment; the pressures of work as well as the tangible benefits and beneficial effects on people's feelings of worth and well-being should be recognised.

8. Carers should receive written follow-up including information about the conclusions of the assessment, care plan decisions and services, identified practitioners for future contact, and details of review arrangements.

9. It should be recognised that carers who have relinquished their main caring role for whatever reason could need and benefit from emotional support and counselling, as well as advice on tangible matters such as finances, health and employment.

10. The importance to carers and service users of continuity of contact with known and named staff should be acknowledged in the way support is allocated and contact maintained.

Possible areas for further research
1. Information networks: investigate how best to ensure that carers link into the appropriate information networks.

2. Older carers: determine the needs and unmet needs of older carers, and ascertain how social workers and other involved professionals can best address the needs of older carers.

3. GPs and primary health care: ascertain doctors' views about supporting carers; evaluate the effectiveness of different models of GP-based carer support initiatives.

4. Black and ethnic minority carers: examine how best to facilitate access for black and ethnic minority carers to the care planning process and assessment under the Carers Act.

CHAPTER 1: INTRODUCTION

Section 1: The research study

This report documents the findings of a two year study looking at the impact of the Carers (Recognition and Services) Act 1995 in four local authority social services departments in northern England. The work was funded by the Department of Health under the Outcomes for Social Care initiative. We began the study in November 1997, two years after the full implementation of the Carers Act. The specific research questions the study addressed were:

1. what are the results of national policy in terms of *local* policy and practice in selected authorities?

2. what are the results of local policy and practice *from the carer's point of view* in terms of assessment under the Carers Act, services and outcomes?

The study's findings will help establish the significance of the Carers Act for adult carers, as well as yielding recommendations and good practice points for those staff in local authorities who are responsible for implementation. At the same time, the results are of wider interest, for instance the research can make a contribution in particular to the implementation of the Carers and Disabled Children Bill (currently making its way through parliament), the National Strategy for Carers (DH, 1999a), and any future policy developments on carers' issues.

Section 2: Carers

The vital role that informal carers undertake in the provision of care in the community is established beyond doubt. The Prime Minister described carers as among the 'unsung heroes of British life' in the foreword to the National Strategy for Carers (DH, 1999a). Whilst figures show that the number of carers has decreased since 1990, there is nonetheless an estimated 5.7 million carers in Great Britain; one in eight adults provides care, and one in six households contains a carer (ONS, 1998). Women are more likely to be carers than men. Some 1.7 million carers spend at least 20 hours a week caring, and 855,000 of these individuals provide care for 50 hours a week or more. Over 60 per cent of carers spending at least 20 hours a week on caring are women. As far as the number of young carers (that is, children and young people under the age of 18) is concerned, there is little hard evidence. However, it has been suggested that there are between 20,000 and 50,000 (DH, 1999a). The value of informal carers to the economy is estimated to be in the region of £34 billion a year (Hirst, 1999).

While there are satisfactions and rewards to be gained from care work (Perring *et al*., 1990; Nolan *et al*., 1996), in the past studies have tended to focus on the negative impacts that caring can have on carers' lives (Toseland *et al*., 1990; Parker, 1993; Phillips, 1994). These include physical and emotional ill-health, loneliness, unemployment and financial hardship. Carers have needs, therefore, in relation to both health and social care, and it is important that service interventions are evaluated to assess how effectively these needs are being met.

The Social Policy Research Unit at the University of York is currently engaged in a five-year programme of research focusing on social care outcomes. A recent report (Qureshi *et al*., 1998) documents the findings of research on the outcomes identified as important by carers of older people. In relation to their own quality of life, outcomes valued by carers could be grouped under four headings: freedom to have a life of their own; maintaining health and well-being; preventing social isolation; peace of mind. In addition, important outcomes carers wanted from service process were: a sense of shared responsibility; having a say in services; confidence in the standard and reliability of services. Finally, achieving quality of life for the cared for person was particularly important, and this was central to how satisfied carers were with services.

Section 3: Policy measures to support carers

The Carers (Recognition and Services) Act 1995 built upon existing community care legislation. The Act came into force in England and Wales in April 1996, and gave carers the right to request an assessment of their needs at the same time as the person they were looking after was being assessed or reassessed for community care provision. Local authority social services departments, the agencies with lead responsibility for implementing the Carers Act, were required to take the results of this assessment into account when making decisions about services. Under the provisions of the Act, carers were people providing, or intending to provide, 'a substantial amount of care on a regular basis'. This meant that not all carers would be entitled to an assessment under the Act. The Act covered three groups of carers: adults (18 and over) looking after other adults; parents of ill or disabled children; children and young people (under 18) who cared. It excluded paid carers or volunteers from voluntary organisations. The Conservative government of the day did not allocate any additional central funding to help local authorities implement the Act. Even though the Carers Act did not automatically entitle carers to any services they might have been assessed as needing (and from that point of view the title of the Act was a misnomer), it nonetheless marked a major step forward for carers. It was the first time in British legislative history carers were recognised as having needs in their own right.

The Carers Act was brief, and supported by policy (DH, 1996) and practice guidelines (SSI, 1996). These documents stated the legal, policy and procedural context of the Act. The practice guide (SSI, 1996) to the Act set out its aims and objectives. These were to bring about a shift in practice towards: greater recognition of carers; an assessment of the 'caring system' to consider the range of support available to service users and carers, and appropriate intervention; an integrated family-based approach; improved practice. Reflecting the then government's emphasis on multi-agency working and partnerships, the guidelines stressed that the Carers Act had important implications for joint working between health, education, housing and social services.

The guidelines accompanying the Act were not prescriptive. For instance, it was left to the discretion of individual local authorities to determine their own definitions of 'regular' and 'substantial' care in terms of who qualified for an assessment. Whether the carer assessment was carried out in the presence of the cared-for person as part of a comprehensive assessment, or instead was a separate procedure taking the form of a private discussion between the carer and the social worker which was then documented on a distinct carer's assessment form was optional, according to each carer's preference.

The present study took place in a changing policy context. The new Labour government launched the National Strategy for Carers (DH, 1999a) during the fieldwork period (February, 1999). Like the Carers Act guidance, the National Strategy required for its implementation that local authorities, health bodies, carers' organisations and employers acted jointly. The Strategy document contained further proposals to improve support and services for carers based around the three elements of information, support and care. One immediate measure was the provision of ring-fenced monies, the Carers Special Grant, for local authorities to use over the next three years (1999-2002) to enable them to provide services that allowed carers a break. Other proposals were more for the future. They included a 'You and Your Services' charter setting out what people could expect from long-term care services, quality standards for carers' centres and support agencies, a second pension for some carers, more carer-friendly employment policies and extra help for young carers. Significantly, one of the recommendations concerned future powers to allow local authorities to provide services directly to carers.

Other Labour government initiatives launched during the course of the present study that made specific reference to carers included Modernising Social Services (DH, 1998a), the National Priorities Guidance (DH, 1998b) and the National Service Framework for Mental Health (DH, 1999b). Again, these policy initiatives stressed multi-agency working and in particular the responsibilities of health services in supporting carers. For example, standard six of the mental health NSF required health services to include carer assessments and support

in service provision. The reporting of the results of our study has been structured to take account of prominent issues in the new policy context, as well as addressing questions relevant to the Carers Act.

Section 4:   Studies of Implementation of the Carers Act
Earlier studies have looked at different aspects of the Carers Act. Some projects included carers of a wide range of client groups (CNA, 1997; King's Fund, 1997), whilst others concentrated on carers of people with learning disabilities (Robinson and Williams, 1999a), young carers (Dearden and Becker, 1998) and carers of elderly people with dementia (Seddon, 1999). Other enquiries took a local authority perspective to examine how social services departments have approached implementing the Act (CNA/ADSW/ADSS, 1997; SSI, 1998a; Cheetham, 1999).

Evidence from these studies suggests that the new legislation does seem to be helping carers, but that there is still a great deal of scope for improvement. For instance the Carers National Association (CNA) investigated how the Act was working for carers (CNA, 1997). A postal survey of members elicited over 1,650 responses; nearly 100 of these respondents were later interviewed by telephone. The postal survey found that the number of carers being assessed was low. Less than half of all carers involved in the survey had been told of their rights to an assessment when the person they were looking after was assessed. The telephone interviews found that many carers had not realised they had actually been assessed, illustrating the need for social workers to formally tell a carer when an assessment was taking place. A little over half of the carers assessed were subsequently offered extra support, although some people declined offers of services because they considered them inappropriate or too costly, or because they wanted to manage without any extra help.

It is important to acknowledge that the carers taking part in the CNA study did not comprise a truly random sample, which means that the results are likely to be somewhat biased and cannot be generalised with confidence to other carer populations. However, some of the causes for concern identified by the CNA, for instance the low number of carer assessments, are consistent with those found in other research. The findings from a study in the south west of England into the impact of the Carers Act on carers and people with learning disabilities indicated that of over 150 eligible carers, just under one-quarter (22 per cent) had received a full carer assessment between April 1997 and March 1998 (Robinson and Williams, 1999b). There was some evidence on care plans to suggest that the needs of a further half of the carers (50 per cent) had been taken into account to some extent. For the remaining carers (28 per cent), there was no record of their needs having been assessed at all.

There is evidence that young carers have less access to assessment. The findings of a survey of over 2,300 young carers in contact with young carers projects in the UK showed that only one in ten had ever been assessed, and of those slightly more had been assessed under the Children Act 1989 than under the Carers Act (Dearden and Becker, 1998). The likelihood of a young carer receiving an assessment under the Children Act decreased with age, while the likelihood of a Carers Act assessment increased.

A report documenting the first year of the King's Fund Carers Impact (1996-99) national development programme provides further evidence of the difficulties carers face regarding assessment (King's Fund, 1997). Many carers claimed they had not been informed of their right to assessment; they were uncertain whether their needs had been assessed; assessments were service-led rather than needs-led; assessments focused on the care recipient, and carers' needs remained marginalised; few carers had received written results of the assessment or a care plan.

The CNA, together with the Association of Directors of Social Work and the Association of Directors of Social Services, conducted a postal survey of local authorities in the UK to find out about social services' experiences of the Act (CNA/ADSW/ADSS, 1997). The findings suggested that the Act served as a prime motivator for change, stimulating new initiatives for carers and enhancing overall support. Areas where support for carers was shown to have increased included: the provision of information for carers, and publicity regarding carers' rights; the number of adult carer assessments; the number of carers' workers; breaks for carers needing support; and respite care both inside and outside the carer's home.

Specifically in relation to assessment, just under one-third of the responding local authorities had introduced separate carer assessments from April 1996. However, interpretation of the term 'carer assessment' was found to vary from one authority to another. Likewise, there were local divergencies in the way the terms 'regular' and 'substantial' care were defined, a finding reported elsewhere (Seddon, 1999). The report pointed out that such discrepancies gave rise to local and regional inequalities in terms of access to assessment and subsequent support.

A more recent report documents the findings of a Social Services Inspectorate (SSI) examination of support for adult carers in seven social services departments in England during 1997-98 (SSI, 1998a). The inspection found that assessment and reviews for carers were not routinely part of social services practice, and that explicit carer assessments were few and far between. Carers had frequently been assessed without realising this event, or process, had taken place. Reinforcing findings from the CNA's study of social services departments (CNA/ADSW/ADSS, 1997), the SSI inspection also identified wide variations in the range

and quality of support for carers. This was often a matter a matter of chance - 'the lottery of location' - depending more on where carers lived and who they were in contact with in social services than on their needs and preferences.

It is early days to draw any firm conclusions, but there is growing evidence to show that some progress is being made and that support for carers has improved in the wake of the Carers Act. It seems that once carers have managed to access the social services system, they receive assessment that may result in (further) service provision. At the same time, implementation of the Act is patchy and it is evident that policy is not translating easily into practice. The present study is an important addition to the existing body of work reporting on the outcomes of the Carers Act. It complements these other studies by first, focusing on an arguably representative group of carers who, according to social services, have received an assessment, and second, by using in-depth methods.

Section 5: Summary of research methodology

Four local authority social services departments in the north of England took part in the study. Two of the departments were also taking part in the King's Fund Carers Impact (1996-99) national development programme. Table 1.1 below shows the main features of the four research authorities.

Table 1.1:   Profile of research authorities

	RA 1	*RA 2*	*RA 3*	*RA 4*
Type	Metropolitan borough council	Metropolitan city council	County council	Metropolitan borough council
Geography	Urban centres and rural villages	Main city and smaller townships	2 urban centres; mainly rural	9 towns in borough
Total population	265,000	726,000	559,000	220,000
Ethnic minority population	21,500 (8%)	40,000 (6%)	5,000 (0.7%)	9,000 (4%)
Carer population	27,000 (10%)	101,000 (14%)	80,000 (14%)	22,000 (10%)
Social Services approach to policy on carers	Carers' issues built into community care policies and strategies	Carers' issues built into community care policies and strategies	Separate community care policies and strategies for carers	Separate community care policies and strategies for carers
Support in place for carers prior to Carers Act	Carers Support Project; Young Carers Support Project; local carers' support groups	Supported the Carer's Charter; operated a separate carer assessment form; carers centre; local carers' support groups	Multi-agency strategy for carers; four carers' resource organisations; local carers' support groups	Strategy for carers; carers centre; local carers' support groups

Sources for figures: Social Trends (1995); Standard Spending Assessment (1998/99)

The planned research design involved two interviews six months apart with a total of 60 adult carers, 15 from each of the four research authorities. In the event, the frequency with which carer assessments occurred proved to be lower than anticipated and a final sample of 51 carers was obtained: 14 from research authority 1; 13 from research authority 2; 15 from research authority 3; and nine from research authority 4. The reasons why numbers were lower than expected could include: carers not knowing of their right to request an assessment; staff may not be asking carers whether they would like to be assessed; the tension between the right to assessment and limited resources to meet assessed needs may inhibit staff from raising the issue of assessment; for the same reason, carers may be sceptical about the benefits of assessment; resource fears may constrain practitioners from asking carers about their willingness to continue caring; the linking of carer assessment with assessment or re-assessment of the care recipient may distract from a direct response to carers' needs; an integrated assessment approach may 'camouflage' the carer assessment.

Thirty-six carers in the study sample were female and 15 were male. Ages ranged from 32 to 87; just over half (N=26) were aged 61 and above. Less than a quarter (N=12) of carers worked at some point during the data collection stage. Most carers (N=37) lived with the person they were looking after. Over half (N=27) had been involved in care work for five years or more; only seven were 'new' carers, that is in their first year of caring. Some 49 carers spent at least 20 hours a week caring; of these, 47 cared for over 35 hours a week.

The total number of care recipients was 54 (three of the 51 carers looked after two people each). There were 34 women and 20 men. Care recipients were aged between five and 90, and comprised people with physical or learning disabilities, progressive diseases such as multiple sclerosis or Parkinson's Disease, as well as older people with a range of physical and/or mental health problems. By the time of the second interview, four care recipients had died.

We held semi-structured interviews with carers at two points in time: as soon as possible after they had been assessed under the Carers Act, and six months after the first interview. The first interview focused on the process and form of the assessment, and any associated service provision. The second interview concentrated on changes during the six month interval, and the perceived outcome of assessment for carers. Additional quantitative data on the difficulties and satisfactions of caring were collected at both interviews using two recently developed and tested instruments: the Carers' Assessment of Difficulties Index (CADI) and the Carers' Assessment of Satisfactions Index (CASI) respectively (Nolan and Grant, 1992a; Nolan *et al.*, 1998).

One senior manager responsible for policy formulation for the Carers Act was interviewed in each authority, together with four practitioners whose duties included carrying out carer assessments. We interviewed professionals once only. These discussions yielded information on policy and practice issues related to the Act and carer assessments, as well as professional understanding about carers' needs. To complement the interview data, each authority's policy and practice documentation concerning the legislation and assessment procedures was examined.

For a fuller discussion of the research methodology, including copies of the CADI and CASI indices, see Appendix A.

The remainder of this report documents the study findings. We start, in Chapter 2, by looking at how the four research authorities responded to the Carers Act and the significance of its implementation for local policy and practice. Chapter 3 takes a chronological look at the process of assessment, including how carers in the study came to be assessed in the first place, the format of assessment and any subsequent follow up and review. In Chapter 4, we report what service provision and support carers received, and discuss how satisfactory this help was in terms of meeting carers' needs.

The following chapters focus on topic areas that feature in the guidance to the Carers Act, and also the National Strategy for Carers: information, local support services and networks, health and employment. Good information is one of the main needs of carers, and Chapter 5 describes how the research authorities addressed this issue. This is followed in Chapter 6 by a discussion of the ways in which carers' centres and local support groups helped carers, together with some reference to how the sites and local carers' organisations worked together. We consider the consequences of caring for carers' health in Chapter 7, and how this is addressed in assessment. There is also a short discussion about joint working between health and social services staff. Chapter 8 looks at the experiences of carers in relation to employment, and shows that carers need the support of both social services and employers to help them balance work and family life.

The final chapter, Chapter 9, draws out central issues emerging from the study in relation to the process of local policy implementation, the actual experience of the process of assessment and the outcomes of assessment for carers. We finish with recommendations to improve the implementation of the Carers Act, together with some suggestions for areas for further research.

CHAPTER 2: TRANSLATING NATIONAL POLICY INTO LOCAL POLICY

Section 1:   Introduction

During the process of implementing national policy there is often considerable scope for differences in local interpretation and consequent action. An understanding of how and why these differences occur may not be easily achieved. The literature on policy implementation indicates that there may be a lack of clarity or ambiguity about the true aims of central policy. For example, Lewis and Glennerster (1996), in their study of the implementation of community care policy in the early 1990s, observed that 'trying to decide what policy the Government was actually aiming to pursue is in itself a controversial matter' (p. 18).   In addition, irrespective of whether national policy aims seem initially clear, they may be subject to adaptation, reinterpretation or distortion as they are translated through local policy makers to front line workers. Lewis and Glennerster argue that 'human services ... are delivered by front line professionals who have a great deal of independence and discretion ... they are no mere deliverers of service goals set by politicians' (p.18). Associated with this, Lewis and Glennester advised caution in assuming causal relationships when tracing the impact of central policy changes.

The difficulties in identifying 'precise cause and effect' were reinforced in a study of the impact of business process re-engineering in a hospital (Packwood *et al*., 1998). Packwood *et al.* advised that 'caution has to be exercised in attempting to assess the impacts of an initiative that is still in progress and whose results will become apparent over time' (p. 409). They concluded that many claims of tangible organisational gains were contentious, and 'it seems that much of the gain is attitudinal; making staff more open to change and giving them some tools for its management' (p. 412).

Judge (1999), writing about the evaluation of Health Action Zones, argued that it was important to distinguish a number of components of the implementation process. These were: the national policy context; the means available to implement policy; the local context and framework; intermediate outcomes (changes in services and organisation); and final outcomes (the achievement of impacts on citizen's health and welfare).

This chapter uses material from our interviews with senior managers and practitioners, as well as documentary evidence, to follow through the local implementation of the Carers Act.

Section 2:   National policy background and context

The defined goals of the Carers Act were to entitle eligible carers to request an assessment of their ability to provide care, and to require the local authority to take account of the results of that assessment in making decisions about providing services to the care recipient.   In

introducing the parliamentary debate on his private members bill, Wicks (*Hansard*, 1995) acknowledged the complex nature of what might appear simple and straightforward. He referred to three reasons for the complexity: the existing 'formidable array' of relevant legislation; the intention that the bill should apply to carers throughout the United Kingdom; and the concern to include all carers: adult carers, parent carers and young carers. The original bill was further amended to: focus on more heavily involved carers; ensure that carers' needs were not considered only as a last resort; emphasise that a carer's willingness to continue to provide care should not be assumed.

Other issues raised during the debate, namely easing the financial pressures on carers, addressing the communication requirements of deaf and disabled carers, and giving carers a direct right to services as well as assessment were not incorporated into the new Act. It was not seen as appropriate to deal with financial and tax allowances within this context. Concern about carers with communication difficulties was seen as best covered in departmental guidance. As an opposition MP, Wicks negotiated some support for the bill from Conservative government ministers, and this led to a compromise on the concept of carers having a right to direct services. Wicks sympathised with those who criticised the Act as not being strong enough. He believed 'there might be a few test cases that go before the courts' (Bell, 1995: 10) before interpretation about local authority duties under the Act were ironed out.

The aim of policy guidance (DH, 1996: 1) issued in July 1996 was 'to set out the Government's view of **what** local authorities should be doing to implement the Carers (Recognition and Services) Act 1995' (original emphasis). These policy intentions are presented in terms of the elements of the policy guidance in the left hand column of Table 2.1. Responses from the research authorities are given in the right hand column.

Table 2.1:   General response of research authorities to central government policy intentions

Carers (Recognition and Services) Act 1995 Policy guidance (DH, 1996)	*Policy response of research authorities*
1 **Entitlement to the carer assessment** Local authorities to form their own judgement on what amounts to 'regular' and 'substantial' care, taking account of 'the relative needs of carers in their area' (DH, 1996: 1,4)	The authorities all used 'substantial and regular' as one starting point, although none laid down strict parameters, relying more on the discretion of care managers and practitioners. (*See later section on entitlement*)
2 **Continuing responsibilities of authorities** Local authorities were reminded of legal duties and responsibilities under other community care legislation which still applied. (DH, 1996: 2, 3)	There was evidence of a conscious process of building on existing policies and practice and seeing the new legislation as a means of reinforcing good practice.
3 **Links with existing policy and practice** 'The Act reinforces existing good practice; over-bureaucratic responses or procedures should be avoided.' (DH, 1996: 3)	Prior to the introduction of the Carers Act, all four authorities already had relevant carer policies and carer support processes in place upon which they built.
4 **The relationship with care planning** 'The Act links the results of a carer's assessment to the local authority's decision about services to the user. Views and circumstances of users and carers should be considered together.' (DH, 1996: 3)	There was some variation with recurring themes: resource restrictions; prioritising; primary focus on user's needs and eligibility; and allowing for carer's assessment within care planning.
5 **The timing of the assessment** 'Local authorities should carry out a carer's assessment when requested by a carer at the time of a user's assessment.' (DH, 1996: 5)	The requirement to consider the carer's right to assessment at any stage in the care assessment process was generally acknowledged in local policy documents and from discussions with policy managers. (*See Chapter 3*)
6 **Information for carers about their rights** 'Local authorities should ensure that their published information about community care tells carers about their right under the Act ... should ensure it becomes part of routine practice to inform any carer who appears to be eligible of their right to request an assessment.' (DH, 1996: 6)	All four authorities produced publicity material to inform carers about their rights and services, and adopted other measures designed to inform carers. Policy and procedures required staff to remind carers of their rights when undertaking care assessments, reviews, hospital discharge etc. (*See Chapter 5*)
7 **The focus of the assessment** 'The focus of the carer's assessment ... should be on the carer's ability to care and continuing caring ... should take account of the carer's circumstances, views and preferences, the amount of support available to them.' (DH, 1996: 6)	Local policy and procedures reflected the need for 'protected time and space', 'the overall impact of caring', 'emotional support', and 'assessment of their own needs'. Forms and procedures devised to guide the process. (*See Chapter 3*)

8	**Equal opportunities**	
	'Where individuals have communication difficulties ... local authorities should take active steps to make suitable arrangements to ensure the carer can fully participate in the assessment ... Authorities will need to respond sensitively to the particular circumstances of carers from all backgrounds, ethnic origins and different life-styles.' (DH, 1996: 8)	Three of the four authorities explicitly addressed the needs of ethnic minority carers in their policy and procedures, publicity for carers, and through carer support networks. There were local initiatives with ethnic minorities and other people with communication difficulties. (*See later section on equal opportunities*)
9	**Inter-agency working**	
	Social services authorities will need to ensure that existing inter-agency arrangements are appropriate for referrals resulting from carer's assessments.' (DH, 1996: 8)	Local policy documents referred variously to facilitating 'multi-disciplinary and multi-agency assessment and support', 'continued work to raise the issue with other agencies', inter-agency carer strategy documents, and joint strategy groups. *(See later section on joint working)*
10	**The effect on care planning decisions**	
	The decision about services to be provided should be informed by ... the results of the assessment and the proposed care plan ... should describe where relevant, how services provided to the user will assist the carer.' (DH, 1996: 10)	Local policy statements acknowledged: 'the allocation of resources to meet need is restricted to the eligibility of the care receiver', concern about 'raised expectations', and the focus on services being provided to the user in a way that assists the carer.
11	**Follow-up to assessment**	
	'The care plan and results of assessment should be confirmed in writing or in a format which is accessible to both user and carer' (DH, 1996: 10)	Follow-up to assessment was largely expressed in terms of written documentation. In discussions with policy managers, written follow-up tended to be linked with the issue of monitoring unmet needs.

Section 3:   Translation into local policy

Local context

There is a profile of the four research authorities in the previous chapter (Table 1.1). As can be seen in Table 1.1 and also Table 2.1, before the introduction of the Carers Act all four authorities already had policies for carers of one kind or another in place. To various extents they had developed and published carers' policies and strategies, including carers' centres and support projects in cooperation with allied statutory and voluntary agencies. Two authorities already operated separate assessment of carers' needs and emphasised the importance of involving carers in community care assessment and service delivery. One of these authorities (RA 2) acknowledged the opportunity to 'respond more positively by working to improve existing Carer Assessment and Procedures, using the Carers Act as a focus for future development'. The other of these two authorities (RA 3) reported to their committee that 'it is unlikely, therefore, that improving separate assessment of carers' needs will add substantially to the workload and resources of the Department'. A further authority (RA 1) acknowledged

to their committee the need to rectify the situation where 'there is at present no separate system of carers' assessment and no formal way to record carers' needs alongside those of the services user'. The fourth authority (RA 4), at the same time as seeing the Carers Act as an 'opportunity to devote significant resources to this area of work', retained a strong emphasis on an integrated joint user-carer approach to assessment.

Overall view

The Carers Act was short and to the point; decisions about defining eligibility and prioritising were left to local authorities; local authorities were required to operate within existing resources without new financial allocations; and detailed central government policy and practice guidance was not published until two months after the Act came into operation. In preparing for local implementation, local authorities had to rely on draft guidance and the parliamentary debate to assist them in interpreting and acting on central policy intentions. Thinking in terms of the 'intermediate outcomes', as used by Judge (1999), in relation to local policy and organisation in response to national policy, how did the research authorities respond to the requirements of the Carers Act?

The research authorities shared the concerns expressed by the Association of Municipal Authorities and Association of Directors of Social Services (Bell, 1995; Waterhouse, 1995) about the practical implications of a duty to assess without the power and additional resources to provide direct services. Their anxieties were reflected in the following excerpts from reports to the research authorities' social services committees:

> The Act gives no entitlement to services provided specifically for the carer, its emphasis is to take account of the needs identified through the carers assessment in meeting the needs of the care receiver. The allocation of resources to meet the need is restricted to the eligibility of the care receiver and if they do not meet the Department's criteria, no services will be provided.

> Whilst the Carers Act has been widely supported, the government has been criticised for failing to recognise the resource implications for local authorities. Increased pressure on Department resources will be felt not only in terms of greater demands on staff time to carry out assessments, but also in terms of carers raised expectations of support services.

The quotes from senior managers and practitioners later in this chapter reflect these anxieties within their concern to improve the situation for carers.

The right hand column of Table 2.1 gives a general flavour of the relationship between the intentions of government policy makers and the local policy response of the research authorities.

In respect of the policy reports taken to the responsible local authority committees by all four research authorities, our general findings confirm those of the SSI (1998a), in that the authorities did give general recognition to the needs of carers through the development of formal statements of principle and policy. The local policy response generally appeared to reflect central policy intentions (Table 2.1).

At the same time, though, the data about the local policy responses and framework showed the effect of local authority services being 'not mere deliverers of service goals set by politicians' (Lewis and Glennester, 1996: 18) and the need to be cautious about identifying 'precise cause and effect' (Packwood *et al.*, 1998: 413). For example:

In respect of the entitlement to a carer assessment, there was limited further definition. Although policy statements and local procedures acknowledged the eligibility restrictions and provision of services to care recipients, practitioners were encouraged in procedures and supervision to use their discretion and initiative in a way that would support carers. The mixed effects of this approach are considered further in the section below on entitlement.

- Authorities' policy response was influenced by demographic considerations. This is illustrated in the later section about equal opportunities.

The local policy response and framework context were influenced by existing local carer policies and support arrangements which varied between authorities. There was contrast between responding to the new legislation as an opportunity 'to devote significant resources to this area of work' and incorporate carer assessment into the defined priority criteria for assessment procedures (as quoted below for authority RA 4); and responding by strengthening the independence of carer support centres and building on the existing separate assessment of carers' needs (as occurred with authority RA 3).

In respect of the relationship between carer assessment and care planning decisions, authorities handled the recurring themes of resource restrictions and prioritising in different ways. On the whole, the authorities tended to emphasise that 'the Act gives no entitlement to services provided specifically for the carer', although the one authority (RA 4) retained a strong joint user-carer assessment approach, with the policy statement that 'the same priorities with regard to assessment and service provision will apply'.

Entitlement and access to carer assessment
This was one element of national policy to which research authorities did not appear to respond as intended. The policy guidance (DH, 1996) said that 'it will be for local authorities to form their own judgement about what amounts to 'regular' and 'substantial' and to make

their views known', defining eligibility 'in their everyday sense', whilst taking account of 'the relative needs of carers in their area' (p. 4). The practice guide (SSI, 1996) confirmed the emphasis on 'heavily involved' carers (Parker and Lawton, 1994) rather than 'helpers', and detailed a number of factors indicative of whether someone was providing substantial and regular care: the type and intensity of care undertaken; the level of supervision involved; whether caring was likely to be a continuing responsibility. Evidence from other studies (CNA/ADSW/ADSS, 1997) shows that local authorities have developed a multitude of definitions of the terms 'substantial' and 'regular'. Consequently, eligibility for assessment under the Act varies both within and between authorities, and some carers find it more difficult than others to access their right to a carer assessment (CNA/ADSS/ADSW, 1997; SSI, 1998; Davis *et al.*, 1998). The results of the present study endorse these findings.

The four research authorities took the national guidelines for the Carers Act as their starting point for devising local entitlement criteria. They went on to develop flexible definitions of 'substantial' and regular, rather than a fixed set of criteria. The data about local policy intentions would suggest an open approach and the possibility that the Carers Act could be reaching more carers than it originally aspired to. It appeared that broad definitions of entitlement criteria were being applied in local policy statements. Each of the four authorities avoided defining eligibility in terms of amount of hours and/or number of care tasks; there were references in policy statements such as:

- 'must also acknowledge the emotional impact of the responsibilities of caring' (RA 1)
- 'cannot manage on their own with help' (RA 2)
- 'heavy involvement also acknowledges responsibility for supervision rather than personal care' (RA 3)
- 'tasks of caring will vary from situation to situation ... would otherwise involve the provision of a rostered service' (RA 4).

Senior managers and practitioners interviewed in the study generally reflected this apparently open and generous policy towards eligibility. Given this, it is surprising that the number of carer assessments carried out nationally remains low (CNA, 1997; SSI, 1998a), and that we struggled to reach our target figure for the study sample.

Despite any differences in formal definitions of entitlement criteria, one key message from the interviews with senior managers was that their authority aimed to be inclusive rather than exclusive. Generally, managers did not think it was especially useful to stick rigidly to time- or job-based criteria when deciding whether or not someone qualified for a carer assessment. For instance, one manager said that a carer undertaking just two or three hours of care a week could qualify for assessment because, to quote 'for that person, that might be just their breaking point'. Senior managers spoke of taking 'as broad a view as possible', 'relying on

good practice', 'not feeling the pressure of tight eligibility criteria', and 'we would be inclusive rather than exclusive'. This open approach was reflected by practitioners with comments about putting in services that 'free up the carers as well as helping the carer do the caring' and 'they've got needs themselves which are now being recognised'. This open approach appeared to lead to staff uncertainty about whether to respond in an inclusive or exclusive way and contributed to varied practice.

The relatively permissive stance of the research authorities towards entitlement criteria put the onus on social workers, in their role of 'street level bureaucrats' (Lipsky, 1980), to make decisions about whether carers qualified for assessment. It is clear from the data that individual practitioners did exercise professional judgement regarding eligibility. Although interviews with staff revealed that they were not always aware of, or clear about, their own authority's interpretation of eligibility criteria, they tended to be inclusive on the basis of what they saw as good practice. Yet, a 'holistic' approach during care planning and reviews sometimes appeared to contribute to staff addressing the needs of carers without the carers being clearly aware and informed of their rights and the process. This is discussed further in Chapter 3.

Equal opportunities
This was another element in which there was variation in the way research authorities responded. The policy guidance (DH, 1996) and practice guide (SSI, 1996) draw attention to equal opportunities and communication issues. The National Strategy for Carers (DH, 1999a) talks about the additional needs of carers from minority populations, suggesting for instance that they might need information about services in appropriate languages. The document also points out that it is important to consider the cultural traditions of minority groups. In the literature, there is a great deal of evidence about the unsuitability and inaccessibility of support and services for black and ethnic minority communities (Atkin, 1992; SSI, 1998b; Yee, 1995, 1998).

Three of the four research authorities expressed commitment to equal opportunities for ethnic minorities in their policy documents. They had attempted to make information available to carers and care recipients from ethnic minority communities; different formats were used including leaflets in local community languages, and audio and video tapes (see Chapter 5). The three authorities recruited staff from ethnic minorities; in one, these staff worked alongside social workers, as interpreters and/or to give insight into particular cultures, religions or customs. These authorities also had support groups catering for carers from particular communities; these included Asian, Jewish and Afro/Caribbean carers' groups.

In the fourth authority, which had an extremely low ethnic minority population, there were other causes for concern associated with geographical variation, rural living and travellers. Providing community care services in rural areas is a significant issue; about one-fifth of the population (ten million people) lives in the countryside (DH, 1999a). Previous research (Atkin, 1992; SSI, 1995b, 1998a) has found that the support available to carers with similar needs varied according to locality. Carers living in rural areas are likely to face greater difficulties and be less well supported than carers in urban areas. This is because services for carers (and users) in rural locations may be more costly in terms of staff time, transport and publicity than similar provision in urban area, and at the same time cater for fewer people (Leat, 1992; SSI, 1999a). The potential difficulties facing carers living in the country are noted in the guidelines to the Carers Act (SSI, 1996), and are discussed in some detail in the National Strategy for Carers (DH, 1999a). The policy manager from the site in question emphasised that carers faced social isolation because of the dispersed population:

> The one thing you can't do here very well is set up a support group of like minded carers because they're just too far away from each other, you haven't got the intensity. So it's the lack of people with similar needs ... unless you get an amorphous [group] and people think 'What am I doing here with this lot?' which is hard. And the transport, you know, getting access to services or even if you've got time off, getting yourself out to somewhere different and that is the downside to rural living.

Section 4: Inter-agency working

Related to the joint working requirements of existing legislation such as the NHS and Community Care Act 1990, all four authorities already had local joint planning arrangements which could be used to address the requirements of the Carers Act. The government policy guidance was explicit in its references to using existing collaborative arrangements for social services to work together with housing, health and education agencies. This was acknowledged in the policy statements of all four research authorities:

- 'There is already good inter-agency work being undertaken and it will be important to build on this, both at an individual level and through initiatives' (RA 1)
- 'Continued work to raise the issue with other agencies, in particular the health provider trusts and service provider organisations in the voluntary sector' (RA 2)
- '*Working with Carers*, an inter-agency policy document which, in some ways, is in advance of the new legislation' (RA 3)
- 'Strategy for Carers - inter-departmental, inter-agency approach to carers' issues - and Joint Strategy Group established 1992/1993' (RA 4).

Senior managers made reference to the importance and actual practice of using the joint planning and staff training arrangements to assist in the development of multi-disciplinary procedures and practice. They tended to place a strong emphasis on the concept that 'carers are not just a social services issue', particularly in relation to general practitioners and primary

health care teams (see Chapter 7). A number of practitioners recognised the joint working requirements of existing community care legislation and advocated a multi-disciplinary approach to assessment as a matter of good practice.

Section 5: Preparation of practitioners and their understanding of local policy
The research authorities acknowledged staff training implications of the new legislation. In each case, policy and practice statements and procedures were revised and developed, with dedicated documentation for carer assessment. Associated with this, authorities disseminated the new requirements and duties, sometimes through modules of training for a wide range of staff and sometimes through a cascade approach through key staff such as care managers. In each of the authorities, senior managers and practitioners acknowledged some uncertainty about the extent to which staff training was being maintained, for instance with new staff.

Even though there were documented policies, senior managers and practitioners were sometimes unsure about what should happen in practice. There were a number of examples. There was uncertainty about how to act on the local policy that defined the carer's entitlement to assessment as dependent on the eligibility of the carer recipient to support and services. Aspirations for an inclusive approach were in tension with the need to manage with finite resources and staff time. Practitioners saw their departments as generally carer aware, although often they were influenced more by their view of good practice than local policy and practice guidance. The initiation and timing of carer assessments sometimes related to the varied practice of staff rather than compliance with policy about the care assessment and review process. Although local policies stated that carers and users should receive copies of care plans and written confirmation of the carer assessment, there appeared to be some ambivalence in the minds of senior managers and practitioners. Sometimes this was linked with the issue of confidentiality; at other times, with concern about the consequences of recording needs which could not be met because of resource restrictions.

Section 6: Monitoring the outcome of local policy
There was a range of responses from senior managers about how departments monitored the outcomes of assessments generally and carer assessments in particular. None claimed they were wholly satisfied with the monitoring arrangements. On the whole, there was a reliance on general statistical returns and decentralised monitoring of care planning by team leaders and review officers. The senior managers spoke of monitoring sometimes having to be 'impressionistic' based on a general overall view, and reliance on limited sample surveys and questionnaires about specific services. The reasons given for not having more effective comprehensive central monitoring included the need to upgrade information technology systems, not enough time, and for evaluation to be undertaken as a task in its own right. To

some extent, it was seen as beneficial to rely on sample surveys and external monitoring by such bodies as the SSI and Audit Commission.

Although local authorities were at different stages of developing effective information and monitoring systems, at the time of the research project none had reached an advanced stage. In one authority, even confirming the number of carer assessments involved time-consuming manual work; in all the authorities, monitoring the impact on services was still largely dependent on the decentralised hierarchical structure of the organisation. A recent study by SSI (1999b) suggests that in these respects the research authorities are not a-typical.

Senior managers did attempt to provide meaningful statistics about carer assessments and outcomes. To some extent the figures provided for the study were from reports compiled for their own use; to some extent information was collected to meet our requests. There was a varied balance between information technology and manual systems. There appeared to be variation between authorities about definitions of data collected and whether it was centrally or area maintained. For instance, one authority (RA 3) recorded that about 350 carers had been entitled to a carer assessment over a 12-month period. That authority recorded that about 100 of the 350 eligible carers had accepted and received a carer assessment (about 28 per cent). Another authority (RA 1) estimated that about 200 carers in contact with one specialist team over the same period had been eligible. The team leader in this authority reported that 15 of the estimated 200 carers whose needs had received consideration along with the care recipient had received a formal carer assessment (7.5 per cent).

It would appear that the attitude and approach of practitioners were influential in determining the extent to which the assessment focused on the carer as opposed to the care recipient. For instance, some staff emphasised 'holistic assessment' to the exclusion of a distinct carer assessment; others viewed carer assessment simply in terms of completing a carer's assessment form. Such variation in practice could help to explain the contrasts between the perceptions of social services and carers, and the uncertainty among carers about whether their needs had been addressed, as shown in this and other studies (CNA, 1997; CNA/ADSW/ADSS, 1997; King's Fund, 1998).

Section 7: Staff views about the Carers Act
Senior managers and practitioners were asked about their perceptions of the benefits and difficulties arising from the new legislation.

Benefits and good practice
The four senior managers responded to questions about the benefits derived from the Act largely in terms of the raised profile of carers, reinforcing good practice with carers and the

opportunity to improve policy and procedures for work with carers. Apart from the direct impact of their new duties, it was seen as a peg for improving the assessment and care management system as a whole, staff training and supervision, and inter-agency working.

The practitioners interviewed in the four research authorities acknowledged that the Act had contributed to a greater awareness of the rights and circumstances of carers and improved care planning and practice generally. A number referred to a higher profile, giving carers a voice. One expressed this in terms of giving carers the opportunity to say 'I don't want to care any more'. Other practitioners spoke of the benefits more in terms of the Act improving their ability to plan and provide services for the service user, and enabling resources to be redeployed elsewhere.

Difficulties and poor practice
In response to questions about difficulties in implementing the Act, senior managers spoke about poor information systems both in respect of information for carers and organisational monitoring requirements. They spoke of the need for social workers to be more proactive about carer assessment and carers to be less cynical about it. For instance, one senior manager, said 'They [carers] don't think it will make any difference'. They alluded to concerns about raising carers' expectations, and the need for increased government resource allocations. Other references were to problems arising from unclear eligibility definitions and the need for agencies such as health to recognise that carers were not just a social services responsibility.

Practitioners' views of difficulties were largely in relation to workloads and finite time and resources. This was often expressed in terms of raised expectations and concern for carers, such as one social worker who said 'I haven't got time to say "I'll come back and see you"'. There was some reference to cynicism of workers who might see carer assessment as 'just another piece of bureaucracy'. A number spoke of difficulties in relation to forms and documentation. In contrast with the social worker who saw the Act positively as a legitimisation of carers who said they were no longer willing to care, another worker expressed this as a cause of anxiety: 'What if they say "I don't want to care any more?"'.

Future developments
Senior managers expressed their recommendations and aspirations for future developments in terms of improvements in the flexibility of services, staff training and preparation, and department information systems. There was also reference to improved information and simplified documentation for carers, advocacy support, and multi-agency working.

The practitioners' recommendations for improvements were largely in relation to smaller workloads and increased resources, improved information systems and procedures, and greater clarity about eligibility criteria.

Summary of key findings

- The research authorities did give recognition to the needs of carers through the development of formal statements of principle and policy, which generally reflected central policy intentions (section 3)

- There was some variation in the local policy responses, which to some extent reflected the influence of existing carer policies and support arrangements developed prior to the Carers Act and also how resource prioritising was handled locally (section 3)

- The ambiguity in national policy about eligibility criteria and the entitlement of carers to assessment and services was reflected in local policy rather than resolved, with the discretion and initiative largely being passed down to front-line practitioners (section 3)

- Senior managers placed a strong emphasis on the concept that 'carers are not just a social services issue', particularly in relation to general practitioners and primary health care teams (section 4)

- Although practitioners saw their departments as generally carer aware, often they appeared to rely more on their view of good practice rather than understanding of local policy intentions (section 5)

- There was some ambivalence in the minds of managers and practitioners about the local policies and procedures about carers receiving written confirmation of the carer assessment, even though this policy expectation appeared to be clear in policy and practice statements (section 5)

- Information systems for monitoring and managing the operational response to policy intentions about carer assessments and reviews and outcomes are at an early stage of development, but this was receiving active attention in the research authorities (section 6)

CHAPTER 3: CARER ASSESSMENTS

Section 1: Introduction

This chapter is concerned with the process of carer assessment. What were social services' intentions? What happened in practice? How aware were carers of the process, and what were their perceptions of being assessed? How did this relate to the intended approach and focus of assessments? The expectation of 'a sensitive, individualised exercise' and 'not some uniform, clipboard response designed merely to satisfy the requirement of a new act' (Wicks, 1996: 7) was reinforced in the policy guidance (DH, 1996) and confirmed in the practice guide: 'It should not be prescriptive but recognise carers' knowledge and expertise' (SSI, 1996: 3).

What has become known as 'assessment' is a major component of the helping cycle that has developed over the years and is incorporated into community care policy and practice. 'Assessment is a key tool in health and social care and forms the basis upon which decisions about services or other intervention can be made' (Heron, 1998: 61). The central policy on the Carers Act adopted a narrow definition of carer assessment: 'The assessment is of the carer's ability to provide or to continue providing care and takes place at the same time as the user assessment' (DH, 1996: 21).

In central policy guidance, national policy intentions about assessment have not always been consistent, being variably influenced by the perceived purpose (Neill, 1989), different models of assessment (Smale *et al.,* 1993), and the ambiguous position of carers in relation to service provision (Twigg and Atkin, 1994). Government guidance on assessment has shown the influence of what Neill (1989) termed *pre-determined* eligibility criteria, *available services,* and the *unique situation* of individual circumstances. Community care guidance (SSI, 1991) has moved away from an earlier expert needs led approach (DH, 1985), similar to Smale's *questioning* or *procedural* model (Smale *et al*., 1993). It has been argued that the additional goals of increasing choice and independence and empowerment require an approach more akin to the *exchange* model (Smale *et al.*, 1993). In guidance, carers have been treated variably as resources, co-workers and co-clients (Twigg and Atkin, 1994). Other studies have found that many authorities still adopt a procedural model, with the goals of assessment focused largely on eligibility and categorising needs and services (Davis *et al.,* 1997*).*

What approach to assessment was advocated in national policy (DH, 1996) and practice guidance for the Act (SSI, 1996)? Key emphases were that the assessment should: not assume a willingness by the carer to continue caring; ensure that both carers and professional staff share the same understanding of the process; discuss with the carer how the assessment

should be done; adopt an integrated family based approach; confirm care plans and assessment results in writing.

Section 2: Carers' awareness of assessment
The study confirmed the findings of earlier work (CNA, 1997; CNA/ADSW/ADSS, 1997) about discrepancies between professional perceptions of carer participation and actual carer knowledge and awareness. For instance, even though the carers in the sample were referred to us on the understanding they had been assessed, around half of them were not fully aware they had experienced an assessment and they had difficulty identifying the event itself. The remainder were aware of an assessment of their needs at least to the extent of an assessment form being self-completed or completed by the social worker. However, for carers to participate positively within the carer assessment and care planning process, they should be informed of the process and what is happening. Carers themselves want to prepare and be ready, as the following quote indicates:

> I think they should tell you they are coming to assess you, and give you a chance to think about it before they come. You haven't a clue what they're going to assess you on ... is it your needs, or the patient's needs or what? I think they could explain to you.

Comparisons were made between the characteristics of those carers who said they were unaware of a formal carer assessment (24) and those who acknowledged some awareness (27). There was no apparent difference in respect of length of time caring, types of disability, or relationship between carer and care recipient. A higher proportion of heavily involved carers (as judged by the extent of care required day and night) said they were unaware of a formal carer assessment compared with the others. Older carers were less aware that they had been assessed than younger carers. Some 15 of the 26 carers aged 61 years and over (58 per cent) were unaware that they had been assessed and could not remember carer's assessment forms being completed. In contrast, 9 of the 25 carers aged 60 years and under (36 per cent) were unaware that a carer assessment had taken place.

The above comparison could be a pointer to help identify those carers in greatest need for informed guidance about assessment and services, for example, older people with heavier caring responsibilities. The recollections of carers about what they were told led us to believe that social workers tended to be more forthcoming with younger carers about their rights and ensuring they were informed about the process; the emphasis for older carers was more on supportive care package planning but without ensuring the carers were aware of their distinct rights. In interpreting this finding about professional practice, account has to be taken of other factors which could be relevant: the relative ability of older people with heavier caring responsibilities to understand and retain information about what was going on; and the difficulty people under stress might have in absorbing and recalling what they are told.

Walker and Walker's (1998) study of people with learning difficulties and their ageing family carers found that older carers differed in a number of respects from other groups of carers. These differences had an impact on their dealings with health and social services, leading the authors to suggest that staff need to look at the way they regard and interact with older carers. In our study, one elderly carer highlighted how age could be a factor in how social workers approached carers, using the example of information. She felt that it was reasonable to ask a younger carer what services they required because, to quote, 'a younger carer can possibly get a brain working' and think for themselves when assistance would be helpful. For older carers, the situation warranted different handling:

> Whereas when they're asking me [what help do I want] and, you know, I'm thinking 'Well, what do I really say?' ... I mean I don't know the ranges of the things that social workers can do for you, to be quite honest. ... But if they could say 'Well, such and such is available, and such and such is available, would that be any help?' Now that would be helpful to me, yes.

Whilst it may be that older carers themselves behave differently when being assessed, it is also possible that assessment practice differs between older and younger carers, in other words it relates to the age group served by the social worker. There is some support for this hypothesis, given the claim that there is a long-standing tendency among social workers to view older people as needing help mainly of a practical nature rather than specialised social work skills (Davis *et al*., 1997). Furthermore, caseloads tend to be higher for services for older people (Challis *et al*., 1998). Challis *et al*. (1998) found that as caseload size increased, follow-up, monitoring and review were less likely to happen. This suggests that positive outcomes such as sustained involvement between individual clients and care managers are less likely for older people.

Section 3: Access to carer assessment

Getting into the social services system

The social services system itself can pose a barrier for people with no prior contact with their local department, and who know nothing about services. A small number of interviewees talked spontaneously of how hard they found trying to access help and assistance, although they did feel that once in the system the response was reasonable, a finding endorsed in other work (SSI, 1995b). Typical comments included 'I felt ignored, and it was very difficult to get into the system, although once in the system there were no particular problems', and 'The system is possibly alright for people that know it'. For a fuller discussion of issues related to providing carers with information about how to get help from social services, available services and the Carers Act, see Chapter 5.

Many carers had been receiving formal help for a long time and could not remember how they first came into contact with social services. By looking only at those people who had been

caring for less than five years, a total of 24 carers, we can say with some certainty that for the overwhelming majority (21) contact was initiated through the NHS, including hospital staff, GPs, district nurses and receptionists in doctors' surgeries. This shows the critical role the health services have to play in the wider network of carer support, and demonstrates the value of joint working. However, this referral pathway was not always effective. For instance, one mother was angry that, despite being continuously involved with health professionals, her child with cerebral palsy had reached the age of 12 before it was suggested that social services could help. Both she and her husband had found the childhood period a difficult time; she spoke of her experiences when the child was younger, and their need for practical help and emotional support:

> I mean there were times when we used to sort of sit at home, bawl our eyes out, think where do we go next ... Boots didn't sell any nappies big enough for him, so we used to buy nappies and get sellotape and sort of sellotape them together, because we didn't know that social services could provide like incontinence pads, we knew nothing about it ... we never had any contact with anybody.

Two other interviewees, whose children were at the point of transition from child to adult services, were finding the 'handover' arrangements difficult and unsatisfactory. The change involved (re)negotiating access and services with unfamiliar professionals. Similar problems have been reported in other work (Fiorentino *et al*., 1998; Morris, 1999).

How carers accessed an assessment

It was often difficult to determine how the assessment of the carers in our study had been initiated, even though carers were explicitly asked about this. However, based on the accounts of carers within the study sample, it was likely that:

- about half of the carer assessments were linked with an assessment of the care recipient, including carers who had come to the attention of social workers during hospital care for the care recipient, and carers who had approached social services because of a crisis
- most of the remainder received a carer assessment linked with a re-assessment, mainly arising from deterioration in the health of the care recipients and/or a change in the carer's circumstances and ability to care, or related to education or health reviews of children.

Just two carers made a direct request to be assessed; a further carer asked for help in relation to being rehoused, and subsequently received a carer assessment. It seems that any fears of a large increase in demand from carers for assessment have not been realised.

Access to assessment from the practitioners' perspective

Although the carers in the sample had been referred to the study by practitioners as people who had been subject to an assessment of their needs, it was often difficult to locate a distinct carer focus within the response of social services. The carers' uncertainty or lack of awareness about whether they had received a formal carer assessment was paralleled by the acknowledgment by practitioners that a clear distinction was not always made between assessment of the care recipient and the carer. By incorporating carer assessment into their practice, some staff maintained an 'integrated' approach, with the assessment of carers' needs being part of the 'holistic' assessment upon which care planning was based. Other staff treated carer assessment as a separate event in its own right, often linked with completion of the carer's assessment form. The danger with the first approach was that the carer might be unaware of what was happening, and therefore not participate in assessment in an active and informed way. The danger with the other approach was that the assessment might be distinct and separate to the extent of being an isolated event having no impact on care planning. In reality, these approaches are probably two ends of a continuum. Central and local policy intentions appear to be for the carer assessment to be both a separate exercise in which the carer can consciously participate and at the same time an element in the care planning decision process. The statements of staff and reported experiences of carers in our study would support the view that this is a difficult balance to achieve.

As discussed in Chapter 2, the attitude and approach of practitioners was influential regarding whether the focus was on the care recipient with the carer as an element in a general assessment, or whether the carer was enabled to 'get into the system' in their own right. The difficulty locating a distinct carer assessment also highlights the tension between aspiring toward an 'integrated family approach' as advocated in national guidance and by practitioners' concepts of good practice, and seeking to ensure a separate carer focus in which the carer can actively contribute.

Not all carers qualify for assessment under the Carers Act. The way the majority of practitioners in the study responded to issues about eligibility for assessment was to look first at the type of caring activities carried out and whether a carer provided short or long hours of care, and then to investigate other issues. Factors named as influencing eligibility included: living at a distance from the care recipient's household; having responsibility for overseeing the caring activities; carers' own abilities and/or incapacities, such as ill health. As with the senior managers, some practitioners also pointed out that caring that was experienced as 'substantial' by one person might not be 'substantial' for another. Similarly, most of the practitioners said they took only limited notice of the number of hours an individual might spend on caring when deciding whether someone qualified for an assessment:

I've never looked at it, sort of, on the grounds of 'Well, you only do three hours a week and that person does 20, so that person can have an assessment and you can't.' I think I just look at it that if somebody is giving some caring input into that person's life, then they're a carer, regardless of how many hours that they're putting in.

Encouraging carers to have an assessment

A number of practitioners stressed to us how important it was to give carers full information about assessment when first introducing the concept and seeking to persuade carers to take up the opportunity to be assessed. In good practice terms, they believed the issues to cover included:
- the purpose of the assessment
- how the carer (and the practitioner) could benefit from the assessment
- what is involved in completing a carer's assessment form
- different ways to get the information down on paper
- what happens to the form
- who will see the documentation

Practitioners felt that the carer's assessment form should be presented as a tool to help solve problems, rather than anything that could threaten the carer or the person cared for.

For their part, carers appeared to find explanations like 'assessments are a record of your side of the story' or 'assessments are all about yourself because you're the carer' persuasive. When told by her social worker that her situation 'was as important as her mother's', the person she supported, one carer said 'This idea was a bit of a revelation to me'.

Section 4:   Method of assessment

All four research authorities had distinct carer assessment procedures, guidance for staff and separate documentation including carer's assessment forms.   Irrespective of written procedures, the evidence showed that the practice of undertaking carer assessments was variable, for instance in relation to whether it involved a personal discussion, who was present and if the occasion was also used to complete a carer's assessment form.

There was wide variation in the accounts of carers in the study sample about the time taken for undertaking a carer assessment. There were clearly recollected examples of time being set aside for the assessment, ranging from half an hour to four hours. A number of carers described how the social worker gained a picture over time through a number of contacts. However, since around half the carers in the sample could not recollect being assessed, we are not in a position to judge from the carers' point of view how much time on average was devoted to a carer assessment.

Assessment discussion

It was often difficult to differentiate between general contact with carers during the care assessment and a distinct carer assessment discussion. Whatever the nature of contact with the social worker, in about two out of three cases the carer and person supported had been seen together. In the other cases, the carer and the cared for person had been seen separately during the contact with the social worker. In some cases, this had been clearly planned; in others, it could have been simply that the care recipient was not present for some reason, such as day care attendance. Carers were normally seen at home (about nine out of ten), with a very small number of carers being seen for assessment or discussion in hospital (prior to discharge) or the social services office. Few carers could recollect being consulted about the detailed interview arrangements, even though the practice guide (SSI, 1996) says that carers should be involved in the assessment arrangements and subsequent monitoring and review.

Carers' views differed about the practice and benefits of meeting social workers privately and separately from the care recipient. There was a wide variation of attitudes, with strongly held views on both sides. Differences of opinion often related to how carers saw themselves: as part of a caring relationship/family unit, or individuals. For example, some carers took the view that discussions should include the care recipient, as reflected in comments such as 'If it's to do with my mum, she's involved and might as well be there' and 'Treated as a family, not an individual'. In contrast, others believed there should be exclusive contact with the carer: 'There should be more privacy away from your wife, instead of involving the ill person' and 'I don't think it's right that she should be sat there while we're talking about her. I think it should be done without her'. Yet one or two others favoured a set of discussions: 'A family interview and then individual ones to piece it all together'.

It is not possible to generalise about a prevailing view, which highlights the importance of informed agreement about arrangements with the carer. There is some data, which relates to a small sample so must be seen in that context, to suggest that carers likely to want a private discussion:
- support younger people with learning disabilities or people with mental health problems associated with advancing age
- have poor/less close relationships with their partners.

Contrasting quotes from carers reflect the importance of discussions with practitioners that cover a wide range of potential needs, not only as an effective assessment but also as supportive evidence of concern about them:

> I think it was very, very thorough. I was really impressed with it. It seemed to cover all areas, the family, the health, the personal side, the finances. Everything seemed to be pretty well covered in it ... I do think [the assessment] is quite important for his dignity and our help as well.

> I just said to [the social worker] that I felt really tired, really tired, worn down, that's all, and he said, 'I'm sure you are' but he didn't ask about anything else. I think he needed to know the situation from my point of view as well.

What were the carers' recollections of the content of discussions during the assessment and their contact with the practitioners? Again, account has to be taken of the carers' awareness about the focus of any discussions. There was little evidence of open consideration of the issue of their willingness to continue caring. What was evident from their recollections was a strong focus on the service provision needs of the care recipient. This was not necessarily seen as inappropriate by carers. But a few did make strong statements to the effect that the focus was too exclusively on the needs of the person they were caring for. One carer who had specifically requested a carer assessment remembered losing patience in the discussion and saying, 'Look, I'm getting really frustrated, I thought this was about me'. One of the key conclusions of a study of the process and outcomes of the Carers Act for carers of people with dementia (Seddon, 1999) was that 'a crucial step in addressing the needs of carers is recognition' (p.46).

Some carers remembered other matters more directly related to them being occasionally raised, such as their need for a break, their health and employment, and financial circumstance. Some struggled to remember anything related directly to their needs being raised in the discussion: 'Not really, no', 'I can't remember'. Issues relating to carers' experiences and needs in terms of health and employment are discussed further in Chapters 7 and 8 respectively.

Only one research authority carer's assessment form asked specifically about financial circumstances, yet such a prompt could provide a useful peg and safeguard to ensure this aspect of carers' lives was not overlooked in any discussion. Generally speaking, finance was a matter of concern for carers, in terms of expenditure associated with travelling expenses, special diets, clothing, laundry, continence materials, holidays, and charges for services. At other times, it was expressed in terms of restrictions on income through reduced or lost employment and/or the interaction between benefit entitlements. In response to the CADI statements (Nolan and Grant, 1992a; Nolan *et al.*, 1998) completed at both first and second interviews, one in four carers stated that worry about their standard of living was stressful or very stressful. A large and increasing minority of carers rated financial difficulties as stressful or very stressful at Time 1 (17 of 45 respondents) and Time 2 (18 of 39 respondents).

Often the same worker who dealt with the carer's assessment also handled the financial assessment for services and was the point of contact for discussing charges. A number of carers clearly found the system in respect of finance complex and confusing, and it was another burden in their already demanding role. As discussed later (Chapter 5), some carers

saw this as an information gap in that social workers had not addressed financial circumstances and carers had either missed out on social security benefits or needed to rely on their own separate enquiries. Furthermore, it was important for carers to be well informed about the financial implications before making crucial decisions such as giving up work (Chapter 8).

Carer's assessment forms

All four research authorities used carer assessment forms to record information about the carer and the caring situation. The content of the forms varied, although all four authorities explicitly addressed: identification details of carer and person cared for; health and leisure interests of carer; references to need for breaks or respite; main difficulties in current caring situation; further help which would be useful; and permission to share information with other agencies.

Methods for getting this information onto the assessment form differed. The principal technique adopted in one authority was self-assessment, whilst the main approach in the others was for form completion to take place during assessment discussions. In practice, the evidence shows that staff in all four sites followed a range of different procedures, including:
- leaving assessment forms with carers to complete on their own and then return
- leaving forms with carers to fill in alone; some time later, collecting the completed forms and at that point discussing the questions/responses with carers
- sitting down with carers, discussing the questions and completing the forms together (the most common method)
- completing assessment forms on the basis of their prior knowledge of the carer and the caring situation; sending completed forms to carers to be checked and agreed
- taking carers' needs into account in an integrated user/carer assessment, but not completing a separate carer assessment form.

There did not appear to be any association between whether the carers or the social workers had completed the form and whether carers were satisfied with any resulting social services support. In each case, about half thought their needs had been recognised and supported.

Carers appreciated sitting down with the social worker, and going through the assessment form question by question. It legitimised what was put down, and they valued the time and attention devoted just to them. In comparison, self-assessment was a more impersonal and formal procedure. Many carers, particularly older carers, found completing assessment forms on their own a struggle. Questions like 'What further help do you think you need?' were stumbling blocks, especially for those people who were not aware of the full range of services

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available and appropriate. A female carer described the self-assessment process as 'nerve wracking' because 'it's not easy to put down personal things'.

Carers' discomfort with self-assessment does not necessarily undermine the recommendation from the CNA (CNA/ADSW/ADSS, 1997) to develop self-assessment as a tool for carer assessments. When the local authorities in the CNA survey expressed support for self-assessment, they were not supporting the practice of simply leaving forms to be completed and returned. The benefits perceived by the respondents related to self-assessment as a means to enhance the assessment process, not to replace the involvement of the social worker, thus giving the carer time to consider their needs and acting as a prompt for the social worker *before* the carer assessment. The findings of our research suggest that self-assessment forms should be used selectively as a preparation for assessment and not routinely distributed as a method of carer assessment.

Some carers were unsure whether a carer's assessment form had been completed or not. One reason for their uncertainty was their involvement with official forms generally, and confusion with other documentation such as social security claims and financial assessment forms. Sometimes, when carers talked about the inconvenience of 'lengthy forms' and their lack of time and energy to deal with them, they were not always sure to which form they were referring.

> You bring a form, she brings a form, he brings a form and more or less they repeat ... there's too many forms.

General approach of social worker

What did carers like about the approach of social workers? Some spoke favourably about practitioners being 'down to earth', not using jargon, 'easy to talk to', or listening to what the carer said. They appreciated social workers being forthcoming with information, ready to help and advise on the process (such as form filling), and recognising the need for encouragement and guidance.

> She's very good because she'll listen, she takes in what I say, she gets [things done]. She's very helpful, very friendly.

In speaking about what distinguished a 'good' social worker, there were recurring themes:
- quick and reliable responses and follow-up
- keeping the carer informed and maintaining contact
- expert and well-informed
- good listener and comfortable to talk to.

Section 5: The influence of carers on care planning decisions

As is described in Chapter 4, help of one form or another was provided to the households of the majority of the study sample. Previous research (Parker and Lawton, 1994) has claimed that the criteria by which services are allocated are not necessarily related to need and can discriminate against certain types of carers. The SSI (1998a) suggested that important factors in variability were how front-line staff worked, lack of supervision and monitoring to ensure equal treatment, and the influence of past policy decision making about the development of support for carers. But what about carers themselves? One of the social workers we interviewed said:

> You know, some carers are better at letting you know what their needs are than some others.

So how did some carers have the edge on others when it came to telling practitioners their perceived needs? There was some consensus amongst carers in the study sample that it was people who articulated clearly and forcefully their needs for help or services that were more likely to receive support. Carers used a variety of phrases including 'kick on doors' and 'be pushy' to describe the sort of behaviours they felt were necessary in order to be heard. The observations of one carer in the study sample summed up the views of many:

> The louder you shout, the more you get done. That's what I basically think. You've got to be able to stand in your own corner.

Having a strong voice does not come easily to everyone, and some carers found it a struggle to obtain help on their own. A small number of elderly carers had asked their grown-up children to be present in meetings with social workers to help them put their case. Two people pointed out that if appointments were made during the working day, however, it was very difficult for their children to get time off from work to accompany them. The carers' centre in one research authority offered an advocacy service to represent carers' interests and help them access services and benefits. According to the carers' officer, carers valued having somebody 'on their side', who would help in negotiations with social services and other professionals. Some of the carers we spoke to agreed that they would have found it helpful to have someone else present:

> At times like these, your brain's in a muddle, and if there's somebody that's clear thinking that, say, has been through it, or understands these things [then that support would be useful].

Being persistent, not being 'side-tracked', and not taking 'no' for an answer were also seen as important when 'negotiating' support with social workers. So, too, was being knowledgeable about service provision, understanding the social services system, being confident rather than deferential and making staff feel appreciated. A carer who said 'I think I get better attention than most people I know' put this down to knowing his rights, and his social worker knowing that he knew what he was entitled to. As found elsewhere (Davis *et al*., 1997), a small number of carers taking part in the study went 'higher up the tree'. For instance, one interviewee said that he had occasionally contacted local councillors when experiencing difficulties in having his (or his wife's) needs met; this had proved particularly fruitful close to election time. Two (female) carers we interviewed had been involved in formal complaints to try to get the services they felt were needed.

Section 6:   Conflict and prioritising between care recipients and carers
When asked about how they handled any conflicts of interest between the service user and the carer, there was a variety of responses from senior managers and practitioners. In respect of 'who comes first?', there was a generally accepted view that the needs and wishes of the care recipient would receive the strongest consideration, linked with the entitlement to services being their's rather than that of the carer. Yet, the tension was generally acknowledged, along with the increased leaning toward supporting carers wherever possible.

Senior managers linked this issue with that of separate assessment of carers' needs, sometimes to the extent of seeing conflict of interest as the main justification for separate interviews or even separate workers and advocates for the carers. Senior managers also acknowledged this as one of the demanding aspects of the social worker's role, involving them in delicate and skillful negotiations and 'complicated partnerships'.

Some practitioners also saw a separate assessment as the way of dealing with friction and different opinions, generally viewing the service user as the priority. At the same time, most did not see the issue as a clear-cut choice, there being times when 'it depends on the situation' or 'one did not have priority over the other'. Some staff spoke of how the Carers Act had highlighted or heightened tensions between users and carers.

When asked about how conflicts were resolved, staff referred to: care planning meetings; independent advocates; involving more senior workers or referring higher in the organisation; complaints procedure; talking to the parties separately; and things sometimes just resolving themselves over time.

From the accounts of both senior managers and practitioners, incidents of conflict between users and carers were not viewed as common, yet could create serious difficulties when they did occur. In this study, we did not find any examples of serious conflict of interest or wishes between service users and carers. There were examples of carers complying with the wishes of the person for whom they were caring at some cost to their own health and welfare, such as when care recipients resisted personal care support from the statutory agencies. For example, one male carer refused to accept any support from outside the home. Instead, he continued to provide for his disabled wife's personal care and organise his life to maximise his time with her to comply with her wishes, despite the increased impact it was having on his own physical health and the stress of not having private time for himself.

Section 7:   Follow-up to assessment

National and local policy guidance say that the results of the assessment should be confirmed in writing or some other accessible format. Among those carers who had received written follow-up, some had been provided with a copy of the carer's assessment form they had completed themselves or brief details about services and financial charges, as opposed to a fuller care and review statement. However, at least half of the carers claimed they had not received anything in writing. One carer spoke of social services staff being wary of committing themselves. A small number described how 'their' social worker had been over-ruled by a more senior manager. Carers from all research authorities who were aware of being assessed were not always certain of the exact results of the assessment, especially if no additional support was provided

Despite clear local policy guidance, there was evidence of uncertainty and varied practice on the part of staff. Practitioners were unclear when it came to: distinguishing between the care plan and carer assessment documentation; issues about whether the care recipient needed to consent to the carer having something in writing; and the relationship of written documentation with the handling of 'unmet need'. Even when staff indicated that it was their

normal practice, they sometimes qualified this by saying 'if they want it' or 'if the user agrees'. Clearly the written follow-up is not a simple process, as it is committing the agency to the assessment and recommendations, and not a simple matter of professional judgement and discretion. This suggests that not only should the policy about written follow-up be confirmed, but also that its status should be clarified and staff should know the policy and follow it.

The finding that it was rare for carers to have been the subject of further review could have been related to the six month period between the two interviews not being sufficient to pick this up in some cases. However, a small number of carers were the subject of review, and in some cases received increased care packages.

Having been assessed, a few carers then experienced their case being closed in terms of future contact with 'their' particular practitioner. When this did happen, people were left feeling deserted. The impact was all the more because the carers in question had expected contact to continue, if only on a limited basis. Any change to the caring situation was likely to mean having to renegotiate access to social services, and although the carers were now better informed, there was no guarantee of continuity in the social worker allocated to the case. Carers were concerned about this, especially the possibility that the relationship of trust built up with the previous worker might be lost.

Section 8: Carers' views of good practice
Carers commented, in the wake of their experiences, about the importance of being well informed about the process of assessment, services and their rights, as well as the condition of the person they were caring for. They spoke of the onus being put on them but 'not knowing what to ask', and the wish that social services had been more forthcoming with information. These issues are addressed further in Chapter 5.

A number of carers would have liked more time to think about what was happening and/or digest any relevant information, before the carer assessment took place, either on their own or with friends or family. This was sometimes linked with still coming to terms with the impact on their lives of finding themselves in a caring situation. In respect of the discussions themselves, some carers appreciated being allowed time just to listen and take things in, before becoming too involved in the actual discussions. Some connected the need for information and time to prepare with their anxieties about involvement with social services and feelings about the caring role.

A number of carers spoke of the benefit of support in preparation for involvement with social services and/or the carer's assessment. Some spoke specifically of carer support groups or

disease-specific organisations. Their need for 'somebody in the same situation' and 'in your corner' is returned to in Chapter 6.

Carers' reflections on assessment practice

The following points set out what carers perceived as good practice, although obviously an approach appreciated by one carer may not be liked by another:
- the assessment process to be made explicit and carers given time and information in preparation for the discussions
- consideration to be given to the timing and arrangements for interviews, particularly when caring responsibilities or work commitments make it difficult to fit in with the office hours of social services staff
- carers to be given the opportunity for an informed choice over the matter of privacy and 'separate' assessment
- carers to have face-to-face discussion, with self-assessment and other forms being an aid to this process rather than an alternative
- care to be taken with the amount of written information, which some carers find difficult to absorb even if they find time to read it
- workers to be prompt in responding to the carer assessment and maintain contact, even when no further direct support services result from the assessment
- written confirmation of the result of the assessment to be backed by some, albeit limited, direct contact follow-up as a support and safeguard.

A carer's account of good practice in assessment

A man looking after his wife with multiple sclerosis had also been very involved in looking after a son who had died around the age of 20. Throughout the carer assessment process, the social worker emphasised that it was 'all about you'. He gave the carer a blank copy of the assessment form so that he could think about it and make draft comments beforehand. This coincided with the social worker gathering information about both the care recipient and carer as part of the care assessment. The social worker returned with a further carer's assessment form for them to sit down together. The carer was asked if he wanted to be seen alone, but his wife was present during the discussion at his own request. The social worker and carer looked at the latter's comments and went through the questions one by one. A wide range of needs was covered. The carer felt listened to and well informed by the social worker. The social worker was honest in the sense of: 'This is what we can do; this is what I can try to do; there's no guarantee'. They agreed exactly what to say and the social worker wrote it down. A sitting service and regular respite breaks resulted from the carer assessment; personal care resulted from the care assessment on the carer's wife. As well as help in terms of practical support, the carer valued the time and attention he personally received: 'I felt for the first time in 25 years that I was a person in my own right.'

Summary of key findings

- Many carers claimed they were aware neither of a formal assessment nor of any carer assessment documentation being completed; arising from this, it was often difficult to determine how the assessment of carers had been initiated and to identify a distinct carer assessment that enabled the carer to participate in an informed way (section 2)

- Older carers with heavier caring responsibilities required special consideration through supportive guidance and encouragement to participate within the carer assessment process. In practice, younger carers were more likely to receive this consideration (section 2)

- Where carers could remember how they had made initial contact with social services, a very high proportion had done so via the NHS although this may have taken a long time to occur (section 3)

- Although practitioners stressed the importance of carers being informed about the assessment process, carers often reported limited if any discussion with them to ensure they were aware of what was happening and had time to consider any relevant information (section 3)

- The arrangements for the assessment, including the question of separate interviews and whether the carer wished to be accompanied, were not always a matter of discussion and agreement (section 4)

- Self-assessment forms were not appreciated as an assessment option, but sometimes seen as helpful in preparing for the interview (section 4)

- Finances were a matter of concern for a significant minority of carers, but carer assessments did not always cover social security benefits or the financial implications associated with caring (section 4)

- Written follow-up (information about the response to the assessment, named workers to maintain contact and details of review arrangements) was appreciated by carers but often not provided (section 7)

- Carers appreciated practitioners who: encouraged them to participate in care planning; maintained contact with them about the impact of services; provided general support (section 8)

CHAPTER 4:   SERVICES FOR CARERS

Section 1:   Introduction

This chapter addresses the results of carer assessments in terms of support and provision. As noted above, the Carers Act does not give carers a right to direct services. The guidance to the Act gives some clarification about the implications and impact of the carer assessment on decisions about services. For instance, the policy guidance (DH, 1996) emphasises that any informal support already available should be taken into account and that many of the services provided to the care recipient already assist the carers. Among its other aspects, the care plan should describe 'where relevant, how services provided to the user will assist the carer'. The practice guide (SSI, 1996) adds certain principles which are relevant:

* give care managers the capacity to arrange flexible services for users and carers
* understand that carers are most satisfied when services resulting from an assessment are carefully planned and efficiently provided.

Section 2:   Service provision and support

Professional priorities

Senior managers were asked about their view of service provision priorities. They tended to reply in more abstract terms about the principles that should be applied in dealing with carers. For instance, in response to questions about prioritising service provision, senior managers made reference to 'carer's voice', 'flexibility', 'partnership', 'ease of access', 'inclusive' and 'holistic'. When pressed further on specific services, they spoke of carers' need for practical and personal care support, emotional and social support, and respite care.

Care managers and practitioners interviewed in the study were asked how they perceived service support priorities.   They often referred to good practice principles that had implications for the 'final outcome' impact and ultimate effects on people receiving the support and services (Nocon and Qureshi, 1996). There were references to: 'not just what tangible services are provided, it's the way its provided'; 'they need to know they are not alone'; 'whatever the carer tells us is the priority for them'; and 'we have to listen to what they are saying'. At the same time as replying in general principles, their responses were specific in terms of describing tangible support services. In their responses, two service priorities predominated:

* practical support and personal care for care recipients
* respite (day and residential) and breaks for carers.

Practitioners spoke about 'support to relieve really high amounts of physical work' and 'packages of care which assists them in all the practical tasks'. They referred to carers needing 'space for themselves' and 'relief from caring'. To a lesser extent, practitioners also

expressed service support priorities in terms of emotional support and counselling, referring to the importance of 'relieving pressure', 'someone to sit and talk to' and 'ventilation' (see Chapter 7).

Actual service provision for carers and care recipients

It proved problematic to distinguish services received specifically as a result of the carer assessment from those support services that were already being received or would have been arranged anyway. One factor was the extent to which carers had been unaware of a carer assessment and were therefore unable to discuss any results. Another factor was the difficulty in differentiating between the care plan services generally and those that could have been influenced by the carer assessment. Many people had been caring for many years and were not 'new' to social services. The care recipient had been receiving services prior to the carer being assessed and/or recent social services contact in at least two of out three cases. In many cases, the package of services had been increased, reduced or changed in some way, perhaps coinciding with the carer assessment. In principle, the carer assessment had been taken into account when the care recipient's needs were being assessed. Yet, even when there had been service changes, it was rarely possible to be clear whether these had been directly influenced by the carer assessment. Generally speaking, the carers were unable to make this distinction, although many appreciated the support they were receiving.

Table 4.1 summarises the services received by the carers and households who participated in the study. It will be seen that a high proportion were receiving services at the first interview (Time 1) and the second interview (Time 2). Of the people receiving services, about two out of three were receiving more than one of the services at both points in time, with a slight increase in that proportion over time. Most were receiving a package of services, involving one or more of the main services as well as other support such as sitting and befriending, mobility advice and meals. The 'no direct services' category includes those carers and households who reported having none of these direct services, although some may have been maintaining contact with social workers. Excluding people cared for who had died or were in long-term care, about one in six carers and households were receiving no direct services, with some slight proportional reduction by Time 2. Three people cared for were in receipt of no direct services at both times. Of the eight care recipients (including two in the same household) not receiving direct services at Time 1, three were in receipt of services and two were in long-term care by Time 2. Two people who had received some direct services at Time 1 (one adaptations/mobility advice and the other cleaning only) were among the five not receiving any direct services at Time 2.

Table 4.1:   Services received by the users and carers
(54 people cared for in 51 households)

Main service received	First interview		Second interview	
	N	%	N	%
Day Care (Adult)	22	44	19	50
Day Care (Child)[1]	2	4	2	5
Respite Care (Adult)	21	42	14	37
Respite Care (Child)[1]	2	4	2	5
Home Care	18	36	16	42
Aids and Adaptations	8	16	8	21
No direct services	8	16	5	13
Total currently being cared for in household	50 care recipients[2]		38 care recipients[2]	
Long-term care	4		12	
Died prior to Time 2			4	

[1] In respect of child care services, it should be noted that the two children receiving both day care and respite care are in fact 50 per cent of the four children among the care recipients in this study.

[2] Percentages relate to total numbers of care recipients being cared for in household (excluding those care recipients who had died or moved into long-term care).

As Table 4.1 indicates, for 22 care recipients (22 households), there was no significant change in the service package between Time 1 and Time 2; three sets of carers and care recipients received no direct services during the fieldwork period. Of the 16 who had died or were in long-term care by Time 2, all but two had received some direct support services previously. There were tangible changes to the package of direct support services in the case of 16 care recipients (15 households). Services had increased for nine households including one man caring for his disabled partner and child. The increased services mainly related to respite care (seven cases), day care (three cases), adaptations (three cases), and mobility support and meals. The reduction in services affected six carers and care recipients; in three cases, home care and cleaning services were cancelled by the recipients because of the cost to the household. In other cases, a sitting service ceased because it was no longer available and day care was stopped as unsuitable in two instances. The variations over time were sometimes not straightforward, in that care packages could be maintained on the whole while specific services were cancelled, perhaps because of the cost.

Emotional support and counselling

Senior managers and practitioners acknowledged the importance of emotional and social support. However, this was not always evident in practice, where the emphasis was put on tangible support services. For their part, a number of carers expressed their appreciation of the support that came from dealing with known staff on a regular basis, and the support that came from contact being maintained by practitioners regardless of whether practical services were being provided. It was clear that the attention given to their needs, feelings and wishes through the carer assessment process was a support in itself. Generally speaking, carers would have appreciated greater recognition of their need for emotional support, someone they could talk to and who would listen to their problems (see Chapter 7).

Section 3:   Carers' perspectives on support services

Carers were asked to rate the extent to which practical services met their needs. The responses in respect of the most commonly received services at Time 1 (Table 4.2) were generally consistent over time, with the same high levels of satisfaction at Time 2. The three carers who reported that they were not satisfied at all with services were no longer receiving them at Time 2. Of two who had unsatisfactory experiences of respite care, one care recipient had died by Time 2 and the other carer and care recipient were still seeking a more satisfactory alternative. In the case of the carer who had not been satisfied with home care, he had left work to take on the responsibility himself.

Table 4.2:   Carer satisfaction with services at Time 1

Service provided	Very satisfied		Fairly satisfied		Not very satisfied		Not satisfied at all		Total
	N	%	N	%	N	%	N	%	
Day care	17	77	5	23					22
Respite care	14	67	5	24			2	10	21
Home care	13	72	4	22			1	6	18

Day care services

The table shows that there was a high level of satisfaction about day care generally. This was backed up by comments from carers: 'It really is a kind of anchor'; 'They help you and give you aid and advice'; and 'I'd be willing to pay whatever it is just to make sure that she got something and it saves me'. People spoke of the importance of the stimulation and care for

the care recipient; particularly in terms of meeting their own needs for emotional and physical relief, and time to do other activities. Where there were difficulties or reservations, these tended to relate to the appropriateness of day care facilities, the care recipient's attitude towards attending day care, or transport problems. The need for more appropriate day care mainly related to people with physical disabilities and/or recovering from a stroke. For instance, day care options were mainly geared towards older people, but younger people with physical and/or learning disabilities required day care with a stronger rehabilitative and/or independent living focus.

Transport to the day care centres was a problem acknowledged by some carers. Sometimes this was related to difficulties for themselves when required to transport or accompany the person to the centre. A number decided to pay privately for transport because of problems such as unreliability or inconvenient collection times with social services' own provision. There were examples where carers had withdrawn day care because of transport problems and/or the attitude of the care recipient. As one man put it: 'It wasn't worth the aggro'. The account of another carer illustrates the frustration that can accumulate:

> The transport that social services provided was very erratic and sometimes they never turned up. Sometimes they forgot and it all depends on the drivers because they are the ones who're supposed to know who to pick up and who not to and four times they forgot to pick him up. We're sitting there waiting and waiting. So I ring up and they say 'Oh hasn't he been picked up?' It was getting on my nerves so much. It was more traumatic waiting for the transport as him going, and eventually I said 'Oh, I won't bother'. Then the week he wasn't supposed to go, the transport turned up.

Home care services

There was a high level of satisfaction expressed by carers in receipt of personal home care. Reservations related to the flexibility, availability, timing of services and lack of continuity of staff. A number of carers commented on the variability of staff: 'Some are better than others'. Change of staff was occasionally a cause of friction between carers and care managers/ organisers; and sometimes was the trigger for carers deciding to manage without the service. Confidence in known staff was obviously important to carers:

> Mum's really taken to her and she's happy for her to do anything, so I'm grateful to her because she made her feel like that.

Respite care services

The importance of respite and breaks was acknowledged by most carers, both in respect of specific respite care services and the impact of services such as day care and sitting. It will be seen from Table 4.2 that on the whole carers were very satisfied with respite care services. This was expressed in terms of benefit for the service user: 'Look after him well'; 'I trust them to look after her, to give her the care and attention she needs'; 'Girls know her there so it's like

a happy little family and she's happy when she's there'. It was expressed most strongly in terms of relief for the carer: 'It's lovely to have a break'; 'It gives me a break so it's good. It's a great help'. Clearly most carers had 'peace of mind' during periods of respite care.

As indicated above, there were some unhappy experiences of respite care that tended to result in reluctance to arrange further short breaks. These experiences related to carers not being happy with the quality of care, or with deterioration in the condition of the service user whilst in care, and disruption due to staff changes. Sometimes the cause of concern aggravated the mixed feelings of the carer about respite care and 'letting go'. One carer spoke of worrying about continuity of care between home and respite care in relation to medication and routines. She had provided a list of 'dos and don'ts' which she thought was being disregarded; and finished up attending to feed her husband herself: 'It wasn't much of a break for me.'

Section 4:   Achieving outcomes for carers

Services can assist carers by providing good outcomes for the care recipient, or by addressing the specific needs of carers. The following quotation is an illustration of good practice in terms of achieving quality of life for the person cared for:

> There's a load of small things, but I think in one main thing it's her independence. The fact that [following extensive housing adaptations] she can now do more things herself ... It frees me up, makes her happier which helps everybody. Well, it's a frame of mind thing.

There were examples of services being tailored to meet carers' needs. For instance, at her first interview, one carer was very concerned about her mother's medication. Three days a week, home care staff supervised this during their visits. However, the care recipient attended a day centre during the other four days, so then the carer used to drive to her mother's house after she had finished work to make sure her mother took her tablets. The carer was concerned about being tied down in this way, and also anxious about travelling during the forthcoming winter months. Having raised the matter with an occupational therapist at the day centre, arrangements were made for a local chemist to send a supply of tablets to the centre. This meant her mother could take the tablets at the day centre, thereby relieving the carer of this responsibility. The carer commented:

> That is brilliant, 'cos at least I know she's getting her medication ... the [occupational therapist] set that up for me, and I'm eternally grateful for that.

The pen pictures below are examples of good practice that show that meeting outcomes for carers is integrally linked with achieving outcomes for care recipients:

One interviewee, a married women medically retired at a relatively early age, temporarily took her mother into her own home; her mother was in the early stages of Alzheimer's Disease. She was advised by her doctor's receptionist to approach social services, who

decided that her mother was fit to live on her own at home. Initially, the social worker appeared to assume that as the woman was not working and could walk to her mother's within ten minutes, then she would be willing to care. The practitioner only took account of the woman's own health problems when her husband pointed them out. Eventually, social services provided a complex care package, comprising daily home care and meals services, twice weekly adult placement and occasional social work contact. The carer felt that social services 'had really tried', and that the help provided was as much for her benefit as for her mother's. She said that the most important thing to come out of her assessment was 'to know that my mum's being looked after, at certain parts of the day'. The carer observed that 'If these people weren't coming in then that would all land on me. It's those certain parts of the day I can actually relax and know that she's OK'.

A male carer looked after his elderly father with early dementia. In order to lead more of a life of his own, the carer contacted social services about cover to enable him to have the occasional weekend away. This led to a carer assessment, which included advice on social security benefits. The carer then began a postgraduate course that involved living away from home during weekdays, for stretches of up to six or seven weeks at a time. At this point, social services put in an elaborate and substantial care package which gave the carer the leeway to complete his course. The carer spoke of the peace of mind which came from the support package: 'If I didn't feel confident I wouldn't have done it ... I didn't feel guilty at all being away during the week and I just got on with my work ... I wasn't sort of sitting there in my room doing my work and thinking, Oh I hope dad's alright'.

One middle aged carer was very frail because of her own health. Whilst her employers had been considerate in respect of both her health problems and the caring responsibilities she had for her aged and disabled mother, eventually she took early retirement. Social services developed an extensive and flexible care package, designed as much to meet the carer's own needs in terms of health and leading a life of her own as her mother's needs. The regular and responsive contact maintained by the social worker was a source of reassurance and emotional support.

Summary of key findings

- Practice priorities appeared to focus predominantly on practical support and tangible care services (section 2)

- The influence of the carer assessment *per se* on service provision was not always clear, in that it was difficult to distinguish services influenced by the carer assessment from those which would have been provided anyway (section 2)

- Changes in care packages over time sometimes related to financial pressures on the household and dissatisfaction with services, rather than being the result of assessment and review of needs (section 2)

- Most of the carers where tangible services such as day care, home care, and respite care were received, were generally satisfied with the benefit of those services to them (section 3)

- There was some concern about the appropriateness of day care options, particularly in respect of younger people with physical or learning disabilities (section 3)

- Problems associated with transport to day care centres was acknowledged by a number of carers (section 3)

- Although generally satisfied with home care support, this was closely related to confidence in and continuity of contact with known practitioners (section 3)

- Although generally satisfied with respite care, unhappy experiences led to carers being reluctant to arrange further breaks because of the experience having aggravated their mixed feelings about letting go (section 3)

- Achieving satisfactory outcomes for carers was related to the way in which services were organised and delivered, and the extent to which they contributed to the quality of life of the care recipient (section 4)

CHAPTER 5:   INFORMATION FOR CARERS

Section 1:   Introduction

A recent report documenting the SSI's inspection of eight social services departments and how they provided information to the public (SSI, 1998a) concluded that information should be seen as a service in its own right. Information is a central aspect of empowerment (Dunst *et al*., 1994). Without the input of full information, people are not in a position to exercise choice and control, and neither can they develop coping strategies to deal with any problems that emerge - points made in the National Strategy for Carers (DH, 1999a). The timing of information-giving is important.   Studies (Nolan and Grant, 1992b; SSI, 1995a) have identified that adequate information is vital at critical transition points in the caring trajectory, and in particular when the carer is new to the caring role.

The policy guidance to the Carers Act (DH, 1999a) states that social services must ensure that their published information about community care tells carers about their rights under the Act, as well as which carers are eligible for an assessment and how assessment procedures work. As far as information generally is concerned, the National Strategy for Carers (DH, 1999a) says that carers from ethnic minority groups may not read English; consequently, local authorities may need to supply information about services in a range of languages.   The document also notes that for some groups of carers, for example older carers, tapes may be a helpful way of conveying information.

Recent studies into the implementation of the Carers Act (CNA, 1997; CNA/ADSS/ADSW, 1997; Dearden and Becker, 1998) suggest there is still a long way to go in informing carers about the Act. In the absence of adequate information, carers are not likely to ask for an assessment. Since assessment is the gateway to services, such ignorance is a significant barrier to the take-up of services. This chapter looks at what we found about information issues relating to the Carers Act and services available, but not information about the process of assessment which is covered in Chapter 3. We concentrate on social services; the role of primary health care professionals in information-giving is considered in Chapter 7 which focuses specifically on carers' health needs.

Section 2:   What information was provided and how

Senior managers and practitioners recognised how important it was for carers to be well informed. All the research authorities provided information about the Carers Act, but the amount provided varied considerably. One authority was exceptional in that it had a small but detailed publication focusing solely on the Carers Act. Topic areas covered included a brief explanation of the Act, who it applied to, how to request an assessment, what being assessed might involve and what the potential benefits might be. In contrast, the other authorities

incorporated information about the Carers Act in leaflets targeted at carers that contained more generalised information about how to access help and the range of services available. One of these three sites tried to empower carers further by offering advice on what they should think about before being assessed; one suggestion included keeping a diary for a couple of weeks prior to the assessment.

In their literature, the four research authorities addressed issues to do with eligibility for a carer assessment differently. Two sites fudged the matter, by using the terms 'regular' and 'substantial' in relation to the amount of care provided but without giving any definition of what they actually meant. The other two did make some attempt. For instance, one authority used the example of a carer who might be involved only once a day to prepare food or put the care recipient to bed but who also worked and had other family responsibilities to manage.

Three of the four research authorities produced leaflets for black and minority ethnic groups in the main community languages. One also had translations on audio tape, as well as a video covering services dubbed into a number of different languages, for people with disabilities. Some of this site's material was available in braille. Another authority had an audio-tape in English giving an overview of services across the department, as well as an audio-taped version of its 'A-Z' guide for carers. The fourth site provided interpretation on request into a different language or format within 14 days.

Information about the Carers Act, support for carers and service provision was distributed across different outlets. The research authorities all placed great emphasis on carers' centres and groups as sources of information, but less than half the carers taking part in the study were in contact with organisations of this sort (see next chapter). For many people, this may not be an effective way to make information available (Parker, 1993). With respect to public places, the two most commonly identified by senior manager interviewees were libraries and GP surgeries. Other information routes for carers mentioned were on their first point of contact with the social services department, the service user's assessment, and specific carers' initiatives such as local 'Carers Awareness weeks'. In spite of these various attempts at wide dissemination, senior managers and practitioners alike acknowledged that carers as a group were hard to reach. They were particularly concerned that the information needs of ethnic minority carers and young carers were not being met.

Section 3: Social work practice and information
Like other studies (Davis *et al*., 1997; SSI, 1998a), the evidence we collected pointed to variability with respect to the provision of information directly or indirectly related to the Carers Act. This was apparent, for instance, in relation to informing eligible carers of their right to be assessed, which should be part of routine assessment practice (see Chapters 2 and

3). One practitioner indicated that her approach was inclusive rather than exclusive. In contrast, a worker from a different authority made the following observation, which is particularly significant in the light of the findings about access to assessment:

> My belief is that whenever we do an assessment of a disabled person, if we are aware that there is a carer we should be telling them of their rights. I cannot hold my hand up and say I know that we do that in every case. I think probably social workers are a tad selective on that and look at those who are probably under the, appear to be under, the greatest stress from caring and who maybe are caring for a person with greater needs.

If one test of the effectiveness of publicity about the Carers Act is the number of carers who themselves initiate a carer assessment rather than wait to be asked, then the evidence suggests there is scope for improvement. Two practitioners, from different authorities, claimed that carers were generally not proactive in this way and as pointed out in Chapter 3 only two carers from the study sample took the lead and requested to be assessed.

Previous work has documented deficiencies in cascading information material to staff, users and carers. For instance, the SSI (1998a) study mentioned at the start of this chapter found that staff did not know of, or use, the information available. They did not always know about the full range of services available, and were unclear about carers' rights and local entitlements to assessment. Keeping up to date was also difficult, especially in areas where facts and advice changed rapidly, for instance in relation to social security benefits. One senior manager in the present study also spoke of problems in ensuring that both carers and staff were well informed:

> I think the fundamental [difficulty in implementing the Act] has been information ... that's a big one, about ensuring that carers are receiving the information sufficiently early in the process. Then when they get the information, that it's accurate; and so that's something about also being clear that professionals, including social workers, have the information and understand it, and understand the importance of it.

Our interviews with practitioners suggested they had some knowledge and understanding of the Carers Act. The results of a small survey into staff awareness of carers' issues conducted in the two research authorities that were also taking part in the King's Fund Carers Impact programme support this view. Part of the Carers Impact work involved asking staff whether they were aware of the Carers Act. Ninety per cent of the total number of respondents (N=41) answered 'yes' in one site, compared to 74 per cent in the other (N=90). The questions used in the two sites were not identical, and the results of additional questions in the latter site give some cause for concern. Staff were asked whether they were aware of the local Black Carers Network, and the Young Carers Development Project. Forty-seven per cent and 25 per cent respectively answered 'yes'. The apparent low levels of staff awareness about these particular

initiatives make it even more likely that the information needs of carers from ethnic minorities and young carers will be overlooked (see above).

There were indications from our interviews with practitioners based in all four sites that some had only a limited appreciation of general carers' issues, and local services and support that could help them. This perhaps reflects the fact that staff from different occupational backgrounds are likely to be involved with carers:

> I'm a home care manager, you have limitations; I'm not a social worker, that to me, is a lot broader and deals with a lot of different things. So I know certain things, but there's quite a lot I don't know but I do pass it on, I do ask, and I do get back to people.

One site had introduced a 'carer's advocate'. This was a social worker who took on the role of 'resident expert' on carers' issues, but at the time of interview had still to develop knowledge about the full range of carers' issues:

> I must admit that I've only recently taken over a carer's role, the Carer's Champion if you like, for our team ... obviously I've got a general idea about what, sort of, we do for carers, and I know that, you know what we do, what I do every day on my case-load and so on. But I've not, you know, I'd be lying if I said I've genned up loads on what exactly [our department's] sort of commitment is, but I know that there is a Carer's Support Worker; I know that there's support groups, I know that there's these magazines that come out and we look at them and sort of share information between ourselves.

Section 4:   Carers and information

Nearly one-third of carers taking part in the study knew something about the Carers Act, although their sources of information differed. Some six carers could recall being given information by their social worker on the Carers Act or their right to assessment. Five remembered finding out about the Act through carers' organisations; three carers thought they had seen a leaflet about it; another had found out about the Act after writing to the Department of Health for information about current community care legislation. In fact, this led to unrealistic expectations. Having read it thoroughly and highlighted the most pertinent sections, the carer then went back to social services and said:

> You're telling me this, and in here it says that. They said 'Well, this is reality.'

The carer's assessment forms used by two of the research authorities specifically asked about carers' information needs, and in this way prompted staff to check whether carers felt they lacked information on particular issues. However, the evidence does not suggest that carers from these two authorities felt any better informed than their counterparts in the other two areas. In all four authorities, there were examples both of good practice and poor practice. Many carers, but by no means all, had been given information and advice in relation to services available, aids and adaptations, carers' support organisations, money matters, social

security benefits and charges for services. One carer who had spent many years caring for both his wife and child had recently moved into one of the research authorities; for the first time he became involved with social services. He was full of praise for all the information and advice he was given during the carer assessment process:

> I mean I didn't have a bloody clue, didn't have a clue. After 25 years. No-one had ever said to me 'Well you're entitled to this' or 'you're entitled to that' or 'someone should be looking after you' ... [the social worker] opened our eyes. We didn't realise we were entitled to as much as we were until he told us.

And a carer from a different authority had this to say:

> [the social worker] did give us a lot of information we weren't aware of ... it was oral and there was information on leaflets. Most of the leaflets she gave my mum were about the DLA, the money side, but that was about it as I recall. The rest was orally, 'phone numbers and such like.

A carer who initially knew very little about services commented on how useful the practitioner had been in providing relevant information during his assessment. For this particular carer, though, having full information was helpful but not essential:

> [social workers] are the professionals - you just state your need, and they're more capable of providing the solution.

Other carers likewise made comments relating to professional expertise, sometimes in relation to choosing long-term care homes. For instance, one interviewee was asked by the social worker whether he would like to visit a home that was considered suitable for his wife. The carer turned down this offer, on the grounds that he was happy to trust the practitioner's judgement.

To return to the earlier discussion in Chapter 3 about whether issues to do with finance were covered during the carer assessment, some carers said that their social worker had not told them about any social security benefits they or the person looked after might be entitled to, with the result that they did not receive allowances from an early stage. The disabled relatives of two carers successfully applied for direct payments from the Independent Living (1993) Fund, having heard about the 1993 Fund over the 'carer grapevine' rather than from social workers. In those instances where quite technical financial matters were concerned, it was likely that social workers did not always have the necessary expertise and instead referred carers on to the appropriate agency. For instance, one carer's social worker suggested she should approach the local Citizens Advice Bureau for help regarding an appeal in relation to Attendance Allowance:

> [the social worker] as good as said they'd know more about it.

One interviewee, who described how eventually he had started to do his own, to quote, 'digging and ferreting and all that sort of thing', singled out not being clear about the financial implications of admission to residential or nursing home care as a cause of stress and high levels of anxiety. Recent research (Wright, 1998) has similarly shown there is a lack of accessible information about paying for long-term care.

There was a general feeling amongst some interviewees that social services would not respond positively unless they were approached by individuals who presented themselves as, in the words of one interviewee, 'a knowledgeable, expectant carer'. However, a number of carers talked in terms of being 'green' or 'in a fog' when they first took on their caring role, a stage which is critical in terms of carers' information needs (Nolan and Grant, 1992b; SSI, 1995a). Their lack of knowledge covered a wide range of issues including carers' rights, how to access the social services system and how it operated, what services were available and how to access them, carers' centres and support groups, benefits and charging systems. Such ignorance could be disempowering, and left carers with little choice but to rely on what practitioners told them:

> I was thrown very much into the unknown ... I don't know what else I don't know.
> I've got no idea what social services offer or what they do - I've had to go off what they've said.

Many carers reached the conclusion that it was up to them to find out what help was available, so where exactly did they obtain information? At interview, carers named carers' centres and support groups, chemists, care assistants and local Crossroads organisations as examples of good sources of information. Others that were mentioned included GPs, doctors' receptionists, district nurses, physiotherapists and occupational therapists.

It is known that information strategies used in urban areas may be less appropriate in rural locations (SSI, 1999a). One carer who partly blamed herself for her lack of knowledge about social services and service provision, at the same time connected this to living in the country:

> Maybe this is a rural problem ... if you're a person who isn't ill and don't go to the surgery a lot and don't get involved in things [then how do you find out?]

The comments of other carers also called into question the assumption that conventional distribution strategies were effective at reaching the intended audience:

> We were going round and round in circles, and didn't know where to go for help.
> Nothing in our GP surgery; I don't look at things in libraries.

There were mixed views on the effectiveness of leaflets. Some carers said that they would not pick up leaflets, or that they would throw them away before they had got round to reading them. On the other hand, there were carers who stated that they would read them, file them

away and return to them as necessary. Irrespective of the particular format, carers wanted useful and easily comprehensible information:

> In general, it's just a case of trying to get as much information, but information that you can understand and that you haven't had to go to college to get through.

The evidence gave rise to a strong sense of caring being a learning process. As carers' particular circumstances and needs changed, they then went back to square one in terms of the depth and breadth of their knowledge. Unfortunately for some carers, information came too late:

> Even when mum died, I found out all sorts of things I didn't know.

However six months later, when we interviewed carers for a second time, a handful of carers believed they were better informed:

> [social services] have told me what facilities are available, what help is available and just to date, to get to the situation that we're at now, which is acceptable, you know, it's really working well.

Taken together, the above points endorse Twigg and Atkin's (1994) claim that information is a complex issue. Not only must service provision be tailored to the individual carer and care recipient, so too must information and the way it is presented if carers are to be empowered and in a position to make informed choices regarding assessment and support. At the same time, information-giving is a continuous process which implies that follow-up after assessment is important if carers' on-going information needs are to be met.

Summary of key findings

- Information about the Carers Act, support for carers and services available was provided by social services in different formats, but there might be opportunities to distribute it more effectively (sections 2 and 4)

- Social services saw carers' centres as an important source of information, but the majority of carers were not in contact with them (section 2)

- Social services staff were knowledgeable about the Carers Act; some practitioners did not know about the full range of services and special initiatives for carers (sections 3 and 4)

- Carers obtained information from a variety of sources, including social services, health services, carers' centres and other voluntary organisations (section 4)

- Some social services staff were very good with regard to providing carers with information about their rights to assessment, what help was available, cash benefits and charges, whereas others were less so (section 4)

- Some carers had to push for information; those carers who were not aware of the full range of services available were disadvantaged in terms of making informed decisions (section 4)

- When carers were assessed, a significant gap in information-giving comprised financial matters (section 4)

- Carers' information needs were on-going: carers who were well informed at one point in time might have little knowledge of what was available and appropriate as circumstances changed (section 4)

CHAPTER 6:   CARERS' CENTRES AND SUPPORT GROUPS

Section 1:   Introduction

The literature shows that carers can benefit from involvement with carer support organisations (SSI, 1998a); the National Strategy for Carers (DH, 1999a) places great value on them as a context for support and empowerment. Potentially, carers' organisations have a valuable role to play in relation to the Carers Act. As we noted in the previous chapter, they are a useful source of information and are well placed to tell carers about the Act, their right to request a carer assessment and the likely outcomes. With the carer's agreement, they may be able to make a referral to the local social services department and help initiate an assessment. They can help prepare the carer, by explaining the process. In this chapter, we look at how carers' centres and support groups helped carers in the study sample, as well as the relationship between these organisations and the research authorities.

Before proceeding, though, it is worth distinguishing between carers' centres and support groups.

Carers' centres provide information, advice and a confidential 'listening ear'. Some offer advocacy services. Many carry out benefit checks to ensure carers and care recipients are receiving all the benefits they are entitled to; they may also try to access grants for carers. Often, they will refer carers to the statutory agencies, and/or initiate and sustain carers' groups. Reflecting the increasing currency within the NHS of local voice initiatives (NHSME, 1992) and consumer rights, carers' centres are likely to be involved in service planning and provision.

In contrast, different carers' support groups have different aims and emphases. Some focus on social and recreational activities whilst others concentrate on providing information, knowledge and training, and yet still others provide a forum for sharing problems and emotional support. In practice, many groups offer a mixture of features. Groups also vary in how they are organised, for instance off-shoots of service facilities, such as day centres or day hospitals, or free-standing with no direct links to service agencies. Carers' groups that are supported by professional workers from the local social services department have an advantage in that the professionals can act as a conduit between carers and the statutory services. On the other hand, if professionals have control and are in charge of decision making, then this can be disempowering to group members (Wilson, 1995). There is some evidence (Mitchell, 1996) to suggest that the character and effectiveness of a carer's group is associated with organisational aspects, for instance the nature of its links with service providers and client group focus.

Section 2: Carer support organisations, and their usage

There was a network of organisations providing carer support in each of the four research authorities. The basic model was similar: one (or more) carers' centre together with a wide number of carers' groups, some of which were attached to the centres. Across the four authorities, there was a total of eight carers' centres (actual titles varied, but for present purposes we are using the label 'carers' centres'). Three were local authority centres, and the remainder independent charities. Between them, they undertook all the activities listed at the start of this chapter, together with others unique to individual centres. These latter functions included: supporting young carers; rural outreach workers; special initiatives, such as working in GP surgeries and offering help and advice to carers. One centre was in the process of putting on a course for carers that would lead to the stage just below an NVQ qualification. Funding for the centres came from local social services authorities, health authorities and other sources including the National Lottery Charities Board, a suggestion flagged up in the National Strategy for Carers (DH, 1999a: 66).

The carers' support groups in the research sites undertook various activities reflecting the fact that carers' needs are wide ranging. As well as offering a chance to relax and make new social contacts, guest speakers were invited to discuss topics ranging from benefits information and advice, to lifting techniques, through to aromatherapy and reflexology. Christmas and other special events were celebrated with meals out; occasionally, parties and day trips were arranged. Organisers prepared a programme of events for three (and in one case, 12) months ahead to help carers plan their time. Carers' groups are not static entities; many flourish, but others come to a natural end. Some of those based in the research authorities remained viable mainly because former carers continued to attend. Staff interviewees included people who were involved in running carers' groups. They were disappointed that groups did not always survive but realised that they did not suit everyone:

> [It's] a great loss really, and it's something that we've deliberated on. But then we've come to the conclusion some carers who want to talk about caring feel that they can't do that in a group. They don't always want to share things with a number of other people. And we felt that we work on a one-to-one basis. And [there's] a carers' centre [here] now, so people get information there.

Carers in the study sample varied in terms of their involvement with support organisations. The majority were not involved at all. Some were long-serving members of local support groups and attended most meetings; the enthusiasm of others had waned and they no longer participated. Some carers did not want any involvement at all. People were more likely to be involved with a support group than a carers' centre, but some carers were on centres' mailing lists and praised the newsletters they received. One carer was a trustee of a centre, and a second carer occasionally took part in training delivered by another centre to social services staff.

Table 6.1 gives a profile of the 20 carers in the study sample who were currently involved, however loosely, with carers' groups and/or centres. Although the numbers are small, there is a suggestion in the table that men under 60 years of age may be disproportionately likely to be involved with support organisations.

Table 6.1:   Carers involved with support organisations

	No.	*Total no. in that age range*
Female Carers		
Under 60 years	7	18
60 and over	7	18
Male Carers		
Under 60 years	4	7
60 and over	2	8

Section 3:   Carers' centres, social services departments and carers

As we noted earlier, carers' centres aim to support and empower carers, providing advocacy services if necessary and/or helping people to pursue complaints. From this perspective, the roles of carers' centres and social services departments are quite different. Given that the latter bodies have to work within available resources, there is potential for less harmonious relationships. Tensions can be further intensified if there is a history of competition for funding between carers' organisations - especially those that are now separate units - and mainstream activities. As can be seen in the following quote, at least one senior manager we interviewed was aware of the possible difficulties, but nonetheless viewed carers' centres as an important means of keeping in touch with carers:

> The carers' centres are to facilitate our contact with carers and help carers, but also to be a voice on behalf of carers to us in terms of what we're doing right, and what we're doing wrong. And they've told us some things clearly we're doing wrong but we're trying to put right.

All four research authorities consulted with carers via their local carers' centres as part of the planning process. As far as the Carers Act legislation was concerned, all the sites asked centres to help them design their respective carer's assessment form. Furthermore, two authorities involved carers in discussions about the assessment process and practice guidance. Another site tried to get carers to help them define the terms 'regular' and 'substantial', but according to the senior manager 'they were just blank; they didn't know what to say'. Another manager indicated that consulting carers on draft plans was more effective than engaging with them at the very outset of the planning process:

You could go with a blank sheet of paper but by and large you get blank looks, you know, you really have to set something up first and people will then very quickly tell you if it's right or not.

One senior manager commented on the importance of tapping into the views of carers who did not use services; to try to do this, his authority would also consult with members of support groups, individuals who were often not in receipt of services.

Carers' centres in the research authorities attempted to increase social workers' awareness of their existence and the support they could provide to either carers or staff. Different mechanisms were used in the various sites. These included encouraging practitioners to visit centres (and support groups) to become familiar with the services they could provide and the information resources they could access; taking part in induction courses and training programmes for staff; and attending team meetings. The carers' officer at one centre always started presentations to social workers by talking about the Carers Act in order to raise awareness about carers' rights and issues.

The findings of the survey into staff awareness of carers' issues that was conducted in the two research authorities that were also Carers Impact sites (see previous chapter) suggest there is scope for further development. Practitioners were asked whether they were aware of their local carers' centre. Ninety-seven per cent of respondents answered 'yes' in one site, and 93 per cent in the other. However, in the latter authority, staff were further asked whether they knew how to access the centre, and if they could suggest three services that it provided. The number of staff replying 'yes' to these additional questions was 63 and 54 per cent respectively.

Social workers gave examples of how social services departments and carers' centres could complement each other in the delivery of social care:

So the carers' centre are really good in doing things, and because it's so time consuming you know finding grants for people and arranging holidays, I find that a really useful resource. ... They'll take that off you, and they'll send out all the information to people and they'll visit and they've got one particular worker in there who does work with the young carers and she'll take them on days out and things like that and it's been really helpful.

However, there was some suggestion that constructive relationships could be held back without on-going commitment on both sides:

The [carers' centre] was very active probably about a year, a year and a half ago ... A representative used to come down to talk to us to tell us of all the various services there are available and to actually remind us where opportunities arise to send in a carer assessment or at least to register a person with the [centre]. Unfortunately for the last year it's been very quiet. ... It's only now I think the onus

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is on the assessor really to take on that responsibility but I would like to see them coming to talk to assessors more often. ... More services are available to carers which we're not aware of, or we have just leaflets on how to register a carer.

As pointed out in the previous chapter, full information is key to accessing services and support. Good practice suggests that all carers should be told about carers' organisations whether staff expect them to make use of such services or not. Reflecting this, the majority of staff said they did supply carers with the relevant information so they could then make an informed choice about accessing them. However, some carers in the study sample claimed neither to have been told that such bodies existed, nor to have seen any of their literature. It could be the case that people had been told but for whatever reason had since forgotten. Alternatively, staff might be selective in deciding who should be told about these organisations. There was some evidence to suggest that departmental procedures might play a part. For instance, the carers' centre in one site, which was actually a local authority centre, had produced a comprehensive carer handbook outlining services and support available, both locally and nationally. The handbooks were not easily available to social workers, however, which made it more difficult for them to routinely distribute the books to carers.

Like other studies (SSI, 1998a), those carers in the study sample who were involved with carers' centres did feel they benefited. The emotional support provided was particularly appreciated. One carer spoke at length in both his interviews about how he had been helped:

> Times when I've supposedly been going to town ... gone and had a word with [the local carers' centre] ... I mean they're very good. I just sort of turn up on their doorstep and say "Help me". ... You just feel you've got to get it off your chest. You've got to have somebody just even if they sit there nodding. That's all it needs.

One carer in the study sample had gained financially. Having seen a leaflet about his local carers' centre, he had initiated contact which later resulted in staff accessing grants for him from two different charitable trusts, one for the purchase and installation of an electric cooker and the second for the accommodation costs of a three day break for him and his disabled wife. This particular carer was full of praise for the help he had received:

> [They've] done pure magic for us ... they're terrific ... remarkable.

Section 4:   Carers' support groups and carers

As indicated, carers had more contact with support groups. One person who attended a fortnightly support group appreciated the focus being on the carer rather than cared-for person:

> That's what I like about the lady that runs the carers' group. She says 'And how are you today?' ... which is a good thing because most people ... [ask] 'How's [my husband]?' ... and sometimes you think 'Well ...'.

Carers thought highly of mutual support and learning from others who had 'been there' before them. Other work has pointed out that professionals and (members of) self-help groups belong to different social worlds, each with their own distinctive knowledge, expertise and values (Borkman, 1976; Wilson, 1995; Arksey, 1998). One carer was challenging the monopoly of professional expertise when he singled out the value of knowledge gained through experience:

> I'd seriously seek the advice of somebody who's in the same situation as yourself ... 'cos the social worker's got a book and he works to that book and he doesn't cut any lines off it. But if you find somebody or some society who's in that situation ... they could put you more wise to it than trying to talk to somebody who's got an education.

In terms of practical help, carers obtained accurate, up-to-date information on services, benefits and practical hints from support groups (and centres). They also heard about new initiatives and developments. As noted in the last chapter on information, a handful of carers had found out about the Carers Act, and their entitlement to an assessment, through carers' organisations:

> Oh yes, I've heard of [the Carers Act], yes. Because, you see, with going to the carers' group, they mention all these things, and try and tell you what you're entitled to, and this, that and the other.

Two or three of the carers' groups had extra value for some carers in the study in the sense that group leaders were also their social workers. This meant they had more frequent and regular contact than might otherwise have been the case, and relationships stood to be enhanced. However, the professional response was not always helpful. One carer was in the habit of telling other carers about the new legislation and the implications of being assessed. His concern that practitioners might not be as committed to carer assessments as one would expect was strengthened in the wake of the following example:

> One [carer] rang up the social worker that's been involved with us and asked for a carer assessment, encouraged by the [carers' centre] to get one. And was told by the social worker that there wasn't any point and if she insisted, the form would be sent to her through the post, she could fill it in, send it back and then it would just be held on the file.

There were examples in the study of carers who attended various groups, each with a different emphasis. One person, for example, belonged to three. One had a medical orientation, the second was more socially focused and the third was for 'talking' and emotional support. Another carer used a carers' centre when she wanted specific information and/or advice, and a local carer's group for friends and support.

Some carers faced social isolation because of their caring responsibilities. One individual talked of wanting to visit friends but not being able to because she could not arrange cover for

the person looked after. She said that eventually 'people stop asking you if you keep saying no', supporting Parker's (1994) claim that friendship networks can weaken in such situations. Attending a carer's group was not an option for this particular carer, in the sense that although she was in regular touch with a social worker and there were groups in her locality, she said that she 'wouldn't know where to find one'.

As indicated above, not everyone wants to be involved in support groups throughout their caring 'career'. One carer in the study did not think groups were relevant because, to quote, 'I don't think of myself as a carer'. Another person preferred to use his spare time in other ways: 'It's not what I want to do on my day off'. A male carer who had 'tried' one at some point in the past refused to have any more involvement because it was, in his words, 'all women'. Yet another carer said she was happy to talk to other carers, but that actually she wanted to get away from her own problems - she did not want to be (further) depressed, even more so since she was caring for a depressive. This is a very real possibility, given that someone else observed that talking to others in like circumstances offered her 'a chance to moan'. A small number of carers had attended groups in the past, but now saw no need - another reminder that carers not only have different needs but needs that change over time.

Over and above personal choice, practical constraints similar to those noted in other studies (Twigg and Atkin, 1994) prevented some carers from attending groups. Lack of time was a barrier for a number of people. So, too, was arranging cover for the care recipient. If sitting services were not available, carers had to leave the person looked after on their own but they paid the price in terms of peace of mind: they found it difficult to relax, worried about being out for too long and had to keep their eyes on the clock. Transport was another problem. Not many groups provided this, so carers without access to a car had to rely on public transport.

Summary of key findings

- The majority of carers had no contact with carers' centres or support groups (section 2)

- Social services and carers' centres played different roles in supporting carers; potentially, differing interests might give rise to discord (section 3)

- Maintaining effective liaison and collaboration between social services departments and carers' centres required on-going commitment from both parties (section 3)

- Even though practitioners supplied carers with information about local carer support organisations during the carer assessment process, carers were still not always aware of them and what services they provided (section 3)

- Carers' centres and support groups were highly valued by those carers who used them. They offered opportunities for socialising, talking to others in a similar situation, as well as acting as an information resource and a point of referral (section 4)

- Not all carers wanted to be involved with support organisations (section 4)

CHAPTER 7:   MEETING CARERS' HEALTH NEEDS

Section 1:   Introduction

This chapter focuses on the health needs of carers. An important quality of life outcome for carers is to maintain their own health and well-being (Qureshi *et al*., 1998). However, not only do carers need assistance to prevent them from suffering health problems, they also need support in carrying out the health-related elements of the caring role. This might mean information about the care recipient's illness and prognosis, medication and potential side effects, the ranges of services available and how to access them; referral and/or signposting to other relevant services; basic training in lifting techniques and nursing tasks.

A joint approach means that all agencies have a duty to respond to carers, and recent policy initiatives such as the Carers Act, the National Strategy for Carers (DH, 1999a) and the National Priorities Guidance (DH, 1998b) for the health and social services all emphasise the importance of providing carers with support and services in order to meet their health needs. For instance, the policy guidance (DH, 1996) to the Carers Act states that doctors should inform patients who are carers they may have a right to request an assessment and, if appropriate, contribute to assessments themselves. The National Priorities Guidance requires that carers should be provided with support and services to maintain their own health, as well as information on the health status and medication of the care recipient (subject to that person's consent). As a first step, GPs, members of primary care teams and social services staff have to ensure that systems are in place to identify carers by April 2000.

Section 2:   The health consequences of caring

Establishing a causal relationship between caring and ill health in general is problematic (Parker and Lawton, 1994). A substantial body of literature exists showing that carers believe care-giving has adverse effects on their own physical and emotional health. Current work in the Social Policy Research Unit (Hirst, 1998) based on secondary analysis of the British Household Panel Survey reveals that caring has the greatest impact on carers' emotional health rather than physical health, especially for carers who provide 20 or more hours of care per week. The work by Hirst (1998) also shows that the health of carers is more likely to deteriorate than improve over time compared with health changes in non-carers, and that carers are more likely to make additional use of primary health care services both during and after the care giving episode. Potentially, then, the NHS has a key role in supporting carers but inadequacies in meeting carers' health needs have been identified within the health service (Parker, 1993; Henwood, 1998). Furthermore, there is evidence to suggest that health professionals view carers as the responsibility of social services rather than health services (Williams and Robinson, 1998).

In the present study, nearly half the carers in the sample reported they were often stressed, 'nervy' or felt depressed. One male carer had been diagnosed as suffering from clinical depression, and another was on medication, in his words, 'to try and lift my spirits'. A female carer in her late 70s was worried she was heading for 'a nervous breakdown'; another, whose very elderly mother had entered residential care by the time of the second interview, reflected:

> A lot of my problem was my nerves. It was nerves, because I used to worry so much about the position I was in and how long it was going to go on for, and how long I could keep it up ... and knowing that I was getting older and could I keep doing it.

Stress-related health problems were not confined to a particular age group. One woman in her late 30s, who had been caring for her mother for less than a year, described an incident that for her (and her husband) was the 'final straw': 'I started crying ... I was in floods of tears over a cherry yoghurt ... I feel so stupid now, but that's how low I was sort of sinking'. It was at that point her husband, in the role of advocate, asked social services for a review which led to an increase in the care package.

It is known that the lack of sleep is related to psychological stress. Like previous work (Parker, 1993), carers in this study experienced problems in respect of sleeping, disturbed nights and feeling tired. Indeed, one person took her husband to the toilet but was so tired that she then sat down, with untoward consequences:

> I must have been fast asleep for half an hour or more and then I just woke up ... and as I looked out [the social worker] was getting out of the car and then it dawned on me 'Oh my God, I've left him in there'.

As well as problems relating to sleep, other causes of stress identified by carers included: not being in control; care recipients being too demanding; strain on family relationships; mobility difficulties; not having enough information on the medical side. One carer whose husband had never really accepted his illness said 'I get all the blame, and his frustration and depression are all pushed on to me'. The following reflection gives some insight into how this was affecting her:

> I'm quite healthy really, but mentally I get run down because of [my husband's] demands on me. I feel as if inside I'm being pulled apart.

Unusually, this particular carer had been asked if she would like to see a psychologist. She said 'yes', and had expected to be given an appointment within the next few weeks. In fact, it was three years before anyone contacted her:

> I couldn't believe it when they wrote to me and asked me. I said 'I'm sorry but some of the problems that I had have been solved.'

Nearly one-third of carers in the study sample experienced long-term illness or disability themselves, including back and heart problems, arthritis and difficulties with mobility. A

small number had suffered physical injuries to their backs, arms and legs since they began caring, reflecting the strength and stamina that care work involves. One said that bathing her husband 'knocked the stuffing' out of her, and she could be in pain for two to three hours afterwards. A male carer believed that if more help, including training, had been available ten years previously his knees, elbows and back would not, to quote, 'be knackered' now. The majority of carers reported they had not received proper training in moving the person cared for safely so they daily ran the risk of (further) injury.

There was some evidence to suggest that the impact on health of caring could be made worse for those carers who did not live in the same household as the cared-for person. One extra-resident carer reported being treated for leg ulcers. It was her feeling that they were exacerbated by waiting for buses every day when travelling back and forth between the two residences. As well as effects on physical health, concern about what might be happening in their absence can be a source of anxiety and affect the carer's emotional health. A second carer who did not live with the person they looked after reflected on the impact of not having peace of mind:

> I used to come home and then many a time I've gone back again ... just to make sure. And then I've come back and I've still not been happy, and then I've wakened in the night and got the most peculiar morbid feelings and it's been on my mind until morning ... till I could ring or go.

What did the data say about changes to the state of health of carers between the two sets of interviews? We explored this using the interview material, and responses to statements in the CADI index (Nolan and Grant, 1992a; Nolan *et al*., 1998) relating to carers' physical and emotional health: it is physically tiring; my sleep is affected; my emotional well-being suffers; my physical health has suffered; I can't relax because of worry about caring.

- the CADI responses indicated that all carers experienced some changes to their state of health between the two interviews. Broadly speaking, movements showed improvements rather than deteriorations, but in any event shifts were not huge.
- the qualitative data showed that 'new' carers, the seven people in their first year of caring, linked positive health changes to a variety of factors: service provision; more peace of mind; a sense of sharing responsibility with social services; having the support of a social worker; reducing the number of hours spent caring. After six months, people new to caring were better informed and understood 'the system' better, which made an important difference.

However, the accounts of some carers suggested that as care-giving continued the potential for negative impacts on their physical and mental health intensified at certain key transition points. For one person who had been caring for over 20 years, this was when he suddenly had

to start dealing with new problems relating to a deterioration in his wife's cognitive ability, difficulties that were unexpected since doctors had not forewarned him:

> It's driving me frigging mad ... 'cos she's repeating herself all the time. And it's a worry ... it's starting to get to me ... anything physical I can cope with, that's no problem, it doesn't matter what it is ... [but] this thing with what's going on in her head, it's already starting to cause problems.

By the time of the second interview, 16 carers had ceased or greatly reduced their caring activities either due to the death or the admission to residential care of the person looked after. The stage of relinquishing instrumental care because of, say, entering long-term care has been referred to as 'a new beginning' (Nolan *et al*., 1996), and can be a period when carers need more support than ever to help them move forward successfully. Carers in the study sample were affected differently. The physical and emotional health of some carers improved, but this was not so in all cases. Two male carers, for example, whose spouses had entered long-term care reported they experienced disturbed nights, were depressed and lonely. One commented he might not speak to anyone for two or three days at a stretch. Both men were withdrawing into the home, despite having far more opportunities to pursue a life of their own than when they were full-time carers. A third (female) carer believed she was finding it more difficult to adjust to her husband's admission to care than he was. She was not used to going out on her own, and did not enjoy it. At this point in the process, carers' contact with social services had more or less ceased, yet like other studies (Nolan *et al*., 1996) we found that this was a time when carers were in want of support. Where contact did continue, it was very much appreciated. For instance, one carer whose wife was now in permanent care reported still receiving occasional visits from the social worker:

> [The social worker] came last night about five o'clock. Stayed till well after six ... [keeping in touch] is wonderful of him ... that was great for him to come yesterday. And he'd made other attempts to call and I'd not been in.

Section 3:   Carers' experiences of general practitioners

Only a few carers in the study sample were in touch with community nurses or hospital consultants. However, the great majority were in regular contact with their GP and it is this group we concentrate on for present purposes. Since the implementation of the Carers Act, GPs are expected to help bring carers into the process of assessment. This can involve initiating the idea of a carer assessment, explaining the purpose and potential benefits and helping carers obtain one. In the event, none of the carers we interviewed said that their GP had told them either about the legislation or that they could ask to be assessed.

Like other studies (Parker, 1993; Twigg and Atkin, 1994), we found good practice was patchy and carers' experiences varied greatly. Some carers were full of praise for the help they received from their GP. This might have been in relation to the provision of information and advice, arranging services and making referrals to other agencies.

Other carers were critical of what they saw as a lack of support from the GP. Some felt they had problems in getting their own health needs recognised, a finding documented in previous studies (Henwood, 1998). Two older carers felt that their respective doctors were more interested in the younger age group, and did not understand older people and the particular problems they faced. Another carer reported that her GP suggested that she paid for respite care for her mother privately to cover holiday periods. She did this for three years, before discovering social services and the help they were able to provide.

Some carers singled out GPs as not being proactive in providing them with information and advice, a finding confirmed in other studies (Parker, 1993; Williams *et al*., 1995), yet it is known that carers can suffer stress because of a lack of information about how to help the care recipient (DH, 1999a). One carer commented that for 15 years his doctor said nothing whatsoever to him in relation to the actual and potential medical and social needs of his wife who suffered from MS, nor about any help that might have been available.

Other research (Twigg and Atkin, 1994) has reported that carers can face problems in relation to medical confidentiality. Some carers from our study sample likewise had to deal with doctors unwilling to disclose relevant information about the care recipient to them, which made care work even more difficult. It was a particular struggle for those who did not have the same GP as the care recipient, or who cared for someone experiencing difficulties in the area of mental health as did the carer who made the following comment: 'It's like talking to a shadow - I can't get anything out of anybody'. However, this sort of situation may become less common in the future. For example, the National Strategy for Carers (DH, 1999a) makes specific reference to medical confidentiality issues, stating that GPs (and other clinicians) should explicitly ask the patient for consent for information about their illness or disability, or about their medication or symptoms, to be given to their carer. Standard six of the new National Service Framework for Mental Health (DH, 1999b) states that health and social services should ensure that carers receive full information in relation to both themselves and the person for whom they are caring (with that individual's permission).

The differences in doctors' handling of carers did not appear to be systematically related to such sociological variables as age, gender or locality; it is plausible that they reflected how individual doctors worked. This is consistent with the claim that GPs adopt different approaches to carers (Twigg and Atkin, 1994). Some routinely try to help carers, while at the other end of the spectrum are those doctors whose agenda just does not include carers. The majority of doctors, according to Twigg and Atkin (1994), respond in an *ad hoc* and arbitrary way which means that carers have to be in the right place at the right time to receive help. Yet the observations below made by carers from different research authorities indicate that carers may not necessarily give full details of their situation or explicitly ask for help:

> It was my fault. I wouldn't tell people how tough it was, and the doctor didn't
> know because I didn't tell her.

> I've never had any help with nursing care. The doctor, the nursing side - I've not
> had a lot of help with that, but then I suppose I've never really asked for it so it's
> my fault.

This reluctance by carers to speak more openly about their situation makes it even more important for doctors to adopt an active role and probe if someone is saying 'I'm fine'. But making positive efforts to take on board carers' issues is a style that does not sit easily with the time constraints and consulting styles which characterise much of general practice.

Section 4:   Carer assessment and carers' health needs

Assessment under the Carers Act is one mechanism whereby carers can be helped to maintain their health. The practice guide to the Act (SSI, 1996) suggests that social workers might cover carers' emotional, mental and physical health when carrying out an assessment, and the carer's assessment forms used by the four research authorities all included specific questions or mention of health problems. In their interviews with us, practitioners stressed the importance of meeting carers' health needs. When assessing carers, they would try to ascertain whether the carer had any health problems, was suffering from stress or emotional difficulties, or was overly tired. According to one social worker, this was by no means uncommon:

> I know people who are carers, who are actually worse off physically than the
> people that they're caring for. They've heart conditions, they've all kinds of
> problems ... and also you've got people who are in their nineties being cared for by
> their spouses, who are actually in their nineties as well.

More carers than not reported that their assessment did indeed cover health matters. One interviewee recalled how in discussions the practitioner had emphasised the importance of keeping well:

> [Social services] have repeatedly told me 'You know, you must keep in mind that
> it is your health that counts. It will fall on you.' And I do realise that now.

Staff gave examples of how they would try to meet carers' health needs. This might include involving the health services, especially if it seemed that the caring situation was about to break down because of the carer's poor health:

> You have to go and arrange things like [respite] when it happens and say to the
> GP: 'Look, this person's not coping. Can Health do something about this? Can we
> have an assessment, respite period in hospital, so we can reassess the situation?'

The services most commonly offered to better support carers comprised short-term breaks, day care or other practical help (see Chapter 4). As implied in the above quote, breaks - both

planned and unplanned - were regarded as very important in enabling carers to continue in their caring role. One practitioner reported that:

> If [carers] ring up at two o'clock in the afternoon, and say 'Can we have some respite care at three o'clock this afternoon?' we'll try and accommodate those needs. The only real obstacle to accommodating those needs is whether there are any beds available. Usually there are.

The tendency to offer practical assistance has been noted in other studies (Twigg and Atkin, 1994; Nolan *et al.*, 1996), yet as we indicated earlier in this section it can be the emotional strain of providing support that can push carers into a crisis situation. Practitioners did see the need for supporting carers' emotionally, and if one interpretation of emotional support is having someone to listen to problems then the carer assessment itself (even without any service provision) might be seen as performing this role. In practice, the availability of emotional support was limited, a gap that was acknowledged by practitioners themselves. This sort of help was anyway outside the scope of some staff involved in assessing carers, according to one practitioner we interviewed:

> It's more on the emotional side where I think a lot of the carers do not get the service, because home care services do not touch on that aspect.

This line of demarcation recalls the claim that qualified social workers have the strongest tradition of counselling, yet carers - especially in cases that are relatively straightforward - are mainly in contact with untrained social workers (Twigg and Atkin, 1994). But in any case, present day care managers frequently complain that the scope for supportive, therapeutic interventions and counselling within their role has diminished since the introduction of care management and the emphasis on assessment (DH, 1993).

Section 5: Joint agency working

We have already touched on issues to do with joint working in the previous sections. Given that the health services also have responsibilities under the Carers Act, what examples were there of the two agencies acting jointly? One senior manager reported that his authority had opened up the training offered to meet the demands of the legislation to health service staff as well as social services. Another said that the health services had been closely involved in consultations prior to the Act coming into effect, and that the relevant health authority was pushing the Carers Act as a health policy and a requirement on trusts. However, he also expressed the view that 'involving GPs and primary care in community care generally has been difficult'.

We asked practitioners about working with their health service colleagues. Generally, staff had mixed experiences, making it difficult to generalise:

I've had some good experiences of GPs working well with us where they've arranged, you know, hospice care or they've rung up and said 'Can you provide some respite care 'cos the carer's on their knees?', literally. And other situations, you go and you think 'Well why on earth hasn't the doctor been in touch?'

Some practitioners felt they had better relationships with district nurses than GPs, but this was not so for everyone. One person thought relationships with colleagues in the mental health field were particularly poor. Comments were made about a lack of awareness of carers and carers' needs on the part of some GPs, and also how few carers were referred via their family doctor. Not only did practitioners wish to see more referrals from GPs, they wanted them to be made at an earlier stage, as a preventative measure. The requirement on doctors to identify carers by April 2000 may be a step towards achieving earlier (and more) referrals.

Staff commented on perceived sources of tension between health and social services. Issues that were mentioned included health professionals seeing carers as the sole responsibility of social services, and also their tendency to focus on the medical aspects of their work at the expense of social issues. Furthermore, whilst practitioners recognised there was a tension for doctors between observing principles of confidentiality and the disclosure of medical information, the suspicion was voiced that on occasions this obligation could be used to their own advantage by doctors reluctant to get involved. One practitioner reported that:

Things like confidentiality, for instance. Some GPs will just refuse to give much help at all, covering themselves with that sort of confidentiality blanket and saying "We can't give you anything".

In spite of these problem areas, there was nonetheless a feeling amongst some staff that links between health and social services were becoming stronger and, as importantly, there was an enthusiasm to work better together. Since input from health professionals is a key factor in meeting carers' health needs, it is important that doctors and other NHS staff are encouraged to see working with social services and carers as part of their practice. This might mean thinking more in terms of multi-agency teams, and less on discrete professional groups such as 'social workers', 'doctors' and so on.

Summary of key findings

- Caring could seriously affect physical and emotional health; carers of all ages could feel depressed and experience stress-related illnesses (section 2)

- Carers' health could be affected when the person they looked after entered long term care. Social services support was often withdrawn at this point, yet this could be one of the key times when carers might continue to need support (section 2)

- GPs did not seem to be engaging in the carer assessment process (section 3)

- Practice varied in terms of how GPs supported carers; some were excellent, but others were very poor (section 3)

- GPs did not always provide carers with full information; medical confidentiality issues could cause problems for carers (section 3)

- Social work practice in relation to dealing with health issues in carer assessments varied; many, but not all assessments, covered health matters (section 4)

- Social workers offered practical assistance to help meet carers' health needs, but there was a gap in providing carers with emotional support (section 4)

- Effective joint working between health and social services professionals was challenging, but there were examples of practitioners and GPs working well together to support carers (sections 4 and 5)

CHAPTER 8: CARERS AND EMPLOYMENT

Section 1: Introduction

This chapter considers carers' experiences of working and caring at the same time, and the challenges this can pose for service providers and employers. The government is committed to supporting carers who wish to combine work and care (DH, 1998a; DH, 1999a). About two-thirds of working age carers are in paid employment (DH, 1999a). Empirical evidence shows that carers can benefit from paid work financially, socially and psychologically (Scharlach, 1994; Kagan *et al*., 1998). At the same time, though, combining work with care-giving responsibilities can have adverse effects. These include restricted career opportunities, reduced earnings and/or future pension benefits, and little time for leisure activities, relaxation and privacy (Laczko and Noden, 1992). Studies (Laczko and Noden, 1992) have found that some carers find balancing the conflicting demands of work and caring too much of a strain and withdraw from the labour market. In particular, carers' physical health and psychological well-being can suffer (Phillips, 1994; Gilhooley and Redpath, 1997).

Flexible working arrangements such as flexi-time, time off with or without pay, jobshare, working from home, and changing from full-time to part-time have been identified as key to enabling more carers to remain in the workforce (Phillips, 1995). 'Carer friendly' initiatives specifically to help carers are not on the agenda for many companies, however (IMP, 1990; Kagan *et al*., 1998). They can be costly and difficult to implement, especially for small and medium size companies. Recent research (Kagan *et al*., 1998) found that improved co-ordination is needed between employers and health, social care and education service providers to better support people who want to both work and care. As the National Strategy for Carers (DH, 1999a) indicates, this is another area where joined up thinking is needed.

Section 2: Working carers, social services and employers

At some time during the fieldwork period, ten of the 27 carers in the study sample of working age (women under 60; men under 65) were either in paid employment or self-employed. Exceptionally, one woman of 62 still worked. One man returned to higher education as a full-time postgraduate student, and is included as a 'working' carer for present purposes. The total number of working carers at any one time was therefore 12. Ten were women, and two men. Ages ranged between 32 and 63. Six carers were the main breadwinner; five did not usually live with the person looked after. Only one carer (female) worked less than 16 hours a week. Ten working carers provided over 35 hours of care a week.

According to the practice guide accompanying the Carers Act (SSI, 1996), carer assessments should cover issues related to employment. To help ensure this topic is actually considered, the carer's assessment forms used by all four research sites specifically mentioned paid work.

However, a common message from the 12 working carers was that social workers did not address work matters in any great detail when they were being assessed. This is possibly because most carers had been employed for some time before they were assessed, so people's existing arrangements were perceived to be well established and taken for granted. But such disregard does not help those carers wishing to rejoin the workforce. For instance, one carer who had not worked for about 20 years at the time of her first interview had in fact gone back to part-time work six months later when we interviewed her for a second time. This was more by virtue of her own initiative, though, than by any assistance from the social worker. Having raised the question of returning to work during her assessment, the social worker had responded by asking her what type of work she was interested in; according to the carer, the discussion was not followed through in terms of information about what support might be available:

> There was no sort of offer of 'Well, we can supply this or that' ... there was nothing offered at all; it was just like passed over.

Practitioners' views on this issue conflicted with carers'. Many of the practitioners interviewed believed they were sympathetic and supportive, some giving examples of care packages they had put together to help carers remain in work. Some workers pointed out that employment was often no longer an issue, because carers had already given up work by the time they came into contact with them. Moreover, practitioners tended to be involved with middle-aged carers, often women in their late 40s and early 50s. Whilst it is likely that many carers would choose to work, this does not apply to everybody and especially those nearing state retirement age.

Social services did provide practical assistance so that carers could combine work and care. Assistance included: home care, day care, short-term breaks and the provision of meals. Generally, carers did not feel that extra help from social services would significantly reduce any difficulties they encountered with regard to combining work and care. They tended to seek additional help to cover gaps in service provision from other family members, friends and neighbours.

Business organisations sympathetic to the needs of staff who are carers can make it easier for people to combine the two roles, and carers identified arrangements that helped them. Generally, these reflected measures documented in other studies (Phillips, 1995). They included having the ability, to use one interviewee's words, 'to be able to drop everything and go' if an unexpected crisis occurred; to take time off; to have access to the telephone. Some carers observed that in order to 'juggle' work and caring, they often had to use their lunch break; this might be to check on the care recipient or make telephone calls. What was highlighted as difficult, however, was having to arrange appointments with social services staff, who were only available during normal hours of work.

Not all carers had supportive employers, confirming the need for (more) organisations to introduce carer friendly policies. As other research has found (Laczko and Noden, 1992) caring can have adverse effects on people's employment prospects. Two carers felt discriminated against on the grounds of their caring responsibilities. One of them lost a promotion opportunity, and by the time of the second interview was doing a less demanding job with fewer hours. This had financial implications in terms of reduced earning and future pension benefits.

Two of the working carers were self-employed. This can provide more autonomy and flexibility than paid employment (Kagan *et al*., 1998), and help carers to meet their dual commitments. However, self-employment can also lead to financial insecurity. One of the carers commented that he lost money every time he was away from his business to care for his wife or take her to hospital appointments during the working day.

The National Strategy for Carers reports that 'nearly three million people successfully combine working and caring' (DH, 1999a: 27). What is meant by 'successfully' is questionable, given that our 12 working carers were more likely to comment on the difficulties of working and caring, describing it as, to quote, 'exhausting' or 'a struggle'. Other studies (Phillips, 1995) have reported negative affects of carers' work performance, and so too did the present research. For instance, one carer who had returned to work after an absence of over 12 months worried about being inattentive:

> I can't concentrate like I used to do. I'm doing silly things ... just daft things, losing things and putting things down. My mind isn't on what I'm doing and I'm finding it more difficult to work, to follow simple instructions, 'cos my mind's still off.

In contemporary society, work is part of normal life-style expectations. Given the difficulties documented here, the question really is: why do carers work? Like previous research (Scharlach, 1994), carers in the present study benefited financially and psychologically. They needed the income, and at the same time enjoyed the companionship of work and the escape from caring. One carer who in fact had stopped work said he missed 'the little bit of sanity of going to work'. Overall, carers found paid work helped them lead a life of their own and had the potential to contribute to their well-being.

Section 3:   Non-working carers, social services and employers
It is not easy to disentangle why the 16 carers in the study sample who were under state retirement age but no longer working had withdrawn from the labour market. The data suggested, though, that for 11 people there was no direct relationship between giving up work and caring. It is a more likely prospect that these carers did not work for reasons like their own long-term disability, taking early retirement and bringing up a family.

This leaves five carers who did give up work largely because of their caring responsibilities some time before they had been assessed under the Carers Act. One such person was a mother looking after a disabled child, who commented that the pressure of (part-time) working coupled with caring caused her to '[burn] a fuse'. Whilst the extra money was useful, she eventually decided she was paying too high a price and 'would rather scrimp'. Another carer had an employer who was unwilling or unable to respond to his needs. When he returned to work after a few day's absence spent looking after his partner who was ill, his boss told him to 'either work or stay at home'. The carer's response was to take off his overalls and leave immediately. In contrast, a further carer felt that social services had put obstacles in his way, a finding reported in other studies (Twigg and Atkin, 1994). This particular interviewee was so dissatisfied with the inflexibility and unreliability of home care that he felt he had no option but to withdraw from the labour market earlier than he would have wished. Examples like the latter two illustrate that some carers may not think they have any real choice between working or becoming full-time carers.

In some cases, people may face genuine tensions between combining work and care and it may be appropriate to encourage them to stop working. One parent carer found caring and work a struggle, particularly as her daughter was growing up and becoming more demanding. By the second interview, she had handed in her notice. In fact, the carer was following the advice of a social worker, who had told her that there was little, if any, financial advantage to working. Being well informed about the financial implications before giving up work is important, yet the evidence points to inconsistencies in practice (see Chapters 3 and 5). For example, a carer from another of our research authorities claimed that in spite of his efforts he was provided with no prior information by his social worker about social security benefits or the consequences of quitting work:

> I tried to find out little bits of information moneywise ... and you can't find anything about anything until you give up work. They seem to be a secret service sort of thing ... you can't go into (a) until you've done (b) ... so you've got to give up work to find out what you can actually do.

Section 4:   Re-entering the labour market

Carers who were not working were at risk of social exclusion. In their interviews, quite a number of carers could see good reasons to rejoin the workforce, for instance: 'I want some money and holidays before it's too late'; 'You need to have your own life still'; 'To be able to converse ... sometimes I feel as disabled as [the care recipient]'; 'I feel I'm getting left behind'.

At the same time, people appreciated the logistical difficulties of carrying out the dual role of carer and worker. Two carers, for example, planned to work afternoons only when the time came to return to the workforce. They did not believe that, in their absence, service providers could be relied on to get the person looked after up, dressed and transported to a day centre. Other problems they envisaged concerned the travelling time to get to work and back, given they were dependent on public transport.

The literature (McLaughlin, 1994; Nolan *et al*., 1996) suggests that the physical and psychological effects of caring can continue long after care giving ends, and that the health of carers may indeed continue to deteriorate subsequent to ceasing care (Hirst, 1998). Our study bears this out. Two people who had spent a long period of providing high levels of care and whose caring had recently come to an end were both going through a lengthy adjustment. Whilst in her first interview, one had talked enthusiastically about returning to work, in the second discussion she instead spoke in terms of 'waiting for motivation' and 'going with the flow'. This particular carer had lost both parents in the past few months, and as a consequence her contact with social services had ceased. For her, the after-effects of caring, which she was managing without any professional help, were preventing an early return to work. If lengthy consequences are typical, then this suggests that a rapid resumption of work when caring finishes is not as straightforward as it might seem.

Summary of key findings

- Support from employers was as important as assistance from (health and) social services if carers were to participate in the labour market (sections 2 and 3)

- Practitioners did cover the needs of carers who worked, or wanted to work, when undertaking a carer assessment, but for some carers more in-depth advice and information might have been useful (sections 2 and 3)

- Combining work and care could have negative effects on carers' health, employment prospects and financial situation. At the same time, though, it could improve carers' feelings of worth and well-being (section 2)

- Carers who had relinquished their caring role might experience health problems that could hinder a quick return to the workforce (section 4)

CHAPTER 9: CONCLUSION AND RECOMMENDATIONS

Section 1: Introduction

In this chapter, we draw attention to the central issues emerging from the study. Section 2 talks briefly about the strengths and weaknesses of evidence collected in relation to the questions we are trying to answer. In Section 3, we consider the process of local policy implementation. Sections 4 and 5 discuss actual experiences of the process of assessment and the outcomes of assessment for carers respectively. We conclude, in Section 6, with recommendations for improving the implementation of the Carers Act, as well as some suggestions for areas for further research.

Section 2: Strengths and limitations of the evidence

Our aim was to investigate the impacts of the Carers Act: first, in terms of changes in local policy and practice; and, second, from the perspective of a sample of carers who received an assessment under the Act. At the time the Act was passed, the climate of opinion among social services departments was favourable to further recognition and acceptance of the needs of carers, although the pace of local change was variable. Thus the Carers Act, at best, gave impetus to a process of change which many would argue was already underway. This changing context makes it difficult to attribute changes in local policy and practice directly to the impact of the Carers Act with any degree of certainty. We are not in a position to know what would have happened had the Act not been passed, but we have been able to seek evidence from participants in the process of implementation, about the influences they perceived to be operating at the time, and the changes they observed. We have collected evidence from contemporary documents and semi-structured interviews with local policy makers and practitioners. This evidence has been the basis of our conclusions about the impacts on local policy and practice.

With regard to carer perspectives, the current study is complementary to other studies of the impact of the Act in a number of respects. First in relation to the sample: the carers included are arguably a representative group of those who have been assessed by social services, rather than having been selected, for example, from the membership of a voluntary organisation. Second, in relation to the methods: open-ended methods, including semi-structured interviews, have been used, in addition to some structured scales and ratings. Such in-depth methods necessitate the involvement of smaller numbers of people than have been covered in postal surveys but provide relatively rich information about individuals.

It was beyond the scope of this study to construct a comparison group of carers who had not been assessed. To undertake this would require a quality of information about users and carers which is not readily available within social services (SSI, 1999b), and it would mean

identifying people with an equal need for assessment who were not then going to be assessed - an untenable situation when people have a legal right to ask for an assessment, and when professionals who make decisions about eligibility are responsible for referring people to the study. Therefore we chose to concentrate on people who had received an assessment, and to ask them about process and outcomes, immediately afterwards and six months later.

We expected to be able to explore in depth with carers the perceived impact and consequences of assessment. However, the finding that over half of those referred by social services were unaware that they had experienced an assessment posed some difficulties for us in establishing attribution. Many people were unable to identify services given as a result of assessment, nor their satisfaction with the process, given that they were unable to identify the event itself. Although this poses a problem for the research, it is only an important practice issue if explicit recognition of the assessment process makes a difference to the process and outcome for the carer.

Section 3: The impact on policy and practice in social services departments

The process of local policy implementation

The implementation of the Act provided an opportunity, in all of our research authorities, for reflection and consolidation in relation to local policy and practice. Whilst being anxious about the practical implications of a duty to assess without the power and additional resources to provide direct services, all the authorities gave further recognition to the needs of carers through the development of formal statements of principle and policy. None made a radical change of direction, and existing differences between authorities shaped the variations in plans for local implementation. For example, existing local joint planning arrangements influenced the way in which joint working implications were addressed, and issues relating to equal opportunities were addressed in variable ways which reflected differing geographical and demographic features, and varying existing policies.

In response to the government intention that local authorities should form and publicise their own judgements about what amounted to 'regular' and 'substantial' care, the research authorities retained broad and flexible definitions for entitlement and eligibility in local policy statements. The impact of this open, inclusive approach was to delegate down to front-line care managers and practitioners the responsibility for determining eligibility for assessment on a more individual basis. Generally, a 'holistic' approach to assessment was seen by staff as good practice, but this integrated approach appeared sometimes to result in carers being assessed without being clearly aware of the process and informed of their rights. Our evidence suggests that decisions about whether to undertake an assessment remain largely a professional matter. Certainly the Act has not resulted in large numbers of carers requesting an assessment, and most assessments are not of people new to services. Given the devolution

of responsibility to the front line, then if professional practice in assessment varies with different user groups (as we know it does cf. Challis *et al.*, 1998), then these variations are likely to carry through into the assessment of carers.

In each of the research authorities, policy and practice statements and procedures were revised, developed and disseminated, sometimes through modules of staff training and sometimes through a cascade approach via key staff and care managers. Yet, senior managers and practitioners acknowledged that there was some uncertainty about the extent to which staff training was being maintained, and that workers were sometimes unsure about what should happen in practice.

On the whole, there was a reliance on general statistical returns and decentralised monitoring of care planning by team leaders and review officers to monitor the impact of the Act. The research authorities were at different stages of developing effective information and monitoring systems, with a varied balance between information technology and manual systems.

Both senior managers and practitioners spoke of the benefits of the Act largely in terms of the raised profile of carers, a greater awareness of their rights and circumstances, and the opportunity to improve care planning and practice with carers generally. Senior managers saw the Act as a peg for improving the assessment and care management system as a whole, staff training and supervision, and inter-agency working. Their main concerns related to raising carers' expectations, unclear eligibility definitions, the need for other agencies to recognise the needs of carers, and the need for increased government resource allocations. Senior managers emphasised that carers were not just a social services issue, and the National Carers Strategy has recognised this. Our evidence indicates that most carers have initial contact with NHS personnel, particularly GPs, long before they access social services, sometimes far too long. Housing, benefits and transport can also be crucial inputs.

The practitioners' and care managers' views of difficulties focused on workloads, and pressures on time and resources. These views were linked to concerns about raising the expectations of carers, and the perceived risk that carer assessment without additional resources would be 'just another piece of bureaucracy'. The implied right of a carer to say, 'I don't want to care any more' was seen variously as a positive right to be encouraged or an anxiety to be avoided. As we have indicated, it would appear that the differing attitudes and approaches of practitioners influenced variations in the approach to assessment. Attitudes ranged from an emphasis on 'holistic assessment', to seeing carer assessment simply in terms of completing a carer's assessment form. This variation could help to explain the contrasts

between the perceptions of social services and carers, and the uncertainty among carers about whether their needs had been assessed.

Summary of implementation issues

Our findings confirm the influence of local independence and discretion when tracing the impact of central policy changes, particularly where there is any lack of clarity or ambiguity in central policy aims (Lewis and Glennerster, 1996). They also support the notion that care should be taken in claiming tangible gains, at the same time as recognising that gains are sometimes attitudinal (Packwood *et al.,* 1998). In response to the broad eligibility definitions in central guidance, local authorities were uncertain as to whether they were expected to be open and inclusive, or restrictive and targeted in their application. Associated with the absence of additional resources to back the new legislation, there was ambiguity about the relationship between carer assessment and resource allocation. To some extent local authorities responded to both these issues by decentralising the responsibility for resolving the dilemma, leaving care managers and practitioners to act largely on their own discretion with limited central monitoring. At the same time, whatever the tangible organisational and service impacts, there appeared to be a positive attitudinal gain in the attitude of departments, managers and practitioners towards carers. The Act appears to have been a peg for confirming and reinforcing an awareness of carers in their own right.

Section 4:   Perspectives on the process of assessment

Despite policy emphasis on consultation and negotiation with carers to facilitate their participation in assessment, as we have observed, half of the carers were unaware that an assessment had taken place. A cause for concern is the existence of a group of older carers, heavily involved in caring, and receiving higher levels of service, who were considerably less likely than younger carers to be aware of an assessment process, and less likely to feel understood by professionals, (although they expressed satisfaction with practical services received). Although it is possible that these carers were simply more likely than others to have forgotten their assessment, there is other evidence (Challis *et al.*, 1998) that the volume of assessments of older people means that older people using services may receive less intensive assessments and follow up than younger groups. In addition, if the carer is also an older person, it is possible that within such a context they are less assertive about their needs than a younger carer might be. This issue requires further investigation to confirm these differences on a larger scale, and to identify appropriate ways of delivering an equal service to older carers. There are implications here for policy and practice including information giving, fair access to care, assessment practice and staff training.

Practitioners acknowledged that a clear distinction was not always made between assessment of the care recipient and the carer. This indicates that there may be some tension between

aspiring toward an 'integrated family approach'(a key emphasis in central policy guidance), and seeking to ensure a separate carer focus in which the carer can participate in an informed way. Few carers could recollect being consulted about the interview arrangements. In most instances, the carer and care recipient were seen together, normally at home, although a very small number of carers were seen in hospital prior to discharge or in the social services office. Carers sometimes had strong feelings about whether a separate or a joint interview was appropriate, and since preferences differ, this is an issue which has to be separately negotiated in each instance.

Many carers, particularly older carers, did not find it easy to complete carer's assessment forms and required assistance. The findings of our research suggest that self-assessment forms should be used selectively, and usually in conjunction with face to face interview.

For some carers, a thorough examination of their needs provided supportive evidence of concern about them, as well as ensuring an effective assessment. On-going emotional support and help with financial matters were two areas which received inadequate coverage from the carers' point of view in a substantial minority of instances. Being able to talk through the financial effects of decisions was a matter of concern for some carers: for example, decisions about giving up work, or re-entering employment needed to be based on a sound knowledge of the financial implications. There was little evidence of open consideration of carers' willingness to continue caring. What was evident from their recollections was a strong focus on the service provision needs of the care recipient.

Carers valued having a known and named worker who was a good listener and comfortable to talk to. Carers also appreciated quick and reliable responses, regular follow-up and contact, and being kept informed. Carers provided pointers for what they saw as good practice: the assessment process being made explicit and being given time and information in preparation for interviews; discussion of the timing and arrangements; the opportunity for an informed choice over the matter of privacy and 'separate' assessment; carers to have face-to-face discussion, with self-assessment and other forms being an aid not a substitute for this; and for carers not to be deluged with too much written information.

The influence of carers on the care planning decisions
Although a few carers preferred to leave decisions to the 'experts', most carers felt that it was important for carers to be knowledgeable about service provision and the social services system, but this begged the question about how they gained and maintained such knowledge. Having an assertive voice does not come easily to everyone, and some carers found it difficult to obtain help on their own. Some who found it a struggle would have welcomed having

somebody 'on their side', who would help in negotiations with social services and other professionals.

Qureshi *et al.* (1998) found that carers appreciated an 'even-handed' approach by professionals in relation to disputes or differences within the family. Incidents of conflict between users and carers in our study were not common, yet could create serious difficulties when they did occur. Senior managers and practitioners sometimes saw conflict as the justification for separate assessment of carers' needs. When asked about how conflicts were resolved, staff referred to: care planning meetings; independent advocates; involving more senior workers or referring higher in the organisation; complaints procedure; talking to the parties separately; and things sometimes just resolving themselves over time. There were examples of the timetable and other aspects of care packages being adjusted in consideration of the needs and wishes of carers, but there were a few instances in which this possibility was restricted by the actual or perceived wishes of the care recipient.

At least half of the carers reported they had not received any follow-up to the assessment in writing. Among those who had received written follow-up, some had simply received back a copy of the carer's assessment form they had completed themselves, or brief details about services and financial charges, as opposed to a fuller care and review statement. Despite clear local policy guidance, there was evidence of uncertainty and varied practice on the part of staff.

Services in response to assessment

As we have indicated, it was difficult to distinguish services received specifically as a result of the carer assessment from those support services that were already being received or would have been arranged anyway. Most carers in the sample were caring for someone who was receiving a package of services. Certainly there were some examples of imaginative packages which enabled carers to pursue their own lives and interests and we have described some of these. In most cases, during the period of our study, there was no significant change in the service package. Where there were tangible changes to the package of direct support services, the variations over time were sometimes not straightforward, and were more usually linked with changing circumstances than formal review. It is a cause for concern that three carers cancelled some services which they had been assessed as needing, because of the cost.

Although senior managers and practitioners acknowledged the importance of emotional and social support, this was not always evident in practice, where the emphasis was on practical support services. The generally favourable responses from carers about the most commonly received practical services were consistent over time. Difficulties or reservations related to: the appropriateness of day care facilities; the flexibility, availability, timing of services and

lack of continuity of staff of home care services; and some unhappy experiences of respite care. Sometimes difficulties with a service aggravated the mixed feelings of the carer about respite care and 'letting go'. The importance of respite and breaks was acknowledged by most carers, both in respect of specific respite care services and the impact of services such as day care and sitting.

Section 5:   The outcomes of assessment for carers

Malcolm Wicks, the Carers National Association and other lobbyists on behalf of the Carers Act intended that the right to assessment should make a positive difference to the lives of carers. The majority of carers taking part in the present study had been provided with support; indeed, some care packages were quite complex. As far as we can see, in a lot of cases assessment did make a difference although not to the extent of relieving carers altogether of the need to help. Qureshi *et al.* (1998) have argued that carers seek outcomes from services in three important areas: the quality of life of the person they care for; their own quality of life; and sharing of responsibility for the caring role and activities. Drawing on this framework, we describe below the outcomes achieved for carers in the wake of their carer assessment.

Peace of mind

The study highlighted that peace of mind was enhanced when carers were confident about the care, safety and security of the care recipient when they were not present. Such feelings were further strengthened if carers believed the alternative arrangements improved the care recipient's quality of life.

Peace of mind was harder to achieve for those carers who did not live in the same household as the cared-for person. Not surprisingly, these carers tended to worry about what might be happening when the care recipient was on their own. These feelings were somewhat alleviated, though, when the person cared for was being looked after by another individual in whom the carer had confidence. Two or three carers in the study admitted they achieved peace of mind only when the person they looked after was admitted to residential care, which happened some time after their carer assessment.

Simply knowing they were 'on the books' of social services and had a named contact to turn to if a problem arose, or for further information or advice, also contributed to carers' peace of mind. However, the study revealed that the carers whose cases had been closed following their carer assessment and/or the arrangement of services felt 'left in the lurch' and upset; they were ambivalent about re-applying for help in the future. The individuals concerned had not expected the social worker's involvement to be short-term, which in any case does not square

easily with the notion of partnership. Neither does case closure accommodate meeting any on-going needs for information, if the caring circumstances change.

Health and well-being
Carers wanted to maintain their own health, both physical and mental, as well as that of the care recipient. However, some were disabled or suffered ill health themselves; quite a number experienced stress-related health problems. Potentially, the carer assessment gave social services staff the chance to check out the health and state of mind of the carer, and also find out whether they needed any information, advice or training in respect of the person looked after.

Some carers did receive increased practical support, more day care or respite breaks for example, which reduced their own input and might have meant they were then less tired or stressed. However, the other side of the coin was that carers' distress or anxiety could be heightened if they lacked confidence in the alternative care arrangements, or thought that their relative was unhappy. This placed them in a difficult position and it was not unknown for carers who felt that service provision reduced the cared-for person's quality of life to cancel the help in question even if this meant they had to provide more care themselves, thus putting their own health at (further) risk.

The accounts provided by carers, and some staff, suggested there was a significant gap in terms of emotional support or having someone to talk to. The process of assessment and contact with a social worker can be supportive in itself. It gives carers a voice, the chance to be recognised as an important person in the caring situation and the opportunity to build up a relationship of trust with the social worker. However, the notion of the carer assessment being an element of emotional support is less persuasive if carers and social workers do not remain in current regular contact. Whilst one function of many carers' centres and support groups is to provide emotional support, the majority of carers are not in contact with them.

The study showed that most carers find the process of placing a close relative in a nursing or residential home a time of considerable difficulty and emotional turmoil. Some carers experienced guilt because they could no longer continue in this role. These feelings were by no means as strong, though, for those carers who believed the care recipient was being better cared for in institutional care than at home, and even improving in health and behaviour. Even so, some carers who had ceased being the primary care giver needed help to re-establish a life of their own; for some this might involve social activities; for others, returning to work. Such help was much appreciated when it was received, but this help was given rarely.

Despite the emphasis on joint agency working, it is evident from the study that practice is variable as far as GPs are concerned. For many carers, the starting point for seeking assistance is their doctor. Whilst some doctors are good at giving advice and information, others are less so and there is scope for development. For instance, by not informing carers of their right to be assessed and telling them how to go about initiating an assessment, GPs are not addressing carers' needs. Furthermore, the accounts of some carers suggested that medical confidentiality issues can make it more difficult for them to manage their caring responsibilities.

Freedom to have a life of their own
Many carers in the study were caring all day, every day. Our research showed that some carers had more free time after they had been assessed, because the care recipient had been allocated extra hours of alternative care. One or two people used this additional time to participate in social activities such as swimming, yoga and ballroom dancing; others went to the hairdressers or the local club; yet others caught up on housework, shopping or sleep. Carers said that planned respite breaks said made their own life better. Many used the time to visit relatives and friends in different parts of the country. Breaks were also an opportunity for carers to take care of their own needs and feel better able to carry on with their caring responsibilities. As announced in the National Strategy for Carers (DH, 1999a), the government has provided a new special grant over the next three years (1999-2002) for local authorities to use to develop short breaks for carers.

Whilst additional help like day care or a sitting services gave carers extra free time, it did not necessarily extend their options. Quite often, it came in short bursts only so carers were still clock watching. From this point of view, the extra time was still not enough to stop them from feeling trapped in their caring role; 'prisoner' was a label a small number of carers applied to themselves, noting ironically that prisoners had their sentences reduced for good behaviour. Carers also found it difficult to do things spontaneously, for example make 'spur of the moment' visits to family or friends if it meant leaving the care recipient alone. Generally speaking, they did not have the freedom to arrange or plan their own lives; any life of their own was ruled by the hours set by service providers. The carers' financial situation was also influential; if money was scarce, then they were more restricted in choice of activities. Financial difficulties affected a substantial minority of carers.

Holding down paid work is one potential way for carers to lead a life in their own right apart from caring. The carers in the study who worked gained economically, socially and psychologically. However, it was clear from the accounts of working carers, and carers who had given up work, that combining work and care is difficult. Carers needed support from different sources if they wanted to continue working. They required quality service provision

that they could be confident would meet the needs of the person looked after. But on its own, this was not enough. Carers also needed carer friendly employment policies (for instance, flexible working hours, time off in an emergency and access to a telephone) to help them combine work with their caring duties. From this point of view, it is important that the government continues its efforts to persuade employers that introducing such measures has the potential to bring business benefits. These include retention of trained, skilled staff; enhanced employee loyalty and motivation; the avoidance of recruitment and (re) training costs (DH, 1999a).

Preventing social isolation

Informal care relies on people's social and support networks. If these are not maintained, then as carers age they are less likely to have such networks to draw on for help. The study showed that many carers were indeed facing increasing social isolation. Both young and old carers reported losing friends as a result of the responsibility and changes in lifestyle that caring brought. Furthermore, many in the study sample were older people with smaller social (and informal support) networks than their younger counterparts. Carers with a spouse suffering from dementia lost their companionship also. As just noted, the carer assessments were sometimes followed by additional breaks for the carer, and one function of these was to help people maintain existing networks. For some carers, being an active member of a support group provided friendship with others in a similar position, a change of scenery and the occasional outing. They were also a valuable source of information, and it is important that all carers are told about organisations in their locality so they can then decide for themselves whether they wish to pursue this option. Belonging to a church or particular faith, or a works retirement club, was an important social outlet for other carers. And when it was not possible to meet friends face-to-face, because of transport problems, dark nights or because respective free times did not coincide, then the telephone was an important substitute.

Shared responsibility and confidence in services

It is known that carers value a sense of shared responsibility, both practically and emotionally (Qureshi *et al*., 1998). The comments of carers taking part in the study confirmed that carer assessments that led to (increased) practical support and a sharing of the physical care of the person looked after helped convey a sense of shared responsibility. Talking things over, especially with a view to reaching decisions about what they should do, also contributed to this same sense of sharing.

It mattered to carers that services were of a similar standard and quality to the care that they themselves could provide for the person looked after. If they had confidence in the assistance provided, this helped carers achieve peace of mind and encouraged them to pursue their own interests. From this perspective, what would help carers a great deal would be for services for

care recipients to be improved in terms of quality, reliability, fitting in with preferred routines and consistency of staff.

Section 6:   Recommendations

On the basis of the findings, as well as discussions at the feedback workshop where representatives from the research authorities were invited to comment on a draft version of the final report, we conclude our report by listing recommendations to improve the implementation of the Carers Act. Some of these are stated government intentions, and this study reinforces the need for action to be taken in these respects. We finish with some suggestions for possible areas for further research.

Central Government: Department of Health
1.   Review or clarify the eligibility requirement restricting carer assessment to carers of people and disabled children already being assessed by the local authority, to ensure that carers are enabled to request a carer assessment directly.
2.   Review or clarify the eligibility requirement restricting carer assessment to people who satisfy locally defined eligibility criteria based on providing, or intending to provide, 'a substantial amount of care on a regular basis', to ensure that entitlement is applied in a fair and consistent way.
3.   Means should be found to reinforce the policy intention that carer assessment and support is not just a social services responsibility nor even dependent on a social services lead role.
4.   Review or clarify the policy of service provision needing to be justified in terms of meeting the assessed community care needs of the care recipient, to enable services to be provided in direct support of carers.
5.   Promote means of support from employers being recognised as important to enable carers to participate in the labour market.

Central Government: Social Services Inspectorate and Social Care Group
1.   When advising and monitoring local authorities, to work toward supporting and building upon the recognition of the needs of carers in local policy statements and the management and practitioner 'good practice intentions' within social services.
2.   Means should be found to reinforce the recognition and practice of allied services (health, housing, education and employment) that carer assessment and support is not just a social services responsibility.

Local Authority: Policy and Senior Management

1. The policy for the entitlement of carers to carer assessment and the eligibility criteria should be reviewed and clarified, with the emphasis on an inclusive rather than exclusive approach to entitlement.

2. The importance of a joint working element to policy formation and implementation in respect of carers should be maintained and developed further where possible, with a particular emphasis on effective joint working between health and social services.

3. The process of developing more effective information systems for monitoring and managing the operational response to policy intentions about carer assessments and reviews and outcomes should be maintained/continued.

4. The information and systems developed to support carers in participating in care planning in an informed way should be reviewed and strengthened where appropriate, including keeping the printed information and its dissemination under review.

5. The policy intention that staff should inform carers of their rights to carer assessment and participate in the care planning process should be reinforced through management supervision and support.

6. Effective liaison and collaboration should be maintained between mainstream services and carers' centres and support networks. In respect of work with carers' organisations:
    -   It should be recognised that not all carers want to be involved with support organisations
    -   It should be recognised that carers' attitudes toward support groups can vary over time and circumstances
    -   Although some carers might normally resist attendance at meetings or other contacts with support groups as an added burden or imposition on their private time, there could be particular times and circumstances when they would benefit and respond to an accessible and flexible support contact.

7. In respect of staff induction, on-going training and preparation for duties under the Carers Act:
    -   The policy about carers being informed of their rights and assisted to participate in a conscious and informed way should be reinforced and maintained
    -   Means should be found of ensuring that practitioners who deal with carers are informed and up to date about carer support facilities and networks
    -   Practitioners should be supported in giving recognition to carers' needs for emotional support and counselling, and not simply focusing on practical support and tangible care services
    -   The policy intention that carers should receive written confirmation of the carer assessment and care plan should be reinforced through management supervision and support.

8. A proportion of staff should be trained to give specialist help to carers who want to discuss the financial implications of any decisions they might make.

9. Although most carers appeared to be generally satisfied with tangible services such as day care, home care, and respite care, they and service users should be regularly consulted in association with management reviews of the quality and appropriateness of these and allied services such as transport.

10. The importance to carers and service users of continuity of contact with known and trusted staff should be acknowledged in the way service provision is allocated and maintained.

11. As one aspect of the policy recognition of carers in their own right, the need of some carers for support when the care recipient moves into long term care or for some other reason is no longer in their care should be recognised.

12. Steps should be taken to reach black and ethnic minority carers, and promote their access to carer assessment.

Local Authority: Care Managers and Assessment Staff

1. In seeking to ensure that carers receive appropriate information and supportive guidance and encouragement to participate in the carer assessment process, special consideration should be given to older carers with heavier caring responsibilities.

2. It should not be assumed that carers are aware that their needs are receiving a distinct focus within the assessment and planning for the needs of the care recipient; practitioners should make their right to assessment and the carer assessment arrangements explicit.

3. The arrangements for the assessment, including the issue of separate interviews and whether the carer wishes to be accompanied, should be a matter of discussion and agreement.

4. Self-assessment forms should be used selectively and as an aid and preparation for the carer assessment, not as a separate assessment option.

5. Carers should be given the opportunity to discuss their financial circumstances as well as the financial implications of the care plan and support services.

6. Carers should be given the opportunity to discuss health issues in relation to their own health as well as that of the care recipient.

7. Carers who are in employment, or who want to work, should have the opportunity to discuss and seek advice on the implications of this during the carer assessment; the pressures of work as well as the tangible benefits and beneficial effects on people's feelings of worth and well-being should be recognised.

8. Carers should receive written follow-up including information about the conclusions of the assessment, care plan decisions and services, identified practitioners for future contact, and details of review arrangements.

9. It should be recognised that carers who have relinquished their main caring role for whatever reason could need and benefit from emotional support and counselling, as well as advice on tangible matters such as finances, health and employment.

10. The importance to carers and service users of continuity of contact with known and named staff should be acknowledged in the way support is allocated and contact maintained.

Possible areas for further research

1. Information networks: investigate how best to ensure that carers link into the appropriate information networks.

2. Older carers: determine the needs and unmet needs of older carers, and ascertain how social workers and other involved professionals can best address the needs of older carers.

3. GPs and primary health care: ascertain doctors' views about supporting carers; evaluate the effectiveness of different models of GP-based carer support initiatives.

4. Black and ethnic minority carers: examine how best to facilitate access for black and ethnic minority carers to the care planning process and assessment under the Carers Act.

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APPENDIX A: TECHNICAL REPORT ON METHODOLOGY

Section 1: Research authorities

Four local authority social services departments in the north of England took part in the study. The fieldwork settings were chosen to reflect a cross-section of authorities; they varied in type, size, location, population mix and policy approach to carers. A further consideration was 'good practice', as evident in, say, existing policies and strategies for carers, or staffed carers' projects. It was thought there was greater likelihood of producing positive examples of how carers were recognised, assessed and supported where some progress had already been made in addressing carers' issues. Two authorities were simultaneously taking part in the King's Fund Carers Impact (1996-99) national development programme.

We were guided by social services staff from the respective departments regarding the actual social work teams we collaborated with. The final choice took account of such issues as the number of carer assessments undertaken and access to a potentially varied carer population. Generally, we worked with teams covering specific geographical areas and responsible for services for adults and older people. Research authority 3 was exceptional in that it was the sole site where one of the teams had responsibility for services for disabled children. All the teams were community-based.

Section 2: Study sample

Carers

The study was designed to collect in-depth information, for which large-scale survey work is not ideally suited. The original research design therefore entailed a major qualitative component in the form of two individual interviews with 60 adult carers who were already involved with social services departments, and had been assessed under the Carers Act. In fact, the final sample (51) compares favourably with the numbers participating in such influential studies as Cornwell (1984) and Parker (1993). Furthermore, there was not a great deal of variability in the study sample which means that smaller samples are more acceptable (Robson, 1993).

In each of the four research authorities, the aim was to interview 15 carers who had just been assessed under the Carers Act. Since the sites did not hold reliable statistics on the number of carer assessments carried out in different geographical areas, there were no benchmark figures for us to use as a sampling frame. Instead, the intention was that all eligible carers assessed in the first six months of the fieldwork period would be invited to take part in the study; recruitment would stop once the target number of carers for each particular team had been achieved. Carers who met the criteria for inclusion in the study were those who had been assessed under the Carers Act whether or not this led to receipt of services, and who looked

after people with physical or learning disabilities and/or older people. Carers under the age of 18 were excluded (carers in this age group were the subject of a study conducted by the Young Carers Research Group at Loughborough University; see Dearden and Becker, 1998).

When negotiating access arrangements with the research authorities, every effort was made to include ethnic minority carers in the study sample. Two of the four authorities were at least at or above the national average for ethnic minority population proportions. Consultations about teams and geographical areas for inclusion in the study allowed for areas of higher ethnic minority populations. Specifically in one authority with a higher than average population of ethnic minorities, we focused on social work teams and areas to the west of the borough where large numbers of Asian people lived. Discussions with the relevant teams in that site, including ethnic minority staff, aimed to facilitate the participation of ethnic minority carers (for instance, establishing links to respond to any need for translation and/or interpretation).

Carers were told about the study by staff workers in the social work teams. With the carer's permission, the researchers then made contact to see whether they were willing to take part. In the event, the timing of people's initial contact with the study varied, and for a handful of respondents the time lag between assessment and being referred to us may have been quite lengthy. In three cases, the person being looked after had been admitted to residential care or nursing homes shortly before the first interview with the carer; one person had moved into supervised sheltered housing. The details in the text and tables that follow, however, relate to the time when all the care recipients were still being looked after at home.

Whilst initially the research authorities had all expected to meet their target of 15, in the event recruitment of carers turned out to be less straightforward than they had anticipated. By the time we reached our deadline for completing the first round of interviews with carers, we had interviewed 51 carers, looking after a total of 54 people. Table A.1 shows the number of carers interviewed in each research authority, together with the number of care recipients. All the carers were recontacted and approached for a second interview. However, two carers withdrew from the study at this stage. In one case this was because the care recipient had died; in the other instance, the specific reason was not disclosed. Consequently, follow-up interviews took place with 49 carers.

Table A.1: Research authorities, carers and care recipients

Research Authority	Carers	Children (under 18 years)	Adults (18 - 64 years)	Older People (65 years and over)
			Care recipients	
RA 1	14[a]	-	6	8
RA 2	13	-	4	9
RA 3	15	4	7	5
RA 4	9	-	4	7
Total	**51**	**4**	**21**	**29**

[a] In one case, there were two joint carers who were interviewed together. For the purposes of tables in the report, we have recorded details of one carer only.

The main characteristics of the carers participating in the study are shown in Table A.2. We interviewed more female carers (36) than male (15). Only eight carers were below the age of 40; 26 were aged 61 or above. Carers were most likely to be caring for a spouse (26) or a parent (15). Most carers (37) lived in the same household as the person cared for; the majority (41) of carers did not work.

Table A.2: Profile of carers on entry to the study

	Carers
Sex	
Female	36
Male	15
Age	
31 - 40	8
41 - 50	8
51 - 60	9
61 - 64	10
65+	16
*Relationship to carer-for person**	
Spouse/partner	26
Parent	11
Child	15
Other relative	1
Residency during caring episode	
Co-resident carers	37
Extra-resident carers	14
Employment status	
Working full-time (over 16 hours)	7
Working part-time (less than 16 hours)	1
Assisting with family business	2
Not working	16
Retired	25

*Two carers, looking after both a partner and child, are included twice: in both the 'Spouse/partner' and 'Parent' categories. Another carer, looking after both parents, is included just once in the 'Child' category.

Carers in the study had been caring for widely varying lengths of time. A minority were relatively new to caring; for instance, seven had been involved in care work for less than one year. A further 17 and 14 had been caring for between one and four years, and five and nine years, respectively. Others had been carers for considerably longer, including 11 who had been carers for 15 years or more. The majority (35) of carers described themselves as the only carer. Eleven said they were the main carer, and five said they were part of a joint or 'shared' care arrangement. The overwhelming majority (49) judged that their weekly caring activities exceeded 20 hours; of these, 47 people cared for over 35 hours a week. This large proportion of 'heavily involved' carers was to be expected, given the eligibility criteria for assessment under the Carers Act.

Despite specifically addressing the issue in preliminary discussions with the sites, none of the carers (or care recipients) was from an ethnic minority group. During the fieldwork period, only one carer from an ethnic minority family (Chinese) was identified as receiving a carer assessment, but unfortunately for the research declined to participate. As far as could be established from subsequent discussions with senior managers and team leaders, this was the only ethnic minority carer who received a formal carer assessment within the selected teams, areas and time allowed for the study. However, the fact that ethnic minority carers were missing from the study sample is not surprising given that it is acknowledged (SSI, 1998a) that it is difficult for social services departments to reach these communities.

It is difficult to comment on how representative of carers being assessed during the Carers Act the study sample was, given the deficiencies in social services departments' information systems (see Chapter 2). However, it is probably not unreasonable to say that the sample does reflect those people receiving an assessment under the Carers Act within teams taking part in the study from the four research authorities during the fieldwork period. How does the sample compare with carers nationally? Whilst it is not possible to compare the data exactly because of differences in sampling, Table A.3 shows a comparison of the 49 carers from this study who spent at least 20 hours a week caring with results from the 1995 General Household Survey (ONS, 1998).

Table A.3:   Comparison of carers spending over 20 hours a week caring, Carers Act study and the 1995 General Household Survey (ONS, 1998)

	Carers from study sample %	Carers from GHS data %
Sex		
Female	69	61
Male	31	39
Age		
16 - 44	14	26
45 - 64	53	47
65 and over	33	27
Relationship to cared-for person		
Spouse/partner	50	39
Parent	21	18
Child	29	31
Other	-	12
Residency during caring episode		
Co-resident carers	75	72
Extra-resident carers	25	28
Employment status[a]		
Paid work	24	39
No paid work	76	61
Main carer		
Main or only carer	92	87
Shared carer	6	-
Joint carer	2	-
Secondary carer	-	13
Disability of care recipient		
Physical only	56	53
Mental only	40	37
Mental and physical	-	-
Old age only	4	10
Number of cases	**49**	**625**

[a] Figures in both columns include carers under 65, regardless of how many hours a week spent caring

It can be seen from Table A.3 that there are only fairly small differences in the two samples in relation to sex, carers aged 45 and over, living arrangements, 'main' and 'non-main' carers, and the nature of the care recipients' disability. However, the present study sample contains a higher proportion of carers who were married or cohabiting, and no carers at all who were distant relations, friends or neighbours. On balance, it seems fair to suggest that our sample, although only small, is a reasonable reflection of the national picture of heavily involved carers. Since there is some sense of typicality, as well as rich and complex data to draw on,

we are persuaded that the findings of the study are credible. As Sapsford and Jupp (1996) point out 'even *one* typical case researched in depth tells us more about a group than superficial information on every member of it' (p. 13; original emphasis).

Of the 54 care recipients, 34 were female and 20 were male. Four were children under 18 years of age, five were aged between 18 and 30 years, 16 were aged between 30 and 64 years, and 29 were aged 65 years and over. It was difficult to fit people neatly into specific illness or disability categories because quite a number experienced multiple problems. However, categorising on a fairly simple level indicates that cares provided support to:

- 1 child (under 18 years) with physical disabilities
- 1 child (under 18 years) with learning disabilities
- 2 children (under 18 years) with physical and learning disabilities
- 16 adults (18-64 years) with physical disabilities and progressive diseases such as multiple sclerosis and Parkinson's Disease
- 5 adults (18-64 years) with learning disabilities
- 29 older people (over 65 years) with a range of physical disabilities, sensory impairments and/or mental health problems associated with advancing age.

Four care recipients died and 16 were admitted to residential care during the six-month interval between the two interviews.

Social services staff

The research design called for individual interviews with social services staff in each of the four local authorities: one senior manager involved with policy formulation for the Act, and four staff workers whose responsibilities included carrying out carer assessments. In the event, the latter interviewees were drawn from a variety of occupational groups. Job titles included team leader, social worker, care manager, home care manager, monitoring and reviewing officer, carers' officer and social welfare officer. Relevant staff were nominated by senior management and approached for interview. Table A.4 provides a summary of interviewees.

Table A.4: Social services interviewees

Research Authority	Senior managers	Staff workers
RA 1	1	4
RA 2	1	4[a]
RA 3	1	4
RA 4	1	4
Total	**4**	**16**

[a] A second social worker took part in one interview, for some of the time only.
For the purposes of this report, we have recorded this as one staff worker only.

Section 3: Data collection

The fieldwork period lasted for 12 months commencing May 1998. The study involved collecting both qualitative and quantitative data through a documentary review, interviews and questionnaires. We undertook an examination of documentary materials related to the Carers Act; these included policy statements, official papers to social services committees and operational guidelines. This exercise helped establish how the documentation related first to national policy and practice guidance, and secondly to policy and practice at the frontline operational level (see working paper, 'Objectives of Document Analysis'). In particular, the documentation gave insights into local definitions of 'regular' and 'substantial' in relation to eligibility criteria for assessment, as well as how concepts such as 'carer' and 'separate assessment' were being interpreted.

Semi-structured interviews were held with social services' managers and staff workers, and carers. One of the researchers (HA) conducted all the interviews in two of the local authorities, and the majority of the interviews in the third. The remainder, and all the interviews in the fourth authority, were undertaken by the second researcher (DH). A checklist of issues to be covered was used to guide the interviews; however, they were also designed to allow interviewees to raise issues of concern to themselves. (For more detailed information, see the respective working papers that accompany each set of interviews.)

In the discussions with managers we concentrated on the following areas: local policy on carers, consultation for the Carers Act; preparation for implementing the Act; assessment procedures; and monitoring outcomes. The interviews with staff workers centred on: local policy and practice on carers; access and eligibility to assessment; the carer assessment process; care planning and service provision; and monitoring outcomes. Having ascertained official departmental policy on the Carers Act, together with information about how staff actually translated the policy into practice, the other element of data gathering involved talking with carers to find out about the actual experience of the process and outcomes of assessment.

We interviewed carers at two points in time: shortly after the carer had been assessed under the Carers Act (Time 1), and six months after the first interview (Time 2). The time gap was sufficient for staff workers to respond to carers' assessed needs and put any (further) support in place. Carers, for their part, had the opportunity to experience and evaluate service interventions. For the purposes of continuity and good relationships, the same researcher carried out both the Time 1 and the Time 2 interview with the same carer. The majority of interviews were carried out in the homes of carers; just two were carried out in the Social Policy Research Unit, by request of the interviewees in question.

The purpose of the first interview was to collect information on: the caring context; how carers came into contact with social services; the process and form of the carer assessment; service provision; carers' hopes and anxieties for the future; examples of perceived good practice, and areas for development. This part of the interview consisted of open-ended questions. In contrast, outcome information about levels of satisfaction with service provision was obtained by using a series of rating scales. Carers were asked to rate how specific services met first their own particular needs, and secondly the needs of the cared-for person, in terms of the following options: very satisfactory, fairly satisfactory, not very satisfactory, not satisfactory at all.

The second interview used a mixture of the same questions and rating scales, together with other questions intended to determine changes over the previous six months in the circumstances of the carer, the care recipient and service provision. A particular concern was to explore carers' perceptions of the extent to which any service support they received after assessment made a difference in terms of change in levels of need, difficulty and satisfaction.

Data about carers' perceptions of their individual situation were gathered using instruments developed over many years of research and clinical practice with family carers (Nolan *et al.*, 1998). These instruments have been tested extensively in the UK, and more recently have been used as the basis for a study of informal care-giving in Sweden (Lundh, 1999a, b, c). Modified versions have been used as the basis for a pan-European study. The Carers' Assessment of Difficulties Index (CADI; Nolan and Grant, 1992a; Nolan *et al.*, 1998) helps identify the demands or events that carers experience as difficulties or potential sources of stress. To complement these data, we also used the Carers' Assessment of Satisfactions Index (CASI; Nolan and Grant, 1992a; Nolan *et al.*, 1998), which distinguishes sources of rewards and satisfactions associated with caregiving (copies of CADI and CASI are included at the end of this Appendix). These instruments were used on a self-administered basis, immediately after the first interview and shortly before the second. In the second interview with carers, responses were used as a prompt to stimulate discussion about perceived difficulties and satisfactions. The response rate was good; 94 per cent were returned at Time 1, and 78 per cent at Time 2. The lower response rate at the second interview was primarily related to carers who had ceased caring because the care recipient was now in residential care, and did not feel the CADI/CASI indices fitted the situation they now found themselves in.

With the individual's permission, all interviews were audio-recorded. Those with social services staff were fully transcribed; so, too, were nearly half the carer interviews at both Time 1 and Time 2. The choice of which interviews to transcribe was made on the basis of relevance to the research questions, as well as 'newness' and similarity and difference in terms of carers' experiences. Comprehensive notes were made of the remaining interviews.

Listening to the tapes and reviewing them was valuable; being immersed in the data in this way improved familiarisation with the accounts.

Section 4: Analysis

Our overall approach to the data analysis was inductive. This is a rigorous technique whereby findings emerge from the data, rather than from the testing of pre-identified hypotheses (Glaser and Strauss, 1967). One advantage of this approach is that the theory and understandings developed are likely to conform closely to the situations studied, and so be usable by people involved in them (Turner, 1981).

We set about this aspect of the work by managing the data in different, but related, ways. The first stage started whilst the Time 1 interviews with carers were still on-going. This involved entering all the interviews that had been transcribed into the qualitative software data analysis package NUD.IST (Non-numerical Unstructured Data Indexing Searching and Theorising). NUD.IST is a sophisticated package, capable of working with large data sets and helping in areas such as coding, retrieval and theory building. Its development was influenced by the grounded theory approach (Richards and Richards, 1987). In a comprehensive review (Weitzman and Miles, 1995) of 24 qualitative software packages, NUD.IST was highly praised.

We developed a coding frame based on topic areas discussed in the interviews. The coding framework identified relevant theoretical and analytical categories. Categorisations spanned a range of different dimensions; these ranged from care work to the assessment process through to social and interpersonal relationships. The transcripts were indexed according to the coding frame. The next stage comprised a manual exercise in relation to those carer interviews that had not been transcribed. This meant scrutinising the interview notes in terms of the analytic categories developed using NUD.IST.

The third stage was to search the data, either electronically or manually, looking for issues that emerged as important to interviewees themselves, as well as connections, recurring patterns and relationships between different analytic categories. In addition, we looked for disconfirming evidence and anomalies.

The analysis of the quantitative data, for example responses to the ratings questions and the CADI/CASI indices, was performed with the statistical analysis package, SPSS for Windows. The statistical analysis added to the scope of the enquiry. For instance, we were able to verify the frequency with which something was reported, which in turn demonstrated the (high or low) salience or significance of the perspectives or experiences being reported.

Findings were fed back to the research authorities. Each authority received a report specifically for their own particular department, which detailed findings at the end of the first round of interviews with carers. In three cases, this was followed by face-to-face discussions between the relevant researcher and social services staff. An important focus of feedback concerned the draft copy of the final report to the Department of Health. We held a workshop for representatives from all four social services departments, where we invited comments on the interpretation and implications of the findings. These were taken into account when writing the final version of the report.

CARERS' ASSESSMENT OF DIFFICULTIES INDEX (CADI)

(Nolan and Grant, 1992a; Nolan *et al.*, 1998)

CADI is a 30 item index and contains a series of statements which carers have made about the difficulties they face. Carefully read each statement and show if it applies by placing a tick ✓ in the space available. Together, responses can be used as the basis for discussing an agreed programme of support with the carer.

Caring can be difficult because:		This does not apply to me	This statement applies to me and I find it:		
			Not stressful	Stressful	Very stressful
1	I don't have enough private time for myself				
2	I can feel helpless/not in control of the situation				
3	I can't devote enough time to other family members				
4	It causes financial difficulties				
5	The person I care for can play me up				
6	The person I care for is immobile/has problems getting about				
7	Professional workers don't seem to appreciate the problems carers face				
8	It restricts my social life/outside interests				
9	It can put a strain on family relationships				
10	It is physically tiring				
11	The person I care for can demand too much of me				
12	I no longer have a meaningful relationship with the person I care for				
13	The person I care for needs a lot of help with personal care				
14	The person I care for doesn't always help as much as they could				
15	My sleep is affected				
16	Relatives don't keep in touch as often as I'd like				
17	I feel angry about the situation				
18	I can't see friends as often as I'd like				

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19	My emotional well-being suffers				
20	I can't have a break or take a holiday				
21	My standard of living has fallen				
22	The person I care for doesn't always appreciate what I do				
23	My physical health has suffered				
24	The person I care for is incontinent				
25	The behaviour of the person I care for is a problem				
26	There is no satisfaction to be gained from caring				
27	I don't get enough help from the health and social services				
28	Some family members don't help as much as they could				
29	I can't relax because of worry about caring				
30	I feel guilty about the situation				

Please add below any further difficulties you face and indicate how stressful you find them:

	This statement applies to me and I find it:		
Caring can be difficult because:	Not stressful	Stressful	Very stressful

CARERS' ASSESSMENT OF SATISFACTIONS INDEX (CASI)

(Nolan and Grant, 1992a; Nolan *et al.*, 1998)

CASI is a 30 item index and contains a series of statements which carers have made about the satisfactions they have experienced. Carefully read each statement and show if it applies by placing a tick ✓ in the space available. Together, responses can be used as the basis for discussing an agreed programme of support with the carer.

	Caring can be satisfying because:	This does not apply to me	This applies to me and provides me with:		
			No real satisfaction	Quite a lot of satisfaction	A great deal of satisfaction
1	Caring has allowed me to develop new skills and abilities				
2	The person I care for is appreciative of what I do				
3	Caring has brought me closer to the person I care for				
4	It's good to see small improvements in their condition				
5	I am able to help the person I care for reach their full potential				
6	I am able to repay their past acts of kindness				
7	Caring provides a challenge				
8	Despite all their problems the person I care for does not grumble or moan				
9	It is nice to see the person I care for clean, comfortable and well turned out				
10	Caring enables me to fulfil my sense of duty				
11	I am the sort of person who enjoys helping people				
12	I get pleasure from seeing the person I care for happy				
13	It's good to help the person I care for overcome difficulties and problems				
14	It's nice when something I do gives the person I care for pleasure				
15	Knowing the person I care for the way I do,				

	means I can give better care than anyone else				
16	Caring has helped me to grow and develop as a person				
17	It's nice to feel appreciated by those family and friends I value				
18	Caring has strengthened close family ties and relationships				
19	It helps to stop me from feeling guilty				
20	I am able to keep the person I care for out of an institution				
21	I feel that if the situation were reversed, the person I care for would do the same for me				
22	I am able to ensure that the person I care for has their needs tended to				
23	Caring has given me the chance to widen my interests and contacts				
24	Maintaining the dignity of the person I care for is important to me				
25	I am able to test myself and overcome difficulties				
26	Caring is one way of showing my faith				
27	Caring has provided a purpose in my life that I did not have before				
28	At the end of the day I know I will have done the best I could				
29	Caring is one way of expressing my love for the person I care for				
30	Caring makes me feel needed and wanted				

Please add below any other aspects of caring that you find satisfactory and indicate how much satisfaction they give you:

Caring can be satisfying because:	This applies to me and provides me with:		
	No real satisfaction	Quite a lot of satisfaction	A great deal of satisfaction

APPENDIX B

COMPLETED WORKING PAPERS

1.   Interview guide and accompanying rationale for:
        First interview with carers (Time 1)
        Second interview with carers (Time 2)
        Interview with social services senior managers
        Interview with social services care managers/practitioners

2.   Rationale for the use of CADI and CASI: general review of literature associated with Mike Nolan and Gordon Grant

DISSEMINATION ACTIVITIES

3.   'The Carer's Act: Legislation to improve a carer's lot'. Paper presented at the seventh biennial conference of the European Society of Health and Medical Sociology. Rennes, August 1998.

4.   'Carers' needs and the Carers Act'. Presentation to a national conference organised by the King's Fund Carers Impact Project. London, November 1998.

5.   Individual, interim site reports on research findings written specifically for each of the four research authorities. January 1999.

6.   Interim report on research findings for the Department of Health. March 1999.

7.   'Assessing carers' needs: Carers' experiences of the Carers Act 1995 in English local authorities'. Presentation to an international conference organised by the British Association of Social Workers and the University of Central Lancashire. Southport, March, 1999.

8.   Hepworth, D. and Arksey, H. (in press) 'Carers' Needs and the Carers Act', in J. Harris, L. Froggatt and I. Paylor (eds), *Reclaiming Social Work: The Southport Papers, Vol 1*, Birmingham: Venture Press.

9.   Two national conferences entitled 'Carers' Assessments: The Key to Caring about Carers?' have been organised in partnership with the King's Fund. The first took place on 10 February 2000; John Hutton, the Minister of State for Health, presented the opening address. The second conference is being held on 22 June 2000; Mrs Sylvia Heal, MP, is presenting the opening address.