

Carers' Assessments in Coventry
Content, Process and Outcomes

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The structure of the report

This report is the culmination of a nine-month research project funded by Coventry Community Services Directorate. It is concerned with the *content, process* and *outcomes* of an individual assessment for (informal) carers in Coventry. The purpose and phases of the project are described more fully in **Chapter 1**, as is the national guidance on carer's assessments.

As part of the research, the first phase involved the collation and statistical analysis of 260 adult carer's assessment forms. The aim here was to provide a statistical profile of a sample of carers who had recently gone through the carers' assessment process, and to assess the quality of the information recorded on the forms about these carers. The findings from this part of the research are reported in **Chapter 2**.

The second phase involved telephone interviews with a sample of 16 assessors who had completed individual carer's assessments. The aim here was to examine how assessors went about conducting a carer's assessment, how they completed the form and drafted a carer's plan, how they identified needs, and how (or whether) they communicated all this to carers themselves. The findings from this part of the research are reported in **Chapter 3**.

The final phase of the research involved individual face-to-face or telephone interviews with a sample of 11 carers who had been assessed recently. The aim here was to examine the *process* of assessment from the carers' perspectives, and the *outcomes* for carers. So, for example, were carers aware that they had been assessed formally? Did they receive any services as a consequence? Were these relevant to their needs? Were carers given a copy of their care plan (if one was drawn up)? The findings from this part of the research are reported in **Chapter 4**. Additionally, throughout **Chapter 4** we identify some key issues for policy and practice that arise directly from the accounts that the carers have given us.

Chapter 5 outlines some issues for policy and practice in Coventry, based on the findings from the study.

Appendix 1 provides the current assessment form as used in Coventry.

Appendix 2 provides a brief summary of a similar study conducted in Nottinghamshire.

Appendix 3 provides the Interview Schedules used in this study.

A note on language

Throughout this report we use the term 'person with care needs' to refer to the person who is receiving care from an informal family carer. Other terms in common usage include 'care receiver' or 'cared for person'. All these terms can be and are used interchangeably, although our choice is based on the preference of many disabled and ill people themselves.

Executive Summary

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1. Introduction

This Executive Summary provides a précis of the key findings from the full report of the same name. The report is the culmination of a nine-month research project funded by Coventry Community Services Directorate. The project ran from April to December 2006.

The principal aim of the research was to examine the *content*, *process* and *outcomes* of an individual assessment for (informal) carers in Coventry, and drawing on the findings, and what we know from best practice nationally, to draft if appropriate a new carers' assessment form that could be used in Coventry.

An intention of the study is to identify how the assessment process actually works, and how it is perceived both by those who are on the receiving end – the carers – and by those who conduct the assessments.

The four phases of the study

Phase 1: Collation and statistical analysis of the content of 260 carers' assessment forms that are held by Coventry Community Services Directorate for the period April 2005 to April 2006. The aim here was to provide a statistical profile of a sample of carers who have recently gone through the carers' assessment process, and to assess the quality of the information recorded on the forms about carers.

Phase 2: Telephone interviews with a sample of 16 assessors who had completed individual carer's assessments. The aim here was to examine how assessors go about conducting a carer's assessment, how they complete the form and draft a care plan, how they determine what are the needs of carers, and how (or whether) they communicate all this to carers themselves.

Phase 3: Individual interviews with a sample of 11 carers who have had an assessment. The aim here was to examine the *process* of assessment from the carers' perspective, and the *outcomes* for carers. So, for example, are carers aware that they have been assessed formally? Did they receive any services as a consequence? Were these relevant to their needs? Were carers given a copy of their care plan (if one was drawn up)?

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2. Statistical profile and analysis of Coventry carers' assessment forms

The data generated from this phase of the research provides a statistical profile of the characteristics and needs of a sample of 260 carers in Coventry, all of whom had been assessed between April 2005 and April 2006. This analysis includes all the assessment forms for November 2005 to April 2006. It also provides sufficient data on which to make an assessment of the *quality* of the assessment process itself, in particular, the quality of the *content* of the forms (the information recorded) and its *relationship* (if any) to the carer's action plan. The statistics show some interesting and important characteristics of local carers and patterns of need, for example:

- *Persons with care needs/service users*: Forty-seven percent of our sample were caring for someone with a mental health problem; 46% were caring for older people; 6% for someone with a physical disability (under 65) and 1% related to learning disability clients (under 65).
- Two fifths of the carers care for their spouse or partner. Another fifth of the carers care for their son or daughter. A quarter of the carers care for their parents or parents-in-law.
- More than two thirds of the carers who had been assessed live with the person with care needs.
- *Other dependants*: Forty-three percent of the carers also care for other dependants in the family, including elderly parents or parents-in-law, children and brothers or sisters. Twenty one percent of all carers have more than one other dependant who they are caring for in addition to the care receiver. Nearly one tenth are caring for three or more dependants in addition to the care receiver.
- *Gender*: Almost two thirds of the carers who had been assessed were female, one third were male.
- *Ethnic origin*: More than two thirds of the assessed carers were White. The ethnic origin of 12% of carers was Asian or Asian British, and 2% were Black or Black British. For more than 16% of the carers the information on their ethnic origin was not stated or was not clear. Non-white carers were more likely to care for greater than 20 hours and 40 hours per week, compared to white carers.
- *Age*: More than two thirds of the assessed carers were above the age of fifty with nearly one quarter of the sample being over the age of 70.
- *Employment status*: Nearly one fifth of assessed carers work full-time; a further 6% are in part-time employment; 43% were retired; 8.5% were classified as 'unemployed'. One quarter was classified as 'other'. Carers in paid employment are more likely to also report that their caring responsibilities are causing problems with their mental health and emotional well-being. This is particularly the case for carers in full-time paid work.

- *Caring tasks:* Carers are involved in a wide range of caring tasks, from shopping through to very intimate care and help with feeding.
- *Time spent caring each week:* Seventy five percent of assessed carers spend more than forty hours caring each week.
- *Duration of caring:* Eighty three percent of assessed carers in Coventry had been caring for more than one year. Of these, 14% had been caring for between 1 and 2 years; 12% between 2 and 4 years; 33% between 4 and 10 years; and 24% for more than 10 years.
- *Willingness to continue caring:* Nearly two thirds of the carers who had been assessed stated that they were willing and able to continue providing the same level of care.
- *Health and well-being:* In two thirds of cases there is evidence on the assessment form that caring responsibilities had *directly* impacted in a negative way on carers' own health and well-being.
- Two thirds of assessed carers felt they did not have enough time and space for themselves. Eighty percent of carers stated that they did not have access to regular short breaks.
- The data show that where the amount of hours spent caring each week varies considerably between weeks, then carers are more likely to experience negative impacts on their mental health and emotional well-being.
- *Disturbed sleep:* Seventy percent of all assessed carers suffered from a lack of sleep due to their caring responsibilities. The more hours that the carer cares per week, the more likely they are to report that their sleep is disturbed. Carers reporting the most disturbed sleep are those with variable caring hours per week – in other words, there was no uniform pattern to their caring routine over time. Disturbed sleep is also more common amongst carers of people with physical disabilities as opposed to other groups of carers.
- *Safety:* Two fifths of carers expressed anxieties about the safety of the person with care needs and sometimes about their own safety. The most commonly identified risks or concerns identified were verbal and physical aggression from the care receiver, suicide attempts of the care receiver, self harm and paranoia – all of which can impact on the carers' own safety, health and well-being.
- *Identified needs:* The Action Plans on the assessment forms identified a range of needs (at the time of the assessment) which required the provision of information, services or other forms of intervention.

In general, the data show that assessed carers in Coventry are providing more care per week than carers generally in the UK. Also, more carers in the Coventry sample live with the person with care needs (i.e. they are co-resident) than is the case nationally. These factors indicate that assessed carers in Coventry are providing care to people with high levels of care needs or 'dependency', requiring the carer to be co-

resident. This may indicate too that Coventry assessments are being successfully targeted on co-resident carers providing extensive hours of care per week.

Quality of the content

The quality of the content of assessment forms, and the consistency of the process in Coventry, are relatively high, for example:

- In 248 assessment forms (95%), *most of the content* provided was relevant to the questions asked (this compares to 58% of forms in an earlier study conducted for Nottinghamshire Social Services Department).
- 239 assessment forms (92%) identified carer's needs which might require support or interventions.
- The content of 226 forms (87%) provides sufficient quality to construct an Action Plan (this compares to 63% in Nottinghamshire).
- For 207 cases (80%) another social worker would be able to familiarise him/herself with the case and review the Action Plan on the basis of the information collected on the assessment form.
- However, there is almost no information whatsoever collected about *outcomes*. National guidance on conducting carers' assessments emphasises the need to focus on outcomes.
- On the vast majority of forms there is also virtually no information recorded about the person with care needs and no explicit discussion of the quality of relationships between the carer and the person with care needs.

3. Findings from the interviews with assessors

Between July and September 2006, a sample of practitioners (n=16) with experience of conducting carers' assessments over the previous twelve month period were interviewed over the telephone. The interview sought their views, perspectives and experiences regarding: preparation for assessments; the assessment form and process; the Action Plan; and implementation and review procedures following an assessment.

- *Time spent on assessments:* The time taken up by carers' assessments varied between assessors and with caseload. One assessor spent 75% of their week undertaking assessments while another said they did 2 per week.
- *Training:* Most assessors had received training on how to conduct assessments with adult carers about nine to twelve months previously. However six interviewees claimed they had not benefited from any training specifically relating to the carer's assessment process.
- *Preparation in advance:* Most of the assessors accessed, gathered and processed relevant information about the carer before contacting and undertaking the assessment. Most assessors also prepared their folder with information on the different services available to carers in Coventry.

- *Number of visits:* Assessors stated that it usually required one to two visits to complete a carer's assessment. In the majority of cases one visit was enough to collect all the necessary information.
- *The form:* Views on the quality of the assessment form varied amongst assessors. The vast majority of respondents were generally positive about the form. However, several interviewees commented that the form was 'not user-friendly'. Some questions were thought to be 'repetitive and therefore time-consuming', 'not well formulated' or even 'inconsiderate'. A range of suggestions for improvement to the form, and to the process itself, were made
- *The action plan:* Many assessors devise the carer's plan together with the carer, but 'write it up' at the office and then send a copy to the carer for signing and revision. All respondents thought the carer's Action Plan to be an essential part of the assessment form and process. Among the interviewees there was much debate as to whether the development of the carer's Action Plan was needs-based or resource-led. Indeed many respondents found it difficult to label their approach as one or the other.
- *Outcomes:* Despite engaging with the above debate regarding needs and resources, no respondents presented a primary or explicit focus on outcomes.
- *Identity:* It must also be noted that no respondents specifically identified a carer's identity, in terms of gender, ethnicity, language or beliefs, as a significant factor determining the Action Plan. Whilst consideration to diversity might be implicit in the assessment process, it was not voiced explicitly by interviewees.
- *Review:* Procedures for reviewing a carer's plan were variable. For many assessors there was no formal review process, and in a number of cases follow up was said to have been impossible given shifting caseloads.

4. Findings from the interviews with carers

The third and final phase of the research involved interviews with a sample of 11 carers drawn from the 260 assessment forms. These interviews were carried out either face-to-face or, where the carer preferred it, via the telephone. The sample included:

- ♣ Three daughters caring for an elderly mother
- ♣ Two wives caring for their husbands
- ♣ One mother caring for her son
- ♣ One father caring for his son
- ♣ One daughter caring for her mother-in-law
- ♣ One husband caring for his wife
- ♣ One son caring for his mother
- ♣ One couple caring for their son

Four different routes to a carer's assessment were identified, although even within each of these categories there was variation:

1. In three cases an assessment was triggered by an admission to hospital.
2. In two cases a carer's assessment was instigated by the social worker assigned to the care receiver.
3. In four cases the carer became aware of their rights to an assessment and contacted social services directly.
4. In the remaining two cases the carers were unsure what led to the assessment taking place.

Carers' perceptions of the assessment process:

- Whilst only two carers could not remember the assessment at all, a number of the other respondents were vague in their recollections of the exact process and outcome.
- Only three carers thought that they had a copy of the Action Plan and assessment form 'filed away somewhere', and only one carer had their copy to hand when our interview took place.
- Despite not recalling the assessment, of the 11 cases within the sample, 10 had signed the form (a copy of which was available to the researcher).
- Those carers to whom the process and purpose of the assessment had *not* been explained prior to the interview saw this as hindering the assessment.
- Whilst the majority of carers had been told about the purpose of the assessment in basic terms, in two cases the carer had not had the process explained. In both cases this led to the carers feeling confused and uncertain as to what had taken place.
- For some carers the communication with the assessors was problematic. The most common reason given for problematic communication was the involvement of a new social worker who appeared to know little of the background to the case.
- Some carers were more positive about the relationship they formed with the assessor, and of the process itself. For some a 'positive' experience of the assessment process was related to their sense of ownership and relevance of the ensuing carer's Action Plan.
- In a number of cases positive outcomes are directly attributable to the assessment. For example, carers were provided with advice regarding the range of benefits that were available; a number were now receiving a flexible carers break; some were taken into the city centre once a week to go shopping and to lunch.
- In many cases, the needs that had been identified in the carer's assessment had not yet been addressed appropriately.

- Other carers felt that no noticeable outcomes had occurred as a result of the assessment.
- In one case, the assessment was felt to have had a negative impact on the carer and the service user.
- *Review:* Whilst no formal review process was apparent, some of the carers felt that they could contact the assessor when required to ask additional questions, query progress towards Action Plan targets, or to inform of changing circumstances.
- For most there was no such ongoing contact with the assessor, and in some cases there was no ongoing contact with social services at all.
- In some cases it was clear that a review of the case was necessary and of particular importance.

5. Issues for policy and practice

In Coventry there are examples of good practice, as can be seen from what local carers say and what assessors say, and there is evidence that most assessors are strongly committed to securing the best they can (within available resources) for local carers. However, the research evidence also suggests that the assessment process is not yet adequate to meet the standards that carers' require and that assessors want to deliver. Twelve key issues for policy and practice were identified:

1. The need for social workers and others to inform carers of their legal right to an assessment.
2. The need for carers to be assessed or offered an assessment when the care receiver is assessed or re-assessed.
3. Should intermediary organisations, such as carers' centres, be mandated to conduct some carer's assessments on behalf of Coventry Community Services?
4. Carers need to be prepared for their assessment, as do assessors themselves.
5. Minimising the number and range of different assessments that carers and their families receive would be valued by carers.
6. Multidisciplinary assessments can be valuable, perhaps involving a 'case conference'-type situation bringing together key professionals in contact with a care receiver and their family.
7. Carers' assessments must be sensitive to religious, ethnic and cultural needs, and service that are provided as part of an action plan must also be sensitive to these needs.
8. Services provided to carers need to deliver agreed outcomes. Services that are inappropriate or not wanted by carers are a waste of resources and are a denial of a service to someone else.
9. Carers' assessments and services must be outcome focused.
10. A formal review of the carer's assessment, and the appropriateness of the action plan, need to be timetabled from the time of the original assessment.
11. The need for regular training to ensure all assessors or potential assessors are up-to-date regarding the purpose of a carer's assessment, carers' rights, the

law and guidance, the availability of local services and sources of information for carers.

12. The carers assessment form in Coventry requires some amending to make it 'fitter for purpose'.

Chapter 1

Context: The purpose and phases of the research, and the legislation and guidance on carers' assessments

Introduction

The principal aim of this research is to examine the *content*, *process* and *outcomes* of an individual assessment for (informal) adult carers in Coventry. The research commenced in April 2006 and was completed by the end of the year.

There are three phases to the study:

Phase 1

Collation and statistical analysis of the content of a sample of carers' assessment forms that are held by Coventry Community Services Directorate for the period April 2005 – April 2006

The aim here is to provide a statistical profile of a sample of carers who have gone through the carers' assessment process, and to assess the quality of the information recorded on the forms about carers. The findings from this part of the research are reported in Chapter 2.

Phase 2

Individual interviews with a sample of assessors (social workers, health workers etc) who have completed carers' assessments

The aim here is to examine how assessors go about conducting a carer's assessment, how they complete the form and draft a care plan, how they determine what are carers' needs, and how (or whether) they communicate all this to carers themselves. We also wanted to know whether they found the existing carers' assessment form a useful tool for conducting an assessment, and whether it needed improving in any way. The findings from this part of the research are reported in Chapter 3.

Phase 3

Individual interviews with a sample of carers who have had an assessment

The aim here is to examine the *process* of assessment from the carers' perspective, and the *outcomes* for carers. So, for example, are carers aware that they have been assessed formally? Did they receive any services as a consequence? Were these relevant to their needs? Were carers given a copy of their care plan (if one was drawn up)? The findings from this part of the research are reported in Chapter 4.

A brief note about research methods

Phase 1 of the study involved secondary analysis of 260 carers' assessment forms (see Chapter 2). Members of the research team read these forms and the content was 'coded' using a coding frame specially designed for the purpose. The data were then loaded onto a specially designed Access database. A computerised statistical package (SPSS) was used to produce frequency tables and cross tabulation tables for analysis. The forms that were coded and analysed for this part of the research were a sample of those held by Coventry Community Services Directorate for the period April 2005 to April 2006. In total, we analysed 260 assessment forms. This included all of the most recent assessment forms for November 2005 to April 2006, and a sample of forms from April 2005 to October 2005.

Phase 2 of the study involved telephone interviews with a sample of 16 assessors whose forms had been analysed in Phase 1 of the research (see Chapter 3 for the findings). These interviews were arranged in advance and conducted over the telephone at a mutually convenient time for both the assessor and the researcher. Each interview lasted between 35 minutes and an hour. Assessors were contacted in the first instance by Coventry Community Services Directorate to gain informed consent to a later interview by the research team.

Phase 3 of the study involved in-depth interviews with a sample of 11 carers whose forms had been analysed in Phase 1 of the research (see Chapter 4 for the findings). These interviews were carried out either face-to-face or, where the carer preferred it, via the telephone. Face-to-face interviews were undertaken in the carers' own homes, with the exception of one participant who asked for the interview to take place at the local Carers' Centre. Carers were contacted in the first instance by Coventry Community Services Directorate to gain informed consent to a later interview by the research team.

Ethics

The research was conducted to the highest standards of ethics and research protocols, as required by the Social Research Association, the British Sociological Association, the Economic and Social Research Council and the Department of Health's *Research Governance Framework for Social Care* (which all provide the ethical frameworks for this sort of study).

Before commencing the study, the research proposal was scrutinised by the ethical review procedures of the Institute of Applied Social Studies at the University of Birmingham (where this research study was first housed). Subsequently, a full application for ethical approval was made by Professor Becker to the School of Social Sciences Research Ethics Committee of the University of Birmingham, and this approval was granted before the study commenced.

Background to the project – the legal context

The Carers and Disabled Children Act 2000 gives family carers over the age of 16 (and caring for someone over the age of 18) specific rights:

- Carers may request an assessment of their own needs, even if the person receiving care does not wish to have an assessment;
- Local authorities may provide services for carers in their own right;
- Carers may receive vouchers for short-term breaks;
- Carers may receive direct payments in lieu of services for which they have been assessed.

The *Practice Guidance* to the Act (DH, 2001) sets out to promote services and other provisions that are designed to sustain the caring relationship in a manner that is in the interests of all parties. Support for carers is essential to their own well-being and also to the well-being of their relatives with care needs. Carers should receive the support that they feel is most appropriate to their needs. In some cases, a cash payment in lieu of services ('direct payments') may be more appropriate so that carers can make their own arrangements and pay someone of their own choosing. Local authorities are able to charge for services that are provided directly to carers, subject to a test of means. Carers under the age of 16 will need to access assessments and services through the 1995 Carers (Recognition and Services) Act or the 1989 Children Act.

Carers can also be jointly assessed alongside the person with care needs under the 1990 NHS and Community Care Act and the 1995 Carers (Recognition and Services) Act:

- The 1990 NHS and Community Care Act established the legislative framework for the restructuring of both the NHS and community care system. Section 47(1) places a duty on local authorities to carry out an assessment of an individual's needs for community care services.
- The 1995 Carers (Recognition and Services) Act gives carers of any age – including young carers – the right to an assessment of their 'ability to provide and to continue to provide care'. Social services are required (if so requested by a carer) to carry out this assessment of the carer at the same time as it assesses or reassesses the person for whom care is provided (the carers' assessment is therefore linked to the cared-for persons' assessment). The Act applies to carers who 'provide a substantial amount of care on a regular basis'. Circular LAC (96) 7 (DH, 1996) states: "it is for local authorities to form their own judgement about what amounts to 'regular' and 'substantial' care". Carers who do not provide substantial or regular care should also have their views and interests taken into account when an assessment is undertaken. 'Care' includes physical caring tasks as well as emotional care and general attendance to ensure the service user comes to no harm.

The Carers (Equal Opportunities) Act 2004 came into force on 1st April 2005. This Act made three main changes to the law with the objective of providing further support for carers and helping to ensure that they are not placed at a disadvantage because of the care they provide. First, the Act requires local authorities to inform

carers, in certain circumstances, that they may be entitled to an assessment under the 1995 and 2000 Acts (see above). Second, when undertaking a carer's assessment, the local authority must consider whether the carer works, undertakes any form of education, training or leisure activity, or wishes to do any of those things. Third, the Act provides for co-operation between local authorities and other bodies in relation to the planning and provision of services that are relevant to carers (HM Government, 2004, para 10).

National Guidance on Carers' Assessments

While the term 'substantial and regular' is not defined in any legislation, the *Practitioner's Guide to Carers' Assessments under the Carers and Disabled Children Act 2000* suggests that "the test that a practitioner should apply will relate to the impact of the caring role on the individual carer. In particular the practitioner will need to address the following questions: Is the caring role sustainable? How great is the risk of the caring role becoming unsustainable?" (DH, 2001, para 14). The Guidance lists 14 questions that help practitioners to identify levels of risk to the sustainability of the caring role, including how long has the carer been caring? How often does the carer get a full night's sleep? How much emotional impact does the caring role have? How far does the carer gain any sense of satisfaction/reward from caring?

Purpose of assessments

The *Guidance* makes it very clear what the *purpose* of a carers' assessment is under the Carers and Disabled Children Act:

- To determine whether the carer is eligible for support.
- To determine the support needs of the carer (i.e. what will help the carer in their caring role and help them maintain their own health and well-being).
- To see if those needs can be met by social or other services (DH, 2001, para 19).

It goes on to state that: "Great sensitivity on the part of the assessors may be required. It is important that the assessment process does not assume that the carer wants to continue to provide care, or should be expected to. Nor should it be assumed that the cared for person necessarily wants to continue to receive care..." (para 20).

Carers UK summarises the purpose of a carer's assessment thus:

"The purpose of a carer's assessment is for you [the carer] to discuss with social services what help you need with caring as well as any help that would maintain your own health and balance caring with other aspects of your life such as work and family commitments. Social Services use assessments to decide what help to provide" (Carers UK, 2004).

The focus on outcomes

The *Guidance* also states clearly that: “A Carer’s assessment should be focused on what the carer identifies as the best possible outcome. The best possible outcome will depend on the impact of caring on the particular carer. This impact is also the best test for ‘regular and substantial’ caring. While many carers may clearly be able to state from the beginning what it is they want to happen to make their lives easier, others may take time to identify their own needs.... It is very important to make a clear distinction between ‘outcomes’ and services.... The best service to provide the outcome will depend on the individual circumstances” (DH, 2001, paras 22-24). The assessment should also be ‘carer-centred’ (see **Box 1.1**).

Box 1.1: What the Guidance has to say about ‘carer-centred’ assessments

“The assessment is not a test for the carer. It should not be prescriptive but recognise the carers’ knowledge and expertise.

The assessment should listen to what carers are saying and offer an opportunity for private discussion so the carer can be candid.

It should not be a bureaucratic process based on ticking boxes. It must focus on the **outcomes the carer would want to see** to help them in their caring role and maintain their health and well-being.

It should be seen as part of a holistic assessment of the needs for support of the cared for person and the carer, identifying the outcomes desired by both and it should be reflected in the care plan (where it is appropriate for cared for person and carer’s issues to be dealt with together) or in a separately held carer’s plan (where there is a need for confidentiality)” (DH, 2001, paras 27-30; emphasis in original).

This emphasis in the Guidance on *outcomes* is critical. The carers’ assessment process is intended to determine the outcomes that carers want for themselves (and for the person with care needs) and the best ways in which these outcomes can be achieved through services or other forms of support.

Research has shown four dimensions (or ‘domains’) of outcomes that are important to carers:

- Achieving quality of life for the person they care for;
- Achieving quality of life for the carer;
- Recognition and support in the caring role;
- Service process outcomes (impacts of the way that help is provided) (Nicholas, 2001).

Assessments need to give carers an opportunity to explore these domains/outcomes with assessors.

Carers in Coventry – how many?

The 2001 Census shows that there are 29,877 people who provide unpaid care in Coventry, of which 20,029 provide 1–19 hours of care per week; 3,405 provide 20–49 hours of care per week; and 6,443 provide 50 or more hours of care per week. 1,093 of these carers are children and young people under the age of 18 (‘young carers’).

Evidence-based policy and practice

The research conducted for Coventry Community Services Directorate is the second in-depth study of carers assessments conducted in UK Social Services Departments by Professor Becker and his team. This research follows a previous study undertaken by Professor Becker exploring adult carers' assessments as undertaken by Nottinghamshire Social Services Department (Becker *et al*, 2005). This previous study informed the methodology and many of the key areas of inquiry for the current research in Coventry. Some of the key findings from the Nottinghamshire study are presented in Appendix 2.

Coventry Community Services Directorate (and Nottinghamshire before them) have demonstrated a commitment to evidence-based policy and practice. This kind of enquiry indicates strongly that they are learning organisations committed to knowing how they are performing with regards to carers' assessments, and committed to improving the process and outcomes for carers where there is research evidence to suggest that improvements are needed. We hope that the research presented here will help Coventry move forward in its commitment to evidence-based policy and practice for family carers.

Chapter 2

Statistical profile and analysis of Coventry carers' assessment forms

Introduction

In this part of the report we provide the findings from the first phase of the research: the analysis of a sample of Coventry carers' assessment forms.

In total, we analysed 260 assessment forms for the period April 2005-April 2006. This included all of the assessment forms for November 2005 to April 2006, and a sample of forms from April 2005 to October 2005.

The data were then loaded onto a specially designed Access database. A computerised statistical package (SPSS) was used to produce frequency tables and cross tabulation tables for analysis. The findings reported in this chapter derive from these tables.

Client groups

We analysed assessment forms for the four groups of clients. These groups relate to 'service users' or person with care needs, as opposed to a description of the carer. Forty-seven percent of analysed forms related to adult mental health service users; 46% related to older people; 6% to physical disability (under 65) and 1% related to learning disability clients (under 65). An original aim was to have a quarter of our sample in each client group but the pattern of carers assessments during this period in Coventry made this impossible.

Carers' characteristics

Gender: Almost two thirds of the carers who had been assessed were female, one third were male.

Ethnic origin: More than two thirds of the assessed carers were White. The ethnic origin of 12% of carers was Asian or Asian British, and 2% were Black or Black British (**Table 2.1**). For more than 16% of the carers the information on their ethnic origin was not stated or was not clear. Non-white carers were more likely to care for longer hours per week (particularly over 20 hours) compared to white carers.

Table 2.1: Carer's Ethnic Origin

	Frequency	Percent	Valid Percent	Cumulative Percent
Asian or Asian British	31	11.9	11.9	11.9
Black or Black British	6	2.3	2.3	14.2
Chinese or other	3	1.2	1.2	15.4
Mixed	2	.8	.8	16.2
Not clear	27	10.4	10.4	26.5
Not stated	15	5.8	5.8	32.3
White	176	67.7	67.7	100.0
Total	260	100.0	100.0	

A Practitioner's Guide to Carers' Assessments under the Carers and Disabled Children Act 2000 states:

"The need for outcomes to be stated and agreed... means that eligibility criteria and assessments must acknowledge the role of cultural and religious identification in individuals' lives." (para 65).

Age: More than two thirds of the assessed carers were above the age of fifty (**Table 2.2**), with nearly one quarter of the sample being over the age of 70.

Table 2.2: Age in categories

	Frequency	Percent	Valid Percent	Cumulative Percent
Under 18	2	.8	.9	.9
18 - 40	34	13.1	14.7	15.6
41 - 50	42	16.2	18.2	33.8
51 - 60	56	21.5	24.2	58.0
61 - 70	45	17.3	19.5	77.5
Over 70	52	20.0	22.5	100.0
Total	231	88.8	100.0	
Missing	29	11.2		
Total	260	100.0		

Employment status: Nearly one fifth of assessed carers work full-time; a further 6% are in part-time employment; 43% were retired; 8.5% were classified as 'unemployed'. One quarter was classified as 'other'. Of those working, 70% have informed their employer of their caring responsibilities; of those seeking employment or working, nearly 40% are aware of Employment Relations Laws.

Carers in paid employment are more likely to also report that their caring responsibilities are causing problems with their mental health and emotional well-being. This is particularly the case for carers in full-time paid work. Two thirds of

carers in full-time work report such difficulties compared with 50% of the whole sample and 53% of carers in part-time work. Carers in full-time work also report more disturbed sleep than other carers. Seventy eight percent of these full-time working carers report sleep problems, compared with two thirds of other carers and 65% of carers in part-time work.

Relationship of carer to person with care needs and other family members

Person with care needs: More than two thirds of the carers who had been assessed live with the person with care needs ('service user', 'care receiver').

Two fifths of the carers care for their spouse or partner. Another fifth of the carers care for their son or daughter. A quarter of the carers care for their parents or parents-in-law.

Seventy five percent of the assessed carers stated that they were 'sufficiently involved' in the service user assessment. Ten percent claimed that they had not been sufficiently involved, often referring to professionals not informing them of their relative's assessment taking place or not taking into account the carer's views.

Other dependants: Fifty seven percent of the assessed carers care for the 'care receiver' and have no other dependants. However, 43% of the carers also care for other dependants in the family, including elderly parents or parents-in-law, children and brothers or sisters. Twenty one percent of all carers have more than one other dependant whom they are caring for in addition to the care receiver. Nearly one tenth are caring for three or more dependants in addition to the care receiver.

A Practitioner's Guide to Carers' Assessments under the Carers and Disabled Children Act 2000 states:

"...caring responsibilities may conflict with other family responsibilities, such as parenting or holding down a job. Any assessment of the carer's need for support has to look at the impact of the whole caring situation." (para 16).

Caring tasks and length of caring

Caring tasks: With regards to the tasks that carers engage in, the three most frequently cited tasks are: shopping (85% of carers are involved in this), cooking/housework (84%) and escorting to appointments (80%) (**Table 2.3**). Table 2.3 also shows, in rank order, the other tasks that Coventry carers are involved in, based on the categories contained on the assessment form. At the lower end of the Table, it can be seen that 24% of carers are assisting with catheter/pads care and 17% assist with feeding. The Table warrants a careful reading to reveal the number and proportion of carers who are involved in a wide range of caring tasks and responsibilities.

Table 2.3: Caring tasks and responsibilities

	Number carrying out task	Percentage carrying out task
Shopping	222	85
Cooking/housework	219	84
Escorting to appointments	208	80
Preparing meal	205	79
Managing finances	201	77
Washing bedding/clothing	200	77
Monitoring medication	191	74
Management of safety in home	186	72
Awareness of relapse	180	70
Management of house security	179	69
Dressing	171	66
Washing	171	66
Walking outdoors	150	58
Preparing hot drinks	147	57
Getting in/out of bed	146	56
Walking and safety outdoors	132	51
Communicating	101	39
Standing	97	37
Using lavatory	85	33
Walking indoors	75	29
Catheter/pads care	61	24
Climbing stairs	53	20
Feeding	45	17
Occupation	36	14

A further 24% of assessment forms indicated that carers were providing ‘emotional support’ to the person with care needs, which included encouraging and motivating the person with care needs in tasks of daily living. Other carers may also be providing emotional support but this was not identified by the assessor on the form itself (particularly because there is no category for emotional support on the assessment form).

There appears to be no major differences between the caring tasks performed by carers of older people, carers of those with mental health problems, physical disabilities or learning disabilities. However, there is some evidence of small variation in the tasks performed for people in these different groups, including: those caring for older people are more likely than other carers to provide support with standing and walking indoors. Those caring for people with physical disabilities are more likely than other carers to provide support with using the lavatory and catheter/pads care. Those caring for people with learning disabilities are more likely to provide support for walking outdoors and safety issues. These differences may have implications for training carers to deal with these tasks/needs.

Time spent caring each week: Seventy five percent of assessed carers spend more than forty hours caring each week. A further 8% are caring for between 20 to 40 hours a week. A comparison with data on carers generally (Census 2001) suggests that our sample of carers in Coventry spend more time in weekly caring tasks than carers in other parts of the UK.

Duration of caring: Eighty three percent of assessed carers in Coventry had been caring for more than one year. Of these, 14% had been caring for between 1 and 2 years; 12% between 2 and 4 years; 33% between 4 and 10 years; and 24% for more than 10 years.

Nine percent of the carers had been caring for under 6 months at the time when they were assessed. Another 8% had been caring for between 7-12 months at the time of assessment. This means that 17% of all our sample of carers were assessed within one year of the commencement of their caring responsibilities.

Willingness to continue caring: Nearly two thirds of the carers who had been assessed stated that they were willing and able to continue providing the same level of care. However, for a third of carers this willingness and ability was premised on certain conditions. The most recurrent conditions were related to the carer's physical health (11%) and emotional well-being (15%), and access to respite care or regular breaks (9%).

A Practitioner's Guide to Carers' Assessments under the Carers and Disabled Children Act 2000 states:

"It is important that the assessment process does not assume that the carer wants to continue to provide care, or should be expected to. Nor should it be assumed that the cared for person necessarily wants to continue to receive care from the carer. Discussion about the future will often be difficult." (para 20)

Impacts of caring

Health and well-being: In two thirds of cases there is evidence on the assessment form that caring responsibilities had *directly* impacted in a negative way on carers' own health and well-being. One third of all carers said that they were experiencing difficulties in terms of their physical health. More than half of all the carers indicated negative effects on their own mental health or emotional well-being.

Two thirds of assessed carers felt they did not have enough time and space for themselves. Eighty percent of carers stated that they did not have access to regular short breaks. Only half of the carers assessed were able to see friends, usually with the help of respite care and/or the support of family members and friends.

The data show that where the amount of hours spent caring each week varies considerably between weeks, then carers are more likely to experience negative impacts on their mental health and emotional well-being. Three quarters of carers who reported variable caring hours each week (ranging from as little as 1 hour to as much as 40+ hours) reported emotional problems. This compares with 51% of carers who each week consistently are involved in 40+ hours of care. The reason for this might be to do with the lack of an established 'caring routine' (Becker and Silburn, 1999). Where carers are able to establish a regular caring routine, including a standard pattern of caring hours per week, there is evidence that this can help them to manage caring tasks and responsibilities, and can reduce the strains on their own health and well-being (Becker and Silburn., 1999).

Sixty percent of carers have informed their GP of their caring responsibilities.

Disturbed sleep: Seventy percent of all assessed carers suffered from a lack of sleep due to their caring responsibilities. The more hours that the carer cares per week, the more likely they are to report that their sleep is disturbed. For example, 73% of carers caring for 40+ hours per week reported disturbed sleep compared to 62% of carers caring for 20-40 hours and 40% for those caring for less than 20 hours.

Carers reporting the most disturbed sleep are those with variable caring hours per week – in other words, there was no uniform pattern to their caring hours over time. Four fifths of carers who had variable caring hours per week reported sleep problems. This may be associated with the uncertainty of what they could expect each night. The difficulties incurred by variable caring hours can also be seen with regards to the impact on the emotional well-being of carers.

Disturbed sleep occurs amongst co-resident carers *and* carers who do not live with the care receiver. While 74% of co-resident carers report disturbed sleep, 60% of carers living separately from the care receiver also report disturbed sleep, presumably connected with anxiety and worry (although sometimes they may be telephoned and woken up by the care receiver), while co-resident carers' disturbed sleep may be more to do with the physical need to provide care during the night.

Disturbed sleep is also more common amongst carers of people with physical disabilities as opposed to other groups of carers. Ninety four percent of these carers

report sleep problems compared with 73% of carers looking after people with mental health problems and 67% of carers caring for older people.

Safety: Another source of anxiety and ill health for carers concerns the safety of the person with care needs. Two fifths of carers expressed anxieties about the safety of the person with care needs and sometimes about their own safety. The most commonly identified risks or concerns identified were verbal and physical aggression from the care receiver, suicide attempts of the care receiver, self harm and paranoia – all of which can impact on the carers' own safety, health and well-being.

Financial impacts of caring: One third of carers expressed concerns about the financial costs of caring. Half of these indicated that certain needs of the service user had still to be met, for example where they required information or support with applications for Disability Living Allowance. A third of carers required help with applications for Carer's Allowance.

In more than 80% of the cases where the assessor identified financial concerns, he/she gave advice to the carer.

Needs

Identified needs: The Action Plans on the assessment forms identified a range of needs (at the time of the assessment) which required the provision of information, services or interventions. In order of most frequently identified needs, these are:

1. Access to regular short breaks or respite (84% of Action Plans identified this need)
2. Time and space for self (68%)
3. Opportunities to see friends (56%)
4. Financial/benefit advice (40%)
5. Aids/adaptations/support with physical tasks (25%)
6. Emotional support (13%)

A number of other needs were identified from the content of the assessment forms:

- Thirty percent of working age carers said that they would welcome support in finding paid employment or in receiving information about employment possibilities.
- One quarter of carers expressed a need for aids and adaptations/support with physical tasks.
- One fifth of carers indicated that they would value specific information regarding the diagnosis of the person with care needs, their illness, the treatment and medication that had been prescribed. They also indicated that they would welcome information on carers groups or self-help groups that they, as carers, might be able to access locally.
- Thirteen percent of carers said that they would value emotional support (see also discussion above).

Content of the assessment forms

The research team assessed various aspects of the form, especially relating to the *content* of the textual information recorded on the forms by the assessors, carers or both. The team devised a coding scheme that enabled the researchers to go through each assessment form, one by one, to assess the extent to which the content of the form (i.e. what the assessor or carer filled in on the form in answer to the questions) was relevant to each question. To ensure consistency, the team worked through a number of forms together and individually and checked each other's assessments and discussed any discrepancies. At the stage where there were few disagreements or inconsistencies generated by new forms, the team then worked separately to code the remaining forms, with joint discussions of any cases where there were difficulties.

The research team assessed that:

- In 248 assessment forms (95%), *most of the content* provided was relevant to the questions asked (this compares to 58% of forms in an earlier study conducted for Nottinghamshire Social Services Department – see Appendix 2).
- 239 assessment forms (92%) identified carer's needs which might require support or interventions.
- The content of 226 forms (87%) provides sufficient quality to construct an Action Plan (this compares to 63% in Nottinghamshire).
- For 207 cases (80%) another social worker would be able to familiarise him/herself with the case and review the Action Plan on the basis of the information collected on the assessment form.
- In 197 cases (76%), there was evidence that the carer and/or person with care needs was already receiving external support, i.e. from outside their family or friends.
- 167 assessment forms (64%) contain an Action Plan which would meet more than half of the needs identified (this compares to 54% in Nottinghamshire). However, where the carer is of Asian or Asian British origin, then only 55% of the assessment forms contain an Action Plan which would meet most of their needs.
- The vast majority of forms had no *explicit* information or reference to *outcomes* for carers – the main purpose in conducting a carer's assessment.

A Practitioner's Guide to Carers' Assessments under the Carers and Disabled Children Act 2000 states:

"The most important element of the content of the carer's assessment will be the focus on what it is that the carer wants to happen (the outcome)." (para 60)

Observations and conclusions

The data generated from this phase of the research provides a statistical profile of the characteristics and needs of a sample of 260 carers in Coventry, all of whom had been assessed recently (between April 2005 and April 2006). It also provides sufficient data on which to make an assessment of the *quality* of the assessment process itself, in particular, the quality of the *content* of the forms (the information recorded) and its *relationship* (if any) to the Action Plan.

The research shows that:

- Assessed carers in Coventry are providing more care per week than carers generally in the UK. Also, more carers in the Coventry sample live with the person with care needs (i.e. they are co-resident) than is the case nationally. These factors indicate that assessed carers in Coventry are providing care to people with high levels of care needs or ‘dependency’, requiring the carer to be co-resident. This may indicate too that Coventry assessments are being successfully targeted on co-resident carers providing extensive hours of care per week.
- Carers who provide variable hours of care per week show considerable signs of strain (sleeplessness, emotional problems and so on), maybe caused by the uncertainty of what will be required as a carer from week to week and the difficulties in establishing a workable and consistent ‘routine’.
- The quality of the content of assessment forms, and the consistency of the process in Coventry, are relatively high.
- However, on the vast majority of forms there is virtually no information recorded about the person with care needs and no explicit discussion of the quality of relationships between the carer and the person with care needs.
- There is almost no information whatsoever collected about *outcomes*. National guidance on conducting carers’ assessments emphasises the need to focus on outcomes.

Finally, the exercise shows that there is the potential for improvement to the design and layout of the assessment form, and the wording of questions. We make some recommendations about this in Chapter 3.

In order to understand more about the *process* of assessment the next phase of the research involved in-depth telephone interviews with 16 assessors in Coventry. The findings of these interviews are reported in the next chapter.

Chapter 3

Findings from the interviews with assessors

Introduction

Between July and September 2006, a sample of practitioners (n=16) with experience of conducting carers' assessments over the previous twelve month period were interviewed over the telephone. The interview sought their views, perspectives and experiences regarding: preparation for assessments; the assessment form and process; the Action Plan; and implementation and review procedures following an assessment. This chapter provides a summary of the key findings from these interviews.

The sample

Sixteen people were interviewed, of which 11 were female and 5 male. Thirteen interviewees were qualified social workers, with a range of different professional qualifications and post-qualifying experiences. The other three were currently studying for social work qualifications.

The sample was deliberately chosen so as to reflect the range of service user groups and practitioner teams operating across the city. As such, 8 worked predominately with older people (over 65), 4 in adult mental health, 2 with those with learning disabilities and 2 with adults with physical impairments. Seven interviewees worked within Assessment and Care Management (ACM) teams in particular areas of the city, with an additional two based in Walsgrave Hospital ACM team. Three interviewees worked within the Community Mental Health Team. A further four interviewees worked in the Centre for Integrated Living and the Community Learning Disability Teams.

Time spent on carers' assessments

The majority of interviewees found it difficult to specify the amount of time spent on carers' assessments, either in terms of 'number per month' or as a 'proportion of assessor's time'. It was clear that the time taken up by carers' assessments varied between assessors and with caseload. One assessor spent 75% of their week undertaking assessments while another said they did 2 per week. Some respondents described how weeks could go by without any assessment, followed by a stream of referrals of adult carers. One interviewee told us: 'I haven't done [a carer's assessment] in months but next week I could have a string of them.' It also depended on who in the team was allocated the task of undertaking assessments of adult carers. In some teams, this task had recently been assigned to a specialist worker within the team, such as a Carers Breaks Coordinator or Carer Support Worker.

A Practitioner's Guide to Carers' Assessments under the Carers and Disabled Children Act 2000 states:

"Practitioners must always tell carers who are identified during a cared for person's assessment, or at a later stage, that they have the right to request a carer's assessment. They should also provide the carer with a copy of the Government leaflet: *How to get help in looking after someone: a carer's guide to a carer's assessment*... Wherever there is reason to suspect risk to the sustainability of the caring role, it will be good practice to **offer** a carer's assessment, and explain what it can achieve. Research shows that carers often are not aware, or do not remember, that the process they are involved in is an assessment. Practitioners need to be clear, and be prepared to repeat, how the process works and why it is important." (paras 31-33; emphasis in original)

Training in completing carer's assessments

Most assessors received training on how to conduct assessments with adult carers about nine to twelve months previously. However six interviewees claimed they had not benefited from any training specifically relating to the carer's assessment process: 'I was given the form ... and you just make it up as you go along'. Four of these six presented this lack of training as unproblematic. Three had received 'general training on carers' issues', and a further two were supported by line managers with experience of the assessment process. Others hoped to complete the training at a later opportunity.

The feedback from those who had attended the two-day training course was positive. Participants described the content as including:

- recent legislation regarding definitions of carers and their rights;
- the purpose of the assessment;
- the importance of the involvement of carers;
- the form and how to fill it in;
- reflecting on current practice; and
- services and support mechanisms available to carers.

One assessor appreciated the training because it taught her how to do the 'nuts and bolts' of the carer's assessment rather than the 'theory' of it. For many, the strength and value of the training resided in the active involvement of carers and the Carers' Centre in the delivery of the training. This involvement was portrayed as ensuring that the importance of 'listening to carers' became a key learning point. Furthermore, it was acclaimed for enhancing participants' knowledge and understanding of the support and services available in the area, for different target groups, for different identified needs, how to establish contact with these services, make referrals, etc. A heightened awareness of the range of services and help that the Carers' Centre could also offer was emphasised several times by assessors.

Preparation in advance of conducting assessments

A Practitioner's Guide to Carers' Assessments under the Carers and Disabled Children Act 2000 states:

"Often the person doing the carers' assessment will be the same care manager or assessor who assesses the cared for person." (para 47)

Eleven of the assessors accessed, gathered and processed relevant information about the carer before contacting and undertaking the assessment. The sources of information that they used varied between assessors. The most prevalent source was the case file of the person with care needs, which is used to collect relevant information on the history, current situation and the level of support that the cared for person and carer receive at the time of the assessment. Frequently the assessor would also be the case worker for the care receiver and therefore have knowledge of the file. However, this was not always sufficient. Often such files may contain only limited information on the carer. One interviewee described having restricted access to case files, with assessors working city-wide but case files stored in specific locations. In such cases information was gathered through the following two means:

- the referral form and/or the person who made the referral (why was the referral made and what kind of support was required?)
- information gathered in the past through working with the carer or cared for person. A range of other service providers and professionals working with either the carer or care receiver were listed as potential sources of information, including the Carers Breaks Co-ordinators, GPs, and District Nurses.

The appropriateness of providing the carer with a copy of the assessment tool *in advance* of the assessment, as standard practice, was disputed. In fact, some (N=3) claimed that this could cause apprehension or anxiety on the part of the carer – ‘oh no, more forms’. Instead, it was common practice to phone the carer, to confirm how and why the request for an assessment had been made and how the process works, and to respond to requests for further information or clarification that may be required on the part of the carer. ‘I talk to the carer to let them know that a carer’s assessment has been requested and to ask them if they are happy for me to do that’. This phone call also served to make arrangements for the assessment to take place, a time and place, and to explore whether the carer preferred the service user to be present or not.

Finally, in anticipation of the assessment, most assessors also prepared their folder with information on the different services available to carers in Coventry. Leaflets explaining the content of the service or project, who is eligible, how referrals can be made and by whom, and contact details are generally brought along to the assessment and are given to the carer, if appropriate. Examples of leaflets referred to are: Carers’ Centre, Crossroads, the service the assessor is working for, benefits line, Direct Payments, and Managing At Home. Commonly, assessors presented this as an ‘informal approach rather than a scientific’, formal, assessment process.

The Assessment Process

Interviewees answered a series of questions addressing the various stages of the assessment process.

Explaining the assessment: In general, interviewees said that the assessment process and its purpose were explained to carers when the referral was made (e.g. by the Carers Breaks Co-ordinator, Carers Support Worker or Social Worker). This was reiterated when the assessor contacted the carer by telephone to make an appointment and/or at the beginning of the actual assessment. Two interviewees stressed the importance of the person making the referral, for example the Carers Breaks Co-ordinator, Carers Support Worker or Social Worker or the GP, giving a brief description of the assessment process and making sure that the person is okay with the assessor contacting them, 'so they don't go into a strange contact'.

The majority of the assessors referred to a carer's right to an assessment, as laid out in legislation. They would explain that this assessment constitutes a requirement for access to (additional) services, determining whether carers are in need of the support on offer and are eligible. As such, the assessment was portrayed as a 'gateway to entitlement and rights', or as 'leading to other openings'. Some highlighted that the information gathered through the assessment process might secure help in the future when, for example, the carer became ill or was taken to hospital and the care package for the service user has to be adapted. One interviewee mentioned that social services were required by law to conduct assessments of adult carers, referring to performance indicators.

While the focus of social services often gravitated towards the needs and interests of the person with care needs, this assessment was portrayed as 'for carers'. 'It is an assessment for them. They have their own copy and are involved in devising their own carer's plan.' One interviewee commented that the service user sometimes has to be reassured about this at an early phase of the assessment process. S/he might react by saying 'why are you talking about me', at which point the assessor then explains that 'they are getting their help from the social worker and it is my time with the carer. [...] And sometimes the carer feels overwhelmed [by the assessment], because they've never had any opportunity to talk about their situation.'

Many assessors presented the exercise as an opportunity for the carer 'to tell their story' or 'their side of the story', to be, and feel, listened to. It was considered as validating the carer's experience and identity (see also later in this chapter.)

Assessors stated that it usually required one to two visits to complete a carer's assessment. In the majority of cases one visit was enough to collect all the necessary information. The time taken to complete an assessment was seen to vary between carers: 'sometimes I'll be in there three hours, sometimes 45 minutes. It all depends how much they want to say.' One interviewee presented the main benefit of the process as giving the carer 'time and space to reflect on [his or her] self' at their 'own pace'. Therefore the process had to take as long as the carer required.

A Practitioner's Guide to Carers Assessments' under the Carers and Disabled Children Act 2000 states:

"It will be for practitioners, in conversation with carers, to work out how complex an assessment is required. Some assessments may be simple, almost single-issue processes. Some will involve a hugely complex range of ties and obligations and practical and emotional issues." (para 23)

Information gathered is then usually 'tidied up' or collated 'back at the office', with the information contemplated and appropriate services further considered. A completed form is then returned to the carer, either by post or in person. A second visit was seen to have particular benefits in allowing the addition of further information from the carer, discussion so as to formally agree the plan, and the provision of further information that the assessor may not have had available at the time of the first assessment; for example, phone numbers or leaflets.

Three assessors commented that the number of visits required, and the quality of the information gathered, depended on the relationship of trust that was already present or had to develop between the carer and the assessor. One respondent commented that:

'...you need to build a relationship with the carer and they have got to be able to trust you. They've got to see that you are there to help, because they might have had other experiences where someone does an assessment and goes and they don't ever see them again.'

One respondent argued that when conducting and introducing an assessment with an adult carer, it has to be borne in mind that some carers have been 'assessed to death'. Another interviewee made a similar point: 'You need to prove you are there to help the carer. You need to go back regularly and go back to check whether the carer has been able to access the recommended service and is having a positive experience of it.'

A Practitioner's Guide to Carers' Assessments under the Carers and Disabled Children Act 2000 states:

"A Carer's assessment should be focused on what the carer identifies as the best possible outcome. The best possible outcome will depend on the impact of caring on the particular carer. This impact is also the best test for 'regular and substantial' caring. It is very important to make a clear distinction between 'outcomes' and services...The best service to provide the outcome will depend on the individual circumstances." (paras 22-24).

Involvement of carer and the cared for person in the assessment process

When arranging a suitable day and time to conduct the assessment with the carer, the assessor generally asked whether the carer preferred for the person with care needs to be present or not. In most cases, the carer chose to do the assessment when the cared for person was absent to avoid distraction, interruption or sensitive situations. The assessors also emphasised that this assessment 'was their time to be heard'; concerns and issues for the service user are expected to be picked up by the social worker.

‘Because for years people have carried so many emotions, but they haven’t had to talk about them. And often the carer cannot speak out when the service user is present about issues of a delicate nature.’

As such, the service user had no or limited involvement in the carer’s assessment, but was often consulted when decisions were made regarding the design and, especially, the implementation of the carer’s plan. One exception though: an interviewee said that the service user was normally present, allowing for a joint assessment of both the carer and the service user. ‘Normally they’re present. Actually I’ve never had one where they asked the service user not to be present.’

The setting for the interview is also determined by the carer so that they feel ‘as comfortable as possible’. The assessor asks whether they would prefer the interview to take place in their own home or at the office of the assessor.

The form was generally filled in by the assessor, either at the carer’s home or afterwards at the assessor’s office on the basis of notes made (there was only one exception to this where the assessor themselves regularly asked the carer to fill out the form, unless they were too old). To ensure that the information collected was correct and adequate, the carer was normally sent a copy of the filled out assessment form and carer’s plan for revision and signing.

A Practitioner’s Guide to Carers’ Assessments under the Carers and Disabled Children Act 2000 states:

“The carer must always receive a copy of their assessment including a statement of the carer’s needs and any differences of views between carer and assessor, in writing or in other appropriate accessible format.” (para 54).

Guidance that underpins the assessment

When asked about the guidance that informed the assessment of adult carers, most respondents referred to a diverse range of leaflets about local services that they took to the assessment and that could also be given to the carer. These leaflets comprise concise descriptions of the support on offer, who is eligible for them, how they can be accessed and contact details. In addition, some assessors referred to leaflets about services that were targeted at particular user groups. For example, with regards to those caring for adults with mental health problems, leaflets that informed the carer about mental health diagnosis were distributed.

Some respondents referred to the Carers (Equal Opportunities) Act 2004 and other laws and policy documents. ‘Carers and Their Rights: The Law Relating to Carers’ (Clements, 2005) was also a valued source of information, as was information obtained from the Department of Health website (www.doh.gov.uk). However, assessors had *not* been directed towards such guidance by Coventry Community Services Directorate and many thought such direction would be helpful. As noted above, those who hadn’t received any training at the end of 2005 or the beginning of 2006 pointed out the need for training on how to conduct assessments and a need for information about the guidelines that are to be followed. Chapter 1 of this report outlines some of the key guidance that underpins carers’ assessments.

The Carer's Assessment Form

A Practitioner's Guide to Carers' Assessments under the Carers and Disabled Children Act 2000 states:

"A carers' assessment under the Carers and Disabled Children Act 2000 is carried out at the request of the carer in order:

- * to determine whether the carer is eligible for support
- * to determine the support needs of the carer (ie what will help the carer in their caring role and help them to maintain their own health and well-being)
- * to see if those needs can be met by social or other services." (para 19)

Interviewees were asked to consider the carers' assessment form (Appendix 1) and to highlight aspects that they felt to be effective or problematic.

What works?

Views on the quality of the assessment form varied amongst assessors. The vast majority of respondents were generally positive about the form. Several interviewees (N=4) gave only positive feedback on the form, making no or very limited suggestions of how to improve it.

Comments included:

'[The form is] good, comprehensive, and gathers the data required for understanding the carer's situation.'

'I think it is OK, I would only rephrase some of the questions.'

'I think it is OK compared to other forms. There is no perfect form ever, is there?'

'I like it. It guides but it gives the carer an open forum to discuss [...]. I like that it is not so prescriptive.'

Specific elements or aspects of the assessment form that were perceived as working well included the following:

- The length of the form was considered appropriate. It was presented as not too short so that 'you are whisking over issues' and not too long so that the exercise becomes 'laborious'. (N=3)
- The breadth of issues covered was also seen to be appropriate (N=8). In particular the section regarding employment was seen to highlight regulations, new laws and entitlements to respite (N=2). Similarly, questions regarding financial concerns lead into discussions of benefit issues and the help that the benefits advice line could provide. 'It's a sum of money that they are entitled to [Carer's Allowance], but they haven't claimed [...] because they don't know about it.' (N=3) In general, this breadth of issues was seen to enable and support good practice amongst assessors by ensuring all relevant topics were covered.

- The section exploring the tasks of the carer was also praised by three assessors for providing an insight into the abilities of the cared for person and the role taken up by the carer. ‘It helps carers to recognise what they do; otherwise they are on automatic pilot.’
- Questions regarding which services provided the most positive and negative experience in relation to the caring role were presented by one assessor as positive, because it gave the opportunity to the carer ‘to talk about services openly’. Another assessor said: ‘And if it [the carer’s experience of the service] hadn’t been positive, I would give them our ‘Three C’s’-form [complaints forms], because some people have justified concerns. [...] But usually they have been quite positive.’

Most interviewees liked, and often emphasised the importance of, the open questions in the form. The significance of these were explained as giving the carer the opportunity to identify additional needs, to expand on those already identified, and to shed light on the complexity of the case. One interviewee continued that when confronted with this kind of complexity it stimulated her to reflect on service provision and current practice:

‘In a perfect world our services would reflect the carer’s needs, but [...] some cases are quite complex [...] It might be something that we would not be able to provide but that’s what they want [...] so I think outside of the box and see if something could be done in that area.’

Open questions were also presented as enabling conversation to be guided by the carer and therefore to ‘flow’ rather than be structured by set questions with multiple choice answers. Most interviewees thought the mixture of ‘tick boxes’ and open questions to be fine, claiming that the open questions allowed carers to come back or elaborate on (often sensitive) issues they touched upon in previous sections or indicate other factors affecting their caring experiences and their capacity to continue caring. ‘You can investigate more.’ However, some respondents argued that ‘tick boxes do not give a good picture of the nature of caring’ and that the ‘Add comments’ sections did not provide sufficient space and/or did not allow the assessor to capture the extensive and complex nature of caring responsibilities under investigation.

Completion of the Carer’s Action Plan

Wood and Watson’s *Guide to Good Practice* states:

“The care [action] plan is not the record of the assessment but rather it is a statement of what help the person will actually be getting – the ‘package of care’. This needs to be set out clearly because people cannot challenge failure to provide services as specified unless they have a specification. The care plan should also highlight how the carer’s role fits in with other services, and is a clear way of recognising the carer’s input.” (Wood and Watson, 2000, p. 46)

A Practitioner's Guide to Carers' Assessments Under the Carers and Disabled Children Act 2000 states:

"These documents [the service user's care plan and the carer's plan] should include a clear statement of outcomes intended for each person, which will form an important source of reference when implementing and reviewing the care plan/carer's plan."
(para 57)

As noted above, the assessment form is normally filled out by the assessor. This equally applies to the completion of the carer's Action Plan. Many assessors devise the carer's plan together with the carer, but 'write it up' at the office and then send a copy to the carer for signing and revision. These assessors saw a need for further reflection after the assessment in order to ensure appropriate services are accessed and to allow for cross-referencing of the information provided on the assessment with that relating to the service user. Others complete the plan at the initial visit seeking immediate agreement of the suggested action, so as to ensure services can be accessed without delay. This was also the stage at which the assessors gave the carer useful contact and emergency numbers, noting these down on the carer's plan or giving out leaflets.

What works about the carer's plan?

All respondents thought the carer's Action Plan to be an essential part of the assessment form and process, indicating the actions to be taken, the kinds of services the carer (and service user) were to access and what objectives were to be attained by doing so. Many assessors also used this section to give a brief summary of the current situation of the carer. Indicating who was responsible for which actions was emphasised by two assessors. As such, for the carer it provided them with a written copy of the carer's plan discussed with the assessor and communicated what actions were to be undertaken next and by whom.

As well as a record of the course of action to be taken, the plan was also seen to provide the carer with a record of the conversation, solidifying the discussion and recognition of the carer's needs that had been identified. As such the plan is used to illustrate the needs that were identified and the range of services that were discussed, rather than 'just what the carer has agreed to' with regard to services to be accessed.

In both cases the 'open section' or 'free box' format was seen to work well. It allows the assessor to write 'whatever is appropriate' rather than being restricted by a predetermined structure to the plan. One interviewee commented that: 'You never get so much information from tick boxes as you do from a paragraph.'

Few of the assessors interviewed indicated any problems with this section of the form. The only common request was that the box should be bigger. One interviewee in particular argued that the current format does not provide adequate space for the necessary 'holistic representation' of the needs of the carer.

Suggestions for the improvement of the form

Despite the majority remaining largely positive about the current form, several interviewees commented that the form was ‘not user-friendly’. Some questions were thought to be ‘repetitive and therefore time-consuming’, ‘not well formulated’ or even ‘inconsiderate’. For example, the fact that the form asks twice for the carer’s details and for the length of caring was picked up by many respondents. Specific questions and topics of which there was some criticism included the following:

Service Provision: The range of questions relating to ‘service provision’ (Section 2G – see Appendix 1) drew the most comments. Rather than asking what services were experienced by the carer as the most positive and negative, some suggested that this could be improved by asking the carer to identify the range of services accessed in the past and present and how s/he experienced these. One interviewee commented:

‘I have to elaborate on that question, because it is not clear what the question is. [...] Sometimes with the least positive experience, they are reluctant to be too honest, fearing the repercussions. But then I say that this is the only way that we can improve our services without making them a target as such.’

In contrast another interviewee questioned whether this information was most suitably collected through this form as any response is only helpful or comprehensible if cross-referenced with further information from other sources regarding service use: ‘otherwise it’s most positive or negative out of what?’

The subsequent ‘open choice’ question, asking carers to identify ‘any additional services that might be useful’ was also seen as problematic. In its current form it was seen by some to ‘build hopes that can’t be met’; raising expectations about the possible outcomes of the assessment that the assessor cannot meet. This was described by respondents as ‘very unfair’ and even ‘ludicrous’. It was suggested that this question should be reworded so as to reveal its intention, which was assumed to be the identification of need for future service development, rather than meeting the needs of the carer being assessed.

The final question in this section, concerning ‘help to learn about matters related to your caring role’, was also criticised. Some assessors reported a reluctance to raise the issue in case they appeared patronising. One interviewee commented that this question tended to be answered ‘no’ and that ‘carers do know what they do ... They want help, good services; not to learn.’

Crisis: Similarly one respondent felt it was ‘patronising’ to ask whether the carer knows ‘what to do in a crisis’, particularly when the answer sought appears to be ‘yes or no’, rather than structured so as to provide useful information of which they might not be aware. This question was seen as an example of the potential for the form to provide more useful information for the carer. This assessor (along with three others) felt that additional telephone numbers and information on services could be provided.

Carer’s Safety: The question ‘have you ever felt at any physical or emotional risk from the person cared for?’ was also presented as difficult to pose, when the service user is present or involved in the assessment. ‘It is an important question for my own

purpose in the future, because it makes us aware of what triggers them [cared for person]. [...] It is a relevant question, but it is a delicate one.’ It has to be appropriately framed and phrased. Notions of risk, particularly emotional risk, are not straightforward.

Time spent caring: Several interviewees voiced concerns with how information regarding the amount of time spent caring was being collected. One respondent believed that the phrasing of the question lacked clarity as to what should be included as ‘time spent caring’, meaning information might be collected differently by different assessors. This vagueness was seen to be exacerbated by the ordering of the questions such that an in-depth discussion of what constitutes caring responsibilities comes later in the assessment.

Three respondents saw the question as unnecessary because the answer ‘24/7’ was assumed or known due to previous work experience with the carer. ‘The carer looks at you ... “we look after them all the time.” Normally what we say is that it is 24/7 if the carer lives with them.’ However, it is known from national census data that not all carers who live with the person with care needs are providing 24/7 care. Many provide less substantial or regular care, anything from 1-20 hours of care per week.

Number of people cared for: Similar misinterpretation was seen as possible in relation to the number of people cared for. Interviewees reported being unsure whether to include in this count the number of children (and grandchildren) that the person (regularly) cares for (as requested in a later question). This information was presented as shedding additional light on the caring tasks and responsibilities. ‘It is all part and parcel of the caring role.’

Costs of caring: A further question presented as open to misinterpretation or varied application was that regarding the ‘costs of caring’ (Section 2E – see Appendix 1). One respondent queried whether it was clear that indirect costs, such as travel expenses, were relevant. As the question was not phrased so as to be self-explanatory as to what might be included as the ‘financial costs’ of caring the question may not capture all of the information needed.

Ethnic origin: The fact that no categories were provided to answer the question about ethnic origin was also picked up by two interviewees as potentially problematic. Once again the question may be asked and interpreted in different ways. This is reflected in the data presented in the previous chapter.

Carer’s involvement with living tasks of the service user: Several interviewees identified tasks relating to the caring role that are not currently included in the list included on the form. In particular the category of ‘emotional support’ was seen to be missing with the potential for such support to therefore go unrecognised throughout the assessment. One interviewee was particularly adamant that such support should be explicitly discussed early in the assessment so as to allow the carer to acknowledge the particular difficulties such a caring role can bring, and therefore recognise their own emotional needs:

‘If you can recognise that as a carer, and you get some time out, you may be able to see the warning signs in the future and avoid burnout.’

The current list of tasks was also felt to be inappropriate for some service user groups. For example, in relation to the user group of 'physical disabilities', a respondent highlighted the fact that in the section on the 'tasks taken up by the carer' this did not provide the option to select 'supervision of cared for person' nor 'encouragement/motivation to sustain or improve physical mobility, self-care, etc.' that the carer engaged in. While some were resigned to this inadequacy, recognising 'the generic nature of the form and assessment exercise', others suggested that additional questions or sections could be added to the current form.

Describing these problems as 'typical' for social services forms, many assessors used the form as a structure when conducting the assessment, reformulating questions, avoiding repetitive questions and the discussion of sensitive information that the assessor had already gathered and discussed in previous contacts with the carer.

However, in those cases when an interpreter is required to conduct the assessment with an adult carer, this more flexible or creative approach could not be adopted. The questions on the form were often directly/meticulously translated, making the assessment a more cumbersome process for both carer and assessor. Here, a general revision of the assessment form and advance preparation for the assessment process on the part of the assessor might be needed.

Suggestions for the improvement of the process

Three respondents did not have any suggestions for how to improve the assessment process, claiming it to be 'good' or 'okay' as it was currently being conducted. However, most interviewees offered potential changes so as to improve the process.

Form design: Some thought the form to be 'a bit unwieldy'. Most assessors agreed that the conversation is guided by the carer and therefore does not always follow the order presented in the form. As a six-page document in triplicate 'turning pages back and forth' whilst trying to 'focus on the person and conversation' can be difficult, leading to questions or pages potentially being missed out.

Interpretation: The issue of interpretation was a recurring issue for those who had done assessments with carers speaking limited English. A respondent suggested that, when interpretation was required, the assessment might have to be conducted differently, by for example, avoiding repetition in the questionnaire, reducing the number of questions and the reporting requirements to a one-page summary and Action Plan, although such suggestions are themselves clearly problematic.

Team structures: Respondents from some staff teams highlighted elements of team structure that they found to be beneficial to the process. The practice of employing a Carers Breaks Coordinator was presented by one respondent as having significantly improved the assessment process, because this person had taken on the role of establishing (longer term) relationships with carers, giving them information of the support and services that are available to them and facilitating their access to that support. The Carers Breaks Coordinator was portrayed as a 'huge benefit for carers and parents', because they 'have someone there that can start networking, who is a real point of contact' who they can turn to.

In another team, the post of Carers Support Worker has had a positive impact on the assessment of, and service provision for, carers. Since the creation of the post, the Carers Support Worker had undertaken all assessments with carers referred to the service. This post also had the beneficial effect of decreasing paperwork, because the Carers Support Worker would normally discuss the case directly with duty social workers and management. This replaced the previous arrangement of presenting the case before a panel, which discussed the assessment and the implementation of the Action Plan.

Knowledge and experience: Assessors said that experience in conducting assessments, extensive knowledge of the services and support that are accessible by carers, and a relationship of trust with carers, were the key ingredients to conducting a good assessment. One interviewee commented that this relationship of trust between the assessor and the carer allowed you to have a better idea of ‘where they are coming from [...] and to make suggestions for support’.

How assessors define effectiveness in assessments

As noted above most respondents had recently received training on how to conduct assessments. Furthermore, most had considerable experience of conducting carers’ assessments and often thought the process to be quite straightforward, while potentially emotionally demanding for the carer being assessed. This might explain why all those assessors willing to assess their own skills thought of themselves as ‘effective’ in conducting assessment of carers. Those who were cautious in assessing their own skills were, however, usually able to report positive feedback from carers who were said to have valued the process for providing ‘recognition’ of and ‘respect’ for their role. However a number of factors were identified as contributing to this effectiveness.

The interviews with the assessors appeared to convey the message that the level of ‘effectiveness’ of the assessments depended primarily on the identification of the carer, the assessment being carried out and, most importantly, on the availability of services that could be matched with the needs identified in the assessment. With regard to the latter, experience was once again a key factor: ‘There is a lot of information [on support mechanisms for carers] that I have picked up over the years.’

Effectiveness is therefore perceived to be dependent on ‘keeping up to date’ with new or changing services and legislation. This is seen to require time within the working week to ‘read, explore and discuss’ carers’ issues. As one of a large number of areas of practice in which most interviewees were engaged, this was seen to be difficult and reliant on colleagues to share information. Two interviewees mentioned that weekly team meetings allowed for the exchange of information about any additional support and changes in services provision.

Pushing the assessment of adult carers higher on the agenda of social services in general was portrayed by some (N=6) as essential for statutory services to become more effective in assessing the needs of adult carers. They suggested that social services’ priorities still seemed to lie primarily with the service user. While interviewees did not question the importance of that, they claimed that the

involvement of carers should not be ‘pushed aside due to other work pressures’. Concern was expressed by the inadequate knowledge of how many carers there were in the local authority – carers who had not been identified as carers and had not been informed of their entitlements. ‘Why have carers missed out?’ An interviewee said: ‘Carers need to be recognised, informed about their entitlements and supported appropriately’. Providing carers with information about what kinds of support mechanisms are available to them, such as the carer’s allowance, the Carers’ Centre and the support groups it organises, was deemed ‘vital ... even if they do not want a service right now’. Young carers were also presented as often ignored (N=3). ‘We have vital information to share with young carers’.

Others seemed to convey a similar message, wondering whether ‘people actually take the time to read this assessment once it’s done’ and, more generally, ‘what is achieved with this assessment? What are we supposed to achieve?’ An interviewee said: ‘I think I get out of it what I want to get out of it – i.e. to understand their situation -, but apart from the actual law ... I don’t really know why we are doing it.’ While interviewees recognised the importance of conducting assessments with adult carers, in terms of rights and entitlements of carers, of gaining a better understanding of the situation of the carer and examining their eligibility for the services on offer, they wondered what happened with the copy of the assessment they sent to the Commissioning Unit: ‘What does Commissioning do with the information that is gathered in the forms? Are the forms read? If yes, what data are gathered on the basis of these forms? And what actions are undertaken as a result of this analysis?’

Changes in the approach to conducting assessments

In general, respondents said that they had gained more experience in the assessment of adult carers. They had, as one respondent described it, become more ‘homed in’.

Respondents also felt that over time they had picked up information on a wide range of services that carers could access (beyond the ones that statutory agencies offered) and, consequently, had a more diverse or broader variety of support from which to choose when responding to the needs of the carer being assessed:

‘The more knowledge you have, the more experience you have – you’ve been networking longer, so you’ve found out various organisations that aren’t mainstream. So depending on what their needs are, you can say “Oh, I know something around the corner.”’

One assessor stressed the importance of these skills and knowledge when confronted with a carer stating s/he could no longer provide (the same level of) care:

‘I sometimes call back, when the service user is not there and discuss issues further. If they say they don’t want to care anymore, we should explore what tasks we can take over [...] and inform the carer of schemes and programmes that they can get involved in [...] so that they can have an independent life and can feel better. They should not feel powerless.’

With experience, ‘the logistics’ of the assessment had been refined; the assessors had become more skilful in guiding the carer through the assessment form and its sets of

questions, ensuring a smoother interview process and a more time effective process. The method of storytelling was put forward by one respondent as ‘a good way to avoid flicking through the pages of the form, to really listen to the carer’s story, to get the necessary data and draw conclusions for future service provision’.

The value that assessors place on the assessment process

Most interviewees perceived the assessment process as validating the carer’s experience, placing value on the important role played by carers and recognising the amount of support they provide. More experienced social workers saw this recognition as a vast improvement on previous service provision:

‘Before I started working, people didn’t see it as a priority to involve carers. Even now I meet people who have been involved for years with the patient [person with care needs] but who haven’t been part of any service assessment or involvement. [...] It is put aside because of other work demands. [...] How come they have missed out? [...] All the carers should receive support.’

The assessment was seen by many assessors as a means to identify the support that individual carer’s need and are rightfully entitled to. An interviewee commented that the information that can be passed on to carers through the assessment and the identification of their needs is vital, because it enhances their knowledge of what support is out there. ‘They often do not know that they are entitled to, for example, Carer’s Allowance [...] Sometimes the social worker overlooks all that, they emphasise more the needs of the service user.’

The process therefore aims to support carers to continue in their role by addressing particular needs. Indeed the assessment was often a requirement before services could be applied for. One respondent said: ‘I am the carer’s social worker. It is my responsibility to support the carer, to make their life easier. It is because of the carer that the client or service user is still there!’

As such, the assessment was seen to have equal importance as the service user assessment, with the carer being seen as a case in their own right. However interviewees felt carers were not yet prioritised as such, with carers often going without an assessment for significant periods:

‘[Often] we hear about [a carer] when the [Coventry] Carers’ Centre contacts us to say “Oh, such and such a carer has been in and they were distressed. So they want a carer’s assessment.” And then we look at the system and find the cases have been open for a long time.’

In addition to providing support for individual carers, the assessment process was also seen as a means to understand the range of needs of carers in Coventry as a whole, and subsequently to develop appropriate services. Some referred to the third copy of the assessment form that they were expected to send to Commissioning for monitoring. As already discussed, many assessors mentioned that it remained unclear to them what happened with this third copy. The opinion that this third copy, and the analysis or monitoring that was (supposed to be) carried out on the basis of it, would be leading to service changes or improvement was rare. Asking interviewees whether

the assessment process constituted an opportunity to influence commissioning, most replied with ‘no’ or ‘it is doubtful’. One interviewee exclaimed: ‘Don’t be daft!’ However, another respondent hoped that data were being gathered on the needs of carers in the local authority, on what could improve their situation (e.g. the question ‘what would help you with your caring role?’), and would inspire small and larger changes in service provision.

Needs-based or resource-led?

Among the interviewees there was much debate as to whether the development of the carer’s Action Plan was needs-based or resource-led. Indeed many respondents found it difficult to label their approach as one or the other.

Several assessors emphasised that at the centre of the process of setting up a carer’s plan were the needs of the carer. These needs informed which services were discussed during the assessment, resulting in referrals to statutory agencies and, if these could not respond to the needs identified, exploration of alternative providers.

Some argued that their approach was increasingly needs-based as the range of resources and services available now meant that the majority of needs could be addressed. Indeed the identification of need was seen to be fuelling this development of new services or approaches (as discussed above). Several assessors stressed the value of increasingly flexible service provision in allowing them to exercise ‘creativity’ in meeting need. The most prevalent example of this was the establishment of eligibility for one-off payments and/or flexible short breaks support and the array of ways in which such provision can be utilised. For example, if washing was proving to be a time-consuming and physically draining task, the option of purchasing a washing machine was explored. ‘Sometimes it might be a mobile phone, so the carer can go out with a piece of mind [...] that they could be contacted.’

Whilst such approaches clearly draw upon knowledge of the resources available they were presented as primarily needs-based. Furthermore, assessors noted that the plan would be used to record needs regardless of the availability of the resources to address it. Thus the carer’s plan was seen as a record of need rather than a statement of action (as noted above).

Alternatively some assessors reported basing the development of the plan on actions rather than needs, and therefore on the resources that the assessor could draw on rather than the issues raised by the assessment. These assessors portrayed themselves as ‘realistic: I know what I can offer. [...] I will try to sign-post the carer to other agencies which *might* be able to offer something different or more.’ The Carers’ Centre was described as ‘excellent’ in that respect, often referring carers on to voluntary organisations offering a range of complementary or alternative forms of support. One interviewee portrayed the centre as ‘thinking outside the box’.

Such an approach was said to start from the assessor’s understanding of the range of services that are available and try to work out how best these can be utilised. As such the experience of the assessor was seen as a key factor:

‘Of course, there are financial restraints on Health Services and Social Services, but it is all about networking and accessing voluntary organisations. And knowing what’s local to that person’s area. [...] For example, a small day centre that only people know about by working in the area.’

Towards actions and outcomes

Despite engaging with the above debate regarding needs and resources, no respondents presented a primary or explicit focus on outcomes. Given the law and practice guidance on carers’ assessments there needs to be a means of prompting assessors to consider what outcomes carers want to achieve rather than following the traditional approach which focuses on assessing needs within pre-defined service availability. The availability of a growing range of increasingly flexible service provision suggests such a shift is possible.

It must also be noted that no respondents specifically identified a carer’s identity, in terms of gender, ethnicity, language or beliefs, as a significant factor determining the Action Plan. Whilst consideration to diversity might be implicit in the assessment process, it was not voiced explicitly by interviewees.

Implementation and Review

A Practitioner’s Guide to Carers’ Assessments under the Carers and Disabled Children Act 2000 states:

“Needs change and so review of any assessment may be required. It should be agreed with the carer when any review of the assessment is likely to take place.”
(para 45)

Interviewees said that it was their responsibility for the implementation of the carer’s plan, although one interviewee stated that before the plan could be implemented, a panel had to approve it.

Usually implementation was presented as providing information and referring the carer to the appropriate agreed services, at which point responsibility was commonly seen to shift to the service provider. In line with the list of actions outlined in the carer’s plan, the assessor had to make sure that information, such as how to contact the benefits advice line, was shared with the carer. If relevant, s/he would make a referral for the carer (and service user) to a particular agency or service and might sometimes facilitate the first contact with the service (hand-holding). ‘We take them for induction, show them around the unit.’ One interviewee described that in addition to the one or two visits undertaken to do the initial assessment, a third visit was arranged if it was decided in the carer’s plan that services were to be provided. The assessor would then arrange and facilitate a meeting with the carer, the service user and a representative of the service provider to give information about the service, how it could be set up and examine whether the carer and cared for person are willing to try this:

‘At this stage, I will ask the carer to inform the service user that this is what we agreed and if they are willing to accept the service, for example

befriending or whatever it might be. Then we follow up with the service that is going to provide the service.'

The agencies to which the referral was made were expected to take over the responsibility for ensuring that this service was delivered. While signposting to other agencies often entailed no formal follow-up on whether the carer was getting the services indicated in the carer's plan, a good working relationship with most service providers allowed for informal and ongoing dialogue in relation to particular cases. The service providers to whom carers were referred will inform the assessor of any eligibility assessment, and subsequently monitor uptake and ongoing use.

Some interviewees also pointed towards support workers as shouldering this responsibility, having to ensure that services were being accessed to the satisfaction of both service user – where their immediate responsibility lies – and the carer. 'The social worker is in contact with the service user anyway, so any issues that come up through that channel, we tackle.' In the teams where a Short-Break or Carers Support Worker was in post, this responsibility seemed to be shifted towards them.

Procedures for reviewing a carer's plan were variable. For many assessors (particularly those operating within ACM teams) there was no formal review process, and in a number of cases follow up was said to have been impossible given shifting caseloads.

Several interviewees said that in general a review would be undertaken 3, 6 or 12 months after the assessment. Walsgrave Hospital ACM Team appear to have a procedure in place: reviewing a case after 6 weeks before passing it on to an area team where there was a yearly review. This review examined whether the carer's plan was being implemented, the services delivered proved to be an adequate response to the needs and concerns identified in the assessment, and whether those needs had changed. The importance of keeping the case open – for as long as the implementation of the carer's plan required further action – was emphasised by some. It should be noted here that one interviewee felt the assessment form 'is not really appropriate' for use when conducting the review, and argued that an alternative approach might be developed, using perhaps a specific review form.

For other assessors the procedure was more informal. In many cases the assessor also had responsibility for the service user. As such they would 'oversee the whole case', providing continual support for service user and their family. In such instances there was often no specific review of the carer's assessment, but 'an ad hoc' and ongoing consideration of the changing needs of the carer alongside those of the service user.

In order to understand more about the *process* and *outcomes* of an assessment the next phase of the research involved in-depth interviews with 11 carers in Coventry. The findings of these interviews are reported in the next chapter.

Chapter 4

Findings from the interviews with carers

Introduction

The third and final phase of the research involved interviews with a sample of carers drawn from the 260 assessment forms. These interviews were carried out either face-to-face or, where the carer preferred it, via the telephone. Face-to-face interviews were undertaken in the carers' own homes, with the exception of one participant who asked for the interview to take place at the local Carers' Centre. The interviews were structured around a list of themes designed to explore: the circumstances leading up to the assessment; the carer's recollection of the assessment process itself (including both the content and how it had been conducted); and events after the assessment (including the implementation and review of the carer's Action Plan and assessment). Although interviewers ensured all aspects of the carers' assessment process were covered, the interviews were intended to take an informal approach in order to allow the carer to feel at ease and to guide the conversation towards issues of importance to their particular case. Subject to the carer's permission, the interviews were tape recorded.

Selection of cases

The sample of carers to be interviewed was taken from the 260 assessment forms analysed in Chapter 2. The sample was purposively chosen to reflect a range of aspects of the carers' characteristics, including age, gender, ethnicity, family structure, family relationships, employment status and caring responsibilities. The sample also took account of the team that undertook the assessment and therefore (to some degree) the associated area of the city in which the carer lived.

The research team sought to undertake around one dozen interviews. In order to take account of potential refusals we therefore contacted 26 carers. It was agreed that Coventry Community Services Directorate would make the initial approach to the families within the sample, informing them by letter of the research aims of the project and the possibility of contact from the research team inviting them to participate. This letter was followed up by a phone call from the research team three to five days later.

Of the 26 cases initially identified, the research team were unable to contact four carers because of wrong or missing information regarding postal or telephone contact details. A further four could not be contacted despite repeated attempts to call at various times, and voicemail messages.

Of the 18 contacted, two felt unable to participate due to their own personal health and a further two due to changes in their caring responsibilities (one care receiver had died and another carer reported that they were too busy). A further four confirmed

that they did not wish to participate. This left 10 carers able to participate from the initial sample.

Between August and October 2006, 10 carers were interviewed¹. Five chose to be interviewed by telephone and five in person, at the family home.

Following consideration of the sample interviewed, the research team decided to approach two further carers. However, rather than return to the initial sample of assessment forms, the team decided to purposively sample two carers from minority ethnic groups in order to ensure that the interviews reflected the ethnic diversity within the population of carers in Coventry. It had been noted that those for whom English was an additional language had been particularly reluctant to participate in the study. Coventry Community Services Directorate identified two such carers who were willing to participate and one of these went on to agree to be interviewed.

As a result we are left with a sample of 11 cases. Of this sample, 7 of the denoted primary carers were women. Three were men, with one case involving a couple with equal caring responsibilities. Seven of the cases involved White British or European respondents. The sample included:

- ♣ Three daughters caring for an elderly mother
- ♣ Two wives caring for their husbands
- ♣ One mother caring for her son
- ♣ One father caring for his son
- ♣ One daughter caring for her mother-in-law
- ♣ One husband caring for his wife
- ♣ One son caring for his mother
- ♣ One couple caring for their son

The carers

The following brief profiles detail the eleven cases we interviewed, outlining their family circumstances and caring responsibilities at the time of the assessment. **All names have been changed to ensure confidentiality.**

Interview 1. Mrs Ferguson is aged 76 and cares for her son, Christopher, who is 47 years old and has learning disabilities. Mrs Ferguson lives with Christopher and is his sole carer. Christopher needs prompting with time keeping, including when to get up, when to eat and when to go to sleep. However Mrs Ferguson highlights the mutual support Christopher provides her by 'doing jobs around the house'. They have a very close relationship and occasionally holiday together, although Christopher is anxious when away from home too long. This anxiety has also made it difficult for Mrs Ferguson to access respite care recently.

Christopher has two jobs, both part-time: one working with the council for a day a week, and the other working in the gardens of a local park. He has kept to the routine

¹ One of the interviews involved a couple who shared caring responsibilities. For the purposes of the sample they are counted as one case.

of work and is performing well in his job, according to his supervisors. He enjoys the time he spends there. However, Mrs Ferguson is not sure that it would be beneficial to increase the number of days he works as it may be 'too much for him to cope with' each week.

Interview 2. Anita Prashad is Asian British and cares for her 32 year old son who is autistic. Anita knew nothing about autism before her son was diagnosed and admits it was initially very difficult to come to terms with. Her son was diagnosed during a routine immunisation. Social Services have been involved ever since. However Anita and her husband's needs as carers had not been assessed before this year's carer's assessment.

Whilst her son was at school Anita felt supported by school staff and other parents. However since leaving school Anita's role has become much more difficult. Over the last 10 years she says that she has been 'fighting' for services for her son and herself.

Interview 3. Dorothy Adams is aged 69. She cares for her mother who has Alzheimer's Disease, as well as being frail and in need of support with all physical tasks. Dorothy also ensures her mother's medicine is taken and manages her finances. She now lives with her mother and has done for nearly four years. Previously she had cared for her for two years, although at that time her mother was able to live on her own.

Dorothy provides '24 hour care' in that she needs to be available whenever her mum requires assistance. As such she loses sleep due to her mother waking up in the night. She is supported in her caring role by two brothers who are 'excellent'. Whilst neither lives with her, they are also resident in Coventry and are willing to help out however they can. She does not have access to short breaks however.

Interview 4. Michael Sainsbury is French and aged 76 years old. He has lived in the UK for over 50 years. He cares for his wife who is physically disabled and suffering from chronic illness. Whilst Michael has cared for his wife for over 10 years, the level and type of care provided has recently altered greatly. Although in the recent past he has provided substantial care, Michael can no longer offer support in the same way due to his own deteriorating mental health and associated physical problems. Michael has become increasingly anxious and does not like to be left alone. An assessment was carried out as a result of Michael not being able to provide the same level of care. This assessment was triggered by a hospital admission and the necessary changes to his wife's care package. At the time of his carer's assessment, a mental health assessment was requested.

Interview 5. Mrs Sainsbury is in her mid-60s and lives with her husband, Michael, for whom she is a carer (and he also cares for her – see Interview 4). Her husband's mental health has deteriorated over the past two years and he now needs considerable support and assistance in everyday tasks. Mrs Sainsbury is herself physically impaired and suffering from chronic illness. As such she relies on her husband to carry out physical tasks on her behalf, such as making drinks and helping her with her

medication. Whilst Mrs Sainsbury is able to offer emotional support to her husband, this is dependent on support she in turn receives, including morning visits from carers to help her out of bed.

Interview 6. Amjad Singh is Asian British and cares for his mother (Mrs Kaur) who has a terminal illness. Amjad has provided such care for four years. As his mother's ability to look after herself deteriorated, Mrs Kaur came to live with Amjad and his family. Mrs Kaur requires 24 hour supervision due to her health needs. She requires support getting in and out of bed and with personal hygiene, and requires drinks and meals to be prepared for her. Due to her immobility she is confined to the upstairs of the house.

Although Amjad is the main carer, he is supported by his wife who was very encouraging when Amjad wanted his mother to come to live with them. She continues to share much of the caring responsibilities, as well as looking after their two young children. Amjad is committed to providing care for his mother within the family home until her death and sought the provision of services so as to maintain, and over time increase, the level of palliative care provided.

Interview 7. Mr and Mrs Vaughan are both in their early sixties and are retired. They care for their 38 year old son, Oliver, who is physically disabled and requires support day and night. They also offer some support to Mrs Vaughan's mother who is in residential care, managing her financial affairs and doing her shopping.

Both carers report physical problems which they attribute to their caring role, including back pains caused by lifting and moving Oliver. Although they love their son and are committed to continuing to care for him, they also admit to being emotionally drained, at times becoming resentful of their caring role and ongoing responsibilities and commitments. Oliver works part-time during the week, which enables Mr and Mrs Vaughan to have some time and space for themselves during the daytime. However, because Oliver currently cannot be left on his own during the night, they are unable to take holidays or overnight breaks. Furthermore, they do not have any family who can provide them with a break from their caring responsibilities, or who live near enough to offer meaningful assistance.

Interview 8. Rachel Browning is 48 years old. She works full time as a teacher, and lives with her husband and two children. Rachel cares for her elderly mother, and has done so for the past seven years. Although she does not reside with her mother, she lives nearby and therefore visits regularly; usually 3 or 4 times a week. Her mother is trying to live independently but her physical health is deteriorating and this is becoming increasingly difficult. Her mother therefore requires more assistance. Due to her full-time job and family commitments, Rachel is finding it increasingly hard to offer the necessary level and regularity of support that her mother needs. Whilst she receives occasional support from a brother who lives locally, Rachel is the primary carer.

Interview 9. Rebecca Doyle is aged 53, and has retired from work in order to care for her elderly and frail mother, who, at the time of the assessment, lived with her. She has been her mother's main carer for the last 20 years, providing: physical support; personal care; meals and drinks; monitoring medication; and housework and shopping. Until recently her mother lived in residential care but became increasingly unhappy. Rebecca is happy to care for her mother in this way and feels that she benefits from being at home. However she is concerned about the impact that her own health is having on her caring role. Rebecca suffers from asthma and arthritis. Her symptoms fluctuate. When they are at their worst she finds it difficult to manage her mother's care needs. She is concerned that, without further support when needed, her mother will require significant periods in respite care.

A carer's service supports Rebecca twice a day, seven days a week; helping her with personal care and transfers from bed to chair. Apart from this service, Rebecca is her mother's only carer. As her mother requires help at various times throughout the day and night, Rebecca finds it hard to keep up with household tasks and other responsibilities. Furthermore she reports frequent disturbed sleep.

Interview 10. Jane Richardson is 52 and works part-time. For four months she has been caring for her mother-in-law who lives in sheltered accommodation. Jane provides regular support every morning and evening, amounting to approximately 14 hours a week. She helps her mother-in-law with many daily physical tasks, such as getting out of bed and getting dressed in the morning, washing clothes, and going shopping.

Although Jane does not see this as a particular heavy caring load 'compared to others', and is willing to continue to offer such support, she finds it difficult to maintain the necessary routine to offer the support when it is required. Her caring role is also affecting the quality of life for Jane and her family, impacting on the time Jane has for herself, to see friends and to spend at home.

She is also anxious that in the near future a heavier caring load may be required, and that there may be needs that she is unable to meet. She is concerned that she may not be able to offer the quality of support that her mother in law may soon require and is therefore keen for her case to be recognised and regularly reviewed.

Interview 11. Harpal Sangha cares for his son who has severe learning disabilities. As such he requires 24 hour support. Harpal and his wife have provided this level of care for 50 years. Although they have a loving relationship with their son, their caring role is at times very stressful, with the couple frequently losing sleep from worry. Their son is also verbally abusive and occasionally violent. This stress is seen to exacerbate Harpal's diabetes and asthma.

How the assessment came about

Across the 11 cases, four different routes to a carer's assessment were identified; although even within each of these categories there was variation.

♣ In three cases an assessment was triggered by an admission to hospital.

In the cases of both Amjad and Rebecca, it was the care receiver who was admitted to hospital.

Amjad's mother was admitted to hospital following a worsening in her condition. Although the hospital was unable to help his mother due to the terminal nature of her condition, staff recognised the needs of Amjad and his wife in maintaining and inevitably increasing their level of palliative support. In order to do so the case was referred to the Centre for Independent Living and an assessor visited within a week.

Rebecca's assessment also came about when her mother was taken to hospital, following an accident in which she broke both her hip and arm. In this instance however the carer was required to request an assessment. Following discharge from hospital, Rebecca's mother was subsequently transferred to a nursing care unit. Rebecca described how each time she went to visit her mother she was upset and expressed her wish to leave the unit. The carer contacted the district nurse who previously dealt with her mother to investigate whether she could be discharged from the nursing care unit and taken home. In order to do so, the community nurse recommended that Rebecca should contact a member of the ACM team based at Walsgrave Hospital to request a carer's assessment so as to identify support that might be available to Rebecca.

In each of these cases the relationship of care was long established. However no such assessment had been carried out prior to the admission to hospital. Instead an investigation of the circumstances of the patient had led to the instigation of an assessment of the needs of both the care receiver and the carer following discharge.

In the previous four years in which Amjad had cared for his mother, he had not received any assessment of his caring needs. Whilst Amjad had not been informed of his rights to an assessment, he also stated that he had not sought to find out about his entitlements as he felt able to manage: 'The routine was working and so we maintained the status quo.' Similarly for Rebecca this assessment was the first time that her needs as a carer were assessed. Again this was the result of a change in the circumstances and needs of the cared for.

In contrast to the above examples, in the case of Mr Sainsbury it was the carer who was admitted to hospital. Although he was admitted due to associated physical problems, Mr Sainsbury was thought to be suffering from deteriorating mental health. As such the hospital staff requested a mental health assessment. Mr and Mrs Sainsbury's case was well known to Coventry Community Services with a support package already in place. However the mental health assessment led to concerns that Mr Sainsbury might not be able to provide the same level of care that he had previously provided for his wife. A review of his wife's care package was therefore also seen to be appropriate.

♣ **In two cases a carer's assessment was instigated by the social worker assigned to the care receiver.**

In each of these cases contact with a social worker who had not previously been involved with the family made the carer aware of their rights to an assessment. For Rachel the assessment was instigated by a social worker newly assigned to her mother (as a service user). Rachel was present when the assessor conducted the service user's assessment, and was asked a series of questions 'there and then' to complete an associated carer's assessment. Rachel said that this was the 'first time [she] was made aware of that service'; several previous social workers who had been assigned to her mother 'had never ever spoken to [her] about this'.

Dorothy's assessment was instigated by the review of her mother's case which followed responsibility for the case moving from one ACM team to another. Dorothy described a long history of difficulties in her contacts with social services. This was primarily caused by her mother's case moving between offices when she came to live with Dorothy. Her mother's files were only finally transferred in August 2006, despite having moved more than 3 years earlier. This had meant that Dorothy had found it difficult to communicate with anyone from social services about her mother as her case worker did not have her files, and the office that had her files referred her calls to the other office.

Although Dorothy was unclear about the process that led to the assessment, she believed it had been carried out as a result of her case finally being recognised as the responsibility of her local office. Having been assigned to a duty social worker for review on the opening of the case an assessment was carried out immediately, despite numerous other social workers having had prior involvement with the family and not instigating such an assessment.

Issue for policy & practice 1: *The need for social workers and others to inform carers of their legal right to an assessment – see Chapter 5 for discussion.*

♣ **In four cases the carer became aware of their rights to an assessment and contacted social services directly.**

The circumstances of these four cases vary greatly. However, in each case the assessment was a result of the carer seeking some form of assistance due to concerns regarding changing or increasing caring responsibilities, or crises occurring.

In two cases support was sought directly from social services. Harpal was aware of his rights as a carer but had previously felt that he had no need to seek support. Indeed his case had been 'closed' by social services at his request. However, during a period in which he and his wife were under considerable stress, contributing to concerns regarding his physical health, Harpal sought to reopen his case in order to seek access to respite services.

Similarly, Jane Richardson sought support when she became concerned that her caring responsibilities might increase. She was anxious that in the near future a heavier caring load may be required, and that there may be needs that she would be

unable to meet. Jane was concerned that she may not be able to offer the quality of support that her mother may soon need and was therefore keen for her case to be recognised and regularly reviewed. As a result she made a direct approach to Coventry Community Services.

In two further cases support from Coventry Community Services was triggered by an intermediary agent. Mr and Mrs Vaughan discovered that they were entitled to support in their caring role as a result of their daughter contacting their local councillor. Their son, Oliver, had been on the housing list for ‘a very long time’ trying to obtain his own bungalow. As both parents were ‘getting older’ and increasingly suffering from back problems, they were concerned that support was needed urgently. An initial intervention from the social worker sought immediate respite, providing financial support to allow a friend of the family to look after Oliver whilst his parents were on holiday. Subsequently, the social worker conducted the carer’s assessment in order to make the respite care a standard element of their carer’s package. Despite contact with social services over 38 years since their son was born, this was the first time in their memory that their needs as carers were assessed.

For Anita Prashad the assessment came as a result of heightened stress and anxiety caused by ‘a string of difficult incidents in supporting [her autistic] son’. This led her to go to the Carers’ Centre to seek emergency help. Staff at the Centre instigated the assessment by referring on to Coventry Community Services Directorate. Anita described ‘a long history of services not being delivered’ as promised or to a suitable standard. She therefore welcomed this recent assessment and the services resulting from it.

Issue for policy & practice 2: *The need for carers to be assessed or offered an assessment when the care receiver is assessed or re-assessed – see Chapter 5 for discussion.*

Issue for policy & practice 3: *Should intermediary organisations, such as Carers Centres, be mandated to conduct some carer’s assessments on behalf of Coventry Community Services? – see Chapter 5 for discussion.*

- ♣ **In the remaining two cases the carers were unsure what led to the assessment taking place.**

In both cases the carer had no (or little) recollection of the assessment taking place, as discussed below.

Perceptions of the assessment process

In this section we consider the carers’ experiences of the various aspects of the assessment process. This includes pre-assessment discussions regarding its purpose, experiences of the process of completing the form, and some consideration of the value of the resultant Action Plan.

- ♣ **Whilst only two carers could not remember the assessment at all, a number of the other respondents were vague in their recollections of the exact process and outcome.**

This was despite the reminders we were able to provide, such as the date the assessment took place, who carried out the assessment, and the questions they should have asked. In the case of those interviewed in person, we were also able to show them a copy of their completed assessment form (which should have been provided to the carer). However only three carers thought that they had a copy of the Action Plan and assessment form 'filed away somewhere', and only one carer had their copy to hand when our interview took place.

Despite not recalling the assessment, of the 11 cases within the sample, 10 had signed the form. The other two were computer generated forms, and so another version may have been signed. Evidence from other research studies confirms that many carers cannot recollect having had an assessment even when this *has* clearly taken place.

Several reasons for the poor recollection of assessments emerge. Some carers described a wide array of assessments as blurring their recollection. Dorothy found it difficult to recall this particular assessment amongst the numerous other forms and paperwork she had filled in during recent months: 'There are too many assessments; too many repeated questions, and so much paperwork.' In particular Dorothy found it hard to recall an assessment of her specific needs, as opposed to those of her mother. She said that similar forms and similar questions are repeatedly asked and 'each time a new assessor starts with a blank form, taking about an hour to ask the same questions'. Dorothy finds this a very frustrating process.

Whilst she did not recognise the form itself, she did, however, remember the assessor as having been to the house and recognised some of the questions as things that she had been asked; for example, regarding whether her GP was aware of her caring role. Dorothy concluded that the form had probably been 'filled in by the assessor back in the office', having collected the necessary information from the assessment of her mother, together with a few questions asked during her visit. Despite this explanation, she had signed the Action Plan however, so she had clearly seen the form at some point.

Whilst the details of the process cannot be agreed, the discussion reveals how the carer's assessment fitted into a far broader assessment of family's needs. This was also the case in relation to Harpal, who, in discussing this assessment, frequently drifted into a broader discussion of assessments, in particular those carried out by medical staff. Angela also recalled contact with the assessor and remembered her involvement with the family, yet could not recall the specific assessment taking place. In both cases, however, the form had been signed by the carer.

- ♣ **Those carers to whom the process and purpose of the assessment had not been explained prior to the interview saw this as hindering the assessment.**

Whilst the majority of carers had been told about the purpose of the assessment in basic terms, in two cases the carer had not had the process explained. In both cases this led to the carers feeling confused and uncertain as to what had taken place.

As noted above, Rebecca's assessment was instigated by her mother's hospital admission. The social worker from the Walsgrave Hospital ACM team met with Rebecca at the care unit, rather than in her own home. The assessment was carried out at the initial point of contact. As such no information was provided to her regarding the content and objectives of the assessment, except for the knowledge that it might allow her to bring her mother home.

Similarly Rachel's assessment was undertaken 'there and then', during the assessor's visit to conduct an assessment with the service user. As such, there was no preparation time for Rachel regarding the assessment: 'I wasn't expecting those sorts of questions.' Furthermore the service user was present. Rachel described how this created difficulties:

'He was trying to make me think [...] that, although I am a part-time carer, that there is a lot of stress [...]. That was difficult, because I didn't want my mum to feel bad about me caring for her. [...] In hindsight, it might have been better to do the assessment separately.'

Had Rachel been informed of the content of the assessment prior to the interview she would have avoided such a situation.

Issue for policy & practice 4: *Carers need to be prepared for their assessment, as do assessors themselves* – see Chapter 5 for discussion.

Issue for policy & practice 5: *Minimising the number and range of different assessments that carers and their families receive would be valued by carers* – see Chapter 5 for discussion.

♣ **For some carers the communication with the assessors was problematic.**

The most common reason given for problematic communication was the involvement of a new social worker who appeared to know little of the background to the case. Whilst this was presented as annoying and repetitive of previous assessments, for several this was felt to be particularly restrictive of the assessment process, preventing the forming of a relationship with the assessor and therefore potentially restricting the range of topics that would be discussed. Caring needs and relationships were portrayed as very complex and therefore difficult to portray in a simple, one-off assessment, particularly if this takes place outside of the home. For example, Rebecca commented that 'It is hard to explain to someone else about the needs of [the care receiver].'

Similarly, Mr and Mrs Vaughan commented that they have felt it difficult to explain to the assessor (and her team) what their caring role and responsibilities consist of:

‘It’s this sort of thing that we really can’t get across to social services. [...] They have never looked after someone 24 hours a day who is physically disabled. They have got no idea what it is like and they can’t relate.’

For others, the structure of the assessment was thought to be unhelpful and restrictive. Amjad was particularly negative regarding the process. He found a number of the questions unnecessary and repetitive. Having had a general discussion about the situation at the outset of the interview, he then found himself ‘repeating the details over and over’, particular regarding ‘the state’ of his mother. He also felt that some questions demanded unnecessary detail. One such line of questioning asked how many times his mother went to the toilet each night: ‘Was it important whether it is 5 or 3 times?’ Whilst he understood the need to ‘tell the story’ he found such a structured and seemingly rigid approach ‘a little annoying’, although ‘typical of such forms’.

♣ **Some carers were more positive about the relationship they formed with the assessor, and of the process itself.**

Whilst being critical of the structure by which the assessment is carried out, Amjad was very positive about the assessor. He felt able to speak ‘frankly and in confidence’, and to ‘say exactly what [he] was thinking’. Like other carers, Amjad also portrayed the assessor as knowledgeable about the needs of carers and of the services available to them.

In addition, Amjad valued highly the interaction of various professionals in undertaking the assessment. In this instance the carer’s assessment was carried out in combination with that of two nurses from the local health clinic who were assessing the needs of his mother. Having initially visited separately, on becoming aware of the other assessment, all of the assessors agreed that they ‘should all meet together’. As a result a combined package of support was agreed, designed to support the needs of both the care receiver and the carer. The carer’s Action Plan was therefore agreed by all parties, including the nurses.

Issue for policy & practice 6: *Multidisciplinary assessments can be valuable, perhaps involving a ‘case conference’-type situation bringing together key professionals in contact with a care receiver and their family – see Chapter 5 for discussion.*

Anita was also particularly positive about the relationship formed with her assessor. Whilst she had no previous contact with the social worker who carried out her assessment, and had been warned that her case would again be referred on once particular services had been accessed, Anita found her to be enthusiastic and committed, taking care to understand Anita’s needs and promising not to ‘pass on’ the case until Anita was happy for her to do so.

Anita was also positive about the form itself, which she found relatively easy to complete despite her limited ability in reading English. Although she had the assistance of the social worker, she found the English easy to understand and could not recall any problematic questions.

- ♣ **For some a ‘positive’ experience of the assessment process was related to their sense of ownership and relevance of the ensuing carer’s Action Plan.**

As a consequence of the positive nature of the assessment process, both Anita and Amjad valued the resultant Action Plan highly. Anita felt that it represented her needs well, reflecting their discussions by recognising the particular sorts of support that Anita felt to be appropriate and translating her needs into identifiable actions.

Amjad commented that his wishes had been respected, forming the basis of the Action Plan. The assessors had recognised that Amjad and his wife wanted to keep his mother at home for as long as possible, despite the obvious difficulties in providing the complex and extensive palliative care required: ‘They appreciated that I wanted to look after my mum [...] even though it was quite hard.’ The assessors discussed all the options and sought to support them in their decision.

Outcomes of the carers’ assessments

In the cases of both Anita and Amjad it is unfortunately not possible to conclude whether the positive perception of the assessment process is matched by positive outcomes in its implementation. Anita believed it to be too soon to judge, with the assessment occurring only three months prior to our research interview. Her main need was thought to be respite care. However, such services have been very difficult to organise in the past. Anita has always struggled to find respite care that meets the religious and ethnic needs of her son, including appropriate food and religious practice, as well as being able to support his needs relating to his autism. Anita was therefore not surprised that this assessment has not (yet) found an appropriate service.

Sadly Amjad’s mother died shortly after the assessment was undertaken. As such the package of support was never provided. Amjad was however keen to praise the support that was received. The assessment seemed to ‘set the ball rolling’ in terms of provision where previously he had not known how to access the support necessary to help them cope. In particular the assessor had identified a care home that was suitable for his mother’s needs given that she did not speak English. However, his mother had a very negative experience and became very scared and anxious.

Issue for policy & practice 7: *Carers’ assessments must be sensitive to religious, ethnic and cultural needs, and services that are provided as part of an Action Plan must also be sensitive to these needs – see Chapter 5 for discussion.*

- ♣ **In a number of cases positive outcomes are directly attributable to the assessment.**

Whilst the confusion amongst many interviewees as to the assessment makes it difficult to attribute service provision to the Action Plan, there are a number of cases where specific actions are explicitly stated and have been addressed. For example, Jane Richardson was provided with advice regarding the range of benefits that were available to her as a new carer. A number of the carers were now receiving a flexible carers break, including Mrs Sainsbury whose husband was being taken into the city centre once a week to go shopping and to lunch.

As a result of Rachel's assessment, some of her responsibilities and tasks of the carer have been taken over. For example, a carer now takes her mother shopping one morning each week. Rachel used to take her mother shopping in the evenings when she finished work. However, her mother was often too tired at that time.

Similarly the assessment (appears to have) led to an additional service for Mrs Ferguson's son. A care worker now visits the house every Saturday to take Mrs Ferguson's son out for the afternoon. This provides both a break for Mrs Ferguson and stimulation for her son through the company of someone his own age. However, Mrs Ferguson has some reservations about the service. Firstly, the service requires her to pay for both her son and the carer for any activity they get up to during their day out. This would typically be the price of two for the cinema or for some food. Whilst this may only be 'a few quid a week it adds up'. Secondly, the carer appears to have 'little in common' with her son: 'I wonder what they find to talk about.' They appear to have divergent interests. However she says her son likes the carer and has got used to him so she has no plans to request a change.

- **In many cases, the needs that had been identified in the carer's assessment had not yet been addressed appropriately.**

Whilst it is unsurprising that carers were able to identify areas of need that had not been successfully addressed, some interviewees also discussed provision resulting from the assessment that was inappropriate to their needs.

We have already noted Mrs Ferguson's minor concerns with the care service offered to her son. Of greater concern was the respite service offered to her, which she deemed to be inappropriate. Her son, Christopher, used to regularly attend Coventry Homes for respite. He had also been on holidays through the group. However funding 'ran out' and has not been renewed. The assessor promised to 'reapply for funding for respite'. Mrs Ferguson is keen for Christopher to get used to spending weekends away from her. She is concerned that as she gets older she will be unable to provide the necessary care to Christopher, and sees such respite care as a chance for Christopher to 'get used to being away from home again.' Given this additional aim of the respite care Mrs Ferguson is very particular about the sort of support Christopher needs, and was not happy with the options for respite that were available. She did not feel that her son would benefit from a residential home as his needs are not sufficient to warrant being looked after in such a way. Instead he simply needs help with the routines of the day. Whilst he can look after himself he does not recognise when it is time to eat or sleep. As such Mrs Ferguson is looking to make contact with a local family that could regularly look after her son by providing a bedroom for the weekend or even visiting him several times over the weekend to check up on him and ensure that he is looking after himself. Mrs Ferguson had identified a potential family and hopes to begin to make links with the family with a view to taking a break in the new year. The assessment had not helped Mrs Ferguson in this regard, providing access only to 'inappropriate' services.

Dorothy told a similar story of inappropriate respite care. Social services had provided her with a week's holiday, placing her mother in a residential care home. However, Dorothy felt that the 'facilities' and level of support and supervision

available at the care home were not suitable for someone with such high needs as her mother. Whilst other residents were able to ‘walk around’ and ‘look after themselves’, Dorothy’s mother requires constant attention and supervision due to suffering from Alzheimer’s Disease. In addition Dorothy felt that her mother’s general care was poor. Immediately prior to the break, Dorothy’s mother had a fall, badly grazing her knee. On Dorothy’s return she found the bandage had not been changed and the wound had gone septic. As a result of this negative experience Dorothy has decided not to take any further respite breaks.

Rebecca was offered home support to assist her with her caring tasks. However the service was felt to be poorly organised, taking no account of Rebecca’s routines: ‘We knew [social services] were coming in, but we were never asked times and things like that. [...] We didn’t know what they were going to do until they turned up.’ The actual support that was provided consisted of washing her mother in the morning and getting her ready for bed in the evening. Although Rebecca ‘was grateful for it [...] it wasn’t much good for where [she] was.’ By limiting the support to early in the morning, Rebecca was left to carry out all other caring roles on her own. Due to her health problems she was unable to cope and eventually had to place her mother back in residential care. In order for the service to be useful, Rebecca felt that it would have been necessary to have had the opportunity to discuss the kind of support that would or could be offered by Coventry Community Services or their partners.

Issue for policy & practice 8: *Services provided to carers need to deliver agreed outcomes. Services that are inappropriate or not wanted by carers are a waste of resources and are a denial of a service to someone else – see Chapter 5 for discussion.*

- ♣ **Other carers felt that no noticeable outcomes had occurred as a result of the assessment.**

In particular Mr and Mrs Vaughan felt the assessment had made no impact on their ongoing attempts to acquire funding for appropriate respite care. Their entitlement to such funding had been disputed by the local authority for over six months prior to the interview. Whilst the carer’s assessment was intended to enable them to describe the caring tasks they perform and the needs of their son, this account is felt to have been questioned and ignored. Despite the carer’s assessment and supporting accounts from specialists (e.g. occupational therapists, district nurses, GP, and urologist) as to Oliver’s need for overnight supervision, social services had instead offered only minimal support helping Oliver in and out of bed.

Issue for policy & practice 9: *Carers’ assessments and services need to be outcome focused – see Chapter 5 for discussion.*

- ♣ **In one case, the assessment was felt to have had a negative impact on the carer and the service user.**

For Rachel the assessment is seen to have ‘backfired’. The assessor not only registered Rachel as a part-time carer, but also informed several organisations that she was to be the primary person of contact. As a result, Rachel’s mother ‘became quite

cross and frustrated [...] that she was no longer in control'. Her mother became offended, repeatedly saying that she 'hadn't lost her mind.' In addition, Rachel 'was finding it difficult because as I was working [...] I wasn't available to take those calls and I kept receiving all these messages to phone them during the day.' As a teacher, this was virtually impossible. 'It took a while to get that sorted. I had to keep phoning people saying "Please speak to my mum. She may be disabled but she is, you know, with it."' Now her mum is again 'in control of the situation'.

Review

At the time of interview, none of the carers had had their assessments reviewed. Whilst some carers had been informed that a review would take place (either one or two years after the initial assessment), only Mrs Sainsbury had been informed that her case was due for a review, and this had been a result of problems with a service being received rather than as a matter of course following a set period of time. Even then this review had been cancelled and no alternative appointment agreed, as discussed below.

- ♣ **Whilst no formal review process was apparent, some of the carers felt that they could contact the assessor when required to ask additional questions, query progress towards Action Plan targets, or to inform of changing circumstances.**

Anita felt that through the ongoing contact she has had with the assessor in accessing services, her assessment and needs are being constantly reviewed. Similarly Rachel felt that she could contact her assessor if she required any further assistance or advice in her caring role.

- ♣ **For most there was no such ongoing contact with the assessor, and in some cases there was no ongoing contact with social services at all.**

Indeed in one case attempts to contact social services had been ignored. Rebecca contacted social services to complain about the support received. However she did not hear from them and 'nothing ever changed'. When asked whether she could not have communicated her concerns to the person who had conducted the original carer's assessment, Rebecca explained that the assessor had already forwarded her case to someone else, whose name and place of work she did not know.

- ♣ **In some cases it was clear that a review of the case was necessary and of particular importance.**

In the case of Michael Sainsbury this was particularly apparent. It is clear that the needs of Michael and his wife have changed greatly since the time of the initial assessment. Whilst services to support both of them remain in place, these services were seen to be uncoordinated and in need of review.

Since the carers assessment had taken place Michael's condition had deteriorated further to the point that he was no longer able to support his wife, and in fact relied heavily on his wife to care for him. Mrs Sainsbury now provides a range of emotional

support for Michael, as well as ensuring he keeps to his routines of eating, washing and sleeping.

The physical support Michael is able to offer his wife is becoming limited as he is unable to cope with basic tasks alone. He is also becoming increasingly anxious and stressed. Whilst the support was described as 'mutual', it is increasingly one-sided, and progressively more reliant on outside assistance. Whilst Mrs Sainsbury had been supported by carers for a number of years, she was becoming increasingly reliant on this service. Whereas previously her husband was able to help her, she was now unable to get up and dressed in the morning until support arrived. As such she was not able to assist her husband until her own paid carers arrived.

In direct contrast to this increasing reliance, the service provided to the couple was described as more and more erratic. The paid carers do not keep to a set routine, making it difficult to predict when they would arrive. On some occasions no support had been provided until the late morning, leaving Mrs Sainsbury bed-bound and Mr Sainsbury unsupported.

Following several 'bad experiences' with the service, Mrs Sainsbury had written to the agency twice to complain about the inadequacy of the service but there had been no response: 'I have put it in writing twice but I have never had an answer. I don't know if I'm sending it to the right place.'

This lack of response led Mrs Sainsbury to contact the Centre for Independent Living, who had carried out the previous carer's assessment. This contact led to the promise of a 'full review' of the needs of the couple, due to take place a few weeks prior to the interview. However in the days prior to the review the meeting was cancelled, following reassurance that improvements would be made to the existing services. However no such improvements have occurred.

Following discussions with the couple it is clear that information contained within the carer's assessment is no longer current. As noted above a mental health assessment was requested at the time of the carer's assessment. However the results of this assessment do not appear to have informed any changes to the care package. It is also apparent that the couple are confused as to how to progress the support they need. This is no specific social worker assigned to the couple: 'We always deal with the duty social worker.' Whilst Mrs Sainsbury felt able to contact staff to complain she was unsure who she should contact in times of emergency or when her carers do not turn up at a reasonable time. It remains unclear to the couple how and when a review will occur, unless their case reaches 'crisis point'.

This is an important case to highlight because it raises many issues for policy and practice, and is likely to be an experience shared by other carers, namely the relevance of an Action Plan that was designed some time ago but which has not kept up to date with carers' and care receivers' changing needs.

Issue for policy & practice 10: A formal review of the carer's assessment, and the appropriateness of the Action Plan, need to be timetabled from the time of the original assessment – see Chapter 5 for discussion.

Chapter 5

Issues for policy and practice

Introduction

In Coventry there are examples of good practice, as can be seen from what local carers say (Chapter 4) and what assessors say (Chapter 3), and there is evidence that most assessors are strongly committed to securing the best they can (within available resources) for local carers.

However, the research evidence presented in Chapters 2 to 4 also suggests that the assessment process is not yet adequate to meet the standards that carers' require and that assessors want to deliver.

In this section we identify a number of issues for policy and practice which policy makers and practitioners in Coventry will need to consider when developing the carer's assessment process.

Policy and practice

The 10 issues for policy and practice identified in Chapter 4 are:

1. The need for social workers and others to inform carers of their legal right to an assessment.

Under the Carers (Equal Opportunities) Act 2004 it is the duty of local authorities to inform carers of their right to an assessment (see Chapter 1 of this report for details). Many carers simply do not know of their right to an assessment even though assessments are the gateway to services and support for carers. Additionally, other organisations in contact with *care receivers* (and carers) should inform family carers of their right to an independent assessment.

2. The need for carers to be assessed or offered an assessment when the care receiver is assessed or re-assessed.

The process of meeting the needs of service users *and* their family carers would be streamlined considerably if the carer was informed of their right to an assessment, or assessed, as part of the same process that is used to assess the person with care needs. Whether both assessments should be done by the same person is a matter for the Directorate, but devising clear and transparent institutional arrangements and processes that bring these two processes together would be a better use of resources, a more 'family-focused assessment, and deliver beneficial outcomes for carers and the person with care needs. Assessors should return to meet with carers after the formal assessment meeting to explain the action that is intended. A written statement should be left with the carer as their record, with clear contact details so the carer can get in touch with the assessor if and when their needs and circumstances change.

3. Should intermediary organisations, such as carers' centres, be mandated to conduct some carer's assessments on behalf of Coventry Community Services?

There may be a case for some carers' assessments to be conducted by organisations that are in (closer) contact with carers, such as carers' centres. Alternatively, there may be a case for a specialist carers' assessment team to be established which conducts all (or most) carers' assessments, although this may conflict with Issue 2 above. It is clear that the more assessments an assessor does, the better they get at doing them. The more knowledgeable assessors become about local resources and services for carers, the more likely they are to be able to deliver beneficial outcomes (see 4 below).

4. Carers need to be prepared for their assessment, as do assessors themselves.

Evidence from this study and elsewhere suggests that carers need some preparation about what a carer's assessment entails for them to be able to answer questions thoughtfully, fully and without anxiety, and for them to get the most out of the assessment process. A 'pre-assessment' form sent to them in advance can help prepare them for the assessment and is recommended by a number of organisations, including Carers UK.

Assessors too need to prepare adequately for the assessment, drawing on information that is known about the person with care needs and family circumstances. This 'case'-level preparation must also be based on good **training** of what is the purpose of a carer's assessment and the relevant law and guidance. Assessors must also have a good knowledge of local (and national) services for carers and how these services can work to deliver particular outcomes. Where assessors do not have this knowledge of services and resources then the assessment process, and outcomes in particular, can be seriously compromised and limited.

The Coventry research also shows that assessors sometimes feel constrained by resources when conducting their assessments and are mindful not to raise carers' expectations in situations where they believe that there is little available for them. This is the antipathy of an outcomes or carer-centred approach and needs to be discussed openly by assessors and policy makers/managers, and guidance drafted for assessors on how to handle these tensions. This situation directly impacts on the quality of the assessment process (for carers and assessors), as well as the outcomes.

5. Minimising the number and range of different assessments that carers and their families receive would be valued by carers.

Wherever possible a carer's assessment should also draw on evidence from other assessments and information collected from other assessments (for example, of the service user), so as to minimise the number of questions asked and the repetitive or intrusive nature of the information collected by different sources.

6. Multidisciplinary assessments can be valuable, perhaps involving a ‘case conference’-type situation bringing together key professionals in contact with a care receiver and their family.

Assessments, particularly outcomes, can be improved where agencies and organisations in contact with carers and people with care needs work together and share information (within the limits of confidentiality and data protection).

7. Carers’ assessments must be sensitive to religious, ethnic and cultural needs, and services that are provided as part of an Action Plan must also be sensitive to these needs.

There is little evidence that assessments take account of ‘identity’ with regards to race, ethnicity or culture. (Other ‘identities’ are similarly marginalised, including sexuality). This is not helped by the assessment form itself, which has no pre-categorisation for ethnic origin – assessors make their own judgement or ask the carer ‘what is their origin?’ Many carers reply to this question that they are ‘European’ or ‘English’ – which makes strategic or case analysis of ethnic origin difficult if not impossible. We recommend that it would be useful to provide assessors with a standard list of categories, such as those used in the Census. Assessors, and services, also need to be more sensitive to the specific needs generated by religion, ethnicity and culture.

8. Services provided to carers need to deliver agreed outcomes. Services that are inappropriate or not wanted by carers are a waste of resources and are a denial of a service to someone else; *and*

9. Carers’ assessments and services need to be outcome focused.

The lack of focus on outcomes, despite the guidance, is a cause for concern, although this is replicated across authorities and is certainly not unique to Coventry. Chapter 1 outlines the guidance on outcome-focused assessments and assessors clearly need information and training on how to make this a reality, and why it is important.

10. A formal review of the carer’s assessment, and the appropriateness of the Action Plan, need to be timetabled from the time of the original assessment.

In most authorities, including Coventry, there is no systematic procedure for reviewing carers’ assessments, despite guidance (for example, the National Service Framework for Mental Health) recommending regular reviews. Coventry needs to devise a system whereby reviews of assessments, Action Plans, outcomes and services can take place as a matter of routine, with the ultimate results of reviews being informed in writing to carers.

There are a number of other issues for policy and practice that arise from other Chapters in this report. These include:

11. The need for regular training to ensure all assessors or potential assessors are up-to-date regarding the purpose of a carer’s assessment, carers’ rights, the law and guidance, the availability of local services and sources of information for carers.

Assessors will need clear training input on all these aspects with a ‘booster session’ (to update their knowledge and skills) probably once a year. This booster session

might include assessors being brought together to discuss issues and mutual concerns, good practice, services etc.

12. The carers assessment form in Coventry requires some amending to make it ‘fitter for purpose’.

For example, in the section on employment, there is no category of ‘carer’ on the form. Some carers or assessors might have chosen this option if it had been available rather than ‘other’ or ‘unemployed’. The category of ‘other’ also seems to comprise those carers who are self-employed – another category which is missing as it has implications regarding employment rights and the need for care/support. We recommend the addition of these two categories: ‘carer’ and ‘self employed’. Additionally, we would recommend the inclusion in the form of the following categories of care-giving: ‘emotional support’; and the separation into two categories of ‘housework’ and ‘cooking’. Other improvements to the form are suggested in Chapter 3.

Good practice in assessments

The research conducted in Coventry is substantiated by other reliable and robust research on carers’ assessments from across the UK. Qureshi et al have observed that nationally:

‘Research with carers showed that their knowledge of the legislation was minimal, that many carers were not aware at the time of the event that they were being assessed, that the arrangements for the assessment – including the question of a separate discussion not in the presence of the care recipient – were not always a matter for negotiation and agreement and that written follow-up and/or further review was often not provided’ (2003, p. 74).

The research conducted in Coventry, and the evidence presented in Chapters 2 and 4, suggests that the above observations to some extent also hold true locally. Earlier research conducted in Nottinghamshire on carers’ assessments (Becker et al, 2005; Appendix 2) suggests that the picture in Coventry is similar (although better on many fronts) to the situation in Nottinghamshire.

Much of the approach perceived as good practice in carers’ assessments involves flexibility in fitting in with carer and user preferences. In that sense process and content of assessment are inextricably linked. Although some carers report benefit from the assessment itself, even if no services are provided, the process is usually expected to result in a care plan which will detail support and assistance to be provided, together with some statement of intended outcomes (Qureshi et al, 2003, p. 79). As Qureshi et al (2003, p. 86) have observed, the emphasis in assessments should not be on the type of services, but whether they are delivered in a way which enables people to achieve the things that are important to them. Arksey et al (2000) have identified a number of features of good practice in carers’ assessment drawing on the views of carers who had received an assessment under the 1995 Carers Act:

- The assessment process is made explicit and carers are given the time and information in preparation for the discussions.

- Consideration is 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 are given the opportunity for an informed choice over the matter of privacy and ‘separate’ assessment.
- Carers have face-to-face discussions with self-assessment and other forms being an aid to this process rather than an alternative.
- Care is taken with the amount of written information, which some carers find difficult to absorb even if they find time to read it.
- Workers are 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 is backed by some, albeit limited, direct contact follow-up as a support and safeguard (quoted in Qureshi, 2003, pp. 78-79).

These characteristics of good practice in carers’ assessments are reinforced by official Guidance for carers’ assessments (DH, 2001). All assessors should read this Guidance before they conduct assessments (see also Chapter 1 of this report for an overview of the Guidance).

We hope that this research report, the evidence it provides, and the issues identified for policy and practice will provide Coventry with a reliable and robust evidence-base from which to develop its carers’ assessments for the future.

Bibliography

Arksey, H., Hepworth, D. and Qureshi, H. (2000) *Carers' Needs and the Carers Act: An Evaluation of the Process and Outcomes of Assessment*, York: Social Policy Research Unit.

Becker, S., Becker, F., Silburn, R., Silburn, P. and Sempik, J. (2005) *Carers' Assessments in Nottinghamshire*, Nottingham, Nottinghamshire County Council.

Becker, S. and Silburn, R. (1999) *We're In This Together: Conversations with Families in Caring Relationships*, London, Carers National Association.

Carers UK (2004) 'Your Guide to a Carer's Assessment', Carers UK website, accessed 7th October 2004.

Clements, L. (2005) *Carers and Their Rights: The Law Relating to Carers*, London, Carers UK.

Department of Health (DH) (1996) *Carers (Recognition and Services) Act 1995: Policy Guidance and Practice Guide (LAC (96) 7)*, London, DH.

Department of Health (DH) (2001) *A Practitioner's Guide to Carers' Assessments under the Carers and Disabled Children Act 2000*, London, DH.

HM Government (2004) *Explanatory Notes to Carers (Equal Opportunities) Act 2004*, London, The Stationery Office.

Nicholas, E. (2001) 'Implementing an outcome focus in carer assessment and review', in H. Qureshi (ed) *Outcomes in Social Care Practice*, York: Social Policy Research Unit.

Qureshi, H., Arksey, H. and Nicholas, E. (2003) 'Carers and assessment' in K. Stalker (ed) *Reconceptualising Work with 'Carers': New Directions for Policy and Practice*, London, Jessica Kingsley Publishers, pp. 72-95.

Wood, J. and Watson, P. (2000) *Working with Family Carers: A Guide to Good Practice*, London, Age Concern England.

Appendices

Appendix 1: Coventry's current assessment form
(not available in this version of the PDF)
Pages 72-77

Appendix 2: Findings from the study of 'Carers' Assessments in Nottinghamshire'
Pages 78-79

Appendix 3: Research Interview Schedules for Assessors and Carers in Coventry
Pages 80-82

Appendix 2: Findings from the study of ‘Carers’ Assessments in Nottinghamshire’

Source: Becker, S., Becker, F., Silburn, R., Silburn, P. and Sempik, J. (2005) *Carers’ Assessments in Nottinghamshire: Content, Process and Outcomes*, Nottingham: Nottinghamshire Social Services.

1. Information recorded on the assessment forms was often of variable depth and quality. There was evidence that questions on the form were often either not understood or not answered by the assessor.
2. There was some confusion as to who should complete the assessment form. One third of forms were completed by the carer rather than a social worker or other professional.
3. On the majority of forms there was virtually no information recorded about the person with care needs and little detailed discussion of the quality of relationships between the carer and the care receiver.
4. Almost no information regarding outcomes was collected, despite national guidance, as noted above. It was very rare for assessors to say that they had explicitly considered the outcomes for carers in determining the Action Plan; rather they more frequently said that their assessments were determined by a carer’s needs and wishes.
5. Over half of the assessors said that they had received no training on completing carers’ assessments.
6. Assessors sought an improved layout and clarity of terminology within the form.
7. Assessors placed a high value on the assessment process for carers in providing both practical and psychological/cathartic benefits. The assessment was also seen as necessary in order to gain access to services and information. However, assessors frequently expressed their frustration at not being able to offer the services that were deemed necessary in order to fulfil the Action Plan.
9. Six out of ten carers had no or little recollection of their own needs being assessed, and only one person could show the researchers a copy of their own Action Plan. The other nine claimed not to have received a copy of the Action Plan.
10. In nearly every case additional help and support had followed the assessment, whether or not it was recommended on the form or whether or not carers could remember being assessed. This included household adaptations, respite care opportunities, vouchers for the purchase of agency services, advice about social security benefits, advice or guidance about the handling of disabled people, contacting social groups, and so on.

11. While many carers were pleased with what they were offered, some commented that the procedures were very slow, and it was sometimes hard to make and then maintain contact with a social worker. Others reported bad experiences with agency workers. Others said that they found it difficult to get information or to find out what kinds of help might be available to them and the person with care needs.

12. Several carers stated that they were reassured by the knowledge that they were not entirely alone, deriving comfort from knowing that someone else knows of their situation, understands it, and can be contacted for advice and moral support.

Appendix 3: Research Interview Schedules for Assessors and Carers in Coventry

1. Questions for Assessors

Assessor Details

1. Name
2. Job role and team
3. Which service users do you work with predominantly?
4. Professional Qualification
5. What proportion of your week would you spend on carer assessments?

Preparation

6. Have you received any training on conducting carers assessments?
7. What preparation do you do in advance of conducting the assessment?
8. What information on the carer and service user do you have prior to the carer's assessment?
9. Do you give the carer any written info before the assessment?

Assessment Form

10. What works about the current assessment form?
11. What are the problems with the current form?
12. Can you suggest ways in which the form can be improved?

Assessment Process

13. How do you explain the assessment process to the carer?
14. On average how many visits/contacts does it take to complete a carer's assessment?
15. Can you suggest ways in which the assessment process can be improved?
16. Do you consider that you are effective in conducting assessments of carers? If yes, why? If no, what would help you in this?
17. What guidance underpins the assessments you do?
18. How do you involve carers in the assessment process?
19. What involvement does the service user have in the carer's assessment?
20. Has your approach to assessment changed over time? If yes, how and why?
21. What value do you place on the assessment process?

Carer's Plan

22. How is the carer's plan completed?
23. How do you use the open questions on the form?
24. What works about the carer's plan section of the form?
25. What are the problems with this section of the form?
26. What are the key factors that determine your carer's plan?

Implementation and Review

27. What is the process once the assessment is completed?

28. How do you know if the carers you assess get the services identified in the carer's plan?
 29. Whose job is it to implement the carer's plan?
 30. How is the carer's plan reviewed and by whom and by when?
 31. Any other comments?
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2. Interviews with carers

1. Do you remember the assessment that I'm talking about?
2. Was this the first time your own needs were assessed (as opposed to those of the person that you care for)? (How often has this happened?)
3. How did you come to be assessed? How did you find out that you were eligible for a carer's assessment?

Preparation

4. How was the process explained to you beforehand? Did you know what this assessment was all about? What information were you given?
5. Were you warned in advance of the sorts of questions that would be asked?
6. Were you helped in any other way/by any other person to be prepared for the assessment?

Assessment process

7. What did the assessment involve?
8. Were you on your own or was the person cared for there as well? [Did this seem appropriate?]
9. Did you help to fill in the form?

Relationship with assessor

10. Did you feel that you could speak frankly and in confidence? Were they knowledgeable about your potential needs and the services that might be available?
11. Did it help to be able to talk to someone about what was involved in being a carer?
12. Were there things that you didn't like about the assessment?
13. Were there any difficulties with the form? [Uncomfortable questions? Pointless questions?]
14. Do you think you were asked the right questions? If not, what should they want to know?
15. Can you suggest ways in which the form or the assessment process might be improved?

Action Plan

16. The form ends with the drawing up of an action plan of some kind. How was the Plan constructed? How were you involved in that? [With you there; completed by assessor in office afterwards?]
17. What did you hope would happen as a result of the assessment?
18. Did you get any extra help as a result of the assessment and action plan? If so what?
19. Has the action plan be reviewed since?

20. Do you have an ongoing link with the assessor (or anyone else) that you can draw on if your situation changes or you want to talk things through again?