

Carers' Assessments in Nottinghamshire

Content, process and outcomes

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Nottinghamshire Social Services Department

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The structure of the report

This report is the culmination of an eight-month research and development project funded by Nottinghamshire Social Services Department in association with NAVO. It is concerned with the *content*, *process* and *outcomes* of an individual assessment for (informal) carers in Nottinghamshire. 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 271 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 13 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 determined what are 'unmet 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 interviews with a sample of 10 carers who had been assessed recently. The aim here was to examine the *process* of assessment from the carers' perspective, 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**.

Chapter 5 provides some brief concluding comments and identifies some key points for further discussion.

The **Resources** section of this report provides two draft forms for possible future use in Nottinghamshire. The first form is a draft 'carer's self-completion pre-assessment form' and the second is a draft 'carer's assessment form'. The development of these two forms has been informed by the research conducted in Nottinghamshire and by our reading and understanding of the wider research literature on carers' assessments and what is known about best practice. Both forms have also been subject to a process of consultation with a sample of Nottinghamshire carers who, almost without exception, would support their introduction locally.

Executive Summary

Carers' Assessments in Nottinghamshire: Content, Process and Outcomes

By Saul Becker*, Fiona Becker, Richard Silburn, Pat Silburn and Joe Sempik

January 2005

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 an eight-month research and development project funded by Nottinghamshire Social Services Department in association with NAVO. The project ran from April to December 2004.

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

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 271 carers' assessment forms that are held by the Carers Unit for the period 2003-04. 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 13 assessors who have completed individual carers' 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 'unmet needs', and how (or whether) they communicate all this to carers themselves.

Phase 3: Individual face-to-face interviews with a sample of 10 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)?

Phase 4: Drafting of new assessment forms. The aim here was to draft new assessment tools (including a self completion pre-assessment form and a new carer's assessment form) drawing on the findings from the Nottinghamshire research and what is known about best practice nationally.

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1. Statistical profile and analysis of Nottinghamshire 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 271 carers in Nottinghamshire, all of whom had been assessed recently (in 2004 and 2003) by social services or health assessors. 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 statistics show some interesting and important characteristics of local carers and patterns of need and unmet need, for example:

- 59% of carers in the sample are aged over 60 (with over half of these over the age of 70).
- 42% of carers provide full-time, 24 hour a day care.
- A quarter of forms contained evidence of a strained and difficult relationship between the carer and person with care needs.
- Two thirds of carers were providing personal care and more than a quarter of these indicated that they had severe difficulties in continuing to care.
- 90% of carers experienced significant restrictions in their lives as a consequence of their caring roles.
- 55% of carers had emotional problems caused specifically by the caring role and 49% had poor physical health.
- One quarter of carers cannot take a break at all, with another 34% only being able to take a break with severe restrictions.
- In one fifth of cases there was evidence of severe difficulties/anxieties for carers in continuing to provide care.
- 41% of carers had some unmet needs.
- In just 47% of cases there was evidence that the needs of the carer to enable them to continue to provide care had been identified.

These figures suggest that many carers in Nottinghamshire provide care in very difficult circumstances – they care for very long hours; experience ill health themselves (physical and emotional); experience severe restrictions on their lives; cannot take a break; and many find it hard to carry on.

The information recorded on the forms is often of variable depth and quality and there is evidence that the questions on the form are often either not understood or not answered specifically by the assessor (which in one third of cases is the carer themselves). Many forms were not completed fully and missed out important information and emergency and other details.

The exercise also shows that there is some confusion as to who should complete the form. One third of all assessment forms were completed by the carers themselves, although most assessments were completed by a social worker or other professional. On the vast majority of forms there is virtually no information recorded about the person with care needs and little detailed discussion of the quality of relationships between 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 are problems relating to the design and layout of the assessment form, and the wording of some questions, which now contribute to the difficulties experienced in completing the assessment form and which help to explain some of the deficiencies in the quality and depth of information collected.

While the form was undoubtedly of value when first designed, things have moved on rapidly in the last 3 to 4 years with regards to carers and carer's assessments. We now have far more information and knowledge about good practice, what carers expect, how carers should be assessed, etc.

2. Findings from the interviews with assessors

Thirteen people were interviewed over the telephone between July and September 2004. The sample was drawn from all of the districts covered by Nottinghamshire County Council. The staff interviewed worked in either a community or hospital setting. Two respondents worked in the mental health sector, one person worked in a physical disability team, and the rest of the sample worked within adult care services. In terms of job titles: six of the respondents were community care officers (CCOs) and seven were social workers, two of whom held specialist carer support roles.

Time spent on carers' assessments: The majority of our sample were completing one or two assessments per month and in only a minority of cases were carers' assessments a major part of their work.

Preparation in advance of conducting assessments: Over half the sample said that they had received no training on completing carers' assessments. The majority (10) of respondents sent carers a copy of the assessment form in advance of the interview to inform carers of the areas which the assessment focuses on and to give them the option of completing all or some of the form in advance of their visit.

The carer's assessment form: Strong opinions were expressed about whether or not the carer should complete the form him/herself. What emerges is that practice and expectations vary on this aspect of carer's assessments. These two different uses of the form consequently affected respondents' perceptions of the form and their suggested improvements for it. Respondents were asked to identify what works well with regard to the carer's assessment form, what doesn't and any areas for improvement. Generally comments were more often negative than positive about the assessment form.

Unmet needs: This part of the assessment appears on the first page of the form along with the factual identification data. About half (6) of the sample used the box in the manner intended; that is to identify unmet needs. For other respondents this box was problematic and so they used it in unintended ways. Several respondents said they did not know how the information in this box was to be used or by whom.

The key recommendations that stemmed from these respondents was that there should be more clarity and guidance about what information was required in the unmet needs box, how it would be used, by whom and how their feedback affected service provision. A couple of staff thought this box should be placed at the end of the form, as it was more logical for it to be there.

The action plan: An improved layout, clarity of terminology and responsiveness to individual need would seem to be the key aspects respondents identified with regard to improving the action plan.

The assessment process: Respondents' ability to identify the law and policy underpinning carers' assessments was very variable. Five staff demonstrated a good understanding. All of the respondents said that they placed a high value on the assessment process for carers because essentially it could bring both practical and psychological/cathartic benefits. They said the assessment process was necessary in order to gain access to services and information. However, considerable frustration was expressed about the paucity of resources available, such that some staff felt embarrassed at how little they were able to offer and others thought that an assessment should not be undertaken if there were no services to offer.

Devising and implementing the action plan: No respondents specifically identified that they take account of the carer's or care receiver's *identity*, in terms of their ethnicity, language, beliefs etc when formulating the action plan. It was very rare for respondents to say that they considered explicitly 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. Frequently, respondents expressed their frustration at not being able to offer the services that they deemed necessary in order to fulfil the action plan. Many expressed a view that what they were doing was resource-led rather than needs-based assessments.

Review of the action plan: There were different practices in operation for the review of the carers' action plan; indeed one respondent described this as 'rather woolly' and said there was a lack of clarity concerning who was responsible for completing these and in what time scales.

3. Findings from the interviews with carers

Face-to-face in-depth interviews were completed with a group of ten carers, selected to reflect the geographical distribution of cases across the region, and differing caring circumstances. Thus:

- 3 daughters were looking after elderly mothers
- 1 son was looking after his aged mother
- 1 daughter-in-law was caring for her mother-in-law
- 3 wives were caring for very ill partners
- 1 husband was looking after his sick wife and two teenage sons
- 1 elderly sister was caring for her younger but elderly brother

It was usually the case that the need to offer care had started in a small way and had gradually increased as the person with care needs had grown older, or their condition had deteriorated. In many cases (five out of ten) the first contact with the social services is made when the person being cared for is about to be discharged from hospital. In some other cases, the carers themselves had directly approached the SSD, to ask for help or advice. It may be that there has been a caring relationship for several, even many, years before such a contact is established.

Six out of our ten carers had no recollection (or at best the haziest) of their own needs being assessed, and only one person could show us a copy of their own carers plan; this one person was the only person to have a copy of their assessment.

The carers who had themselves approached the SSD were much more likely to remember the assessment than those where the hospital-based staff were involved. For this group, this is probably a time of considerable anxiety and confusion, when everyone, especially the carers, focuses on the needs of the patient. In this case it is easy to confuse a carer's assessment with a concern for the care package for the person with care needs. Some did not think of themselves as carers, nor did they wish to.

The Action Plan contains key information designed to support the carer. Nine out of ten of our carers claimed they had not received a copy of the Action Plan.

However, in nearly every case some additional help and support had followed the assessment, whether or not it was recorded on the form. This might include household adaptations as recommended by an OT, 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 support groups and so on.

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

Several people spontaneously stressed one thing that was very important to them: while they willingly accept, and will continue to accept their responsibilities as carers, they are reassured by the knowledge that they are not entirely alone. This goes beyond taking advantage of any practical help they are offered. It is the comfort they derive from knowing that someone else knows of their situation, understands it, and can be contacted for advice and moral support.

4. Resources: Draft assessment forms

The Resources section of the full report provides two draft forms for possible future use in Nottinghamshire. The first form is a draft 'carer's self-completion pre-assessment form' and the second is a draft 'carer's assessment form'. The development of these two forms has been informed by the research conducted in Nottinghamshire and by our reading and understanding of the wider research literature on carers' assessments, national Guidance, and what is known about best practice. Both draft forms have also been subject to a process of consultation with Nottinghamshire carers who, almost without exception, would support their introduction locally.

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) carers in Nottinghamshire. The research commenced in April 2004 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 the Social Services Carers Unit for the period January 2001 – April 2004

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 'unmet 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 271 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. Data were then entered into an Access database to enable statistical analysis of the content. The forms that were coded and analysed for this part of the research were a sample of those held in the Carers Unit for the period January 2001 – April 2004.

Phase 2 of the study involved telephone interviews with a sample of 13 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 on average for a little over one hour. Assessors were contacted in the first instance by the Carers Unit to gain informed consent to a later interview by the research team.

Phase 3 of the study involved in-depth face-to-face interviews with a sample of 10 carers whose forms had been analysed in Phase 1 of the research (see Chapter 4 for the findings). In-depth interviews were conducted in the carers' own homes. Carers were contacted in the first instance by the Carers Unit to gain informed consent to a later interview by the research team.

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) new 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 comes into force on 1st April 2005. This Act makes 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). Relevant questions have been built into our draft carer's assessment forms presented in the Resources section of this report.

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? Again, relevant questions have been built into our draft carer's assessment forms presented in the Resources section of this report.

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 (ie 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 from this carer...” (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. Relevant questions on outcomes have been built into our draft carer’s assessment tools presented in the Resources section of this report.

The local context

The 2001 Census shows that there are 83,181 people who provide unpaid care in Nottinghamshire, of which 56,904 provide 1–19 hours of care per week; 9,062 provide 20–49 hours of care per week; and 17,215 provide 50 or more hours of care per week. This means that 26,277 carers in Nottinghamshire provide a ‘substantial amount of care on a regular basis’ (operationalised locally as providing more than 20 hours of care each week).

The 2003-2006 Carers Plan for Nottinghamshire identifies a principal objective of developing the process and quality of carer assessments. Other principal objectives include ‘learning from carers’, through assessments and other means, what services are appropriate and how services can be improved, and to use this knowledge in commissioning services; and to ‘develop guidelines and training’ for staff in order to raise awareness of issues about carers and to improve assessments and care planning. The Carers Plan makes it clear that, in order to achieve these objectives, the Social Services Department will:

- Collect information from carer assessments to get a better understanding of need;
- Survey carers about assessments and services;
- Review the format of existing assessment forms particularly those completed by carers themselves, in consultation with carers;
- Review the quality of assessments;
- Produce guidelines on assessment;
- Develop a training programme for assessors.

The research and development work reported here is part of the strategy for improving the process and quality of carer assessments in Nottinghamshire.

In 2002, the Adult Commissioning Performance Review Team and the Carers Unit, both part of Nottinghamshire Social Services Department, conducted a small-scale study of carers’ experiences of being assessed by social services (Berry, Johal and Oxley, 2002). Twelve carers who had received a separate carer’s assessment between January and April 2002 were interviewed. The results are shown in **Box 1.2** (next page).

Box 1.2: Main findings from the 2002 study of carers' experiences of being assessed by Nottinghamshire Social Services Department

1. Carers were generally poorly informed about their rights to a separate assessment, and what it might entail.
2. The majority of carers entered the assessment process with no sense of their rights or what they could expect from an assessment.
3. Assessors rarely planned and prepared in advance for the assessment.
4. A third of carers could not remember being assessed although they recalled the circumstances of the visit.
5. Carers' description of what the assessment involved varied a great deal. Carers' main recollections of the process were of going through the practical concerns of caring – the caring tasks that they carried out and discussing what help might be available. Only one carer reported a discussion of the feelings invoked by his caring role.
6. Carers were generally very positive about being able to talk about their caring role and the nature of the service user's condition, irrespective of the outcome of the assessment.
7. For ten out of 12 carers, the assessment resulted in a Plan to provide services, although this was not always taken up.
8. The services which carers said resulted from their assessments were: sitting services, usually using the Voucher Scheme; day care for the service user; personal care for the user from home care or Crossroads; contact with a carer's support group.
9. Most carers felt that the assessment had been worthwhile and would recommend the process to other carers. This was partly because of the focus on their role as a carer, and the demands it made, but mainly because it was a means to receive help.
10. Carers' experiences following the assessment were mixed. Most were generally satisfied, but two found the process and outcomes to be unacceptable.
11. Some carers felt that care workers who came to assist in the home were reluctant to build relationships with them, and the timing of their visits could be problematic.
12. While the provision of carer support groups for carers identified as having social or emotional support needs was useful, some carers would have liked other options.

Source: Berry, S., Johal, J. and Oxley, D. (2002) *Carers' Experiences of Being Assessed by Social Services*, Adult Commissioning Performance Review Team, unpublished.

The research reported in Chapters 2 – 4 suggests little has changed since this earlier study in 2002 (**Box 1.2**). It also provides a detailed profile of the needs and unmet needs of local carers, and a set of draft assessment tools that could lead to improvements in the assessment process.

2

Statistical profile and analysis of Nottinghamshire carers' assessment forms

In this part of the report we provide the findings from the first phase of research: the analysis of a sample of Nottinghamshire carers' assessment forms (see also Chapter 1).

The Carers Unit was holding a total of 513 carers' assessment forms for the period 2001-2004. Specifically, 77 of these forms were carers' assessments conducted in 2004; 332 were assessments conducted in 2003; 94 were from 2002 and 10 were from 2001. The Carers Unit holds copies of approximately one quarter of all carers' assessment forms that have been completed in the County.

In total, just over half of all the forms held by the Carers Unit (n = 271) were coded and analysed by the research team. All 77 forms for 2004 were coded, and just over half of the forms held for 2003 were selected at random and coded.

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 here derive from these tables.

District of assessment

Table 2.1 (below) shows that half of all the assessments were of carers living in the Broxtowe/Gedling/Rushcliffe District of Nottinghamshire, followed by carers living in Bassetlaw/Newark/Sherwood (36%), and then Mansfield and Ashfield (14%).

Table 2.1: District of assessment

	Number of completed assessments analysed	Percent
BGR (Broxtowe, Gedling, Rushcliffe)	131	50%
Mansfield & Ashfield	37	14%
Bassetlaw, Newark & Sherwood	94	36%

Note: 9 missing cases where district of assessment is unspecified

Type of Assessment

***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)

Most (n = 224, 83%) of the carers' assessments we analysed had been conducted by social services personnel (for example, social workers, community care officers), with a further 32 (12%) being conducted by health service workers (for example, mental health workers). In 15 cases it was not possible to identify which agency had the primary responsibility for the assessment.

Carers' gender

Two thirds of the carers who had been assessed (n = 184) were female, while one third (84) were male (see **Table 2.2**).

Table 2.2: Carers' gender

	Number	Percent
Female	184	67.9
Male	84	31.0
Not specified	2	0.7
Couple	1	0.4
Total	271	100.0

Carers' age and gender

Table 2.3 shows the carers' ages and gender. So, for example, only 2 carers in our sample (one female, one male) were under the age of 18 – a group commonly referred to as 'young carers'. The largest group of carers (77 carers or 31% of the total) was aged over 70. Another 28% of the sample was aged 61-70. This means that almost 6 out of 10 carers in the sample were over the age of 60. The male carers in the sample were generally younger than female carers.

Table 2.3: Carers' age and gender

	Female	Percent	Male	Percent	Total	Percent
Under 18	1	0.4	1	0.4	2	0.8
18 - 40	7	2.8	3	1.2	10	4.0
41 - 50	17	6.8	7	2.8	24	9.6
51 - 60	45	18.0	22	8.8	67	26.8
61 - 70	53	21.2	17	6.8	70	28.0
Over 70	50	20.0	27	10.8	77	30.8
Total	173	69.2	77	30.8	250	100.0

Note: missing data in 21 cases

Carers' religion and ethnic origin

***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).

The vast majority of the sample was defined as 'White British' (n = 247, 91%). Of those from a minority ethnic origin, 2 were African-Caribbean, 2 were Indian, 1 was Bangladeshi, 2 were from other Black or ethnic groups, and the remainder were 'unspecified'.

Over 80% of carers in our sample (n = 229) defined themselves as ‘Christian’. Only a handful (n = 4) described themselves as Hindu, Sikh, Muslim or ‘other’.

The quality of relationship between the carer and the person with care needs

In 107 cases (40%), the carers’ assessment forms contained evidence of a *loving, supportive and positive relationship* between the carer and the person with care needs.

However, in another 63 cases (23%) the forms contained evidence of a *strained, problematic and difficult relationship* between the carer and the person with care needs.

The data show that those carers who had a *problematic relationship* with the person with care needs were themselves far more likely to display signs of *emotional problems* – eight out of ten carers with problematic relationships had emotional problems compared with just half of those with positive relationships.

The types of care-giving tasks carried out by carers

The type of care most frequently provided by our sample of carers is *emotional care and support*; 187 carers (69% of the total) provide emotional care, which includes keeping an eye on the person with care needs, supervising them, spending time with them, providing moral support and reassurance, and so on. **Table 2.4** shows a ranking of the types of caring tasks undertaken by carers.

Table 2.4: Ranking of the types of caring tasks

1. Emotional care & support	187	69%
2. Household tasks	184	68%
3. Personal care	167	62%
4. Health/nursing care	99	37%
5. Financial management	71	26%

Note: numbers are greater than 271 and 100% because many carers undertake a range of caring tasks

The second most frequent type of support given by carers is the performance of *household tasks*. One hundred and eighty-four carers (68%) were involved in cleaning, domestic work, shopping, gardening etc.

One hundred and sixty-seven carers (62%) were involved in *personal care* (including help with washing, dressing, toileting needs, feeding, moving and handling). Just over a quarter of these carers (28.1%) indicated that they had severe difficulties in continuing to provide care.

A further 99 carers (37%) provided *health and nursing-related care* (including administering medication), while 71 carers (26%) were involved in *financial management* tasks, including paying bills and organising the household money.

Frequency of care provided

The vast majority of carers in our sample were providing either *full-time care* or *at least daily care*: around 4 out of 10 carers (n = 113) were providing 24 hours per day care to the person with care needs (see also **Box 2.1**); a further 109 (38%) helped at least daily. Only 13 carers helped once a week and just one carer was helping less than once a week.

Box 2.1: Full-time (24 hours per day) carers in Nottinghamshire

Forty-two per cent of the sample provides full-time, 24 hour per day, care.

Those involved in full-time care, perhaps not surprisingly, are also most likely to be providing personal care to the person with care needs: 85% of those caring for 24 hours per day provide personal care.

Two thirds (n = 74) of carers who provide full-time care also have emotional problems of their own, and 59% of these full-time carers also show evidence of poor physical health. Only 8% of full-time carers are in good health.

One third of carers who care for 24 hours per day have been identified as having *specific unmet needs*. In contrast, just 4% of full-time carers have *no unmet needs* and are seen as coping well emotionally with their caring role.

The older the carer is, the more likely it is that they provide full-time care. So, for example, two-thirds of carers aged over 70 provide full-time care.

At the other end of the age band, however, one of the young carers aged under 18 also provides full-time care.

Restrictions on the carers' lives

***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).

Around 90% of carers experienced significant restrictions in their lives as a consequence of their caring roles. In almost two-thirds of cases (n = 173) there was evidence in the carers' assessment forms that the caring role was directly *restricting the other activities and relationships* of carers.

In 41 cases (15%), there was evidence that the caring role was *restricting employment or employment opportunities* of the carer.

In just 26 cases (10%) was there *no* explicit evidence that caring had restricted the activities, relationships or employment opportunities of the carer.

Not surprisingly, the likelihood of caring leading to restrictions increases with the amount of care that is being provided. Just 1% of those who care for 24 hours a day have no evidence of restrictions on their lives, compared with 13% of those who care daily who have no evidence of restrictions.

The data also show that:

- Carers who are not restricted in their activities/relationships are more likely to have a positive relationship with the person with care needs.
- Almost three-quarters of those whose activities or employment was restricted by caring were still willing and able to continue to provide care.

Carers' health

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

"It is not only the time each week spent caring that has an impact on carers. For some, such as those caring for disabled children or adults with learning disabilities, the caring role can have the additional impact of being a life long commitment...The carer may not be physically or practically caring at all at certain times, but still be anxious and stressed waiting for, or trying to prevent, the next crisis." (para 15).

There is evidence that a substantial number of carers in our sample have one or more conditions of ill health themselves:

- In 149 cases (55%) there was evidence that the carer had *emotional problems* caused *specifically* by the caring role. In 19 cases there was evidence that the carer had *poor mental health* (see also **Box 2.2**).

Box 2.2: Carers with emotional problems or poor mental health

Ninety per cent of Nottinghamshire carers with poor mental health were themselves having to provide emotional care to the person with care needs.

Fifty-eight per cent of carers who had poor mental health were also carrying out personal care.

Almost one quarter (22.2%) of carers who had poor mental health and 26.8% of carers with emotional problems were not able to take a break at all from caring.

Around 6 out of ten of those with poor mental health or emotional problems were willing and able to continue to care.

Almost all (84.2%) of the carers with poor mental health said they needed more information about their rights, services etc.

Mental health problems are most likely to be found amongst carers aged 51-60.

- In 133 cases (49%) there was evidence that the carer has *poor physical health* (see also **Box 2.3**, next page).

Box 2.3: Carers in poor physical health

Poor physical health amongst Nottinghamshire carers increases with age. Three quarters of carers aged over 70 are in poor physical health compared with 20% of 18-24 year old carers, 25% of 41-50 year old carers, 38% of 51-60 year old carers and 46% of 61-70 year old carers.

Seventy one percent of carers who had poor physical health themselves were carrying out personal care and 41% with poor physical health were carrying out health and nursing-related care.

Almost one third (29.5%) of carers who had poor physical health cannot take any breaks from caring and 30.1% experienced severe difficulties in continuing to provide care.

However, almost three quarters (72.2%) of carers in poor physical health were willing and able to continue to care.

In just 15 cases (6%) there was evidence that the carer was actually *coping well emotionally* with the caring role, and in just 24 cases (9%) there was evidence that the carer was in *good health*. Having said that, however, around 30% of those in good health or those with no health needs still experienced some difficulties in their ability to continue to care.

The quality of relationship between the carer and the person with care needs is strongly associated with the health status of the carer themselves. Thus:

- Carers who had a problematic relationship with the person with care needs were more likely to have emotional problems caused specifically by the caring role. The extent of emotional problems is lower among carers with a positive relationship with the person with care needs.
- Thirteen per cent of carers who have a positive relationship are themselves in good health as opposed to just 5% of those who have a problematic relationship.

Can the carer have a break?

Many carers in our sample find it difficult if not impossible to take a break from their caring responsibilities. Data on breaks was available for 263 carers (missing data on 8 cases):

- 61 carers (23%) *cannot take a break at all*.
- 89 carers (34%) can take a break but only with *severe restrictions*.
- 78 carers (30%) can take a break but with some *moderate restrictions*.

In just 15 cases (6%) was there evidence that the carer can take a break with *no or little restrictions*.

Not surprisingly, the more heavily involved a carer is in caring, the more difficult it is for them to take a break. So, for example, 39.3% of those who care 24 hours per day cannot take a break at all, compared with just 11% of those who help daily who find

that they cannot take any breaks. No one who helps once a week or less than once a week is unable to take a break.

Not being able to take any break is associated with poor physical health. Almost two thirds (63.9%) of carers who cannot take a break have poor physical health themselves.

No carer in our sample ever took a break with the person with care needs.

Carers' needs and unmet needs

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

"Carers outcomes may be delivered through carers' services under the Carers and Disabled Children Act 2000, or through additional services for the cared for person through the provisions of community care legislation. They may be delivered through advice and information about other services easily available in the community.... Any outcome valued by the carer may be a legitimate use of council resources **if it genuinely will support the carer** in their caring role or help them maintain their own health and well-being." (paras 67-68; emphasis in original)

Data from the Action Plan and other sections of the assessment form show that there is a hierarchy of identified needs among Nottinghamshire carers, from a need for *services*, to *breaks at home*, to *breaks outside the home*, to *carer's support*, to *information*, to *a review of their care plan*, to *counselling*, and to a need for *aids and adaptations* (see also **Box 2.4**).

Box 2.4: A hierarchy of identified needs

Three quarters of carers were assessed as needing *services* or had *other needs*.

156 carers (58%) were identified as having a need for *breaks at home*.

150 carers (55%) had a need for *breaks outside the home*.

137 carers (51%) had a need for *carer's support*.

Just under half of the carers in our sample were identified as having *specific needs for information*. A *specific* need in this context refers to a clearly identified and specific information need, rather than a need for *general* and broad-ranging information. In 80 of these cases (30% of the total sample) the *specific* information needs were identified in the assessment form *and* a 'provider' was also identified who might be able to meet those needs. In a further 46 cases (18%), while a specific information need was identified in the assessment form no corresponding provider was identified. Information needs are high among carers irrespective of how much care they provide.

65 carers (24%) had a need for a *review of their care plan*.

29 carers (11%) had an identified need for *counselling*.

29 carers (11%) had a need for *specified aids and adaptations*.

(Percentages add up to more than 100 because many carers have a number of identified needs)

In addition:

- 46 carers (18%) were identified as having *financial difficulties* requiring a referral to the *welfare rights* service.
- 46 carers (18%) were identified as having *physical/manual handling* needs requiring a referral to an *occupational therapist/physiotherapist*.
- 19 carers (7%) were identified as having *medical difficulties* requiring a referral to a *primary care team*.
- 12 carers (5%) were identified as having *housing difficulties* requiring a referral to the *housing department*.
- 11 carers (7%) were identified as having *other* needs.

In just 11 cases (4%) was there evidence that the carer had *no* specific needs.

Just over half (52.6%) of carers who were in poor physical health themselves, and 54.4% of those with emotional problems, had their specific (i.e. unique) needs identified in the assessment so that they could continue to provide care. Two thirds (63.2%) of those with mental health problems had their specific needs identified in the assessment so that they could continue to provide care.

Unmet needs

Nottinghamshire County Council's brochure, *Caring Together in Nottinghamshire* (2003), states that:

"Every County Council Social Services Carers Assessment form has a section to record unmet needs. When you [the carer] tell the person assessing your needs as a Carer ways in which your needs are not met, they will record your comments. This helps us to know what services we should plan to commission for Carers in the future."

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

"When a carer's needs cannot be met, a record should be kept and used as part of a feedback mechanism to local authority managers. You [the assessor] will need to find out what feedback mechanism exists in your authority, and your part in it. If possible, explain to the carer how this mechanism works so that they can see that at least the information will be noted or reconsidered at some point."

A little under half of our sample of carers (n = 110, 41%) were identified as having *some unmet needs*:

- In 86 of these cases (61 female, 25 male), carers were identified as having *specific* unmet needs (i.e. unique/individual needs that are specific to that carer). Thirty-three per cent of all female carers and 30% of all male carers had specific unmet needs that were identified in the assessment form.
- A further 24 carers (18 female, 6 male) were identified as having *general* unmet needs (i.e. a broad/general range of unmet needs) – that is 10% of all female carers and 7% of all male carers.

- Only 18 carers (7% of the total) were *explicitly* assessed as having *no* unmet needs at all. Male carers had fewer unmet needs (11% of all men had no unmet needs compared with just 4% of female carers).

Almost half (48%, n = 40) of the carers identified as having specific unmet needs were full-time carers.

Is the carer able to continue providing care?

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)

While there was evidence that the majority of the carers in our sample (n = 188, 69%) were able and willing to continue to provide care, for many carers this was mixed with difficulties and anxiety:

- In 58 cases (21%) there was evidence of *severe difficulties/anxieties* for carers in continuing to provide care.
- In 80 cases (30%) there was evidence of *some difficulties/anxieties* for carers in continuing to provide care.

In 12 cases (4%) there was evidence that the carer was *unable or unwilling* to continue to provide care.

In half the cases (n = 126, 47%) there was evidence that the needs of the carer to enable them to continue to provide care had been identified in the carer's assessment form.

What is the carer's involvement in the development of the service user's care plan?

In 117 cases (44%) there was no evidence on the assessment form as to whether or not the carer had been involved in the care plan of the person with care needs ('service user').

In almost half the cases where data was available (n = 127, 47%), there was evidence that the carer *had been involved* with the service user's care plan. In 2 cases (1%) there was evidence that the carer had been *unwilling to be involved* with the user's care plan while in a further 17 cases (6%) there was evidence that the carer had *experienced difficulties* or had *been excluded* from the user's care plan.

Process

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).

The Nottinghamshire carers assessment form has space on the final page for the signatures of the carer and the assessor, as well as for collecting details of emergency contact numbers and other information concerning complaints procedures etc.

In 157 cases (59%) the eight main assessment questions (rather than the front sheet and care plan) were completed by an assessor only. In a third of cases (n = 82, 31%) the questions were completed by the carer only. In an additional 23 forms (9%) these questions were completed by the carer and the assessor together.

A little over a quarter of the carers (n = 70, 26%) had not signed the carers assessment form, and 30 assessors (11%) also had not signed the form. It was recorded that in 156 cases (59%) a copy of the plan was given to the carer, and in 148 cases (56%) carers were informed of the complaints procedure. In just one third of cases (n = 89, 34%) was an emergency contact number entered onto the form to be used in the event that the carer was themselves unable to care. In just 59 cases (23%) was a crisis plan identified, again in the event that a carer might not be able to continue to provide care.

Content of the assessment forms

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)

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 148 cases (58%) *most of the content* recorded on the forms was *appropriate* to the questions asked.
- On 107 forms (42%) *most of the content* recorded was *not appropriate* to the specific questions.
- In 145 cases (55%) the forms contained *detailed evidence of the carer's needs*.

- In 120 forms (45%) the forms did *not* contain detailed evidence of needs.
- The information recorded on the forms provided *sufficient evidence to construct an action plan* in almost two thirds of cases (n = 165, 63%).
- In 98 forms (37%) there was *insufficient evidence* to enable an action plan to be constructed.
- *All* sections of the action plan were completed in just 26% of cases (n = 69).
- In 138 cases (54%) the action plan *would meet most of the needs* identified in the text.
- In 120 cases (46%) the action plans were *not adequate* to meet the carer's needs.
- The action plans were responsive to the specific religious or ethnic needs of the handful (n = 6) of non-Christian carers.
- Unmet needs were identified adequately in 99 cases (38%).
- In 142 cases (54%) was there any evidence of the carer or family receiving any other external support.
- The vast majority of forms had no explicit information or reference to *outcomes* for carers – the main point of conducting a carer's assessment.

Some concerns, 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 271 carers in Nottinghamshire, all of whom had been assessed recently (in 2004 and 2003) by social services or health assessors. 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 recoded) and its *relationship* (if any) to the action plan. The information recorded on the forms is often of variable depth and quality and there is evidence that the questions on the form are often either not understood or not answered specifically by the assessor (which in one third of cases is the carer themselves). There are some findings about the content of the form that must give particular cause for concern, not least:

- In 42% of the forms, *most* of the content/information collected was not appropriate to the questions asked.
- In 45% of the forms, there was no detailed evidence of carers' needs.
- In 37% of the forms, there was insufficient evidence to enable an action plan to be constructed.
- All sections of the action plan were completed in only 26% of cases.
- The quality of action plans is very varied. In 46% of cases the action plans that were constructed were not adequate to meet the carers' needs.

- In just 34% of cases was an emergency contact number provided in case the carer could not care.
- In just 23% of cases was a crisis plan identified.

Because much of the content/information collected on the forms is of limited relevance (to the questions being asked on the form itself), or is limited in its application, this means also that the profile of carers and their needs contained in this chapter is based on data/information that is often partial. It would be dangerous, therefore, to plan service responses to carers based solely on the statistical profile presented here when the statistics themselves are drawn from limited information. However, what the statistics do show are some interesting and important characteristics of local carers and patterns of need and unmet need, for example:

- 59% of carers in the sample are aged over 60 (with over half of these over the age of 70).
- 42% of carers provide full-time, 24 hour a day care.
- A quarter of forms contained evidence of a strained and difficult relationship between the carer and person with care needs.
- Two thirds of carers were providing personal care and more than a quarter of these indicated that they had severe difficulties in continuing to care.
- 90% of carers experienced significant restrictions in their lives as a consequence of their caring roles.
- 55% of carers had emotional problems caused specifically by the caring role and 49% had poor physical health.
- One quarter of carers cannot take a break at all, with another 34% only being able to take a break with severe restrictions.
- In one fifth of cases there was evidence of severe difficulties/anxieties for carers in continuing to provide care.
- 41% of carers had some unmet needs.
- In just 47% of cases there was evidence that the needs of the carer to enable them to continue to provide care had been identified.

These figures suggest that many carers in Nottinghamshire provide care in very difficult circumstances – they care for very long hours; experience ill health themselves (physical and emotional); experience severe restrictions on their lives; cannot take a break; and many find it hard to carry on. However, given the deficiencies in the information recorded on the assessment forms, it is likely that the extent and severity of hardship amongst carers in Nottinghamshire generally will be *greater* than that indicated in the statistical profile of our sample of 271 carers. Indeed, the profiles of ten carers that were interviewed as part of this study (presented in Chapter 4) provide a clear picture of the day-to-day experiences and hardships of Nottinghamshire carers.

The exercise also shows that there is some confusion as to who should complete the form. One third of all assessment questions were completed by the carers themselves, although most assessments were completed by a social worker or other professional. When carers complete the form (self-assessment) they sometimes refer to the needs of the person with care needs rather than focus on their own needs or unmet needs. Having said that, however, on the vast majority of forms there is virtually no information recorded about the person with care needs and little detailed discussion of the quality of relationships between carer and the person with care needs. Even more

worrying, 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 are significant problems relating to the design and layout of the assessment form, and the wording of questions, which contribute to the difficulties experienced in completing the assessment form and which help to explain the deficiencies in the quality and depth of information collected. Thus, having an 'unmet needs box' on the first page of the form, before any other information has been collected, is confusing and leads to many unmet needs sections not being completed at all. And, when the unmet needs section is completed, it rarely relates to the textual information collected later in the assessment process. Overall, there is no clear pathway or progression on many of the forms from the information collected to 'assessment' to 'action plan' to 'implementation'. It is often difficult to identify what the actual 'assessment' is, and almost impossible to know whether or not this has led to any interventions or services for carers.

In order to understand more about the *process* of assessment, and to identify why some of the deficiencies identified in the content of forms had come about, the next phase of the research involved in-depth interviews with 13 assessors. The findings of these interviews are reported in the next chapter.

3

Findings from the interviews with assessors

“Assessments will be used as the key mechanism for consulting carers about needs in order to inform the commissioning of services.”

(Caring Together: The Carers Plan for Nottinghamshire 2003-2006)

Introduction

A sample of practitioners (n=13) who were responsible for conducting carers' assessments were interviewed by telephone in order to get a more detailed picture of their views about the carers assessment form, and the assessment and review processes for carers' assessments. What follows is a summary of the key findings from these interviews. This chapter will describe:

- Characteristics of the sample, time spent on carers' assessments by our respondents and, the pre-assessment preparation tasks they completed.
- Respondents' views of the assessment form and suggestions for improving it.
- Respondents' views of the assessment process, implementation of action plans and reviews of carers' assessments.

The sample

Thirteen people were interviewed over the telephone between July and September 2004, of which two were male and the rest female. The sample was drawn from all of the districts covered by Nottinghamshire County Council (see **Table 2.1**). The staff interviewed worked in either a community or hospital setting. Two respondents worked in the mental health sector, one person worked in a physical disability team, and the rest of the sample worked within adult care services. In terms of job titles: six of the respondents were community care officers (CCOs) and seven were social workers, two of whom held specialist carer support roles.

All the social workers held either the CQSW or DipSW and two of them were qualified as ASWs. The professional qualifications held by the CCOs were more varied: two had NVQs and were currently studying for the degree in social work, two held City and Guilds certificates and the remainder said they did not have a relevant professional qualification.

The purpose of the interviews

Broadly the interviews concerned practitioners' views of the carers' assessment form, the assessment process and any suggestions for change. Our questions related to the carers' assessment form ref ACM/7/ASS(C) used by staff in social services. It should be noted that there was a difference in the form being completed by staff who worked

within mental health services as their form had been previously adapted so that it contained a separate box specifically for self-assessment by the carer.

At the time of the interviews a change had just been introduced in social services in that the assessment form had been entered on to the Council’s intranet for its completion and storage. Also at this time, a consultation was underway within the Nottinghamshire Healthcare NHS Trust about a proposed new carers’ assessment form.

The Findings

Time spent on carers’ assessments

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)

Apart from the staff who held specialist roles, most staff said that the time spent on carers’ assessments was variable depending on the through-put of cases and because they often assessed carers as part of a joint assessment process rather than a specific carer’s assessment. The majority of our sample were completing one or two assessments per month and in only a minority of cases were carers’ assessments a major part of their work (see **Box 3.1**).

Box 3.1: Time spent on carers’ assessments

<i>Expressed as number per month</i>		<i>Expressed as proportion of assessor’s time</i>	
1 to 2 per month	8	5%	1
4 to 8 per month	1	30% - 50%	3

Preparation in advance of conducting assessments

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)

Over half the sample (7) said that they had received no training on completing carers’ assessments. The rest said that they had received some training either whilst undertaking community care assessment training, or on-the-job coaching from their line manager.

Nearly all the respondents said that they gathered relevant information about the carer in advance of conducting an assessment – usually this consisted of looking at the referral form and checking any records about the person with care needs. A minority of staff said they contacted other professionals involved with the family. Those working in a hospital setting said that they usually looked at the patient’s medical/nursing records and that they also picked up information through multi-disciplinary team meetings. A minority of staff said that they would check what services were available in advance of conducting an assessment. Most staff said it was rare to be asked to complete a carer’s assessment without the department having already assessed the person with care needs.

The majority (10) of respondents sent carers a copy of the assessment form in advance of the interview to inform carers of the areas which the assessment focuses on and to give them the option of completing all or some of the form in advance of their visit.

Ten staff said they send out information leaflets in advance of the assessment whilst the remainder (3) were unaware that such leaflets existed. There was variation in the type of leaflets sent out (see **Box 3.2**) which was partly attributed to the particular needs of the carer, but also due to what leaflets were held or available by each office at the time. Many staff found it hard to identify the leaflet titles. Only two respondents specifically mentioned the leaflet produced by the County Council *Caring Together in Nottinghamshire*. One person did not distribute the Department of Health leaflet deliberately because she thought it unfairly raised carers’ expectations, which she considers the Department cannot meet, she felt similarly about the *Caring Together in Nottinghamshire* leaflet.

Box 3. 2: Frequency of types of leaflets distributed

Title of leaflet	Frequency
General information on carers support services (e.g. carers vouchers, Crossroads, support groups, Carers’ Federation)	6
How to get help in looking after someone (Dept of Health)	4
Caring for someone with a mental illness (Notts)	2
Caring Together in Nottinghamshire.	2
Good practice guidelines (Notts)	1

Respondents said that referrals for a carer’s assessment came from several sources: self-referral by carers, GPs, district nurses, ward staff, relatives or friends. One person said that the person with care needs was least likely to make a referral.

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)

The Nottinghamshire assessment form is essentially divided into three main sections:

- the factual front sheet for identification-type data
- the eight key assessment questions
- the action plan

The Nottinghamshire Healthcare NHS Trust form has a couple of additional sections:

- A box for other needs identified following on from the eight assessment questions.
- At the end of the ‘carer’s care plan’ there is also a box for the carer’s response, for completion by the carer and chosen advocates or helpers.

It emerged from the interviews that the assessment form is used in different ways by staff. Some staff used it primarily as a self-assessment form to be completed mainly by carers whereas others regarded it as a tool to be completed by themselves during or following the assessment interview.

Strong opinions were expressed about whether or not the carer should complete the form him/herself. What emerges is that practice and expectations vary on this aspect of carer’s assessments. Comments on this included:

“Carers say they feel different if they complete the form. The process of writing about it unburdens the carer for the first time and makes them aware of just how much they are doing”.

“Generally they [carers] want to fill in the form themselves – important to give them a choice”.

“Often the carer will write down more about themselves than they would say verbally”.

“I fill in the form myself. I don’t think it is appropriate for carers to do. We don’t do this for service users. It is an emotional situation for carers so it is unfair for them to complete it [the form]”.

“In our locality we are advised not to give the form to the carer to complete. I think it is better practice to talk through the form with the carer”.

These two different uses of the form consequently affected respondents’ perceptions of the form and their suggested improvements for it.

Respondents were asked to identify what works well with regard to the carer’s assessment form, what doesn’t and any areas for improvement. Generally comments were more often negative than positive about the assessment form: ‘it feels like a paper exercise’, and ‘absolutely nothing works about the form’ were typical responses.

In terms of the *front sheet* some respondents said that carers disliked being allocated a computer number and that reducing personal information to a code (for example, their ethnicity) was regarded as offensive by some carers. One respondent explained how difficult it was to obtain personal information from carers because they do not regard

themselves as service users. Her solution to this was not to request this information at the start of an interview but to wait until rapport and trust had been established.

The *unmet needs box* of the assessment form appears on the first page of the form along with the factual identification data. About half (6) of the sample used the box in the manner intended; that is to identify unmet needs. They understood that this information would be utilised by others within the department responsible for commissioning services. Indeed two respondents had a direct input into this process themselves and additionally they used this box to flag up problems with service provision or to identify available services that an assessor had not identified. Two respondents spoke of alerting their manager to the unmet needs they identified partly to keep them informed but also to pre-empt any complaint that could follow from a carer.

For other respondents this box was problematic and so they used it in unintended ways, for example, to list the needs of the carer, or to explain the reason for the assessment, or to identify services to be provided, or they chose to ignore it. Several respondents said they did not know how the information in this box was to be used or by whom.

The key recommendations that stemmed from these respondents was that there should be more clarity and guidance about what information was required in the unmet needs box, how it would be used, by whom and how their feedback affected service provision. A couple of staff thought this box should be placed at the end of the form, as it was more logical for it to be there.

With regard to the *actual assessment questions (Box 3.3)*, just over half the respondents thought that the questions were appropriate and/or well focused such that they enabled the assessor to gather relevant information on a carer’s needs. Three respondents considered that the questions were useful for the purposes of self-assessment by the carer. Two respondents thought the form ‘generally good’ and another two thought it provided vital factual information.

Box 3.3: Frequency of responses to positive features of Q1 – 8 of the assessment form

Appropriate number of questions/well focused questions	7
Useful as a self assessment tool /validates carers’ experience	3
Form is generally good	2
Provides vital factual information	2
Meets performance indicator	1
Useful that we give carer a copy	1
Useful that we ask for consent/complaints procedure	1
Useful structure	1
Good links to patient’s form	1
Q 1,3,5 are most useful to carers	1
Inclusion of crisis plan	1

Concerns with the assessment questions were also identified and these are highlighted in **Box 3.4**. For example, five respondents thought that the questions needed to be re-worded for greater clarity either for the assessor or the carer; for example, one respondent said:

“Carers can’t always understand the language used in some of the questions”.

Three respondents thought that there was insufficient space on the paper form for writing responses. On the other hand one person thought that the form was too long and described it as “daunting for staff and carers because people feel they have to complete all of it whether relevant or not”. A couple of respondents thought the questions were too difficult or intrusive which may have reflected their discomfort at the process as much as the carer’s. Comments were made about the prompts under each question. Some respondents thought these were helpful to them as assessors but distracting for carers. A further comment was that these prompts tended to focus on negatives or problems and there was concern about how carers perceive these prompts if they are completing the form as a self assessment.

Box 3.4: Problems with assessment questions 1 – 8 (frequency)

Reword questions	5
Insufficient space for responses	3
Difficult /intrusive questions	2
Q4 and 5 can become muddled	1
Q2 and 5 seem to be duplicate questions to carers	1
Does not account for episodes of illness or new illnesses	1
Very prescriptive and too many tick boxes	1
Too long and not always relevant to all carers	1
Tends to focus on negatives	1
Insufficient focus in the questions on financial /employment issues	1
Unclear which sections carer completes	1

Respondents suggested how the assessment form and the questions it contains could be improved (**Boxes 3.5 and 3.6**). The suggestions varied depending on what the assessor saw as the function or purpose of the assessment form itself and the extent to which they used it as a self-assessment tool.

Box 3.5: Ideas for improvements to the assessment form

More tick boxes (x2)
Reduce to one side A4 and make it more of a narrative approach. New form should have pointers of areas to look at (x2)
Crisis plan and unmet need should both be on front sheet
Emergency contact number and crisis plan should be in a box and should follow Q6
A separate sheet for carers to complete before the assessment interview
Clearer layout
Should put all the information about carer’s assessments plus the form in one booklet
More explanation about the purpose of the form is required on the form itself
More carer- friendly

It was evident that some assessors use their interviewing skills to reframe the questions in a manner which was more sensitive to carers, for instance, using more of a narrative approach with them. For example, Question 1: *History and quality of relationship and caring role. Describe current situation and levels of support* - one respondent re-worded this as “Tell me about the person that you are caring for”.

The use of these skills was often critical in securing information from carers about areas and issues that can be highly sensitive and often quite painful. However, whilst interviewing skills are critical, the questions posed on the form are also important in that they guide the assessor through the relevant sections for which information is required. This is particularly important for less experienced staff or staff who have not

received any training on carers' assessments. **Box 3.6** identifies changes which respondents thought would improve the questions on the assessment form.

Box 3.6: Suggested changes to improve questions on the assessment form

Add a question/ or provide tick boxes re: what do you do each day and each night (x2).
Q1 is intimidating - better to say "tell me about the person you are caring for".
Reword Q2 e.g. "what do you like doing in your spare time? Would you like to carry on doing that?".
Include a question on manual handling as part of Q3 - could integrate Q3 and 6.
Q8: a lot of stigma in being identified as a carer and attending a carers group – need to give more information here.
Merge Q2 and 5.
Add a separate question on finance and work issues.
Add a question about the reason for the carer's assessment.
Split factual information from emotional impact type questions.
Questions need to match up better with requirements on the 'care package' forms.
Add more examples or cues to questions.

The 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)

One of two approaches was taken by respondents in completing the action plan (also known as the 'carer's care plan') section of the assessment form. Some said that they completed the action plan once they were back at their office, after reflecting on the assessment interview(s) and seeking out relevant information on resources. Others said that they completed the action plan during the actual interview with the carer. A few respondents said that they seek advice from either their line manager or a care co-ordinator if they are unsure about what is available or how to access a service.

Respondents identified the features of the action plan section of the form that worked well. Most often they said that it was helpful because it clarified what service/information would be provided and by whom (7) and it acted as a prompt for either themselves or the carer when considering what was needed (3). A minority of respondents said that though the action plan was useful because it highlighted identified needs, it provided information for colleagues in their absence or because it was a record for the carer of what had been agreed.

Respondents identified a number of problems with the action plan section of the form, as identified in **Box 3.7**. The main criticisms were that it contained too much information and that it was too prescriptive.

Box 3.7: Problems with the action plan section of the form

Too much information/ too cramped (x3) Too prescriptive and doesn't allow for the identification of an individual plan (x3) Not user friendly (x2) Repetitive (x2) Contains unclear terminology

In discussing the problems with the action plan, respondents commented that:

“Crisis plan and emergency contact number are rarely filled in as these come last and are lost in the action plan”.

“Knowing who to send a form onto within a PCT can be confusing”.

“Often it [action plan] is rushed through at the end of the interview”.

“Some carers are worried about signing the form and who else will see it”.

“You can't always distinguish between a service for the carer and a service for the care receiver”.

“Hate the bit on the back, too regimented – often there isn't a yes/no answer”.

“If it's already in the text I do not necessarily put it in the action plan”.

There were only a few suggestions as to how the action plan section could be improved (**Box 3.8**) although we must assume that respondents also wanted their concerns addressed too. **An improved layout, clarity of terminology and responsiveness to individual need would seem to be the key aspects respondents identified with regard to improving the action plan.**

Specific reference to the need to improve the collection of information on outcomes was non-existent among our respondents.

Box 3.8: Suggestions for improving the action plan

More blank space to fill in with the things relevant to that carer (x2) Place the action plan section at the front of the form Provide more guidance on its completion Expand the section headed 'information for carers'. Add date to section headed 'support for carers'.

The assessment process

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).

Although we had not sought information on why some carer's refused to have a carer's assessment this theme frequently arose in the interviews. Respondents attributed this reluctance to a combination of factors:

- some carers prefer not to identify themselves as 'carers', rather they believe they are doing what any son or daughter should do.
- carers are reluctant because they have little to gain from the assessment in terms of services.
- carers disliked the idea of becoming 'a case file' and being known to social services.
- the formalisation of the assessment process.
- the assessment process is too onerous when carers are already under pressure in meeting the demands of the service user/patient.
- the term 'assessment' is problematic for some carers, particularly for those caring for people with mental health difficulties.
- fear of impact on the person with care needs, for example the withdrawal of services they already receive.
- fear that the Social Services Department will contact social security.

Given these barriers to carers' assessments we can deduce that where staff are successful in completing carers' assessments they have had to be sensitive and empathic with carers, acknowledge the high emotions that can surround the assessment process and address some of their fears about engaging with the process.

On average, respondents said it took one or two contacts/visits to complete a carer's assessment. A couple of people said it depended on the complexity and that it could take up to 3 contacts/visits. One respondent said that since the form had gone onto framework (intranet) it slowed things down, as the assessor needs to fill in the form on framework and take it back to the carer to read and sign. A couple of respondents speculated that assessors may seek less information in future because of the implications this has for them in terms of having to enter the information onto the electronic record.

Respondents' ability to identify the law and policy underpinning carers' assessments was very variable. Five staff demonstrated a good understanding whilst the rest had either partial or very little knowledge.

Respondents described how they explained the assessment process to carers. The most frequent explanation they gave was that the assessment process gives an opportunity to reflect on what the carer does for the service user/patient and to explore what services may be available to help support the carer. Less frequently mentioned

explanations were: the carer has a legal right to an assessment; that the purpose of the assessment is to identify needs; the purpose is to identify unmet needs.

“ I explain what the process is about; what the outcome of an assessment might be eg services, and to give them [carer] the opportunity to talk and to direct them to services. Need to be honest that we might not be able to provide services to meet needs. But the assessment is a service itself and staff need to recognise this too”.

“ I say that it is for them [carer] to express their feelings on what they do for the person”.

Most staff said that they offer the carer a choice as to whether or not the person with care needs is present during the carer’s assessment. They said carers might feel inhibited talking in front of the person they care for. However, the level of care needs of the service user/patient may necessitate that the assessment is done in their presence. One respondent who commented summed up the dilemmas involved in this decision:

“The decision about the cared for person’s involvement varies a lot and does depend on whether the cared for person has a physical or mental health problem. You have to be sensitive to the cared for person as it could upset them, on the other hand the cared for person can be very useful in saying how much the carer does for them and the toll it takes”.

The majority of staff thought they were effective in carrying out carers’ assessments. They attributed this success to a variety of factors: an ability to empathise/good interpersonal skills (x6); experience of conducting assessments (x3); personal experience of being a carer (x2); knowing the system well and how to access services for carers and service users (1); knowledge of the law (1). Eleven staff thought that their approach to carers’ assessments had changed and improved over time, which they attributed to their own knowledge and experience of conducting assessments gained over time; their recognition of the importance of carers assessments; and an awareness that the Department expects and encourages such assessments to be done. For example, a respondent commented that:

“My attitude has changed. I really do push them now [carer’s assessments] because I think carer’s are essential. The carers assessment makes you think about the carer and not just as part of the service user assessment. Now we can put in the services for carers even if the service user doesn’t want them”.

Two staff thought they were not effective in carrying out carers’ assessments. In one case the person wanted more training on how to conduct carers’ assessments and in the other the person (based in a hospital setting) thought he was less effective because it was not his role to follow up carers once a patient was discharged.

All of the respondents said that they placed a high value on the assessment process for carers because essentially it could bring both practical and psychological/cathartic benefits. They said the assessment process was necessary in order to gain access to services and information. However, considerable frustration was expressed about the paucity of resources available, such that some staff felt embarrassed at how little they were able to offer and others thought that an assessment should not be undertaken if there were no services to offer. Only a few staff recognised that the assessment process could aid the identification of unmet need and link back with the

commissioning side of the department. Some respondents thought that the assessment process helped to prepare the carer for changes ahead, for example where the person with care needs was terminally ill. Many respondents identified that the assessment process itself was helpful to carers as it presented an opportunity for carers to recognise and reflect on their role as carers and consider the needs of the person with care needs. For example, a respondent commented:

“I see the assessment process as a means of getting services for carers and so that they can release their feelings and recognise what they do. Many carers have coped for years without having an opportunity to share their feelings”.

Respondents suggested how the assessment process could be improved (**Box 3.9**). Broadly speaking they were requesting more information for themselves and for carers, and more resources for carers.

Box 3.9: Factors which would improve the assessment process

A leaflet with details of the assessment process, support services and a summary of the questions, which the assessment will focus on.
A shorter assessment process.
A self-assessment sheet for the assessment form.
More resources to meet need – increased carer’s vouchers were most frequently identified.
More tangible benefits as a consequence of receiving a carer’s assessment eg emergency call centre number, alert carer’s GP.
Full details of what services are available for carers and their eligibility criterion to be contained in a handbook for assessors and on the intranet.
More preventative work with carers.

Devising and implementing the action plan

Respondents identified five key factors which determined their action plan and, in order of frequency, these were the:

- carer’s expressed views
- assessor’s professional judgment
- available services/resources
- outcomes identified by the carer
- availability of support from other family members.

It was of concern that no respondents specifically identified that they take account of the carer’s or care receiver’s identity, in terms of their ethnicity, language, beliefs etc when formulating the action plan. It was very rare for respondents to say that they considered explicitly 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. Given the law and practice guidance on carers’ assessments there needs to be a means of prompting assessors to consider what *outcomes* carers seek to achieve rather than following the traditional approach which focuses on assessing needs within pre-defined service availability.

Frequently, respondents expressed their frustration at not being able to offer the services that they deemed necessary in order to fulfil the action plan. Many expressed a view that what they were doing was resource-led rather than needs-based assessments. They thought that this year the situation was far worse than previously in this respect within social services. A few staff said the shortage of resources affected

their assessments in that they purposely did not explore certain areas within assessments because they knew that there were no resources to meet those needs. On a similar theme another respondent commented:

“Restriction in services means we don’t want to offer assessments”.

Most respondents said it was their job to co-ordinate the implementation of the identified action plan. This might involve them in: providing information, referral to other professionals, submitting requests to panel(s) responsible for service allocation, explaining how to use carer’s vouchers etc. Several staff said that a care co-ordinator was involved if the action plan identified that improved services were necessary for the person with care needs.

Responsibility for implementing the action plan could rest with a number of people other than the assessor depending on what a carer needed. For example, a hospital social worker described that she might liaise with the welfare rights officer, physiotherapist and housing department prior to a patient being discharged. She might also make referrals to carer support services, for example for counselling, support groups and breaks. Generally assessors assumed a co-ordination role for the action plan. However, assessors in hospital settings relinquished this role when the patient was discharged from hospital, at which point the case was closed (more usually) or responsibility was transferred to the district offices. Some hospital-based staff thought it would be better for carers if they did the follow-up after the patient was discharged from home.

Most respondents in community settings said that they checked with the carer, usually by phone, whether or not they had received the services that had been identified in the action plan. Normally the carer’s file was then closed at this point – several assessors suggested this was usually within four weeks of completing the assessment.

Different practices emerged for the storage of carers’ assessment forms: some assessors said they were placed on the carer’s file, some on the care receiver’s file (with the carer’s consent), and in some cases on both files. In some cases, a copy of the form would be forwarded on to a relevant professional or panel if a specific service or support was being sought, for example for residential care.

Review of the action plan

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)*

It was apparent from the interviews that there were different practices in operation for the review of the carers’ action plan; indeed one respondent described this as ‘rather woolly’ and said there was a lack of clarity concerning who was responsible for completing these and in what time scales. Other comments were:

“We don’t routinely review carers’ assessments – we do a phone contact unless something has gone wrong”.

“ Reviews should be done by the care co-ordinator but the pressure of resourcing reviews is problematic and a lot of reviews get left”.

“The reviewing officer would pick up from the patient’s record that there had been a carer’s assessment and they would be responsible for reviewing the carer’s assessment”.

Six respondents said that where the person with care needs received a care package, the carer’s assessment would be reviewed at the same time as a review of the care package. A reviewing officer conducted these reviews. Some respondents said this happened six weekly, six monthly or annually.

In the next Chapter we report Nottinghamshire carers’ perspectives of the assessment process.

4

Findings from the interviews with carers

Introduction

The final data-gathering element of the research project was the completion of a number of face-to-face interviews with a sample of carers, to be carried out in their own homes. These would be in depth interviews and, subject to their permission, would be tape-recorded. The interview was to be structured around a list of themes designed to investigate what the carer remembered about their assessment and how it had been conducted. The check list of questions included those asking for concrete answers, such as whether or not the carer had been briefed about the purpose of the assessment, who had completed the form, was the care receiver present during the meeting etc., as well as 'open' questions designed to probe their views on the process of the assessment in order to elicit their frank evaluation of how much or otherwise it had helped them. It was the intention to aim for an informal style of interview whilst ensuring that all aspects of the carers' assessment process were covered, including outcomes and subsequent developments.

Selection of cases

Our target number was in the range 10 to 14 interviews; in order to allow for refusals twenty-one cases were selected from the 271 assessment forms analysed in Chapter 2. This was not a random sample but chosen to meet specific aims, most importantly to form a mix, as far as possible, of the family relationships and circumstances leading to the caring role, with the concern also to include a proportion of minority ethnic group families. The sample covered all seven Districts and was drawn from all parts of the County. Thus, it included families in the suburbs of Nottingham, in other large urban areas such as Newark and Mansfield, and in smaller village communities, including some of remoter parts of the county near the border with Lincolnshire. Finally, some cases were selected because the assessment form appeared to have been completed most thoroughly and comprehensively, suggesting good practice, whilst others were brief and often incomplete.

It was agreed that Nottinghamshire Social Services Department would make the initial approach to all families in the sample, informing them by letter of the research aims of the project and the possibility of an invitation to participate in it. They followed this up with a phone call to confirm whether or not the carer agreed in principle to take part.

From the 21 cases in the sample the Department was unable to make contact with 5 because of wrong or missing information on file with regard to their contact number. There were three carers who confirmed they did not wish to participate. A further one person explained that he had never taken on the carer's role because his wife had sadly died after a very brief illness. Thus, of the original sample, 12 carers agreed to take part if asked. Since this group fitted the selection criteria for the original sample it was decided to request interviews from all these assenting carers.

During the summer of 2004, the research team contacted these twelve, and at the end of the period a total of ten face-to-face in-depth interviews were completed. One of the remaining two subsequently changed his mind. The other, although confirming her commitment to contribute to the research, made a series of appointments with the interviewing team but missed them all. Given the extremely heavy demands of her caring role this was entirely understandable. Our particular regret was that this was the only parent-carer/child relationship we had in our sample.

Of our sample of ten cases, eight of the nominated primary carers were women, though it should be noted that where there were partners involved in the caring relationship they played an active role in sharing responsibility for tasks.

Who was caring for whom?

- 3 daughters were looking after elderly mothers
- 1 son was looking after his aged mother
- 1 daughter-in-law was caring for her mother-in-law
- 3 wives were caring for very ill partners
- 1 husband was looking after his sick wife and two teenage sons
- 1 elderly sister was caring for her younger but elderly brother

The carers

Here we provide brief profiles of the ten carers we interviewed and their family circumstances at the time of the assessment. **All names have been changed to ensure confidentiality.**

Interview 1. Sally Jeffries has cared for her 92 year old widowed mother for the past ten years. Her mother lives in her own house in the same small village where all the family have been well known members of a supportive local community. Her mother's mobility has degenerated over time to the point where she is now virtually housebound and to where Sally's caring role has needed to encompass all aspects of her mother's life. Sally's husband Peter has always played a supportive part in the care of her mother, but at the age of 75 he has recently undergone a triple by-pass operation. Sally has a history of migraines and though she regards herself as capable and level-headed she worries at the effect the increased level of stress will have on her.

Interview 2. Clare Brown has been looking after her mother for two years but in recent times, as her mother had grown increasingly frail, the demands on her time and caring role had grown more acute. Her mother lives close by and Clare's grown up children are very supportive, though their work and family responsibilities limit the amount of practical help they can give. Clare has a loving and close relationship with her mother but her full-time job as warden of a sheltered living complex has been producing a clash of responsibilities with her increased carer role, particularly in the mornings. There are times when she feels so pulled in different directions she worries she is not doing any one thing as well as she should.

Interview 3. Barbara Daniels is a professional woman who has struggled to combine a busy working life with caring for her increasingly ill and totally dependent husband, Jim. His health, never robust, deteriorated over a nine year period to the point where he has long required twenty four hour a day, seven days per week, care. Longstanding heart problems were compounded by the onset of Parkinson's and then Alzheimers which has resulted in severe loss of short-term memory. Grown up children live too far away to provide practical help, leaving Barbara with sole care responsibility. She is utterly determined to continue in this.

Interview 4. Robert Price, an only child, took on the main carer role towards his 95 year old mother following the death of his father twenty years earlier. Her health then deteriorated to the point where she could no longer manage in sheltered housing so that she now lives permanently with Robert and his partner, Meg. They jointly run a small interior design business that they manage from home, which makes it possible (with effort from both of them) to juggle work/care responsibilities, though it is taking a toll. Robert is an insulin dependent diabetic and stress levels have led recently to an increase in hypo incidents. His mother suffers from hallucinatory dementia and is often querulous and very demanding but Robert is a conscientious and devoted carer constantly looking for ways to improve the quality of his mother's restricted life.

Interview 5. Mary Farr, who is herself 78 years old and a widow, has been the main carer of her brother Jack, aged 74, for several years but the burden had grown heavier since the onset of his arthritis and hip replacement. Jack also has Parkinson's and a history of severe depression. Despite this he still insists on living alone in the family farmhouse that has been his lifelong home. This house is large, unheated and now in a rickety and neglected condition. Mary lives in the same village and visits most days to clean and cook for him, having to travel to and fro by bicycle. Other sisters and their partners live in the region and share some of the caring role but Mary worries about her brother if she doesn't see him. Mary is hearing-impaired, has herself had a hip replaced and suffers from osteoarthritis.

Interview 6. Rose Mulligan and her husband Peter have been sole carers of his elderly mother since her health started to deteriorate several years ago. She had moved to be near them when his father died in 1991. She hasn't made many new friends since then and since most of the extended family live in Ireland she has relied on Rose and Peter for company. They live just 10 minutes walk away and have always visited regularly but since the onset of severe arthritis and latterly Alzheimers, Mrs Mulligan's need has increased dramatically to virtually round-the-clock care. Neither Rose, who works part-time, or Peter who has taken early retirement from the police force, enjoy good health. Peter has always been close to his mother and is feeling very stressed by her deteriorated condition.

Interview 7. Betty Cook (aged 75) and her husband George are a devoted couple and have had a long, mutually supportive, happy married life. So she was reluctant to acknowledge that she needed help when his health started to decline several years ago. It had come on gradually but reached the point when Parkinson's had so reduced

his mobility, and onset of dementia had so disrupted their night times, that Betty had lost two stones in weight and her daughter insisted she went to the doctor. He prescribed medication for depression; she was also being treated for angina and osteoarthritis. She has continued to do everything for George, including lifting him at night when he falls from bed, as has frequently happened. He was recently hospitalised with a severe bout of pneumonia; as an ex miner there has been a tendency to breathing-related illness. Betty is determined to continue to care for him but is worried that her own health might let her down.

Interview 8. Eduard Rani is an Iranian who has been caring for his wife, Parissa, and their two teenage sons full-time for the last two years. Parissa suffers from a severe, seemingly deteriorating mental health condition which has resulted in her becoming largely bed bound, physically helpless and subject to hallucinations. Her condition appears to have been exacerbated by the social isolation she experienced following her move to the UK. Eduard is deeply anxious that his wife is not responding to treatment and at the uncertainty about her condition. He gets very little time off from his caring role, only when his sons sit with his wife, which allows him to shop.

Interview 9. Janet Hiller has been caring for her mother, unaided, for eleven years. For seven of those her mother has been bed-bound, suffering from emphysema which has required 24 hour oxygen. Janet moved into her mother's home at this point to prevent her admission into a residential care home. She moved on to part-time work to begin with which she then had to give up when her mother's care requirements increased to needing 24 hour attendance and support. Janet does not regret the care role she has taken on but is stressed by her social isolation. The GP who attended her mother was aware of Janet's situation but she had never been alerted to the services she might have called on. A recent acute episode resulting in her mother's hospitalisation has brought Janet to the attention of Social Services and provided her with immediate information about possible future support.

Interview 10. Mrs Usha Kapoor has been the main full-time carer of her husband since he suffered two serious strokes in 1999 which left him seriously incapacitated. He also suffers from speech failure and confusion and his behaviour can be very disruptive. Renal failure now requires him to attend the City Hospital three times a week for dialysis; because of his uncertain behaviour Mrs Kapoor has to attend alongside him throughout the treatment which can last several hours. Lifting and dressing her husband are the tasks she finds most difficult as he is a big man. Her son and her daughter-in-law, Venu, are supportive but can only help in the evenings.

The onset of care

- **It was usually the case that the need to offer care had started in a small way and had gradually increased as the person with care needs had grown older, or their condition had deteriorated.**

For example, Peter and Rose, reflecting on how their caring role had changed in respect of Peter's 92 year old mother, commented "it sort of built up over quite a long time. It got from doing little bits to help Mum until it became full-time. It came so we couldn't leave her."

Betty looked back to the onset of her husband's Parkinsons Disease and mild dementia: "It came on gradually. I could see it coming but he didn't realise, and it just got worse and worse." Betty described how looking after George affected her. Her age (75 years) and medical condition, osteoarthritis and angina, made the physical strain of moving him extremely taxing: "I was having to get up, I couldn't get no sleep, and I'd come and sit here. I used to sit here, and I was crying because I felt there's no use settling down in there again, because he'll only wake me again. He used to have nightmares and shout out... it got worse and worse, he used to tumble out of bed, and I couldn't lift him up... It was terrible, terrible. I lost two stone. My daughter said to me, 'Mam you've got to do something or you'll end up in hospital.' It really got me down. I used to be sitting here, crying and crying, I couldn't help it, I just couldn't." The GP prescribed tablets for Betty's depression: "I wasn't getting any rest while he was still at home, no rest at all."

Barbara's husband Jim had never enjoyed good health. Longstanding heart problems became compounded by the onset of Parkinson's Disease and later Alzheimers and "as he got progressively worse, I just carried on looking after him."

Janet's mother had been suffering acute respiratory problems caused by emphysema, for 11 years, eventually requiring 24-hour oxygen. Janet had been caring for her all that time. She did everything, both in the house and outside. As the condition got worse so Janet became more and more isolated as she was unable to leave the house for any length of time, not even to do essential tasks: "Mum was upstairs for 12 years, in bed for eight and for the last couple of years she never got out of bed at all. Up to two years ago though she could walk to the bathroom... so at that time I could still do a little bit of my own work part-time, but that gradually dropped off."

How did the Social Services Department get involved?

- **In many cases (five of our ten) the first contact with the social services is after a spell in hospital.**

Although in several cases there had been an increasing pattern of care over a period of years it was only after the person with care needs had been admitted to hospital that social services first become involved. As the time for the patient to be discharged draws near, so that person's home circumstances are investigated. It is often at this point that a care package is put together for the after-care of the patient, and at about the same time, an assessment of the carer's needs may also be completed.

Janet's mother went into hospital in April 2003, "and it was only then that social services in hospital got the ball rolling." She had already been caring for her mother

for years, but throughout these many years of care Janet was unaware that she could have been helped: “When I spoke to people they said ‘Why didn’t you ask?’. But I didn’t know what to ask for, or who to ask it from. The doctor said to me ‘You are knocking yourself out; you should have a holiday’, but he never mentioned the possibility of respite care. Until you’ve done it you just don’t realise what help there is.”

Betty had been caring for George for more than three years before an attack of pneumonia meant that he had to go to hospital. It was then that social services became involved, and a care package for George and for Betty herself was put together.

Mary, who is now 79 years old, is one of a large family. Her younger brother Jack (aged 75) demands and receives considerable care from Mary and her other sisters and their partners. Although Jack suffers with both physical and mental problems, both his sisters insist that, “it is not because he is physically incapable but because he is a helpless type, and he is quite happy to be helpless... he has just got used to other people doing everything for him. By himself he would do nothing. He wouldn’t even open a tin of beans.” They suggest that this pattern of dependence has been the case for most of his life, when he has always expected other people to take all responsibility. He first came to the attention of the Social Services Department in September 2003 when he had need of an operation.

- **In some cases, the carer directly approached the SSD.**

Peter and Rose first approached the SSD to enquire about walking aids for Peter’s mother, and some small household aids. They were told there was a five-week waiting time before they could be seen, so “I just rang them every day and made a nuisance of myself... in the end they realised that we were desperate. Once the wheels got in motion they were brilliant, they were first class... we got everything we needed. Social services were very good, once everything was rolling you couldn’t fault them, but they were slow to get going.” In the event a more elaborate care package was prepared, including attendance at a day centre.

Robert and Meg care for Robert’s 97 year old mother, who has been living with them since she left sheltered accommodation in 2003. They had become increasingly more involved with her needs over a five-year period on an occasional, then a regular and finally a daily basis, until she became so confused and forgetful that she could no longer continue on her own. At this point the GP suggested that they contact the SSD: “It wasn’t easy. You ask about one particular aspect, and they tell you about that. Then a bit later on you pick up some information that social services could also do this. You come to realise that it is a different department and you need to find the right name. Then it turns out to be a different person and you ring them up. It’s uncoordinated. There are social workers, and occupational therapists and psychologists and so on. It took about three months altogether to get everything into place.”

For some people a direct approach to the SSD has worked well. Clare had been caring for her mother for about two years, and asked for help when the time and effort required getting her mother up in the mornings clashed with her duties as warden of a sheltered housing complex: “This was the first time I had had any dealings with the social services about my own family... she was getting very frail, and so I rang and

asked whether there was any help I could have, I had managed as long as I possibly could... a lady rang and made an appointment to meet me, with my mother, at my mother's flat...."

The Carers' Assessment

- **Seven of the assessments in our sample are written in the first person, as though the form had been filled in by the carers or, alternatively, at their dictation. It is not apparent which process was followed. In two cases the pro-forma had not been used, but a separate typewritten statement was attached, one of which was extremely long and detailed and typed on Nottinghamshire County Council headed paper.**
- **Six out of our ten carers had no recollection (or at best the haziest) of their own needs being assessed.**
- **Only one person could show us a copy of their own carers plan; this was the one person who had a copy of their assessment.**

It quickly became apparent that our carefully prepared checklist of themes to be explored was likely to be redundant, as only three of the people we interviewed had a clear memory of taking part in a needs assessment and were able to discuss it. We had a number of prompts to aid people's recall. As well as the reminder of when the assessment would have taken place we listed some of the questions they would have been asked to respond to. We also showed them a copy of a blank action plan form since this would have required their signature and they should have had a copy given to them at the end of the process. Despite these prompts, and even in those cases where people had kept meticulous records, we drew a blank in most instances.

Peter and Sally Simons appear extremely capable and because of Peter's past health needs they have had to be very well organised in their approach to the all round care they have given to Sally's 92 year-old mother over the past ten years. Neither she nor her husband had any recollection (despite considerable prompting) of having completed the assessment form, nor of any discussions with a social worker about it. Sally referred frequently to assessments and to discussions with social workers about her mother's needs, but nothing about her own. She had a file of correspondence with both social services and the health services, but no copy of her carer plan or note of assessment that was apparently completed in March 2003: "We haven't had an assessment at all have we... not really, I mean, they have never been here to this house, it's always been with my mother, and that puts you back a bit, because when she's sitting there you can't say too much in front of her, can you."

Mary Farr's sister, June, who attended our interview, remembers a conversation they had in a corridor with a social worker while their brother Jack was still in hospital. The social worker said she would pass information on to a colleague. But neither of them remembers Mary signing anything nor expectation (still) that Mary might be entitled to access support in her own right. No surprise then that Mary did not have a copy of a care plan. It had in any case been left blank. Neither was the *man* who signed off the form as the assessor the same person as the *lady* Mary had spoken with.

Robert and Meg Price's assessment form is typewritten in the first person and is extremely detailed. But they are very unsure about it: "Hmm...you've got me there. I

don't remember filling in the form myself, but I may have done. I can't remember what the form looked like. I don't remember signing anything, and if I had I would probably have copied it before sending it back... But I do have a note here that a form was left on the 9th of April for me to fill and return." (April 9th was the date given as the assessment start day.)

Barbara Daniels is a professional woman who has meticulously filed all correspondence for many years. Her assessment form is also typewritten, in the first person and is immensely detailed. It became clear during the course of the interview that it is also very accurate. Yet Barbara says, "I never filled in any of those forms, the social worker did it. I didn't type out anything; they must have done it, after a conversation with me." Had she seen the form and the action plan? "I have never seen one... all I've got is the care plan for Jim. I can't remember signing anything, but I suppose it is possible. But I can say categorically that I have not filled in a form, nor read one. I vaguely remember something being read back to me, but I can't remember which form it might have been. But that is not the same as reading it, it's like being given instructions over the phone."

Peter and Rose Simon's assessment probably took place after they asked for a respite break (although they are a bit uncertain about how, when or why): "It rings a bell vaguely but I can't actually remember filling anything in." They don't remember seeing an assessment form or signing a carer plan form: "She came to the house but I can't remember any more about it... I suppose it could have gone in one ear and out the other."

- **Others *did* remember their assessment.**

Janet Hiller has a clear memory of an assessment: "I went to a support group in Sherwood, and someone from social services was there and said that all carers should have an assessment of their own needs. It was just after that Monica rang me and asked if could she come and do it... It was probably about a month after Mum came out of hospital... I remember her filling things in... I think I got a letter afterwards... Monica checked that I was getting all the benefits I was entitled to... Actually, I was a bit surprised that they were looking after *me*..." However, Janet doesn't think she saw a copy of the assessment or was given a carer plan. She checked her files to make sure of this.

Clare Brown also had a clear memory of the assessment, and that everything was explained to her. It was made clear to her that it was her own needs that were to be assessed: "She did give me a basic idea about what it was all about... she asked me to have a look at the form to make sure I understood it, she did say that if there were any problems to ring her and she would advise me... I brought the form home and filled it in... sometimes you need time to think about these things."

Eduard Rani first became involved with the SSD before his wife became seriously ill and in need of care. He and his family came to the UK as refugees and at first were found (very unsatisfactory) temporary accommodation in a hostel. His first dealings with the SSD were to discuss his housing difficulties. Subsequently his wife started to display signs of a severe and deteriorating mental condition, which is ongoing. A carer's assessment was carried out in January 2004 and an action plan prepared.

Eduard remembers this clearly, and was the only one of our ten interviewees who was able to produce a copy of the assessment form and his carer plan.

Vikram Kapoor and his family originate from Pakistan; Vikram suffered two strokes in 1999, and is severely incapacitated. Renal failure requires him to attend the City hospital three times a week for dialysis; he is also losing his memory and gets confused. His daughter in law, Venu, says she would have filled in the assessment form on behalf of her mother-in-law. She remembers the visit by the social worker who then signed it. She doesn't have a copy of the carer plan but she remembers what she wrote so thought it was probably unnecessary. However she was not able to answer anything further about the process of the assessment.

Why is there so much uncertainty about the assessment?

During the course of the interviews some remarks were made that give some clue as to why people's recollections of the assessment are so vague. These refer to the timing of the assessment, the explanations (or lack of them) that are offered about it, the methods of recording that are followed, even to uncertainty about what is meant by the term 'carer'.

It is clear that a substantial proportion of assessments are carried out by staff linked with the hospital while the person with care needs is still in hospital; for many carers this is their first contact with the SSD. This is probably a time of considerable anxiety and confusion, when everyone, especially the carers, focuses on the needs of the patient. In this case it is easy to confuse a carer's assessment with a concern for the care package for the person with care needs.

Barbara Daniels said "Right at the beginning I didn't understand that they wanted to talk about my needs. It wasn't made clear to me; when he said that we have to take account of the needs of the carers it took several weeks for it to register that they were talking about me. It was the same with the OT who arranged for all the alterations, she did a great job, but I didn't associate myself with it. It isn't actually spelled out. I thought they were talking about putting things in place for Jim, not as a support for me personally... to begin with I thought it was just about money, rather than other ways of support. I got it in the end, but it took time."

Robert Price commented: "I do remember someone saying to me that there is assistance for carers, but at the time, being new to the game and with so much to think about at once, it probably wouldn't have gone in exactly what they were saying, rather than 'ah yes, that is about me'."

Peter and Rose Simons were assessed at home but "I can't remember any more about it... it may have gone in one ear and out the other, we were just focussed on getting help... it all blends into one."

Only Clare Brown remembers having the whole process explained to her, being taken carefully through the form before taking it away to complete at leisure, being asked if she understood all the questions, and told what to do if she was uncertain about anything.

Both Barbara Daniels and Clare Brown had strong views about the term 'carer'. Barbara was emphatic that "I have never considered myself to be a carer. *To me the*

girls that came in, the care assistants and so on, they were the carers. I was asked whether I was prepared to do the caring, and for how long would I be prepared to do it. I nearly swore at them... I said Jim is my husband and I will go on doing it for as long as I am physically able to."

Clare disliked the term too. She has not thought of herself as a carer, but was just doing what a dutiful daughter would do for an ageing mother: "What I found very difficult was being called a carer... I said to the lady, 'look she's my Mum, I'm not her carer, I'm her daughter' ... *a carer is a lady who comes in from social services*, but what I am doing is something you do naturally, you look after them don't you, they looked after me when I was little, and now I look after them...."

Outcomes

The carers assessment form concludes with an action plan where are listed any services that the carer may require, any medical, financial or other difficulties that have been identified, and any information needs to be addressed. Some or all of these points may be re-iterated in the 'unmet needs box' on the first page of the assessment form.

The Action Plan contains key information designed to support the carer and according to Nottinghamshire Social Services own guidelines all carers should be offered a copy of their action plan at the conclusion of the assessment. Nine out of ten of our carers claimed they had not received a copy.

However, in nearly every case some additional help and support had followed the assessment, whether or not it was recorded on the form. This might include household adaptations as recommended by an OT, 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 support groups and so on.

Clare Brown, who was extremely happy with the support she received, told us: "Well, I more or less said what I would like, and the plan was drawn up from that... they offered more help than I asked for. I was quite surprised with what help they were willing to give... they gave me some tickets that I could take to an agency if I wanted a break and couldn't go to mum's at tea-time. It was wonderful... she arranged for the occupational people to come in for aids in the house, I hadn't asked about that at all... you don't always know what's available."

Satisfaction with the service offered

How satisfied were our interviewees with the services that they had been offered? Opinions varied quite considerably. In general, Clare Brown was very pleased, although she did have one criticism to make: "Everything worked well, except sometimes at the weekends. It might be 12-o'clock before they came to get Mum up, by which time she was in such a state... I wish they had said 'Look it's difficult at the weekends', and I could have gone down myself." But apart from this her experience of contact with staff of the Social Services Department was entirely positive: "The lady I dealt with was excellent, she really was, very nice, very down-to-earth, very caring, very thoughtful about my own feelings... I did feel that my social worker was very concerned about me... she was very understanding. She gave me her phone number, and if she wasn't there she rang me back. I would leave a message, and not

once did they not get back to me... everything was very smooth... there were no problems at all.”

Janet Hiller was also pleased with her treatment: “I can’t fault social services at all. Respite care worked very well... it was the same with the carers support group, you found out about things and there were people you could ask... sometimes you only find out about things by accident, like I used to do my Mum’s feet, until one day the nurse said you shouldn’t be doing that and she arranged for a chiropodist to come.”

For Barbara Daniels the support systems worked well. She spoke ruefully of the difficult early days, as her husband Jim resented changes to his routines, and was disturbed by the arrival at the house of people he didn’t know. Once these problems were overcome, however, she was very appreciative of all the efforts of the Psychiatric Nurse, the OT and the care assistants.

For Betty and George Cook a care package was put into place, which worked well: “They did everything they could.” Eventually George had to go into a nursing home. Betty visits him every day for several hours. George has settled in so well he believes Betty lives there with him. Betty told us, “he says to me... I didn’t hear you come in last night. Bless him.” Betty is still well supported by a social worker, who is always available for help and advice.

From others there are mixed messages. For Robert and Meg Price. “Once the ball has been kicked off, the service has been pretty good. They provided us with all the things we asked for. The weakest area that I have found in my dealings with social services (and all the other services come to that,) is in simple practical advice. For example I wanted to know whether there were things that elderly people could get involved in to keep them occupied, but no one could suggest things that I could try. Yet that is so basic. I’ve asked social services, and the caring organisations, and no one seems to be able to say you want to read this or try that. Age Concern couldn’t help either. Nor the people at the Day Centre.” They added that: “It would have been much easier if there had been one person who took overall responsibility, a coordinator, who could point you in the right direction and say what is available. Another area that is confusing is the relationship between the social services activities and the medical activities. You see... originally, because of mum’s mental state, we had a psychologist, and a doctor from Lings Bar. Then he sent some sort of a nurse, and then as well there’s the District Nurse... and so it goes on.”

Peter and Rose Simons had a bad experience with agency workers. They told us that the workers were never the same twice, the staff were inexperienced and badly supported: “It was a bit of a disaster; at first we thought this will be great, we will get a night off, but it just didn’t work... what we needed was a regular visitor, an experienced person... the second night it was someone quite different. If we could have had a break from it at the weekends, we might have been able to go on longer, and we wouldn’t feel resentful.”

The strongest criticisms of the service they received came from Peter and Sally Davies. We half anticipated this, as the assessment form was very inadequately completed. The Action Plan was a blank, and the ‘unmet needs box’ was empty, despite references in the earlier pages to Sally’s feelings of inadequacy and depression, her worries about her own health and that of her husband, and of their

need for a holiday. On the last page Sally's surname is spelled wrongly, and the emergency contact number given is actually Sally's own home phone number!

Both Peter and Sally were critical of aspects of the services they had experienced, but their comments were measured, resigned rather than angry. The home care arrangements did not always work well; for example, home care was offered in the mornings and evenings but because of the uncertainty about exactly when the care assistants could arrive (e.g. between 6 and 10) "it is so much easier to do it yourself.... it's all very well in theory but it just doesn't work out in practice.... Anyway you have to go down to check that they've been, so you might as well do it yourself. Eventually you get so frustrated you say, 'Right I'll look after her myself'...we are young enough and fit enough to do it."

Even making contact with the SSD proved to be a source of great frustration and irritation: "We had a few problems and I tried to get hold of the social services and I'm still waiting, I'm still waiting for the reply, for them to get back to me."

They found getting through was only the start of the problems. For Peter and Sally getting any action was even more difficult: "You really have to lose your temper with people and shout. I don't like doing that. To get anything these days you have really got to be irate with people, and that's not right is it? I kept ringing my social worker but she was never there; first she was off sick, and they don't know when she's coming back, but they don't put you on to anyone else... then I kept ringing, but she's off on holiday now, and this is what I got, this person was never there, and no-one took her place." At this stage Sally's mother had gone into hospital on what proved to be a six-week decline before her death. They were desperate for information on whether, or how, they could care for Sally's mother at home and if so, what support might be available: "You just don't know where you are, you're working in the dark. There seems to be a multitude of layers, of bureaucracy, they've all got their little titles, and it's amazing how much leave they have! Normally when you ring, there is just a kid who answers the phone, who hasn't a clue what you are talking about, or who to pass you on to. Honestly dealing with social services is like trying to pin down a jelly."

One last but important point. Several of the men and women we spoke with spontaneously stressed one thing that was very important to them, and that is that while they willingly accept, and will continue to accept for as long as necessary, their responsibilities as carers, they are reassured by the knowledge that they are not entirely alone. This goes beyond taking advantage of any practical help they are offered, whether this be household aids and adaptations, or respite care, help from community care assistants, or the modest freedom that vouchers provide. It is the comfort they derive from knowing that someone else knows of their situation, understands it, and can be readily contacted for advice and moral support.

As Clare Brown said, "it was nice to think that there was a nice caring voice at the end of the telephone. Even after she said 'well I won't be seeing you now for a little while, but here's my number and if you do have any problems ring me', and I felt that I could have done... I had a lot of confidence in the lady."

Janet Hiller made the same point: "I always knew that Monica was there at the end of a phone, if I wanted... that was what I had missed, being able to ask people questions.

Things needed to be explained.” Similarly, Barbara Daniels said of her social worker: “He was my lifeline... I still rang him, even after he moved from one job to another... it makes all the difference if you have got somebody who listens, and is not thinking ‘Oh I’ve heard this all before’.”

5

Some concluding comments

Qureshi and her colleagues 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 Nottinghamshire, and the evidence presented in Chapters 2 and 4, suggests that the above observations appear to hold true locally to some large extent. Moreover, very little has changed since a similar national study in 1999 (Becker and Silburn, 1999). Earlier research conducted in Nottinghamshire on carers’ assessments (Berry et al, 2002; see **Box 1.2** of this report for a summary) suggests that there has been little, if any, improvement in the process of carers’ assessment in the County during the last two years.

In this Chapter we offer some brief concluding comments and identify some points for further discussion.

Good practice

Arksey et al (2000) have identified a number of features of good practice in carers’ assessment drawing on the views of 51 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).

Qureshi et al point out that: “It will be evident that much of the approach perceived as good practice in the process of assessment 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” (p. 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).

Qureshi et al (2003, p. 86) observe that:

“...it is not so much what services that counts (although insufficient quantity is bad news) but whether they are delivered in a way which enables people to achieve the things that are important to them in reducing stress, improving satisfaction, making good opportunity costs and helping them to cope. Again this points to the importance of individual tailoring of support around the outcomes which carers identify as important”.

In Nottinghamshire 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 some assessors are strongly committed to securing the best they can (within available resources) for local carers.

However, the evidence presented in Chapters 2 – 4 also suggests that the assessment process, including the existing assessment form, are not adequate to meet the standards that carers’ require and that assessors want to deliver. The draft assessment tools presented in the **Resources** section of this report draw on these findings, particularly the experiences and views of local carers and assessors, the national Guidance, and what is known about best practice, to present new assessment forms that could lead to significant improvements in the assessment process in Nottinghamshire.

Box 5.1 identifies a number of further ‘points for discussion’ which policy makers and practitioners in Nottinghamshire will need to consider when developing the carer’s assessment process, and when refining the two major resources (the self completion pre-assessment form and the carer’s assessment form) developed as part of this project.

Box 5.1: Points for discussion

A staged approach to assessment is needed. This should include a pre-assessment stage (see **Resource 1**) followed by a formal assessment (see **Resource 2**). However, the formal assessment may require a 'brief' version for some carers, developing into a more detailed assessment where there are far more issues/needs to be examined and met. Assessors should also return to meet with carers after the formal assessment meeting to explain the action that is intended.

Assessments need to be much more heavily focused on outcomes (as the Guidance requires). "... a clear conceptual framework and tools based on carers' views of valued outcomes could be useful in focusing assessments on what was most important to carers" (Qureshi et al, 2003, p. 89).

A proper balance between self-completion and assessor completion is needed. The proposed self completion pre-assessment form (**Resources 1**) is intended for carers to complete (or to think about) while the carer's assessment form (**Resource 2**) is for use by assessors.

Training and support for staff. Some assessors have had little or no formal training on the purpose of a carer's assessment and how to go about conducting one. Many are also unaware of the detail of the Guidance on assessments or the legal framework. A strategy for training and updating is required.

Tensions between needs-led and resources-led assessments. The Nottinghamshire research shows that the assessment process is constrained heavily by resources, so that assessors are mindful not to raise carers' expectations in situations where 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. This situation directly impacts on the quality of the assessment process (for carers and assessors), as well as the outcomes.

The research presented in this report identifies the areas that require further development if local carers are to experience a more positive and beneficial assessment process. The **Resources** that are proposed in the next section of the report will help move this process forward.

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Resources: Draft forms

In this section of the report we present a draft ‘carer’s self-completion pre-assessment form’ and a draft ‘carer’s assessment form’.

The development of these two forms has been informed by the research conducted locally in Nottinghamshire, particularly the views of local assessors and carers (outlined in Chapters 3 and 4); by national Guidance on carers’ assessments (see Chapter 1); and by our reading and understanding of the wider research literature on carers’ assessments (reviewed very briefly in Chapters 1 and 5, and summarised by Saul Becker in a regular series of articles on ‘carers’ in the journal *Research Matters* from 1998 to the present).

Both forms have been subject to a process of consultation with Nottinghamshire carers. The Carers Unit sent a draft of the pre-assessment form to 20 carers who had had an assessment of their own needs within the last year, and sent a copy of the draft carer’s assessment form to another 20 carers who had also been assessed in the last year. The forms presented here take into account any changes suggested by these carers available at the time of publication.

For the *pre-assessment form*, carers were asked:

1. Is the form a good idea?
2. Would the form have helped you prepare for your own assessment?
3. Is having such a form better than not having any ‘pre-assessment form’?
4. Is there a better way of preparing carers for their own assessment?

The 18 carers who responded *all* said that the form was a good idea and 16 of the 18 said that it would have helped them prepare for their own assessment and 17 thought that the form was better than not having any pre-assessment form. One commented: “I give the form 98 out of 100”.

For the *carer’s assessment form*, 20 carers were asked a similar range of questions, but unfortunately the response rate was low (the consultation coincided with the run up to Christmas). However, those carers who did reply thought that the new form was a marked improvement on the old form and would make the assessment process more clear and understandable for carers.

Nottinghamshire Social Services Department is now refining these draft forms and consulting more widely, with a view to finalising the content of the forms, preparing guidance for assessors on how the assessment process should be undertaken, and determining the training implications.

Resource 1

Carer's self-completion pre-assessment form (draft)

The carer's self-completion pre-assessment form

Carers National Association (now Carers UK) has developed what Wood and Watson (2000) call a 'practice self-assessment form' for carers which they can complete before their actual assessment and which enables them to focus on their role as carer, the main difficulties they experience and what they would find helpful (reproduced in Wood and Watson, 2000, pp. 29-30, although a more up to date 2004 version is available on the Carers UK website and drawn on below, amongst other forms).

Wood and Watson (2000) suggest that working through a 'practice' assessment form will prepare carers for the 'real thing' and help them to get more out of it. It will also help them to realise just how much care they are providing (p. 27).

Below we provide a 'carer's pre-assessment form' (we prefer this title to Wood and Watson's notion of a 'practice self-assessment'), which can be designed and printed as a 4-page A4 booklet. This is intended for carers to complete in as much or as little detail as they want (if at all), a few weeks or days prior to their 'formal' assessment meeting. This will enable carers to give thought to their situation and caring roles and to prepare themselves for the assessment and what they also want to raise with the assessor and get out of the process. The form draws on ideas from Carers UK, other local authorities and from our knowledge of what is required in the assessment process.

Carers would be sent the pre-assessment form with a covering letter from the assessor, probably also informing them of the date for the assessment meeting itself.

As indicated above, this draft form has been subject to a process of consultation with a sample of Nottinghamshire carers.

Getting ready for your assessment

Things for carers to consider before you have an assessment of your needs

Before you start – information about this form

This form has been designed to help you prepare for a carer's assessment and give you time to think about what you might want to talk through at an assessment.

If you are providing 'regular and substantial care' for a relative or friend who is ill, disabled, elderly, has some mental health problem or any other needs for care or supervision, then you may be entitled to a carer's assessment.

The purpose of a carer's assessment is to enable **you** to discuss with social services what help **you** might need with caring as well as any help that would maintain your own health and well-being. Nottinghamshire Social Services Department uses assessments to decide what help, if any, they can provide to **you** as a carer. Carers are not charged for these assessments.

This form does not replace the assessment, which will come later when an appointment has been made with you at a suitable time. **The questions below are intended to help you give some thought about your role as a carer and what support you might need. There are no right or wrong answers.**

Please answer the questions as fully as you wish, or if you prefer, you could just think about what your answers would be. You do not have to fill it in if you do not like forms. It is also up to you whether or not you want to give this form to the assessor when they come to meet with you, or whether you want to keep it to yourself. Please keep the form handy so that you can refer to it when you have your assessment meeting.

If you have any questions about the form, you can contact [name of person, telephone number] who should be able to advise you.

Questions for you to consider

Housing

Do you and the person you care for live together? Yes No

Are you happy with this arrangement? Yes No

If not, what changes are needed?

.....
.....
.....

Health of the person you look after

Does the person you look after have any physical or mental health problems, or behaviour, that you find hard to deal with? Yes No

Please describe these here:

.....
.....
.....

Your own health

Do you have any health problems of your own? Yes No

Are you getting enough sleep? Yes No

Is your health being affected by caring? Yes No

Are you anxious or depressed? Yes No

The time you spend caring

About how many hours a week are you involved in caring?

1-9 hours a week 10-19 hours a week 20-40 hours a week 40+ hours

Do you have to help with the following tasks? Please tick ALL that apply:

Housework	Other personal care (like dressing)
Shopping	Keeping an eye on the person to prevent any harm
Extra laundry	Dealing with money (cashing pensions, etc)
Bathing	Helping the person take medications
Toiletting	Keeping the person company
Cooking	Taking the person shopping or to appointments

When do you help?

Day time Night time Day and night

Relationships

Does caring affect your relationships, either with the person you look after or other members of your family or friends? Yes No

If you are a parent, is caring making this role harder? Yes No

Work

If you are in paid work:

Are you finding it hard to combine work and caring? Yes No

Have you had to reduce your hours of work? Yes No

If outside paid work:

Would you like to return to work? Yes No

Other interests

Do you want to do any training or adult education? Yes No

Do you want to pursue any leisure interests/hobbies but are prevented from by your caring role? Yes No

Help or support you and the person you look after currently receive

This can be from social services, health services, housing or other family members

The help you get	Who from?	How often?

The future

Are you able to begin or continue caring? Yes No

Are you ever ‘off duty’? Yes No

Can you regularly get a break from caring? Yes No

What help and support would make caring easier?

Make a list of all things, even if you are not sure whether they are available. Here are some ideas to get you thinking (someone to talk to, counselling, a few hours break from caring, information about local carer’s projects and support groups, benefits advice, etc)

.....

.....

.....

.....

.....

What are your main concerns and wishes for the future?

.....

.....

.....

Dealing with emergencies and unplanned events

Do you need help to plan what needs to happen should you suddenly become ill or have an emergency?

Yes No

Do you know who to contact in an emergency?

Yes No

The next step – arranging your carer’s assessment

Is there anything you think social services needs to understand about your culture, religion, language, the way you communicate, or any other areas of your life, before they try to assess your needs as a carer?

Yes No

You can have a friend or relative or someone else you know with you at the assessment to help you tell us about your needs. Would you like this?

Yes No

Do you want to talk to your assessor together with or separately from the person you care for?

Separately Together

Please keep this form handy so that you can use it to help you at your assessment meeting.

Thank you for taking the time to go through it.

Resource 2

The carer's assessment form (draft)

The carer's assessment form

Below we provide a draft of a new carer's assessment form to be used in Nottinghamshire. The form draws on the research evidence presented throughout this report (particularly the experiences and views of assessors and carers), and our knowledge of the law and good practice in carer's assessments. It also incorporates what we see as useful questions from assessment forms used in other parts of the UK.

This form would be completed by an assessor, not by the carer. It is anticipated that the assessment itself would require a minimum of one face-to-face meeting, but may in many cases require more interviews.

As indicated above, this draft form has been subject to a process of consultation with a sample of Nottinghamshire carers and guidance on its completion is now being drafted by Nottinghamshire Social Services Department.

Carer's Assessment Form

Referral monitoring information

Date of referral to SSD

Date carer's assessment started

Date carer's assessment completed

Date review due

Assessment type 30

Input on KPR by initials

(Plus any other standard items required)

Details about the carer and their household

Carer's details

Carer's name

Address

Postcode

Telephone

Mobile

Email

Date of Birth

Relationship to the person with care needs

Employment status: Not in work full-time work Part-time work

Occupation

Work telephone number if applicable

Gender F M

Ethnic origin

Details of person with care needs

Religion

Name

Address if different

Postcode

Telephone

Date of Birth

Relationship to carer

Gender F M

Ethnic origin

Religion

Assessor's details

Name

Job title

Team

Address

Telephone

Email

Housing

Does the carer and the person cared for live together?

Yes No

Is the carer satisfied with this arrangement?

Yes No

If not, what changes are needed?

Health of the person cared for

Why does this person need care?

How long has the carer been caring for this person?

Does the person receiving care have any physical or mental health problems, or behaviour, that the carer finds *particularly* hard to deal with?

Physical problems

Mental health problems

Behaviour problems

Please describe these difficulties:

What areas of the caring role does the carer find rewarding?

The Carer's own health

Does the carer have any health problems? Yes No

If yes, please specify here.....

Is the carer's health being affected by caring? Yes No

If yes, please specify how.....

Is the carer anxious or depressed? Yes No

Is the carer getting enough sleep? Yes No

The time spent caring

About how many hours a week is the carer involved in caring?

1-9 hours a week 10-19 hours a week 20-40 hours a week 40+ hours

What types of care does the carer provide?

Type of care	Tick as appropriate	
	Day	Night
Housework		
Shopping		
Laundry		
Bathing/washing		
Toileting		
Cooking		
Assisting with feeding		
Keeping an eye on person to prevent harm		
Dealing with money/household accounts etc		
Helping with medication		
Moving person		
Keeping person company		
Accompanying person		
Dressing		

Relationships

In what ways does caring affect the carer's relationships with the person they care for?

In what ways does caring affect the carer's relationships with other family or friends?

Work

If the carer is in paid work:

Is the carer finding it hard to combine work and caring? Yes No

Have they had to reduce their hours of work? Yes No

If the carer is not in paid work:

Would they like to return to work? Yes No

Other interests

Does the carer want to do any training or adult education? Yes No

If yes, please specify.....

Does the carer want to pursue any leisure interests/hobbies but are prevented by their caring role? Yes No

If yes, please specify.....

Carer's Identified Support Needs

Tick all boxes that apply

Carer's identified support needs	Need information on	Need practical support
Alterations to house		
Aids (eg hoist, bath chair, taps, etc)		
Benefits/money advice for carer		
Short break at home (eg care attendant/sitting service at home)		
Short break outside home (eg residential break for cared for person)		
Medical/health care for carer's needs		
Stress relief for carer		
Emotional support (eg counselling, befriending) for carer		
Support groups for carer		
Training in moving & handling		
Training in behaviour management		
First aid training		
Information on diagnosis/illness of cared for person		
Advocacy services for carer		
Day care for cared for person		
Community alarm/alert response system for cared for person		
Direct payments for carers		
Power of Attorney issues		
Legal matters (eg guardianship)		
Carers vouchers		
Other information needs (specify).....		
Other support at home (specify).....		
Review of cared for person's care plan		
Other		
Other		

Carer's Support Plan

Complete only those that apply (see Table above)

Information and services required	Action that might help to meet needs (specify for each)	By whom?	Carer's Priorities: 1 (highest) 5 (lowest)
Alterations to house			
Aids (eg hoist, bath chair, taps, etc)			
Benefits advice/money check for carer			
Short break at home (eg care attendant/sitting service at home)			
Short break outside home (eg residential break for cared for person)			
Medical/health care for carer's needs			
Stress relief for carer			
Emotional support (eg counselling, befriending) for carer			
Support groups for carer			
Training in moving & handling			
Training in behaviour management			
First aid training			
Information on diagnosis/illness of cared for person			
Advocacy services for carer			
Day care for cared for person			
Community alarm/alert response system for cared for person			
Direct payments for carers			
Power of Attorney issues			
Legal matters (eg guardianship)			
Carers vouchers			
Other information needs (specify).....			
Other support at home (specify).....			
Review of cared for person's care plan			
Other			
Other.....			

Unmet needs (to be completed by assessor after the assessment meeting)

List below all those needs identified in the Table on Carer's identified support needs which have not been addressed in the Table on Carer's support plan, particularly any needs identified as a 1-5 priority by the carer.

If no unmet needs state 'NONE'

Crisis plan

Does the carer know who to contact in an emergency? Yes No

Who would the carer contact? Provide details of name and contact details for day and night time use

Day:

Night:

What arrangements does the carer have in place if they become unable to care?

Declaration

I have been involved in putting the support plan together and consider it is an accurate reflection of my support needs.

I have been involved in putting the support plan together but consider that it does *not* meet my support needs.

Signature of carer *Date*

Consent

The information that the carer has provided may need to be shared with other agencies in order to obtain information and services

I give my consent to the sharing of personal information with agencies (including health, social care, voluntary and private organisations) necessary to meet my support needs.

I give restricted consent to the sharing of personal information. My information should *not* be shared with the following people or organisations:

.....

I do *not* give consent to the sharing of my personal information and I understand that this can restrict the support that I might receive.

Signature of carer *Date*

Note: Information recorded on this form will be held manually and on computer. Maintenance of the records and the information contained therein is subject to the provision of the Data Protection Act 1998

Signing off details to be completed by assessor
Date copy of assessment and support plan given to carer:
Date complaints procedure given to carer:
Date assessment and support plan sent to Carers Unit:
Date set for review:

[ENDS]