

# Family Carers on the Margins: Experiences of Assessment in Mental Health

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*Report to the National Coordinating Centre for NHS Service Delivery and Organisation R&D (NCCSDD)*

*Summer 2008*

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## ACKNOWLEDGEMENTS

In a project of this length and complexity it is not possible to thank individually all those people who have helped to ensure that the work was completed. However, we would like to offer our sincere appreciation to:

- All members of the project advisory and reference groups.
- The leads for the NIMHE Regional Centres.
- All those at the case study sites whose help was invaluable in organising data collection, and all those staff who gave of their time to share their experiences with us.
- The carer researchers who worked closely with us throughout the project, and who contributed significantly to its success.
- To Barbara Langridge at SDO for her patience and understanding.
- To Joanne Clarkson for administrative support in the early phases of the project.
- For the smooth running of the project, and particularly the production of the final report, we are deeply indebted to the Project Administrator, Helen Mason, for her invaluable expertise and support.
- We would like to acknowledge the important contributions made by Professor Pam Enderby, especially during the early stage of the project and the generation of the report of the carer consultation days, and to Dr Peter Goward for conducting staff interviews at two sites, and for his repeated efforts to engage with the PSI site.
- Ultimately, however, we cannot thank enough those carers who, in their already very busy and often stressful lives, were kind enough to share their experiences and in doing so made this study possible.

## **EXECUTIVE SUMMARY**

### **Key Findings and Recommendations**

#### **Background to the Partnerships in Carer Assessment Project (PICAP)**

The need for the present project was identified following a major literature review on interventions with family carers in mental health (Arksey et al 2002) and a scoping exercise (Newbrunner and Hare 2002) funded by the NHS SDO programme on carers of people using mental health services. These reports highlighted the current limited understanding of the practice of carer assessment and carers' experiences of, and the consequences arising from, such assessments. They recommended the need for further research which the SDO duly commissioned.

In submitting a tender we argued that any project should identify areas in which good assessment practice existed and explore their characteristics in detail in order to distil key lessons that could be applied elsewhere. We also believed that the project should focus on the nature and quality of partnerships between family carers and formal service systems, and that the best way to explore such partnerships was to involve carers at all stages of the research process. Accordingly we called the project 'The Partnerships in Carer Assessment Project' (PICAP).

In relation to carers of people with mental health problems the overall aim of PICAP was to provide an improved understanding of:

- the rationale for assessment;
- the processes, experiences and consequences of the assessment;
- the challenges and opportunities of partnership working.

Our ultimate goals were to:

- provide insights to inform theory, policy and practice; and
- generate principles and guidelines for best practice that would help to empower and inform carers and those conducting assessments.

## **Methodological approach**

In addressing these aims we adopted a multi-method, multi-phase approach underpinned by constructivist principles that actively engaged carers throughout, including the employment of 'carers as researchers'. The methods employed involved: an analysis of the Local Implementation Team (LIT) plans for Standard 6 of the National Service Framework (NSF) for Mental Health; consultation exercises with carers in the eight NIMH[E] (National Institute for Mental Health [England]) regions of England; a comprehensive and systematic conceptual synthesis of the literature on the experiences of family caring in mental health; and detailed case studies at 9 sites involving analysis of documentation and in-depth interviews with a range of key informants and carers, the latter after an assessment and 6 months later. These case studies focussed primarily on assessment and support for carers of adults with mental health problems. In a later addition to the study we sought to explore carers' experiences in sites providing assertive outreach (AO), psychosocial interventions (PSI) and family group conferences (FGC). One of the initial sites focussed specifically on the needs of young carers. Recruitment of carers proved challenging at all the adult sites (see Chapter 1) and, despite repeated efforts, it proved impossible to recruit any carers at one site (that providing PSI, see Chapter 3).

Whilst our initial intent had been to focus on carer assessments, it was not meaningful to carers to divorce assessment from the on-going and often negative experiences that they had of the wider service system in mental health.

PICAP concluded with a workshop that identified the key messages from the project for creating partnerships between family carers and services. These are produced as a separate document to this report.

## **Overall findings**

With the exception of the site supporting young carers the main messages emerging from these diverse data sources were markedly consistent and, at one level, might be seen as disappointing, given that we had specifically targeted areas in which there were grounds for believing that good practice in carer assessment was evident.

Whilst we encountered some dedicated and committed practitioners who were passionate about the rights of carers, and also many carers who had found the process of assessment itself a positive and affirming experience, carer assessments across all the adult sites were not realising their full potential.

The number of assessments undertaken was low, the carer refusal rate high, and subsequent action was often minimal or absent. Furthermore, eligibility criteria limited access to assessments for many carers, particularly those caring for people not using mental health services. Regular follow-up was the exception rather than the rule, as was innovation in service design and delivery. Within the context of heavy workloads and limited resources, carer assessments were often not prioritised, and if they were undertaken then the reasons for their completion were often instrumental – either to meet targets or to access resources such as carers' grants. Carers themselves disliked the word assessment and saw it as little more than a 'tick box' activity and

'paper' exercise in many instances. Given all the legislative and policy attention to carer assessment, the key question is: Why do systems for carer assessment seem so poorly developed and applied in practice?

It is important to point out that this situation is not confined to the field of mental health, several recent reports highlighting that carer assessments generally suffer from problems of low uptake, limited awareness amongst carers, and little or no subsequent action (Audit Commission 2004, SCIE 2005, Roulstone et al 2006, Newman and Hughes 2007). It seems that, despite the legislation over the last decade, professionals' attitudes to carers and their understanding of carers' needs and contributions remain poor. The Audit Commission (2004) declared itself 'surprised' at professionals' attitudes to carers, and in the recent survey conducted by Carers UK the most frequently requested improvement amongst carers was greater recognition from professionals (Carers UK 2007).

The roots of such difficulties are complex and long-standing but are exacerbated in mental health by several factors, including: the isolation and stigma associated with mental health problems; the fluctuating and unpredictable nature of the challenges carers face; and the history of antagonistic and conflicted relationships between carers and service providers in which carers are frequently still blamed for their relative's condition. Such issues have been recognised for some time, and recently there have been renewed calls for a culture change within mental health services and a reappraisal of professionals' relationships with families (SDD 2006, Simpson and Benn 2007). Our own results forcibly support this conclusion. However, the challenges of achieving such a culture change are significant as difficulties are rooted in historical legacies, often implicit, tacit, and deeply entrenched beliefs and the general failure to fully appreciate the complex nature of caring in mental health.

### **Findings from the literature**

The results from all phases of the project were remarkably consistent and highlighted the marginal position that carers continue to occupy in the mental health system. For example, the literature synthesis confirmed and extended the conclusions reached by Arksey et al (2002) that our understanding of the caring experience in mental health remains rudimentary, and the major focus remains on schizophrenia to the relative neglect of other forms of mental illness, with the continued dominance of a burden model being used to understand carers' experiences. Consequently, with a few notable exceptions, our appreciation of the meanings that carers bring to their situation, and how these may change over time, remains limited. As a result there is little in the way of well developed theory to inform proactive work with carers.

The literature also made it abundantly clear that the nature and quality of carers' relationships with mental health professionals and service systems are crucial, with early encounters being formative. However, these are frequently characterised by limited attention to carers' needs and contributions, with carers often describing how they have to battle with service systems. Consequently, whereas carers generally have ambiguous relationships with services, those in mental health are more likely to be antagonistic and alienated. Such relationships present formidable barriers to genuine partnership working which include:

- the persistence of a 'blame culture' towards family carers;
- the failure to recognise and draw upon carers' expertise and knowledge;
- services that remain focussed on the individual service user rather than mutualities and interdependencies between family members;
- the continued reliance on a system focussed approach to mental illness;
- the tensions caused by systems and practices designed to maintain confidentiality.

Such factors are exacerbated by the lack of training and skills for work with carers, limited incentives and high workloads. These educational and workforce factors constrain the ambitions of those who wish to work in a more proactive fashion. With regard to the limited literature on carer assessment, whilst examples of good partnership working do exist, their routine and widespread application is not the norm. Consequently, in mental health the number of carer assessments completed is very low and assessments may not subsequently be acted upon.

## **Building on the literature**

We wanted to explore whether the above situation remained the case, or whether/how any of these difficulties had been overcome. To do this we adopted two main approaches. One investigated the ways in which carer assessments are organised and delivered; the other explored carers' experiences of assessment and its consequences. As noted earlier, the former activity comprised an analysis of LIT plans for Standard 6 of the NSF for older people and detailed case studies in 12 areas, 9 operating carer assessments and 3 providing support to carers via different service models (psychosocial interventions, assertive outreach and family group conference). Carers' experiences of assessment in particular, and mental health services in general, were captured by means of 8 consultation days involving some 99 carers, and in-depth interviews with carers after an assessment ( $n = 93$ ) and again some 6 months later ( $n = 77$ ). The main themes arising from these two later analyses were then synthesised with those emerging from the literature.

## **The organisation and delivery of carer assessments**

### ***The national picture***

Our aim was to complete a census of LIT plans across England to provide a comprehensive picture of the 'state of play' in respect of carer assessment. However, despite repeated attempts our efforts to obtain the LIT plans had limited success (42 plans returned from 166 teams, see Chapter 3). Overall, those we managed to obtain were in a rudimentary state of development and most were brief.



Relative to other standards in the NSF, the attention given to Standard 6 was limited, and most plans focussed only on carers of people on CPA. The proposed focus of assessment varied but was often highly structured and concentrated mainly on instrumental aspects of caring. The service responses suggested in most LIT plans were 'traditional' rather than innovative.

The overriding impression gained from the exercise was that on a national scale, at least in so far as can be judged from the LIT plans, arrangements for carer assessments were, with a few notable exceptions, in an early stage of development.

### ***Local implementation***

Case studies confirmed the impression gained from the LIT plans that many areas were still in the process of developing assessments alongside other carer services and supports. The rationale for assessment was largely policy driven, but their form and process were influenced by the values of key stakeholders – including local carers. Overall, two models of carer assessment emerged, one in which assessments are conducted by dedicated carer assessors, the other in which assessments are carried out by service users' care co-ordinators. There are advantages and disadvantages to each approach. Irrespective of the model used, interpretation of 'regular and substantial care' varied between sites, with eligibility often being confined to carers of people on CPA, which effectively excluded significant numbers of carers.

Even in 'good practice' sites the number of assessments completed was low, due largely to reluctance on the part of practitioners. The primary motivation for completion of many assessments was often instrumental, either because there was a requirement to do so, or to access resources available under the Carers Grant. However, this did not necessarily mean that all carers were unsupported. Routine therapeutic support and information for carers was often provided by care co-ordinators who saw little advantage in undertaking a lengthy assessment. Much of the emotional and practical support for carers was provided by the voluntary sector, but assessments were primarily undertaken by statutory agencies, leading to duplication of work.

In sites offering alternative forms of carer support (AO, FGC and PSI) there were difficulties identifying and engaging with families. Although the AO approach was appreciated by carers, a regular assessment of every carer's needs would have offered additional benefit. The PSI service did not engage with one family during the one year recruitment period. It may have been possible to provide at least a minimal level of support if all carers were offered an assessment. Family group conference provided an opportunity for friends and family members to meet and discuss their roles and responsibilities in relation to the service user, but did not provide support to carers in their own right.

### **The experience of assessment – hearing the carer's voice**

In providing a comprehensive understanding of the experience of assessment we synthesised three sources of evidence: the main themes emerging from the literature; the results of the carer consultation days; and the analysis of the interviews with carers

after an assessment and 6 months later. The main issues emerging were remarkably consistent, and a number of main themes were generated. These were:

- 'The talk is of partnerships, the experience is more like conflict'
- 'What's in a word?'
- 'Crisis, what crisis?'
- 'No great expectations'
- 'It's both what you do and the way that you do it'
- 'Promises. Promises'

These are briefly described below. However, before doing so, it is important to make clear that the vast majority of carers who took part in the study felt that an assessment of their needs would not be required if better services were available for their relative. This was their top priority.

#### ***'The talk is of partnerships, the experience is more like conflict'***

The aim of PICAP was to focus primarily on the experiences and outcomes of assessment but it became abundantly clear at an early stage that this could not be divorced from carers' prior experiences of, and contact with, the mental health system. These were usually long and often conflicted.

As with the literature, carers described their early days as being characterised by uncertainty, with little understanding of what knowledge and skills they needed, who to turn to for support, and what help they could reasonably expect from services. They received little support at this time. As time went by carers accumulated experience and expertise but this was often unacknowledged by services, and carers felt that they were stereotyped in various ways. Too often they felt they were perceived as 'part of the problem rather than as part of the solution'. In particular they reported that a 'confidentiality smokescreen' was used inappropriately by professionals to keep them 'out of the loop'.

As a result of their experiences relationships with services were often fraught and such relationships tended to set a context for the assessment that was less than positive.

#### ***'What's in a word?'***

Both the term 'carer' and 'assessment' raised concerns in carers' minds. Many, with long experience of supporting a relative, did not see themselves as carers but rather as a parent, partner or sibling. Yet to qualify for an assessment and subsequent support 'carers' had to be recognised as such both by themselves and the 'system'.

With regard to assessment most carers disliked the term, feeling that their competence to care was somehow under scrutiny. There was also some confusion about the purposes of assessment - for some carers the litmus test was whether in the end it benefited the cared-for person, but for others it was felt that the focus should be more on their needs. Concerns were expressed that certain carers were being excluded from carer assessments because they did not meet the enhanced CPA criteria, and there were widespread feelings that anyone offering care and support to a relative with an enduring or episodic mental health problem should be able to access a carer assessment.

### ***'Crisis, what crisis?'***

Both the carers' legislation and Standard 6 of the NSF make explicit that certain carers have the right to an assessment on a regular basis and that there should also be periodic review. This suggests a proactive and planned approach. However, carers' experiences were rather different.

Despite their prior contact with services, for most carers the offer of an assessment was the first time that specific attention had been given to their needs. However, because of negative prior experience of services, some rejected it. Many other carers did not want to focus on their needs but rather their main goal was to achieve better services for their relative.

For those carers who accepted an assessment, the arrangements were often ad hoc and seemingly unplanned. The assessment itself was sometimes precipitated by a crisis in the user's care, sometimes by a series of random events, sometimes by a proactive carer initiating the process, and occasionally following a complaint by the carer. Far less often was it a planned process. Consequently, carers often had little, if any, prior warning, limited understanding of the nature and purpose of the assessment, or what to expect of it.

### ***'No great expectations'***

Due to the nature of their prior contact with mental health services, and the fact that many of the assessments were arranged at a time of crisis (see above), most carers either did not know what to expect of the assessment or had very low expectations, seeing the process as little more than a 'tick box' activity designed to ensure that targets were met.

### ***'It's both what you do and the way that you do it'***

Notwithstanding the difficulties numerous carers experienced with the events leading up to the assessment, many found the process of having an assessment positive and affirming. This was largely dependent both on the person conducting the assessment and the way in which it was delivered.

The process of assessment was considered particularly important, with carers wanting a sensitive approach that allowed sufficient time to build rapport. Preparatory material that alerted carers as to what to expect was also much appreciated. Carers believed that there should be a choice as to venue and whether or not the service user was present. With regard to content carers were clear that assessment framed by a pathological view of family functioning was not appropriate. They wanted the opportunity to explore their subjective views and experiences of their situation, and how these changed over time, how they might cope better, with due attention being paid to the needs of the wider family.

Given the often difficult situation carers find themselves in, they typically wanted an opportunity for a full and frank exchange of ideas and expertise with assessors. Partnership working was viewed as highly desirable, though it was acknowledged that potential conflicts of interest needed to be accommodated. Advance directives were advocated as a useful part of planning for the future, as they provided carers and the rest of the family with a sense of security. The need for greater cultural sensitivity was widely endorsed.

Over and above these considerations carers recognised that conducting an assessment was a highly skilled process and demanded well developed interpersonal and communication skills. It was clear that the quality of the assessment depended largely on the personality, skills, knowledge and experience of the assessor, and their ability to establish rapport and trust quickly. Importantly, carers wanted assessors to be credible and to have the authority to 'make things happen' following the assessment. This was not always the case, as the final theme – 'promises, promises' illustrates.

### ***'Promises, promises'***

A key consideration was the intended outcomes of assessment. Carers had some clear views on this. At the heart of their desires lay better support for the person with mental health problems. However, over and above this, they hoped that assessment would lead to: more acknowledgement of their situation and expertise; greater respect for their contributions; and their fuller inclusion in the team. At a more concrete level they wanted a clear care plan to address their needs, with named responsible people and their contact details, especially at a time of crisis. Services needed to be more innovative and flexible, including options available if carers did not want to continue in their role.

Outcomes immediately following the assessment were often limited. Other than the opportunity to be 'listened to', the most frequently perceived benefits were: advice about financial benefits; more information about the user's illness/treatment; and the offer of some form of respite break. Many carers greatly enjoyed and benefited from such a break but, despite desperately needing a break, some were unable to take one because of lack of confidence in the user's care, or guilt about enjoying themselves when the user was ill. Several carers would have been unable to accept the break without the support of their wider family, who adopted their caring responsibilities whilst they were away.

Whilst grateful for what they received, most carers would have valued much earlier the advice about social security benefits, or the provision of a break.

### ***What happens next?***

Following the assessment some carers felt that they now had a point of contact if they needed further help. However, a number still did not know what was available or who to turn to at times of trouble. Based on their prior experience some carers thought that the assessment was a 'paper exercise' and that no action was likely to ensue. The follow-up interviews bore this out in many cases.

Unfortunately 6 months later there had been little or no formal follow-up for most carers. The range and type of support they were offered was limited in most cases, and for some the promised support failed to materialise. During the ensuing 6 months the situation of some carers had deteriorated markedly and they would have welcomed extra help. Despite this many carers' concerns still revolved around the support needs of their relative.

Whilst in theory carers now had a named contact person, many were still confused about who they could turn to for advice and support. However, where a carer support worker had been allocated and established regular contact, this was greatly valued.

Even after 6 months, for some carers the assessment itself, and the chance to talk, remained the main benefit, but those carers who had been able to organise a break valued it greatly. However, difficulties in arranging respite persisted for some carers, and for others the offer of a break or 'pamper' day was seen as laughable in light of their dire circumstances. Carer support groups were valued by those who used them, but not all carers could attend owing to transport or other difficulties.

Overall one of the chief limitations of the assessment for many carers was its narrow focus and the failure to consider the needs of the wider family, such as siblings or partners. A 'family-centred' model would have been appreciated.

Such a model appeared to be operating in the young carers' project.

### **The young carers' project**

By way of contrast to the above, the young carers' case study illustrated very positive experiences of assessment and support. These experiences were founded on close inter-agency working between statutory and voluntary, children's and adult services, shaped and informed by a clear statement of philosophy and values that emphasised: the young person's views and experiences as being the key to the framing of support; the young person's strengths and resources being recognised as important as their needs and personal safety; the integration of child- and family-centred orientations into assessment practice and support; and a recognition of how structural and environmental factors can shape the lives and opportunities of young people facing caregiving responsibilities.

The need for parental engagement was shown to be important, especially during the early stages of assessment, so as to reassure the family about intentions to protect and support the young person whilst seeking to maintain family cohesion and parental mental health and wellbeing. The key to success in assessment appeared to hinge on two over-arching considerations; the first concerned finding customised ways to build trust with the young person, borne from a recognition that this can take a lot of time given personal histories of vulnerability, distress, bullying and exclusion; the second consideration was the symbiotic link between assessment and support - assessment in all its forms worked best when integrated into 1-1 and group activities with young people.

### **Engaging carers as researchers**

The use of carers as researchers was an innovative element of the PICAP project and the study allowed important insights to emerge. Our findings suggest that there are both advantages and disadvantages to such an approach, and that whilst carers can play a central role throughout such a project their impact is most useful in the planning, conceptualisation, identification of key messages and in the dissemination phases. Carers' role in data collection itself is less clear cut. As our recommendations highlight, the use of carers requires considerable investment in terms of training and support, and there are resource implications with regard to this. Chapter 1 of the report reflects on the preparation of carers for a research role, and in the final chapter we consider some of the lessons we have learned.

## Recommendations

From the outset it was our intention to explore examples of good practice in terms of assessment for carers of people with mental health problems. We believed that this required the creation of genuine partnership between carers and service systems to ensure that the needs of both carers and the person with mental health problems were being met. Our suffix to the proposal – ‘The way forward’ reflected our sense of optimism at that time. The fact that we feel it more appropriate to entitle the final report ‘Family carers at the margins’ captures, we believe, the underdeveloped state, not only of carer assessments, but also of relationships in general between family carers and the wider mental health system. Whilst it did not focus explicitly on carer assessment, the young carers’ project demonstrated what it is possible to achieve when efforts are co-ordinated.

Notwithstanding the limited access to well developed assessment systems, carers were quite clear about what they wanted from an assessment, and we have distilled their thoughts into the practice guides that accompany this report. However, our recommendations below reflect the need for considerable further development work with carers as a matter of priority.

The last few months have seen the publication of several potentially far reaching documents on: the future of adult social care in England (Putting People First, HM Government 2007); the Carers Strategy that sets out a vision for carers’ support over the next 10 years (HM Government 2008); the review of the NHS in England (Darzi 2008) and a recent vision for the future of mental health services (The Future Vision Coalition 2008). We make our recommendations both in the light of our findings and the major thrust of the above documents, especially the Carers Strategy that both explicitly reinforces the need for partnership working in which carers are viewed as experts and sees holistic assessment as being the ‘key’ to integrated services. At the outset we wanted to make recommendations relating to theory, policy and practice so we group our recommendations accordingly. We conclude with some recommendations on the use of carer researchers.

### *Theory*

- Funders, including the SDO, should actively promote and commission more qualitative and longitudinal studies into the experience of caring in mental health that explore the conceptual gaps identified in the synthesis of the literature, and build on relevant theoretical perspectives that can inform good empirical research and generate evidence for subsequent practice initiatives.

### *Policy*

- Government, as a matter of urgency, undertakes a review of the National Indicators Set and identifies a more sensitive and appropriate outcome indicator that more fully reflects carers’ experiences, not only of assessment, but of contact with the wider mental health system.



- Government activity seeks to promote the greater involvement of the voluntary sector in the assessment and support of carers of people with mental health problems and ensure their financial security in the longer term so that highly promising initiatives do not flounder.
- Government actively pursues the introduction of legislation that clarifies and strengthens a carer's right to information in order that they can play a full and active role in providing care and support.
- Government recognises the relatively stigmatised and disadvantaged position of carers of people with mental health problems and pays particular attention to ensuring that they benefit from the principles contained within the Carers Strategy.
- The government advances moves to produce and agree a uniform definition of 'carer' that is widely understood and accepted. This should involve extensive consultation with carers and their organisations and, once agreed, should be widely disseminated so that the current confusion as to the meaning and status of 'carers' is reduced.

### ***Practice***

- In the longer term those responsible for both the initial and on-going education and training of mental health practitioners review the emphasis placed on, and content dedicated to, carers in the curriculum and adapt it according to Simpson and Benn's (2007) 3 stage model, so that work with carers in general, and assessments in particular, are seen as an important and skilful activity. In the short term the profile of carer assessments needs to be raised and staff given the skills and resources necessary to complete them effectively.
- That local authorities, and others with responsibility for ensuring carer assessments are conducted, actively promote early positive and on-going contact with all new carers, so that the foundations of partnership working can be laid from the outset.
- Those authorities responsible for ensuring that carers' assessments are conducted take steps to ensure that all carers eligible for an assessment are offered one, not just those on CPA.
- Authorities give more consideration to the range and type of services offered to ensure that they are sensitive to carers' circumstances and that carers are able to take full advantage of them. This will require greater creativity and flexibility.
- Though important in its own right, assessment should not be divorced from support for carers, for supportive activity is likely to provide clues important to understanding carers' needs and their understanding of their situation. For vulnerable

groups of carers, time and pacing appear to be crucial in the building of trusted relationships with professionals; without this, good assessment is compromised.

### ***Carer researchers***

- Carer researchers require careful selection and comprehensive training that is sensitive to, and accommodates differences in, socio-economic backgrounds, culture and ethnicity.
- Future projects using carer researchers should not automatically assume that carers wish to be interviewed by other carers, and sensitivity is required in offering carers the choice of being interviewed by another carer or a professional researcher.

## CHAPTER 1

### Background, Aims and Methods

#### Background

The last 20 years has seen an 'explosion' of research in the field of 'informal' (family) care (Fortinsky 2001). Policy initiatives have been introduced in an attempt to ensure that carers' needs are adequately addressed and these have emphasised the need for partnership working between family and formal caregiving systems (DoH 1999a). In moving towards this aim, successive governments have introduced a series of legislative changes over the last decade. These began in 1995 with the passing of the Carers (Recognition and Services) Act which, according to Clements (2006), contains 'the core statutory responsibilities' towards carers. The Act introduced the concept of a 'carers assessment', by which carers who provided, or were intending to provide 'a substantial amount of care on a regular basis', were entitled to a separate assessment of their needs providing that the person they were supporting was also having an assessment. In order to further enhance the status of carers the UK government introduced the 'Carers National Strategy' (DoH 1999a) to provide specific services for carers, notably in the form of 'short breaks'. To facilitate this strategy an annual 'carers grant' is given to local authorities to promote the more widespread and innovative provision of such breaks.

The rights of carers were further enhanced by the Carers and Disabled Children's Act (2000) which afforded carers the right to an assessment, even if the person they were caring for was not receiving one. Notwithstanding these changes, a review of support to carers conducted by the Audit Commission (2004) noted that the government's aspirations for carers were not being met in the majority of cases. The same year also saw the passage of the Carers (Equal Opportunities) Act (2004), which mandated that local authorities inform carers of their right to an assessment and extended the focus of the assessment to specifically include issues to do with work, education and leisure.

Carers supporting people with mental health problems have the same rights as other carers but their situation received particular recognition in the National Service Framework for Mental Health (DoH 1999b), which identifies seven standards in five areas intended to ensure improved and equitable provision of services throughout the country. Standard 6 focuses specifically on the needs of carers and states that:

All individuals who provide regular and substantial care for a person on CPA (Care Programme Approach) should:

- have an assessment of their caring, physical and mental health needs, repeated at least on an annual basis;
- have their own written care plan, which is given to them and implemented in discussion with them.

It was against this background that the need for the study reported here emerged. Following a major review of the literature on interventions for carers of people with mental health problems (Arksey et al 2002), and a subsequent consultation exercise (Newbrunner and Hare 2002) funded by SDO, the need for further research, including that into carers' assessments was identified. This resulted in a competitive tender from the NHS Service Delivery and Organisation (SDO) programme of research, to which a team from the University of Sheffield submitted a successful bid. This chapter describes the rationale behind the study, and the methodological approach adopted by the team in taking the proposal forward.

### **Starting point: some basic assumptions**

As Arksey et al (2002) noted, the literature on carers of people with mental health problems is not as extensive as that in other fields, with more limited conceptualisation and a dearth of qualitative studies. Addressing the call from SDO, the study reported here was designed to consider the extent to which the principles and practice of assessment, as described in particular in Standard 6 of the NSF for Mental Health, are enacted in practice. In submitting our proposal we argued that whilst the existing literature on family care provides useful insights, caring for someone with a mental health problem poses unique challenges. These include: the isolation experienced by carers (Karp 2002), exacerbated by the stigma associated with mental illness, which remains misunderstood and feared (Reifer and Cox 2001); the unpredictable nature of many mental illnesses (Jeon and Madjar 1998, Newbrunner and Hare 2002) fuelling fears of relapse and of services not responding 'until something dreadful has happened' (Howe 1995); the guilt and blame carers may feel for the mental illness of their family member – a feeling that, until recently, has been reinforced by services (Hatfield 1994); and potential conflict between carers and service users about appropriate care, particularly at times of crisis. However, notwithstanding the 'uniqueness' of each caregiving situation, literature on the experiences of carers of people with mental health problems suggests the emergence of common themes, which can help to inform the assessment process. These common themes constitute the explicit assumptions upon which this study was predicated. These themes are:

- It is essential to understand the 'meanings' that carers of people with mental health problems ascribe to their situation (Jeon and Madjar 1998, Rhoades and McFarland 1999, Strang and Haughey 1999), and the impact such meanings have on their sense of identity (Tuck et al 1997, Karp and Tanarugsachock 2000). This suggests that any assessment should take a carer's perspective and appreciate and explore such meanings if appropriate support is to be provided.
- Caring has temporal dimensions with carers' needs changing over time (Jeon and Madjar 1998, Rose 1998a, b, Karp and Tanarugsachock 2000). Assessments must therefore be aware of, and responsive to, carers' changing experiences and their need for differing services over time (Spaniol and Koehler 1994, Karp 2002), particularly when planning for the future (Jeon and Madjar 1998, Rose 1998a, b).
- It is important to recognise that caring, while often difficult and stressful, is not a universally negative experience (Perkins and Repper 1998a, Veltman et al 2002), and that assessment should promote a strengths-based approach (Rose 1998b,

Berg-Weger et al 2001) that acknowledges experienced carers as co-experts (Newbrunner and Hare 2002). At the same time carers, and particularly new carers, value help in understanding and interpreting both the mental illness and their responses to it (Rose 1998a).

However, central to our approach to the study, and the basis upon which the tender was accepted, is the belief that family carers and professional support services should work together as 'partners', and that a partnership approach is essential to the most positive outcomes for all concerned. Consequently we called the study the Partnerships in Carer Assessment Project (PICAP). In submitting our tender we argued that, in order to be true to this partnership approach, carers should be fully involved throughout all stages of the project. As a result we have worked closely with carers who played a key role in identifying the types of questions to be addressed, undertook much of the data collection, and contributed to data analysis. This was an ambitious undertaking. We believe it was the right

decision but it has had a number of implications, not least of which is the considerable time and effort invested by carers in working with us, and our own efforts, some successful, some less so, in supporting them in their endeavours. Consequently, in addition to the insights the study provides into carer assessment in mental health, there are also some important lessons about working with carers in future research projects. We will briefly reflect upon these later.

One other central premise of the study needs to be made fully explicit at this point - from the outset it was our goal to focus on the positive, to identify what is working well in carer assessment in mental health, and to consider how such practices could be transferred elsewhere. This was captured in our suffix to the project: Partnerships in Carer Assessment Project: The way forward. Furthermore, when we were invited to bid for extra funding, we retained this note of optimism and entitled the additional element 'Winning hearts and minds'. That we have entitled the final report 'Family carers on the margins' can only in part convey the extent to which our initial hopes failed to materialise. We must stress that during the project we encountered committed, skilled and dedicated individuals in both the statutory and voluntary sectors who had carers' interests close to their hearts, and who invested considerable effort into ensuring that assessments were a positive event and hopefully resulted in sensitive and appropriate support for carers. We also talked to many carers who had found the actual assessment itself an affirming experience. However, despite the fact that we were explicitly looking for best practice, carers' assessments, and particularly service responses to them, were not realising their full potential.

As we shall point out, this situation is not unique to mental health. Similar conclusions have been reached in respect of carer assessments in different fields of practice. Nevertheless, despite our difficulties in locating fully integrated and well established systems for carer assessments, we believe that important insights emerge from the study both about what carers of people with mental health problems want from assessment, and from support more generally.

## **Aim and objectives**

The overall aim of the study was:

- to provide a comprehensive and contextualised understanding of the rationale for, and the processes, experiences and consequences of, the assessment of carers of people with mental health problems, and the barriers to, and facilitators of, partnership working.

More specific objectives were:

- to consider the range of assessment approaches (and their rationale) as currently used with diverse groups of carers of people with mental health problems;
- to explore current 'good practice' as identified by a variety of key stakeholder groups;
- to identify perceived barriers to, and facilitators of, the implementation of good practice in assessing and meeting carers' needs;
- to explore the experience and outcomes of assessment longitudinally from the perspectives of the carer and, to a lesser extent, the assessor;
- to identify both 'good practice' and areas for improvement in current assessment approaches;
- to identify potentially differing needs of carers from varying groups (for example, 'minority' ethnic groups, young carers, and carers at different stages in their caring 'career');
- to produce and seek to disseminate principles for best practice and carer/practitioner guides to inform and empower both carers of people with mental health problems and those undertaking assessments.

In order to address these aims and objectives a multi-method, multi-phase approach was adopted.

## Methodology

As noted earlier, we explicitly based this study on a partnership model and in operationalising this adopted a 'co-constructed' approach in which the key stakeholders, particularly carers themselves, played a full and active role (Rodwell 1998, Charmaz 2000). A multi-phase, multi-method pluralistic method (Bond 2000) was used to explore the range and type of current assessment practice for diverse groups of carers of people with mental health problems across England. The research was organised around the eight NIMH[E] (National Institute for Mental Health (England)) Regional Development Centres (RDCs) in England (subsequently NIMH[E] has been subsumed into CSIP), all of which had a specified programme of work with service users and carers, often developed in tandem with Local Implementation Teams (LITs). Prior to the commencement of the study all RDC leads were contacted and they agreed in principle to support our work.

The study comprised a number of linked phases, some concurrent, some sequential, which unfolded as follows.

### Phase 1

This comprised three elements which were undertaken concurrently.

#### *Element 1: Conceptual synthesis of the literature*

In order to avoid potential misunderstanding and confusion it is important to note at the outset the scope and purpose of the literature synthesis reported here. As noted earlier, in our initial tender for the PICAP project we made explicit four assumptions about the factors likely to impact on assessment that were seen to underpin the project. These were as follows:

- Any comprehensive and sensitive assessments of carers' needs must be built on an understanding of the 'meanings' that carers bring to their role and the influence that these meanings have for their experiences of caring.
- Assessment needs to take due account of the temporal nature of the caring experience and recognise that the demands carers face, and the needs they have, are likely to vary depending upon their 'stage' in the caring career.
- Assessment must not focus only on the burdens or difficulties of care but give due attention to the potential satisfactions or rewards that carers may experience, the strengths and resources that they have (or not) and the 'expertise' that they acquire over time.
- Assessments should be based on a partnership model in which both the assessor and carer bring differing but complementary forms of knowledge and expertise to the process.

The scoping studies conducted on behalf of SDO, comprising a review of the literature on interventions for carers of people with mental health problems (Arksey et al 2002), together with a consultation exercise with stakeholders (Newbrunner and Hare 2002), identified the need for further research in several areas, including carers' assessments. It was noted that while the literature on caregiving in general is extensive, that in mental health is much more limited with a dearth of qualitative studies on the experience of caring. Moreover, Arksey et al's (2002) review indicated that the available research focussed primarily on schizophrenia, with far fewer studies involving people with conditions such as depression, anxiety and eating disorders, which are more prevalent forms of mental illness. Furthermore, Arksey et al (2002) concentrated mainly on **interventions** for carers and not assessment or the experience of caring, and it was not our intention to repeat or update their review. Rather our aim was to provide a synthesis of what is known about the caring experience in mental health, the relationships that exist between carers, professionals and service systems, and the implications of these for assessment and support. As the title of our study suggests, we are particularly interested in the notion of 'partnerships' between carers and mental health professionals, and the potential barriers to, or facilitators of, such partnerships. With this in mind we primarily drew upon both qualitative and quantitative studies, and the grey literature that focussed on:

- the experience of caring in mental health;
- the relationship between carers and professionals/service systems, and the implications of these for the formation of 'partnerships' between family and formal care;
- the literature on carer assessment and the implications of the above for the way such assessments are conducted and experienced.

This process is quite distinct from more traditional forms of systematic review, as it is not predicated on strict inclusion and exclusion criteria based on study methods with a view to demonstrating the effect of a particular intervention. Nevertheless, it is a replicable and rigorous process which seeks to identify all literature in the area of interest and to conceptualise the current state of discourse within a defined subject area.

The search process itself was conducted by the information section at the School of Health and Related Research (ScHARR) at the University of Sheffield, a centre of recognised excellence in data searching techniques.

A comprehensive literature search was undertaken to identify published literature on 'family caring in mental health' using six bibliographic databases. These were three major general health related databases (Medline, Embase and Cinahl), an evidence based database (the Cochrane Library which includes the Cochrane Database of Systematic Reviews, Database of Reviews of Effects, NHS Health Technology Assessment database and the CENTRAL – the Cochrane Controlled Trial Register), a psychology subject specific database (PsycInfo) and a citation index database (Science Citation Index / Web of Science). A sample of the search strategy used can be found in Appendix I.



Once a comprehensive list of references was obtained, titles and abstracts were read and decisions made as to their relevance. An inclusive strategy was adopted and, where appropriate, opinion pieces and editorials were included in addition to empirical, theoretical or policy related material, provided they addressed the issues above. This was considered important in order to provide as comprehensive an overview as possible on the current discourse about carers in mental health. Once references were obtained a detailed and comprehensive three stage process of review, analysis and synthesis occurred, in which each piece of literature was treated as if it were a primary data source (see Nolan et al 1996 for a fuller discussion). In essence a constant comparison approach was applied in which each piece of literature was seen as the equivalent of an 'interview', and a process of analysis and synthesis applied both within and between articles. Consequently, a first reading of each reference was undertaken and detailed notes made, highlighting the main themes or arguments presented. In this way several hundred sides of 'first order' analysis were compiled, identifying initial codes and themes. Subsequently, these codes and themes were re-read and second order analysis undertaken to further refine these, and to identify their differing dimensions. For example, one key theme was that of 'partnership working', with sub-themes including:

- The rhetoric of partnership working
- The reality of partnership working
- Barriers and facilitators to partnership working

Following this a third level of synthesis was completed in order to identify common or unique aspects and to elaborate upon the themes identified in the level two analysis. The aim here was to provide a comprehensive and in-depth understanding. For instance, under barriers to partnership working, several sub-themes were identified such as:

- Professional/cultural barriers
- System related barriers
- Carer-related barriers

Where appropriate the above were further subdivided, for instance with professional/cultural barriers comprising:

- Professional attitudes
- 'Blame' culture
- Threats to professional role
- Focus on the service user
- Confidentiality
- Lack of training and skills

The aim was to produce a synthesis and nuanced understanding of the background and context to carer assessment that would provide a point of comparison and contrast with the empirical work. We present the results of this synthesis in Chapter 2, beginning with the experience of caring for someone with a mental health problem. The literature relating to young carers is considered separately in Chapter 5.

## ***Element 2: National survey of Local Implementation Team (LIT) Plans for Standard 6 of the National Service Framework (NSF) for Mental Health***

As already discussed, it is a statutory requirement for **all** carers providing (or intending to provide) 'regular and substantial' care for a person needing support to be offered an assessment of their own needs. The National Service Framework for Mental Health supposedly strengthened this requirement for carers of people with mental health problems by stating that "local health and social care communities should ensure that:

- each carer's needs are assessed;
- each carer receives easy to understand information about both the help available to them, and the services provided for the person for whom they are caring;
- a written care plan is agreed with the carer and covers their caring, physical and mental health needs, also educational and welfare needs of young carers;
- the care plan is reviewed at least annually" (page 17).

In principle the inclusion of carer assessments in the NSF brings with it additional systems for developing and monitoring services for carers of people with mental health problems. For each Standard of the NSF, local implementation teams (LITs) were set up, with membership from various organisations and agencies, representing different professions and service users and carers. Their remit is to oversee the planning, commissioning and delivery of services at a local level (see DoH 2001). They produce an annual report or 'service map' to illustrate the facilities and services that have developed and this is collated by each of the regional offices to produce a national map (see Glover and Barnes 2003). Given the necessary emphasis placed upon the areas covered in each of the NSF standards, these plans should comprise an overview of mental health services both provided and planned relating to Standard 6 – carer assessment. Therefore, analysis of documentation gathered and produced by Standard 6 LITs was undertaken to:

- provide an overview of the stated (and implied) aims and actions to be taken with respect to meeting this standard;
- identify any underlying philosophy or approach to addressing carers' needs (again with a particular emphasis on assessment), and
- consider the process and structures that may have been, or were intended to be, put in place with respect to addressing carers' needs.

### ***Obtaining LIT plans***

At the time the study commenced approximately 160 Local Implementation Teams existed in England. These teams produce annual reports on their activity for the National Institute for Mental Health (England) (NIMH(E)) regional offices. We therefore asked each

of the 8 NIMH[E] Regional Offices to provide contact details for LIT (Standard 6) leads and asked these leads for a copy of the report of activities relating to Standard 6. Our aim was to achieve a census of these LIT plans. This did not prove possible for a variety of reasons.

In some RDC areas key individuals volunteered to contact colleagues and seek the LIT plans on our behalf, whereas in others a list of contact details was sent to the project team and personalised letters were then sent to those on it providing an overview of the project and a request for relevant documentation. We requested LIT plans from **all** those for whom we were provided contact details (n = 93) and, after repeated contact with several sites, 42 replies were received, representing a 45% response rate. Despite our best efforts, we failed to obtain any LIT plans from four out of the eight regional areas we contacted. This was probably due to the immature state of development of many of the LIT plans, the likelihood being that some areas had little, if anything, to send.

### *Exploring the LIT plans*

The level of detail provided in response to the request for the plans varied enormously. Some comprised little more than a polite letter stating that no LIT plan was available, or that it was still being produced. These comprised 17 of the 42 replies received. Amongst those who provided plans some made brief reference to the carers' assessment but gave no detail as to its goals or aspirations. These were classified as having 'little' emphasis. Others provided a short 2 or 3 page strategy statement outlining aspirations and intentions, often linked to achieving NSF 'targets'. These were classified as providing 'some' emphasis. At the other end of the spectrum a number of replies included detailed and often extensive plans, together with relevant assessment procedures and proformas, local audits of carer services, and/or small-scale research studies that had sought carers' views on a range of issues. These were classified as providing 'considerable' emphasis. To add a further layer of complexity, certain respondents forwarded plans for all the standards of the NSF, including those not relating to carers.

Given these differences the level and depth of analysis that was possible varied considerably. In order to apply a consistent approach the following activities were undertaken:

- Where the level of detail permitted, consideration was given to how much emphasis there was on carer related issues. As noted overleaf, judgements were made as to whether this was considerable/some/little. Similarly, where such information was available, consideration was also given to the extent to which assessment of carers' needs, relative to other standards, was considerable/some/little.
- Where the level of detail permitted, attention was turned to who should conduct the assessment in order to identify potential 'models' of assessment practice.

- In the small number of instances (n = 8) where assessment proformas and procedures were supplied, the orientation of the assessment was considered. For example, was the assessment highly structured with questions being largely predetermined, or was there scope for the carer to express their own views? How detailed was the assessment, and did it focus primarily on the 'tasks' of caring, or were less tangible and hidden aspects of caring also considered?
- Was there any indication of the nature of service responses to identified needs? Were these innovative and flexible or more traditional and routinised?

The results of this exercise are reported, together with the organisational case studies (see later), in Chapter 3.

### ***Element 3: Carer consultation days***

These consultations were designed to increase understanding of the experience of caring in mental health in general, and assessments in particular, from the perspective of carers, and to inform the research process by:

- sensitising the research team to personal, environmental and organisational factors bearing upon the experience of assessment;
- highlighting localities where there was thought to be good practice in the implementation of carer assessments.

All 8 RDCs were included in the consultations to ensure national coverage and maximise the representation of carers by diversity (role relationship to the cared for person, ethnicity, length of caring experience), geography (urban and rural areas) and organisational arrangements for delivering carer assessments. As part of the consultation process carers were asked to nominate examples of good practice. Suggestions made by carers were used to inform decisions about the selection of the sites where more detailed studies were to be undertaken.

Each of the regional offices employed a 'carer lead' who facilitated consultation meetings. They advertised the consultation events among local carer groups through newsletters, personal contacts and attendance at carer meetings. They specifically sought adult carers (aged over 18 years) who would like an opportunity to speak about their experiences of caring and of carer assessments. A total of 79 carers attended in person and a further 20 were unable to attend but provided either written commentary or expressed their views during telephone conversations with the research team. Of the 79 who attended one of the days, 31 had been offered an assessment of whom 19 refused. Of the 12 who received an assessment, only 5 found it helpful.

All those attending the consultations were adult carers (age range 22 to 80 years), over two-thirds were women (69% female, 31% male), almost 8 out of 10 (78%) were white British, but a wide range of ethnic backgrounds were represented. The length of time caring varied, but most participants had been carers for over 5 years, several for over 20 years. Although the majority of

carers were parents (76%) caring for a son or daughter with a diagnosis of schizophrenia, a range of relationships was represented, and the diagnosis of the person they cared for also differed. Despite these variations the views and experiences of men and women of different ages, cultural backgrounds, or caring roles were remarkably similar. It must be acknowledged, however, that these carers were not necessarily typical of all carers; as a result of the selection process, most of the participants (95%) not only had experience of caring themselves, but also had a role in voluntary organisations and groups, and/or of representing other carers in Local Implementation Teams, at Service Level, and at Trust Board level. Characteristics of those attending consultation days are summarised in Appendix 2.

### ***Structure of consultations***

Each of the consultations was facilitated by two members of the project team, and detailed notes were taken to record the views expressed. Based on the study aims, the following key questions were used to guide the discussions:

- What were carers' experiences of the mental health system/services?
- What were carers' experiences and expectations of carer assessments?
- How should assessments be organised?
- How should assessments be structured?
- What should assessments cover?
- Is it possible to identify areas/services where good assessments are currently being carried out?

The results of each discussion were then analysed and key themes identified so that they could be further considered at the next consultation. As part of the analysis all the carers who participated were sent a copy of the themes for agreement and refinement. There was a remarkably high degree of consistency in the views expressed. Although the detail of individuals' experiences inevitably differed, the stories that they told illustrated consistent themes. These were further refined in written feedback from carers and during discussions at the various meetings.

The detailed results of the consultations were provided to SDO as part of the interim report. Here they are reported together with the interview data from the carers in Chapter 4. A copy of the full report of the consultation is provided as Appendix 3.

## **Phase 2: The Main Study**

The main study comprised a series of in-depth instrumental case studies (Stake 1995) based on Primary Care, Mental Health and Partnership Health and Social Care Trusts providing mental health services. The case studies were both organisational (Eisenhardt 1988, Mintzberg et al 1998), with the hope of identifying diverse models and processes for the assessment and support of carers of people with mental health problems; and theory-generating, using a grounded theory constructivist model (Charmaz 2000) to identify key components of successful partnerships between carers and assessors in areas where things

were 'working well', and the wider organisational features that support such partnerships. Case study design helps illuminate the dynamics operating in complex settings using a combination of data collection methods, and multiple sources of data (staff, service users, carers) (Yin 1994). The intention was that in-depth study of a limited number of sites would allow for diverse aspects of assessment to be studied, and more importantly, to be explored in a systemic manner within their organisational context – from the formation of organisational strategy for carer assessment to the receipt of individual assessment.

Case studies do not promote generalisability per se (Eisenhardt 1988), but instrumental case studies (Stake 1995) generate insights which can be 'transferred' or 'recontextualised' (Morse 1994) to other contexts and settings. It is through such insights that we sought to identify common or shared principles which were sufficiently flexible and sensitive to promote an individual assessment of need.

Consistent with a constructivist methodology, participants played active roles in establishing the 'trustworthiness' of the analysis (Rodwell 1998), and to this end trained and supported 'carer researchers' (see later) were pivotal to elements of data collection and analysis.

Data collection and analysis involved a range of sources including written/published documents and assessment proformas, together with focus group and individual interviews with key stakeholders. We had hoped that the analysis of the LIT plans would allow a mapping of assessment approaches but their rudimentary state made this impossible. However, at the case study sites it was our intention to identify examples of good practice, with the main emphasis placed on the assessment process and its impact in order to address questions about:

- Who gets an assessment and how do eligibility criteria operate?
- What is the focus of the assessment, how comprehensive and holistic is it?
- Who conducts the assessment and what skills and training do they have, what implicit or explicit models do they draw upon?
- How is the assessment conducted and to what extent does it actively involve the carer as a genuine partner in the process?
- How sensitive is the assessment to, for example, the expertise of the carer and their stage in the caregiving trajectory, differing cultural and ethnic factors, age, gender and employment status of the carer?
- How is the assessment 'experienced' by both the carer and the assessor, and what are its goals in terms of direct services, and to what extent are these goals seen as important by carers themselves?

- What are the individual and team skills and orientations, and the organisational structures and contexts that promote or inhibit partnership working?

### *Selection of Trusts for in-depth case-study investigation*

A purposive sampling strategy informed by the views of carers was used. First, a long-list of all services recommended by carers and those areas with a clear Carer Assessment Strategy (as reflected in Local Implementation Team plans) was drawn up. From this list 10 sites were selected to represent:

- broad geographical spread across England including Northern and Southern regions, London, rural and urban sites;
- different types of mental health services including at least one Mental Health Trust, a Primary Care Trust and a Partnership Health and Social Care Trust;
- different organisational models of carer assessment including dedicated carer assessors within statutory services, responsibility for carer assessment delegated to non-statutory services, and all mental health practitioners taking responsibility for assessment;
- specific groups of carers, for example carers from black and minority ethnic groups, rural carers, carers of people on acute wards, young carers. Whilst it had been our intention to identify sites offering assessments to different groups of carers, other than those in the rural areas, young carers or carers from black and minority ethnic groups, no differing models could be identified. Since it is not possible to select sites focusing on all diverse carer groups, many were to be examined through cross case analysis (eg carers who are service users, rural carers).

Part way through the study the research team was invited to bid for additional funding. This opportunity was used to extend the range of case study sites. As a result of the consultations it became clear that further exploration of non-assessment sites might enhance understanding of the support carers' receive.

During the consultation meetings carers recommended several models of working, which met both their needs and those of the person they were supporting. However, some of these did not include a formal assessment process, as defined in the NSFMH, the Carers (Recognition and Services) Act 1995, the Carers and Disabled Children's Act 2000, and the Carers (Equal Opportunities) Act. They therefore did not fit the remit of the project as originally conceived, but their inclusion appeared to be important if we were more fully to understand the type of 'culture' that promotes partnerships between carers and practitioners.



Three models were identified that explicitly included providing individualised support for the person with mental health problems, and also addressed the needs of family carers in their overall philosophy, but do not prioritise the completion of formal carer assessments. These services were:

- Assertive outreach (AO) teams – all Trusts are required to provide AO for people with serious disabling mental health problems who are difficult to target using existing services. AO, a form of intensive case management, improves engagement by working towards clients' own goals with their families, friends and communities.
- Services providing psychosocial interventions (PSI) in routine care – PSI is an umbrella term that refers to a range of interventions that have been shown to be effective for people with serious mental health problems, including behavioural family intervention, cognitive behavioural therapy, early intervention/relapse prevention and case management. During the consultations, carers who had received psychosocial interventions felt better able to cope with their caring role, understood services and treatments better, and were able to discuss their needs with professionals.
- Family group conference (FGC) services aim to fully involve the service user, their family, friends and significant others in the assessment and care planning process in order to increase support, challenge isolation and combat discrimination. It is a specialised service, separate from CMHTs, which organises full assessment meetings (or family group conferences) but does not implement the subsequent care plan.

The NHS SDO programme subsequently agreed to fund the extension of the study in these ways, enabling us to incorporate more working models that might shape the practice and experience of carer assessment and support.

### ***Conducting the in-depth case studies***

The in-depth case studies are a major element of the project and focused primarily on the key questions relating to the assessment process noted earlier, and the contexts which support partnership working. Each of the selected teams, and the Trusts of which they are part, were studied to gain a comprehensive picture of how carers' needs are conceived, assessed and met, including perceptions of the barriers to, and facilitators of, good practice. Core data collected at all sites included:

- discussion with assessors about the implicit and explicit models they employ, the skills they feel they possess, and the factors that both help and hinder their work with carers.
- an in-depth exploration of carers' experiences of assessment processes and their outcomes. It was originally our intention to interview both the carer and the assessor following the assessment and some 6 months later. However, this did not prove possible (see later) and so the following strategy was adopted.

Contact with each site usually began with a meeting with the Carer Lead for the Trust to exchange information and begin to negotiate access to the site. Following Research Governance approval (including Local Research Ethical Approval), data were collected in various ways and from a number of different sources, including interviews with personnel involved with the support of carers and analysis of relevant documentation.

A snowball sampling strategy was used to identify and select participants who were involved in the development or delivery of carer assessments, or provision of services for carers more generally, for example service managers, commissioners, carer assessors, and members of voluntary sector groups with a key role in carer assessment and support. Interviews focused on the carer assessment strategy, how it had been developed, how it was being implemented, problems in the implementation of assessment, ways of overcoming difficulties, and the effectiveness of assessments. Interviews were transcribed and returned to interviewees for comment and amendment before analysis.

Documentation obtained included: the local carer strategy; guidelines regarding eligibility for assessments and access to carer grant; assessment documentation (proforma plus any guidance); minutes of carer group meetings; and any local audit or evaluation of carer assessments.

Based on an analysis and synthesis of the interviews and documents, individual case reports were produced for each site to provide an overview of the key characteristics of the organisation and implementation of assessments based on Pawson and Tilley's evaluation model (1997) and this included:

- context: characteristics of organisation, demography, service structure;
- approach/model: organisation of assessment and its place in overall carer strategy;
- value base: drivers for carer assessment;
- implementation/mechanisms for assessment: who does what to whom;
- development/mechanisms for identifying good practice and areas for further development;
- outcomes: what difference it makes to individual/service;
- future plans: further developments intended and why.

A draft site report was sent to all interviewees for comment. This resulted in lengthy discussions on a number of sites where interviews with practitioners undertaking assessments indicated that the strategy was either not fully known/understood, or not being implemented as intended. Once all site reports had been agreed at a local level and approved, then the individual site reports were synthesised through cross case analysis. This process involved comparing cases and making connections between them, drawing out common features and testing emerging themes in order to construct a model of processes and relationships

associated with particular consequences. The results of this activity, together with those relating to the analysis of the LIT plans, are reported in Chapter 3, which explores the organisation and delivery of carer assessments.

### ***Carers' experience of assessment processes and outcomes***

Our original intention had been to interview 120 carers across 12 sites, including three sites that offered possible alternative models of addressing carers' needs that might not necessarily involve a formal assessment (assertive outreach, early interventions, family group conference). In the event this target proved impossible to achieve and at all sites recruiting carers provided significant, and in places insurmountable, challenges. We cannot give definite reasons as to why this proved to be the case, but can provide an indication of the considerable efforts that were made to recruit carers, and offer some potential explanations as to why they were not always successful based on our own impressions and those gained from conversations with staff at the sites.

Given the requirements of the data protection act and local research governance regulations, we could not be provided with the contact details of carers directly. Therefore detailed negotiations took place at each site as to the best way to approach carers and the most appealing ways of presenting the project to them. We also worked closely with the carer researchers at the sites to design the letter of invitation and to make it clear to carers that their views would be extremely valuable. The invitation letter might include, for example, photographs and a brief biography of the potential interviewers and, as required by the MREC, the option of being interviewed by either a carer researcher or the professional researcher (see example Appendix 4). Subsequently considerable efforts were made to both identify carers and to determine the best way of approaching them.

We originally attempted to recruit carers through their assessors who agreed to hand letters of invitation and information sheets to all carers when an assessment was completed. These letters were developed with carers on each site so that they were accessible and acceptable to carers. In this letter, carers were asked to complete a form either agreeing to be interviewed or not, and to return it to the research team in an enclosed stamped addressed envelope. This system proved unworkable: we received very few responses from carers. It is not clear why this was the case, but on several sites assessors later explained that they often forgot to hand out invitations. It was subsequently agreed that assessors would contact carers by phone and ask whether they could be called by the research team to be invited to participate in the research. This was more successful: when carers gave permission for their contact details to be given to the research team they were phoned by the member of the research team responsible for that site and the majority agreed to be interviewed.

However, numbers were extremely slow to accrue due to the low numbers of carers offered an assessment by the service. Surprisingly, even where dedicated carer assessors were employed, only two to four new assessments were undertaken each month, and at times there was a delay in completing even this number due to difficulties with the carers' or service users' personal circumstances. We originally intended to interview only those who had been assessed within the previous month (to ensure that they had a clear recollection of the assessment procedure) but we eventually extended this and invited all carers

assessed within the last 6 months to participate. This proved fruitful in some areas and we achieved the required 10 interviewees, but they took as long as a year to complete.

On other sites the service simply did not assess 10 carers during the data collection period. For example, we had intended to explore practice in an Early Intervention Service which claimed to use a psychosocial intervention approach in their work, offering all families of service users structured, evidence-based family work. However, as this team was part of the extension research project, there was only 6 months available for data collection. During this period not one family was offered either a carer assessment or family intervention. The team was relatively new and hoped to increase this aspect of their work but their only explanation for the lack of work with family members was that the service's priority lay with service users and few had carers who needed further work. Similarly, the Assertive Outreach team had 56 clients on their books but only one carer assessment had taken place in the previous year, and they could only identify 6 service users who had carers who were provided with support by the team. In another community team where the care co-ordinators had responsibility for undertaking assessments, only eight assessments took place over a two year period. Local audits of assessments showed that, despite ongoing staff training, the total number of assessments undertaken per annum decreased during the study period. All this lends further credence to carers' claims that they are not informed or involved, and remain largely excluded by, and from, services.

This difficulty in recruiting carers, due both to problems with accessing those who had received an assessment and the very low numbers of carers who were offered assessment (and the even lower numbers who accepted the offer), meant that our original intention to interview the assessors proved unworkable. Due to the often considerable delay between the completion of the assessment and our interview, and the frequently rather superficial nature of the assessment, assessors usually had little recollection of the assessment itself. We interviewed assessors responsible for conducting the assessments at one site but gained very little usable data. A decision was therefore made to focus our efforts with the assessors as described above.

We had particular difficulties in attracting carers at the site where we tried to recruit BME carers, for reasons that the project workers at the site found hard to explain. When we initially approached them they were confident that there would be little difficulty in identifying 20 carers (10 from BME groups) who would be interested and willing to be interviewed. They thought that the most direct route would be for each of the 10 project workers to either identify carers who had recently had an assessment and approach them directly, and to ask carers if they might be interested in participating at the end of an assessment.

To this end 100 information packages were sent to the team. Although we do not know exactly how many were distributed, we were assured that they were regularly given to carers. Following this only two carers expressed an interest in being interviewed. After detailed discussion with the team leader it was decided to take another approach and to invite carers to attend a focus group to discuss their experiences. Personal invitations were sent to 20 carers from non BME groups and 10 carers from BME groups. Our desire to let the carers' voices be heard was stressed, taxis and alternative care for the user were made available, a small payment was offered, a buffet and refreshments were laid on, and translation facilities organised. One carer from the non-BME group attended the first focus group, which became an individual interview, and three carers attended the BME group. Even

here, however, one carer came believing that the researcher was a representative from the Department of Health who had come to listen to a complaint she had about the support her husband received. Subsequently a third attempt was made to recruit more carers and the carer's team sent a personalised letter to 50 carers who had had an assessment in the last 6 months. One carer came forward for interview. Clearly here the issue was not the number of assessments, as 50 had been conducted in 6 months, but recruitment still proved very difficult. We offer potential explanations below.

Due to the very necessary and appropriate safeguards built into the recruitment process in order to maintain carer anonymity and freedom from coercion, direct access to first hand accounts of why carers were reluctant to participate in the research was not possible. However, discussions with people from a range of sites indicated that the reasons for non participation may, amongst other things, include:

- **The avoidance of stigma** - Despite the best efforts of health care providers there remains a stigma attached to mental ill health. This was particularly, though not exclusively, apparent in the more rural communities where carers appeared worried that any contact, other than that which was strictly necessary, would draw attention to their plight and increase the potential for negative responses by friends and neighbours.
- **Privacy** - Although in part linked to avoidance of stigma the desire on the part of potential informants to 'keep themselves to themselves' was very apparent. This desire appeared to be founded on potential embarrassment that they were in some way to 'blame' for their family member's predicament. Their solution, according to those at the sites, was to 'keep it in the family' and to relate only to those care staff who were seen as both necessary and trustworthy. Research, and researchers, did not appear to fit easily into these categories.
- **Time constraints** - Being a carer, often alongside other family and work responsibilities, is recognised as being a taxing, albeit often rewarding, activity that takes up a lot of time. Whilst the project was mindful of this and researchers did their best to minimise the impact of the interviews many potential contributors felt that participation would detract from other activities and that the time could be better used.
- **Lack of reciprocity** - Carers, by the nature of the task, are forced into making choices in terms of where they should expend their energies and efforts. In doing so they appear to employ an intuitive 'cost/benefit analysis' in order to prioritise their activities. Despite efforts by clinicians and researchers to describe the long term benefits that research participation can bring, the 'what's in it for me and the person for whom I care' question may not always have been answered to their satisfaction.
- **Humility and self-deprecation** - many carers appeared to perceive their actions as being 'just what you have to do' and therefore found it difficult to see how their accounts could be of use. This was compounded by their perception of themselves as 'nothing special' and that researchers were only interested in 'important' things.

- **Past experience of researchers** - Some carers had past experience of participating in research projects that made them disinclined to participate. Insensitive data collection and broken/unrealistic promises had been experienced by some.

The notable exception to the above difficulties was the centre offering support to young carers, where 10 carers were easily identified. However, this site had a number of advantages: young carers attended a centre so were not interviewed in their own home; formal assessments were not undertaken so all young carers who cared for people with mental health problems were invited to participate; staff were fully engaged with the study and helped to develop an appropriate letter of invitation and information about the study which they explained to potential recruits.

After the initial interview we planned a longitudinal consideration of the impact of the assessment from a carer's perspective, including an analysis of assessment goals and subsequent implementation. In order to gain these data, where possible, carers were re-interviewed approximately 6 months after the initial assessment.

Given the above difficulties our failure to recruit the numbers envisaged is not surprising. Ultimately we feel pleased to have completed 93 initial interviews and 77 follow-up interviews as indicated in Table 1.1.

### ***Gathering the data: the role of carer researchers***

As a team we are committed to fostering a culture of collaborative work with carers that recognises their expertise and experience. For the carer interviews we therefore recruited, trained and worked alongside carers as researchers, something with which we have experience (eg Repper et al 2003). Although the academic project team are all experienced in interviewing carers, we were also conscious that highly sensitive topics were to be addressed, and that carers might feel more comfortable being interviewed by someone from their own peer group. Carer researchers were therefore carefully selected in conjunction with the RDC, and training provided by the research team. There was open access to the research fellow with day-to-day responsibility for the project. Moreover, for each of the case study sites one of the principal applicants (MN, JR, GG), or the research fellow, acted as mentor/facilitator for carer researchers in these areas.

**Table 1.1: Number of carer interviews undertaken on each site**

<b>Site</b>	<b>Carer Interviews</b>	
<b>Assessment Site</b>	<b>Baseline</b>	<b>6 months</b>
A	10	10
B	10	10
C (target 20 carers)	7	2
D	9	7
E	9	9
F	9	7

G (young carers)	10	7
H	10	9
<b>Non-Assessment Sites</b>		
I (Assertive Outreach AD)	7	7
J (early intervention)	0	0
K (family group conference)	7 (12 carers)	6 (9 carers)
<b>Total</b>	<b>93</b>	<b>77</b>

All interviews were tape-recorded and transcribed for later analysis, with 'carer researchers' being involved with the analysis of the interview data at some sites. In its implementation, involving carers as researchers worked very well in some situations but less so in others. In regard to the site where we interviewed young carers, we took advice from the young carers project concerned and used experienced academic interviewers only. This worked well.

The principles that we applied to working with carers as co-researchers are summarised in Appendix 5.

Carers were involved in the project in the following ways.

### ***Advisory group***

During the development of the proposal representatives of different stakeholder groups were invited to join the project Advisory group. The carer members of this group were selected for their ability to represent the viewpoint of carers of people with mental health problems. To avoid tokenism, it was also considered appropriate to select individuals with the skills and confidence to contribute to a discussion around research strategy, design, ethics and methods. They included: one regional carer lead who was also the carer of a sibling with serious mental health problems; another regional carer lead who worked exclusively with carers promoting their involvement in service planning and delivery; and a representative from the Alzheimer's Disease Society with experience of working with carers in research. The draft proposal was sent to all members of the Advisory Group prior to submission but few changes were suggested. Ideally, with more time and available funding, we would have developed and written the proposal with carer researchers. However, the adoption of a flexible, evolutionary design and a constructivist approach ensured that carers had ongoing influence on the project. In the early stages of the project members of the Advisory Group contributed to meetings to discuss progress, and carer members brought valuable insights and suggestions which added to the ongoing development of the study.

### ***Reference group***

In order to elicit the views of service users and carers with concurrent experience of services – and as such different from the carers selected for the Advisory Group – we approached an established user and carer group with experience of research to provide ongoing comment and suggestions. We met with this group before the project began and, for the first two years, at 6 monthly intervals to discuss our plans and gain their views. There are few sources of advice for working with reference groups in this way so we negotiated and agreed a plan for meetings, including a clear purpose and payment. We sent all papers in advance of meetings and the reference group met to discuss their views before meeting with members of the research team. Following the initial meeting to discuss the overall project plan, we set an agenda which addressed specific questions – from us and them – to ensure that our meetings had a clear focus. Of particular use were their comments about the training of carer researchers. Since they had undergone research training themselves, they made valuable suggestions about our proposed training plan, for example, increased interviewing practice using role play, providing additional time to discuss ethical issues. They also raised interesting questions about inclusion criteria for the carers we would be interviewing. As the project progressed we found that we had less to discuss with the reference group, as we had input from carers at all the study sites, so meetings became more of a forum for us to feedback and them to ask questions, and eventually these meetings ceased.

### ***Carers as researchers at the case study sites***

It was in this phase of the study that we worked most intensively with carers. At each of the case study sites between 2 and 5 carers were recruited, trained and supported to contribute to the development of carer interview schedules, undertake carer interviews and, where appropriate, analyse transcripts. This was approved by the MREC with no difficulties other than a requirement that participants in the research were given a choice of interviewer: either professional researcher or carer researcher.

The process of working with carers developed iteratively with experience on each site informing the implementation on subsequent sites. Thus, for example, the research training was piloted on one site and amended before use on another site; the carer interview schedule developed on the first site provided a template for the next site to adapt as they saw fit. Analysis was undertaken to varying degrees on each site independently to test the validity of the findings.

Each of the sites differed in terms of methods and ease of the recruitment of carer researchers; support provided by local R&D office; skills and experience of the carers recruited; independence of the carers organising and undertaking interviews; and participation of the carers in analysis.

**Recruitment of carer researchers:** We began the recruitment process through Carer Leads in the NIMH(E) Regional Development Centres. However, it became clear that although many carers were interested in improving services, as indicated by the numbers attending the consultation exercise, very few carers had experience of research. In all but one region, therefore, we were ‘starting from scratch’. In the region that was the exception, two carers were recruited to work on the study who had training and experience of research and teaching. They were part of a regional carers group who met regularly through their



involvement in various service development, research and training initiatives. This demonstrates the potential value of building capacity among local carers and supporting a group for ongoing involvement in relevant initiatives.

In all other sites, we worked through the teams being studied, identifying local carer centres and sending or posting advertisements outlining the nature of the work to be done and the payment offered. The response to our invitations varied, but we did eventually identify between 2 and 5 carers in each site who remained interested in the project and joined the research training on offer. The majority of recruits were women aged 40 to 65 years who had spent several years caring for a child (now entering adulthood) with serious mental health problems. Most of the recruits had not previously done any research but they all had relevant experience of caring. There were some concerns expressed by local carer assessment services about issues of confidentiality (Would local carers be willing to speak openly to carers they may already know? How would we select suitable carers for the project?). These were pertinent questions. We had not set selection criteria; rather we intended to assess carers' suitability for the work throughout the training and assign work accordingly. This is discussed further below.

Before any research can be undertaken on NHS Trust sites, research governance procedures require all researchers to have Criminal Records Bureau (CRB) clearance and honorary contracts. This was an onerous process for the carer researchers. Some Trusts had no system for signing off the CRB paperwork for non-employees, and new systems had to be put in place which was lengthy and delayed the commencement of interviewing. Honorary contracts required the completion of complex forms, citing of referees, and occupational health clearance. Carer researchers understandably needed help and reassurance during this process, which necessarily took place soon after our first contact with them, before trusting relationships had been built up. This also proved a lengthy process, taking up to a year to complete, which disrupted the timing of interviews and meant that the gap between research training and commencing interviews was so long that revision sessions were required. In future researchers who intend to involve consumers need to be aware of the complexity of this process and the implications for the timing of the research.

**Training:** Training was developed to reflect the requirements of the project, drawing on the formats provided by Charlesworth and Poland (2001), Allam et al (2004) and Nichols et al (2003). It took place over an initial 3 days, with time for some reading and rehearsal in between.

Areas covered in training:

Session 1: Ground rules, introductions, what carers bring to the research, doing constructivist research, introduction to research, different kinds of research, stages of the research process, role of researchers, reliable and valid research.

Session 2: Aims of PICAP, research design and methods, involvement of carers, case studies, interviewing carers in PICAP, analysing data, dissemination, your role as carer researcher.

- Session 3: Qualitative research methods, qualitative research in PICAP, qualitative interviews, interviews with carers in PICAP, open ended questions, qualitative interview questions for PICAP, building PICAP questions for carers, agreeing the PICAP interview schedule.
- Session 4: Interviewing skills, active listening, and managing distress, some interviewing problems and how to avoid them, difference in interviewing styles, thinking about tape recorders, using the PICAP interview schedule.
- Session 5: Ethical issues and research governance, maintaining anonymity and confidentiality, providing information to participants, gaining informed consent, minimizing distress, organizing interviews and introducing PICAP, making arrangements to interview.
- Session 6: Working safely, working in other people's homes and neighbourhoods, dealing with complaints, concerns and difficult events. Practicalities: expenses and finances, access to support, useful contacts.

A training manual was prepared and all carer researchers who wanted one were given a copy. This provided an accessible description of the study, and an explanation of all the areas covered, including exercises to practice and test knowledge, and a list of useful contacts and additional reading.

Early in the training carers introduced themselves and their reasons for getting involved in the research. The majority wanted to do something to improve services and/or gain new skills. The payment for some was an added incentive, as was the research focus on carers - rather than service users. Many carers were initially concerned about their ability to 'do' research. However, most said they enjoyed their role and were keen to get involved in further research.

On every site the carer researchers were able to use their experience of caring and of assessment to: understand the need for the research and the study design and methods; amend the interview schedule and make the information sheet and invitation letters accessible; articulate and apply ethical issues; and to understand the practicalities of interviewing. They had clear opinions and contributions to make. For example, the interview schedule followed a chronological sequence of events based on their own experiences of assessment and their priorities: how much choice, explanation and information they were given; whether they felt able to ask questions and raise issues. However, it was striking how raw and painful their past and ongoing experiences of caring were. It was accounts of their lives as carers that took up a lot of time on research training days; every conversation triggered memories and sessions were often emotional. It was helpful to devote some time at the beginning of each day to share recent events and experiences. It was also useful to set ground rules for speaking one at a time, listening to each other, not making value judgements, and maintaining confidentiality within the group.

During the second day of training we discussed interview skills and practiced active listening. Although initially reluctant, most carers found role-play was a helpful way of rehearsing active listening skills (such as following up issues that interviewees mentioned, responding to comments to open up the discussion, acknowledging responses and encouraging respondents to give more detail). Carers worked in threes, playing carer, interviewer and observer, each giving feedback before 'de-rolling' and then feedback to the larger group what had been learnt. Many continued to find it difficult to detach from their own experiences and remain focused on the respondents account – which often prompted memories or unexpected emotions based on their own experiences. It is difficult to witness someone else's distress, particularly when you identify strongly with the feelings, and even more so when your role is not to offer solutions or suggestions, just to listen. The carer researchers, used to having an active role, wanted to volunteer their own experiences, suggestions and ways they had coped. Repeated practice and feedback helped them to remain 'other focused'. We provided a list of local resources for carers that the interviewers could discuss with them at the end of the interview so that they felt they were not abandoning them entirely without help. One group of experienced carers preferred to discuss a range of issues rather than engage in role play.

Perhaps hardest of all was achieving a balance between disclosing enough information about themselves to facilitate the interviewee in telling their story, and disclosing too much: taking over or leading the interview. We were employing carers as researchers because of their caring experience but it is still not clear how they could use this experience most effectively during interviews. All interviewees knew that they were being interviewed by another carer, and interviewers gave some more details about their personal situation when introducing themselves before the interview. During the interview they were encouraged to use non-verbal cues to convey agreement and familiarity, and brief comments ('I know what you mean', 'I've been there', 'it is awful when that happens...') to show empathy. However, no blanket rule can be made about how to answer direct questions asked of them (such as 'I'm terrified at times - are you?', 'Has your son ever been sectioned?'). Some carers were reluctant to talk about the person they cared for as this compromised their privacy; others found it hard to know when to stop talking about their own situation. For this purpose it was useful to work in pairs, monitoring the amount and appropriateness of self disclosure and giving each other feedback.

In all but one area (where the carer researchers had considerable previous experience), we found that the planned 3 days training were not sufficient so we provided additional days to practice skills until the majority of carers felt confident and were considered able to undertake interviews independently. Some continued to lack confidence; others found interviewing difficult to master so they worked with the professional researcher. This begs questions about the selection of consumer researchers. We did not set selection criteria. If people considered themselves to be a carer for someone with mental health problems and were interested in the project then we invited them to join the training. However, it may be more appropriate to conduct some selection procedure. Not surprisingly, carers with experience of research during higher education, or through more recent work, were more confident and found the skills easier to pick up. Most of the difficulties were overcome with training and targeting areas in which they lacked confidence, and through careful complementary pairing of researchers. However, it became clear that a certain level of literacy was necessary, and some understanding of research and the role of the researcher were helpful.

**Undertaking interviews:** The carers were working at some distance from the research centre so local systems for organising interviews were set up. This was complicated as carers often did not have access to an office or administration; they needed to rent local rooms to undertake interviews, and they had to access funds to pay for postage, stationery and transport. Arrangements differed on each site. One group of four carer researchers working on a south coast site will be described as an example. On this site, one of the carer researchers, a retired teacher, volunteered to organise interviews. This involved:

- maintaining clear records of the names, addresses and contact numbers of each of the 10 interviewees and keeping this locked in her home;
- contacting interviewees, writing initially and then speaking on the phone to negotiate a convenient time and place for interview, then texting them the day before interviews to remind them of the appointment;
- arranging interviewers for each interview, and calling them following interviews to check for any difficulties;
- contacting the professional researcher if there were problems;
- completing records: dates at which interviewees were first contacted, interviewers, dates and places of interviews, and dates at which tapes were sent for transcription, returned, sent to interviewee etc;
- booking venues for the interviews and ensuring that everything needed was at the venue when required (tape recorders, interview schedules, interview notes sheets, consent forms, information sheets, list of local resources for carers, box of tissues and petty cash to pay interviewee's transport costs).

On three occasions the interviewers were concerned about the distress of interviewees and asked their permission to let the carer assessors know their situation. This was agreed by the interviewee and the carer assessors were pleased to have been informed. The carer researchers attended the same carer support group as many of the interviewees. This did not appear to have either a positive or negative effect on the interviews. Without exception, all 10 interviewees on this site spoke in detail, and agreed to talk at three month phone interviews and when visited again for the 6 month follow-up interview.

Interviews were more difficult to organise on sites where the carer researchers did not feel fully confident to co-ordinate things. So, for example, on one other site, even after 5 days training, the carer researchers did not feel confident to work independently and the professional researcher organised all the interviews and accompanied the researchers on interview visits. This research site was a deprived inner city area and many of the interviewees were living in precarious and risky situations. The experience of working on this site raised questions about the ethics of expecting consumer researchers (with just 5 days training) to undertake interviews in these situations without the presence of a professional researcher.

On the first site to commence interviews, interviewees were given a choice of interviewers, and all 10 asked to be interviewed by a professional interviewer; although they were interviewed by a professional researcher a carer researcher observed the interview. On subsequent sites interviewees were given a choice of interviewer but informed that, unless they specifically requested otherwise, they would be interviewed by a carer researcher. No-one specifically requested not to have a carer researcher. It is interesting to note that although carer interviewers felt they established a good relationship with interviewees and were able to converse about shared experiences of caring, the interview transcripts of professional interviewers often differed from those conducted by carer interviewers: they were usually considerably longer and more detailed. This is understandable. Interviewees often introduced issues relating to service provision, types of interventions and local services that were followed up by professional interviewers who had greater knowledge of mental health and more confidence moving away from the set transcript. On the other hand, carer researchers were more inclined to stick to the interview schedule with additional text being their accounts of their own experiences.

Carers were involved in the analysis of transcribed data on a number of the study sites. They all received copies of the interviews from their site and met with a professional researcher to discuss the main 'things going on' in these interviews. Although analysis was carried out independently – by different professional and carer researchers on each site – there was striking consistency in the coding frameworks that developed.

A different approach was adopted in the work with young carers on the advice of the Action With Young Carers Project (AWYC). Here, there was a stated preference for interviewing to be carried out by academic researchers from the PICAP team, and at the Project's base. This was a secure and familiar environment for the young people. It was here that they met their project workers on a regular basis, sometimes engaging in group work activities with their peers. The AWYC Project made contact with the families of the young people to explain the aims and purposes of the study and obtained permission for approaches to be made to young carers about participating in the study. The design and wording of invitation letters, and the formulation of assent and consent questions were agreed between the PICAP and AWYC Projects. Interviews with project workers and managers, and also staff from partner agencies, also took place at the AWYC base. All interviews were taped and transcribed with the permission of participants.

Interviews with staff about the AWYC project were used in conjunction with agency policy documents to build up a description of the AWYC project, its aims, values and practices, laying the basis for the outline presented in Chapter 5. The outline presented there was agreed with AWYC staff and, as with all the sites, can be regarded as a co-constructed account.

When the young carers were re-interviewed, care was taken to re-familiarise them with themes they had raised at the first interview as a way of checking that these were what they had intended to convey. These were affirmed and used as a basis for taking soundings about how their lives had moved on following subsequent assessment and support work from the AWYC Project. In this way the constructivist principles informing PICAP's chosen methodology were put into practice.

### **Phase 3: Consensus Workshop**

The aim in the original proposal was to conduct consensus workshops at each of the sites involved in the study in order to identify and agree the principles of practice for assessment, and the indicative content for carer and practitioner guides. However, as the project unfolded, most sites preferred the idea of a joint workshop to share ideas. On this basis a workshop was held at the King's Fund in July 2007.

The goal of the interactive workshop was to bring together key individuals from each of the sites to explore issues that had been raised, share 'best' practice based on their experiences, and agree a set of principles that could underpin carers' assessment and help to structure guidelines for both carers and professional/voluntary organisations. It was intended that participants represent a good cross section of individuals from each site, including carers, carer researchers and those working in voluntary or statutory agencies locally. As the aim was to make the event as interactive as possible, it was important to keep the numbers manageable so it was decided to extend six invitations to each site. Our experience of working closely with each site was used to identify key individuals who were invited personally or asked to nominate a representative. The maximum number of participants was envisaged as 55-60. In the event we had 40 people who wanted to attend.

Whilst our goal was to allow as much free discussion as possible, it was necessary to have a degree of structure and focus so that maximum use could be made of the relatively brief period available. In order to achieve this each of the participants was sent some reading material in advance of the event. This comprised a number of points relating to:

- Principles for working with carers, and of good assessment practice.
- Guidelines for preparing for and undertaking the assessment.
- What the assessment should cover.
- The outcomes of assessment.

A copy of this material is included as Appendix 6.

This prior reading was drawn from a number of sources. It was informed primarily by the results of the data analysis at each of the case study sites and the work that had already been completed at the Young Carers Project. However, it also incorporated key ideas from a variety of published material such as that produced by NIMH[E] (2004) relating to working with carers, guide for carers and valuing carers, the recent guidelines published by the Family Carers Alliance (FCA 2006) in the US and earlier extensive work on carer assessment from the UK (Nicholas 2001, 2003, Nolan et al 1994, 1998). Participants were informed that the day would comprise two components, the morning being devoted to small group work that would seek to achieve consensus as

to the principles and processes of good assessment, with the afternoon focussing on barriers and facilitators to applying the agreed principles in practice.

Inevitably when people have work and caring responsibilities, attendance at a 'workshop', as appealing as it might be, is not always possible. However, we were very pleased that of the 40 people who expressed an interest in attending, 28 were able to come on the day. These comprised 13 individuals from the statutory or voluntary sectors, 10 carer researchers and 5 carers. However, as the carer researchers were also all carers the mix of participants was approximately 50/50, as we had intended. No young carers attended as they had been involved in a prior event. Three members of the young carers' project attended to give their opinions on the wider issues.

Participants had been allocated to workshops in advance to ensure that there was a balance in each group between both sites and carers/practitioners. The intention of the day was to stimulate debate and promote critical thinking, and this certainly proved to be the case, with the workshops and subsequent feedback being both lively and informative.

Fortunately there was broad consensus about the material both within and between groups, but also the identification of areas for further refinement and development. Several perceived barriers were also identified.

At the end of the day it was agreed that members of the project team would go away with the copious notes and flip charts, modify the principles and guidelines to incorporate the views expressed during the day, and circulate these revisions to the participants for their comments and feedback. Following this, re-drafted material was sent to participants for further comment. The resultant outputs are separate from, but related to, this report.

### **Intended outputs**

As a result of the above the primary intended outputs for the project are:

- the identification of best practice principles providing a framework for the assessment of carers of people with mental health problems, to inform both assessment and the education of practitioners;
- a carer orientated 'consumer guide' to assessment that will inform and empower carers with respect to their own assessments, and a practitioner guide to assist assessors in evaluating and enhancing their assessment practice;
- a scientific report for SDO highlighting theoretical, policy and practice implications.

This document comprises the latter.

Having described the background to the project and the methodological approach adopted, attention is now turned to the literature synthesis that was conducted to inform the study as it unfolded, to place the empirical findings in the context of the literature on caring for someone with mental health problems and, where appropriate, the wider caregiving literature.



## CHAPTER 2

### Literature Synthesis

#### Key messages

- This chapter comprises a comprehensive conceptual synthesis of the literature relating to the experiences of caring in mental health, the relationships between carers and service systems, the literature on assessment and the implications of this for the assessment process.
- This synthesis confirms and extends the conclusions reached by Arksey et al (2002) that our understanding of the caring experience in mental health remains rudimentary. This is due in large measure to the emphasis placed on schizophrenia to the relative neglect of other forms of mental illness, and the continued focus on burden, which remains the 'major conceptual framework' applied to the field.
- The limited longitudinal research on carers' experiences reinforces the need to better understand the meanings that carers bring to their situation and how such meanings change over time. A temporal model that incorporates a strengths-based, family orientated approach is required, but not well developed either conceptually or empirically.
- The nature and quality of carers' relationships with mental health professionals and service systems appear crucial. Attitudes are often based on early encounters which are frequently characterised by limited attention to carers' needs and knowledge, resulting in poor relationships.
- Carers frequently describe how they have to 'battle' with service systems, and relationships with professionals often remain conflicted. Whereas carers generally have 'ambiguous' relationships with services, those in mental health are more likely to be 'antagonistic and alienated'. Consequently carers lose trust in service systems.
- Such relationships present formidable barriers to genuine partnership working which include:
  - the persistence of a 'blame culture' towards family carers;
  - the failure to recognise and draw upon carers' expertise and knowledge of services that remain focussed on the user rather than mutualities and interdependencies between family members;
  - the continued reliance on a primarily 'medical model' approach to mental illness;
  - the tensions caused by systems and practices designed to maintain confidentiality.

- These factors are exacerbated by the lack of professional training and skills for work with carers, limited incentives and high workloads. These educational and workforce factors constrain the ambitions of those who wish to work in a more proactive fashion.
- Whilst examples of good partnership working do exist, their routine and widespread application is not the norm.
- In mental health the number of carer assessments completed is very low and assessments may not be subsequently acted upon.
- Despite legislative changes in the UK the practice of carer assessment is limited, and several recent reports have described current systems as inadequate in important ways. This applies to all carers and not just those in mental health.
- Enduring problems remain in relation to the reach and effectiveness of carer assessment generally. The persistence of these problems has been described not only in the UK, but also in other countries.
- Models that provide a framework that assist professional and family carers to negotiate service outcomes have been developed, and may be relevant to mental health contexts.

### **The experience of caring in mental health: a synthesis of the literature**

In common with the wider literature, that in mental health increasingly recognises that in order to assess and respond fully to carers' needs it is necessary to have as complete as possible an understanding of the experience of caring and the 'meanings' that it has for carers (Jeon and Madjar 1998, Rhoades and McFarland 1999, Strang and Haughey 1999, Karp and Tanarugsachock 2000). An appreciation of the temporal nature of caring and how it may change overtime is also widely seen as being essential (Jeon and Madjar 1998, Rose 1998a, b, Karp and Tanarugsachock 2000).

In respect of carers of people with mental health problems any such understanding is at best partial and incomplete. This is due to several factors. As Arksey et al (2002) note, the majority of research has been of a quantitative nature and the review completed by themselves and the scoping exercise of Newbrunner and Hare (2002) highlighted the dearth of good qualitative studies. To compound difficulties most studies have focussed on schizophrenia to the relative neglect of other more common manifestations of mental illness (Hill et al 1998, Arksey et al 2002, Haigh and Treasure 2003). Arksey et al (2002) stress the limited attention given to depression, eating disorders, anxiety and substance abuse, a point reinforced by our review (see, for example, Haigh and Treasure 2003, Winn et al 2004). Other notable gaps are apparent in respect of carers from black and minority ethnic (BME) groups (Finley 1998, Hines-Martin 1998, Ho et al 2002, Rungreangkulkij and Chesla 2001, DoH 2002, Schulze and Rössler 2005); rural carers (DoH 2002); young carers (DoH 2002, Pagnini 2005); carers of people with obsessive compulsive

disorders (Laidlaw et al 1999); sibling carers (Hatfield and Lefley 2005); carers of adults with attention deficit disorder (Hare et al 2004); carers of people with HIV/Aids (Flaskerud and Lee 2001) and carers of people with Huntington's disease (Lowit and Teijlgen (2005). However, with the exception of dementia, probably the most notable absence is the limited attention given to mental health problems in older age (Horton-Deutsch et al 2002, Ferguson and Keady 2002, Jeon 2003, Bartels 2005). As will be readily appreciated, the dominance of schizophrenia has resulted in the experiences of the majority of carers for people with mental health problems being relatively ignored.

To compound matters the overwhelming focus of most research has been on caring as a negative or burdensome experience (Greenberg et al 1994, Magliano et al 1998, Lefley 1997, Rose 1998, Horton-Deutsch et al 2002, Chakrabarti and Gill 2002, Doornbos 2002, Jungbauer et al 2003, Simpson and Benn 2007). Authors have suggested that this reflects the fact that research in mental health is *'largely weighted towards the negative'* (Karp 2001), or is *'notoriously pathology based'* (Allison et al 2003). Countering such a trend a wider stress-coping paradigm has been applied by some (Szmukler et al 1996), and recently several commentators have called for a much broader perspective on caring to include a focus on potential satisfactions (Rose 1998, Arksey et al 2002) and, in particular, an appreciation of the strengths, resources, competence and resilience that carers may possess or be helped to develop (Finkelmann 2000, Rungreangkulkij et al 2002, Cleary et al 2003, Saunders 2003, Schulze and Rössler 2003, Addington et al 2003, 2005). This was eloquently captured some time ago by Szmukler et al (1996) who note:

'In psychiatric research we are unaccustomed to examining positive aspects of functioning, we would do well to recall that caregivers of relatives with serious mental illness cope effectively with taxing and enduring problems. In attempting to measure the experience we should resist the tendency to pathologise; identifying and understanding coping is as pertinent as detecting psychopathology'.

Despite such a plea, and emerging research on the potential satisfactions of caring (see below), burden still exerts considerable influence. Commentators continue to call for yet more research in order to better understand burden (Ivarsson et al 2004, Meijer et al 2004, Östman 2004, Perlick et al 2004, Provender et al 2003), a trend highlighted by Schulze and Rössler (2005). They note that burden has been the focus of research attention since the 1950's but suggest that, despite recent calls for the adoption of a more holistic approach, the influence of burden is still pervasive. They illustrate this by pointing out that between 1980 – 1995 there were 50 major studies of carer burden in mental health, but in the 18 months between January 2004 and May 2005 alone there were 48 published studies looking at burden. Mirroring the conclusions of others (Arksey et al 2002, Newbrunner and Hare 2002) they call for more robust qualitative studies, and a greater focus on the satisfactions of carers.

Notwithstanding the predominance of burden, there is growing recognition of the importance of a better understanding of the potential satisfactions or rewards of caring (Greenberg et al 1994, Szmukler et al 1996, Rose 1998, Schwartz and Gidron 2002, Morullo 2002a, Heru and Ryan 2004, Foldeme et al 2005, Schulze and Rössler 2005). Rose (1998) argues that key to a better appreciation of the experience of caring is an understanding of the relationships and interactions between the carer and the person with mental health problems, as herein lies the major source of both difficulties and satisfactions. In terms of

satisfactions studies have suggested that caring can provide carers with companionship (Greenberg et al 1994, Schwartz and Gidron 2002), opportunities for personal growth (Hill et al 1998, Schwartz and Gidron 2002), and enhanced self-awareness (Schwartz and Gidron 2002). Whilst most studies have been relatively small-scale and exploratory (Chen and Greenberg 2004), Chen and Greenberg (2004) explored satisfactions in 560 families and concluded that they were *'prevalent'* and had the potential to *'positively transform'* the lives of carers. Based on their work Chen and Greenberg (2004) contend that interventions should help to increase caregiver satisfaction, a point noted by others (Szmukler et al 1996, Schwartz and Gidron 2002). However, it seems that the potential satisfactions of caring have been largely ignored by professionals (Schwartz and Gidron 2002).

Despite such studies the predominance of burden within research on the experience of caring for someone with a mental health problem was noted sometime ago (Johnson 1990), and this remains a *'major conceptual framework'* (Jeon 2003). Consequently, our understanding of the wider caring experience remains *'rudimentary'* (Szmukler et al 1996). Indeed, as will be discussed more fully later, the combination of burden with the considerable focus on expressed emotion (Rose et al 2002, Jeon 2003, Mubarak and Barber 2003) has laid the foundations for the strained and often negative interactions that occur between carers and mental health professionals. A more balanced relationship is unlikely to emerge until there is a significant shift away from the preoccupation with burden:

'towards more positive formulations of the caring experience, recognising that it can be a fulfilling aspect of a relationship and therefore both good and bad effects need to be taken into account'.

(Wooff et al 2003, p30)

One area in which a broader appreciation is beginning to emerge is in understanding caring as a temporal experience.

### **Caring as a temporal experience**

'The form, content and timing of interventions should depend to a considerable extent on where carers are in their careers and involve an understanding of what has passed before, and what is likely to lie ahead. That is the problems encountered today should be viewed against the backdrop of yesterday, and with an eye towards tomorrow'.

(Aneshensel et al 1995)

Whilst acknowledging that each caring situation is unique the literature, especially in the field of dementia, has increasingly recognised the importance of understanding caring as a temporal experience (see, for example, Wilson 1989a, b, Willoughby and Keating 1991, Kobayashi et al 1993, Wuest et al 1994, Nolan et al 1996, Keady 1999, Keady and Nolan 2003). The belief is that this allows for the identification of key 'transition' points in caring when the nature of support required is likely to vary (Aneshensel et al 1995, Schulz and Williamson 1997, Montgomery and Kosloski 2000, Whitlach et al 2001, Cavaye 2006). It is not suggested that it is possible to 'predict' the course of caring but rather that *'threads of continuity'* (Aneshensel et al 1995) or *'consistency'*

(Montgomery and Kosloski 2000) can be identified. The metaphor that has often been applied is that of the caring 'career' (Aneshensel et al 1995, Nolan et al 2003), which comprises certain phases that give an indication of the type of help and support that is needed, and when. For example, Aneshensel et al (1995) identified three such broad phases:

- Preparation for, and acquisition of, the caring role
- Enacting the caring role
- Disengagement from the caring role

Taking a similar stance Montgomery and Kosloski (2000) talk of caring having a '*beginning, discernable temporal extension, and an end*'. They suggest seven phases:

- Performing tasks previously undertaken by others
- Self-definition as a carer
- Giving personal care
- Seeking assistance and formal service use
- Considering nursing home placement
- Nursing home placement
- End of caring, either because of the death of the cared-for-person, or because the carer 'quits'

It is obvious from the above that much of the existing work on the temporal nature of caring has involved carers who support older people with dementia and/or those who need considerable physical care. Such considerations may be less important in several forms of mental illness. Nevertheless, a number of authors have adopted a temporal perspective in an effort to better understand the changing nature of the caring experience in mental illness. The major studies identified in the review are briefly discussed.

Understanding the temporal experience of care is important, not simply for theoretical reasons, there being growing recognition of the benefits of tailoring support for carers of people with mental health problems so that it reflects their changing needs and relationships (Godfrey and Wistow 1997, DoH 2002, Pagnini 2005, Walton-Moss et al 2005). As Dawson et al (2004) suggest, support should be '*choreographed*' to match carers' unfolding needs. However, this rarely seems to be the case, especially in the early stages of caring (Winefield and Harvey 1994, McCann et al 1996, Howard 1998, DoH 2002, Addington et al 2003, Chien et al 2004, Rethink 2003).

Contact with professionals at an early stage is often limited (DoH 2002, Rethink 2003, Sin et al 2003b) with the result that carers are rarely able to choose to care or not (Rethink 2003), and are frequently poorly prepared for their role (Chien et al 2004).

Similarly carers need help to think ahead and plan for the future, but again such considerations are often not addressed (Kaufman 1998, Mafullul 2002, Dawson et al 2004).

The insights provided by temporal models may help to redress such deficits.

One of the most comprehensive descriptions is that provided by Karp (Karp and Tanarugsachock 2000, Karp 2001), based on several years of ethnographic observation of a carers' support group and repeated in-depth interviews with carers over time. A range of carers, including spouses, parents, children or siblings were included who were supporting family members with either bi-polar disorder or schizophrenia. The goals of the study were to explore emotions and reactions over time and to identify '*turning points*' in the joint experiences of both carer and the cared-for person. Karp and Tanarugsachock (2000) describe four '*interpretive junctures*' with associated emotional reactions:

- Before diagnosis when carers experience a sense of '*emotional anomie*' characterised by uncertainty and confusion as they are confronted by unexplained behaviours that make no sense within existing frames of reference.
- Diagnosis – is seen as a '*pivotal*' moment when a potential explanation, albeit in medical terms, is available. At this point carers crave information and actively work to 'learn' about the 'illness'. This is a period in which carers usually embrace their role enthusiastically in the belief that they can 'save' or 'cure' their loved one. At the same time carers may find it difficult to fully empathise with their relative, and can feel frustration when there is little apparent reciprocity in their relationship.
- Realisation of permanency – as time passes there is increasing recognition that carers' initial hopes for a 'cure' will not be realised and this is often a period of deeply conflicting emotions when the 'permanency' of the illness is acknowledged. Carers can feel anger, resentment, loss and grief as their own hopes/aspirations are put on hold and there is little apparent focus on their needs.
- Acceptance that they cannot control the illness – eventually most carers come to accept that much of the illness is outside of their control and they may begin to decrease their involvement without feeling guilty. Their ability to do so depends on achieving what Karp and Tanarugsachock (2000) call the 4 c's:
  - I did not **cause** this
  - I cannot **control** this
  - I cannot **cure** this
  - I can only **cope** with this

In a more detailed account Karp (2001) elaborates upon the above model. Here, diagnosis is described as an *'epiphany'* for carers that triggers a sequence of *'experiential moments'* comprising:

- hope and planning – this includes the initial hope of cure to the eventual recognition of the permanency of the illness when there is a need to;
- revise expectations and;
- assess responsibility – here the cared-for-person is expected to actively contribute. Eventually carers recognise the need to;
- preserve oneself – and to disengage from care in order not to be overwhelmed.

During the above processes Karp (2001) argues that carers develop, refine and consolidate their own theories of care. He captures this as follows:

'All human beings are theorists. We may not think of ourselves that way since we usually take our implicit theories largely for granted. Still it would be impossible to live without some practical theories about all sorts of things'. (p151)

Due to the changing nature of their experience carers' theories constantly evolve. However, their theories may not, and often do not, correspond with those of professionals, and it is here that difficulties and tensions arise. Indeed Karp (2001) suggests that carers and professionals often seem to be speaking *'different dialects of the same language'* and consequently one of the biggest hurdles that carers face is learning to 'survive' the mental health system. This will be discussed in greater detail later when partnership working is considered more fully. However, for Karp (2001) tensions between carers and professionals are most profound at key transition points, especially during crises because:

'...what family members experience as traumatic and chaotic turmoil, they [professionals] experience as routine, even boring... this ritualisation of their crisis feels callous to them [carers]'. (p200)

To compound matters carers' need for information, especially in the early stages, is often ignored and they feel marginalised and disregarded. In such circumstances carers soon become *'cynical'* about the whole system, and loose trust, which subsequently can be very hard, if not impossible, to re-establish. Such dynamics are typified in carers' contact with psychiatrists who, according to Karp (2001), tend to base their therapeutic model on a *'two-person social system only – doctor and patient'*. Consequently carers often see psychiatrists as:

- being unwilling to listen to them;
- decontextualising treatment by disregarding their expert knowledge;

- making 'snap' judgements without sufficient knowledge;
- behaving in a callous way and making carers' pain worse;
- being quick to blame carers.

The consequent negative relationships that form lay the foundations for carers' future interactions with mental health professionals, something that will again be considered in greater detail shortly.

The '*ambiguity*' that Karp (2001) describes as characterising carers' experience of their relative's mental illness has also been identified by Rose et al (2002), who explored the experiences of 17 families over a two year period. They identified '*living with ambiguity*' and '*searching for normalcy*' as being the key processes that carers engage in. As with Karp (2001), Rose et al (2002) describe a complex mixture of conflicting emotions including grief, anger and guilt. The extent to which carers are able to resolve such feelings hinges on their ability to work with the person with the mental illness to redefine '*normalcy*'.

Mirroring Karp's (2001) account, Rose et al (2002) found that carers' emotions change over time ranging from shock, fear and frustration, to sadness, grief, and eventually to potential optimism. In situations where carers are able to construct a satisfactory definition of '*normalcy*', they are better equipped to resolve issues of responsibility between themselves and their relative, to redefine their relationships and to strive for growth. This involves confronting their initial ambiguity, identifying limits to the control that they can achieve, and constantly redefining normalcy. In such circumstances carers are far more positive about the future for both themselves and their relative. As Rose et al (2002) point out, their model extends the vision of the caring experience beyond the traditional confines of burden and expressed emotion and offers an alternative view that better reflects the diversity and complexity of the realities of caring.

Rethink (2003) also characterise mental illness as '*a journey*', both for the person affected and their carer. They describe eight stages or phases, with the latter four often being cyclical. These are:

- Initial good mental health
- First experience of mental health problems
- First contact with services
- Initial diagnosis/treatment
- Holistic support
- Recovery process
- Relapse
- Recovery journey



The main aim of this model is to identify barriers to early treatment and support for people with a psychosis and their carers. Several barriers are identified, including poor public understanding of mental illness, difficulties in accessing the system and variable experiences of initial contact, difficulties in getting the best treatment, lack of user and carer involvement, and patient confidentiality (Rethink 2003).

The models developed by Karp (2001) and Rose et al (2002), whilst clearly having practical implications, were primarily concerned with adding to the theoretical literature. That of Rethink (2003) is less empirically grounded and focuses mainly on the issue of early treatment for people with psychosis. In contrast Pagnini (2005) aimed explicitly to develop a theoretically and empirically based framework with direct practical application for carers of people with mental illness, appropriate to the stage of their caring journey, their life stage and their relationship with the person with mental illness. Drawing on the lived experience of 60 carers, and an extensive review of the literature, she identified 6 distinct phases within a life course framework, intended to capture:

- lifelong development and ageing;
- human agency;
- the timing of events in people's lives;
- historical time and place such as current views of mental illness and policy directives;
- linked lives - between the carer and person with mental illness.

Her literature review revealed that hitherto there had been very little focus on resilience and adaptation in mental illness, and very limited prior longitudinal work that was based on the experiences of carers themselves. Building on the review of the literature and focus groups with 60 carers, six 'definable' phases of caring were identified. These were:

- *Something is wrong* – characterised by confusion, fright, chaos, with carers having little idea where to turn. This could be a relatively short or a prolonged phase.
- *Confirmation of mental illness* – characterised by difficulties in getting information, and patient confidentiality.
- *Adjustment/re-adjustment*.
- *Management* – with carers learning to live with the situation.

The stages of adjustment and management often iterate back and forth:

- *Purposeful coping* – carers are now proactive and have increased levels of knowledge, skill and confidence.
- *End of active caring* – often as a result of death of the carer or cared-for-person.

Pagnini (2005) argues that this model helps to identify when differing types of support are needed, particularly in phase 2, when carers' needs are often the most intense but paradoxically the least well addressed.

In summary, our understanding of the caring experience, and consequently our ability to underpin an assessment of carers' needs with a full appreciation of their circumstances, is limited by the dominance of research on schizophrenia, and the continued preoccupation within much of the literature on the burdens of care.

However, there is growing realisation of the importance of adopting a more holistic perspective to include a focus on the potential strengths and resources that carers possess, and to understand the temporal nature of the caring experience. Studies in the latter area have highlighted the ambiguity and complexity of caring over time, but also stress carers' unfolding understanding of their situation and the 'theories' they develop to explain it. They point to the tensions that can arise when carers' efforts to engage with professionals meet with apparent disregard for their knowledge and expertise. This makes achieving 'partnerships' difficult. It is to this area that attention is now turned.

### **Partnerships in mental health: a conflict resolved?**

'In no other area of treatment for illness have families of the ill been such objects of contempt and scathing criticism by professionals'.

(Johnson 1990, p52)

'A cultural shift within mental health is required: professionals must change their attitudes towards working with families. Carers ask for professionals to respect their expertise and knowledge'.

(SDO 2006, p5)

Partnerships have become '*the new rhetoric of caring relationships*' (Nolan et al 2003) and have been widely promoted in policy initiatives targeted at carers (DoH 1999, SDO 2006). However, as the review by Appleby (2004) has noted, progress with Standard 6 has been slow, and this reflects the wider situation of carers generally, who remain fairly marginal figures (Roulstone et al 2006). In the field of mental health Sampson and House (2005) contend that it is time to move beyond the rhetoric of partnerships, but paradoxically the NSF has '*too little to say*' about good practice for working with carers (Hervey and Ramsay 2004). Indeed, whilst the NSF is putatively based on the best available evidence, that supporting Standard 6 is scant, there only being eight references cited, four of these from official DoH or SSI sources. The purpose of this section is to consider the

literature on partnership working in mental health and to identify barriers to potential progress and the lessons that might be learned from the wider caring literature. As with mental health, conceptual and perceptual issues about the nature of caring remain, with burden providing a clear example.

Mental health is not the only area where the caring literature has been dominated by a burden perspective. Indeed burden provided an early '*unifying notion*' guiding research on family care generally (Kahana and Young 1990) and consequently most interventions have been designed to reduce caregiver stress, with this being '*a major tenet of gerontological policy and practice*' (Zarit et al 1999). This, according to some, has restricted innovation in the development of carer support services (Qureshi et al 2000), by providing a 'unidimensional' view of the caring experience (Kahana and Young 1990).

Recognising the potential limitations of such a restricted conceptual framework Kahana and Young (1990) called for the development of dynamic, multidirectional models of caring that not only captured change over time but also the complex interactions between family carers, cared-for-persons, and the formal care system. Such dyadic and triadic relationships have since received increased attention and this literature underpins much of the current thinking on the nature of potential partnerships with family carers. While partnership working is promoted throughout the developed world, the creation of effective partnerships between family and professional carers remains one of the most consistent and enduring gaps between policy and practice (FCA 2006, Seddon et al 2006, Newman and Hughes 2007). This appears to be particularly true of mental health.

The importance of family and professional carers working together effectively has long been recognised in mental health (Terkelson 1990) but recently has been extensively promoted, not only in official policy (SDO 2006), but also in the theoretical and empirical literature (Finkelman 2000, Allison et al 2003, Anderson et al 2003, Schulze and Rössler 2003, Pinfold et al 2004, Simpson and Benn 2007). Such partnerships should be '*true*' (Biegel et al 1995) and '*genuine*' (Schulze and Rössler 2003), based on an '*emancipatory*' approach (Jungbauer et al 2004) with families playing a '*full and valued*' role (Sin et al 2003b). Central to the success of such an approach is the recognition and valuing of carer expertise (Kaas et al 2003, Seddon et al 2006) in which professionals draw on carers' '*deep knowledge*' (Sin et al 2003a) and '*unique perspective*' (Hervey and Ramsay 2004), not only of their own situation but also that of the person with a mental health problem.

However, this should not be a one-way exchange but rather a reciprocal relationship in which the strengths, resources and expertise of both family and professional carers are valued (Biegel et al 1995). There is, as Bernheim (1990) suggests, a need to develop:

'...mutual respect and a reasonably equal balance of power. As we ask families to acknowledge our expertise, we should acknowledge theirs. As we teach, so should we learn'. (p104)

It is also necessary to incorporate the views of the service user so that differing perspectives can be recognised and, where possible, reconciled (Hancock et al 2003). The importance of this was highlighted in a study by Fischer et al (2002) who, when

exploring the perceptions of 60 caring triads, found little agreement between any set of perspectives. Reaching potential consensus requires good communication (Anderson et al 2003, Schulze and Rössler 2003) based on a '*quality exchange*' of information and feelings (Proverder et al 2004) that is '*reciprocal and bi-directional*' (Doornbos 2002). Whilst such an exchange is now considered by some to be more likely (Jubb and Shanley 2002, Livingston and Cooper 2004), it can hardly be regarded as routine.

Indeed in their major study on the provision of information to carers Pinfold et al (2004) identified a considerable divergence of opinion between carers, service users and practitioners as to the extent to which carers should be privy to information about the service user and the circumstances in which it was acceptable for practitioners to share information with carers. They found that policies and procedures concerning confidentiality were often confusing and contradictory and that there was a need for considerable further work to address this important issue. As will be apparent later, our own data, both from the consultation exercises and the interviews suggest real and enduring problems in this area.

Consequently the gap between carers' desire to be involved and their actual participation is significant (Pinfold and Corry 2003, Wooff et al 2003). A recent review has concluded that carers perceive a universal lack of information and inadequate involvement across all service settings (Bee et al 2005). Even when the person with a mental health problem is on enhanced CPA and carers want to be involved and have regular contact with the service user (Krupnik et al 2005, Wynoden and Orb 2005), very few are engaged as active participants in sharing their knowledge and expertise, leaving them frustrated and resentful (Wynoden and Orb 2005). The literature would suggest that the reasons for this are multiple and complex.

The quote by Johnson (1990), cited at the start of this section, provides a telling indication of one of the main reasons for the often fraught and difficult relationships between family and professional carers. The ambiguous situation that all carers occupy within the formal service system has been extensively described by Twigg and Atkin (1994) who concluded that carers are predominantly viewed as resources, occasionally as co-workers, and sometimes as co-clients. However, in mental health the relationship does not so much appear ambiguous as antagonistic and alienated (Hatfield 1990). The roots of this lie in early theories as to the role of the family in either the aetiology of mental illness (particularly schizophrenia), or as a major cause of relapse. Johnson (1990) contends that the belief that the family is '*dysfunctional*' is pervasive in mental health and describes three successive views of the family as either:

- a cause of relapse;
- an agent of aetiology;
- a person in need of support, based on an understanding of their own situation.

The later emergence of the carer as a person with needs in their own right is to be welcomed, but the prior two beliefs remain as a '*persistent mythology*' in which the family is still cast as part of the problem (Shooter 2004).

The family has '*suffered greatly*' (Lefley 1997) from the traditional perception of them as part of the pathogenesis of mental illness (Lefley 1990, Anderson et al 2003, Jungbauer et al 2003, Krupnick et al 2005, Sjöblom et al 2005), being cast as the '*enemy to be avoided*' (Bernheim 1990). Whilst it has long been recognised that there is a need to replace '*animosity and mistrust with a mutual capacity for respect and collaboration*' (Terkelson 1990), families may still feel the '*full brunt of blame*' (Finkelmann 2000). Although more enlightened views are now in evidence, '*formidable barriers*' to better relationships remain (Sjöblom et al 2005) including '*well entrenched*' beliefs about the families' role in the causation or exacerbation of mental illness (Walker and Dewar 2001). Much of this has to do with the literature on the role of expressed emotion in the aetiology of mental illness (Rose et al 2002, Jeon 2003, Mubarak and Barber 2003).

In addition to the above 'blame culture' several barriers to better relationships relate to the professional psyche and practice. The need for a '*cultural shift*' in mental health has been recognised at the highest level (SDO 2006), and such a change of paradigm has been long promoted (Lefley 1990, McCann and Clark 2003, Hervey and Ramsay 2004, Pinfold et al 2004). However, several formidable barriers to greater partnership working between professionals and carers remain, including:

- The continued adherence to a model of care based on symptoms and medical treatment (Godfrey and Wistow 1997) in which the professional is seen to be the expert (Hatfield 1990), holding specialist knowledge (McCann and Clark 2003). Treatments therefore tend to be given **to** people rather than developed **with** them (Anderson 2000, Anderson et al 2003). Accepting carers as 'co-experts' (Nolan et al 2003) poses a threat to professional status (Walker and Dewar 2001, Lloyd and Carson 2005).
- The focus of professional interventions is primarily on the user/client (Karp 2001, McCann and Clark 2003), and this can result in a conflict of loyalty (Sjöblom et al 2005) and fosters the belief that involving carers may threaten or compromise the care that the user receives (Kaas et al 2003). A recent review has concluded that virtually all current family based interventions in adult mental health care focussed on the user, and rarely on the needs of carers (Simpson and Benn 2007).
- The above situation is exacerbated by the thorny issue of patient/client confidentiality. This is widely recognised as a significant impediment to the greater involvement of family carers (Godfrey and Wistow 1997, Rethink 2003, Wynoden and Orb 2005, Pack 2005, Sjöblom et al 2005, Cormac and Tihanyi 2006) that requires urgent attention (Hervey and Ramsay 2004, Pinfold et al 2004, SDO 2006). Moreover, whilst guidance is available this is often interpreted in a 'conservative' fashion (Marshall and Solomon 2005). Recent extensive research has argued for the need to find ways of reducing the limitations imposed by a strict adherence to confidentiality in order to promote open and honest communication between carers and professionals (see Pinfold et al 2004), but it is still recognised that individually tailored solutions requiring a '*carefully weighted judgement*' are needed (SDO 2006).

- Professionals lack the training and skills to work collaboratively with families (Kaas et al 2003, Sin et al 2003b, Pack 2005). Improved training is seen as a pre-requisite (Thomas et al 1999) if professionals are better to understand carers' perspectives (Mafullul 2002) and to this end the greater involvement of families in professional education is now widely promoted. This has recently been reaffirmed in the extensive scoping exercise by Simpson and Benn (2007).

Such is the importance of a change in professional culture that it has been argued that modifying attitudes towards carers may well be preferable to the development of carer-specific services (Newbrunner and Hare 2002).

However, not all the barriers to greater partnership working concern professional attitudes and practices, with some appearing inherent to health care systems themselves, whilst others reflect carers' experiences of services.

Karp's (2001) eloquent account of the difficulties carers can face when confronted by mental health service systems draws attention to the need for widespread change, with others suggesting that '*system induced setbacks*' (Hart 2001) present formidable obstacles. This has been captured as follows:

'Thus the caregivers not only had to deal with the demands and stresses related to the care of the (mentally) ill person, they also had to battle the healthcare system and the professionals that work within it'.

(Jeon and Madjar 1998, p703)

System related barriers include a lack of incentive to work with carers, limited time and resources, and too little attention to developing the skills required (Kaas et al 2003, Rose et al 2004, Wynoden and Orb 2005). Consequently professionals can see carers as being additional work, thereby reinforcing existing negative perceptions (Newbrunner and Hare 2002). Difficulties often seem insurmountable and as a consequence carers may effectively give up trying (Kaas et al 2003).

This is unfortunate as carers' expectations of services are often modest and cannot be considered as unreasonable. It is widely acknowledged that carers' primary concern is to get the best possible care for their relative (Rethink 2003, DoH 2002), with their own needs often being a secondary consideration. As noted earlier, most carers wish to be involved and consulted in the care process and to have their expertise acknowledged (Godfrey and Wistow 1997, Beck and Minghella 1998, Doornbos 2002, Rethink 2003, Wooff et al 2003). However, they are rarely involved to the extent that they wish to be. For example a survey of over 1000 carers conducted by the Princess Royal Trust for Carers (2004) found that over half those polled did not think that professionals listened to them. Carers' dissatisfaction with their interactions with service systems/professionals has been noted for some time (Johnson 1990) and remains a persistent area of concern (Biegel et al 1995, Östman and Hansson 1999, Thomas et al 1999, Walker and Dewar 2001). Rather than being involved, carers often feel taken-for-granted and ignored (Rethink 2003), with such negative experiences often stemming from carers first contact with the 'system' (Bernheim 1990, Godfrey and Wistow 1997, Karp 2001, Finkelman 2000, Jeon et al 2005), which inhibit further involvement. As Karp (2001) notes, cynicism can soon set in and

trust, once lost, is difficult to re-establish (DoH 2002). Doornbos (2002) compared the characteristics of a supportive service with an unsupportive one as follows:

### **Supportive**

- Affirming the carers' role
- Flexible, open and willing to listen
- Based on establishing good quality relationships

### **Unsupportive**

- Poor communication
- Carers feel undervalued and blamed
- Carers do not feel supported

Carers' accounts most usually describe the unsupportive model and it is small wonder that they are often dissatisfied with the quality of the services they receive (Luckstead and Dixon 1999). This is in large part due to the fact that services for carers in general, and how to assure their quality in particular, have received relatively little attention, with some *'bedrock conceptual issues'* such as whose outcomes and whose definition of quality counts, not having been addressed (Luckstead and Dixon 1999).

The consultation phase of the SDO scoping project (Newbrunner and Hare 2002) identified four key characteristics that carers wanted from services, stressing that quality is as much about the 'process' of service receipt, as the service itself. Carers wanted services that are:

- Positive and inclusive – so that carers are seen as an integral part of the system, rather than being marginalised or blamed. A willingness to share information is essential, as is acceptance of carers as partners/co-experts.
- Flexible and individualised – services that are person-centred, delivered on time and are consistent with existing routines, cause minimum disruption and provide as normal a life as possible for their relative.
- Accessible and responsive – services that are reliable, available outside 'office' hours provide rapid access in a crisis, and have a low trigger threshold so that they can be genuinely preventative.
- Integrated and co-ordinated – services that cut across agency boundaries, and provide 'seamless' access and delivery.

Consistent with the literature we have considered, the consultation exercise (Newbrunner and Hare 2002) stressed the need for a change of attitudes, systems and practices if appropriate services are to be developed. This is particularly true of carer assessment.

'In my opinion the NSF and the NHS Plan are the two most influential policy documents in the lifetime of anyone currently working in mental health. Their importance is not only in what they say but in what they

signify – a transformation in the status of mental health within the NHS and in responsiveness of services to patient need’.

(Appleby 2004, p66)

The launch of the National Service Framework (NSF) for Mental Health (DoH 1999) was, as Appleby (2004) notes, intended to mark a watershed in the development of services for people with mental health problems and their carers. The overall aim was ambitious, to overcome centuries of stigma and poor public understanding, and to ensure that people with mental health problems and their carers received the attention they deserved. At the core of the NSF were seven standards in five areas, the implementation of which was intended to redress ‘*unacceptable variations*’ in the provision of services in order to ensure ‘*safe, sound and supportive*’ care for everyone. Each standard, supported by the best available evidence and knowledge base, addressed a particular area of practice. As noted earlier, Standard 6, the focus of this study, was entitled ‘Caring for Carers’ and stated the following:

All individuals who provide regular and substantial care for a person on CPA should:

- have an assessment of their caring, physical and mental health needs, repeated at least on an annual basis;
- have their own written care plan, which is given to them and implemented in discussion with them.

With these aims in mind one might have hoped that the carers’ experience of assessment in mental health would be improved. However, a recent review of the implementation of the NSF over its first five years (Appleby 2004) concluded that, with respect to Standard 6, whilst there had been some progress ‘*we have too little to report on improving the support we provide to carers...*’ (p74). Indeed the data cited in the report were minimal, indicating an increase in support services for carers, and modest success in ensuring that carers of people on enhanced CPA had a care plan, but giving no information at all on the provision or uptake of carer assessments. Achievements in Standards 4, 5 and 7 were considered ‘impressive’, and those in Standards 2 and 3 as ‘reasonably good’ and these might justify Appleby’s (2004) conclusion that the NSF has had ‘*an exciting, impressive and promising start*’. This can hardly be said to be true of Standard 6.

However, while disappointing, it is important to set such scant progress in the overall context of developments for carers in general, and for carer assessments in particular. As outlined in the introduction, the last decade or so has seen carers’ rights enshrined in three Acts of Parliament: The Carers (Services and Recognition) Act 1995; The Carers and Disabled Children’s Act 2000; and the Carers (Equal Opportunities) Act 2004. In principle these statutory instruments provide carers with several rights, including the right for some to a separate assessment of their needs. However, despite numerous policy initiatives, recent evidence indicates that the uptake of carer assessments has been very limited. The policy guide on implementing the Carers (Equal Opportunities) Act 2004 notes that ‘*progress in carrying out carer assessments is slow, and few separate assessments*



*are carried out*' (SCIE 2005, Section 2, p2). Similarly, in reviewing the success of several initiatives designed to promote stakeholder participation in England, Wales and Northern Ireland Roulstone et al (2006) concluded that carer assessment represents '*one of the least consistent and least satisfactory elements*' p69. Their report highlights the continued uncertainty and lack of clarity surrounding carer assessments, stressing the low awareness and uptake of assessments and the fact that, even carers who have had an assessment are often unaware of this and/or receive little or no feedback and subsequent support. The recently published review of the Modernising Adult Social Care (MASC) (Newman and Hughes 2007) research programme reaches a remarkably similar conclusion.

Clearly, therefore, the challenge of providing a comprehensive assessment of carers' needs is not unique to mental health, nor indeed is it confined to the UK, with several studies and reports noting similar issues in a number of countries, including the USA (FCA 2006), Canada (Guberman 2005) and Australia (Guberman et al 2003). Indeed a symposium held on carer assessment at the FICCDAT (Festival of International Conferences on Caregiving, Disability, Aging and Technology) Conference in Toronto (June 2007) identified progress, but noted on-going concerns about carer assessment in the UK, US, Canada, Australia and Sweden (Feinberg et al 2007). Whilst this would suggest the existence of shared and enduring issues, it has long been recognised that difficulties relating to carers generally are exacerbated for those supporting people with mental health problems (Hogman and Pearson 1995).

Up to this point we have used the literature to highlight the relatively limited understanding of the caring experience in mental health, with most studies being dominated by schizophrenia and focussing primarily on burden. We have also described the rhetoric of partnership working with carers, and the formidable barriers that need to be addressed if this is to be achieved. Here we focus more explicitly on assessment, the challenges of which are best understood in the context of the wider literature.

## Carer assessments: the rhetoric and the reality

The challenges of carer assessment in mental health mirror those for carers more generally, where: uptake of assessments is low; carers are often unaware of their rights to an assessment; do not know if they have had one; and, even if they have, often find the experience negative, with little consequent action (Seddon and Robinson 2001, Rethink 2003, Roulstone et al 2006, Seddon et al 2006). Indeed carers often have problems with the concept of an 'assessment' itself, seeing it as a 'test' of their ability rather than an opportunity to engage in an exchange of opinions (Seddon et al 2006). Small wonder that the number of completed assessments is low in mental health, even if carers are in regular contact with the person with mental health problems (Krupnick et al 2005). In a review of care plans over one year Krupnick et al (2005) discovered that 81% of clients had contact with their family but that only 7% of the family had been in receipt of any assessment. This is again consistent with the wider literature where carer support, such as it is, is rarely underpinned by an holistic assessment of need (Seddon et al 2006), reflecting the general failure to incorporate assessments into routine practice (Audit Commission 2004, SDO 2006). This low uptake of assessment will be noted later from the case study sites.

In identifying a potential way forward it is important both to make explicit the assumptions that underpin assessment (Anderson et al 2003), and to consider the intended goals. According to the Department of Health, assessment provides the '*gateway to support*' and, following agreement with the carer, should result in a focussed support plan that identifies who will be responsible for services, when they will be provided, and what the intended outcomes are (DoH 2002).

A recent extensive consultation exercise conducted by the Family Carers Alliance in the US defined assessment in the following way. Assessment is:

'... a systematic process of gathering information that describes a caregiving situation and identifies the particular problems, needs, resources and strengths of the family caregiver. It approaches issues from a caregivers' perspective; focussing on what assistance the caregiver may need and the outcomes the family member wants for support and seeks to maintain the caregivers own health and well-being'.

(FCA 2006, p5)

Ideally assessments should be undertaken as early as possible in the caring career (Godfrey and Wistow 1997, DoH 2002, Rethink 2003, FCA 2006), but in reality they often occur at a time of crisis (DoH 2002). Mirroring the earlier arguments about partnership working the process should be one that is based on a relationship of trust and respect, actively drawing on the carer's existing experiences, skills and strengths (Bernheim 1990, Godfrey and Wistow 1997, Seddon and Robinson 2001, Khoo 2002, Allison et al 2003, Oyeboode 2003). The focus should be broad ranging and holistic, moving beyond burden to consider satisfactions, resources and resilience (Gall et al 2001, Allison et al 2003, Anderson et al 2003, FCA 2006).

In reality such tenets are rarely achieved due to: the continued focus on the person with mental health problems (DoH 2002); the relative failure to adopt a family centred approach (Sin et al 2003b); and the reliance on a task orientated model that concentrates mainly on the instrumental aspects of care (Seddon et al 2006). Therefore, despite the existence of extensive guidance on the suggested content and approach to assessment (SCIE 2005, FCA 2006), and the development of assessment tools specifically designed for use in mental health settings with carers (see, for example, Lelliott et al 2003), the extent to which such approaches are adopted is questionable.

If the situation is to improve it is suggested that assessment needs to shift from a '*professionally controlled*' process to one where the role of the professional is that of facilitator (Khoo 2002). However, this is difficult to achieve for assessment may:

'...provide the worker with an invaluable opportunity to step back and adopt a different viewpoint and, as such, can prove to be a challenging analysis of the professional's own practice and assumptions about what it means to be a carer'.

(Khoo 2002, p17)

The purpose of the assessment should be clearly understood by all parties (FCA 2006), with the present emphasis being on adopting an 'outcomes' focussed approach (SCIE 2005, SDO 2006). However, what is often lacking is an appropriate 'conceptual framework' for assessment (Bernheim 1990) that provides an underlying rationale and philosophy (Guberman 2005). Guberman believes that the primary goal of assessment should be to give carers genuine choice and not simply to 'shore up' their situation. Unfortunately carers' assessments generally represent a '*last opportunity*' to create better relationships between carers, professionals and the wider service system (Audit Commission 2004). Recent policy directives in Scotland have called for a '*bold new vision*' of carer support underpinned by recognition of carers as full partners in care, and the creation of a rights based policy for carers (Scottish Executive/DPM 2005a), with good assessment lying at its heart (Scottish Executive/DPM 2005b). However, an extensive review of the current situation found a mismatch between carers' perceived needs, and those of service providers, consequently carers often see assessments as offering 'empty promises' (Scottish Executive/DPM 2005c), with any service being '*off the shelf*' rather than '*bespoke and responsive*' (NHS Scotland/Scottish Executive 2005). Based on their extensive consultation the Scottish Executive promote a more holistic and interactive assessment process underpinned by an open and reciprocal exchange between carers and professionals (Scottish Executive/DPM 2005c). The challenge is how this can be achieved, and the outcomes carers want delivered.

### **Towards a negotiated assessment model**

Probably the most extensive development work conducted on promoting an outcomes based approach to carer assessment was that of Nicholas (2001, 2003), undertaken at the Social Policy Research Unit at the University of York.

Underpinned by the 'carers as experts' model (Nolan et al 1996), and drawing on three detailed carer assessment tools, the Carers' Assessment of Difficulties Index (CADI), Carers' Assessment of Satisfaction Index (CASI) and the Carers' Assessment of Managing Index (CAMI) (see Nolan et al 1996, 1998) Nicholas (2001, 2003) undertook an action orientated study exploring the implementation of a new approach to carer assessment in order to promote an 'outcomes' focussed model of assessment and review. Consistent with the 'carers as experts' framework she argued that fundamental to any attempt to define or assess outcomes for carers was the need to *'understand the nature and complexities of caring and the relationships between unpaid carers and those who provide services to support them'*. Basic to her approach was the belief that 'success' has to be defined in terms of outcomes that are relevant to carers themselves and based on a partnership that gives due consideration to both carer and professional expertise. However, she also recognised that to be acceptable any approach has to be seen as reasonable by practitioners and also deliverable in terms of the resource and other constraints under which services operate. In other words, the outcomes agreed should reflect *'the purposes and concerns of carers, practitioners and managers'* (Nicholas 2003).

Using CADI, CASI and CAMI as *'tools to assist in the identification of desired outcomes as an integral part of carer assessment'* (Nicholas 2001), and following focus groups with carers and practitioners, Nicholas (2001, 2003) identified four broad domains of outcomes that were seen as important, especially from a carers' perspective. These were:

- Achieving a good quality of life for the cared-for person
- Achieving a good quality of life for the carer
- Recognition and support in the caring role
- Service process outcomes – support that is consistent with carers' values, routines, expertise and so on

Again drawing on the existing literature, and the results of her own work, Nicholas (2001, 2003) identified a number of key principles that should guide further work. These included:

- The definition and recording of outcomes should be carer-centred, specific and relevant to the individuals concerned.
- Reaching a common understanding of the intended outcomes requires a thorough and sensitive assessment.
- The carer should be actively engaged as an 'expert' in the process of identifying and reviewing outcomes.
- The evaluation of outcomes should begin with clarity about the goals intended.

With regard to carers Nicholas (2001, 2003) found that the introduction of an outcomes focussed approach into practice:

- was helpful in enabling carers to talk over and reflect on their situation;
- allowed carers to release 'bottled up' feelings;
- provided the opportunity for them to be more honest about the difficulties they were facing;
- enabled them to state more clearly the things that they wanted.

Practitioners found that the approach:

- raised their awareness of the complexities of caring situations;
- challenged pre-existing expectations and assumptions about carers;
- encouraged a more proactive and comprehensive carer assessment;
- shifted their thinking about the type of outcomes that carers wanted.

This is highly significant for carers because, as Nicholas (2001) notes:

'Sensitive assessment where the carer is given the opportunity to think more broadly about their situation can open up whole new opportunities for carers'.

Nicholas (2001) believes that such an assessment helps carers and practitioners to '*think outside the box*' with regard to the provision of new and innovative forms of support, encouraging carers to develop new coping strategies and enabling them to accept help that would previously have been rejected.

Extending the work of Nicholas (2001, 2003), Hanson et al (2006) have recently developed the Carers Outcome Agreement Tool (COAT), as an approach to promoting more effective dialogue and negotiation between carers and practitioners.

### ***Developing COAT***

COAT builds on over 15 years of research into assessing carers' needs (see for example Nolan et al 1990, Nolan and Grant 1992, Nolan et al 1994, 1996, 1998, Nolan and Philp 1999, Nolan et al 2003) and is underpinned by the 'carers as experts' model (Nolan et al 1996), that recognises carers and professionals as 'co-experts' each with differing but complementary forms of knowledge and expertise which, when considered together, provide a more complete picture of the caring situation.

The overall goal is to promote partnerships between family and formal carers that recognises the expertise of both. Following Guberman's (2005) advice the underlying rationale and philosophy for COAT are explicit and ensure that it is underpinned by extensive prior theoretical and empirical work. After considerable consultation and trial assessments with carers and practitioners, it was found that:

Carers considered COAT:

- allows them to raise issues that are causing concern;
- helps them to discuss such concerns in an open and frank manner;

- provides new insights into their own situation
- focuses on issues that they had not previously considered;
- helps to structure their discussion with the assessor;
- helps to validate their experiences as carers.

Importantly all of those carers taking part enjoyed the experience of an assessor spending time talking to **them** about **their** needs, and a number compared the experience favourably with previous 'assessments' that had not allowed them to fully express their views.

The practitioners adopting the 'assessor' role identified a range of benefits to using COAT:

- all the assessors felt that COAT worked well in promoting a personal and detailed discussion about individual caring situations;
- despite assessors having detailed prior knowledge of the caring situation, completing COAT provided new insights for many of them;
- assessors considered that COAT enabled them to get to know the carers well, and provided a comprehensive view of the caring situation from the carers' perspective;
- COAT enabled carers to talk openly about their situation, and helped them to focus on areas that they had not previously considered, such as their own quality of life;
- the process of completing COAT allowed the assessors to begin to address some of the carers' concerns, for example, for further information;
- completing COAT was seen by some as potentially therapeutic in its own right.

Although COAT was developed with carers of older people, the principles upon which it is based, and the potential benefits it provides, suggest that it also has considerable potential in the field of adult mental health. However, as the literature indicates, several potentially formidable barriers need to be addressed before progress is likely, particularly the poor relationships that often exist between carers and professionals in the mental health field, and the difficult issue of confidentiality which, despite recent guidance (Pinfold et al 2004), remains a significant problem.

## Conclusions

A consideration of the literature in adult mental health suggests that there is as yet limited understanding of the nature and experience of caring. That which exists derives primarily from carers of people with schizophrenia, and this paints a picture in which there are often enduring tensions in carers' relationships with formal service systems. This inevitably impacts on the way in which assessment is both conceptualised and conducted, resulting in several potential barriers to the creation of genuine partnerships with carers. In Chapter 4 we will use the principle of 'emergent fit' (Glaser 1978) to synthesise the themes arising from the literature with the data from the consultation days and carer interviews. Prior to this the next chapter explores the organisation and delivery of carer assessments.

## CHAPTER 3

### **The Organisation and Delivery of Assessments for Carers of People with Mental Health Problems: National Picture and Local Implementation**

This chapter provides an overview of the state of development of assessment approaches for carers during the early stages of the project as indicated by the analysis of the LIT plans relating to the Standard 6 of the National Service Framework for mental health. It then considers the organisation and delivery of carers' assessment as evidenced at the case study sites. The methods used to undertake both the review and the case studies were described in Chapter 1. Here we consider the main results.

#### **Analysis of Local Implementation Team Plans for Standard 6 of NSF**

##### **Key messages**

- Local Implementation Plans for Standard 6 were in a rudimentary state of development, many not being available. Those that did exist were mainly superficial. Of the 42 LIT plans received, only eight gave detailed consideration to carers' assessment.
- Relative to other standards in the NSF, attention given to Standard 6 was limited. Plans focussed on the provision of carer assessments as an integral part of the Care Programme Approach to assessment and review of the person being cared for; and suggested that the care coordinator was the 'ideal' person to conduct the assessment. This potentially ignores the fact that *all* carers providing regular and substantial care have the right to an assessment of their needs.
- Only two LITs mentioned assessments for carers of people not using services (and therefore not in CPA); there were no systems for the identification of carers in such instances, and no suggestions about who should undertake assessments where there was no identified care co-ordinator.
- Service responses suggested in most LIT plans were 'traditional' rather than innovative.
- Our results reflect the conclusions of the policy analysis conducted by Pinfold et al (2004) who noted that initiatives for carers remain 'underdeveloped on a national scale'.

##### **Overview of results**

##### ***Emphasis on carer-related issues***



Of those 25 sets of LIT plans that made explicit reference to carers' needs, eight appeared to give these considerable emphasis, another eight some emphasis, and nine little emphasis. In the latter case carer issues received little more than a line or two, or were confined to rather vague and non-specific statements of intent rather than providing any clear evidence of strategic direction. More often than not, even when carer issues were given more detailed consideration, this focussed on the provision of information and/or efforts to more fully engage carers in service planning and development. An explicit consideration of carer assessment, its rationale, and how it might be implemented figured less prominently. With a few notable exceptions, attention to carer assessment appeared a quite recent phenomenon, and several of the plans indicated that an agreed approach was still an ideal to be pursued rather than a concrete reality.

In the few instances where the LIT plans for all of the standards of the NSF were received it was apparent that the emphasis accorded to carer issues was small in comparison to the other standards. For example, one submission identified 38 areas for action, only one of which related to carer issues. In another instance 62 action points were highlighted, of which 4 were carer-specific. In several instances where carers' needs figured more prominently, it was clear that action had only been taken very recently, often within the last few months. Although caution must be exercised in drawing too many inferences from documentary sources of this type, it seems that the emphasis on carers' needs generally was limited relative to other standards of the NSF, and that action was being taken later rather than sooner.

### ***Who should get an assessment, who should conduct the assessment, and on what should it focus?***

From the relatively sparse information provided in most plans it was not possible to identify many different models of assessment practice; it was most commonly seen as an integral part of the Care Planning Approach (CPA) process. Plans often made an explicit link between the right to an assessment and the fact that the person with mental health problems was in receipt of CPA, or in some instances, enhanced CPA (and thereby had demonstrable mental health needs). In only two plans was there recognition that carers may have needs arising from caring for a person who had mental health problems but did not use mental health services. This is despite legislation requiring that all carers providing regular and substantial care are offered an assessment – even where the person is choosing not to use services (The Carers and Disabled Children Act (2000)).

With reference to who should conduct the assessment the most frequently stated '*ideal scenario*' was that it should be the care coordinator for the CPA who was responsible for ensuring that the assessment was conducted and, where possible, carrying out the assessment themselves. This effectively restricts assessments to carers of people on CPA. In other instances responsibility for ensuring that the assessment occurred was vested with the care coordinator, but any member of the CHMT could actually conduct the assessment. Other plans indicated that certain areas had employed dedicated carer assessment workers whose main job was to conduct assessment. This was sometimes linked to clearing a perceived 'backlog' of assessments as quickly as possible.

Whatever the approach, considerable emphasis was placed on the role of the Carer Support Worker (CSW). It was usually acknowledged that the CSW should not be conducting the assessment but that subsequently they would have a major part to play in the provision of appropriate support services. References were also made to the role of voluntary sector carer associations and organisations in the provision of services for carers.

With regard to the focus of the assessment itself, eight respondents forwarded the assessment documentation, sometimes accompanied by an associated philosophy and protocol. These ranged along a continuum, with the highly structured and largely predetermined at one end (lists of specific questions/forms to be completed), to the far less structured, much more open at the other (identifying the topic areas to be covered in a discussion with the carer). Those at the more structured end gave priority to the 'daily tasks' of caring, often with an emphasis on practical/instrumental elements of care and/or the needs and difficulties of the person being cared for. It seems likely that many of these were generic protocols utilised for carers of people with all difficulties, not specific to those caring for someone with mental health problems. Any detailed consideration of carer identified issues and the strengths and resources of the carer were notably absent. Conversely, assessment at the less structured end gave more attention to carer perceived issues, and at least acknowledged issues such as carers' ability and willingness to care, and their potential strengths rather than a focus primarily (or exclusively) on deficits and problems. The latter approaches were more likely to be accompanied by standards describing carers as 'partners', and some of the documents had been constructed in consultation with carers themselves.

### ***Carer 'plans' and service responses***

In instances where carer assessment documents were forwarded to us, most contained 'carer plans' and, in some instances, reference to the type of service responses. The level of detail provided in both instances was relatively sparse but suggested that service responses were often 'traditional' in character with relatively little evidence of innovation. In marked contrast a small number of plans demonstrated a more creative response. For example, in one instance particular emphasis was placed on encouraging the greater uptake of 'direct payments' to carers, and whilst these still tended to be used for some form of respite/break from caring, others suggested that the money be used to pay for a wide variety of activities and supports to help carers continue caring, for example aromatherapy massages, gym membership, driving lessons/car maintenance.

Overall the analysis of the LIT plans is best described as 'disappointing'. Interestingly this exercise was conducted at the same time as the review of the NSF was being undertaken, and our experiences would reinforce the conclusions of Appleby (2004), who noted limited progress with regard to Standard 6, with a marked dearth of information regarding the provision and uptake of carer assessment. With this in mind our own experiences are hardly surprising. Moreover our findings reflect those noted by Pinfold et al (2004) on information sharing with carers who identified few examples of good practice with the principal investigator concluding that 'it seems that many Trusts and providers neglect the relevance and importance of carers to the

mental health system' (Huxley 2006). The results of the detailed case studies also suggested that carer assessments are not particularly well developed. It is to these results that we now turn, beginning with the key messages that emerged.

## **Implementation of Carer Assessments**

### **Key messages from case study sites**

- Many services are still in the process of developing assessments alongside other carer services and supports.
- Assessments are largely policy driven but their form and process is influenced by the values of key stakeholders – including local carers.
- Interpretation of 'regular and substantial care' varies between sites, but eligibility was often confined to carers of people on CPA which excludes significant numbers of carers who under law might be entitled to an assessment.
- Two models of carer assessment prevail: assessments by dedicated carer assessors or assessment by service users' care co-ordinators. There are advantages and disadvantages to each approach.
- Although assessments are undertaken by statutory agencies, much of the emotional and practical support for carers is provided by the voluntary sector. This can lead to duplication of work.
- Routine therapeutic support and information for carers is often provided by care-co-ordinators on an informal and ad-hoc basis. They see little advantage in undertaking a lengthy assessment. Assessments are often completed only because statutes require it, or because of the need to access resources such as carer grants.
- Consequently, even in 'good practice' sites, the number of assessments completed is low. This is largely due to reluctance on the part of practitioners to undertake assessments, but this does not necessarily mean that carers are entirely unsupported.
- In sites offering alternative forms of carer support (assertive outreach [AO], psychosocial interventions [PSI] and family group conference [FGC]), there were difficulties identifying and engaging with families. Although the AO approach was appreciated by carers, a regular assessment of every carer's needs would have offered additional value. The PSI service did not engage with one family during the one year recruitment period. It may have been possible to provide at least a minimal level of support if all carers were offered an assessment. Family Group Conference provided an opportunity for friends and family members to meet and discuss their roles and responsibilities in relation to the service user but did not provide support to carers in their own right.

## **Introduction**

Both the literature (Chapter 2), and the analysis of the Local Implementation Plans (above) indicated that carer assessment policy is interpreted and implemented in different ways in different areas. Yet little is known about how assessments are organised, which models are adopted, or the effect(iveness) of different approaches on the support provided for carers. A key question for this study therefore concerned the development and delivery of carer assessment at an organisational level. As detailed in Chapter 1, in-depth case studies of health and social care services implementing various models and approaches for the assessment and support of carers of people with mental health problems were undertaken to:

- explore the range of assessment approaches (and their rationale) as currently used with diverse groups of carers of people with mental health problems;
- identify the organisational components that support successful partnerships between carers and assessors;
- explore current 'good practice' as identified by a variety of key stakeholder groups;
- identify perceived barriers to, and facilitators of, the implementation of good practice in assessing and meeting carers' needs at the organisational level.

We report the results of these case studies here, beginning with Table 3.1 that summarises the key characteristics of the sites.

**Table 3.1: Brief description of organisational characteristics of sites selected**

Site	Type of Service	Location and Population	Organisation of Carer Assessments	Comments
<b>ASSESSMENT SITES</b>				
<b>A</b>	NHS Trust providing community, mental health and child services.	Mixed suburban/rural coastal population of 250,000 in South of England	<p>2 Carer Care Managers (CCMs) funded by health and social services, one nursing background, one not professionally qualified, specifically responsible for assessing carers of working age adults on ECPA.</p> <p>Voluntary Sector Carer Centre provides carer support.</p> <p>Referrals come from care team, carer centre, carers themselves.</p>	<p>CCMs also run carer support group, educational courses for carers, advocacy with individuals and for carers as a whole within Trust.</p> <p>Carer Centre offers counselling, case work support, runs courses for carers and supports their involvement in service development.</p>
<b>B</b>	Primary Care NHS Trust	Mixed suburban/rural coastal population of 190,000 in South of England	<p>The carer support service (funded by social services and managed by health) comprises manager, p/t assessor, p/t inpatient carer support worker and 3 p/t posts at Carer Centre. None professionally qualified.</p> <p>Referrals come from all services and carers themselves. No eligibility criteria – assessment offered to all referrals.</p>	Carer support service provides assessment, support groups, ongoing support for carers, advocacy, staff training, involvement in service development and manages carer grant.
<b>C</b>	Mental Health Trust	Large city in Northern England population circa 450,000	CPA care co-ordinator responsible for ensuring assessment and review occur. Assessment restricted to those on CPA only. Majority of assessments, however, conducted by a dedicated Carer Team	<p>History of commitment to carers issues, specialist Carers Team comprising 5 development and 5 support workers plus an Education Development worker; and specialist BME worker.</p> <p>Team provides carer support, carer development and carer education. Services usually 6 x 1 hour sessions in the first instance. Team undergoing considerable re-organisation.</p>
<b>D</b>	Mental Health Trust	Diverse inner city borough of London with population of 220,000. Around 200 languages spoken.	<p>Assessment carried out by Carer Assessment Officer managed by CMHT manager, with support from 2 care co-ordinators in each team.</p> <p>3 voluntary organisations funded by Trust to provide carer support.</p> <p>Referral comes from inpatient wards, carer centre, and through CPA. Carers are eligible for assessment if they care for client on CPA.</p>	<p>Mental Health Carers Support Association provides information, counselling, advocacy, support group and carer representation in service development.</p> <p>Ward staff can undertake preliminary assessment and can refer for formal assessment. This means carers of inpatients more likely to have full assessment than carers of community based clients.</p>
<b>E</b> <b>F</b>	<p>Two sites selected in one Partnership Mental Health Trust</p> <p>E is a mixed urban and suburban relatively affluent area.</p>	Largely rural middle/ eastern England with a mixed population of 800,000	<p>Carer assessments are undertaken by all care-co-ordinators (or, if appropriate another member of the team) triggered by the CPA.</p> <p>Carer assessment is just one part of a comprehensive carer support strategy involving social services, health services and the voluntary sector.</p> <p>All carers of clients on CPA or eligible for CPA should be offered assessment.</p>	<p>Carer confidentiality policy has been introduced within the Trust.</p> <p>Carer link workers exist in all parts of the service to lead on carer support, training is provided for assessors, PSI training is a priority for staff.</p>

	F is a very rural patch with pockets of rural deprivation			
<b>G (young carers)</b>	A voluntary sector project for young people, including a young carers' project providing ongoing support for young carers including those of adults with mental health problems.	Inner city (population 450,000). Project is part of the city 'Supporting carers Strategy' jointly funded and working closely with social services and mental health Trust.	Children using the project are assessed following the guidelines for young carers assessments produced as an adjunct to the city's Supporting Carers Strategy. However, assessments do not constitute a formal carer assessment and are unrelated to the CPA.  Children are referred typically from child and adolescent mental health services, children's services or adult mental health services largely as a result of the project's own awareness raising work with local organisations and communities.	The project emerged as a result of local research which gives rise to the Keeping the Family in Mind (KFIM) project which is now an integral part of the Action for Young Carers Project. KFIM seeks to <i>'improve and enhance the range of appropriate, accessible, non-stigmatising and timely services to families with children who are impacted by adult mental health in the city'</i> .  Between them the Action for Young Carers Project and KFIM provide specialist one-to-one support for each child and engages in indirect work - strategy planning, development, training and promotional work with other agencies.
<b>H</b>	Primary Care Trust	North East suburban coastal population of 150,000 with several large council estates.	Assessment is initiated by Carer Support Worker and undertaken by Care Co-ordinator. A voluntary organisation part-funded by the Trust and local authorities provides much carer support. Referrals come through CMHTs and CPA.	In the first year of the PICAP project only the designated care co-ordinator carried out carer assessments. In the final year of the project, CSWs undertake preliminary assessment and refer to carer co-ordinator for this to be signed off.

<b>'NON-ASSESSMENT SITES'</b>				
<b>I Assertive Outreach AO</b>			Carer assessments are the responsibility of care co-ordinators, they are undertaken by care co-ordinators or carer support workers in the team.  Assessments are triggered by CPA, all carers providing regular and substantial care should be offered assessment.  Assertive outreach service offers routine support to family and friends and should undertake carer assessments where appropriate – as in other teams.	AO is an intensive community based service for people who are difficult to engage in services and have serious disabling and disturbing mental health problems.  One of the key principles of AO is working with family and social networks of clients. Carers have evaluated the service positively despite the fact that few assessments are conducted.
<b>J Early intervention</b>	Mental Health Trust	South Yorkshire		
<b>K Family group conference</b>	Partnership Trust	Mainly rural south east area with population of 170,000	Carer support service provides respite, information and support. Carer support modernisation manager and Carer Champion are in post.	<b>Family Group Conference</b> involves assessing the needs of the service user and all the most important people in their lives and agreeing a plan for care and support.

			<p>Carers are offered a 'Family Group Conference' (FGC) or an assessment by care co-ordinator if they do not wish to have FGC.</p> <p>All carers of clients on CPA are eligible for assessment.</p>	<p>FGC is service user led but involves visits to assess main carers and a meeting for all involved - family, friends and professionals - lasting around 3 hours. This may or may not result in completion of a formal carer assessment.</p>
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## Results

### *Assessments as part of an overall carer strategy*

Assessments formed just one part of the Carer Strategies that had been developed on all but one site (where the strategy document was still in the process of development). These strategies seek to provide local integrated responses to the wide range of recent policy initiatives referring to carers and are generally underpinned by the recognised requirement to involve carers (including those from diverse groups, eg working age carers, carers of older service users, users of forensic services, those with learning disabilities, those from BME groups, and young carers) at all levels of the organisation. This participation is not only a statutory obligation for services (Health and Social Care Act 2001), its value in developing services that are more effective and suited to the needs of service users is recognised in strategy documents, as are the positive benefits for carers who get involved. For example, Trust C's strategy document specified the benefits of the involvement of diverse groups of carers:

'Involving carers with diverse backgrounds and experiences enables services to develop partnerships and get feedback from a wide range of people, with less likelihood of developing a skewed perception of what local needs are and how services are responding to them'.

Strategies were typically based on a number of common principles or beliefs about the significance and carers and their needs, as summarised below in Box 3.1. These provide an implicit statement of intent that often proved difficult to deliver:

#### **Box 3.1: General principles underpinning carer strategies**

- Carers provide invaluable support for the people they care for. This support is often not recognised or measured but can be crucial in helping aid recovery.
- The demands of caring can affect the physical and emotional health of carers.
- Carers of people with mental health problems and learning disabilities are often difficult to identify, support and involve.
- Services to carers should be designed and delivered in a way which promotes autonomy, empowerment and choice.
- Carers providing substantial and regular care have a right to an assessment of their own needs and a written care plan that is agreed with them, implemented and reviewed regularly and when there is a change in circumstances.
- Carers have a right to continue employment and education and support needs to be put in place to facilitate this.

Carer Strategy documents also specified the supports and services offered locally for carers and those planned or under development. Many of these were aspirational: goals which authorities sought to achieve through training and continuous development. Strategies varied in focus and detail but generally included a number of areas (see Box 3.2):

**Box 3.2: Areas covered in carer strategy documentation**

- The policy for information sharing with carers and the development of information packages for carers (eg in Trusts E and I this was based on the Royal College of Psychiatry Guidance on Confidentiality; in Trust E this had been explicitly adopted at Board level and followed up by training in all teams).
- Training for staff in carer assessment and support, and in psychosocial interventions.
- Communication of carer developments between parts of the service (eg Trust E had appointed Link Workers responsible for communicating carers' issues to and from carer strategy meetings; in several other Trusts this was the responsibility of carer support workers).
- Conditions for accessing the carer grant.
- Access to family intervention for carers of people with psychosis; although there was general acknowledgement that carers of people with psychosis have a right to psychosocial family intervention and education (as specified in the NICE guidelines for schizophrenia) few Trusts were able to provide this as part of routine care. Several Trusts ran regular family education courses for groups of carers, but these were rarely based on a psychosocial intervention model.
- The use of advanced directives as a way of planning carer involvement at times of crisis - again a strategic objective, supported by training.
- Services for specific groups of carers including young carers, older carers, carers of people with substance misuse problems and BME carers (including training for staff).
- The carer assessment system including eligibility criteria.

It became clear that these strategies were most familiar to those who had been involved in their development. Although aware of their existence, practitioners were often unsure about services and supports for carers and in many places not clear about conditions for accessing the carer grant or planned developments for carers. In most sites there was ongoing training for staff but in only one Trust was there a system of auditing progress in the implementation of the Carer Strategy.

***Assessments: variation across sites***

Although strategic principles were fairly consistent across the different sites, there were clear differences in the system of carer assessment. The brief descriptions given in Table 3.1 indicate this diversity and demonstrate both common features and differences (eg common features include the provision of carer support services by the voluntary sector funded by health and social care; differences include the qualifications of personnel undertaking carer assessments).

Not apparent in Table 3.1 is the variation in levels of development and integration of carer assessment across sites. Whereas several teams had been undertaking assessments well before statute made this a requirement, others had only recently introduced mechanisms for carer assessment. Carer assessments on Sites A and B had been led by individual workers who had a keen interest in carers for several years prior to legislation being introduced, whereas on Site I assessments had only become part of Trust policy in the previous year.

On all sites, carer assessments were considered to be in the process of development: new policies, changes in performance indicators, changes in service structures, evidence of difficulties or under-implementation were all instrumental in creating constant adjustments so that during the course of the project major changes occurred in the ways in which assessments were provided and the population they were provided for (eg on Site E Guidelines for application for funding from carer grant were revised three times in the two year data collection period).

As researchers, we sought to be flexible so that we were able to gain a full understanding of the circumstances of each site. Not surprisingly in such fluid situations, different personnel within the same organisation had different understandings of local policy and strategy and different experiences of implementing them. Everyone was struggling with a number of new and changing initiatives and different stakeholders accorded carers with different levels of priority so we interviewed different personnel on each site, observed relevant meetings, read documentation from various agencies, and took into account the changes reflected in revised guidance in order to reflect developments on each site as accurately as possible.

### ***Why do carer assessments?***

The over-riding reason for doing carer assessments was simply that "...it is policy". On every site, carer strategy documents recounted recent policy directives as a rationale for the development of carer assessments. These policies do not just exist as abstract guidance. Evidence of their implementation influences the standing of services and their levels of funding. Within health services the 'traffic light' grading of Local Implementation Plans for the implementation of Standard 6 of the National Service Framework is published as a national report which has some influence on Trusts' drive to implement carer assessments. Whilst within Social Services (where ultimate responsibility for carers assessments lies), performance indicators based on the number of carer assessments completed as a proportion of the local population influences the amount of funding available. Carer assessments are no longer an option; they are an essential part of modern mental health services. However, carers have never been a priority in the nationally determined 'Local Delivery Plans' (the key driver for mental health service activity that is

published annually, [see DH LDPs 2006/7]), and this means that, for commissioners, they take second place to national priorities. Yet, as one commissioner stated at the beginning of an interview about the development of carer assessments: "If I stop breathing it is because of my profound embarrassment about the plight of carers here. There is no excuse for it" (Site I).

If services implement carers' assessments merely because legislation dictates that they must, then there is a danger that they approach the activity with little commitment or intention to change things. This risk was recognised in the repeated references to 'assessments as a tick box activity'; a phrase used on all sites by carer assessors and by carers. There was widespread recognition that the tokenistic offering of assessments simply to 'make up the numbers' should be avoided at all costs. Many assessors felt that assessments would not be implemented if they were considered to be merely a 'tick box activity'; carers themselves said they would only take up the offer of an assessment if it were seen to be a useful exercise rather than a 'tick-box activity'. In theory at least, participants on all sites expressed the need for assessments to be value driven with real commitment to the process and a beneficial outcome:

'My view is that assessments should reflect a flexible and responsive way of working, the slavish use of tools can lead to a tick box approach, instead we would see the assessment as a conversation, working things out together, that is the attitude that I hope all of my staff would take in working with carers'.

(Carer Support Manager, Site B)

All staff leading on carer support within services viewed assessments as one way of improving the support provided for carers both to enable them to continue supporting the service user, and to improve the carers' own quality of life. However, they had different views about the importance of assessments. For some, individual carer assessments were considered pivotal to the development of carer services, with results of assessments informing the development and delivery of carer services; as one carer care manager said:

'...carers are offered an assessment and it is up to the carer assessors to use the information to inform services'. (Site A).

For others, assessments were considered one part of an overall carer support strategy comprising a range of services, supports, training programmes and approaches to raise awareness of carers' needs:

'Carers ought to be able to access a number of things: an assessment is one of them but ... I think actually a carer's assessment is to a lot of people irrelevant, what they should be is part of routine care but we do have to demonstrate that we are doing assessments and they can be useful as a process as well as for what they find out'.

(Director of Social Services, Site E)

There was some ambivalence at all levels about the necessity for carer assessments, particularly as so many carers apparently refused them when offered. Many service providers considered carer support to be an integral part of their work so that formal assessments were only necessary in order to qualify for funds (for respite, specific support and care) from the carer grant. Inevitably, perspectives on the function and importance of assessments influenced both the rate and method of implementation:

'...well I think that carers are often offered an assessment and may not want it, but I think their needs do emerge, even if they don't want a formal assessment they are usually informally assessed, in fact often it is the formality of the assessment that they find off-putting but if they don't have an assessment they may not get the financial help they need'.

(Social Worker, Care Co-ordinator and Carer Assessor, Site F)

'I think assessments are important but they are not the whole thing, there are lots of relatives that I see in my clinical practice who... turn down carers assessments just because of the name of it, the title of it. But assessments help us to make better use of the carer strategy grant'.

(Community Mental Health Nurse, Care Co-ordinator and Carer Assessor, Site H)

For others the carer assessment had become associated in carers' eyes with 'charity and handouts':

'Part of the problem is that the forms we have to complete are labelled 'Social Services', so some carers see that and think that they're a 'charity case' asking for handouts, that puts them off'.

(Carer Educational Lead, Site C)

Despite such different views about the part that assessment plays in overall carer support, and attitudes to carer assessments, the benefits of carer support, whether or not explicitly linked to assessment, were consistent (see Box 3.3):

**Box 3.3: Perceived benefits of carer support**

- Offering choices to people providing significant care about whether they wish to identify themselves as carers or to have a carers' assessment.
- Asking for, listening to and taking into account the views of carers of people with mental health problems.
- Valuing the carer as an integral part of the support system that keeps the user well.
- Recognising that caring can cause stress and anxiety and helping carers to cope with this.
- Providing appropriate and accessible information, taking into account carers' religious, sexual and cultural needs, so that they can make informed choices.

- Devising the support that carers need to continue doing that role.
- Telling carers how the information provided will be used and asking for their consent to share it with relevant providers.

### ***Who is eligible for assessment?***

All carers who provide regular and substantial care for a person with serious mental health problems have a right to an assessment – whether or not the person they care for uses services. Yet most Trusts providing mental health services offer assessments only to those people caring for people using mental health services and therefore on the Care Programme Approach (CPA). Six sites specified eligibility for carer assessments as only those people who provided regular and substantial care for service users on CPA. As noted elsewhere, this is clearly contrary to carers' rights to an assessment as provided under the Carers (Disabled Children's) Act 2000.

Site E defined 'regular and substantial' care clarifying the limits of eligibility for assessments: 'Regular meaning usually living with, if not at least weekly face to face contact. Substantial – providing a level of care that is integral to care plan and enables the service user to remain independent... if the carer were unable to provide the support outlined in the care plan, the service user would be at risk....'.

In Site A there were no eligibility criteria: if a carer was referred to the carer assessment team, or if they self referred, they received a full assessment of their needs. This had not led to great numbers of additional referrals, but it meant that all carers who believed themselves to be in need of support could be assessed and referred on to appropriate services, such as the voluntary sector carer support services which were, on all sites, open to all carers.

By limiting access to assessments to carers of service users on CPA, services are effectively denying assessments to carers of service users with serious mental health problems who either refuse to use mental health services, or only use primary care services. Not only does legislation give these carers a right to assessment, but these carers often have high levels of need as they are replacing the function of mental health services, often providing considerable support, observation and care at home in the absence of statutory provision. Such strict eligibility criteria also exclude carers who have been bereaved by the death or suicide of the person they cared for. Of the nine sites studied, only one Trust positively promoted carer assessments for carers of people with serious mental health problems who either refuse to use services or use only primary care services.

Carer Support workers in Trust B had visited all General Practices in the area and spoken to practice managers about the carer support service, leaving information about assessments and support. Even so, referrals from primary care were rare.

Two sites had set up a system for identifying carers whilst the person they care for is an inpatient. On one site the inpatient carer support worker provided information, emotional support and referred them directly for a formal assessment; on the other site ward staff assessed their needs at that time but this was not linked to the formal assessment procedure. As expressed

during the consultation, carers often feel particularly desperate when the person they care for is admitted to hospital; they have little knowledge about what is happening, what to expect, why the crisis has happened, and they may be afraid of discharge and a repetition of traumatic events. Additional support at this time seems to be a positive move forwards. However, what becomes apparent through these two initiatives is the importance of close communication between the inpatient units and the carer assessment system as a whole; and the availability of resources to meet the needs identified in the assessment during the inpatient stay. One advantage of both of these initiatives is that they ensure that carers are aware of their right to a formal assessment so that, if they wish, they could be identified as carers, receive an assessment and have their needs met in the longer term.

On Site B a dedicated inpatient carer support worker provides afternoon and evening support for carers on a daily basis. He runs a carer support group, provides emotional support and information and refers carers on for a formal assessment to identify their longer term needs.

On Site D carers seen in the hospital setting were recognised as less easily able to access assessments, leading to access to resources from social services. A hospital-based assessment was piloted, therefore, from which all referrals were sent to a Mental Health Act office. However, staff in this office had no procedure for referring assessments on to the next stage for gaining services. It was decided to pilot joint assessments between care coordinators and inpatient staff who would initiate assessments. However, again there were problems because inpatient staff did not know about and could not access funded services. The pilots showed carer assessment records were not being consistently stored or sent, and there was no follow-up process. The pilots, therefore, are being repeated. Currently, very few carers of adults in acute services are choosing to register as carers at all, let alone be reviewed.

### ***Who gets assessments?***

Eligibility criteria are only one way of limiting the accessibility of carer assessments. Where figures were available we found that of those carers eligible for assessments, many were not being assessed.

On site I, in 2005-6 it was estimated that 1905 carers should be identified and assessed. Of these only 575 carers were identified (27% of estimated total), 492 (86%) were offered an assessment, of these 299 (61%) refused and only 157 were assessed.

Site D had a total population of 216,507. Of these 15,967 people said that they provided unpaid care but only 481 carers were registered the first year of carer assessments. This figure rose to just 1,253 when assessments began in 2003-2004. The Carers' Partnership Board noted these findings with concern, particularly that only a small percentage of assessments led to any further action or services for carers.

There are a number of reasons for this shortfall. First, it appears that many carers are either not identified, or not considered to be 'carers' in need of assessment. A number of community mental health workers had only completed 2 or 3 carer assessments as they felt that most of the family members they were aware of would not need an assessment as they had a limited caring role. Community mental health workers generally prioritise the needs of the service user to the exclusion of their family and friends. With a heavy workload and competing demands on their time, it is the service user who is given priority:

'...I'm struggling a bit with staffing issues and that makes it difficult and I guess that ...we deal with the person in crisis first and I guess what can happen in all of this is that carers needs can be, not forgotten, but secondary for the time'.

(Social Worker, Site F)

'Care co-ordinators can be very protective of service users and they don't want to harm their relationship with them so carers can get left out'.

(Carer Care Manager, Site A)

Although the care programme assessment documents used with service users do include questions about family carers, this relies on service users informing their assessor about the people who provide emotional and practical support for them. Service users may consider themselves to be fairly independent, and they may not mention the support they receive from others. They may, understandably, not be aware of the stress they can create for family members and genuinely feel that that they do not have 'carers'; the term itself is problematic as it implies a dependent role for the 'cared for'. There may be some disruption within the family so that they are reluctant to involve family members in their care, or they may actively request that family members are not consulted or contacted with regard to their needs. Thus, although carers have a right to an assessment, they may not be identified or they may be excluded from assessment.

Both the literature and the consultation exercise suggested several reasons why carers themselves may be reluctant to accept the offer of an assessment of their needs. Many of these were reinforced during the interviews with staff. For example, carer assessors thought that many carers referred for an assessment after long contact with services had lost faith in services' ability to make a difference, many feel 'traumatised' by their contact with services and reluctant to get involved further. Carers may also have concerns about the responsibilities that they perceive to run alongside formal identification as a carer. They may not understand, or even object to, the term 'carer', seeing themselves as a mother, father, sibling or friend rather than a 'carer'. They may also misunderstand the meaning of the term 'assessment,' perceiving it to be an assessment of their ability to care. For some carers, the assessment forms can be a barrier, seeming like yet more bureaucracy.

Several of the sites recognised the difficulties in identifying carers and making them aware of their rights, even if strategy documents specifically recommended a more positive promotion of carer assessments. On all sites there was ongoing training for all staff which included the identification of carers and promotion of assessment. There was also acknowledgement that



where carers refuse assessments, or where family and friends are not eligible for a formal assessment, they should still be involved and informed.

Site I specified the sorts of questions that might help service users to identify carers, for example: 'if you feel unwell and cannot sleep who would you contact?' 'If you do not feel like cooking is there anyone who would do it for you?' 'Does anyone remind you to take your medication?' However, it is recognised here that there is 'no systematic approach for identifying what people want or need or the gaps in services'.

The carer strategy in site E states 'they should be kept informed of non-confidential information relating to the service user's care...and be given information and advice... This activity should be recorded in the service user's care plan'.

### ***Who undertakes carer assessments?***

Within the case study sites the organisation of carer assessments followed two distinct models. Either there existed a dedicated carer support service responsible for providing assessment, support and education for carers, education and training for staff, advocacy throughout services and communication across different sectors; or carer assessments were undertaken by care co-ordinators as part of the service provided for the service user.

### ***Dedicated carer support***

Four of the sites studied have developed a dedicated carer support and/or assessment team whose role was not only to undertake assessments, but also to provide time-limited support to carers and promote awareness of carers and their needs throughout services. These services vary in their precise remit but their functions included (but were not confined to):

- Offering all carers referred, or those meeting eligibility criteria, an assessment so that their needs can be identified and a care plan agreed. If they do not want assessment, some effort should be made to provide appropriate ongoing support.
- Providing short-term support prior to referral on to appropriate services. For example, listening/talking, providing information, helping them to make their views known (writing letters, filling in forms, arranging meetings, attending meetings with them, going to court, gaining information for them, providing advocacy).
- Providing information, time and support for carers when the person they care for is admitted or in times of crisis.

- Referring on to appropriate services and support (eg interventions/therapies for the family, themselves or for the service user; counselling, complementary therapies, gym, massage for themselves; arranging sitters to look after the person they care for so they can go out).
- Co-ordinating direct payments for any needs identified that might enable people to care more effectively eg mobile phone, holidays, driving lessons, kennelling for their dog, any other financial problems identified in assessment.
- Running carer support groups and carer education/training courses in hospital and in the community.
- Liaising closely with voluntary sector carer support services, where much practical and emotional support is provided in the longer term.
- Promoting awareness of carers and carers' assessments inside and outside services (eg visiting all GP practices; placing information cards in waiting rooms; providing education and training for staff and carers through induction visits and 2 training courses per year).
- Feeding back carers' views through appropriate channels (eg details of gaps in services, difficulties in accessing services, problems in communication) so that services develop in line with carers' needs.
- Managing the carer grant or making applications to the carer grant.
- Promoting carer involvement (eg in service development, staff recruitment, training).

Dedicated carer assessment/support services rely mainly on care co-ordinators to identify carers and refer them on for assessment. In every site that had adopted this approach there were also voluntary sector services that promoted carers' rights and needs and referred carers on for a formal assessment as appropriate (see voluntary sector contribution, below). Having completed the assessment, the assessors return the assessment and care plan to care co-ordinators, communicating any further action to be undertaken by the service user's workers, or attending reviews to advocate for the carer.

Those services that employed dedicated carer assessors were clear about their reasons for doing so. These were mainly linked to the need for some staff to focus exclusively on carers' needs to avoid the risk of carers always taking second place to service users:

'It is all about raising awareness about carers, not just doing assessments, but going into CMHTs, advocating for carers and educating staff... I think historically carers are seen as causing trouble, as unhelpful,

interfering ... if there was not a team dedicated to putting carers first then they would continue to be neglected'.

(Manager, Social Services, Site A)

However, many of the dedicated carer assessors were not professionally qualified and this was considered a problem by several participants:

'Why should carers be assessed by people who aren't qualified? Why shouldn't they be assessed by people who actually are qualified professionally in something.... and have knowledge about mental health?'

(Commissioner, Site E.)

Throughout interviews there was much debate about the type of model that was most appropriate. Participants gave clear justifications for their choice of one model and rejection of another generating a list of advantages and disadvantages (see Table 3.2).

**Table 3.2: Advantages and disadvantages of dedicated carer assessors**

<b>Dedicated carer assessors</b>	
<b>Advantages</b>	<b>Disadvantages</b>
No conflict of interests, focus solely on carers, prioritise carers' needs without recourse to service user and have time to provide dedicated support for carers.	Not familiar with the needs or wishes of service user.  No contact with service user so cannot address difficulties in the relationship between service user and carer.
They provide a local source of expertise about carers, maintaining current awareness of national policy and developments, local carer strategy and progress with carer services in the area so they can advocate for carers at service level.	If expertise about carers is confined to a small number of workers, then carers may not be involved in care as part of the service users' care planning process but always referred on to someone else. This perpetuates a culture in which carers feel separate from the service user, and carer support is considered separately from service users' support.
Many dedicated assessors do not have mental health training but they are experienced and knowledgeable about carers' rights, legislation, resources and needs.	Those not trained in mental health work may not be able to provide carers with information and explanations about therapeutic strategies, medications, mental health act, and aspects of the service provided for the service user.
As they are independent of the service users' care, dedicated assessors are able to advocate on behalf of carers in CPA reviews and communicate carers' wishes to service users' care team when there are problems.	As they usually work separately from the service users' care team, their influence on day to day practice is limited.
Able to promote carer assessments outside of mental	If every eligible carer (on CPA, in primary care, not using services,

health services – in primary care and voluntary sector, so that <b>all</b> carers of people with serious mental health problems more likely to receive an assessment.	all ages etc) were to receive a full assessment and subsequent annual reviews, the number of dedicated carers would need to be far higher than at present.
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### *Care co-ordinators as assessors*

In other areas, carer assessment was as an integral part of the care co-ordinators' role. Within this model, it is intended that carers are identified through the service users' Care Programme Approach assessment and, if they fit local eligibility criteria, they are offered an assessment. The assessment is usually undertaken by the service user's care co-ordinator, but if the service user or carer wishes, it can be completed by another community mental health worker in the team. Alongside this system of assessment, sites adopting this model funded voluntary sector services to provide additional support, and all had appointed a designated group of staff to administer the Carer Grant.

The success of this approach depends largely on the ability and willingness of care co-ordinators to seek out family and friends with a caring role, and to be familiar with assessment procedures, local services and resources available for carers the benefits system, and carers' rights. These skills and attitudes vary from individual to individual and there was some acknowledgement that more recently trained staff were more likely to work with carers, but all sites were providing training for staff and systems were being put in place to promote awareness of carers and developments in services for carers through carer link workers or carer champions.

Site I is appointing 'carer champions' in every team. These are usually community support workers who promote carers' needs and raise awareness of all the carer services that are available.

Site E has identified carer link workers in every team. These people are existing staff who have an interest in carers and promote their needs. They meet regularly in local strategy groups to feed information back to central strategy group and down to practitioners.

In Site D Primary care workplaces including GP practices have identified Carers' Champions to be responsible for ensuring that the initiatives for carers would happen in practice and to be a knowledge resource for other team members. There are quarterly meetings of the Champions' Group to review issues like changes in the documentation and processes for carer assessments, channel back views from each patch and share information and good practice.

Services that had deliberately developed a system of carer assessments being undertaken by care co-ordinators considered this the most appropriate model as it links carers into the service users' care; it ensured that qualified, skilled workers involved carers in care planning for the service user and provided them with support to meet the service users' needs as well as the necessary supports to enable them to continue caring.

The advantages and disadvantages of this model of Care Co-ordinators as Assessors are summarised in Table 3.3.

**Table 3.3: Advantages and disadvantages of care co-ordinators as assessors**

<b>Care co-ordinators as assessors</b>	
<b>Advantages</b>	<b>Disadvantages</b>
Aware of service users' problems and needs and the difficulties that this places on family and friends so in a good position to identify carers and build up a long term relationship with them.	Where there are problems in the relationship between the service user and their carers, it may be difficult to build up a relationship with both parties due to lack of trust.
Potentially in a position to work with both service user and their carers to address difficulties in relationship.	Prioritise service user and have limited time available for carers.
Care co-ordinators are aware of medications, therapeutic strategies and services available, they can explain decisions about care, inform carers about the services, strategies and treatments, and they will be aware of the most appropriate interventions for families and possibly able to implement these interventions.	There is a possibility that professionally qualified mental health workers will consider 'segregated' service and treatment options for carers rather than supports and facilities available in the community more generally.
	Access is limited to carers of people on CPA who have a care co-ordinator. This means that all carers of people eligible for mental health services (even if they are not using them) are not able to access carer assessments and subsequent support.

'On site E the commissioner justified an integrated approach (carer assessments undertaken or overseen by service users' care co-ordinator) with a specific example "This older woman said that she was drained dry because her adult son who was well in to his thirties or forties could not cope on his own and she had to physically cook his dinner every day and take it over to him. Well of course what that situation would benefit from is ... actually working with them as a family unit helping him to acquire skills to manage himself ... but it does strike me, with that person that the skill there is about working with that whole situation, that is why it would be inappropriate to have somebody else quite separate from the whole situation talking to that carer, ... tackling it by saying, let's put carers out on the edge so much so that they have their own workers, is not actually tackling the issue of acknowledging that carers are an integral part of some people's lives and should be taken in to account when working with the service user'.

There were, however, recognised difficulties with linking assessments to the CPA as this automatically excludes those carers who support someone not using mental health services:

'I'm acutely aware that there is a disadvantage for those people not linked into the teams ... they may slip through the net and somebody already receiving a service from the team is much better off in some respects than somebody getting nothing at all - there must be thousands of people getting nothing'. (Site A)

A commissioner interviewed on site I saw a useful role for care co-ordinators and for carer support workers:

'Care co-ordinators are the only ones able to give information as per NICE guidance. Above and beyond this, carers offering regular and substantial care need emotional and practical support from carer support workers'.

Two sites had developed a more amalgamated model where care co-ordinators did routine assessments but have access to dedicated carer workers who undertook assessments if there were complications. Another Trust employed carer support workers in every team. These dedicated workers refer on to care co-ordinators for full assessment. In one Trust a carer was employed as a Board member to represent carers' rights at executive level. He had been instrumental in ensuring that the Royal College of Psychiatry guidance regarding confidentiality and carers' rights to information had been adopted at Board level and implemented across the Trust. As on all sites, these approaches were still developing and, in practice, the majority of assessments were still undertaken by the dedicated carer workers but it was anticipated that as training was provided, and as assessments became more familiar, then a greater proportion of assessments would be done by care co-ordinators.

### ***The role of the voluntary sector***

In all the sites voluntary sector services, funded at least in part by the carer grant (administered by social services), had an open door policy, providing emotional and practical support to all carers. They promoted their services through newsletters, posters, and information leaflets in public places such as health centres, mental health day centres, leisure centres and so on. The support provided by voluntary sector carer support services was, in all cases informed by an assessment of their needs but this was not recognised by statutory services, so in most places, in order to qualify for individual support from the carer grant they were referred for a formal carer assessment by services. On two sites voluntary sector carer support services were able to access the carer grant for funding even though they were not permitted to complete a full carer assessment.

Voluntary sector services take the form of carer centres and individual support workers linked to carer services such as Rethink and Turning Point. Although not professionally qualified, voluntary sector workers were well informed about carers and had usually undertaken training themselves. Many provided training for care co-ordinators, seeing the main task as 'winning hearts and minds' so that workers begin to think differently rather than providing technical skills in assessment.

Site A had a large voluntary sector Carer Centre (funded through statutory services and the Carer Grant) providing generic carer support for all carers, whether or not they are eligible for assessment; specific funded carer projects (eg young carers, cancer support); advocacy; information; liaison; emotional and practical support; 'Carer Voice' training to enable carers to work in Trust groups, in education and training and now, in research. The Centre also co-ordinates meetings between carers and service managers to share experiences and information and ensure that carers' views are heard and directly responded to. The Carer Centre does not undertake formal Social Services Carer Assessments but they undertake their own assessments of people who contact the service, including those who are not eligible for formal assessments under current criteria. They then work with statutory services to implement planned support. They work closely with the carer assessors in the Trust to influence individuals' support and service development so that carers' needs are prioritised.

In Site D several organisations deliver services to carers. These include three main voluntary organisations, one of which is the Mental Health Carers Support Association (MHCSA). This began in 1993 and became a registered charity in 1996. It was formed by a multi-racial group of carers working with a local community worker who shared concerns about quality of Mental Health Services and Psychiatric Services being provided to the loved ones of carers. They wanted to exercise some influence over Mental Health Service Provision when large MH institutions were sending many people out to live in the community. An important dimension of the group, when it formed, and now, is the many members from minority ethnic communities. Funded by the Trust, carers can access MHCSA without going through carer assessment. It provides, respite to carers, a counselling service, an information service, a casework and advocacy service for carers, a support group for carer and carers outings once or twice a year.

The voluntary sector has an important role in: campaigning for carers; members sit on strategy groups, planning meetings and service developments; they are involved in training staff; and providing education and training for carers. Voluntary Sector services themselves feel that they provide a more accessible support service for carers and can provide them with valuable opportunities for peer support – from others going through similar experiences to their own:

'...people come here and say that it is very very positive, they feel it is like opening a door, its about being heard, people actually wanting to know what it is like being a carer and what their needs are and actually changing things as a result of that'.

(Voluntary Sector Carer Centre Manager, Site B)

In Site D a charismatic and experienced leader highly involved in voluntary sector support for carers has been employed by statutory services to lead the development of carer support services. Close cooperation between voluntary sector and statutory agencies has influenced both the recognition of the need for carer support and how the carer assessment strategy and procedures have been developed.

However, there was frustration in the voluntary sector that they were not commissioned to undertake formal assessments which inevitably leads to duplication of work. Commissioners on several sites expressed the view that if carers are to receive the information, support and therapeutic interventions such as those required by the NICE guidelines for schizophrenia, then qualified professionals must be involved in assessment and the provision of carer support. On Site I, one interviewee proposed a separate role for voluntary sector carer support workers and service users' care co-ordinators:

'In an ideal world, all carers would receive education and information as per NICE guidance from care co-ordinators who identify carers' needs through CPA assessments, and those carers offering regular and substantial care would receive emotional and practical support from voluntary sector carer support workers including: ongoing support to maintain their role, time and space to talk, a choice of whether to be carer, chance to widen their support networks through contact with other carers, and relief of demands to allow them to care'.

(Commissioner, Site I)

### ***What is assessed?***

Assessment tools were either specifically designed for (and in some cases, with) carers of people with mental health problems, or comprised a generic carer assessment form with a specific section referring to carers of people with mental health problems. They included tick box questions for standard information (like socio-demographics) and free response sections for open questions. All sites used tools that covered similar areas in more or less depth (see Box 3.4). Where an unstructured approach was advocated, with broad topic areas addressed through free text responses rather than specific closed questions, guidance notes were available to prompt consideration of the full range of issues.

On some sites carers were given the opportunity to complete the form themselves – self assessment – with a follow up visit to discuss the sort of support that would be helpful. Assessors spoke of the need to be flexible, adjusting their approach to the wishes, level of understanding and role of each carer.

Completed assessment forms generally gave limited space for a brief and factual summary of the discussion that had taken place between the assessor and the carer. On several sites, the assessment was written up in the first person, as if in the carers' own words and the carer was sent a copy to read, amend and sign as a valid account of their situation and needs. However, the text on these forms did no justice to the detailed, lengthy and often emotional conversations that took place during the assessment. Both assessors and care co-ordinators felt that many carers received ongoing support through regular visits to the home – ostensibly to see the service user – but this was neither reflected in numbers of assessments completed, nor in individual assessment documentation.



#### **Box 3.4: Areas covered in carer assessment tools**

- socio-demographic characteristics of the carer and ethnic monitoring section,
- who and how many people they care for;
- information about the cared for person;
- nature of support provided by carer;
- services required to ensure *user's* needs are met in short and long term including the need for more information about the diagnosis and medication; relationships with professionals supporting person with mental health problems;
- carer's health and well-being;
- what kind of services would help with caring role;
- perceived support needs in terms of any specific difficulties, equipment needs;
- emotional support, breaks/holidays, information and training needs, any health problems, any ethical, cultural, religious needs;
- carers views about caring;
- risks to carer's safety;
- carer's involvement in wider community life and other responsibilities relating to work, children, other caring roles and services required to maintain involvement in work, education etc;
- financial/practical issues such as benefits.

Generally the assessment tool was used only as a loose guide to the assessment process. Assessors spoke of the need to listen carefully to carers' accounts of their day to day routines, roles and relationships in order to assess sustainability and appropriateness of the caring role; levels of understanding, exhaustion and risk; relationship problems and areas of role conflict.

On Site E assessors completed a standard assessment form but used a checklist of questions and prompts to aid a full discussion ranging from carers' views about the future to their access to information, advocacy and help in an emergency. All assessors received training in the assessment procedure with an emphasis on achieving positive outcomes for carers (rather than a high number of completed assessments for social services performance indicators).

The process of assessment was considered far more important than the tool/form that was used. All assessors emphasised the importance of taking time to do the assessment: on most sites assessments were undertaken over two or three visits to the carer's home; talking, listening, conveying to carers that they have rights and that their role is valued – for many carers this was the first opportunity they had ever had to speak about their experiences:

'...people say that it is very very positive, they feel it is like opening a door, it's about being heard, people actually wanting to know what it is like being a carer and what their needs are and actually changing things as a result of that'.

(Local Service Manager, Site B)

However, assessment itself is only the start of what should be an on-going process.

### ***Care planning, review and outcomes of assessments***

After the assessment the aim was to complete an Action Plan specifying the needs identified, the action to be taken, and by whom. This usually comprised a very brief section of the assessment and there was no system for ensuring that action had been taken, or for checking up on follow up arrangements. Even though all carers have a right to a review of their needs on an annual basis or if their needs change, none of the sites had an effective system for reminding assessors when reviews were due and there was some awareness that carers could get 'lost' following their assessment if they were referred on for support elsewhere:

'The one thing I find difficult is remembering to redo assessments because like care plans... they need to be updated and reviewed'.

(Community Mental Health Nurse and Carer Assessor, Site F)

'Once a carer has been referred to voluntary sector, we can lose touch with them ... you wouldn't specifically know how it is for them'.

(Carer Care Manager, Assessor, Site A)

The assessments led to the identification of a wide range of support needs that could be met by the assessors (eg information, counselling, advocacy, provision of carer support groups, communication with mental health team), the mental health services provided to the service user (information, involvement, psychosocial intervention), voluntary services (peer support, advice, information), or through direct payments (from the carer grant) for individualised services and supports (payment for sitters, mobile phone, holidays, pet care, leisure activities, educational courses, household appliances and aids):

'Carers can now get what they really need through the direct payments budget; we can be really creative with that. I do feel that we should be encouraging people to have carer assessments because we can do

something for them as well as doing what we should always be doing which is looking at what we can do for the cared for person to relieve the burden on the carer – which always gets missed, that goes back to the 95 act, and that just doesn't work with an assessment service that isn't based with the care co-ordinators, I don't know whether the carer assessors are really able to influence the care packages and care plans of the cared for'.

(Social Worker, Team Leader, Care Co-ordinator, Site F)

Much of the support relied on the carers grant and there were differences between sites in the administration of this grant. For example on one site it was administered by the carer support manager, on three sites it was administered by voluntary sector carer support services and on another site it was administered by a committee chaired by social services. Whereas some sites insisted on a formal assessment being completed before a carer qualified for payments from the carer grant, other sites were more flexible. Similarly, some sites used the carer grant to pay for holidays for service users - either with their family (to give them all a break together) or separately (to give their family respite), whilst other sites strictly refused to pay for service user holidays out of the carer grant.

Interestingly, many assessors and carers saw the main purpose of the carer assessment being to access funding from the carer grant. For example when criteria for accessing the carer grant were tightened on Site F, the number of assessments completed reduced and assessors openly admitted that it did not seem worth doing assessments if they did not lead to specific services as they were already working with carers routinely and saw no value in completing a form merely to document this.

### ***Assessing 'special' or minority group carers***

The documentation of all services explicitly stated that carer's assessments must be provided in a sensitive manner to avoid discriminating against people on the grounds of race, religion, sexuality or disability.

In selecting the case study sites we intentionally sampled sites that expressed a particular interest or focus upon a minority group (eg Site C had a carer support worker for black and minority ethnic groups; Site A served a population with high numbers of same sex couples and long distance carers, Site I and Sites E/F covered large rural areas). Even so, there were limited specific practical strategies in place to ensure that services were offered in a non-discriminatory or inclusive manner, and service reconfigurations sometimes meant that dedicated services for BME groups were under review (eg Site C).

Although we interviewed a number of carers from minority groups (for example, 5 were service users themselves, 2 were partners in a same sex relationship, 10 were from an ethnic minority group and 25 lived in rural areas), there were no particular strategies in place in any of the sites to ensure their inclusion or identification as a carer, nor for providing them with a particularly sensitive and accessible service. When asked, interviewees spoke of all carers having different characteristics and

needs so a flexible, inclusive and reflexive approach was taken during the assessments to tailor them to the carers' level of understanding, situation and needs.

The only exception to this came from the rural teams who felt that there was something different about their work and the people using their services. They felt that families were closer and took more responsibility for caring and for finding out how to do this. However, there was a risk that families did not seek help when they needed it, partly out of independence and partly because of the stigma of mental health problems:

'I think the philosophy, certainly in the kind of rural area that we are in, is very much to include families and carers because we couldn't manage without them... Families used to caring, closer knit and traditional extended families don't see themselves as carers, they are used to caring ...'.

(Community Mental Health Nurse, Site F)

'...what's really struck me, having come from quite an urban area, I've found that families are more likely to come to you and ask questions...they'll seek you out and speak to you on the street about things I'm not used to...'.

(Social Worker, Site F)

This was not always a good thing. Several workers felt that the intimacy of living in a small village could reduce privacy:

'...stigma of mental illness is accentuated in close rural communities where everybody knows everybody else's business'.

(Community Mental Health Nurse, Site E).

## Conclusions

It seems that carers of people with mental health problems are a low priority in both planning and in practice. At Local Implementation Team level, carers receive relatively little attention, and carer assessments are only a minor consideration in local carer plans. Similarly, at Trust level, assessments comprise a small part of carer strategies and have been considered in a minimal manner. In most Trusts, carer assessments are seen as part of the Care Programme Approach, added to service user assessments and reviews with little or no thought to the limitations of this system. Carers of people who use primary care services, or who choose to use no services at all, are therefore excluded, and carers who are not identified by the service user in their own assessment are effectively denied assessment.

Closer scrutiny of the implementation of carer assessment policies and procedures on eight sites confirm these findings. In many sites the employment of carer assessors within secondary services, or the development of assessment eligibility criteria

linked to the CPA serve to exclude many carers who have a right to assessment: carers of people with mental health problems who are maintained outside the mental health system – often by virtue of the intensive support provided by family carers.

Although two distinct models of carer assessment can be identified, neither offers discernible advantages over the other. The employment of dedicated carer assessors ensures that there is at least one person within the Trust who prioritises carers and is aware of their rights and relevant resources so can advocate on their behalf at both an individual and service level. However, where care co-ordinators take responsibility for carer assessments, carers become 'every bodies business' and the intention is to move away from an individually focussed model of care, towards a more family and community based model for assessing individuals, their needs and their resources. It may well be advisable to develop a hybrid model, in which all care co-ordinators routinely identify carers and undertake assessments and care planning with family members, but dedicated carer workers take on more complex assessments where, for example, there is conflict between the service user and their family /carers. These carer workers could maintain responsibility for raising awareness of carers throughout the service: their needs, rights, opportunities and resources, and could take on carer advocacy in CPA reviews as well as liaison with the voluntary sector.

Clearly the voluntary sector has an important role to play in the practical and emotional support of carers. On every site the voluntary sector services for carers were valued, particularly for their accessibility to carers who were reluctant to seek help from mental health services, and for the peer support opportunities that they provide. Although none undertook formal carer assessments, they all assessed carers' needs following referral and so there was some duplication of work. There appears to be a need for greater clarity in the division of roles and responsibilities between statutory and non-statutory sector services, with commissioners clearly specifying their expectations. It may well be helpful for mental health services to take on therapeutic and information giving roles to the carer in relation to the service user, whilst the voluntary sector undertakes carer assessments and provides emotional and practical support for the carer in their own right.

Most staff saw formal carer assessments simply as a means of accessing the carer grant for direct payments (for a diversity of activities and supports to help them continue caring) or for respite care (a break for themselves or a break for the service user so that their family had some respite from caring). Many staff felt they built relationships with carers on an ongoing basis and rarely found the process of undertaking assessments valuable and informative; an annual assessment and written plan of care was not considered to be the way towards providing a service that valued, involved, informed and enabled carers. Rather, this was reliant on changing the philosophy of services away from an individualised, symptom focussed approach towards a more inclusive, community based approach. Carer Strategies aspired to do this through: comprehensive plans to increase staff training; in 'working with carers' develop 'carer champion' posts; increase carer involvement in staff recruitment, training, service planning and evaluation; provide more information for carers, involve carers in Advance Directives to reduce conflicts between them and service users; adopt confidentiality policies to reduce the 'smokescreen' through which many carers felt excluded. Interestingly, the potential value of assessments to identify gaps in services was not mentioned in Carer Strategy documentation. Although carers had suggested that assessments might be helpful in this way, practitioners were reluctant to

identify needs that could not be met – instead they found some way of meeting of all needs identified in assessments – and direct payments do, theoretically at least, make this possible.

Given the limitations of assessments, the question remains, are they necessary or helpful, or can carers' needs be met through a family based model of care? We seek to address this in the following section.

### **Supporting Carers in Routine Care: What can we learn from alternative service models?**

It was noted during the consultation days with carers that few participants had positive experiences of assessments. However some were pleased with the support they received from mental health services. These carers had not been formally assessed yet they described services which provided adequate support to both the service user and themselves. They were listened to, informed about the care provided for the service user, provided with the support they needed to continue caring, and had their contribution valued. Some of these carers attributed the success of their support to individual care co-ordinators:

'We each have discreet, personal needs that need to be assessed separately ... so, when our CPN visits, she talks to my son, who doesn't often want us to be around, then she invites our son to join her in a conversation with my husband and I. Often he doesn't want to be there, but he understands that we will have a chat and he is welcome to join in. This way all of our concerns, needs, observations are taken into account and there is openness'. (London)

Conversely, others felt that things had changed since the service user had transferred to the Assertive Outreach team:

'I must say that things have changed since [our son] has been in the Assertive Outreach team. His worker has so much more time to talk to us and really does involve us in decisions about what is best for him'. (South West)

Or since they had received family work from the psychosocial intervention team:

'The one thing that really made a difference was doing the family education training. It helped us to see what was going wrong and how we rubbed each other up the wrong way, we are better at understanding our relationship and stopping disagreements before they get too bad now'. (West Midlands)

In addition, carers raised questions about the value of one-off carer assessments rather than carer support as an ongoing and routine part of care for the service user:

'But why should this need to be part of an assessment? Why can't it be a routine part of the care of the person I care for'. (North West)

'I don't want an assessment, I want people there to look after my son and for me to call on when I need it'. (North West)

'You can't expect an assessment to sort your life out, what we want is someone to support us ... we just need the support'. (South West)

They were critical of services based on a medical model which focussed on alleviating the symptoms of the service user rather than considering the impact of mental health problems more broadly, and spoke of the need for a shift towards services in which service users are supported to find positive roles within their community, involving family friends and their social network to rebuild their lives in a meaningful manner – with or without symptoms:

'There is no point in going through GPs. GPs live by a medical model and define their work in terms of the individual they are treating, not the carers' needs'. (South East)

'Education for staff is essential in order to change the whole culture and system of care so that it becomes family orientated rather than individually focused'. (North West)

'What is needed is a complete shift towards a family-based model for all community services in which whole lives matter, not just symptoms'. (North West)

Such carers' views were validated in site visits as described in the previous section: care co-ordinators spoke of their reluctance to undertake (what they saw as) the lengthy and bureaucratic formal carer assessment unless there would be a tangible advantage in doing so. For many, the process was only justified if there was a possibility of accessing resources from the carer grant.

These issues raise questions about the effectiveness of carer assessments: what difference do they make? Are they worth the time they take? Can carers be provided with adequate and appropriate support without a formal assessment?

In order to address these questions, three further organisational case study sites were selected for in-depth study. These sites operate specific service models: assertive outreach, psychosocial interventions as part of an early intervention service and family group conferences. In principle they provide support for carers as part of their integral service model or approach. Thus although they may refer carers on for assessment when they feel it is necessary, they do not prioritise carer assessments.

The aim of these further case studies was therefore to provide a better understanding of the structures, processes and 'cultures' in operation in services where carers said they felt that their needs were well addressed, but without a formal assessment necessarily occurring.

The case studies followed exactly the same process as utilised on the assessment sites: interviews with key players throughout the service; analysis of relevant documentation; and, repeated interviews with carers (following the assessment and 6 months later).

## **Assertive Outreach**

### **Background**

Assertive outreach is a form of intensive case management that improves engagement by working towards clients' own goals with their families, friends and communities (SCMH 1998). All Trusts are required to provide AO for people with serious disabling mental health problems who are difficult to engage in existing services (DoH 1998, 1999). AO has been shown to be more effective than standard community care in terms of: more sustained contact with services; less time spent in hospital; improved clinical and social outcomes in terms of accommodation status, employment, and patient satisfaction.

AO is a highly specified, team-based approach to caring for people with serious mental health problems in the community. It is clearly defined to permit assessment of fidelity. Indeed, there are now validated fidelity scales that measure adherence to the ACT model (McGrew et al 1994, Teague et al 1998). The rationale, important features and operating principles of AO have been characterised as:

- a multi-disciplinary team approach;
- providing comprehensive social and psychiatric care from within the team;
- having nominated key workers with caseloads of 1-10;
- sharing responsibility of all clients throughout the team;
- providing evidence based interventions;
- high levels of accessibility;
- continuing to contact and offer services to reluctant or uncooperative people;
- providing ongoing support, integrated into wider system of care

(McGrew and Bond 1995, Marshall et al 1999)

There is very little literature on assertive outreach in relation to carers. However one evaluation of a local AO service undertook an in-depth qualitative study of users' and carers' views of the service, and reported that carers were highly positive about the



service; they particularly appreciated the time available for them; the information they received; the responsiveness of the service; and the efforts made to work in partnership with both the service user and their family (Repper et al 2000).

### ***Study site***

The AD team selected for in-depth study provided intensive support for 56 people with serious mental health problems, all of whom had been difficult to engage with services. It operated in a large, sparsely populated, rural area with little public transport and few mental health facilities easily accessible. All team members had received several days training in assertive outreach and service user assessment, and they had also all attended one days training in carer assessment.

The team documentation and the individual staff members interviewed emphasised the importance of working with clients' family and friends; they recognised the value of informal carers and the difficulties they often faced living with people disabled by serious mental health problems. They spoke of spending time supporting the individual and their families so that they could live as independently as possible. Although they had relatively low numbers of clients on their case loads, they still found that service users took priority and they felt they would do more with family members if they had more time. Few had any experience of undertaking carer assessments. Despite a one day training event they were not confident about how they worked, and they were not convinced of their value. However, two workers who had undertaken a carer's assessment had found it enlightening to take a more structured approach to understanding the carer's situation, family relationships and the service user's needs:

**Q: What benefit did doing the assessment bring to her or you?**

A: 'Well, when I spoke to her about this, she thought I got nothing from the assessment, how could I possibly because it was very emotional for her, I learnt so much about a service user, the mother and their relationship because I found the paperwork meant I had to ask involved questions, hopefully it was useful for her, but it was emotional for her, it brought back things you know that were obviously painful'.

**Q: And did it lead to any plan of action; did it elicit some needs that you could do something about?**

A: 'Yes, she wanted some more information on the nature of the illness of her son, it led to a re-referral to the carers organization Rethink because she'd kind of let it slide, she'd been referred to them before and had paper work sent every month but had not really done much about it and it led, well the rethink referral to get involved with the group and one to one input'.

However, once the study began, staff found it difficult to identify carers supported by the team. Staff members went through the case list and could only identify 4 clients who had carers who received support from the team; one of these had received a full

carer assessment; two more AD clients were identified through the local Rethink office which provides carer support and assessment. The following section is therefore based on the views of only 6 people.

### ***Carers' views about support provided***

Carers of people receiving care from the AD service all recognised the difference that this intensive, social model of care had made to their lives. They described the slow development of trust with a team of workers who became "like friends":

'I used to tell them to eff off but they just kept coming and now things couldn't be better, they are like friends, they'd do anything for us'.

(Mother and Fellow AD Service User 1, Site 1)

The range of different activities that the AD service engaged in benefited both the carer and the service user: shopping, cooking, sorting out finances, sporting activities, arranging for modifications to the home (a banister, bath seat, changing light bulbs).

Indeed, the AD approach appeared to be designed to support the family of the individual rather than existing purely for the benefit of the service use. Two carers described the provision of respite care:

'Well it used to be a Saturday and Sunday that I used to dread because he could get up in the morning and start and go on all day, his voice would get louder and so assertive outreach team used to come over and take him out for a couple of hours so that gave me a break... I asked for him to go into hospital in April and they can't always do it so they come out and sit with Paul and talk with him and calm him down and tell him that he can go in at such and such a time but Paul is great and always says my mum should have respite, he is very good at going'.

(Mother and Fellow AD Service User 1, Site 1)

'Since AD things have been much better... before we had the AD I didn't feel confident, they were nothing like A.D. My other daughters took me to a show in London and whilst I was there AD took my daughter out. I felt at ease at show because I knew she was being looked after'.

(Mother of AD Service User 2, Site 1)

It was also a huge relief for carers that the service were available 24 hours a day, 7 days per week:

'When it first started if anything happened to us on a Friday evening there was nobody to phone up because nobody is going to sort it out till Monday which is no good to people in our situation but now they are on this 24 hour all through the weekends which should have happened a long time ago... For the last ten years, if we ring [AD worker] up and say

'look he is not very good at the moment' then there is somebody here and somebody will come which is important for us'.

(Parents of AD Service User 4, Site I)

The AD service were able to value the role of family members and work in partnership with them to provide better support:

'I just think that the fact that they actually do listen to me is a big help, and when I said about what was going on they actually told me this is a thought disorder... I found it very helpful and what they said is, if we can actually get to know how its working we can actually help you to help him as well which will make it so that it doesn't go on for so long'.

(Mother of AD Service User 5, Site I)

Another carer described the importance of having someone to talk to – and not always about the person you care for:

'And they mainly come to see [wife] but [AD worker] will talk to me and it's nice to talk to her... and we don't necessarily talk about the problems, we talk about anything which is sort of nice. Then about up until a year ago there was Darren... well he was nice and sometimes you feel as though you want a man to talk to, he would talk about cars, anything like that, he used to say 'how are you' and just to talk to somebody. Just to get it off your chest, I mean I can't to my children...'

(Husband of AD Service User 4, Site I)

Carers were generally extremely pleased with the support provided by AD, particularly for the service user:

'I cannot see what else they can do - I think we have been offered everything'.

(Mother of AD Service User, 3, Site I)

'Now that I have the assertive outreach team I can't actually see how [a carer assessment] could actually give me anything that would help me more really ...I just think that now I've got assertive outreach if I do have problems then I would be able to get help within a reasonable time'.

(Mother of AD Service User, 5, Site I)

In several other cases, carers had been offered an assessment but had declined as they felt they were "...already getting everything". However, there were clearly ways in which carers could have received more effective support. For example, few had been given information about ways of coping with the behaviour of the person they cared for, few had a real understanding of the nature of the problems; one wanted to have a man to speak to regularly, one couple felt that siblings needed support as well

as parents and there was nothing available for them. It is possible that a formal assessment of their needs might have revealed these gaps, whereas ongoing, routine involvement alone did not.

Only one client interviewed was critical of the AO service. She wanted more than the AO service was offering; although they visited her and monitored her son, they were not providing information or therapeutic interventions:

'I expected outreach workers not just to sit round have coffee, decide what the problems are yet again and say 'well it's a long time and it needs time and it takes a long time ...' and as lovely as they all are as people ... I was hitting a wall'.

(Mother of AO Service User, 6, Site 1)

The comments from the only AO client to have a full carer assessment suggest that she did not find it useful:

'I have had an assessment, I was quite happy that what xxxxx had written down was true and really it was just me saying how life was, and yes, I was quite happy with this because no one told me what to expect... the agreed action was fortnightly visit with [AO] for support and to ensure they were aware of family perspective of current problems, support from Rethink and attendance at their support meetings and education and provision of respite. But it has been useless' (partly because of problems securing respite care due to son's drug problems)'.

(Mother of AO Service User, 6, Site 1)

In conclusion, although the Assertive Outreach is a family centred, social model of care, the team selected for this study found it difficult to identify family members able to participate in the research. Over the course of a year, only 6 family members were recruited to the study. When examining the family situation of the clients of this service it became apparent that many of them are socially isolated, relationships with family have broken down and for many, the AO service had become a substitute family.

All interviewees recognised the difference between the support provided by AO and routine services: they had more intensive, flexible support; the workers had more time, they were available 24 hours a day, 7 days per week so could respond in a crisis and provide evening and weekend support; they had more trusting, familiar relationships and they received practical as well as emotional support.

Although team members used assessment tools in their clinical/therapeutic work with families, only two team members had undertaken formal carer assessments and they had found this helpful as a systematic approach to getting to know more about the family as well as the service user, it had also identified additional needs. Even so, they had not offered more formal carer

assessments as they were not convinced that identified needs could be met due to existing limitations on the carer grant. The one carer who had been formally assessed did not feel that it had made any difference to her existing levels of support.

Overall, AO does appear to offer an approach that family carers want – more responsive, flexible and personalised. However, carers' expectations are perhaps low, and unless they are aware of possibilities and alternatives, they are unlikely to ask for them. A formal assessment is one way of systematically finding out whether family carers are aware of all available resources. It is notable that none of the carers interviewed here had received information or help with coping with difficult behaviour or symptoms in the person they cared for.

## **Psychosocial Interventions (PSI)**

### ***Background***

PSI is an umbrella term that refers to a range of interventions that have been shown to be effective for people with serious mental health problems, including behavioural family intervention, cognitive behavioural therapy, early intervention, relapse prevention and case management. During the consultations, carers who had received PSI felt better able to cope with their caring role, understood services and treatments better, and were able to articulate their needs with professionals. This is consistent with previous reviews of family intervention studies (Dixon and Lehman 1995, Goldstein and Miklowitz 1995, Mari and Streiner 1994, 1995). All conclude that psychosocial interventions with families of people with schizophrenia consistently result in a better outcome than medication and routine follow-up only. In the Cochrane Collaboration meta-analysis of family psychosocial intervention studies, Mari and Streiner present a meta-analysis of 6 (1994) and 10 (1995) trials and conclude that as part of a multi-faceted approach, family intervention with people who have a diagnosis of schizophrenia decreases the frequency of relapse and hospitalisation, improves compliance with medication and reduces the cost of care. They calculate that seven families need to be treated for one year to prevent one relapse. However, a more recent Cochrane Review (Pharoah et al 2006) concluded that the results of studies were not strong enough to be confident of the effects of family interventions.

Despite the above, the National Institute for Clinical Excellence (NICE) guidance for schizophrenia requires the families of all people with a diagnosis of schizophrenia to be offered family intervention and significant funding has been made available for PSI training for mental health workers. Even so, only a minority of carers have received family intervention and studies of the implementation of taught PSI skills indicate that very few trainees ever work with families. Kavanagh et al (1993) reported that of 160 therapists trained, 44 took part in the treatment trial but 28 of these therapists only saw one client or family. In a further training programme for 14 therapists in a committed service, Kavanagh et al (1993) reported that despite taking every opportunity to make it easier for therapists to apply family skills, after 6 months only 4 therapists had seen a family. In a study which specifically examined the implementation of taught skills, Fadden (1997) surveyed 86 therapists who had received training in behavioural family therapy. Of the 70% who responded, the mean number of families seen per therapist was only 1.7.

## *Study site*

It was difficult to identify a service which provided routine psychosocial interventions and family work – and wanted to participate in the study. After two lengthy false starts (in which ethical approval was obtained and initial visits were undertaken but rapid changes in service structures and staffing prohibited further work) an Early Intervention for Psychosis team volunteered to be a case study site. This South Yorkshire team serves a mainly urban population of around 250,000 (2.5% ethnic minorities). It was set up to 'provide advice, assessment and intensive treatment to individuals aged 13-35 years experiencing their first episode of psychosis', it won the South Yorks Health and Social Care PROUD Award in July 2006 for outstanding achievement in mental health. It's stated mission is 'An holistic family orientated service using therapeutic approaches for young people ...with an emphasis on optimism and recovery' and the team philosophy similarly stated 'there is an emphasis on meaningful engagement which will lead to best evidence based assessment and intervention leading to the provision of best quality care for all service users, their families and friends'. Members of the team did not see carer assessment as necessary since family support is central to their purpose and practice; all staff recognised the importance and centrality of family work:

'It's shared care, not one individual, not just financial and housing but education for users and their families and anyone else who is involved... Our belief is that we look after all aspects that are putting the person under stress, not just the person we are caring for but also friends'.

(EI team member 1 with nursing background)

'One of the aims of the service is to identify and support the needs of the carer as part of the support of the client... Psychosis affects everyone around, mum, dad, friends'.

(EI team member 3 with nursing background)

Team members spoke confidently about their work with families. They took a discreet approach to identify and engage with those people around the young service users but they conceded that they could only go as far as the service user allowed:

'It is always difficult... easier if it's mum or dad, husband or wife. If it's a neighbour we are a bit more cagey but at the end of the day that person provides support and care... but you have to negotiate it all with the service user'.

(EI team member 1 with nursing background)

Although the team professed to using a structured psychosocial approach "most of the staff have psychosocial intervention training, we have to do it like that because of how disorganised some families are" (EI team member 3 with nursing background), they described their methods of carer assessment loosely:

'I gauge their needs just by chatting and having conversations about what their experiences are'

(EI team member 1 with nursing background)

'Its better not to go in with a bit of an assessment tool, but just go in and chat with them because otherwise people can find it intimidating'.

(EI team member 4 with nursing background)

When asked about the place for formal carers' assessments team members did not see the point of them unless they needed to access something very specific through the carer grant:

'We don't need to refer for a formal carer assessment as we have enough tools in our box'.

(EI team member 2 with nursing background)

'I always offer informal sessions and ask if they want formal sessions, if they do I do what I call a relatives assessment to find out what they do and don't know and base interventions on that'.

(EI team member 2 with nursing background)

Team members felt their approach was successful: that families were well supported and that they made a difference:

'It works, there is lots of evidence, in most cases we will go in and identify dynamics and with a little intervention you start to see an improvement'.

(EI team member 3 with nursing background)

Indeed, one senior staff member felt that the emphasis on carer support was a particular feature of the team and had led to the Trust planning to close down a local voluntary sector carer support group. This did not, however happen during the course of the present study.

### ***Carer Support in Practice/Carers Experiences of Support***

Despite all of the heartfelt discussions about the importance of providing support for families and friends and their success at including, involving and engaging with informal carers – the team failed to identify any participants for the research. Over a nine month period (during which local carers were trained in research skills ready to interview carers using the Early Intervention service), the team was visited, written to, emailed, different personnel were contacted separately, yet nobody was recruited to even speak to the local researcher about the project. Different reasons for this were put forwards:

- Carers were too busy
- Carers did not value their own input and did not think they were worthy of inclusion

- Carers had bad experiences of services and did not want to speak about them
- Carers avoided services due to bad experiences, mistrust, reluctance to be judged
- Staff were busy and not seeing many carers at that time
- No carer group running at that time
- Fewer clients than usual had family carers
- Family carers had very complex needs and were not suitable for the research.

It is difficult to know how to account for the discrepancy between what the team members said they were doing and what was actually happening but this is not a new finding in research on psychosocial interventions. As described above, even when training and supervision is provided in a geographical area where a critical mass of clinicians are working in a family centred manner, the average number of families seen following training is only 1.7 per therapist! (Fadden 1997). This echoed the disappointing rates of implementation reported in Australia by Kavanagh (1993). However, these researchers attributed low implementation rates to services that did not value or support family work, staff without confidence or practice in the skills; lack of time and lack of systems for paying out of hours work. None of these could wholly account for the findings in the present study. Moreover, families were denied not only routine support and specialist psychosocial interventions, they were also denied the opportunity for formal carer assessments as the team did not recognise the potential value of these, and they did not have the opportunity to benefit from services paid for directly through the carer grant.

In conclusion, although psychosocial interventions have the potential to help families cope, and to provide them with valuable support, their complexity and the training and confidence required to deliver them create barriers to their full implementation with every family. It would appear that they need to be offered as *well as* rather than *instead of* routine family support and carer assessments so that an 'all or nothing' situation is avoided.



## Family group conference

### *Background*

Family group conference (FGC) services aim to fully involve the service user, their family, friends and significant others in the assessment and care planning process in order to increase support, challenge isolation and combat discrimination. It is a specialised service, separate from CMHTs, that organises full assessment meetings (or family group conferences) and refers on to relevant services to implement the subsequent care plan. These meetings may identify the main carer(s) and complete a formal carer assessment but this may not be deemed necessary or appropriate.

In the site under study the FGC service was an independent team set up to meet the needs of service users by supporting and co-ordinating informal support. The process begins with a meeting with the service user to discuss their situation, get to know their views and help them to try to identify some positives in their situation and not just focus on the difficulties. This information is written down, in a process called Family Information Sharing which also helps address confidentiality procedures which normally limit the sharing of information with carers without service users approving this each time. This document is signed by all participants and taken for discussion with the wider group. The service user decides who FGC workers should contact and invite to take part in the conference. Service users and family members are given information about the FGC main meeting and know this is a time to explore what can be offered and to discuss whether service user or carers want to use services or support.

Co-ordinators contact everybody who might be involved to check how much contact they have with the service user, what they understand of the situation, how it impacts them, how they are coping, and what information and support they need. This may involve two or three visits for the main people with regular contact with the service user. A range of professionals may also be involved in the FGC main meeting, usually the users' Care Co-ordinator, and sometimes their psychiatrists.

The main FGC process begins with the professional present for the first hour of a typically three hour conference held in the family home, but sometimes somewhere more neutral like community centres or church halls. Food and refreshments are provided. The professionals are there to provide information on available services, clarify diagnoses and answer questions on these issues. Most professionals then leave, possibly with a care co-ordinator, or a doctor staying. The family group then has private time to consider the information themselves with the independent co-ordinator of the FGC remaining available but only participating if asked to contribute. Although not the primary aim of the FGC, carers' needs often arise as a consequence of the discussion and may subsequently result in a formal carer's assessment being initiated.

The service we explored in the PICAP project was located in a largely rural area with a population of approximately 170,000. At the time of the project the Trust was working on a first draft of its carer's strategy. However, carer support services had been

established since 2004 with the provision of respite care as its main goal. However, due to resource scarcity, provision was currently limited.

The case study conducted at this site explored the experience of FGC from a carer's perspective. This involved interviewing carers (n = 12) who had attended one of seven conferences and re-interviewing a further nine carers 6 months later. The results were equivocal, suggesting that carers perceived benefits to the conferences but equally noting that little, if any, attention was given to their own needs, even when they considered their situations to be difficult and challenging.

On the positive side carers particularly valued the opportunity the conferences provided for the family to have a full and frank discussion, allowing the exploration of difficult issues in an open, non-hostile climate:

Sibling 1: I think xxxxx [user] did, I know that we all felt, it was like a big relief after the conference I think because you know before that you only ever chat, not altogether, if we ever... the kids are all there and you can't really, you can't talk about things like that.

Sibling 2: No and we didn't want to be talking about xxxxx [user], we'd want her to be there but like we say, when we've got kids and stuff its really hard, you don't want to be talking about certain things in front of them, but I thought it was a really good thing.

(Siblings of user with bipolar disorder, Site K)

Such frank discussions allowed for better shared understanding to emerge and helped to facilitate open channels of communication and enhanced problem solving that, in some instances, became part of the families' coping repertoire:

'Got to get round the table and thrash this one out, and we did have a stupid argument, I can't even remember what it was about, like all these arguments are, and the whole three generations were involved so we all decided, I took action 'we got to get round the table' we all sat round here in this room and we debated what we did? Where we went wrong? Why did we do it? Why did we explode? Where are we going to go forward? Now that was the very, very first one that we did that wasn't too far short after xxxxx [facilitator] had been here, and since then that is what we do, we sit and debate and we talk'.

(Husband of wife and daughter both with mental health problems)

Despite these benefits many carers wished they had received such support earlier, and others expressed concerns about how long the conference had taken to organise. There was also disappointment that many of the key professionals who had been invited failed to attend:

'But my biggest criticism of the whole system from when they were first involved to the present day was that it takes so long. I mean when I went to see her CPN and said 'I'm desperate' I did not envisage that this would take 6 months and in that 6 months I've still got this behaviour problem to deal with'.

(Site K – mother carer of daughter with obsessive compulsive disorder and multiple disorders)

Unfortunately the opportunity to have their views heard by the person other than the conference facilitator was sometimes denied carers. Despite a range of professionals being invited, it seems that many did not attend. This could cause considerable anger:

Sibling 1:       Actually the psychiatrist was invited, didn't turn up, wouldn't come, obviously too busy and xxxxx [CPN] was invited, obviously too busy.

Sibling 2:       And the doctor.

Sibling 3:       I don't think he even got back to her did he?

Sibling 2:       No, none of them turned up, and it would have been really good to speak to them.

Sibling 3:       I was disgusted that they didn't even get back and they've got this job and are supposed to be helping people, what, when they feel like it?

(Sibling carer of user with bipolar disorder, Site K)

However, possibly the biggest disappointment was the fact that because the primary focus of the conference was on the person with mental health problems, carers had very little say as to what was on the agenda and they often felt that opportunities to explore their own needs were overlooked:

'At the end of the day what you discussed or whatever the issues are, you are still left on your own, they are saying 'right this is your problem' like with me because of the behaviour problem with xxxxx [user] there were no suggestions with me telling me whether I'm handling it right whether I'm handling it wrongly, if I should go and get, if there is anywhere I could go to help me in the way I handle the problem'.

(Wife carer of husband with severe depression, Site K)

Moreover, despite the fact that these carers were now clearly 'known' to the system, none had been offered or received an assessment of their needs following the FGC and many felt isolated. The follow-up interviews 6 months later indicated that little had changed. Several carers still valued the honesty and openness that the initial conference had engendered, allowing them to 'clear the air' and understand behaviour due to the provision of diagnosis:

**And did you think the family group conference helped you helped him with that, or helped you in relation to alleviating some of the annoyance if you like?**

Erm yes I think so. I think we can, well we can understand a bit more because he has actually had a diagnosis so that's all come out of the family conference in a roundabout way.

**Okay.**

Because of the diagnosis, you know, we understand some of the things that he does are due to erm... his disorders.

Yeah, I mean I would say yes and no. Yes to some of the things. Yeah, I mean xxxxx [son] and his dad certainly talk more.

(Mother carer of son with autistic spectrum disorder and multiple mental health problems. Site K)

In some instances this enhanced communication was maintained and people appeared to be more reflective about their situation:

'Brought that to light and we can now manage our ways and affairs a lot better by taking the attitude of just stop a minute, take a step back, recharge, rethink and go forward, and that's what it's taught us'.

(Husband carer of wife with severe depression, Site K)

However, none of the carers interviewed had received any further contact with services, and none had a carer's assessment, despite some now describing their situation as 'desperate':

'I mean you keep getting all this at the carers group, that, you know, we consider carers, the carers are important, and carers matter, and all this, but when it comes to a situation where you are **desperate for help** (*original/emphasis*), because you don't know, you're not a professional, you don't know how handle it any more, and you can see it spiralling out of control, there you are, you've got to fight to get help'.

(Mother carer of daughter with obsessive compulsive disorder and multiple disorders, Site K)

In conclusion, although family group conferences may offer a forum for discussing the care and support of the individual, or airing feelings openly with others involved, they are not a substitute for carer assessments. Nor do they claim to be: the focus is explicitly upon the person with mental health problems and needs rather the needs of those providing support. Although it was

apparent that some of the family carers involved clearly needed more help and support, they were not referred on for assessment and some remained marginalised, unacknowledged and battling for the support that they needed.

## Conclusions

These three additional case studies set out to test some of the questions that arose from initial site visits: do carer assessments make a difference? Are they worth the time they take? Can carers be provided with adequate and appropriate support without a formal assessment? By examining services that provided an explicitly family based model of care and support, we sought to gain a greater understanding of the role and value of formal carer assessments.

Overall, it would appear to be difficult to establish a system that effectively identifies and assists all of those who provide support for the individual with mental health problems. In two of these three case studies it proved difficult to recruit participants to the study because the services were not working with many families. This was partly due to family break down and the isolation of service users, partly due to difficulties engaging with families, and possibly also because family members were not identified during assessment of service users.

The flexible, responsive, 'open all hours', social model of care provided by the Assertive Outreach team was valued by all interviewees, but without a thorough, systematic, carer focussed, assessment it was possible to overlook some aspects of carers' needs (for example, none of these carers had been given information about managing behavioural difficulties or symptoms, some would have liked specific additional support but had not been asked about it). Clearly, this approach does not replace assessment: ongoing involvement and support was invaluable but a regular in-depth assessment could bring additional benefits.

Services providing routine psychosocial interventions may have the potential to help families – as evidenced by research, but in practice the complexities of the approach and difficulties engaging families mean that few families benefit – and if they do not receive PSI they receive nothing at all. Once again, a formal assessment of every carer would bring a minimal level of support whilst PSI has clear additional advantages for those who engage with it.

Family Group Conference services are not set up to meet the needs of informal/family carers; it does involve them in meetings to arrange support for service users, and in doing some it may provide an opportunity to discuss their role, relationship with the service user and feelings. In no way does it replace a full assessment of carers and a plan of care and support to meet their needs. Indeed, despite the benefits carers described in terms of better channels of communication, many felt that their needs were still overlooked by the system.

Having in the final section of this chapter briefly explained carers' experiences of services not offering a routine assessment, the next chapter provides a synthesis of the carers experience as captured in the literature, consultation days and case studies.



## CHAPTER 4

### The Experience of Assessment: Hearing the Carer's Voice

#### Key points

- This chapter provides a synthesis of the main themes arising from the literature review, carer consultation days and interviews with carers at the case study sites.
- It represents a co-constructed account between the academic team, carer researchers and carer participants that reflects the context, process and outcomes of assessment as experienced by carers themselves.
- Whilst our aim was to focus primarily on carer assessment the majority of participants in both the consultation days and the case studies stated that if the service users' needs were met then there would often be no need for a carer assessment.
- Despite our focus on assessment carers found it impossible to discuss their experiences without extensive reference to their often lengthy prior contact with mental health services. The importance of this prior contact was reaffirmed by the literature and consultation days.
- Such experiences 'set the scene' for the assessment and carers described the often difficult relationships that they had developed with the service system. This was reflected in the first main theme in the data 'the talk is of partnerships, the experience is more like conflict'.
- Our goal in PICAP was to focus on 'good' practice but this was not as widespread as we had envisaged and, despite individual practitioners being committed to carers' needs, routine support and resources were often not available in the wider 'system'.
- However, it was clear that a well planned and sensitively conducted assessment in which carers felt listened to, were actively involved, and action agreed (and subsequently delivered) had considerable potential to enhance carers' lives and circumstances.
- When attention was turned to the assessment experience itself a number of themes emerged. These were:
  - 'What's in a word?' which captures the difficulties many participants had both with the word 'carer' and 'assessment'. Many saw the former as not applying to themselves, whilst assessment had negative connotations being seen as a 'test' of some sort.

- 'Crisis what crisis' captures the ad hoc way in which many assessments are organised, often being precipitated by a crisis in the user's condition or a complaint by carers. Far less often are they proactive and planned.
- 'No great expectations?' highlights carers' limited understanding of the assessment and their generally low expectations of what it would achieve, with it often being seen as a 'tick box' activity, following which things rarely happened.
- 'It's both what you do and the way that you do it' describes the importance carers attached to a carefully planned assessment, the interpersonal skills and qualities required of the person conducting the assessment itself, and the need to adopt a wide-ranging and holistic model that was sensitive to cultural and other differences.
- A major part of the study was to identify the outcomes of assessment for carers, and this is reflected in the theme 'promises, promises' which captures the sometimes limited action and follow up that carers received. What carers most valued following the assessment was: better support for the service user; information, especially about the illness and the help available, particularly financial support; the chance to have their voice heard, and the opportunity for respite. However, to be beneficial respite needed to be of high quality, provided when required, and with sufficient support available for the service user. This was not always the case. Moreover, it was clear that planned assessment/review was rarely conducted as very few of those involved in the study had any further contact with the assessor following their original assessment.



## Introduction

This chapter captures the context, process and outcomes of assessment as experienced by the carers who participated in the project. In doing so it draws upon multiple sources of evidence constituting the major themes emerging from: the literature synthesis; the carer consultation days; and the in-depth interviews with carers after an assessment and six months later. As described in Chapter 1, PICAP adopted a multi-method, multi-phase approach which explicitly engaged carers in the main empirical elements of the study by applying the principles of constructivist grounded theory (Charmaz 2000, 2006). Consequently the results are best seen as 'co-construction' between the academic team, the carer researchers and the study participants. For example, the results of the carer consultation days were developed in an iterative fashion with the findings from one day informing the content of later days, with the overall conclusions being generated by a process of constant comparison during which the main categories were developed by an iterative process of comparison and synthesis between the data from all eight days. The final synthesis was forwarded to participants in order to agree its content.

Given the difficult circumstances of many of the carers who had received an assessment it was not considered appropriate to engage them in the analysis process, but the carer researchers played an active role in data analysis to varying degrees depending on their confidence, available time, or the number of interviews they had conducted. Some limited this to a distillation of the main themes/issues emerging from each interview which were forwarded to the academic team for comment and discussion. At a more engaged level the carer researchers who played a larger role conducted an initial analysis, identified similarities across interviews, and 'named' the main themes that for them captured the key issues to emerge. The academic team undertook the same exercise simultaneously and separately with a high degree of concurrence.

This chapter provides a synthesis of the themes emerging from the literature, the consultation days and the in-depth interviews. The role of the literature in grounded theory is a contested area, with some arguing that it should not be consulted until after data collection and analysis (Glaser and Strauss 1968), some suggesting that it should be used to identify 'sensitising concepts' or 'foreshadowed questions' (Rodwell 1998) that alert the researchers to key issues, whilst others believe that the literature should be consulted as fully as possible to avoid 'reinventing the wheel' (Morse 1994). Here we take a slightly different approach. In PICAP we used the literature in two primary ways.

A full conceptual synthesis of the literature was undertaken concurrently with the early stage of data collection (see Chapter 2) and was used to identify 'sensitising concepts' to be explored in the later interviews. During the analysis and synthesis we applied the principles of 'emergent fit' (Glaser 1978) with the literature being treated as if it were data. This is the analytic approach we adopted for the literature synthesis where each reference was viewed as an 'interview' with the entire literature being synthesised in a three stage iterative process of analysis and constant comparison. In this chapter the major themes that emerged from the literature are treated as separate but related data sources, as are the results of the consultation days and the in-depth interviews, and these have been synthesised to provide the themes identified below. The detailed results of the consultation days were submitted to SDO as part of the interim report and are included here as Appendices 3.

As a result of the above process carers' experiences of the context, process and outcomes of assessment as described here are truly 'grounded' in three detailed sets of 'evidence' and provide what we believe is a comprehensive and nuanced account. However, in keeping with the principles of co-construction we have, wherever possible, named the themes using carers' own words, or have adopted titles that we feel both capture the essence of the theme and 'speak' to people in a language that is readily understandable and conveys what are essentially complex concepts in a way that is easily accessible (Charmaz 2000).

One of the primary aims of PICAP was to provide a comprehensive and contextualised understanding of carers' experiences of the processes and outcomes of assessment, and the barriers to and facilitators of partnership working. Therefore, during the interviews we actively encouraged carers to focus primarily on their experiences of assessment, and the events preceding it and following it. However, this was usually not possible without a fairly lengthy consideration of their prior experience of contact with mental health services and the support provided to the person they were caring for.

This is consistent with the literature that stressed the influence of carers' experiences of mental health services and the need to interpret on-going relationships in the light of such prior, often lengthy and difficult interactions. In providing an account of carers' views we therefore follow a broadly temporal approach that begins with their prior experiences, before considering the processes and outcomes of assessment as described by the carers themselves.

Considerable attention is given to carers' prior contact with mental health services, and this reflects the emphasis placed on these experiences by carers, not only in the literature, but also in both data sets arising from the PICAP study. This reinforces our belief that a full appreciation of the way that carers experience assessment can only be gained by better understanding the meanings that they bring to their situation. It is these meanings that we highlight here.

### **Setting the scene – the assessment experience in context**

As we have stressed at numerous points in this report, the primary aim of PICAP was to identify examples of 'good' practice in carer assessments and to distil their key characteristics in order that they might be applied elsewhere. However, such practice was not as widespread as we had anticipated and whilst many carers clearly benefited from or enjoyed the **process** of assessment, the events preceding it and the subsequent action (or often non-action) were not always so positive. Nevertheless, we consider it important to stress that a well conducted assessment has the potential to greatly enhance a carer's situation, particularly when the assessor focuses on the carer's individual needs and well being, seeks actively to involve them and recognise their expertise, explains the purpose and goals of the assessment in advance and adopts an open and proactive style. In such circumstances the facilitation of open and honest dialogue allows both carers and assessors to explore issues, even where there might be differences of opinion. In the best circumstances assessment is not a 'one-off' event but rather part of an on-going relationship. This is captured in the case study of Jenny below:

Jenny had been caring for her husband with bi-polar disorder for 20 years and had also started to care for her daughter following a recent breakdown. Her daughter does not live at home and her husband and daughter are being supported by two differing mental health teams in the city who appear to be liaising well. Jenny has had three carer assessments, this being her third. Following her second carer assessment, a year prior to this one, she was identified as being in need of considerable support and was allocated a carer support worker who had provided several counselling sessions in the year between the current assessment and the previous one. Jenny had found this support very helpful, describing her carer support worker as 'excellent'.

The most recent assessment had been initiated by the carer support worker who felt that Jenny's situation was in need of review following a difficult year. Jenny was used to the assessment format and had been sent the form in advance of the agreed visit in order that she could read it and be given time to reflect on any issues. Jenny's assessment 12 months ago had been an affirming experience and, as a result, she had undertaken a course for carers that she felt gave her a far better understanding of her situation and how to cope with it. As a result she approached the current assessment with a positive attitude. Jenny found the assessment a very positive event, with time being taken to explore any concerns that she had, and to clarify understanding and agree a course of action.

At the time of the assessment Jenny was happy with the services both her husband and daughter were receiving, and considered that she had developed a good relationship with both their psychiatrists, whom she felt 'really listened' to what she had to say. She contrasted her recent experiences with her daughter, when she felt that she had been involved from the outset and provided with all the information she needed, with what had happened when her husband was first diagnosed 20 years ago when she was given no information at all and had little understanding of what was happening. Currently, she felt that she was able to work with both psychiatrists and that they respected her views and both worked with her to 'get the right results'.

In contrast she was very disillusioned with her GP who had no idea of the support that she was providing and did not, in her view, seem to care.

Following the assessment several courses of action were agreed:

- Because of the difficult year Jenny had experienced it was agreed that a break would help her. Both her husband and daughter were, as she put it, 'in a good phase', but she was reassured that extra support would be readily available if she needed it. Three hundred and fifty pounds was made available to arrange a break of her choice.
- With her permission it was agreed that the carer support worker would make the GP aware of Jenny's situation.
- Although Jenny was not now receiving counselling, she was given the contact details for her support worker and informed that she was available immediately if any help were needed. This gave Jenny considerable peace of mind.

- It was agreed that Jenny would be sent a copy of her care plan to sign and keep.

At the follow up interview, some 8 months later, Jenny had received a copy of her care plan as promised and had been able to arrange and take a short break with her husband, which she had enjoyed greatly. She had started to attend a carers' support group and she found this very helpful. Although it had taken a little time, Jenny had been to her GP for a carers' health check and had another appointment the following week. With input from the support worker the surgery was now taking more interest in the needs of carers and was adopting a policy of active support.

Unfortunately, Jenny had some recent concerns about the care her daughter was receiving and felt the need to lodge a formal complaint. Having considered the situation her carer support worker agreed that a complaint was warranted and was actively working with Jenny to ensure that she followed the correct procedures and knew how the system worked.

As the above account illustrates, when assessment is followed by concerted action, there is the potential to radically improve carers' circumstances. The importance of this was highlighted at the consultation events:

We need pro-active support, regular phone contact, not just left to us to phone someone in an emergency. I have a support worker who has changed my life, listens, takes the initiative to phone me regularly to ask how I am, and doesn't wait for me to contact her. It has made everything easier. (NW Carer)

As we shall see, the above experiences, whilst not the exception, were certainly not the norm and it is important to try and understand why this was the case.

Before doing this, however, it must be stressed that the primary concern for the majority of the carers who took part in both the consultation exercises and the in-depth interviews was to ensure better services for the person they supported, with their own needs often being a secondary consideration. Indeed many argued that if better support were provided to the service user their own needs would in large part be addressed:

The priority is to relieve the stress on carers by ensuring that their relative is adequately supported; carers need to see their relative having a good quality of life through social activities and employment to relieve boredom and inactivity; then my son needs housing support and financial support to prevent him getting into debt; then we need to plan what will happen when we are not here any more – this needs contingency planning. (WM Carer)

The need to ensure that their relative had the best possible quality of life was reiterated throughout the data:

I would like somebody to come and help me in the day with him, either to take him out to do football or take him out and go to the gym or, you know, or learn him how to read because he is not capable, his IQ is not very high, learn him to read, learn him to do maths.

(Mother of son with schizophrenia, Site D)

However, rather than services providing such support most carers reported having to 'fight' with existing systems in order to ensure a minimum quality of care. Below, a husband and wife who had been caring for their son with schizophrenia for several years describe the difficulties they have recently been experiencing, but also illustrate how things can be transformed when appropriate support is provided:

No, he's been transferred from there [inpatient unit] because we had such a fight last year with them over things that were going on with xxxxx [son] while he was on this section. He even, at one stage, he overdosed with his drugs and he was bouncing off the walls. Another stage they forgot to give his main medication for 3 weeks and he was in a terrible state, and it was one of the nurses that left that let that slip out. So I made a second complaint about that and I had a few meetings with the managers, and so did my husband, and I think to be perfectly honest in the end I think they got a bit sick of us, but he's our son.

However, the situation improved considerably when the user described in the quote above was transferred to a different, seemingly more receptive environment:

And anyway he's in what is a secure unit and everything, you know, we're over the moon now, because we've seen for ourselves in this place, he's only been there about 8 weeks now, and the people there, the staff there are doing what staff should be doing, you know. And very caring as well with it, you know, listening to what we have to say as well.

(Father and mother of son with schizophrenia, Site H)

As noted above, whilst the interviews were intended to focus primarily on the assessment, it was not possible to discuss this with most carers until they had recounted their experiences of the wider service system. This forms the first major theme to be discussed. To reflect the carers' views this is named 'the talk is of partnerships, the experience is more like conflict'.

### ***The talk is of partnerships, the experience is more like conflict***

As we noted in Chapter 2, the current policy rhetoric is overwhelmingly one of 'partnerships' between family carers and formal service systems with the literature on caring in mental health talking of the need to develop 'true' or 'genuine' partnerships that draw on the 'deep knowledge' of carers in order that both carers and service providers can 'learn' from each other. However, it

is also noted that the gap between carers' desire to be involved and their actual participation is significant. Therefore whilst the rhetoric may be of partnerships, the metaphors are of conflict, with carers talking of having to 'battle' with, or 'survive' the formal system and of being marginalised or ignored. The roots of such difficult and often antagonistic relationships provide a context for many of the assessments and can be traced to carers' early experience of, and contact with, the mental health system.

The limited number of temporal models of carers' experiences that have been developed in mental health (see Chapter 2, especially the work of Karp 2001, Rose et al 2002, Pagnini 2005) all highlight the early confusion that carers experience when mental health problems first present themselves, and their feelings of not knowing *'what's it all about'*, of being left to *'sink or swim'* by services, and of being overwhelmed by the different people with whom they come into contact. These feelings were clearly reflected in our own data:

...at first it felt as though I had a 500 piece jigsaw; all the pieces were there, some had straight edges and some had no picture and I had no idea how to put them together. I had no idea who to go to for what. (SE Carer)

Early on one of the problems we have with all the contexts is knowing exactly where everybody fitted in, there were so many different institutions and individuals involved in his care, who would you go to for a particular thing was not transparent, because he is on the cusp of adult care we had, first of all we had the people at the xxxxx [hospital], then we had [his CPA Coordinator], then we had the intervention team people, and then we had people, his psychiatrist and the nurses and it was never quite clear, it still isn't quite clear to me who precisely I could go to in a particular circumstance...

(Mother of son with schizophrenia, Site B)

Sometimes it could take months for carers to learn to navigate their way around the system:

Well as I said earlier, when my wife was first took into hospital it would have been very very helpful to have some card or paper explaining how mental health services work, what sort of things treatment is, because you've got the nurses, and what I call the 'watchers', and probably specialists, doctors and so on wandering around, all in ordinary clothes and you've no idea is that a cleaner, is that a watcher, is that a nurse, or what, you didn't know who was who apart from the board on the wall. You didn't even know if they were patients, so it was all very strange and nothing seemed to happen, you didn't know what sort of treatment was going to happen, it was all just strange. It took me 5 or 6 months to kind of work out how it was operating, you know, something very simple or even a chat with somebody, it wasn't until we saw the specialist after about three months that we got an inkling of what was going on.

(Husband of wife with severe depression, Site E)

As the old adage notes 'first impressions count', and such were impressions often lasting, setting the tone for relationships which, over time, often become increasingly fraught. First impressions were usually forged at a time of acute crisis during which carers had their initial contact with mental health services. Below a mother whose son had a recent schizophrenic episode, and also has a problem with drug abuse, talks of her concern and feelings of helplessness at finding him smoking cannabis and of the 'what can we do about it' attitude of the staff:

Before they didn't have the fence [around the hospital] me and my mother went. They used to put drugs through the window. One day I came to see him and he was smoking weed, cannabis, and I said [to staff] 'look I'm sending my son in here to stop this and look what is going on' 'oh well we can't do anything about it!' You know, it's like where do you go? What do you do?

(Mother of son with schizophrenia, Site D)

Others also talked about believing that their relative was in a place of safety when in an acute environment, only to have such beliefs dispelled. The father and mother below describe how their son was allowed simply to 'wander out' of an acute unit and turn up at home or go missing:

...he was turning up all hours of the night and we've phoned the police, the police were looking for him, we were out in the car in the middle of the night looking for him and then they all of a sudden found him on the ward. Well bearing in mind the doors are supposed to be locked at 9 o'clock at night and we sat one night, we sat there right until half past nine with those still... we were sitting in the car and the staff we could see them in the office laughing and carrying on at the front and we'd seen him go into the door hadn't we? And the next thing he came back to the door thinking we'd gone and he was ready to walk out again, well I jumped out the car and I just went ballistic, and the staff seen me from the window and then decided to come and lock the door, well that shouldn't be happening.

(Father and mother of son with schizophrenia, Site H)

Not surprisingly, in such circumstances, these parents simply could not relax, wondering if their son was safe or not. Early experiences like these often resulted in a lack of trust in the mental health services that, once lost, was very difficult to re-establish.

Such accounts are reinforced in the literature, where the diagnosis of a mental illness is often described as a 'pivotal moment' or an 'epiphany'. The longitudinal models that have been developed note that carers are extremely receptive to help and support at this point, being eager to learn as much as they can about their relative's illness (Karp 2001, Pagnini 2005). Their needs shortly following diagnosis are often very intense but paradoxically are not well addressed

by service systems (see Pagnini 2005). Repeated contact with the 'system', both in the early days and later, often create and cement feelings of mistrust, particularly when carers' views are seemingly ignored:

We need to be taken seriously. Too often you get the person to AGE - often with difficulty - and the psychiatrist says 'we can't do anything at the moment, take them home'. We have to cope and we know that they are going to get worse. The psychiatrist needs to believe us, and take our views and our knowledge of the person seriously. (London Carer)

It is at such early stages that carers most value assessment and support so that they can better understand what they can do:

Assessment needs to take place right at the start. We need to know what is best for me - how to handle my own emotions and needs, and what is best for my relative - so that I can help them to access appropriate support, and to help me to manage them. (WM Carer)

Need to recognise our changing needs over time - recognising the implications of the onset and course of mental illnesses and the implications for how carers acquire knowledge and expertise. I felt there was no-one out there who can cope with him as well as I can - at least initially. I needed some certainty much earlier: a diagnosis, some idea of what might happen next, and when he would get better. (SW Carer)

In theory the Carers' (Recognition and Services) Act 1995 affords carers who 'provide or intend to provide substantial care on a regular basis' the right to an assessment but in no instance did we come across a proactive, early intervention and offer of support. Rather, as noted above, carers' first contact with services during the initial acute crisis usually served to alienate them rather than laying the foundations for a solid partnership. The poor early experiences that carers have with services have been highlighted as a problem by Rethink (2003).

Nor did things seem to improve with time, with carers increasingly feeling that they were viewed as *'part of the problem, rather than as part of the solution'*. Carers who were more proactive and tried to voice their feelings were often seen as 'troublesome' or felt 'ignored' or 'blamed':

They [service providers] need to value my views, and believe my experiences. I am pro-active in calling them, so that they can do their job better, but they see me as troublesome. We have the same goal (they and I want the best for my mother) yet they do not consider my contribution to her well-being. (SE Carer)



It is difficult to represent our own needs at times. Carers are just ignored or blamed (even more so in the past), so it would be useful to have an advocacy service for carers, someone we could go to discuss our rights and who would go to meetings with us and help us to present our view. (East Carer)

The literature graphically describes how carers have in the past been 'blamed' as part of the cause of mental illness or relapse and how, despite efforts to address this belief, the view of the family as dysfunctional remains a 'persistent mythology' (Shooter 2004); indeed they are sometimes characterised as the 'enemy' to be avoided (Johnson 1990).

Carers' wishes to be involved were further thwarted by what they termed a '*confidentiality smokescreen*' by which service providers refused to share information with them in order to preserve the users' confidentiality. As a result carers felt '*outside the loop*':

Carers are not treated with common courtesy and respect. They are kept outside the loop. We are not informed of fundamental changes such as when a psychiatrist has changed, or when our daughter is being moved to a different home. We have to hear through third parties. (SW Carer)

Carers were sensitive and recognised that there might be conflicting interests, particularly when their relative was acutely ill and may not, at that time, feel that they wanted their family to be involved:

Frequently there are conflicting views between service user and carer when they have been admitted, often unpleasant process, paranoia, parents involved in sectioning etc, so (they) may have different views and (the) service user may not want carers present.... but carers still need support. There are still situations when carers need to be present – ie when decisions are made that impact on the carer, particularly pre-discharge CPA meetings, carers' views about future living arrangement is essential. (London Carer)

Over time such experiences could further erode both carers' confidence in the 'system' and their relationships with service providers, sometimes to a worrying extent.

The husband below describes his experiences of caring for his wife with severe depression, whilst also supporting a young daughter following leukaemia. During this period his wife had been repeatedly self-harming, burning and cutting herself before eventually trying to hang herself with wire. The following, appropriately lengthy quote, captures his experiences after he had managed to prevent his wife's suicide:

I mean she's been in and out, in and out, but they took her in, there was supposed to be a big meeting about everybody, I went there thinking that the psychiatrist and everybody would say they had to keep her in for about 2, 3, 4 months, whatever its going to be, and there was this young, this one young lady about 27 or

something. You've never seen anything like it in your life, she says [to my wife] there is nothing wrong with you, there has never been nothing wrong with you, its all the drink, stop the drinking and you'll not self harm, you'll not be depressed, you'll not get panic attacks, I'm discharging you, you shouldn't be here, this hospital is for sick people. This is after nine years of hell, well there was hell in that hospital, there was a manager there within half an hour and I'm suing them because she got thrown out that day, she cut herself worst ever, the next five days she cut herself to bits, they [children] all saw her doing that in the bedroom, covered in blood. The youngest daughter caught her on the kitchen floor with the kettle boiled ready to pour on her face, she screamed and it went down her leg and then I took (it off her). The next day, two days later, I took the girls to school and the little one had a trip to York with school and I had to go and ask to take some boxes, some egg boxes and I thought oh to hell with that I can't be bothered so I came home, and by the grace of god I come home. If I hadn't come home she would have been dead in that garage, she was hanging by a piece of wire. Whipped straight back in, all through her treating her like that.

(Husband of wife with depression, Site H)

Of course most cases were no where near as graphic or disturbing, but the majority of carers interviewed came to their assessment after years of, at best, either patchy and unproductive relationships with services, or minimal contact despite their efforts. This tended to set a particular, and often not very positive, context for the assessment. It is to the assessment experience that we now turn, beginning with the theme 'what's in a word' that captures the carers' uncertainty both about their role as a 'carer' and the meanings attributed to 'assessment' itself.

## **The assessment experience**

### ***'What's in a word?'***

The recent carers' legislation enacted between 1995 to 2004 afforded family members, and others who provide or intend to provide substantial care on a regular basis, certain statutory rights, one of which is the right to an assessment of their needs. However, in order to avail themselves of such rights at least two conditions have to be met. Firstly, the individual concerned has to be recognised as a 'carer', both by themselves and formal services, and be deemed to be providing 'substantial care on a regular basis'. Secondly, carers have to see an assessment of their needs as being both a legitimate and acceptable activity. Much here turns on two words 'carer' and 'assessment', both of which caused difficulties for many of those who participated in the study. Numerous participants did not see themselves as 'carers' and did not feel that the term was appropriate, especially for some who had been 'caring' for many years:

I didn't know I was a carer until I was told. I thought being a carer meant you had to take on extra responsibilities. (SW Carer)

Well first of all they said that because I was his carer, and up until then I'd been his mum. You know, I've been looking after him for nine or ten years and all of a sudden I'd just been his mum and then they said 'no, you are his carer, you are looking after him', you know, 'we are here now to start helping you with everything'.

(Mother of son with schizophrenia, Site D)

I don't think anyone knows fully what a carer is. All I know is a carer is someone that is looking after another person but they don't go on to say that. Some carers, not all of us, but they are entitled to this, this, that and that and we'll see if you are entitled and if you are not entitled to it then we'll let you know. You know, those sort of things they don't tell you because when I left the hospital with him, no one said to me 'you are a carer' I just left the hospital and that was it. He is my son and I have to look after him, do you know what I mean. That is how I looked at it, he is my child, I look after him, I looked after him as a child, and I still look after him now he's an adult with problems.

(Mother of son with schizophrenia, Site D)

It seems that there is considerable work to be done, both to achieve greater clarity as to what a carer is, and when one becomes a 'carer'. Early proactive intervention, when it is clear that someone is likely to provide 'substantial care on a regular basis', would be one obvious approach but, as already noted, we did not come across this in any of the case study sites.

In addition to confusion around the word 'carer' the use of the term assessment was problematic, both with regard to its relationship to on-going support and its overall purpose:

There needs to be clarity of terms - assessment, reassessment, review all mean different things. We may need a formal separate carer assessment once a year, but this does not replace the ongoing flexible assessment of carers' needs as they change day by day in relation to the person they care for. (London Carer)

It must be clear that carer assessments are not about assessing our ability to care. We have been doing it for years regardless! Assessment should focus on our needs. (East Carer)

I refused a carer assessment... I always felt that they were judging **me**. (NE Carer)

The above quotes highlight two important issues. One concerns the extent to which assessment is seen as a separate activity from the sort of on-going support that carers would prefer, the second is the association of the term 'assessment' with some form of 'test' of the carer's ability or competence. As can be seen from the final quote above, this can lead to some carers

refusing an assessment, even if one is offered. Mirroring the point made earlier, many carers did not want or see the need for an assessment of their needs if appropriate services could be provided for their relative:

I don't want an assessment, I want people there to look after my son and for me to call on when I need it. (NW Carer)

The lack of clarity about the term carer, and the ambivalence a number of carers had towards the word assessment and what it is perceived to mean, reinforce the potentially negative context within which the assessment itself is undertaken. This was not helped by the fact that routine assessments of carers' needs rarely seemed to take place, and the events precipitating the assessment process were often either a complaint or request from the carer themselves, or a deterioration in the service user's mental health. This is reflected in the next theme 'crisis, what crisis'.

### ***'Crisis, what crisis?'***

Standard 6 of the NSF suggests that carers of people on CPA have the right to an annual assessment of their need (with regular review). Implicit within this is that assessment should be seen as an integral part of the work of mental health teams and that it takes place during a period of relative calm with assessment occurring on a planned basis, or when there is a significant change in the carer's circumstances. However, the data indicate that assessment most usually occurred when either the carer was proactive, and having heard about the assessment actively sought one out, or when there was a sudden crisis in the service users' situation. In the latter circumstances carers were often not expecting the assessment, and/or found it difficult to focus on the process itself amidst the turmoil they were experiencing.

The first quote below highlights that proactive carers who were more likely to receive an assessment:

I think it was when he actually had a diagnosis that I made contact in a more diligent way, I kind of explored what you are entitled to, and requested an assessment... I was the one that actually phoned [carer assessor] and made contact and proactively did it because someone suggested it.

(Mother of son with schizophrenia, Site B)

In marked contrast the following quotes from different carers illustrate that a 'crisis' was often the key event triggering an assessment. In the first case this was not necessarily deleterious to the assessment itself, as it served to put the carer (by chance) in touch with the appropriate person. Of course this leaves unanswered the reason as to why such contact arose serendipitously rather than by planned means. The second quote demonstrates the confusion carers experience when an assessor arrives unannounced at a difficult time, and what can happen when an assessment is conducted during a crisis, with the result that the carer has no real recollection of what occurred:

No what actually happened, I was having considerable trouble getting him [son] back into hospital and I knew that he needed to be in, it ended up outreach crisis team and then through some quirk or other I phoned outreach and I got [assessor] and I tried explaining things to her and she says 'well I'm on the carer side' I said 'oh its nice to know that there is somebody there'.

(Mother of son with severe depression, Site H)

I didn't understand who was sending the assessor. I was going to get a carer's assessment, I didn't firstly understand what that meant or what it was, the carer's assessment and I didn't understand which body was sending the person, where do they come from? Do they just appear, you know, out of a van or something, where do they live, they are not part as far as I could tell and I've been in and out of hospitals for years, I've been around mental health teams for years. Where all of a sudden does this carer thing, where is their office? Who are they? And then I understood at that that ok they are carer support voluntary agencies so it must be that and she must be from that.

### **Did you know what was going on?**

No not really because at the time, I explained to, [assessor] came and I thought she was part of the crisis team so my son was in actual in crisis at that time and I had loads of people coming back and forward to the house and it was very unclear and it was very stressful and I can't really remember very much about it to tell you the truth.

(Mother of son with schizophrenia, Site H)

The latter instance illustrates that assessment can happen in far from ideal situations. The unexpected nature of the assessment means that the carer did not know what to expect and this reflected the situation for many carers, with the result that several of them had 'no great expectations'.

### ***'No great expectations'***

One of our goals in PICAP was to discuss with carers their initial expectations of the assessment, for example: when should it occur?; what should it involve?; what did they want to get out of it?, and then some 6 months later, to ask them if these initial expectations had been met. This proved difficult, as carers had few or no expectations of the assessment, either because, as highlighted above, it came 'out of the blue' at a time of crisis, or because their prior experiences had led them to be cynical about the process, seeing it as little more than a 'tick box' activity, following which things rarely, if ever, happened. This latter sentiment was fairly pervasive, and was also noted in the assessor interviews (see Chapter 3). The quotes below illustrate that such beliefs usually had their roots in carers' feelings of 'no great expectations' of mental health services in general.

There are negative attitudes towards assessment (among service providers). Key people in my Trust have openly said to me that carers' assessments are a waste of time because we can't do anything about them – there are no resources to provide the services that are needed. (London Carer)

Carer assessments are part of the CHI [Commission for Health Improvement] review and LIT [Local Implementation Team] reviews so there is pressure to say they have been done; in danger of becoming 'tick box' activities, yet they will only make a difference to carers if they are a **'hearts and minds'** thing. (East Carer)

A carer assessment is not a one off thing, it can't only be a piece of paper that you're left with, so people can say we've 'ticked that box'. (NE Carer)

I think the assessment was a basic routine, and if you want my frank opinion.

### **Which we do**

Okay, well it's a CYA

### **I'm not good with abbreviations**

Cover Your Arse

(Man caring for neighbour with paranoid psychosis, Site F)

As seen above, the 'tick box' view was succinctly, if pithily, described by one carer as a CYA (cover your arse) model, which not only tellingly indicates the perceived futility of the assessment, but also the lack of meaningful support that often followed an assessment. This is something we will return to later under the theme 'promises, promises'.

However, as we noted earlier, when assessment was well planned and conducted in a thoughtful and systematic manner that actively engaged carers, it was often a positive experience, with the nature of the process itself being a key factor. This is reflected in the next main theme 'it's both what you do and the way that you do it'.

### ***'It's both what you do and the way that you do it'***

Although only five of the 99 carers that took part in the consultation days had actually had a positive assessment experience, all the participants were quite clear about what they would want from one. The points they raised were reinforced by the carers we

interviewed, who either described the positive characteristics of the assessment they had received, or identified ways in which their own experience could have been improved. Many of their suggestions were fairly simple, such as: some advance notice of the assessment; some information about what to expect and, ideally, a copy of the assessment documentation itself prior to the visit. Depending on the models operating in their area carers had been assessed either by the care co-ordinator or the carer support worker (see Chapter 3). However, what was important to most carers was not so much **who** did the assessment in terms of the person's job, but rather **how** it was undertaken, including its focus and content. This is illustrated in the case study of Frank below:

Frank was an older carer who had been supporting his wife who had had depression for several years. He had managed on his own for most of this time but over the last couple of years had been finding it increasingly difficult to cope. More recently his wife had been seen by a Community Psychiatric Nurse (CPN) who, noting Frank's situation, suggested that he might like an assessment himself. Frank agreed and the CPN contacted the carer support team who arranged for a support worker to visit Frank. This was the first time that Frank had spoken to anyone about his needs.

Prior to the visit he described himself as being both rather anxious and somewhat guilty, feeling that after all these years he was 'going behind his wife's back'. However, he felt that Dave, his carer support worker, had made what could have been a daunting process a pleasant one. Dave organised the assessment over two visits. On the first visit he 'got to know' Frank by asking him about his situation, but also about himself as a person, his likes and dislikes, hobbies and interests. From the outset Frank felt very comfortable as Dave put him at his ease, was a good listener who appeared genuinely interested in him as an individual, and took the time to clarify their understanding of what had been said before proceeding. Following this initial visit Dave arranged a second visit to conduct the 'assessment'. Frank also found this a positive experience, feeling that he had been given as much time as he needed and that the assessment covered all the issues that were important to him. Frank wanted to have the assessment away from his house in order that he could talk more freely without his wife being present. Dave, who had found out during the initial visit that Frank liked to walk, suggested that, if the weather was fine, they could talk during a walk in the local woods. Frank readily agreed. Frank found the opportunity to talk to someone interested in his situation revelatory, as he said:

You feel joined with someone who understands. You have your friends but unless they've experienced it they don't really understand, you need someone who knows the situation you're in. Just to go for a walk in the country for a bit was good!

Following the walk (assessment) Frank felt that he did not want to be 'drowning in support' but that the opportunity to walk with Dave once a month would be helpful. This was organised for a 6 month period. When Frank was interviewed he felt that he had now discovered a life outside of caring, and that the talks with Dave had 'opened his mind to other things'. Although his walks with Dave were due to stop, Dave had given him his telephone number and told Frank to contact him 'if ever you feel the need'.

With the help and support of his wife's CPN, Frank had started to attend a local carers' group and renewed his interest in painting. In his own words Frank had previously thought that 'his life had come to an end' but now he had a renewed sense of optimism.

Clearly Frank's assessment had had very positive outcomes. When asked what was most important Frank said:

'It's all about the attitude, from the start I felt listened to and like a partner. That's still the way I feel'.

It is clear that the skills and personality of the assessor themselves are key attributes, and carers saw it as important that they establish some rapport and understanding with them. The carer below emphasises how she thinks her assessment might have been improved:

Yes I think the emphasis, well yes, because as I say, I didn't completely understand what it was about initially, and if it was me doing it, I would actually explain what the whole thing was about before I even started. Instead of what she did was she came with a form, as an assessment, and I wouldn't have done that, I would have said, right, okay, we'll do the form in a minute and let's break the ice with an informal chat to find out basically how your day is, how you cope, where your needs might be, and then I would have said, right, well okay, now we need to fill in the form because we need to.

(Mother of son with schizophrenia, Site E)

However, whilst the interpersonal skills of the assessor were seen as important, it was also crucial that he or she inspired some confidence and was perceived to have the authority to 'get things done' and 'report' back the carer's true feelings:

The skill of the assessor is very important, more important than whether the assessor has experience of caring themselves. (SE Carer)

The role of the assessor should be accorded value and status, and the person should have some authority to act upon the results of the assessment. (London Carer)

...the whole experience felt very good, she [the assessor] seemed very committed, on the ball, energetic, she seemed like somebody who was able to get things done so she inspired confidence.

(Husband of wife with post-natal depression, Site B)

Not talking down she was talking as if she was one of my friends, you know, you could sort of tell her anything because you knew that when she went back she would only say what you wanted her to say, you know.

(Mother of son with schizophrenia, Site H)



A further indication of the skills that carers saw as important to a good assessment was the ability of the assessor, not only to establish rapport, but to communicate in a way that carers could relate to:

I think there is a problem asking anyone what they need. Carers Assessments are not just about asking this question but about setting up a meaningful dialogue with a person they have built a good relationship with. You need to speak the same language, avoid jargon, explain what is available and what might be helpful to help me to define what will be best for me. (SE Carer)

Another important consideration was that the assessor was experienced and knew their way around the service system, because good interpersonal skills alone were not sufficient. The carer below compared her recent experiences with those of a previous assessor:

Yes in the way of like, the previous mental health social worker, she would get anything that was going, we would get it, everything do you know what I mean, and you see it doesn't sound very nice to xxxxx [new assessor], she is a nice person that is why it's really hard to. xxxxx [previous assessor] was a lot older and she had been doing it for a long long time. xxxxx [new assessor] is quite young and perhaps she just hasn't got the experience, but I still haven't got this money and I should have had it months ago, months ago, now that wouldn't have happened with xxxxx [previous assessor].

(Mother of daughter with severe depression, Site E)

The main thing that carers wanted to highlight was that assessment should be acknowledged as a highly skilled process, that needs not only to be conducted by an individual with the appropriate knowledge and experience, but also someone with the authority to 'make things happen'.

The need for a major part of the assessment to focus on what was right for the carer was reiterated a number of times, as was the importance of extending the focus beyond the instrumental, largely physical aspects of caring. If this did not happen then the relevance of the whole process was questioned:

Most conversations in carer assessments focus on the needs of the service user, to make things worse questions are often about physical care... you have to seriously wonder about their relevance. (NE Carer)

However, consistent with carers' desire for the needs of their relative to be met there was recognition that a focus on the service user was also desirable, although many carers were quite clear that this did not necessarily mean being assessed together:

The needs of the carer and the relative are entangled, inextricable. Much of the relative's assessment will cover issues of importance to the carer, but there is a need for the carer to have their own assessment as an individual, not just in relation to the needs of the person they care for. (East Carer)

I wouldn't have wanted my assessment to have been done with my mother because I couldn't speak openly. On my own I could say what I wanted to say without offending her. (SE Carer)

Carer assessments have been about my needs. I would not want to be assessed with my husband because I wouldn't want to say things in front of him. He already has the guilt of not being able to support me the way that he wants to because of his illness and I wouldn't want to make that worse by talking about my needs in front of him. (SE Carer)

One carer eloquently described how a balance might be achieved:

What I want from carer assessment, I see this as some sort of continuum, a line on which the majority of my own needs and my son's needs overlap - and can be assessed together as part of routine care, but we each have discreet, personal needs that need to be assessed separately (maybe that is where my carer assessment comes in). So, when our CPN visits, she talks to my son, who doesn't often want us to be around, then, she invites our son to join her in a conversation with my husband and I. Often he doesn't want to be there, but he understands that we will have a chat and he is welcome to join in. This way all of our concerns, needs, observations are taken into account and there is openness. (London Carer)

In addition carers wanted an holistic and wide ranging assessment that addressed the host of complex factors that impacted on their lives, including whether they wanted to care and, if they did how they could be enabled to cope more effectively:

Issues that should be covered include basic needs – physical health and well being, emotional health, risks to physical and psychological health, impact of caring for life, impact on others' lives as a result of the carers' caring role....It would be helpful to ask carers how they feel about their role; whether they felt they have choice, control, are being manipulated. (SE Carer)

Crucially carers wanted the assessment to recognise the impact of mental illness on the wider family:

CA must take into account the needs of different members of the family - Mum, Dad, siblings all have different needs. A subset of carers will need a detailed assessment of their own need. They may need physical help to enable them to carry on caring. (NW Carer)

The need for assessment to be sensitive to cultural differences and to be available to all those carers who might need one, were other important attributes of an effective and well integrated system. Recognising different ethnic beliefs and the stigma that mental illness holds should therefore be recognised and addressed during the assessment:

For many Asian families, what needs to be understood is that services will not try to separate the family. I spent 2 hours with the CPN emphasising this on behalf of my parents. Families will not go near services if they fear being separated. (NW Carer)

Carers emphasised the importance of staff receiving training in cultural awareness, to ensure that the needs of people who were English speaking but from another culture were not overlooked:

Cultural differences are overlooked if we speak the same languages, so African-Caribbean's have different beliefs, different food etc, but this is often forgotten because they speak the same language. This is also the case with Irish people, different cultures overlooked because they have the same colour skin. There needs to be sensitivity to words and language. (WM Carer)

Staff are not aware of different cultures, so for example there is more stigma about mental illness in Asian cultures - people still feel we 'look after our own. (NW Carer)

It was considered important that practical arrangements to support the assessment, such as interpreters, be booked in advance. However, even with the help of interpreters, it must also be recognised that people from other cultures may have additional difficulties understanding medical terminology and the UK healthcare system:

When my husband became ill I had no idea how the medical system worked, how it differed from the Japanese system. I had to learn everything – who to tell, how to access services, what services existed. This was hard because my husband initially refused help and I was desperate but had no idea what to do. My husband's family saw supporting my husband as my role so I was very alone. (SE Carer)

Carers had some positive suggestions for ways of ensuring the cultural needs were met:

I think it would be helpful to have someone to go with me to the GP or to be there at a home assessment to help me make myself understood and to help me understand medical terminology. (First language Japanese). I needed information but I didn't know what information, and I couldn't always understand what they were talking about. (SE Carer)

We have a team with members from different ethnic groups with people who speak different languages. We take a member of this team when we assess a person from an ethnic minority, not just as an interpreter, but also because of their cultural awareness. (SE Carer Worker)

Considered together the above issues provide an indication of what carers view as the key attributes of a sensitive and appropriate assessment, with the whole being far more than the sum of its parts.

However, even well conducted assessments count for little if there is no subsequent action. The widely held belief that assessments were in many instances little more than a 'tick box' activity has already been described and, whilst many carers did benefit from the process of the assessment itself, action did not always follow. This is captured in the next major theme 'promises, promises'.

### *'Promises, promises'*

The consultation exercise undertaken prior to the PICAP study clearly illustrated that carers want services that are:

- positive and inclusive
- flexible and individualised
- accessible and responsive
- integrated and coordinated (Newbrunner and Hare 2002)

In many ways such attributes also characterise the best assessments. However, even the best of assessments count for little if nothing subsequently happens. Unfortunately, the literature on carer assessment generally, and that on mental health in particular, suggests that assessments promise much but often fail to deliver (see Chapter 2). Our experience in PICAP would reinforce this. Those that took part in the consultation days were quite clear about what they wanted to result from their assessment, and this included, but was not confined to:

- better support for the person with mental health problems;
- better understanding of carers' situations and expertise, leading to (i) more respect for their contributions and (ii) their fuller inclusion in the team;
- a clear plan to address carers' needs with named responsible people and their contact details;
- a focus on empowerment options, as defined by themselves, as well as support;
- more creative and innovative services, including wider use of direct payments;
- attention to the options available if carers feel unable to continue in their role;
- linkage of identified unmet needs from assessments to future service planning.

The need for something concrete to emerge from the assessment was clearly and quite forcibly expressed, as was the requirement for on-going follow-up and support:

A plan to address the carer's needs should be agreed following the assessment and action should follow. Assessment without subsequent support reinforces the belief that only lip service is paid to a carer's assessment, and that they are carried out largely to meet official 'targets'. (NE Carer)

However, one of the important benefits to flow from an assessment was simply the opportunity it gave carers to talk to someone about their situation. It is an indictment of how little attention is given to carers' needs that, despite their usually extensive contact with the mental health services, the assessment was often the first opportunity that many carers had to simply 'tell their story':

The carer assessment was the first time I could speak emotionally. Previously when speaking to the GP it was about my husband but the carer assessment was about me. I felt safe and there was time for me to be open and to be emotional. (SE Carer)

My CA was really good. It wasn't about going through a form ticking boxes, it was listening and talking. The approach is as important as the content. (NW Carer)

For some the 'process' was more important than the end product as it validated who they were and what they did:

Well that is always more difficult to precisely say because my feeling is that in a sense, it's the process of the assessment rather than the output, you know, the thing that is actually written and sent to me... people. It's good that it's done but the most valuable part for me is the process of talking through my concerns with xxxxx [assessor], and being able to let other people know that I have support as a carer and I'm aware of my carers' rights, things like that, and that I'm not a carer on my own, I've got carer support and I think that is really important so it's the process more than the end product, so I would say that things have changed as a result of the assessment but its more to do with the process really.  
(Mother of daughter with obsessive compulsive disorder and depression, Site D)

For many other carers the provision of clear and readily understandable information was a key outcome of the assessment process. Once again, however, given that many carers had lengthy and repeated contact with services, it is disappointing that they did not already have such information, with the lack of understanding of even basic elements of the system being a matter of concern. An indication of the range and breadth of information that carers would value is provided in the quotes below:

What is important to us is being listened to first, followed by action and support. Being given information about what is available and what should be available as support. Often we don't know what exists. (SE Carer)

We need to know about what might help before we can possibly know what we need. Therefore assessment needs to include a list of all the possible things that might help us (with information about them) and we can say whether we would like that service. This is how carer assessments can become creative and empowering tools. (London Carer)

We don't understand the language, the roles of different staff, shift patterns, who are staff and who are patients (no uniforms). We need an assessment to find out what we don't know and begin to answer our questions. (East Carer)

Information is absolutely essential from the very start - medication, side effects, treatment, symptoms, how to manage behaviour etc; the whole family needs support as different views mean that family conflict arises. (London Carer)

We need to be given information – a package telling us about mental illness, the medication and side-effects and the services and therapies that are available, and then we could do a self assessment on what our needs are rather than have a formal meeting. (East Carer)

The provision of such information allowed carers to feel more empowered and proactive, not just in terms of their understanding of mental illness, but also the benefits that they were entitled to:

Yes, financial, she has been very, very helpful to me personally, financially, which I hadn't told my husband a great deal about but I actually, she asked me if I would like to go privately to xxxxx [local centre], and I saw her privately in one of her little offices and she didn't do things for me but she explained how to go about sorting out a very severe financial problems. She showed me the phone number, she said 'there is the phone, there is the number and she left the room' and I got it all sorted out.

(Mother of son with schizophrenia, Site B)

We were given some advice and a number to ring about filling out some [benefits] forms and that came from [assessor] so that was really helpful, since then that has been really helpful, it has really helped us out.

(Husband of wife with post-natal depression/depression and anxiety, Site B)

Unfortunately, not everyone was so well informed, and consistent with the wider literature, some carers were unaware that they had had an assessment, and remained largely 'in the dark':

We still don't know what it's about. I was under the impression that we're going down there we'll get carers assessment and we'll tell them the problems that we are having, could get some... And that is as far as we really know about it.

(Mother of son with schizophrenia, Site D)

Although valuable, the opportunity to talk and be informed was, of itself, not enough:

It's wonderful to have an hour or so to talk about what you might need but although that is helpful, often nothing else happens. (NE Carer)

The other major benefit that many carers gained following the assessment was the opportunity to get a 'break' or some 'respite' from their caring role. The provision of 'breaks' from caring lies at the centre of the government's strategy in respect of carers. The original Carers National Strategy (DoH 1999) placed considerable emphasis on breaks and created the carers grant largely to facilitate such opportunities. The recently re-launched carers' strategy (DoH 2008) provides a vision of carer support for the next 10 years, and also has the provision of breaks at its heart. However, respite represents a paradoxical situation in that it is the most frequently requested service for carers and yet is the one that is most often refused. The reasons for this are complex but comprise a potent mix of carer guilt and overriding concerns about the respite experience for their relative and the quality of the care they are likely to receive. Carers want respite services to be consistent with their routines and provided in a flexible way. Such canons are frequently not met. Carers' ambivalence towards respite was abundantly clear in our data.

Those carers who were able to accept the break without feeling guilty and were happy with the quality of care/support provided for their relative whilst they were away clearly benefited enormously:

We had a wonderful holiday, with no problems. Oh yes I had a marvellous four days, three days with the Buddhists in the Buddhists centre, that was a revelation to me, it really was, looking back it must have been a very expensive holiday. We all decided amongst ourselves that it must have cost an awful lot of money, I couldn't fault it. It makes me quite tearful.

(Mother of son with schizophrenia, Site B)

Such a break was desperately needed by many of the carers, as the following quote from a carer who was trying to balance her care for one child with support for her other children:

A break definitely a break, a break away from all of the stuff that I do at the minute. I'm tired, yes very tired. All I'm doing recently is just sleeping and to me that is just my body that is tired, so I come home from work, get the kids something and I'm asleep. So it's hard to do the two, the housework, but I know I need to work because I've got a mortgage I'm paying on my own, the kids are not working so I need to work.



(Mother of son with schizophrenia, Site B)

However, despite the very challenging circumstances that most carers found themselves in, for a number it was difficult, or impossible, to take the break offered unless they were confident in the support that the user would receive whilst they were away:

We'd be worried sick, he couldn't care for himself, and you'd be thinking what's going to happen to him, and you come back and you know for a fact you are going to be right back to where we were two years ago, and he'd get sectioned within a week.

(Parents of son with schizophrenia, Site C)

Some carers were only able to go away if other family members took on their caring role. Here a mother explains how their daughter had to take time off work to support her son whilst she and her husband were away. Even then they felt the need to be in constant contact via the mobile phone:

...but she took the time off work so she could just go and sit with him, because without me going to see him sometimes he doesn't say anything much so even though... everything he could possibly need and everything had been sorted for him he still needed somebody to talk to him. We had a four day break, the thing was though, although honestly, we were desperate for it, it cost a fortune on my mobile.

(Mother of son with schizophrenia, Site H)

Many carers clearly relied on their relatives to support the service user or themselves whilst they were away. For example, the carer below is a 75 year old woman caring for her son with schizophrenia and her husband who has had a stroke, but the only way she could realistically organise a break was to take her 72 year old sister with her:

Wait a minute I think our [relative's name], she's [in her 70s], so what she does when we are on holiday is she'll make a cup of tea, make the tea and bring it out to us. Things like that is a good help because I feel as though I am having a rest.

(Elderly mother of son with schizophrenia, Site H)

The husband and wife below could only enjoy the break because they were confident that sufficient support was available for their son whilst they were away:

We were offered, and we've had two short breaks, which were absolutely brilliant and that (a) we couldn't afford and (b) we wouldn't even have considered it, but I've got loads of help for xxxxx [son] while we were away that was capable of organising everything to make sure that everything was alright while I was away.

(Father and mother of son with schizophrenia, Site H)

Carers who could not rely on support from their own family often had to refuse the break offered. In other circumstances carers were given a sum of money (typically £300) to either organise the break for themselves or had 'pamper days' arranged for them. However, in many situations the whole idea of a break (or other 'leisure' activity) seemed unthinkable, if not absurd, in light of the multiple difficulties carers faced. Some, for instance, used the £300 cheque to deal with pressing financial problems, such as rent arrears. Others were quite clear that they wanted more direct practical assistance:

I just think you know like..., they think I can take what's on offer, a trip to a museum, you know, the painting class, I'd love to do them things, you know, but I've got top priority things. Help to walk the dog, do the housework. Move xxxxx [son'] furniture now, move his TV, his music system from where he was, pick up all his stuff. I need some practical help that totally takes priority over me going, you know. My house has been repossessed and all this business, and I'm supposed to go up and sit in the painting class.

(Mother of son with schizophrenia, Site H)

The whole notion of a 'pamper day' or other leisure activity in such circumstances seemed laughable to many of the carers concerned.

This raises important issues as the Carers (Equal Opportunities) Act 2004 mandates that in the future assessments must consider carers' wishes with regard to employment, education and leisure opportunities. However, unless their complex needs are taken into account the risk is, as with the offer of a 'pamper day', efforts to many will appear at best tokenistic, and at worst highly insensitive in the light of their own parlous situations.

Similar considerations apply to the offer to attend a carers' support group. This was a service that carers generally appreciated, and those who were able to attend often benefited. However, arrangements were often made with little thought as to whether the service was available at a time that the carer wanted, or was accessible using public transport. Some carers told of their concerns about travelling at night, especially during the dark winter evenings, whilst others talked of the difficulties of access in rural areas where there might be a limited bus service, involving multiple changes, or where there was a bus to take them to the meeting but none available to bring them back.

Given the emphasis placed on re-assessment, one of the striking things to emerge from the case studies was the fact that very few of the carers, at any of the sites, had received a subsequent assessment, even when their own circumstances had changed for the worse.

The carer below had been repeatedly 'let down' in terms of routine re-assessment over the last two years, and yet since his last assessment, not only had his caring situation deteriorated, but he had had three heart attacks:

No I was given a date and naturally it was 4 or 5 months prior to that that I was given the date. I assumed that somebody would drop me a line to say they are coming on such and such a date but nothing. It happened the year before as well, same thing. Yeah, but I haven't heard from her since [the last assessment] neither. Would you believe in the past 3 months I've had 3 heart attacks.

(Father of son with schizophrenia, Site H)

Some carers had been in contact with formal services but, despite a considerable deterioration in their circumstances, this was more often as a result of a change in the user's situation, rather than a consideration of their own needs. Not surprisingly such individuals tended to take a dim view of their own assessment:

**So actually no-one's made contact with you since the assessment?**

Well I think since my son has been sectioned he has been to two different accommodations, and been turned out of two different accommodations. I've lost my job and my house has been repossessed, and no I haven't seen anybody at all. Well I think the carers assessment, I think the whole thing is a paper exercise, giving gainful employment and information for higher channels which actually means nothing to the person on the street actually doing the job. I think it's a complete waste of time and it's probably very unfair on the carers themselves because they actually get nothing out of it at all. All they are doing is being leached for their information.

(Mother of son with schizophrenia, Site H)

Such occurrences reinforced the perceived 'tick box' view of the assessment as providing largely broken promises.

However, in some locations the assessment had resulted in the carer being allocated a carer support worker, and where this occurred and regular contact was established (or at least the carer could initiate regular contact if they wanted), this was very much appreciated:

Yes, she [carer support worker] does all that. I mean I can just lift the phone up anytime to her and she sees to things for us. She will make a home visit if I can't get down. She'll make a home visit and she does the activities to give me a break, you know, like holidays.

(Mother of son with schizophrenia, Site H)

Overall, therefore, the 'evidence' from the literature, the consultation days and the detailed carer interviews paint a remarkably consistent picture both of carers' general experiences of the wider mental health systems, and their experience of assessment in particular. Whilst there were examples of dedicated practitioners working hard to ensure that carers' needs were addressed, well functioning and fully integrated systems for working proactively with carers as 'true' partners did not feature in the adult

case study sites. This, in many respects, stands in stark contrast to the young carers' project, and it is to this case study that attention is now turned.

## CHAPTER 5

### Supporting Young Carers: Findings from the Action for Young Carers Project

#### Introduction

All but one of the case studies in the PICAP project focused on services supporting adults with mental health problems. However, one was concerned with a project designed for young carers. Because of its relatively unique nature this case study is reported separately, but it does though provide some lessons that might be learned and possibly used to inform other, adult-orientated, services.

Following the key points summary, this chapter begins with a review of literature about young carers. It then provides an account of a young carer's project based in a city in the North of England, detailing its aims, philosophy and operation. Following the methodological approach adopted in this study the account of the young carer's project was co-constructed with project staff and can therefore be regarded as an authentic commentary. The core of the chapter considers what the young carers had to say about assessment and support they received, followed by a concluding discussion. Guidelines for assessment practice with young carers were generated based on the consultations and a workshop with the project workers, and these are provided separately, along with those resulting from the work with adult carers.

#### Summary of key points

This chapter introduces the Action With Young Carers (AWYC) project as an example of an innovative way of engaging with young carers in assessment and support. Findings from the experiences of young carers and project workers add to the recent but steadily growing literature about young people caring for parents and relatives with mental health problems. The following points can be emphasised:

Assessment of young carers works best when:

- shaped and guided by protocols agreed between local health, education and social care agencies that are crucial to early intervention work, outreach, staff development and the determination of assessment parameters, supporting imperatives set out in the Cabinet Office (2008) *Think Family* report;
- built upon checklists that are themselves the product of accumulated expertise and evidence (CAF for example);

- the agency and resilience of young people is respected (and reinforced as appropriate) as well as their possible vulnerability, reconfirming recent literature about young carers that recognises the limitations of frameworks that too easily pathologise children and young people;
- personal, familial and environmental factors are explored sensitively, especially in the early stages, as these can be linked to fears about disclosure of matters that might be regarded by young carers as personal or family secrets;
- understandings are reached with young people about conditions under which privacy rules are breached in order to safeguard them;
- linked to 1-1 and group activities that are engaging and fun; and to forms of respite, education and support for young people that are perceived to be externally validated;
- carried out by workers who are easy to contact, dependable and empathic (for young people portable technologies like mobile phones or notebook computers seem to be useful devices for staying in touch and bringing some personal security into their lives);
- ways can be found to enable young carers to demonstrate their continued attachment to the extended family, not just parents or other family members with mental health problems.

Based on the findings from this part of the study and the associated literature, guidelines have been developed that are designed to assist the further development of assessment work with young carers. These consider the following dimensions: prior to assessment, the process, content and outcomes of assessment, and finally the attributes children and young people like to see in assessors.

### **Literature about young carers**

Compared with the long history of research literature on adult carers, that on young carers is more recent and less well developed. What follows draws on the literature on young carers in general, and is not confined to those supporting people with mental health problems (SCIE 2005). Despite the relatively scant literature, Becker et al (2000) note that there has been growing awareness of the existence of young carers since the late 1980s. Indeed, some argue that the insights gained have brought about a '*sea change*' in the policy and practice in the UK with far greater attention now being paid to the experiences and circumstances of young carers (Becker 2005). The result has been growing recognition of such individuals and a rapid increase in the number

of special projects designed to support them (Becker 2005). However, the whole issue of support for 'young carers' is still seen as contentious by some.

For example, Olsen and Clarke (2003) question the appropriateness of construing children as 'carers' and note that they have only emerged as a 'welfare category' in the late 1980's to early 1990's. Despite this the term 'young carers' has entered the public and policy lexicon to the extent that no-one questions the celebration of 'Young Carer of the Year Awards'. Olsen and Clarke (2003) challenge the legitimacy of supporting young carers in their role and contend that uncritical acceptance of the term is inappropriate. They state the question should not be 'how can children labelled young carers best be supported in their caring role?' but rather 'what kind of support do disabled parents need that will enable them most to rely on their children for support?'. They argue that the way that illness (including mental illness) and disability are construed is still largely dominated by a medical, pathology based model rather than a more holistic, social and family orientated approach. There are merits to such arguments that are beyond the scope of our discussion here but we will return briefly to some of these debates in the concluding chapter.

### ***Definitions and estimates***

Possibly the most widely accepted definition of young carers is that offered by Becker (2000) as follows:

'Young carers can be defined as children and young persons under 18 who provide or intend to provide, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility that would usually be associated with an adult. The person receiving care is often a parent, but can be a sibling, grandparent or other relative who is disabled, has chronic illness, mental health condition, or other condition connected with a need for care, support or supervision.'

(Becker 2000, p378)

Although this definition is not limited solely to the type or intensity of care, it is nevertheless intended to differentiate children who are involved in '*significant, substantial or regular care*' (ie young carers) from those who may be involved in providing care that is neither substantial nor regular (Becker 2005).

Whilst such a definition is useful, not all 'young carers' identify themselves as a carer (Jones et al 2002), and the circumstances of young carers varies substantially (SCIE 2005). So, for example, those supporting relatives (usually parents) with severe mental illness are more likely to provide emotional care and support than physical or instrumental assistance and, for reasons that will be expanded upon shortly, are more likely to be invisible to formal services (Becker 2005). Despite what Becker (2005) calls a '*small but relatively trustworthy body of evidence*' on young carers, significant gaps remain. So, for example, most of the research has been conducted on young carers who are in some way associated with a specific young carers programme (Banks

et al 2002), and there are far fewer studies on *'hard to reach'* or *'seldom heard'* carers (SCIE 2005). Furthermore, most studies concentrate on children supporting their parents (SCIE 2005), and there have been very few longitudinal studies (Becker 2005).

There have been three national surveys of young carers, based on their membership of young carer programmes, the latest being the most extensive (Dearden and Becker 2004). This polled the views of 6178 young carers, 30% of whom cared for a relative with mental health problems. Estimates of the total number of young carers have traditionally varied from 19,000 – 51,000, but the 2001 census figures suggested that this number might be as high as 150,000 (Becker 2005). However, this estimate was based on young carers providing any form of support, who would have been unlikely to have met Becker's (2005) criteria for inclusion.

### ***Charting the circumstances of young carers***

What can the above growing but still limited evidence tell us that is of relevance to the present project? Many of the issues relating to adult carers also apply to young carers, but are exacerbated, especially for young carers of adults with mental health problems. Such individuals are often *'hidden'* from formal services (Armstrong 2002, Becker 2005), both because they fear the potential consequences if their caring circumstances are known, for example, their parents being *'taken away'*, and because of the stigma associated with being the carer of a parent who is mentally ill (Dearden et al 1994, Armstrong 2002, Becker 2005, SCIE 2005). Consistent with the literature on adult carers, much of the research on young carers focuses on the range of negative experiences and outcomes. These are extensive and can include: poor emotional and physical well-being; limited psychosocial development; poor educational performance; problems with peer relationships; limited time for recreation and leisure; feelings of having no-one to talk to about their situation; lack of recognition and praise, and difficulties in adjusting to the transition to adulthood (Becker et al 2000, Banks et al 2002, Becker 2005, SCIE 2005).

Some studies do suggest that caring can have positive consequences such as enhanced child parent relationships (Aldridge 2002, Aldridge and Becker 2003), greater maturity, better practical life skills (Dearden and Becker 2005, SCIE 2005) and greater knowledge, understanding and a sense of responsibility (Dearden and Becker 2005).

However, the empirical evidence available is not yet sophisticated enough to identify those factors that predict which young carers are most likely to experience adverse or positive consequences of caring.

### ***Contacts with services***

Aldridge and Becker's (2003) study showed that young carers play a vital role in supporting families where mental illness is a problem. Despite all the parents in their sample receiving services, gaps in these services reinforced a reliance on their children as carers. Children were not unwilling partners in providing this support to their parents, and in this they demonstrated considerable commitment, resilience and skill. However, there were difficulties in providing effective assessment and



intervention procedures for young carers. As a result the developmental, emotional and social needs of the young people involved were far from being addressed.

It has long been suggested that young carers should be viewed as 'partners' in their relationships with formal services (Dearden et al 1994) but, consistent with the literature on adult carers, the reality still fails to match the rhetoric. Despite the suggested '*sea change*' in approaches to working with young carers (Becker 2005), this has not necessarily translated into widespread professional awareness of their needs and circumstances. Although awareness has generally improved (Banks et al 2002), this is still generally low (Jones et al 2002, SCIE 2005, Warren 2006). To compound difficulties there is relatively little cohesion and co-ordination between adult and child services (Jones et al 2002, SCIE 2005). Young carers often miss out as a consequence (Aldridge 2002), and there is appreciation of their needs from many statutory agencies, including education, and health and social care services (Jones et al 2002, SCIE 2005). There is a need for a more proactive approach from statutory agencies if this situation is to improve (Warren 2006).

The limited awareness of the needs of young carers impinges on the assessment process. It is widely recognised that the number and proportion of young carers receiving an assessment is low (Aldridge 2002, Becker 2005, SCIE 2005). A survey reported in 2004 indicated that approximately 18% of young carers receive an assessment, this figure being far higher amongst those from BME groups (Dearden and Becker 2004). These assessments are more likely to be triggered under the Children's Act than any legislation relating to carers. Whilst the figure of 18% is an improvement from earlier surveys (Becker 2005), the numbers of young carers receiving assessments remains low, especially when it is remembered that all those involved in the survey were members of special young carers' projects.

### ***Assessment***

It is recognised that assessments should ideally occur as soon as possible (Becker 2005), and therefore it is important to be able to identify the triggers that indicate the need for assessment (Aldridge 2002, Warren 2006). Eligibility should not be confined to those young carers providing 'regular and substantial care', as is the case with adult carers (Armstrong 2002). The practice guide that accompanied the Carers (Recognition and Services) Act 1995 provided a checklist for the assessment of young carers that seeks to combine individual attention to the child with a 'whole family approach' (Banks et al 2002). This is reproduced below.

SSI checklist:

- Listen to the child or young person and respect their views
- Give time and privacy to children who may need this in order to talk about their situation
- Acknowledge that this is the way the family copes with disability or illness

- Acknowledge the parents' strengths
- Beware of undermining parenting capacity
- Consider what is needed to assist the parent in her/his parenting role
- Consider the needs of the child(ren) arising from caring responsibilities
- Consider whether the caring responsibilities are restricting the child's ability to benefit from his/her education
- Consider possible impairment of the child's emotional and social development
- Remember children must be allowed to be children
- Provide information on the full range of relevant support services, young carers' groups and contact points for further advice or information on specific issues

Building on the results of one of their earlier surveys into the circumstances of young carers, Dearden and Becker generated a similar set of guidelines, identifying the principles of a good assessment with young carers (Dearden and Becker 1998):

- Give advance warning
- See the young person separately for at least part of the assessment
- Give the young person choice about the location of the assessment
- Explain the purpose and nature of the assessment
- Listen carefully to carers
- Allow for more than one visit
- Encourage the young carer to have an advocate present if desired
- Give written feedback
- Avoid jargon
- Avoid assumptions about gender, age, ethnicity etc
- Explain any time-limits if these apply to service provision

More recently it has been suggested that those undertaking an assessment should 'respect' both the disabled person/parent and the young carer (Becker 2005). However, achieving the necessary balance between not patronising the young carer, whilst also focusing on the parent, rather than simply making judgements about their 'parenting capacity', is difficult (Aldridge 2002, Banks et al 2002).

Often young carers see themselves as being '*actively excluded*' from the assessment process, rather than having their contribution recognised (Aldridge 2002). Moreover, as with assessment of adult carers, young carers are often not aware of their rights to an assessment, generally do not know what support is available, and may not even know that they have had an assessment (Armstrong 2002, Becker 2005, SCIE 2005).

Holistic models of assessment are available, for example, that based on the 'Framework for the assessment of children in need and their families' (Department of Health 2000), which address the child's developmental needs, the parental capacity/needs of the parent and the wider family, and environmental factors that could be applied to young carers (Banks et al 2002). However, these are rarely applied and most assessments are reported to be superficial, narrow and needs-led, often focussing on the carers' eligibility for entry to young carers' projects (Banks et al 2002), the quality of the assessment is therefore highly variable, and rarely as good as it might be in the view of some commentators (Dearden and Becker 2004).

Overall there is a limited literature on the assessment of young carers, with that available suggesting that these are often:

- Limited in number
- Needs led
- Conducted in a way that does not fully engage with young carers, who may not be involved or aware of why they are having an assessment

(Banks et al 2002)

While 'burden and blame' do figure prominently in the limited literature on young carers, professionals often see the caring experience as '*wholly negative*' (Aldridge 2002), and this inevitably colours the context for assessments. As with the adult caring literature, there have recently been calls to adopt a more balanced view of the experience of young carers with a greater focus on 'resilience'. This has been captured as follows:

'If the focus of research turns away from the 'vulnerability' of young carers to one concerned with resilience, then our ability to explain **differences** in experience and outcomes **between** young carers, based on research evidence, becomes more likely'.

(Becker 2005, p17, original emphasis)

According to Becker (2005) resilience should be at the heart of future research into the needs, circumstances and experience of young carers if our understanding is to improve. Such enhanced understanding seems essential to better assessment practice. Research in Australia by Pakenham et al (2006, 2007) has reaffirmed the need to resist frameworks that too easily pathologise children with caregiving responsibilities, and to focus instead on interventions for these young people that emphasise social support building, cognitive appraisals (how to assess stressors) and coping skills such as problem solving, support seeking and acceptance.

It has been argued that 'the assumed normative roles of dependent child and protective parent may have masked the contribution children and young people make to the family and the full range of effects that parental mental illness has on them' (Gladstone et al 2006, p2546). These authors argue that frameworks are required that recognise children's personhood, agency and

intergenerational relationships in order to provide a deeper understanding of parental mental illness and its effects. One way to achieve this is to provide children and young people with opportunities to narrate their own stories of caring.

From a professional perspective, achieving this more balanced outlook can be too easily compromised, according to Gopfert (2004), by implementing child protection procedures that may be a way of addressing professional anxieties rather than meeting the needs of children and parents. Further support for this view comes from some research in the US indicating that beginning caregiving at an early stage does not have long-term negative consequences for everyone providing such care, though the proportion of individuals who appeared subsequently to be at risk of depression in adulthood was considered to warrant effective support programmes that focus on young carers (Shifren and Kachorek 2003). Interestingly these authors comment that there were few places (in the US) where such support was available.

### **The young carers' case study**

The project in question is located in a large city in the North of England, census data suggesting that about 11% of the population provide unpaid care to relatives, friends or neighbours. The City Council works in partnership with local agencies to ensure that a database of carers is maintained.

Support for young carers in the city is provided through the Action With Young Carers Project (AWYC), led and hosted by a large national children's charity. The project is a demonstration of strong partnership working with the City Council, the NHS Trust and other organisations. There has been a keen sensitivity to mental health issues faced by young carers. These emerged with force from some local research that gave rise to the Keeping the Family in Mind (KFIM) project, now an integral part of the Action With Young Carers Project. KFIM seeks to *'improve and enhance the range of appropriate, accessible, non-stigmatising and timely services to families with children who are impacted by adult mental health in [the city]'*. KFIM works across children's and adult services in order to ensure that they have a strategic voice, and that their experiences influence how services are shaped and delivered.

KFIM is heavily involved in outreach activity and seeks to influence the strategies of local health, social care and other organisations to meet the needs and aspirations of young carers with mental health problems or whose lives are impacted by mental health issues in the family.

### ***Philosophy and values***

The philosophy and values of the AWYC project were critical to an understanding of how the project operated, and can be summarised as follows:

- All young carers identified under the agreed criteria should be recognised as potential children in need in order that they can access services in their own right
- Assessments should be child- and family-centred; inclusive; involve listening to, consulting with and valuing young people; they should be appropriately paced and spaced; and take forms suited to the needs of each child
- Children with caregiving responsibilities have skills, strengths and capacities as well as needs and aspirations
- Structural and environmental factors can play a significant part in the diminished opportunities children have in living satisfying lives with hopes and dreams comparable to their peers

### ***Referrals and outreach work***

Since young carers find it difficult to present themselves, and rarely if ever do so, referrals to the project are largely the result of the Action With Young Carers and KFIM projects' awareness raising work with local organisations and communities. The projects have done a lot of training with mental health professionals, particularly around young carers' issues. There is therefore a focus on professionals meeting up with families, with an acuity for those young people who appear to have responsibilities in the family that are over and above what would normally be expected of another young person of their age or are impacting on their everyday life. Caring might be impacting on their education, their social inclusion, their self esteem and confidence, and there may be indications of bullying, withdrawal or isolation that may be indicative of mental health issues.

These were typical of the issues triggering a dialogue between child or mental health professionals and the project. Accordingly children were often referred from child and adolescent mental health services, children's services or adult mental health services.

Between them the AWYC and KFIM projects provide assessment, specialist one-to-one support for each child, out of school and out of home activities, advice giving, counselling and group work. There was a pragmatic orientation to problem-solving. This came from being sensitive to the rules and norms shaping family interdependencies. For example, the best way to alleviate the stress and burden faced by young carers was often by more direct action to support their parents. AWYC and KFIM sought to achieve this through partnership work with health and social care agencies responsible for adult mental health support. In addition to individual case work, the two projects also placed an emphasis on indirect work with local agencies that included strategy planning, development, training and promotional work to ensure that local services were joined up.

### **Assessment and support**

### ***Initial work***

Upon presentation, children and young people usually have a low opinion of themselves. Sometimes it can be because they have blamed themselves for their parent's mental health difficulties, sometimes it is because adult mental health services have unwittingly reinforced a sense of negativity around them, and sometimes it is because they feel they are underperforming in other areas of their lives compared to their peers. Helping young people like these to re-establish positive self identities is not easy and cannot be put right by quick fixes – hence the emphasis placed by project workers on the building of trusting relationships with the youngsters concerned, a process that can take a long time.

Children are assessed every six months, with re-assessments designed to fit the Every Child Matters outcomes.

Emphasis is placed on sharing accurate information with children about the mental health problems faced by their parents/relatives. Accordingly a high premium is placed upon letting the children know that project workers can be contacted at almost any time if the going gets rough – this safety blanket feature is one that seems to be greatly appreciated.

Creative approaches are used to engage children and young people in the assessment process. Self assessment may sometimes be appropriate, but for young children especially this is unlikely to work so alternative methods are sought or adopted. These have included role playing and drama, videos, poetry workshops, storyboards, narrative work, group work and person-to-person interviews. At the project work base there is a strong emphasis on providing a relaxed but stimulating environment where the child can participate in activities. Rooms provide pictorial and written evidences of other children's lives and interests, designed to make it conducive for children who attend to feel encouraged to tell their own stories. Assessment is therefore incorporated into activities as a continuous process rather than a one-off event.

### ***The compass of assessment and support***

Interdependencies between the children and young people concerned and other family members are central foci in the work of the projects and their partners. Accordingly, an emphasis is placed on both parental/family relative and the child's perspectives in the assessment process. This is especially important at the beginning of the process when it is necessary to be clear about whether the situation is about young people caring for a parent or the parent needing some support and guidance to parent the children – project staff recognise that this can still be an extremely difficult issue to determine.

Priority is given to devising activities that are fun. Experience has shown that activities, such as ten-pin bowling for example, can provide a context where young people feel relaxed about talking in a more personal way, especially when they see others doing the same. It therefore becomes a meaningful way of garnering information relevant to assessment.

Importance is attached to building trusting relationships between the project workers and the young people. Should they not turn up to planned activities, which are in any case voluntary, efforts are made to establish why. Reasons for non-attendance can be usefully diagnostic – children may be unable to leave their parent, they may be frightened to leave in case they get into trouble, or it may be a particularly difficult period for them for some other reason. It is recognised that young people may be taking a big risk in saying things that are bad at the minute because they feel they have little control over what might happen next; or they may feel, especially if they are new to the project, that adults are unlikely to listen to them. Accordingly, the project seeks to pre-empt this by encouraging the young people and their families to recognise such fears as a natural response to what they have been going through. Receiving assurances that the child can feel safe disclosing information without fear of the child protection system being contacted, unless of course there are safeguarding concerns, appears to make a big difference.

## **The interviews**

In order to discover how the project was perceived from the young carers' perspective we interviewed 10 young carers at the initial phase of data collection and 7 were re-interviewed approximately nine months later. The young people interviewed were aged between 11 and 16 years, some having recollections of caring for their parents since they were four years of age. There were 7 girls and 3 boys. In all 10 cases the parent with the mental illness was the mother. However, as will be seen, many of these young people shouldered caregiving responsibilities for other family members. They were all co-resident with their mothers.

## **The young carers' views**

The findings are presented with regard to themes that arose from the interviews. The themes are summarised in Table 5.1 below:

**Table 5.1: Main themes arising from interviews with young carers about assessment and support**

- Family-centred work: recognising interdependencies
  - multiple caregiving demands
  - mediating family conflicts
  - help for the 'looked after' person
- Building and valuing relations of trust
  - attention to pacing
  - absolute trust in project workers
- One-to-one work
  - dependability and consistency

- continuity of relationships
- problem-solving
- like surrogate parents
- laid back and fun
- feeling in control
- group work
- forming friendships
- 'we're in this together'
- respite
- outside recognition

### ***Family-centred work: recognising interdependencies***

It quickly became apparent that whilst the young people interviewed were talking to us primarily about what had brought them to the Action With Young Carers project, and therefore, as it turned out, about their mothers who had mental health problems, some were also supporting other relatives. These additional responsibilities were unavoidable, and were themselves an evidence of the attachment and commitment that these young people felt to their own kin. Two examples:

#### **(i) Multiple caregiving demands**

In this first example Amy talks about her experience in a very matter-of fact way. Engaging these responsibilities required her to visit and support family and relatives living in different households on a regular basis, something she appeared to take in her stride.

Like with my mum, I have to help her get a shower. I have to help her around the house. I have to help her out of bed in a morning and that. With my granddad, he's got arthritis and he finds it quite hard dealing with my nan, because my nan had a stroke five years ago and she can't speak and she's paralysed, and so I just go round there and he has a lie down and I cook him his tea and that, and I look after my nan for the day to take it off his hands. With my nan I just get her stuff, try and understand what she's saying as well, and make her tea. With my cousin, she's autistic, so if she goes on a big xxxxx she's really heavy-handed and she just bites and kicks you, so I have to calm her down by taking her into a room and sorting her out, so we do role plays....  
(Amy)

Subsequently Amy went on to describe how she also helped her aunt to teach her children how to walk and talk, and how she became involved in helping her aunt's family to move house. Mental health issues in the family were the trigger for Amy's



involvement in the AWYC project, but the project has acknowledged and is working around the multiple demands on Amy's time and personal resources.

## **(ii) Mediating family conflicts**

In another case Peter's father had had a stroke but he also had additional problems with becoming overweight. With his father's increased incapacity, loss of confidence and dependency on support at home, Peter had found himself caught up in arguments between his parents that were difficult to resolve. Neither parent was well enough to support the other so Peter became their primary source of support, something for which in the early stages he felt ill-equipped.

Both Amy and Peter had been given plenty time and encouragement to talk about family structures and dynamics so as to allow familial and environmental factors that shaped their caregiving experiences to come to light. This was typical of the way the AWYC and KFIM projects placed an emphasis on working with families from the start, supporting as they did the promotion and maintenance of positive attachments in family relationships.

## **(iii) Help for the 'looked after' person**

Without exception, all the young people we interviewed expressed the hope that their mothers would eventually either recover from their mental illnesses, make health gains, or learn how better to adapt to the consequences of their mental illnesses. This was not just wishful thinking, several of the young carers pointing either to stabilising factors in their mother's illnesses or else to definite improvements, but this was not the case for everyone. The undercurrent in this was a view that if their parent could be more directly helped then this would be one of the best ways to address or alleviate the difficulties they faced as young carers. The Action With Young Carers project helped in this where it could, principally by offering to act as a signpost to other services when parental needs came to light, and sometimes by engaging in direct work with families where the work involved did not compromise the responsibilities of other agencies. Common examples would be to do with the completion and return of forms sent to families by schools, the Benefits agency and so on.

However young carers were at times acutely aware of the failings of health and social care services that were supposed to be helping their parents. Abbie speaks here of her mother's battle with depression:

I go to the doctor's with my mum. She was supposed to go today but she didn't get up. But then I hope like when we go there they don't just give her anti-depressants and tell her to go home, you know what I mean, because it's not the answer and most doctors now just give you anti-depressants just so you'll get out of their face, to give them a decent life. But it's not on really. What they should do is just help her a bit more and speak to her. She's not well, but she's not an invalid. (Abbie)

Some of the young carers were less sure of how support to their mothers was being organised, suggesting that they were 'out of the loop'. On a day-to-day basis this could leave individuals in positions where they were unable to query reasons for interruptions to that support:

She used to have a carer that came out at least once a week, twice a day and once every two weeks, or something like that, but I don't know whether they seem to be coming out any more.... I think she went on vacation or something like that. (Stephanie)

### ***Building and valuing relations of trust***

Not uncommon in the lives of these young people were experiences that had led them to be mistrustful of others. Bullying at school, rejection by their peer group and lack of understanding or validation of their caring roles by teaching staff were fairly typical:

Well, no, at school I got bullied so school is like, stay away, I don't go. Walking down to come to the bus to come here I got happy slapped with a glove, which is like being hit over the head with a glove and someone records that on their phone. So school is a bit of a not nice place. (Sophie)

Experiences like this, all too commonly, led to truanting and withdrawal from peer networks. Negative encounters with others predisposed individuals to keep things bottled up. Missing therefore in the social networks of these young people were close and confiding relationships. Conscious of this, the Action With Young Carers project placed a high value on building close and trusting relationships with each young person to help them feel relaxed, valued and free to talk about their needs, hopes and anxieties.

### ***(i) Attention to pacing***

In the early stages when AWYC project workers were still building up a picture of the young people and using different ways of assessing their needs and aspirations, it was important for the young people not to feel that they were being pressured, or to divulge things before they were ready to do so. Experience had also shown that it was necessary to avoid labelling as depression those signs and symptoms, like being taciturn for example, that spring from a desire to keep things private. Time and patience were required to allow individuals to feel comfortable about talking about their experiences. Peter exemplified this well:

I didn't tell him (project worker) a lot about it because I don't tell people things straight away. It takes a while to get to know people well enough to tell them things about home, and after being bullied at school about my family I don't trust people easily... Yes he (project worker) seemed to pick up some things, and when we went through some questions together. And then I started to see him about, well about 30 times in a year, and I think he knows me well now. (Peter)

### ***(ii) Absolute trust in project workers***

Being able to trust project workers was fundamental to continuing relationships with them as far as young carers were concerned:

She's (project worker) like a teacher and if I tell her me problems she doesn't tell no-one apart from (team leader) because she's like the boss and she is like dead close to me. (Maria)

There were times when maintaining privacy about involvement in the Action With Young Carers project itself was essential:

Like I wouldn't tell my college mates that I come here though it's only up the road, but if I ever see (project worker) in town with my mates she wouldn't come over to me and say 'hello Abbie', and they wouldn't turn round and say 'well who was that?' because coming here is no-one else's business. I come here like on my own. (Abbie)

Later on in the interview Abbie provided a hint about when it would be acceptable to breach this privacy rule, whilst still maintaining trust in her project worker:

Unless I turn round to (project worker) and say I'm going home and I'm going to slice my throat, you know what I mean, unless I say something like that I know that it's not going any further than these walls. (Abbie)

Other ingredients in building trusting relationships were identified by the young people we interviewed. Amy indicated being conscious of body language, active listening and empathy in this connection:

Do you feel that they really listen to you?

Yes, you can tell they are being attentive when they listen to you because they lean in and that; and they actually note what you said afterwards. With some people they just sit there daft and say 'What did you say again?' They're not really listening to you.

And how do they show they are listening to you?

They lean in and it's like empathy. And they give you really good advice on what to do. Because they've listened to you they can imagine what was it like and they can end up helping you with advice and stuff like that.

Harvey was less sure about how he knew when his project worker understood his situation, but he trusted his own judgement nevertheless:

How do you know she understands?

I can just sense what people know and stuff like that.

### ***One-to-one work***

Once having worked on building relations of trust, it was then easier to maintain an honest interpersonal dialogue. Without exception all the young people we interviewed emphasised the value to them of *just talking*. This is unremarkable but also vitally important. However, from the way that these young people 'talked about talking' some key requirements emerged.

Bearing in mind that these young people had typically been let down by the education system and also by their own peers, they had come to view inconsistency and disappointment as typical experiences in their lives. One of the first themes that arose from talking to the young people about their interpersonal relationships with project workers was the way they were characterised in terms of dependability and consistency:

#### ***(i) Dependability and consistency***

Can you tell me about the sort of things that you do when you are engaged with the project?

Just really basically talks. Any concerns, she'll deal with. That's it really. She's there if a need her.

Can you explain to me why it's important to you?

It's like consistency within your life, cos she's always been there.

#### ***(ii) Continuity of relationships***

Individuals typically had one project worker assigned to them. Gender issues were important in deciding who to pair with whom. Young people's views about this were respected. This also meant that there was a close familiarity with and understanding of each person's needs, preferences and home circumstances, the youngsters concerned readily acknowledging this as something they prized. Consequently, relationships were typically long-term, stable and highly valued for that.

#### ***(iii) Problem-solving***

By maintaining an ongoing dialogue and getting to know each young person really well, project workers were able to address practical problems that were important:

The thing that's helped the most is like (project worker) just being there to talk to when you are stressed out or I've got a big problem at home and I don't know what to do about it and my mum is not much help because she is not well. I just ring up and get information and then they'll help you. Like if I'm getting chucked out of college or there's something happened at college and I don't know how to work something out... (project worker) will get on to the college straight away. (Abbie)

#### ***(iv) Like surrogate parents***

Another perspective on advice and problem-solving came in the link made to project workers as *parent figures*. Faced with the vagaries of maternal ill health and, implicitly at least in the case of mental health conditions like agoraphobia, depression and anxiety disorders, these young carers at times needed access to adult role models and the wise counsel they can provide to help them solve problems and make decisions. Abbie expressed this succinctly:

Come to think of it now, I suppose they (project workers) are like parents, like parent figures that you can depend on when your mum can't do it for you. The sort of stuff your mum can't do for you they do for you. (Abbie)

#### ***(v) Laid back and fun***

Participating in the Action With Young Carers project was not serious all the time and neither was it intended to be. The project realised that it was important to allow young people to 'let their hair down', to vent their frustrations and to 'have a good time'. They were encouraged to 'talk out' their difficulties, even if at times this was difficult for others to hear:

So I can speak to them in a way that I may not be able to speak with (other people). They are very laid back people, extremely laid back people, and you can have a laugh with them. (Sophie)

#### ***(vi) Feeling in control***

Because of the pressures that these young people faced in their everyday lives, project workers avoided adding to this wherever they could. Involvement in the AWYC project was not compulsory so the youngsters knew they could withdraw at any time without feeling guilty. Equally they knew that they could contact and speak to project workers at virtually any time if anything was on their minds. Some used texting for this purpose as it was more convenient. For two individuals, getting to the project base was initially difficult as they had never acquired the skill and confidence to use public transport as a result of all the family care that faced

them over a period of years. Project workers accordingly worked with these youngsters and helped them to practise these skills until they were self sufficient and able to determine how and when they could move around the city.

### ***Group work***

A vitally important part of the AWYC project was dedicated to group work activity. As explained earlier there was an emphasis on developing group activities that would engage people's interests. Participants themselves helped to shape and in some cases organise things, particularly those things that were fun, this having been a missing element in their young lives as carers. Many activities, particularly those with an education or self-help purpose like health groups and yoga were based at the project base, but things were also organised that took the young people to other interesting places like theme parks, the theatre or cinema, gyms and so on.

All 10 young people we interviewed talked with enthusiasm about their experiences of group work in all its forms, and of the opportunities and benefits it brought to them.

#### ***(i) Farming friendships***

Before they started participating in project activities many of the young people had lost friends or had no time to maintain friendships with their peer group. Attending AWYC activities made a big difference here in helping individuals to re-constitute friendships and to bond through affirming common identities:

It was very helpful going to the group and learning about yourself and that; and I have made friends there. I have two friends here. I meet them here and we get on well. (Peter)

Beforehand I never really had any friends and I never knew anyone who understood my situation. And then when I came here they kind of noticed that so they put me in with the girl's group so I could make friends and there were people there that understood..... (Sophie)

I mean we are different in our ways but people that come here do most of the same stuff as me (at home) so you haven't got to hide nothing from them really. (Abbie)

#### ***(ii) We're in this together'***

Through association with their peers living in similar circumstances, a number of the young people commented how useful they found this in contextualising their own circumstances, in appreciating that they were not alone or unusual, and in being able to see that other groups of young people may be worse off than them in some respects:

Well we actually help each-other. Most of them, people don't like them, because of the way they dress but they do have a lot worse problems than what I would have had, well I have really anyway, say they dress in Goth's but they do have a lot more problems than what we do, I mean they're bullied, picked on a lot.

And how does that make you feel?

It makes me feel a bit down because I know how they feel, but not as bad as they (are).



### ***(iii) Respite***

There were lots of comments about the value of group activity in diverting participants from constantly thinking about their families and their caregiving responsibilities, and from the associated stresses. The following comments from Amy and Abbie were typical:

I think it helps me to keep, well I'm still stressed, but as distressed as I can be, because at the moment I am doing all my GCSEs so I'm stressing out with that, but I think it helps me be a bit more calmer around the house and less stressed out with my mum. (Amy)

It just helps you a bit and takes a little bit of stress away from what you are doing. (Abbie)

There were some exceptions to this general rule. Jess for example mentioned that in breaks of project activity or even when she was at her work placement she phones her mother to check how she is, a reminder of the constancy and pervasiveness of the concerns that she felt for her mother. Stephanie always kept her mobile phone switched on in case her mum needed to text her about something, more often than not to ask her to come home to help her. Maria summed it up briefly but cogently:

I even miss her now. I even miss her now because I'm here.

### ***(iv) Outside recognition***

Some of the young people had been drawn into helping to produce educational materials like videos and booklets about children and young carers supporting parents with mental health problems. As expressions of their 'expertise by experience' these educational products carried with them an implied validation by a wider public that was status enhancing. These products also carried the official stamp of approval by the national charity and its partners, and were promoted at conferences and other public events attended by the young people themselves. For the young people involved this enhanced their self esteem and self confidence, and seemed to have been instrumental in tempting some to think about career prospects in health, education or social care.

## **Conclusion**

The findings from the case study first of all indicate that, despite their vulnerability, young people supporting mothers with mental health problems have agency and can clearly articulate and reflect on their experiences. However, it has also been demonstrated that when these youngsters initially present themselves to a project like the Action With Young Carers this is not always the case. As some have admitted in telling the stories of their experiences, it can take months to build up the confidence to speak more freely about their lives, and to convince themselves that they are not betraying family secrets about mental health in disclosing

their experiences to project workers. This signals the importance of any allied assessment activity not being viewed as a one-off event, but rather as a continuous and natural process that is interwoven into project activity. The emphasis placed by the project on building close and trusting relationships with these young people was a cornerstone in accomplishing this.

The experiences of the young people reported in this chapter lend some validation to the assessment checklists put forward by the SSI mentioned earlier and also Dearden and Becker (1998). In particular the findings reinforce the importance of being able to balance concerns about the safety and vulnerability of young carers against their expressed desire to be supportive to their families. However, the findings would also suggest that attention is paid to:

- personal, familial and wider environmental factors that may lead to a reluctance by the child or young person to disclose important details about their circumstances, especially their fears, anxieties and multiple identities;
- different ways in which young carers want to express continued attachment to their families, including ways of communicating with them;
- reaching an understanding with each young carer about conditions under which privacy rules may need to be breached in order to safeguard them;
- assessment linked to 1-1 and group activities that are engaging and fun;
- assessment with support from workers who are dependable, empathic and easy to contact;
- assessment leading to forms of respite, education and support for young people that are perceived to be externally validated.

It is clear that the AWYC Project went much further than merely giving young people an opportunity to talk and have their situation recognised and acknowledged. By working with young carers over time, the project enhanced the capacity of young carers to find meaning and agency in stressful situations, and to affirm the manifestations of their contribution, not only to themselves, but also through their educational and promotional work to a much wider public. This did much to validate their contribution to society and strengthen their self-esteem. Consequently the project filled important gaps in young lives - friendships and strengthened peer relationships, dependable, consistent and continuous relations with adults, a sense of control, opportunities to enjoy themselves and some respite from caregiving responsibilities.

The experiences of the young people we have shared here are mostly upbeat and validate the philosophy and values espoused by the AWYC project. When the PICAP research was coming to an end, funding for the AWYC project was under threat, reminding us unfortunately that the sustainability of more innovative forms of practice like this cannot be assumed.

## CHAPTER 6

### Conclusions and Recommendations

'Putting People First' for the first time in a government document enshrines the concept of carers as partners and experts in care.

(Carers Strategy, HM Government 2008)

#### Introduction

We started this project optimistically with every intention of identifying 'good' practice in carer assessment and of distilling the organisational and relational factors that promote positive partnership working between carers and service systems. We end it on a rather more sober note. Despite finding examples of excellent practice, these were far from the norm and were usually due to the dedication of individual practitioners who often succeeded despite, not because, of the wider system of which they were part. Nevertheless, carers were quite clear about what they wanted, both for the person they cared for (their first priority) and themselves, so we have captured their views in the practice guides that accompany this report. In this final chapter we begin by anchoring the study to important policy and theoretical issues, using these as a means to present recommendations based on the main findings. We end by reflecting on our experiences of working with carer researchers, adding some fresh perspectives to the growing literature on inclusive research.

Before doing so, however, we briefly consider the extent to which our original aims have been met.

Our overall aim for the project was:

- To provide a comprehensive and contextualised understanding of the rationale for, and the processes, experiences and consequences of, the assessment of carers of people with mental health problems, and the barriers to, and facilitators of, partnership working.

We feel that this has been achieved and that PICAP provides the most detailed account yet of carers' experiences of assessment in mental health. In addition, we feel that the project has also provided several detailed insights into the nature and importance of carers' prior contact with mental health services, and the impact this has on the context within which the assessment is carried out.

More specific objectives were:

- To consider the range of assessment approaches (and their rationale) as currently used with diverse groups of carers of people with mental health problems.

These were described in detail in Chapter 3. The rationale for the conduct of assessment was often instrumental (to meet targets or access resources) and assessment was not usually underpinned by explicit or well articulated theoretical models. Two main approaches were adopted, one in which assessment was led by the care co-ordinator, the other in which assessment was conducted by specifically employed carer assessors/carers care managers. There are advantages and disadvantages to each (see Chapter 3).

- To explore current 'good practice' as identified by a variety of key stakeholder groups.

These have been captured in the guides that accompany this report.

- To identify perceived barriers to, and facilitators of, the implementation of good practice in assessing and meeting carers' needs.

Barriers were more evident than facilitators and were identified both in the literature and the empirical elements of the study. As the title of this report suggests, barriers are primarily to do with the marginal position that carers still occupy, and their often prolonged and antagonistic relationships with the service system. Facilitators turned largely on the dedication, skills and interpersonal qualities of individual practitioners.

- To explore the experience and outcomes of assessment longitudinally from the perspectives of the carer and, to a lesser extent, the assessor.

For reasons elaborated upon in both Chapters 1 and 3, methodologically PICAP presented considerable challenges and, despite concerted effort and innovation during the whole project, recruitment was a constant struggle. There was a reluctance on the part of carers to participate and the number of assessments completed was very low, or non-existent in some areas. Despite this we obtained a considerable volume of rich data and the longitudinal experience of carers was captured in Chapter 4, based on a synthesis of three diverse sources of evidence (the literature, the consultation days and detailed interviews) which demonstrated remarkable consistency in the results obtained.

- To identify both 'good practice' and areas for improvement in current assessment approaches.

This has been addressed in the guidelines.

- To identify potentially differing needs of carers from varying groups (for example, 'minority' ethnic groups, young carers, and carers at different stages in their caring 'career').

The young carers' chapter captures the results of this particular group. We had varying success with adult carers.

On the site selected for BME groups it proved impossible to recruit sufficient carers to determine how well their needs were being addressed. However, one of the other sites served a predominantly African-Caribbean population and here the needs and experiences of these particular carers could not be distinguished from those of carers from other ethnic groups.

However, the consultation days highlighted some specific challenges for BME populations and these are outlined in Chapter 4. Of the differing groups it was probably rural carers that seemed to suffer the greatest disadvantage, especially with respect of access to services such as carer groups, with transport presenting particular challenges.

Due to the fact that most carers had been supporting their relative for a number of years prior to their assessment, it was not possible to identify carers in an 'early' stage of their career. However, their retrospective accounts provide testament to the difficulties they experienced at this point.

- To produce and seek to disseminate principles for best practice and carer/practitioner guides to inform and empower both carers of people with mental health problems and those undertaking assessments.

Separate guidance has been produced to address these objectives.

Having briefly reviewed the extent to which the initial aims and objectives were met, we now consider recent policy initiatives that relate to the above findings and inform our recommendations.

### **The policy scene: a time of change**

The latter months of 2007 and the early months of 2008 witnessed the publication of several far reaching policy documents in England, and a 'radical rethink' of the principles for mental health services produced by a consortium of seven mental health organisations (The Future Vision Coalition 2008). The 'Putting People First' initiative was described as a 'landmark protocol' outlining fundamental reforms to the system of adult social care in England (HM Government 2007), the Carers Strategy (HM Government 2008) presents a 10 year vision for the future support of carers, promising them 'A caring system on your side: A life of your own', whilst the Darzi review of the NHS (Darzi 2008) promoted 'an NHS that gives patients and the public more information and choice, works in partnership, and has quality at its heart'. The 'New Vision for Mental Health' (The Future Vision Coalition 2008) calls for a substantial shift in policy away from a medical model to a more integrated approach.

We noted in the introduction that partnerships had become the new rhetoric of caring relationships (Nolan et al 2003), and recent pronouncements cement their place at the heart of welfare reform. Indeed, as the quote above notes, the statement in 'Putting People First' is the first time that the government has explicitly endorsed the concept of carers as partners and experts in care. Both 'Putting People First' and the Carers Strategy recognise the need to replace existing paternalistic and uncoordinated service systems which, for carers, often result in a 'constant struggle' with services that 'frustrate them at every turn' (Carers Strategy 2008). The Carers Strategy promotes holistic assessment for both the cared-for person and the carer as the 'key' to achieving an integrated system. The 'New Vision' says little specifically about carers, but once again promotes an integrated approach. What can the results from PICAP tell us about what might need to be done to achieve such aims in mental health?

### **The experience of caring in mental health – a theoretical void?**

We predicated the PICAP study on a number of explicit assumptions which asserted that genuine partnerships between carers and service systems would not develop unless interactions, including assessments, are:

- Based on an understanding of the 'meanings' that carers bring to their situation and how such meanings might change over time. As Karp (2001) suggests, whether people are aware of it or not, everyone 'theorises' in order to understand the world, and when mental health problems present themselves difficulties are likely to arise when the theories brought to bear by carers are not consistent with those that professionals implicitly draw upon.
- Able to respond to changing demands over time. This requires an appreciation of the temporal nature of caring and the identification of critical transitions when carers are most in need of, and most receptive to, support. There are a limited number of such models in mental health but those that do exist, especially in the work of Karp (2001) and Pagnini (2005), provide some important messages for the development of services that we will consider briefly later.
- Holistic and wide ranging, moving beyond the typical 'burden' model of care to recognise the strengths and potential satisfactions of carers, the resources they may possess, and also the contributions of their wider social network. This means acknowledging carers as 'experts' in their own situation.

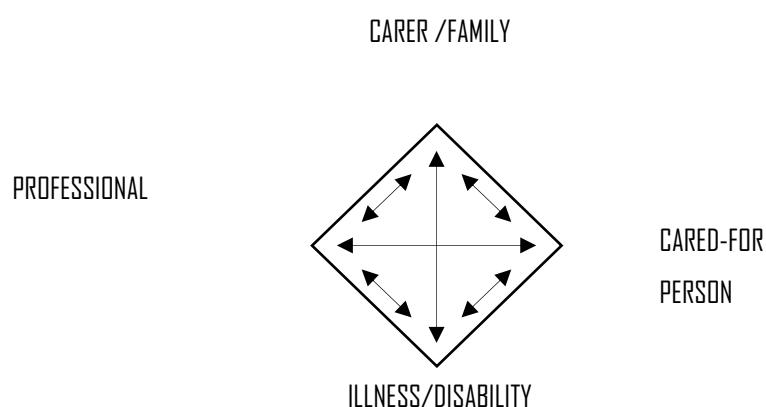
The conceptual synthesis of the literature highlighted the rudimentary state of theoretical development in this area, with some 'bedrock conceptual issues' (Luckstead and Dixon 1999) remaining unaddressed. The field is dominated by a focus on schizophrenia and burden, with large gaps in our understanding of carers' experiences in a whole range of situations. With a few notable exceptions, longitudinal studies are absent and although there is a growing literature we still know relatively little about the strengths and resilience of carers in mental health and the dynamics of caring based on dyadic and triadic models that include the perspectives of all those involved in caring situations. What is required is a model that provides an accessible and appropriate framework stimulating the formation of partnerships in mental health, and which recognises the delicate and often

difficult relationships that exist. In the past we have found Rolland's (1988, 1994) concept of the 'therapeutic quadrangle' very useful in this regard (Nolan et al 1994).

This recognises the varying tensions that may arise in complex situations and acknowledges that the character of such tensions is interwoven with the nature of the long-term condition. This means, for example, that the particular demands placed on services and families in schizophrenia are likely to be quite different from those in depression or dementia.

The basis of Rolland's (1988, 1994) argument is that the currently inadequate service responses to complex, long-term conditions are the result of applying a primarily medical approach that fails to take into account qualitative and quantitative variations in familial and lay-professional relationships over time. He advocated the use of a more holistic bio-psychosocial approach that takes a far broader view. This is captured in the figure below:

**Figure 6: The Therapeutic Quadrangle**



(Modified from Rolland 1988)

However, adopting such an approach will require the sort of culture change mandated in 'Putting People First' and the Carers Strategy, and this is something to which we will return shortly.

Based on our conceptual synthesis of the literature (see Chapter 2), it is clear that there is a need for far more research into caring in mental health and our first recommendation would be that:

- Funders, including the SDO, should actively promote and commission more qualitative and longitudinal studies into the experience of caring in mental health that explore the conceptual gaps identified in the synthesis of the literature, and build on relevant theoretical perspectives that can inform good empirical research and generate evidence for subsequent practice initiatives.

### **Policy – turning rhetoric into reality**



Recent documents make the government's policy intent quite explicit about the idea of carers being recognised as both partners and experts. There is also recognition that existing service systems do little to enable such an approach. The results from PICAP would amply reinforce such a conclusion. However, whilst the policy goals may be apparent, how to ensure that they are achieved is quite another matter.

The challenges of translating policies to practice are well documented and there are no perfect solutions or universal models that guarantee success. In their recent synthesis of the results of the Modernising Adult Social Care (MASC) programme, Newman and Hughes (2007) suggest that two basic approaches can be identified. The first comprises transactional approaches that are based primarily on regulation (and occasionally legislation) that mandate action be taken, with sanction to follow if this does not happen. This tends to result in compliant behaviour. People act in a certain way because they have to. Conversely there are transformational models that seek to modify the values and beliefs that inform peoples' actions. Such approaches tend to generate commitment and are more likely to result in enduring change. However, they are complex and time-consuming to introduce.

In looking at the relatively limited success of the MASC programme Newman and Hughes (2007) contend that too much emphasis has been placed on transactional and too little on transformational approaches. They argue that the more complex the policy initiative the more important it is to use transformational change.

The issues could hardly be more complicated than they are in mental health, as the field appears to be dominated by relatively entrenched positions underpinned by often tacit belief systems. Yet, despite this complexity, carer assessments continue to be driven primarily by transactional models. As noted, we did encounter several practitioners who were fully committed to the process but were faced with: excessive workloads; a value base that prioritised the needs of the service user; and a wider system that tended to marginalise and isolate carers from the outset, resulting in conflicted and usually fractious relationships. The need for the greater use of transformational policy implementation models seems self evident.

And yet transactional approaches still have a role to play. We noted that one of the primary motivations for the completion of the carers' assessment was that they addressed one of the 'targets' that local authorities are required to meet (see Chapter 3). In the Carers Strategy the government notes that it is to consider replacing the current performance indicator NI 135 that relates to 'carers receiving a needs assessment or review and a speciality service', with a new outcome indicator that better reflects carers' real experiences. Based on PICAP we would strongly support this. Our second recommendation would therefore be that:

- Government, as a matter of urgency, undertakes a review of the National Indicators Set and identifies a more sensitive and appropriate outcome indicator that more fully reflects carers' experiences, not only of assessment, but of contact with the wider mental health system.

Of course such transactional approaches can only achieve so much and the case for a transformation of service systems is manifest, not only in the Carers Strategy, but also in 'Putting People First', the Darzi review, and the 'New Vision'. One of the areas that the government acknowledges in the Carers Strategy is the preference of carers for support provided by the third sector, and they recognise the potential for greater input from this source, as does the 'New Vision' (The Future Vision Coalition 2008). PICAP highlighted the very valuable role played by those voluntary agencies involved, but also the duplication of effort that often ensued when assessments were repeated (see Chapter 3). Furthermore, the funding base of even highly successful initiatives, such as the young carers' project, was fragile (see Chapter 5). On this basis our third recommendation would be that:

- Government seeks to promote the greater involvement of the voluntary sector in the assessment and support of carers of people with mental health problems and to ensure their financial security in the longer term so that highly promising initiatives do not flounder.

Carers in the study were often highly critical of the way that confidentiality was used as a 'smokescreen' to effectively limit their full involvement in the care of their relative (see Chapter 4). The Carers Strategy acknowledges this and provides a 'case example' illustrating how a carer was able to overcome this problem. Unfortunately this meant taking their case to appeal where it was upheld by the Care Commission. In light of similar situations the government suggests within the Carers Strategy that it will consider moving towards legislation that enables carers to receive more information, especially when mental capacity is an issue. Our next policy recommendation would be that:

- Government actively pursues the introduction of legislation that clarifies and strengthens a carer's right to information in order that they can play a full and active role in providing care and support.

Apart from the case study alluded to above, and a few isolated references to substance abuse, issues to do with caring in mental health received very little attention in the Carers Strategy and are treated synonymously with the needs of other carers. There is of course considerable overlap. However, experience with PICAP would suggest that carers of people with mental health problems are uniquely disadvantaged with respect to the way they are implicitly (and sometimes explicitly) perceived by the service system. This was graphically described in the literature, and amply reinforced in the consultations and interviews in this study. Based on this our fourth policy recommendation would be that:

- Government recognises the relatively stigmatised and disadvantaged position of carers of people with mental health problems and pays particular attention to ensuring that they benefit from the principles contained within the Carers Strategy.

This latter point raises questions about the ways in which carers in mental health are perceived, and indeed how mental health itself is viewed within society (see the New Vision: Future Vision Coalition 2008). Within PICAP we noted the difficulties carers had with the terms 'carer' and 'assessment' (see 'What's in a name?', Chapter 4). The Carers Strategy recognises that the term

carer is widely interpreted, even to the extent that it is differently defined by varying departments within the government. The government suggests that a uniformly agreed definition of a carer would be desirable, and provide an example. Without commenting on the example they provide, our next policy recommendation would be that:

- The government advances moves to produce and agree a uniform definition of 'carer' that is widely understood and accepted. This should involve extensive consultation with carers and their organisations and, once agreed, should be widely disseminated so that the current confusion as to the meaning and status of 'carers' is reduced.

Ultimately, however, transformational approaches require that we challenge the values and beliefs that inform society and its views about, and attitudes towards, difficult issues, such as mental health. Olsen and Clarke (2003) note that the prevailing model is a symptom based and individualistic approach to what they term 'mental health impairment' which requires official 'diagnosis'. They contrast this with what they term 'mental distress' which reflects the subjective experience of individuals. The need to adopt a wider approach such as this lies at the heart of the 'New Vision for Mental Health' (The Future Vision Coalition 2008). Olsen and Clarke (2003) argue that the way in which the family has been viewed as a 'causal agent' both represents a significant barrier to their inclusion in policy and practice, and also a source of much of the 'mental distress' they experience. We have no doubt that whilst most of the carers we interviewed would not be diagnosed as having a 'mental health impairment', all were suffering greater or lesser (usually greater) degrees of mental distress. It is to be hoped that some of the recommendations above, if implemented, together with the Carers Strategy will do much to reduce this distress, but this will require that changes in practice are implemented.

### **Practice: a change in culture**

Appleby (2004) contends that the NSF for Mental Health and the NHS plan are the two most significant documents in the lifetime of anyone currently working in the field of mental health, and that they are set to transform the field. In his review of progress over the first 5 years he noted significant achievements in several of the standards, but has 'less to say' about Standard 6. PICAP has demonstrated why this is the case. Amongst several competing demands, carer assessments are generally not prioritised either by the system as a whole or by individual practitioners. The former promote carer assessments often because they meet a performance target, and the latter either undertake assessments primarily to access resources via the carers grant or do not see the need for a separate assessment of carers. Clearly, while there are transactional reasons for undertaking assessments, the 'transformation' of assessments into an activity of perceived value has largely not occurred. The battle for 'hearts and minds' has not so much been lost, as not even yet fully enjoined. There are several things that need to change before this can occur.

The generally less than positive position that carers occupy in the mental health system has been amply demonstrated, and it was also noted that practitioners often lack the knowledge and skills to complete holistic assessments (see Chapter 4). This will require initiatives to address fundamental attitudes and beliefs.

In respect of work with family carers in mental health Simpson and Benn (2007) outline the need for what they call a 'wide ranging and comprehensive education and training programme' based on the fact that despite the recent legislative changes (a transactional approach) support for carers remains low. They suggest that such a programme should operate at several levels:

- Education on the importance of working in partnership with families should be provided to all mental health students and trainees throughout their pre-registration training.

Subsequently, on-going training should be provided at 3 levels:

- Level 1 – all staff should gain awareness of the experience and needs of carers and family, and an appreciation of what family work involves via staff education programmes, work place training and regular updates.
- Level 2 – smaller numbers of staff across all services and sections should be trained to provide expert family based work.
- Level 3 – a suitable number of staff should be trained and supported to provide on-going supervision, training and support of staff providing family work and interventions.

We would entirely support such a suggestion so our next recommendation would be that:

- In the longer term those responsible for both the initial and on-going education and training of mental health practitioners review the emphasis placed on, and content dedicated to, carers in the curriculum and adapt it according to Simpson and Benn's (2007) 3 stage model, so that work with carers in general, and assessments in particular, are seen as an important and skilful activity. In the short term the profile of carer assessments needs to be raised and staff given the skills and resources necessary to complete them effectively.

Of course if such education is to be successful and level 2 and level 3 practitioners supported, then family work generally has to be valued and actively promoted as a skilled activity so that it is accorded due status. The difficulties in introducing models of PSI suggest how problematic this is likely to be, and clearly this will require longer term concerted action. However, in the shorter term carer assessment needs to be valued for other than instrumental reasons and the introduction of a new performance indicator could do much to achieve this.

On the other hand, current legislation provides carers 'intending' to provide regular and substantial care the right to an assessment of their needs, but this is rarely utilised (see Chapters 3 and 4). Given the central importance of early positive encounters between carers and the mental health system, and the part such encounters can play in forging future relationships (see 'The talk is of partnerships, the experience more like conflict', Chapter 4), our next recommendation is:

- That local authorities, and others with responsibility for ensuring carer assessments are conducted, actively promote early positive and on-going contact with all new carers, so that the foundations of partnership working can be laid from the outset.

Issues of access and eligibility figured prominently in PICAP and it was abundantly clear that several areas had made a literal interpretation of Standard 6 and **only** provide assessments to carers on CPA (sometimes enhanced CPA) (see Chapter 3 in particular). This effectively excluded many carers. Our next recommendation therefore is that:

- Those authorities responsible for ensuring that carers' assessments are conducted take steps to ensure that all carers eligible for an assessment are offered one, not just those on CPA.

However, such assessments must not be a substitute for regular on-going contact between families and those supporting people with mental health problems. Moreover, if assessments are to be undertaken with appropriate action to follow, then it is essential that adequate resources are available to provide the support required. Some of these resources may flow from the Carers Strategy but it is important that they are used creatively to meet person- and family-centred aspirations that arise from the assessment process.

The provision of breaks from caring is one of the primary goals of the Carers Strategy and, as noted in PICAP, when these are provided, and carers are able to take them, they are greatly appreciated. However, for many carers breaks (and other forms of support, such as carer groups) were offered without any real consideration of whether they were appropriate to the carer's circumstances (for example, pamper days when the carer's situation was highly volatile) or whether they felt able to take them (see 'Promises, promises', Chapter 4). If the Carers Strategy is to succeed then attention must be turned to such issues. Our next recommendation is that:

- Authorities give more consideration to the range and type of services offered to ensure that they are sensitive to carers' circumstances and that carers are able to take full advantage of them. This will require greater creativity and flexibility.

Overall what is needed is an approach that enables practitioners and carers to enter into an open and informed dialogue. This was a centrepiece of practice in the young carers' project described in Chapter 5, demonstrating in that case that assessment and support were indivisible. For potentially very vulnerable groups like young carers, supportive activities provided contexts in which good and continuing assessment could take place. This leads to our next recommendation which is:

- Though important in its own right, assessment should not be divorced from support for carers, for supportive activity is likely to provide clues important to understanding carer's needs and their understanding of their situation. For vulnerable groups of carers, time and pacing appear to be crucial in the building of trusted relationships with professionals; without this, good assessment is compromised.

One approach to creating partnerships between family carers and professionals that shows promise is the Carers Outcome Agreement Tool (COAT – Hanson et al 2006). This was briefly referred to in the literature section. It was developed in consultation with carers and practitioners and its principles were endorsed by both. COAT is underpinned by the original 'carers as experts' model (Nolan et al 1996) and is theoretically consistent with all the latest policy initiatives. It focuses on the four outcomes for carers suggested by Nicholas (2001, 2003):

- Quality of life for the cared-for person
- Quality of life for the carer
- Help and support in the caring role
- Service/process outcomes so that services are consistent with carers' routines and wishes

Our work in PICAP would indicate that these outcomes are just as relevant in mental health, suggesting the potential for COAT to be implemented. The work with older people identified several benefits that would address many of the difficulties identified in PICAP (Hanson et al 2006).

After considerable consultation and trial assessments with carers and practitioners, it was found that:

Carers considered COAT:

- allowed them to raise issues that were causing concern;
- helped them to discuss such concerns in an open and frank manner;
- provided new insights into their own situation
- focussed on issues that they had not previously considered;
- helped to structure their discussion with the assessors;
- helped to validate their experiences as carers.

Importantly all of those carers taking part enjoyed the experience of an assessor spending time talking to **them** about **their** needs, and a number compared the experience favourably with previous 'assessments' that had not allowed them to fully express their views.

The practitioners adopting the 'assessor' role identified a range of benefits to using COAT:

- All the assessors felt that COAT worked well in promoting a personal and detailed discussion about individual caring situations.
- Despite assessors having detailed prior knowledge of the caring situation, completing COAT provided new insights for many of them.
- Assessors considered that COAT enabled them to get to know the carers well, and provided a comprehensive view of the caring situation from the carers' perspective.
- COAT enabled carers to talk openly about their situation, and helped them to focus on areas that they had not previously considered, such as their own quality of life.
- The process of completing COAT allowed the assessors to begin to address some of the carers' concerns, for example, for further information.
- Completing COAT was seen by some as potentially therapeutic in its own right.

Although COAT was developed with carers of older people, the principles upon which it is based, and the potential benefits it provides, suggest that it also has considerable potential in the field of adult mental health.

We hope that the principles and guidelines that will result from this project will assist in highlighting key areas requiring further attention and provide a basis for beginning to 'transform' the ways in which carers and service systems work together. Adopting the COAT approach provides one potential way forward.

Ultimately, what all the carers we spoke to wanted was better support for their relative. Appleby's (2007) recent review gives the promise of this but the absence of any consideration to carers' needs is worrying, and provides a telling indication of the work that remains to be done before mental health services genuinely and routinely 'think carer', and carers are enabled to move from the margins of policy and practice and become genuine partners in care.

We now turn attention briefly to the lessons learned about the use of carer researchers within PICAP.

### **Methodological reflections on our experiences of working with carer researchers, and other issues**

PICAP is one of very few projects to collaborate with carers at every level and stage of the research process. Whilst it has been a valuable learning exercise, it has raised as many questions as answers about carers as researchers.

As far as possible we followed good practice at all times. For example, every effort was made to select carers for different phases of the research according to their skills and experience. However, there is a scarcity of carers already trained in research skills which meant that training and support needed to be more intensive than was planned. The relative ease with which experienced carer researchers worked in the region where an established group existed reinforces the recommendations of Rose (2003) that effort needs to go into capacity building and ongoing support of local carer researchers. In some areas this may mean providing intensive and/or prolonged support and in-depth training that is sensitive to ethnic and cultural differences if potentially excluded carer researchers are to have the opportunity to contribute. Further engagement with carer researchers is already in place with the inception of FACTOR (Friends and Family together in Research), a group dedicated to identifying carers' priorities for research and furthering their involvement in, and influence on, research.

Although training was provided for carer researchers this had variable success. Where recruits gained the skills and confidence to work independently as a group, with a self-selected co-ordinator, the experience was successful and both interviewees and interviewers expressed satisfaction with the process. However, training needs to be sensitive to linguistic codes and traditions as influenced, for example, by class and/or ethnic background. In particular, caution should be taken to avoid middle class assumptions and vocabularies if those from other backgrounds are to make their optimal contribution. It may have been due to a failure on our part to recognise such influences that some recruits did not acquire sufficient confidence to act independently and were subsequently accompanied by a professional researcher. However this was not a 'one way street' and carer researchers



still had a valuable contribution to make with the professional researcher relying on the support and the knowledge of the local carer researchers to make links and establish credibility within a primarily working class and multi ethnic community. Our next recommendation is:

- Carer researchers require careful selection and comprehensive training that is sensitive to, and accommodates differences in, socio-economic backgrounds, culture and ethnicity.

Interestingly, while the literature suggests that service users often prefer interviews by another service user, and speak more freely to them, this may not necessarily be the case for carers. Given the choice, some of the carers in our study chose to speak to professional researchers. Indeed our experiences in the case study sites show the importance of being sensitive to the different needs of carers, and of acknowledging differences between carers, with class and ethnic background being very important. Some carers felt very uncomfortable about being identified as carers within their community and wanted to ensure that their experiences would **not** be shared with 'other carers'. This is a good example of inclusive research presenting new ethical challenges to be faced in the field. Our final recommendation is that:

- Future projects using carer researchers should not automatically assume that carers wish to be interviewed by other carers, and sensitivity is required in offering carers the choice of being interviewed by another carer or a professional researcher.

On the whole the interviews with professional researchers tended to generate fuller responses, possibly due to the interviewers' additional confidence and knowledge of the mental health system. To be fair, carer researchers had very limited research training compared with professional researchers, but this raises questions about the best means of using carers as interviewers, as the time and resources invested in the process may not always pay dividends. Careful thought needs to be given to the selection process and to recruits' potential ability to work independently. On the other hand it needs to be recognised that carers and professional researchers can have an interdependent relationship, where each brings unique knowledge and skills to the situation.

Training in research skills clearly needs to fit potential carer researchers for purpose and, as noted above, to be tailored to individual skills and abilities. We placed an emphasis on qualitative interviewing skills. It was active listening that proved most difficult for many carers who were often immersed in their own painful experiences. In most sites practice using paired role play was helpful in giving trainees feedback about their performance. However, at one site more experienced carers declined the opportunity for such role play, suggesting the importance of tailoring training to individual requirements.

Ethical issues such as confidentiality, managing distress, reporting concerns, and providing support following the interview proved important. Like Lockey et al (2004), we found that an interactive process of discussion based on real experience was

useful. But additional training was needed before we made decisions about trainees' willingness and ability to work independently in a safe, ethical and effective manner.

Consequently carers contributed most to the planning and analysis stages of the research, rather than to interviewing. Their experiences of caring and of using services were particularly helpful in the consultation exercise which influenced the selection of study sites and the questions asked about services on those sites. Carers were also very helpful in the development of the interview schedule, information sheets and introduction letters for use with carers; and their insights into what it is like to be a carer gave us additional sensitivity when inviting carers to participate in the research.

Finally, carers were helpful in the analysis of interview data. They read the transcripts and together suggested themes, categories and either worked up a coding framework or provided a synopsis of key messages. However, their interpretation of the interviews did not differ from that of the professional researchers who categorized the data independently. Whilst this demonstrates the validity of the findings, it also suggests that the carers were not necessarily bringing new insights to the data in this particular instance. However, it should be remembered that the professional researchers were all very experienced, with some of us having been active in research involving carers (with one exception albeit not in the field of mental health) for many years. Moreover, we all had at one time or another been a family carer. It may well be that such extensive experience accounts for the close concordance between our insights and those of the carer researchers. The same may not be true for professional researchers less experienced in this particular field, when carers could well bring insights that professional researchers would not.

In conclusion it is often assumed that carers of people with mental health problems have the same support needs as service users when engaging in research as partners. Yet, carers clearly have a very different experience of services from service users themselves and different views of what services should provide and to whom (see Perkins and Repper 1998b). Carers' particular perspectives and experiences of caring can be helpful in: determining research priorities and carer-specific research questions; accessing carers for research; and in designing interview schedules for use with carers. Moreover, our experience of working with carers in PICAP suggests that carer researchers may have different training needs from service user researchers and that carer interviewees may not gain the same benefits from interviews with other carers as service users appear to gain from interviews by their peers (Polowycz et al 1993). Clearly the advantages of carers interviewing need to be balanced against limitations. Questions also remain about levels of self disclosure. Some personal information needs to be disclosed for carer researchers to establish their common identity with the interviewee, yet there is a danger of them taking over the interview, compromising the privacy of the 'cared for' person, as well as raising issues of privacy between carers themselves. Care needs to be taken to avoid transforming the research interview into a peer support event.

Another methodological issue that would benefit from further reflection is the difficulties we encountered in recruiting carers. Despite the active engagement of carers themselves in designing information and letters of approach, and the considerable efforts both ourselves and those at the study sites expended in attempting to recruit carers, we failed to attract our hoped-for

numbers at some sites. We have reflected on the reasons for this in Chapters 1 and 5, but our experience suggests the challenges that remain in undertaking this type of research in the future, particularly when current ethical and governance procedures seem to impede rather than enhance necessary processes.

Overall the PICAP has raised a series of important questions about using carers as researchers, the benefits gained and the challenges to be addressed if diverse groups of carer researchers are to be enabled to make effective contributions, and if carers interested as potential researchers are to be identified, recruited and appropriately supported.

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# APPENDIX 1

### Sample search strategy for the Medline <1966-2005 Database

#	Search History	Results
1	Caregivers/	9360
2	carer\$.tw.	3365
3	caregiv\$.tw.	13234
4	care-giv\$.tw.	2301
5	informal care.tw.	342
6	friend\$.tw.	19183
7	((family or families or neighbour\$ or relative\$) adj2 (care or caring or support)).tw.	6399
8	1 or 2 or 3 or 4 or 5 or 6 or 7	45316
9	exp Mental Disorders/	585521
10	mental disorder\$.tw.	9621
11	mental\$ ill\$.tw.	11900
12	mental health.tw.	32903
13	psychiatric disorder\$.tw.	12420
14	schizophrenia.tw.	38486
15	dement\$.tw.	36393
16	alzheimer\$.tw.	43243
17	psychiatric problem\$.tw.	1484
18	Psychiatr\$ ill\$.tw.	3738
19	mental\$ impair\$.tw.	773
20	mental disease\$.tw.	1061
21	eating disorder\$.tw.	5594
22	Cognitive disorder\$.tw.	901
23	mood disorder\$.tw.	4204
24	anxiety disorder\$.tw.	7249
25	personality disorder\$.tw.	7591
26	anorexi\$.tw.	15082
27	bulimi\$.tw.	4206
28	exp Substance-Related Disorders/	150927
29	hysteria.tw.	1437
30	(neurosis or neuroses).tw.	4111
31	(psychosis or psychoses).tw.	16435
32	manic depression.tw.	293
33	or/9-32	647853
34	8 and 33	10734
35	exp Needs Assessment/	11752

36	assessment\$.tw.	294227
37	exp "Health Services Needs and Demand"/	25514
38	(need\$ adj2 assess\$).tw.	7090
38	35 or 36 or 37	330910
39	34 and 38	1912

# **APPENDIX 2**

### Characteristics of carers participating in regional consultation meetings<sup>1</sup>

<b>Total Number: 79</b> (31 had been offered an assessment; of these only 12 had been assessed, most had refused an assessment, only 5 found the experience helpful)			
<b>Caring Status</b>	75 (95%) carers 4 (5%) carer workers	<b>Gender</b>	24 (30%) male 55 (70%) female
<b>Age</b>	1 (1%) under 25 yrs 23 (29%) 25-45 yrs 36 (45%) 46-65 yrs 19 (24%) over 65 yrs	<b>Ethnicity</b>	61 (78%) White British 4 (5%) White Irish 1 (1%) Black British 2 (3%) Caribbean 1 (1%) African 6 (8%) Asian 1 (1%) White American 1 (1%) British Indian
<b>Relationship to person cared for</b>	33 (41%) Mothers 27 (34%) Fathers 8 (10%) Wives 1 (1%) Husband 1 (1%) Niece 2 (3%) Daughters 3 (4%) Sisters 2 (4%) Friends	<b>Age of person cared for</b>	10 (14%) under 25 yrs 54 (77%) 26-45 yrs 9 (13%) 46-65 yrs 2 (4%) over 65 yrs
<b>Number of years in caring role</b>	2 (4%) under 5 yrs 35 (49%) 5-10 years 32 (48%) over 10 years	<b>Primary diagnosis of person cared for</b>	48 (80%) Schizophrenia 9 (15%) Bipolar Disorder 3 (5%) Depression 19 Not stated
<b>Used mental health services</b>	13 (18%)	<b>'Representative' role in carer groups/ services</b>	75 (95%)

<sup>1</sup> Where numbers do not add up to 79, this is due to missing data, or where one person cares for more than one person. Where percentages do not add up to 100, this is due to numbers being rounded up.



## **APPENDIX 3**

## **Experiences of mental health services and carer assessments: results of a carer consultation exercise in England**

This presents the results of a series of consultation meetings with carers held in each of the eight NIMHE Regional Development Centre (RDC) areas throughout England. As part of the first phase of the research, the consultations were designed to sensitise the research team to personal, environmental and organisational factors bearing upon the experience of assessment, and to highlight localities where there was thought to be good practice in the implementation of carer assessments. The decision to include all 8 RDCs in the consultations was made in order to maximise the coverage of carers by diversity (role relationship to the cared for person, ethnicity, length of caring experience), geography (urban and rural areas) and also the organisational arrangements for delivering carer assessments. As part of the consultation process carers were asked to nominate examples of good practice. Suggestions made by carers were used to inform decisions about the selection of case study areas where more detailed studies were to be undertaken.

Seventy-nine carers were consulted in person and a further 20 or so, who were unable to attend, provided either written commentary or expressed their views during telephone conversations with the research team.

All those attending the consultations were adult carers (age range 22 to 80 years), over two-thirds were women (69% female, 31% male), almost 8 out of 10 (78%) were white British, but a wide range of ethnic backgrounds were represented. The length of time caring varied, but most participants had been carers for over 5 years, several for over 20 years. Although the majority of carers were parents (76%) caring for a son or daughter with a diagnosis of schizophrenia, a range of relationships was represented, and the diagnosis of the person they cared for also differed. Despite these variations the views and experiences of men and women of different ages, cultural backgrounds, or caring roles were remarkably similar. Nearly all the participants (95%) not only had experience of caring themselves, but also had a role in voluntary organisations and groups, and/or of representing other carers in Local Implementation Teams, at Service Level, and at Trust Board level. Characteristics of those attending consultation days are summarised in Table 3.1

**Table 3.1: Characteristics of carers participating in regional consultation meetings<sup>2</sup>**

<b>Total Number: 79</b>			
<b>Caring Status</b>	75 (94%) carers 4 (6%) carer workers	<b>Gender</b>	24 (31%) male 55 (69%) female
<b>Age</b>	1 (1%) under 25 yrs 23 (29%) 25-45 yrs 36 (45%) 46-65 yrs 19 (24%) over 65 yrs	<b>Ethnicity</b>	61 (78%) White British 4 (5%) White Irish 1 (1%) Black British 2 (3%) Caribbean 1 (1%) African 6 (8%) Asian 1 (1%) White American 1 (1%) British Indian
<b>Relationship to person cared for</b>	33 (41%) Mothers 27 (34%) Fathers 8 (10%) Wives 1 (1%) Husband 1 (1%) Niece 2 (3%) Daughters 3 (4%) Sisters 2 (4%) Friends	<b>Age of person cared for</b>	10 (14%) under 25 yrs 54 (77%) 26-45 yrs 9 (13%) 46-65 yrs 2 (4%) over 65 yrs
<b>Number of years in caring role</b>	2 (4%) under 5 yrs 35 (49%) 5-10 years 32 (48%) over 10 years	<b>Primary diagnosis of person cared for</b>	48 (61%) Schizophrenia 9 (13%) Bipolar 3 (4%) Depression
<b>Used mental health services</b>	13 (18%)	<b>'Representative' role in carer groups/ services</b>	75 (95%)

<sup>2</sup> Where numbers do not add up to 79, this is due to missing data, or where one person cares for more than one person. Where percentages do not add up to 100, this is due to numbers being rounded up.

## Structure of consultations

Each of the consultations were facilitated by two members of the project team, and detailed notes were taken to record the views expressed. Based on the study aims, the following key questions were used to guide the discussions:

- What were carers' experiences and expectations of carer assessments?
- How should assessments be organised?
- How should assessments be structured?
- What should assessments cover?
- Is it possible to identify areas/services where good assessments are currently being carried out?

The results of each discussion were then analysed and key themes identified so that they could be further considered at the next meeting. There was a remarkably high degree of consistency in the views expressed. Although the detail of individuals' experiences inevitably differed, the stories that they told illustrated consistent themes. These were confirmed in written feedback from carers and during discussions at the various meetings.

Although only a minority of carers had received assessments, all participants were able to draw on their experiences of being a carer to express ideas about the desired structure, process and outcomes of assessment. It was clear from the meetings that the issue of assessment could only be fully understood in the context of carers' wider experiences of mental health services. Accordingly the remainder of this section is organised around the following linked themes:

- *Carers' experiences of mental health services*
- What carers want from services overall
- Carers' general views about assessment
- Who should GET an assessment
- Who should DO the assessment
- WHEN assessment should be done
- HOW assessment should be conducted
- WHAT assessment should cover
- Dealing with conflicting views
- Sensitivity to cultural and contextual issues
- OUTCOMES of assessment

### *Carers' experiences of mental health services*

## Key messages

- In the early stages carers reported feeling isolated and unsure about what to do. Information and help in navigating services and support for themselves was too often missing;
- As time went by carers accumulated experience and expertise, but this often remained unacknowledged by services;
- Carers felt that they were stereotyped in various ways by services and seen as part of the problem rather than as part of the solution;
- They reported that the confidentiality smokescreen was too often used by professionals to keep them 'out of the loop'.

Discussions provided vivid insights into carers' experiences of mental health services. Many participants recalled early feelings of despair when they were unclear about what was happening, what they could do, who to turn to, and how to find help and support:

"...at first it felt as though I had a 500 piece jigsaw; all the pieces were there, some had straight edges and some had no picture and I had no idea how to put them together. I had no idea who to go to for what". (SE Carer)

Often the help and support they needed at this time was not forthcoming and carers felt left to cope alone until a crisis point was reached:

"If ever I needed support it was in the early days... carers should be recognised as soon as possible and not left like me until things reach crisis point". (NE Carer)

As time went on, carers recognised that they were the main source of support and expertise for the person they cared for, but they often felt that services neither recognised this nor provided the back-up that they needed:

"Carers are there 24 hours a day and 7 days a week and yet we are having to re-justify who and what we are to professionals all the time; our expertise is not acknowledged. Recognition, communication and understanding of the limits of our involvement are more important than 'assessment'. We need to be valued". (SW Carer)

"I know what my daughter's needs are, but no one will listen to me". (NE Carer)

Carers frequently spoke of the lack of information they received, about being kept 'outside the loop', yet 'expected to keep on caring whatever the circumstances':

"The 'confidentiality' smokescreen is used all the time to keep carers out of necessary dialogues". (WM Carer)

"Carers are not treated with common courtesy and respect. They are kept outside the loop. We are not informed of fundamental changes such as when a psychiatrist has changed, or when our daughter is being moved to a different home. We have to hear through third parties". (SW Carer)

Carers felt that they were treated unequally as professionals often wanted information about the service users' problems but gave carers little or no information in return:

"They always want me to tell them when my son is well but they're not so keen to tell me about him... ". (NE Carer)

Carers were almost unanimously disappointed both with the attitude of service providers and with the support provided by services. They used words like 'patronising', 'disbelieving', 'invalidating', and 'insulting'. More specifically, carers spoke of feeling that they were viewed negatively by services, and they were made to feel 'branded' as a 'problem child/parent', 'troublemaker', 'fusspot', 'always complaining', 'part of the problem rather than part of solution'. Several felt that the 'whole family was pathologised:

"There is still a culture where they [the professionals] know best and are reluctant to admit that carers might also have a view that should be taken into account. We are important. We make an important contribution and they need to recognise that. ...a good indication of quality of care is just how much interest a service has in us". (WM Carer)

"They [service providers] need to value my views, and believe my experiences. I am pro-active in calling them, so that they can do their job better, but they see me as troublesome. We have the same goal (they and I want the best for my mother) yet they do not consider my contribution to her well-being". (SE Carer)

"Carers are not involved in care planning or assessment of the person they care for so they have no ownership in the process; in my case there was no care planning or review". (SE Carer)

Carers often felt that services, particularly primary care services, relied heavily on the support they provided for their relative, but paid little attention to their own needs. For example, one carer recounted how she went to her GP because she was feeling under severe pressure, only for his response to focus primarily on the needs of the service user, while also placing implicit pressure on her to continue in her role:

“The GP told me ‘you’re the captain of the ship, we all rely on you... but don’t tell your husband about your problems as he’ll only dwell on them and that will make him worse...’”. (NE Carer)

Poor recognition of carers’ needs was not confined to primary care settings and several recounted the difficulties and resistances they experienced when their relative had been admitted to acute care, often involuntarily:

“I left that acute ward in floods of tears several times and the nurses used to watch me walk out. No-one once said to me ‘look love, let’s go and talk’”. (NE carer)

### **What carers want from services**

#### **Key messages**

Carers were clear about the qualities that they wanted from services, and those providing them. They wanted services and staff that:

- listened to them, valued their knowledge and expertise, and treated them as partners;
- were proactive, dependable, consistent, responsive and family or community orientated;
- respected their personal values and cultural beliefs;
- took account of their established routines and ways of caring;
- provided hope and positive ways of coping;
- recognised other commitments such as employment and child care;
- identified what to do and who to contact at times of crisis.

Despite the above accounts all responses were by no means negative. Several carers recounted positive experiences of services. Assertive outreach services were frequently praised for using a more carer-friendly approach, and several carers talked about the time and support provided by support workers. Interestingly, in neither of these scenarios was support the result of a formal assessment; rather it was based on working 'with' the carer to optimise their ability to care, as opposed to seeing them as a difficulty to be assessed or worked round:

"Assertive outreach workers provide very positive support for carers without calling on a specialist carer support service. The whole approach is based on engaging the person on the basis of their situation and their aspirations – starting where the person is at. There is a recognition of the social and psychological needs of individuals and that you can't divorce the person from their social context. You need to work with the carers in order to provide the most effective support – carers may not need a separate assessment in this situation". (SW Carer)

"I'm happy with CPA. I didn't want full carer assessment. Our AD worker spends a lot of time listening to problems identified by us, the carers, and will respond quickly to emails that I send him". (London Carer)

"We need pro-active support, regular phone contact, not just left to us to phone someone in an emergency. I have a support worker who has changed my life, listens, takes the initiative to phone me regularly to ask how I am, and doesn't wait for me to contact her. It has made everything easier". (NW Carer)

Despite the above examples many carers, as noted earlier, had negative experiences of services. However, they all had suggestions about how things could be improved, and identified the same qualities of a 'good' service. They emphasised the importance of their role, knowledge, views and expertise being understood and respected, and their limitations, fears and ongoing grief acknowledged. They wanted information about services (who to turn to for what) as well as help to acquire skills to manage the challenges involved in caring for a person with mental health problems. They also wanted dependable support that fitted family and household routines. It was important to them that this was delivered by a multidisciplinary team that communicated with carers, and with each other, so that carers did not always have to ask for help. In addition, they needed to 'off-load' their emotions and feelings with someone who would acknowledge their role, their feelings, and help them with the difficulties that caring often caused (such as financial, employment, health and relationship problems). Furthermore, they wanted to feel that they could look forward to the future with hope and expectation:

"Hope is an essential part of being able to care. It is hard to have hope after three relapses... you need help to grieve when your relative 'dies' - the loss of the person you thought they were. You have lost all the hopes and dreams that you had for them". (SW Carer)



We need help to understand and come to terms with what is happening to our relative. We need to know – from the start – what is happening, what to expect, and what we can do. (East Carer)

Carers' contact with services was often limited to times of 'crisis' and the response they received in such circumstances usually left a lasting impression. Unfortunately, it was frequently less than positive:

"We need to be taken seriously. Too often you get the person to A&E - often with difficulty - and the psychiatrist says 'we can't do anything at the moment, take them home'. We have to cope and we know that they are going to get worse. The psychiatrist needs to believe us, and take our views and our knowledge of the person seriously". (London Carer)

"It is difficult to represent our own needs at times. Carers are just ignored or blamed (even more so in the past), so it would be useful to have an advocacy service for carers, someone we could go to discuss our rights and who would go to meetings with us and help us to present our view". (East Carer)

Carers wanted greater flexibility, more thought given to future planning, and also attention to how caring impacted on their wider life, for example, employment:

"I think we need 'rainy day' agreements, not assessments, plans we can rely on about what will happen when things go wrong – contingency planning and preventative strategies". (SE Carer)

"Employment should be a constant theme in work with carers: preventing loss of jobs and facilitating return to work. We have user employment workers, but there may be a case for carer employment workers to broker with employers and advocate on carers' behalf". (SW Carer Worker)

There was a general plea for a change in the culture of services so that people with mental health problems who had family help were seen to live within a community of support, with mental health workers being just one part:

"Education is essential in order to change the whole culture and system of care so that it becomes family orientated rather than individually focused". (NW Carer)

"There seems to be a need for a change in culture and values so that carers are seen as part of the solution, not part of the problem, and everyone is seen as part of a network of carers, not as an independent individual". (London Carer)

We need a change in culture so that carers are respected and involved throughout - a move away from blaming carers to seeing them as partners". (East Carer)

## **Carers' general views about assessment**

### **Key messages**

- In the early stages of caring participants were often unaware that they had 'become a carer'. Most participants were unsure about what they were dealing with, the skills and knowledge they needed, who to turn to for support, and what help they could reasonably expect from services.
- Most carers disliked the word 'assessment', feeling that their competence to care was somehow under scrutiny.
- There was some confusion about the purposes of assessment - for some carers the litmus test was whether in the end it benefited the cared-for person, but for others it was felt that the focus should be more on them than the cared-for person.

In all of the discussion groups, one of the first issues that carers wanted to address was the term 'carer assessment'. Both the term 'carer' and 'assessment' were challenged. Many participants asked what was meant by the term 'carer', at what point was a person recognised as a carer, how and when did they move from being a 'person who cares' to a formal 'carer'. The term 'assessment' was also considered problematic, with carers feeling that it suggested an assessment of their mental health and/or competence to care, rather than of their own need for support. Assessments were also viewed more as a one off 'measurement' rather than a long-term process of engagement and support. Many participants had not heard of 'carer assessments', and most had not been offered an assessment for themselves:

"I didn't know I was a carer until I was told. I thought being a carer meant you had to take on extra responsibilities". (SW Carer)

"There needs to be clarity of terms - assessment, reassessment, review all mean different things. We may need a formal separate carer assessment once a year, but this does not replace the ongoing flexible assessment of carers' needs as they change day by day in relation to the person they care for". (London Carer)

"It must be clear that carer assessments are not about assessing our ability to care. We have been doing it for years regardless! Assessment should focus on our needs". (East Carer)

"I refused a carer assessment... I always felt that they were judging **me**". (NE Carer)

Despite wanting recognition of their own needs the primary concern of most carers was the provision of adequate services for the people they care for. They repeatedly claimed that carer assessments would not be necessary if mental health services provided reliable, responsive and effective support for their relative. Indeed, several carers had chosen not to have an assessment when it was offered because they were unconvinced of its value and confused about its purpose:

"There is confusion about the scope and purpose of assessments among carers, and who is responsible for doing them. Carer assessments don't mean a monkeys to me as long as my son is looked after". (SW Carer)

"I don't want an assessment, I want people there to look after my son and for me to call on when I need it".  
(NW Carer)

To make matters worse several participants had been told, by staff, that carer assessments would not make a difference because resources were not available to meet identified needs:

"I think one of the problems for staff is that if carers' views are listened to they must be responded to and that is often difficult. It is far easier not to hear them in the first place". (SE Carer)

"There are negative attitudes towards assessment (among service providers). Key people in my Trust have openly said to me that carers' assessments are a waste of time because we can't do anything about them – there are no resources to provide the services that are needed". (London Carer)

"Staff do not know enough about carer assessments, and say we are not eligible for assessments. You have to really push to get an assessment in many places". (East Carer)

Several carers who had been assessed considered many of the questions irrelevant, finding them designed primarily for carers of people with physical needs rather than mental health problems, or concerned with the needs of the service user rather than the carer:

"Most conversations in carer assessments focus on the needs of the service user, to make things worse questions are often about physical care... you have to seriously wonder about their relevance". (NE Carer)

"In my experience carer assessments are very restricting. They don't ask me about what I need. All of the things that I have said I would find helpful, I have been told are not available. I'd like two things: family

intervention and mediation. I have been told that this won't be possible, they are not available, no resources, not prioritised". (London Carer)

"The problem with the expectation of carers' assessment is that they are seen as a way of meeting the needs of a client". (NW Carer)

Assessments were generally seen as a 'tick-box' 'one-off' activity, required by local commissioners to meet 'targets', rather than being for the benefit of carers:

"Carer assessments are part of the CHI [Commission for Health Improvement] review and LIT [Local Implementation Team] reviews so there is pressure to say they have been done; in danger of becoming 'tick box' activities, yet they will only make a difference to carers if they are a '**hearts and minds**' thing". (East Carer)

"A carer assessment is not a one off thing, it can't only be a piece of paper that you're left with, so people can say we've 'ticked that box'". (NE Carer)

### **Who should GET an assessment?**

#### **Key messages**

- Concerns were expressed that certain carers are excluded from carer assessments because they do not meet the enhanced CPA criteria.
- There were widespread feelings that anyone offering care and support to a relative with an enduring or episodic mental health problem should be able to access a carer assessment.

Participants were concerned about the ways in which carers are defined for the purpose of assessment. They pointed out that many services only offer assessments to the carers of people on enhanced CPA (Care Programme Approach). This runs the risk of excluding many people, for example: young carers; older carers; 'long distance' carers; carers of people who refuse to use services, and carers who provide such good support that their relative is not on enhanced CPA.

There was agreement that anyone providing support for a person with mental health problems should be offered an assessment – whether they consider themselves to be a 'carer' or not. This places responsibility on Primary Care services to better understand the process of carer assessment and to proactively identify carers. Many of the carers who attended the sessions

had refused assessments because they had no confidence in them. For them simply offering an assessment was not sufficient: workers must be positive, ensure that people are clear what assessment is about, and that assessment leads to changes in support:

“Carer Assessments need to take into account different needs over time, and the needs of carers before the service user agrees to use services; also that younger carers have different needs, knowledge base, experience and outlook ...and people who refuse to use any services at all - their carers have an even greater burden”. (NW Carer)

“Many people don't identify themselves as carers so they would never come forward to be assessed. They don't know their needs or rights and may feel totally isolated”. (NW Carer)

“Older people care for each other, but at what stage do they become carers? They may be reluctant to see themselves as carers but often provide huge amounts of support from each other and a carer assessment may help to identify the help they need to continue caring”. (SE Carer)

## **Who should DO the assessment**

### **Key messages**

- Carers felt that different people could undertake carer assessments. A variety of arrangements were identified, both professionally-led and voluntary sector-led.
- The pros and cons of having joint or separate assessments with service users were described. Most carers wanted an element of shared assessment, but also a separate consideration of their needs.

Views about who should undertake assessments were largely influenced by personal experiences. Some participants had found that the care co-ordinator of the person they cared for was able to support them, as they had a good understanding of the service user. Others preferred a separate system of support for themselves, and considered that other carers were in the best position to assess their needs and understand their situation. Conversely another view was that assessment should be carried out by a health or other professional with authority to act on the findings. There was concern that if carer assessment was separated from care delivery it may well become a one-off event which does not lead to improved support:

“The only people who can understand the situation of carers are other carers. Given training and authority, they could be best assessors”. (NW Carer)

"Ideally the person conducting the assessment should have some familiarity with the users' situation as well, in order to be able to see the carers' needs in an appropriate context". (NE Carer)

"The skill of the assessor is very important, more important than whether the assessor has experience of caring themselves". (SE Carer)

"The role of the assessor should be accorded value and status, and the person should have some authority to act upon the results of the assessment". (London Carer)

There was overall agreement that assessors must receive specific training in assessing carers' needs, managing conflicting views, legal rights and confidentiality issues, helping carers to manage difficult behaviour and to access local resources. It was considered that some of this training should be provided by carers themselves:

"The assessor should be trained in assessment, clear about legal rights and confidentiality issues, have good knowledge of local resources for carers and authority to act upon results of the assessment....". (NE Carer)

"Professionals need education about information and confidentiality issues; there are ways of working openly with carers; staff often refuse to talk to carers when a client is ill. They can get over this by having crisis plans or advanced directives where a person makes plans for involvement of relatives when they are well because they are likely to become paranoid/angry with relatives when they are ill". (East Carer)

## **WHEN assessment should be done**

### **Key messages**

- Carers wanted assessment to be a continuous process that recognised changing needs and circumstances, signalling the importance of regular reviews.
- One-off assessments were thought to have little value and typically yielded few results.
- Carers were especially critical when an assessment resulted in little or no action.

As noted earlier, carers were clear that they needed support and information from the first days of trying to cope with caring for a person with mental health problems. However this did not *necessarily* require a formal carer assessment. There was

consensus that appropriate carer support should be provided as part of the routine care of the 'patient' from first contact with services. Carers consistently expressed the view that assessment should be a continuous, pro-active and preventative process rather than an annual event or, worse, occur only at a time of crisis.

"Assessment needs to take place right at the start. We need to know what is best for me - how to handle my own emotions and needs, and what is best for my relative – so that I can help them to access appropriate support, and to help me to manage them". (WM Carer)

"I don't want an assessment when I am in crisis. At those times I need help to make sense of what is going on, and support". (NW Carer)

"At times of crisis there is no time to do an assessment. We just need the support. Right from the very beginning we need support and care ourselves and for the person we are caring for". (East Carer)

"I worry about annual assessment of need. CA should be continuous, flexible, ongoing, not just a one off". (NW Carer)

## **HOW assessment should be conducted**

### **Key messages**

Carers emphasised that:

- form was as important as content in assessment. This meant being sensitive to family norms and culture that could dictate if assessments could be carried out with the carer alone or with the service user present;
- being given preparatory material before assessments took place could be useful;
- interdependencies, and the informal rules governing them, between family members and the cared-for person were thought to need closer consideration in the way assessments were focused and organised. This meant ensuring that carer assessments were linked to care plans;
- it was important to have more choice and control over assessment methods.

There was much discussion about carers' experiences of being assessed and how they would like an assessment to be conducted. Carers advocated a flexible, loosely structured, assessment in the form of a dialogue in which information was shared by both parties:

"I think there is a problem asking anyone what they need. Carers Assessments are not just about asking this question but about setting up a meaningful dialogue with a person they have built a good relationship with. You need to speak the same language, avoid jargon, explain what is available and what might be helpful to help me to define what will be best for me". (SE Carer)

On the basis of several discussions a five stage process could be identified: first a loosely structured discussion where the assessor listened carefully; second, agreement over priority of needs; third, giving information about available services and resources, fourth, practical organisation of tailored support; and finally, regular review:

"What is important to us is being listened to first, followed by action and support. Being given information about what is available and what should be available as support. Often we don't know what exists". (SE Carer)

"The assessment should provide an opportunity to talk about their experience". (SW Carer)

The qualities of the assessor were considered to be paramount, in particular: genuineness; sensitivity; a willingness to listen to *and believe* carers, while also valuing and respecting their expertise. Several people described how the assessment process in itself was tremendously supportive. This was largely because time had been dedicated to listening to these carers' views and experiences, as for most it was the first time this had happened. They recommended that sufficient time was allowed for a two-way discussion. This might need a number of meetings:

"It's wonderful to have an hour or so to talk about what you might need but although that is helpful, often nothing else happens". (NE Carer)

"A good carer assessment should meet the needs of my relative; offer me time to talk through things; recognise me as an expert; acknowledge the risks in my life as a carer; having a choice to take on this role; respite often needed, in its many forms". (SW Carer)

"Best carer assessments are not a one-off but continuous good practice in routine care, proactive, valuing, supportive". (NW Carer)



Carers wanted information about the assessment process in advance, with copies of the documentation to be used. However they emphasised that the assessment should be flexible; eg some carers preferred self-assessment, others formal interview, diary or informal conversation:

"It is useful to have a copy of the assessment form before the assessment so that you are prepared". (SE Carer)

"A good CA is: part of routine practice, based on a family model of care, based on a trusting I:I relationship, evolves over time, respects the fact that needs differ over time, and is available to carers who do not use health services". (NW Carer)

Overall only 5 carers recounted positive experiences of being assessed, and even here they sometimes had to 'fight' for the attention they needed. However, they clearly identified the benefits of a supportive assessment:

"The carer assessment was the first time I could speak emotionally. Previously when speaking to the GP it was about my husband but the carer assessment was about me. I felt safe and there was time for me to be open and to be emotional". (SE Carer)

"My CA was really good. It wasn't about going through a form ticking boxes, it was listening and talking. The approach is as important as the content". (NW Carer)

"I requested a carer assessment for myself because I had physical problems and cared for three young children, but all the care was focused on my husband who has mental health problems; but there are arguments about which professionals should carry out assessments and you may have to fight for an assessment. They are necessary because they are about our own needs and circumstances and identities – not part of the service users' care. In the end I got a good social worker who did an assessment and got the ball rolling. This made a difference because it looked at ways of helping me – I got a grant towards driving lessons to free me up. Also my daughter is a young carer who now helps me and can cook a family meal. She gets help for herself". (WM Carer)

Carers had different views about whether their assessment should be conducted with the person they care for or not. On balance there was agreement that their needs overlapped but, that for both the service user and carer, there were some issues that were best discussed separately. One (London) carer described, and illustrated this, as follows:

"What I want from carer assessment, I see this as some sort of continuum, a line on which the majority of my own needs and my son's needs overlap - and can be assessed together as part of routine care, but we each

have discreet, personal needs that need to be assessed separately (maybe that is where my carer assessment comes in). So, when our CPN visits, she talks to my son, who doesn't often want us to be around, then, she invites our son to join her in a conversation with my husband and I. Often he doesn't want to be there, but he understands that we will have a chat and he is welcome to join in. This way all of our concerns, needs, observations are taken into account and there is openness.

Needs:

just the	both	just the
user	user and carer	carer
[ _____ / _____ / _____ ]		

Others clearly highlighted the benefits of having an assessment without the service user present:

"I wouldn't have wanted my assessment to have been done with my mother because I couldn't speak openly. On my own I could say what I wanted to say without offending her". (SE Carer)

"Carer assessments have been about my needs. I would not want to be assessed with my husband because I wouldn't want to say things in front of him. He already has the guilt of not being able to support me the way that he wants to because of his illness and I wouldn't want to make that worse by talking about my needs in front of him". (SE Carer)

However, the interdependency of needs and care plans were also recognised and it was felt that ideally the carer assessment could be a route to creating a 'dialogue' between the carer and the user:

"Assessment should feed into the CPA; it needs to be 'joined up' in this sense; importance of recognising interdependencies between 'cared for' and carers' in the family". (SW Carer)

"The needs of the carer and the relative are entangled, inextricable. Much of the relative's assessment will cover issues of importance to the carer, but there is a need for the carer to have their own assessment as an individual, not just in relation to the needs of the person they care for". (East Carer)

"Joint assessment may be very useful to establish ground rules with the service user, carer and service provider about who gets what, when, make plans and contracts. But conflict and change is to be expected". (London Carer)

## WHAT assessment should cover

### Key messages

Carers were clear assessment framed by a pathological view of family functioning was not appropriate. They called for attention to:

- their subjective views and experiences of the situation;
- a sensitivity to temporal factors in caring arrangements and also the course of mental health problems they were likely to face;
- how they can cope better;
- the needs and contributions of family members, not just the 'main' carer.

Carers specified a number of areas that they felt should be covered in assessments. These were not only about the difficulties they encountered in their caring role, but also their feelings about that role – their limitations and fears – and what would help, their engagement in community life, their general health, their views about services, and the skills they would like to help them cope:

“Issues that should be covered include basic needs – physical health and well being, emotional health, risks to physical and psychological health, impact of caring for life, impact on others’ lives as a result of the carers’ caring role....It would be helpful to ask carers how they feel about their role; whether they felt they have choice, control, are being manipulated”. (SE Carer)

“Need to recognise our changing needs over time - recognising the implications of the onset and course of mental illnesses and the implications for how carers acquire knowledge and expertise. I felt there was no-one out there who can cope with him as well as I can – at least initially. I needed some certainty much earlier: a diagnosis, some idea of what might happen next, and when he would get better”. (SW Carer)

“CA must take into account the needs of different members of the family - Mum, Dad, siblings all have different needs. A subset of carers will need a detailed assessment of their own need. They may need physical help to enable them to carry on caring”. (NW Carer)

"Assessments should include essential practical things about us, questions like: How are you feeling? Have you eaten/when did you last eat? Have you been out/when did you last go out? Everyday nitty gritty rather than a one off formal assessment to last the year". (NW Carer)

"We need services to know what we think about them, and our views on ways that a change in services for our relative would help us". (London Carer)

"I want services to know what my limits are; if they assessed my ability to care they would understand the things that I find it difficult to cope with". (East Carer)

## **Dealing with conflicting views**

### **Key messages**

- Good assessments should provide an opportunity for a full and frank exchange of ideas and expertise between assessors and carers. Partnership working was viewed as highly desirable, though it was acknowledged that potential conflicts of interest need to be accommodated.
- Advance directives were advocated as a useful part of planning for the future as they provided carers and the rest of the family with a sense of security.

In all of the groups, carers discussed the difficulties that arose when their views differed from those of the person they care for and/or from service providers. This was most problematic when the carers' recognised signs of deterioration that were not apparent to the person they cared for. This frequently resulted in conflict – both with the service user and with service providers who refused to increase treatment or admit that person. As carers pointed out, it was assumed that they would continue to care for the person even when they felt their views were not heeded, and when they felt they and/or the service user were at risk in some way.

A central concern in this process was the exclusion of carers from decision-making; service providers claimed that they were unable to keep carers informed about progress and plans (even when these included discharge to live with the carers) because of the need to respect 'confidentiality':

"Workers always hide behind the need for 'confidentiality', they need to see us as part of the care team".  
(NW Carer)

"Confidentiality is a veil of secrecy which workers hide behind". (NE Carer)

"Staff use confidentiality as an excuse not to share information".

"There is a tacit assumption by professionals that families are willing – or have a moral duty – to care under almost any circumstances". (SW Carer)

Carers felt strongly that they needed to be informed of, and ideally valued, in decisions that were made, for example, about discharge:

"At very least, if the patient does not want carer involved, the carer must be informed of any changes that effect their health and safety - they have a right to know". (SE Carer)

"Frequently there are conflicting views between service user and carer when they have been admitted, often unpleasant process, paranoia, parents involved in sectioning etc, so (they) may have different views and (the) service user may not want carers present.... but carers still need support. There are still situations when carers need to be present – ie when decisions are made that impact on the carer, particularly pre-discharge CPA meetings, carers' views about future living arrangement is essential". (London Carer)

There were suggestions about how conflict could be reduced. For example, 'Advance Directives' provide a plan of action formulated by service users in collaboration with carers and services. These plans specify what the service user would like to happen in a crisis or relapse, and who should be consulted and informed about decisions:

"People who we care for want us to be involved. It's just when they get ill that they can become paranoid about us. You can get over this by having an advanced directive to plan what happens in a crisis and all agree to it". (NW Carer)

"Planning ahead for potential difficulties can help although there are difficulties when plans are over-ruled. ...but there must always be agreement to breach contract for confidentiality in extreme circumstances". (SE Carer)

"The general point here is the importance of getting permission from the service user when they are well (advanced directives)". (WM Carer)

"I have a sticker on my husband's notes at the GPs to state that he is willing for me to talk to GP about him.....There are real problems when you think someone needs admitting and services don't agree – I have

got over that by refusing to take my husband home – so that services have no choice but to give him a bed following an assessment at the hospital”. (WM Carer)

A small number of carers taking part in the consultations received ‘psychosocial interventions’ (PSI), that is formal family training in communication and the management of psychological and social difficulties, tailored to the needs of that family. This had proved useful in reducing conflict within the family, and improving awareness of signs of impending problems:

“Try behavioural family therapy (psychosocial interventions); we did and it has helped us to understand each others’ perspectives and our relative now allows us to go to professionals when we think they need help”. (WM Carer)

### **Sensitivity to cultural and contextual issues**

#### **Key messages**

- It is not easy to offer ready prescriptions for dealing with cultural issues in carer assessments. Efforts to develop family-centred assessment practices that are culturally sensitive necessarily implies having (i) an affinity with cultural contexts, (ii) an understanding of how cultural beliefs and values shape norms, expectations and responsibilities for family care, (iii) an ability to address first language preferences.

It was considered important that assessments should be sensitive to the identities of carers and their role relationships, for example rural carers, those from black and minority ethnic groups, young carers, and carers with differing relationships to the user, such as spouses, siblings and parents. There were suggestions about how this could be achieved:

“At very least carers need a choice of worker, for example, from the same culture or not, people from some cultures do not want a worker from own culture as this potentially threatens privacy”. (NW Carer)

“For many Asian families, what needs to be understood is that services will not try to separate the family. I spent 2 hours with the CPN emphasising this on behalf of my parents. Families will not go near services if they fear being separated”. (NW Carer)

Carers emphasised the need for staff training in cultural awareness, for example, to ensure that the needs of people who are English speaking but from another culture are not overlooked:

"Cultural differences are overlooked if we speak the same languages, so African-Caribbean's have different beliefs, different food etc, but this is often forgotten because they speak the same language". (WM Carer)

"This is also the case with Irish people, different cultures overlooked because they have the same colour skin. There needs to be sensitivity to words and language". (WM Carer)

"Staff are not aware of different cultures, so for example there is more stigma about mental illness in Asian cultures - people still feel we 'look after our own". (NW Carer)

It was considered important that interpreters be booked in advance of assessments for carers who do not speak English, but it must also be recognised that people from other cultures may have additional difficulties understanding medical terminology and the UK healthcare system:

"When my husband became ill I had no idea how the medical system worked, how it differed from the Japanese system. I had to learn everything – who to tell, how to access services, what services existed. This was hard because my husband initially refused help and I was desperate but had no idea what to do. My husband's family saw supporting my husband as my role so I was very alone". (SE Carer)

Again, some positive suggestions for ways of meeting cultural needs were made:

"I think it would be helpful to have someone to go with me to the GP or to be there at a home assessment to help me make myself understood and to help me understand medical terminology. (First language Japanese). I needed information but I didn't know what information, and I couldn't always understand what they were talking about". (SE Carer)

"We have a team with members from different ethnic groups with people who speak different languages. We take a member of this team when we assess a person from an ethnic minority, not just as an interpreter, but also because of their cultural awareness". (SE Carer Worker)

## **OUTCOMES of assessment**

### **Key messages**

Carers had some clear views about the desired outcomes of assessments:

- better support for the person with mental health problems;
- better understanding of carers' situations and expertise, leading to (i) more respect for their contributions and (ii) their fuller inclusion in the team;
- a clear plan to address carers' needs with named responsible people and their contact details;
- a focus on empowerment options, as defined by themselves, as well as support;
- more creative and innovative services, including wider use of direct payments;
- attention to the options available if carers feel unable to continue in their role;
- linkage of identified unmet needs from assessments to future service planning.

Carers were able to identify what they wanted to achieve through assessments. A common feature within their comments was that more timely and tailored support directed at the cared-for person would first of all be the best way to alleviate demands upon them as carers:



"Carer assessments should facilitate recovery of the client and identify where the carer fits into that and the support they require to do this."

An outcome domain associated with the above was the need for assessors to have a better understanding of carers' situations and expertise, leading to more respect and inclusion in the care team:

"Agreements (rather than assessments) to agree roles, responsibilities, what will happen in given circumstances (a bit like a contract)". (SE Carer)

It was considered that this required a clear plan to address carers' needs, with named responsible people and their contact details:

"A plan to address the carer's needs should be agreed following the assessment and action should follow. Assessment without subsequent support reinforced the belief that only lip service was paid to a carer's assessment, and that they were carried out largely to meet official 'targets'". (NE Carer)

"Assessments should be 'followed up' in a flexible manner, with carers themselves having the name of a contact person who they could get hold of, if and when their circumstances changed". (NE Carer)

Carers also stressed the need for support that truly empowered them. By this they meant the striking of relationships with assessors and named workers that led to a win-win situation in which both they and the person they care for can articulate and achieve what they want:

"The assessment process is an opportunity to give information, and to support carers and empower them to ask the right questions, identify the services that they need and the questions they might ask to ensure the best services for the person they care for". (NW Carer)

Wider use of direct payments was thought to be a potentially valued mechanism for achieving these goals in some circumstances:

"Any needs identified can be met through direct payments. It is important that people are aware of their rights for direct payments. Once a number of requests are put in for a service then commissioners become aware of the need for a new service/training etc (eg psychosocial interventions could be paid for through direct payments, but would be more effectively provided through commissioning of a PSI worker/course locally)". (SE Carer Worker)

When no longer able to continue in their role, it was important for carers to feel that there were contingency plans agreed with agencies:

"The priority is to relieve the stress on carers by ensuring that their relative is adequately supported; carers need to see their relative having a good quality of life through social activities and employment to relieve boredom and inactivity; then my son needs housing support and financial support to prevent him getting into debt; then we need to plan what will happen when we are not here any more – this needs contingency planning". (WM Carer)

Carers also felt that their experiences, as expressed through assessments, should be used to inform future service planning:

"Carer assessments are not just important on an individual basis; they provide evidence of gaps in services where needs are not being met. This evidence is essential if we are to present a case for funding new projects (eg respite care). It is essential therefore that assessments do establish what carers would want if it were available, rather than only offer them existing provision. We need to use assessments to shape services so that they meet our needs rather than us fitting into existing provision". (East Carer)

"If we use CA to identify unmet needs carers assessment can become a driving force for change and improvement". (London Carer)

Finally carers had some very specific views about what should be done to help them feel as though they were fully engaged as partners with services in addressing the mental health care needs of their relatives. They felt that the assessment was a potentially important, but often missed, opportunity to provide emotional support, to give them information about mental health problems, treatment (including effects and side effects of medication), the type and range of support/help available, who to contact in a crisis, and ways in which they might manage the problems of living with the person with mental health problems, and strategies for managing their own distress, financial problems and employment issues:

"We need to know about what might help before we can possibly know what we need. Therefore assessment needs to include a list of all the possible things that might help us (with information about them) and we can say whether we would like that service. This is how carer assessments can become creative and empowering tools". (London Carer)

"We don't understand the language, the roles of different staff, shift patterns, who are staff and who are patients (no uniforms). We need an assessment to find out what we don't know and begin to answer our questions". (East Carer)

"Assessments need to assess our understanding and our ability to cope with the patient ourselves, and they need to be sure that we are told what we are expected to do, otherwise you find your son arrives home from hospital with no prior notice and breaks the door down to get in and nobody has asked whether you can cope". (London Carer)

"Information is absolutely essential from the very start - medication, side effects, treatment, symptoms, how to manage behaviour etc; the whole family needs support as different views mean that family conflict arises". (London Carer)

"We need to be given information – a package telling us about mental illness, the medication and side-effects and the services and therapies that are available, and then we could do a self assessment on what our needs are rather than have a formal meeting". (East Carer)

"We need to know what is happening; and we need to know about our rights and entitlements as carers. We can miss out on years of benefits and support just because we don't know what we are entitled to". (WM Carer)

# APPENDIX 4



The  
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School  
Of  
Medicine  
& Biomedical Sciences.

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## AN OPPORTUNITY FOR YOU TO MAKE A DIFFERENCE

As someone who has had a carer's assessment we would like to invite you to help us with an important research project. The aim of the project is to find out what carers **really** want from an assessment, and your views would be invaluable.

If you choose to take part we would like to hear about your experience of the assessment, what worked well, what could be improved, and whether you feel it will make a difference to you as a carer.

This will involve talking, in confidence, to a member of the research team, either a carer trained in interviewing techniques, or a full-time researcher experienced in working with carers. The choice is yours.

We are talking to over 100 carers throughout England and, based on their experiences, we will be presenting the results at a series of conferences involving carers, practitioners and policy makers in order to produce best practice guidelines to ensure that all carers benefit from assessment.

Please find enclosed further information about the study, brief details about members of the project team, a reply form indicating whether you would like to help us, and if so who you would like to talk to, together with a freepost (no stamp necessary) envelope for your response.

We look forward to hearing from you.

Mike Nolan  
Project Investigator



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Partnerships  
In  
Carer  
Assessment  
Project.

A study looking at assessments for carers of people with mental health problems

# Carer Information Sheet

## What is the study about?

Although carers of people with mental health problems are entitled to an assessment, we know from previous studies that the type of assessment they get can vary. We want to know what carers **really** want from an assessment. That is the main aim of this study. We would like to explore with you what your assessment was like, what went well, and what could be improved. But before you decide if you would like to take part it is important that you understand why the research is being carried out and what it will involve. This leaflet provides you with this information. Please read it carefully and discuss it with others if you wish. If you would like further information, or anything is unclear, please feel free to call Mike Nolan (Tel: 0114 226 6851/6849) to ask him any questions you have.

- Your name, address, or any other personal details will not be disclosed to anyone outside the research team.
- Taking part in this study will in no way affect the services you receive or your right to receive services.

## Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Even if you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the services you receive.

## What will I have to do?

We would like to talk to you about your assessment and what it was like. This will either be a carer trained in interviewing, or a full-time researcher. With your agreement we would like to tape-record our conversation. If you do not want the conversation to be tape-recorded then we can take notes if you prefer.

With your permission we also want to talk to the person who carried out the assessment to get their views on the process. However, we will **not** tell them what we have discussed. We would also like to look at the assessment documents.

## Where will the interview take place and how long will it last?

You can choose where the interview takes place, for example, at your home or another place that you prefer. The first interview will last approximately an hour.

## Will my taking part be confidential?

- All the information collected about you will be strictly confidential.
- You can have a copy of the taped conversation to keep if you wish and you can ask to see all the information we hold relating to you at any time.

## What will the information be used for?

The information will form part of the research findings. These findings will be presented to national organisations representing carers of people with mental health problems, and to service agencies and policy makers so as to spread the word about what carers want from an assessment. Reports and articles will be produced from this information, and copies of the published reports or articles will be

- We cannot supply any services.

### **When will I have the time to discuss my participation?**

If you would like to take part, a member of the research team will contact you to arrange a convenient time and place. You can ask any questions you like at this point. You may also discuss the project at the start, or the end, of the interview, or at any time during the interview.

### **What happens to the information collected?**

- The information that you give us, along with that from other carers in a similar situation, will be analysed to identify similarities and differences in experiences so that we can see what a good assessment looks like.
- The tapes will be destroyed at the end of the study.

### **What are the benefits of taking part?**

Unfortunately, we are not able to pay you for taking part, but we will of course pay any expenses, such as travel, that you might incur. However, you will have the chance to give your opinions about your assessment and the services available to you as a carer. This information should help to influence policy and practice and lead to better assessments for carers in the future. If you wish we can provide you with contact details of organisations that support carers. A copy of the best practice guidelines produced from the research findings will be made available to you at the end of the project should you wish.

available if you would like them. The information will also be used to produce the best practice guidelines discussed above.

### **How long is the study likely to last?**

The study itself will take three years and will be completed in early 2007. The interviews will be conducted in the second and third years of the study.

### **Who is organising and funding the research?**

The research is organised by the University of Sheffield and funded by the Department of Health.

Financial indemnity for this project is being provided by the University of Sheffield.

## Members of the Project Team

### Who would you like to talk to?

In addition to exploring carers' experiences of assessment the Partnerships in Carer Assessment Project (PICAP) is interested in finding out if carers would prefer to talk to other carers trained in interview techniques, or a full-time researcher experienced in working with carers. To help you decide, below you will find some brief information about the carer researchers and the full-time researcher. Please read this and then indicate on the reply form who you would like to talk to about your experience of the assessment. Note that the carer researchers may work in pairs in order to provide support to each other.

#### Carer Researcher



**Jen Kilyon**

Jen has been a carer for her son for almost 6 years and lives near Bradford. She campaigns locally, regionally and nationally to make mental health services more responsive to the needs of carers and those they care for. She is keen to find out directly from other carers how assessments can make a difference to their lives and to help disseminate this work nationally.

#### Full-time Researcher



**Mike Nolan**

Mike has a background in nursing and has worked with family carers of older people, including people with dementia, for over 20 years. He is particularly interested in understanding how caring changes over time and how services can be provided to carers when they need them most. He is currently based at the School of Nursing and Midwifery, University of Sheffield.





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**Email:** m.r.nolan@sheffield.ac.uk

## AN OPPORTUNITY FOR YOU TO MAKE A DIFFERENCE

Name: .....

I am interested in taking part in your research study and would be happy for you to contact me via:

Postal address: .....

.....

.....

Telephone: .....

Email: .....

Having read the brief details about project team members I would like to talk to (please tick appropriate box):

The carer researchers ☐

A full-time researcher ☐

I don't mind ☐

Please return this form as soon as possible in the freepost envelope provided.

Many thanks

# APPENDIX 5

## **Working with carers of people with mental health problems as researchers**

Although UK health policy now requires 'consumer' or 'public' involvement in health care research, the term is generally assumed to refer to service users and there exist very few accounts of the involvement of carers as researchers. Here we describe the ways in which carers were involved in PICAP, and their contributions to the research, later we reflect upon the lessons that we all learnt along the way.

As noted earlier, the role of carers in general, and mental health carers in particular, is the focus of increased government attention. In 2002 the DoH published guidance on developing services for mental health carers that are: positive and inclusive; flexible and individualised; accessible and responsive; integrated and co-ordinated with mainstream services. Practical initiatives to enhance the involvement of carers as partners in mental health care include: the development of carer support services (eg Supporting Carers Better Programme - [www.scbnetwork.org](http://www.scbnetwork.org), and the Partners in Care Campaign run by the Royal College of Psychiatrists and the Princess Royal Trust for Carers - [www.rcpsych.ac.uk/campaigns/pinc](http://www.rcpsych.ac.uk/campaigns/pinc)); carer education projects (eg the Meridan programme - [www.meridanfamilyprogramme.com](http://www.meridanfamilyprogramme.com)); and carer involvement leads in regional development centres. However, initiatives to involve carers as partners in research have not developed at the same rate.

Although mental health service users have documented their role in all aspects of the research process (Faulkner and Morris 2002), and the Mental Health Research Network has published a strategy for the involvement of service users in research (MHRN 2004), there is no parallel strategy or co-ordinated approach for carers. Pinfold et al (2004) scoped the involvement of mental health carers in research and found three relevant initiatives: the Institute of Psychiatry manages a website providing information about research into mental illness for carers; a carer research network is being set up to enable carers to work on research projects undertaken by the Avon and Wiltshire Mental Health Trust; the Alzheimer's Society runs the Quality Research in Dementia (QRD) Network in which carers and people with dementia are actively involved in setting the research agenda, awarding grants and assessing outcomes. However, at the time of the study, there were no papers published in England describing carer involvement in research; one paper described the experience of users and carers working collaboratively in a research project (Repper et al 2004), and several 'Carer Focussed Monitoring' groups have been developed to audit services following the User Focussed Monitoring approach developed by Rose (2001). The National Co-ordinating Centre for Service Delivery and Organisation (NCCSDO) has commissioned a number of studies (of which PICAP is one) in its carer research programme (see [www.sdo.lshtm.ac.uk/carers.htm](http://www.sdo.lshtm.ac.uk/carers.htm)) but (with the exception of PICAP) carers are mainly conceived of as the subjects of, rather than participants in, the research process. Rose et al (2002) undertook a review of user and carer involvement in change management in mental health. They found only a small number of projects describing carer involvement, and only 25% of papers made reference to carers.

### **Carers as researchers**

In 1996 the DoH established the Standing Advisory Group on the Involvement of Consumers in the NHS Research and Development Programme, 'Involve', to 'improve the ways in which healthcare research is prioritised, commissioned, undertaken and disseminated'. This was followed by publication of the Research Governance Framework for Health and Social Care (DoH 2001), which requires involvement of consumers at every stage of research, and greater transparency in reporting research; moves which have resulted in funding streams requiring bidders to demonstrate appropriate involvement of consumers in research.

Although in policy terms 'consumer' refers to the public as a whole: service users; their families and community members, the guidance that has been written on consumer involvement generally refers to service users. It appears to be assumed that the same issues pertain whoever the 'consumer' is. They may be a user of services as diverse as primary care and/or cancer or mental health services; they may be a carer or a lay member of the public. Yet it is a truism that different people have different expectations of services, so they may have different priorities and different preferences. In mental health, service users and carers often hold different views about mental health services (Perkins and Repper 1999), and have different experiences and motivations for getting involved in research. Despite this many of the principles for, and of, involvement may be similar for all consumers. However, these should be seen in the context of good practice in consumer involvement more generally.

### **Good practice in consumer involvement**

Guidelines for consumer involvement have been produced by Involve (Baxter et al 2001, Royle et al 2001, Hanley 2003), and the Mental Health Research Network has produced guidelines for service user involvement (Faulkner 2004). These practical guides all cover similar areas including: the benefits of consumer/service user involvement in research; ethical issues; capacity building; training; support; payment, and resources. These are essential considerations for researchers undertaking projects involving consumers: all should be clear about why and how a partnership philosophy is to be adopted and implemented. Perhaps the first decision to be made is the level of involvement that is required: consultation – obtaining consumers' views to inform decision making; collaboration – ongoing partnership throughout the research process; or user-controlled research – where the locus of power and decision making lies with consumers (Hanley 2003 provides a description of the advantages and disadvantages of working at these three levels). The following discussion about principles of consumer involvement refer largely to collaborative research, which was the approach taken in the PICAP project.

Consumer involvement may benefit both the consumer researcher – increasing skills, confidence and future work opportunities – and the research process and findings (Involve, Hanley 2003). Consumers bring expert knowledge of their experience of services and of health problems so they can help to ensure that the research is relevant to clinical practice and meaningful to those using services (Trivedi and Wykes 2002, Hanley 2003, Allam et al 2004). Their views can complement and challenge mainstream perspectives (Rose 2003) having an influence on the research subject, method, questions asked (Trivedi and Wykes 2002, Allam

et al 2004) and the indicators of a successful outcome (Trivedi and Wykes 2002, Wykes 2003). Several authors suggest that interviewees are more likely to speak freely and honestly to another service user or carer than to a professional (Allam et al 2004), and there is some evidence to suggest that service users respond in more detail when interviewed by someone else with experience of using services (Polowycz et al 1993, Clarke et al 1999), and that response rates are higher, especially among groups who are generally hard to access (Fleischman and Wigmore 2000, Hanley 2003). Thus, people who are difficult to engage in both services and research may be more willing to participate in research conducted by another service user, and may find it easier to speak to someone with a similar agenda: someone other than the professionals who they associate with services. However, it cannot be assumed that this is necessarily the case for carers. Although a marginalised group, they may actively wish to speak to professionals to make their experiences explicit, they may have very different feelings about sharing their experiences or engaging with service providers.

If consumer involvement is to avoid 'tokenism', it is not sufficient to simply invite consumers onto the advisory panel of the research. Wherever funding, time and appropriate personnel are available, consumers should be involved in the planning stages of the research so that the underpinning principles and design are agreed – rather than consumers joining an established project after it has begun (Thorne et al 2001, Faulkner and Morris 2003, Faulkner 2004). This is most successful where local expertise has been identified and relationships built up over time. Rose (2003) emphasises the importance of local capacity building so that interested consumers receive training and support to pursue research qualifications so that they have the skills, language and confidence to join a team of researchers from the beginning of a project. This requires a willingness to: negotiate aspects of the research; view all collaborators as having a valuable contribution to make and to take each other seriously; a genuine sharing of power (Trivedi and Wykes 2002, Faulkner and Morris 2003, Wykes 2003). This may create tension, and is a particular issue in mental health where service users may be seen as not able to make rational judgements due to their 'madness' (Macran et al 1999, Beresford 2002, Rose 2003), and carers may be viewed as having a biased view of services due to their - often negative - personal experiences. It is just these different experiences and views that are of value in collaborative research; if consumers were in total agreement with the professional researchers they would not be contributing to the research process. However, this must go beyond a shared philosophy; practical issues of transparency, clarity of language, and accessibility (in terms of organisation to take account of the difficulties that consumers may experience) must be considered so that non-professionals are able to make a full contribution.

A considerable number of papers describe the research training provided for mental health consumers to prepare them for a participatory role in research (Nichols 2001, Nichols et al 2003, Faulkner 2004, Lockey et al 2004, Repper et al 2004). Training is often specifically designed to prepare them for a particular project, but in a review of research training provided for service users, Lockey et al (2004) identify a number of common features: clarity about the aim and purpose of the project and the specific research tasks involved; a focus on demystifying research, particularly the language used; an interactive format so that all participants can contribute and recognise their own skills and experiences; and a safe, flexible and accessible environment. Nichols et al (2003) provide a detailed description of the training provided to service user researchers for the Mental Health Foundation's Strategies for Living Project. This included: introduction to research; ethical issues; questionnaire design;

interviewing skills; focus groups; analysis; writing up and endings. Similar training was provided for service users and carers by Allam et al (2004) who emphasise the need to focus on active listening skills in interviewing. These skills proved to be most difficult for participants to grasp due to the need to be reactive and flexible during in-depth interviews. All authors emphasise the need to provide a thorough training to maintain the standards of research, some suggest that training is also required by professional researchers to prepare them for working with consumers in research (Townend and Braithwaite 2002, Trivedi and Wykes 2002).

Finally, ongoing support for consumers is essential to the success of the project (Allam et al 2004, Faulkner 2004). This needs to cover three areas: emotional, practical and supervision of research skills. Interviewing people who experience similar difficulties, or who have been through traumatic experiences, can be disturbing and participants need to be prepared for this during training. Allam et al (2004) suggest proactive contact following every interview to talk through any difficulties. In addition, the time pressure of the project may be stressful for people who are vulnerable, and it is essential that they have access to support, and that timescales are both realistic and flexible. Practical support includes considerations of such things as transport, meeting times and payment. There are various ways in which payment can be organised but it is important that it is realistic. Allam et al (2004) found that interviews took far more time than was anticipated if preparation, travel time and debriefing was allowed for. There are barriers to the amount of payment that people on benefits can receive which can make payment complicated, full guidance is provided by Involve (Hanley 2003). As well as payment for time, travel expenses and subsistence should be paid immediately or in advance. Other resources to be considered are access to office equipment, stationary and administration, all issues that can be problematic if consumers are working from home or at some distance from the research centre.

The PICAP research team members had experience of working with consumers and several of the professional researchers are, or have been, carers themselves. We were aware of the principles of good practice and endeavoured to maintain these standards throughout, but this was not without difficulties.

# APPENDIX 6



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# **Partnerships in Carer Assessment Project (PICAP) Interactive Workshop**

King's Fund, London

Wednesday 18 July 2007



## **Principles for working with carers, and of good assessment practice**

Assessment must be part of an ongoing partnership between carers and services, where there is regular contact with a known person.

Contact with carers should be initiated as early as possible and the carer engaged as an equal partner from the outset.

The carer's role and expertise must be fully explored, recognised and respected (equally, areas where carers may lack knowledge and expertise should be acknowledged and addressed).

Carers should be involved in planning and agreeing the care plan for the person for whom they care.

Carers must receive the information and support they need in order to help them to care most effectively.

A carer's willingness or ability to care must not be taken for granted.

Assessment should start by exploring carers' understanding of what the assessment involves.

Assessment must be proactive and planned rather than crisis driven.

Assessment should focus on the outcomes or goals that are important to carers.

Assessment should take an holistic approach and recognise the needs and preferences of both the carer and the person they care for.

Assessment should result in a care plan developed in collaboration with the carer that makes clear the type and level of support to be provided, when and by whom.

Assessment must take account of differing cultural, ethnic or other beliefs and value systems in families.

First language preferences of carers should be respected.

Good carer assessment requires assessors to have specialised and broad ranging knowledge and highly developed interpersonal skills.

## Guidelines for preparing for and undertaking the assessment

Carers should have information about the assessment well in advance, this should include a list of things to think about/questions to ask during the assessment so that they are clear about what to expect.

Assessment must not be seen as a 'test' nor adopt a 'tick box' approach.

Carers should be told that they can have a friend or advocate present if they want.

It has been suggested that a good assessment should EMPOWER carers by:

- Establishing a suitable environment for the assessment and ensuring sufficient privacy and time.
- Making a genuine effort to build trust and rapport.
- Providing interest in the carer as an individual with needs of their own, not just as a resource or a problem.
- Offering honest, realistic options of what support might be available, with an indication of likely delays or limitations in service delivery.
- Willingly listening to the carer's and user's beliefs and values in order to obtain a balanced picture.
- Engaging in an open dialogue where the experience and expertise of carers is validated and incorporated into the assessment process.
- Relinquishing their professional perspective, having an open mind and being prepared to learn together.

**Do you think that:**

- a) This captures the characteristics of a good assessment?
- b) The acronym EMPOWER is an appropriate one for use in the context of mental health?

## What the assessment should cover

Assessment should give carers the opportunity to focus on the outcomes or goals that they consider appropriate, and may include the following areas:

Context and background	<ul style="list-style-type: none"><li>- relationship to cared for person</li><li>- physical equipment</li><li>- financial situation</li><li>- employment status</li><li>- quality of relationships</li><li>- family circumstances</li><li>- caregiving history</li></ul>
Carers' definitions and perceptions of	<ul style="list-style-type: none"><li>- health and status of cared for person</li><li>- nature of illness and contributing factors</li><li>- relationship with cared for person</li><li>- treatment regime</li><li>- support provided for, or required by, cared for person</li><li>- their role as a carer (now and in the future)</li><li>- their own health and wellbeing</li><li>- things they find difficult about caring</li><li>- things that they find positive about caring</li><li>- any conflicts of interest</li><li>- caregiving contributions from family members and scope for mutual help</li><li>- the resources (material, accommodation, social) they have to help them care</li><li>- their feelings about the future</li></ul>

Support that might help improve the quality of life of the cared for person.

Support that might improve the quality of life of the carer.

The type of support they need to help them to care more effectively from:

- within the family/their own support networks
- formal services.

## **The outcomes of assessment**

### **Assessment should result in:**

Better support for the person with mental health problems, both from statutory services and from informal/family networks.

More informed carers, with a better understanding of the situation of the person with mental health problems.

Better support for carers, both to continue caring if they wish, and to have a life outside of caring.

A better understanding of the carers' situation and expertise, leading to more involvement and inclusion in the care team.

A clear plan to address carers' needs, with a named responsible person and their contact details.

More empowered carers, with better awareness of the type of help and support available and how to get it.

More creative and innovative services.

Carers' feeling more in control.

Carers' feeling safe at home and in the community.

Carers' having more hope for the future.

Identification of need to inform future service planning.

Having a contingency plan (advance directives for example) to cover any sudden changes of circumstances.

A clear idea of who to contact in an emergency/crisis.

## **Disclaimer**

This report presents independent research commissioned by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, the NIHR SDO programme or the Department of Health. The views and opinions expressed by the interviewees in this publication are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, the NIHR SDO programme or the Department of Health

## **Addendum**

This document was published by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) research programme, managed by the London School of Hygiene & Tropical Medicine.

The management of the Service Delivery and Organisation (SDO) programme has now transferred to the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton. Prior to April 2009, NETSCC had no involvement in the commissioning or production of this document and therefore we may not be able to comment on the background or technical detail of this document. Should you have any queries please contact [sdo@southampton.ac.uk](mailto:sdo@southampton.ac.uk).