

# 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)*

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## **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.

**Disclaimer**

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**Addendum**

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