Services to Support Carers of People with Mental Health Problems

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Consultation Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO)

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prepared by

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Acknowledgements

We are grateful to the many people from both statutory and voluntary sector organisations who willingly gave their time and their expertise to contribute to the consultation exercise. We would also like to express our particular appreciation to the 'key informant carers' for sharing their experiences and perspectives and, in many cases, for travelling considerable distances to take part in the discussion groups.

Executive Summary

Introduction

This report summarises the findings of a consultation exercise carried out as part of a scoping study commissioned by the NHS Service Delivery and Organisation R & D Programme, and carried out by a research team from Social Policy Research Unit (SPRU) at the University of York and the primary and community care consultancy Acton.Shapiro, during the period October 2001 to March 2002.

The overall aim of the scoping study was to advise on further research in the area of services to support carers (including young carers), of working-age adults and older people with mental health problems. The study drew on evidence from published and grey literature (both UK and international) about such services, and on consultation with key stakeholders, to identify the main gaps in existing knowledge, and to define what is meant by 'effectiveness' and 'cost-effectiveness' in relation to these services.

This report summarises the findings from the consultation exercise. The results of the literature review are contained in a separate *Literature Review Report*, while a third document, the *Overview Report*, draws together the key themes and issues from both the literature review and the consultation, and identifies priorities for further research.

Methodology

The key stakeholders involved in the consultation included national statutory and voluntary sector organisations concerned with policy and practice in relation to carers and mental health; a small number of individuals with particular expertise in the support of carers from specific groups; and key officers from selected local areas of the country which had taken significant steps to improve support to carers of people with mental health problems. All the interviews were carried out on the telephone, following topic guides.

A number of 'key informant carers' also contributed to the consultation, either by taking part in a discussion group or a telephone interview. These carers had direct experience of caring for a person with a mental health problem but also, through their involvement in national bodies or networks, or local or national initiatives and groups, had a broad perspective on carers' needs and services. The aim of this final stage was to validate and check with carers the findings from the earlier stages of the work, and in particular to examine whether they endorsed the concepts of effectiveness and cost-effectiveness, the models of good practice identified, and the priorities for future research.

Additional information and perspectives were obtained in response to the publicising of the project at two national conferences, and via mailings through the networks of three national organisations.

The data obtained from the consultation exercises were analysed using the 'framework' technique (Ritchie and Spencer, 1994), which involves familiarisation with the data collected, followed by the identification and interpretation of key topics and issues that emerge from the accounts. Supplementary information about 84 services was put into a database, although it was not possible, due to time and resource constraints, to assess whether the services identified were effective or constituted 'good practice'. Material from the database was used to inform the research team's thinking about service structures and service delivery.

Findings

The consultation with key stakeholders enabled the research team to explore a range of different perspectives on the issues under consideration and to set the evidence from the literature review within a broader context.

Supporting carers – understanding their needs

A common understanding of the broad pattern of services needed to support carers emerged from the discussions with the contributors. They highlighted the need for a range of services which could provide information, support and advice, training and education, and time off from caring. They also emphasised the central importance to carers of effective services to support the person with mental health problems.

Supporting carers – underlying principles

The consultation highlighted that services would only be effective if they were underpinned by certain underlying principles, or if they demonstrated certain key characteristics. Effective support was in fact perceived to be as much about good practice, i.e. about the *process* of delivering services, as about the specific types of services provided. The contributors suggested that services for carers were most effective when they were positive and inclusive, flexible and individualised, accessible and responsive, integrated and co-ordinated. The importance of effective communication between professionals and carers to achieve a two-way flow of information was particularly stressed.

Supporting carers – services and interventions

Contributors identified and commented on the different ways in which services were attempting to address the support needs of carers for people with mental health problems. Some of these initiatives were in response to Standard 6 of the National Service Framework (NSF) for Mental Health, for instance the development of specific carer assessment forms which were often integrated into the Care Programme Approach (CPA). In many areas, efforts were being made to develop practical solutions to issues relating to information sharing and the rights of the person supported to confidentiality. In some areas, specialist mental health carers' workers had been appointed either as *carers' development workers* (or specialist social workers) or *carers' support workers* (or family support workers). Other support services provided for carers included short breaks from caring (often developed through the Carers Special Grant); support groups and social events; educational and training programmes; telephone and computer-based services; and user-friendly, accessible written information.

Contributors did not, however, identify a single blueprint or service model which could be regarded as 'ideal' or effective. Many felt that, if services were to be effective, they had to be tailored to local needs and circumstances. They emphasised the importance of providing a coordinated range of services in order to meet carers' different support needs and to offer them choice. Contributors also stressed that support for carers was likely to be most effective when offered as part of a holistic response to the family situation. They highlighted the importance of integrating carer support into local mental health services, and a number suggested that effective support for carers of people with mental health problems may best be achieved by changing attitudes, systems and practices within mental health services, rather than by developing dedicated services to support carers.

Effectiveness and cost-effectiveness

Contributors conceptualised effectiveness in five main ways, in terms of benefits for:

- the carer
- the person with mental health problems
- the family as a unit
- service usage
- society as a whole.

They held mixed views about methods to evaluate effectiveness including, for example, measuring utilisation rates, the use of satisfaction surveys or evaluation forms, and performance indicators (for instance, those developed by the King's Fund). It was also suggested that carers should evaluate the effectiveness of their own support packages through the CPA. It was acknowledged, however, that evaluating the effectiveness of support services could be difficult and time-consuming, and consequently was not necessarily prioritised by service providers.

Cost-effectiveness was seen as a complex area which did not necessarily equate to cost minimisation. Any evaluation of a support service would need to take account of both the *quantity* and the *quality* of support provided, the need for skilled and experienced staff, adequate time and possibly home visits, and the duration of the intervention. Support that was too short term might not be cost-effective if benefits were not permanent; alternatively, support that was too long term could increase dependence on service and in turn affect cost-effectiveness negatively.

Contributors noted that many carers were involved in caring activities for a long time, and therefore sought support that would be effective on a long-term basis. Short-term funding arrangements for many carers' services were seen as potentially reducing their cost-effectiveness as staff might have to devote time to generating further income.

Current evidence and dissemination

In general, contributors took the view that, where research on interventions was available, it was of high quality and/or comprised a relatively large body of knowledge. Areas perceived as supported by empirical evidence included some specific interventions or services to support carers or to support the person with the mental health problem as well as the carer/family as a whole; carers' needs; and the emotional, physical and financial impacts of caring. Some contributors, however, questioned whether available research might be too narrow or specific a context to be useful in a wider or different setting. Overall, they believed that the knowledge base about effective support for carers for people with mental health problems was sparse.

Contributors emphasised the need to further improve the dissemination of existing and future research evidence. They highlighted the importance of research findings being presented in accessible forms and through professional networks. They defined evidence, however, in very broad terms and regarded formal research evidence as only one part of the knowledge base. While they recognised the importance of research evidence, most drew on a number of sources of evidence, including applied research, local evaluations, consultation exercises and knowledge of 'good practice' passed on by fellow workers.

Gaps in research and suggestions for further research

Contributors suggested a need for:

- research into the comparative effectiveness of different models of *service delivery and interventions* for carers
- research to inform how attitudes within mental health services could be changed
- research into specific groups such as young and young adult carers, black and ethnic minority carers, carers of people with dual diagnosis and carers supporting more than one person
- research into the long-term *impact* of caring for someone with a mental health problem.

In terms of *research design*, contributors wanted to see both longitudinal research that looked at the impact of caring and the impact of new policies and systems, and also relatively short-term, practical research which could directly influence service planning and delivery in the short to medium term. They particularly highlighted the need for rigorous qualitative research that encompassed the experiences and perspectives of carers, people with mental health problems, and mental health professionals.

Many contributors felt that research in this field could usefully draw on other relevant areas of research. These included research on organisational/change management; psychosocial interventions generally, and family therapy in particular; family support, including fostering and child protection; and inter-agency working and the provision of integrated services.

Conclusions

The consultation exercise provided a valuable insight into the perspectives of key stakeholders in this field. Contributors identified different approaches currently being adopted to develop support for carers of people with mental health problems, and stressed the importance of the way in which support is delivered. They identified a number of areas for further research which they felt would assist in the implementation of current policy and/or provide a deeper understanding of the most effective approaches to supporting carers.

The *Overview Report* from the scoping study draws together the key themes and issues from both the consultation and the literature review, and identifies priorities for further research.

The Report

Section 1 Introduction

In October 2001, the NHS Service Delivery and Organisation R & D Programme commissioned the Social Policy Research Unit (SPRU) at the University of York to undertake a scoping study on the effectiveness and cost-effectiveness of services to support carers of people with mental health problems. The study was carried out by a research team from SPRU and the primary and community care consultancy Acton.Shapiro, during the period October 2001 to March 2002.

1.1 Aims and objectives

The overall aim of the scoping study was to advise the SDO Programme as to what further research should be commissioned in the area of services to support carers (including young carers), of working-age adults and older people with mental health problems. There were two main components to the study:

- an examination of the evidence from published and grey literature (both UK and international) about effective and cost-effective services to support carers of people with mental health problems
- consultation with key stakeholders from national and local bodies concerned with mental health and carers' issues, and with mental health carers themselves.

The study then drew on evidence from both the literature and the consultation with relevant stakeholders, to identify the key gaps in existing knowledge, and to define what is meant by 'effectiveness' and 'cost-effectiveness' in relation to services to support carers of people with mental health problems.

This *Consultation Report* details the findings from the consultation with national and local bodies and key informant carers. The results of the literature review are contained in a separate *Literature Review Report*. A third report, the *Overview Report*, draws together the key themes and issues from both the literature review and the consultation, and identifies priorities for further research.

1.2 Structure of the report

The report is structured into nine sections. The methodology for the consultation with the key groups of stakeholders is described in Section 2 of the report. These included three groups: representatives from national statutory and voluntary sector bodies (and some key individuals); representatives from commissioning or provider organisations in selected local areas; and a small number of nominated 'key informant carers'. This section also explains how other opportunities were taken to obtain supplementary information from relevant sources.

In Section 3, the authors describe the views of the contributors from the stakeholder groups about the main support needs of carers of people with mental health problems. Section 4 focuses on the key features and underlying principles of support for carers, again from the perspective of the contributors, and in Section 5, the authors discuss how services have developed to address the needs of carers.

In Section 6, the discussion moves on to look at the ways in which the key stakeholders conceptualise effectiveness and cost-effectiveness in relation to support for carers. Section 7 focuses on the current use of research evidence and the suggestions of the contributors as to how evidence can best be disseminated. Perceived gaps in, and priorities for, research in this area are discussed in Section 8. Finally, Section 9 presents the conclusions from this part of the study.

1.3 Terminology

In order to ensure consistency between the three reports, the same terminology has been used wherever possible. With the exception of direct quotations, the term 'carer' has been used in preference to 'informal carer' or the American term 'care-giver'; and the terms 'person supported', 'person with a mental health problem' or occasionally 'patient' in preference to 'care recipient', 'service user', 'cared-for person' or 'dependant'. The term 'key informant carer' is used to describe those carers who directly contributed to the study, as explained in Section 2.3.

Section 2 Methodology

Three groups of key stakeholders were involved in the consultation: representatives from national statutory and voluntary bodies, managers and practitioners from a selected group of local organisations, and a number of key informant carers. In addition, in the course of the study other opportunities arose for consultation with interested individuals and groups, and these are described in Section 2.4 below.

2.1 Consultation with national bodies

At a national level, four key groups of organisations were involved in the consultation process:

- carers' organisations (2)
- mental health organisations (5)
- organisations concerned with young carers (4)
- national statutory bodies concerned with policy and practice in relation to carers and mental health, and in particular with the implementation of the National Service Framework for Mental Health (8).

Also included were a small number of individuals who had been identified as playing a key role in the development of support for carers of people with mental health problems (5) or as having particular expertise in the support of carers from black and minority ethnic groups (3). In total, 27 individuals were consulted (see Appendix A). The main objectives of the consultation were:

- to explore their understanding of what constitutes effectiveness and cost-effectiveness in relation to services to support carers of people with mental health problems
- to understand what research they would find useful, either in their own work or that of the groups with whom they work
- to use the knowledge and information held by these organisations to identify specific examples of good practice, and areas of the country which have made particular progress in supporting carers of people with mental health problems.

All the interviews were carried out on the telephone. The topic guide used in the interviews (see Appendix B) was sent to interviewees in advance, and detailed notes were taken during the interview.

2.2 Consultation with local managers and practitioners

The team also identified a sample of key officers from a number of agencies (both statutory and voluntary) or local areas of the country, which had taken significant steps to improve support to carers of people with mental health problems. It was judged that staff from these agencies and areas would have a better understanding of carers' issues, and be more familiar with the evidence currently available, than colleagues in areas that had made less progress in addressing carers' needs. The literature review, the consultation with the national bodies, the postal questionnaires (see Section 2.4) and the team's own knowledge and contacts all contributed to this process of identification.

Of the seven areas selected, three were predominantly rural and four predominantly urban. There was a good geographical spread, with two areas in the North of England, one in the Midlands, one in the South-West, one in the East and two in the South.

A total of 18 individuals were involved in the local consultation. Of these, 13 were based in the statutory sector and 5 in the voluntary sector. The contributors were all selected because they played a key role in the development of carer support services in their local area. Some were manager/planners and some were practitioners, though this was a secondary issue; in some cases the contributors had a dual function, particularly, though not solely, if they were based within the voluntary sector.

The purpose of the consultation with these local contacts was to seek their views on the main issues in relation to services and in particular to understand what research they would find useful in their work. The interviews also sought to develop greater understanding of what evidence about effectiveness and cost-effectiveness would help them in making decisions about developing and funding services.

As with the interviews with the national bodies, all the interviews were carried out on the telephone. The topic guide used in the interviews (see Appendix C) was sent to interviewees in advance, and detailed notes were taken during the interviews. Following the interviews, many contributors also provided additional written information about the services that had been developed in their areas.

2.3 Consultation with the 'key informant carers'

The aim of this final stage was to validate and check with carers the findings from the earlier stages of the work, and in particular to examine whether they endorsed the concepts of effectiveness and cost-effectiveness, the models of good practice identified and the priorities for future research. In undertaking this part of the consultation, it was considered essential to avoid duplicating the evidence about carers' needs which is already available in both published and grey literature, and to ensure that the views expressed were generalisable.

Given these aims, the research team decided to focus on a small number of 'key informant carers'; these were carers who had direct experience of caring for a person with a mental health problem but who also, through their involvement in national bodies or networks, or local or national initiatives and groups, had a broad perspective on carers' needs and services.

The contributors from the national and local bodies were asked to suggest 'key informant carers' who met the criteria outlined above. The research team contacted carers whose names had been put forward and invited them to be involved in the consultation, either by taking part in a discussion group or a telephone interview. Two discussion groups were organised, one in London and the other in Bristol and a total of 13 carers attended (7 in London and 6 in Bristol). The carers who attended had a broad range of personal experience, including caring for a partner, parent or adult child with mental health problems. A number of the informants had caring responsibilities for two or more members of their family. Two of those present were from minority ethnic groups. One of the key informants was a former young carer, and one was the father of two children affected by their mother's mental illness.

A 'scenario' approach (see Appendix D) was used to stimulate discussion within the groups about the key issues being considered by the scoping study: the key features and types of support for carers; underlying principles; concepts of effectiveness and cost-effectiveness; and gaps in or priorities for research.

The discussion groups were recorded and then transcribed in an edited form by the research team.

Those carers who were unable to attend either meeting were offered a telephone interview. Six carers took up this offer. The interviews followed a simple topic guide based on the key questions addressed in the groups, and detailed notes were taken during the interviews.

2.4 Supplementary consultation

As the project progressed, certain opportunities presented themselves by which the team could reach a broader range of organisations and individuals involved and interested in this field of work. These included two national conferences held during the early stages of the project, one by the Princess Royal Trust for Carers, in Colchester, and the other by NSF (Scotland), in Edinburgh. Questionnaires and fliers about the study were distributed at both events, and to members of the ‘Supporting Carers Better’ Network run by the Mental After Care Association (MACA), as well as to organisations on the Carers UK mailing list. A brief article about the study was included in a Children’s Society newsletter.

Over 70 completed questionnaires or letters were received from these sources. Communications were often accompanied by additional information about particular approaches, or copies of relevant articles or papers. The material from this correspondence proved particularly helpful in identifying key informant carers, areas perceived as developing good practice in carer support, and perceived research gaps and priorities.

2.5 Analysis

The data obtained from the interviews with representatives from national and local bodies, and from the discussion groups and interviews with key informant carers, were analysed using the ‘framework’ technique (Ritchie and Spencer, 1994), which involves familiarisation with the data collected, followed by the identification and interpretation of key topics and issues that emerge from the accounts. As part of the analysis, the research team also examined the information provided by those who returned questionnaires.

As was noted earlier, many contributors, including those who returned questionnaires, also provided supplementary information about services in their area. Brief details about these services were put into a database. However, the data it contains do need to be treated with caution. It was not possible, within the time and resources available for the scoping study, to assess whether the services identified were effective or constituted ‘good practice’. Nevertheless, 84 different services were identified, and almost a quarter of these were put forward by more than one contributor. The database did provide a useful mechanism for structuring this information, and material from it was used to inform the research team’s thinking about service structures and service delivery.

Section 3 Supporting carers – understanding their needs

In 1990, the Social Policy Research Unit at the University of York published a pioneering review of the literature (Perring *et al.*, 1990) that summarised what was known about carers of people with mental health problems. It highlighted how caring for someone with a mental health problem differed from caring for someone with physical disabilities, and noted that the substantial work on informal carers had often overlooked carers of people with mental illness. In the decade since the review was published much more has been learnt about the needs of this group of carers. There is evidence that the impact of caring means that carers of people with mental health problems need a range of services, including emotional support, respite, advocacy, crisis support and information (Allen, 1997). It is also apparent from the literature (Godfrey and Wistow, 1997) that this support needs to come from a wide range of agencies and it needs to be well co-ordinated.

The purpose of the scoping study was not to explore the needs of carers of people with mental health problems. However, during the consultation, the contributors made it clear that an understanding of these needs was fundamental to understanding what constitutes *effectiveness* in support – what patterns or types of services *work best* for these carers. This section therefore briefly discusses the key issues raised about the support needs of carers, and as such sets the context for the discussions about the characteristics of services and patterns of provision which follow in Sections 4 and 5.

There was considerable consensus amongst the contributors to this study – including the representatives from national and local bodies, and the key informant carers themselves – as to the main types of support that carers need. For the purposes of discussion, these have been summarised into four themes, although each theme contains elements which may overlap into another:

- information
- support and advice
- training and education
- time off from caring.

3.1 Information

Information was frequently highlighted as one of the most crucial aspects of support, enabling carers to understand the illness and its effects, and empowering them to make their own choices. Contributors said that carers needed two main types of information. First, specific information about their individual case – the illness of the person supported and the effects of their treatment – and second, more general information on a wide range of issues, including research into the effectiveness of treatments, viable alternatives to standard therapies, coping techniques, mental health legislation, benefits, carers' rights and, of course, available services and how to access them.

It was considered important that information should be offered *proactively* to carers, and generally at an early stage. It was also stressed that the language used in giving the information, whether verbal or written, must be sensitive to the culture and age of the carer. Carers whose first language is not English should have access to information in their own language. For young carers, information should be provided in a child-friendly format, possibly with the use of cartoons or other illustrations. It should also take account of their particular information needs.

Information-giving was presented, however, as a two-way process, with the mutual exchange of information between carer and professional seen as crucial not only for the carer but ultimately for the welfare of the person supported. Many contributors noted that members of the family (including children) could often provide a valuable insight into the behaviour and illness triggers of the patient. At the same time, carers need information about the care of the person they support. This exchange of information can be particularly problematic for carers who do not live in the same house as the person supported and who may not even be related. There was concern that their need for information and the insights they could contribute were often overlooked or discounted.

The potential for conflict in relation to carers' needs for information and the rights of people with mental health problems to confidentiality has been documented (Gardner, 1999). Many contributors, including both local practitioners/managers and key informant carers, felt that confidentiality was often over-emphasised by mental health professionals. This can result in carers not being given information vital to their caring role, and which might in fact be necessary for their own protection or for the safety of others. The contributors acknowledged that this kind of practical information should be clearly distinguished from the sharing of information exchanged between patient and professional in a therapeutic context. As one key informant carer put it:

> *We don't need to know everything, but we do need to know some things, especially if the person is living under our roof.*

3.2 Support and advice

Many contributors stressed the need for access to 'low-level', one-to-one or group support through befriending and a 'listening ear'. Carers, including young carers, need access to an individual or individuals with whom they can share fears and worries. The key informant carers emphasised the importance of having someone separate 'for them', in other words, not the key worker of the person supported. They felt this reduced carers' concerns about prejudicing the relationship with the service on which that person depended. Promoting interaction with other carers was seen as a way of facilitating mutual support among those 'in the same boat', while also providing the carer with an opportunity to relax.

It was recognised that some carers also needed more skilled support in the form of family therapy and counselling. It was also stressed that professional support should be available quickly and consistently for carers (including children) who were coping with a crisis or who had been involved in a traumatic event such as a suicide.

Finally, contributors suggested that advocacy support was often needed to empower the carer in their own situation. Carers frequently find it difficult to articulate their own views, especially if the attitude of the professionals is perceived as intimidating or even hostile. Advocacy is also needed to enable carers to become more meaningfully involved in the planning, commissioning and evaluating of services.

3.3 Training and education

A number of contributors perceived training and education for carers as an important element of support. Training was seen as playing an important role in giving information on practical issues such as the nature of mental illness and the effects of, and alternatives to, mainstream drug treatments. Some contributors also emphasised the place of psycho-educational approaches, which could include the development of carers' skills in behaviour management, assertiveness, coping with violence, and 'self-management' (for example, in setting boundaries to their caring).

Training courses were also seen as providing a therapeutic break for carers, and a chance to 'recharge their batteries', particularly if they were held in pleasant surroundings.

3.4 Time off from caring

Contributors stressed the importance of 'time off' for carers, both on a planned basis and in a crisis. It was emphasised that the provision of short breaks had to be very flexible if it was to meet the needs of, and be acceptable to, both the carer and the person supported. In particular these breaks had to be flexible enough to meet the individual needs and preferences of the carer, and be a positive experience for the person supported.

It was suggested that there was also a need for social opportunities which the carer could enjoy *alongside* the supported person. This could be particularly important to couples.

3.5 Services for the person supported

Although the contributors identified the above as the four main types of support needed by carers, there was a widespread view, particularly among the key informant carers, that the quality of support for the *person with the mental health problem* is as important, or often more important, to the carer than the support they *themselves* receive. In other words, however effective carer support services are, it is the quality of the mainstream mental health services which may have the most significant impact on the carer's quality of life. As one key informant carer put it:

> *The better the service for the user, the less is needed for the carer.*

It follows therefore that a carer is most likely to feel 'supported' in an area that has well-developed mental health services which respond well in a crisis and which stimulate rather than institutionalise. Carers also emphasised the importance *to them* of staff really taking an interest in, and developing a rapport with, the person supported. If staff are able to develop genuine relationships with that person, this takes some of the emotional pressure off the carer.

Section 4 Supporting carers – underlying principles

The discussions with contributors also confirmed that, whatever services are designed to meet the needs outlined in Section 3, they will only be effective if they are underpinned by certain *underlying principles,* or if they demonstrate certain *key characteristics*. Support is in fact perceived to be as much about good practice – about *process* – as about the delivery of specific services to carers. The contributors suggested that support for carers was most effective when it was founded on the key principles described below.

4.1 Positive and inclusive

There was a strong and widely held view that the quality of the relationship between carer and professional is of central importance. However, a number of contributors felt that mental health professionals often focused solely on the person with mental health problems and saw the carer as peripheral or even as 'part of the problem'. These attitudes often prevented professionals establishing a positive relationship with carers and as a consequence carers could feel excluded or ignored. The key informant carers felt that negative attitudes towards carers could be reinforced by the fact that some professionals might only see families when they were in crisis and the relationship between the carer and the supported person was at its most strained. They felt that initiatives such as the use of Advanced Directives described in a recent report for the Mental Health Foundation (Green, 2001) and the development of Action Plans, which has been promoted by the Manic Depression Fellowship, could be used more widely.

Several of the local managers and practitioners who contributed noted that many mental health workers still saw their role as primarily about treating and caring for the person with the mental health problem, and viewed supporting and involving carers as 'extra work'. The expectation that they should assess carers separately was felt by some to have damaged, rather than improved, their relationships with carers. Conversely, other contributors noted that in areas where key workers had been actively and positively involved in carers' assessments, relationships between carers and Community Mental Health Teams (CMHTs) were felt to have significantly improved.

Willingness to share information was perceived as central to the relationship between carers and professionals. As noted in Section 3.1, contributors highlighted the need for carers to be given practical information about the care of the person they support, and this should be clearly distinguished from the information exchanged between patients and professionals in a therapeutic context, which should remain confidential. The barriers to information sharing were felt to be greater for certain groups of carers, notably those who are not co-residents, those who are not relatives, and young carers. Many contributors felt that, if services were to support carers effectively, they needed to adopt a broader definition of the term ‘carer’.

Contributors also wanted to see carers involved at a strategic and service delivery level. They emphasised that carers should be involved at every stage of the planning, commissioning, developing and evaluating of services. However, they also highlighted the difficulties of involving carers meaningfully, and in particular the dangers of tokenism.

Overall, contributors wanted carers to be seen as ‘partners’ and ‘co-experts’, whether in the care of the person with mental health problems or when planning and delivering services. They felt that only services which had a positive attitude to involving and including carers could really be considered effective.

4.2 Flexible and individualised

One of the most widely shared convictions amongst contributors was that services should be person-centred: they should take account of the carer’s preferences and their existing relationships and responsibilities. Carers’ assessments should be proactively offered whenever appropriate, and assessors should invest *time* to understand the carer’s perspectives. Assessments should aim for a holistic view of the caring situation, and recognise that some people care for more than one person or that one person may be supported by several carers.

Services resulting from the assessment should demonstrate a flexible approach – they must be convenient to the carer and fit into the family’s lifestyle, enabling them to live as normal a life as possible, and minimising disruption to education, employment or social opportunities. It was also stressed that service providers should recognise that even an individual carer’s needs changed over time. It was suggested that the wider use of vouchers or direct payments could promote flexibility in the support available to carers. This might be of particular value when the person with mental health problems refused any formal support.

In recent years there has been growing recognition that carers are not a homogeneous group, and that services should reflect and respond to the diversity of the carer population they serve. Contributors endorsed this view and noted that it was essential that services should be sensitive to local and cultural issues, using language and terminology which was appropriate and acceptable to the carer and taking account of the carer’s preferences concerning the ethnicity or gender of workers and volunteers.

There was also a strong view that support for carers had to be non-stigmatising and that interventions had to promote the dignity of families, rather than increase their dependence. This point was made with particular strength in connection with young carers’ services, a number of contributors being adamant that these should focus on the whole family. They cited examples from the field of child protection, such as the American 'family-strength, solutions-focused' model of intervention, which enabled the parents to parent, rather than singling out the children for intervention.

If intervention with the child was essential, it was suggested by some that it needed to be time-limited to avoid creating dependence and difference, which would risk turning the child or even the whole family into a 'welfare case'. Professionals needed to focus on enabling young carers to live *normal* lives, and to be included rather than excluded from their peer group and from wider society.

4.3 Accessible and responsive

It was considered particularly important that services were reliably and promptly available both during and outside 'office hours'. Support services should be able to provide a rapid and appropriate response in a crisis, offering, whenever possible, viable alternatives to A & E or acute hospital admissions, or to police intervention. For those carers who might be put in danger by their role, rapid access to support was felt to be an important element of protection.

Easy access also depends on services being well publicised and signposted. Some contributors stressed the importance of a central point of contact to facilitate access, citing Australian respite centres as a model of good practice.

It was also felt to be important that support services reach out to 'hidden' carers who may have had little or no contact with mental health services. Many contributors working in local services were only too aware that, given the large numbers of mental health carers and the small number of assessments done, their services, however effective, represented 'a drop in the ocean'. It was acknowledged too that some recent service developments had tended to focus on carers of working-age adults, largely because of the thrust of government policy and the criteria of funding streams.

Two other important service characteristics highlighted by contributors, closely linked to accessibility and responsiveness, were continuity of contact and reliability. It was suggested that services should offer regular, proactive contact with the carer, based on a supportive relationship rather than on 'tasks to be done'. Services should have a low threshold, so that they could offer ongoing preventive support to carers who were not necessarily in crisis. It was felt that this approach would alleviate their sense of isolation and provide reassurance to carers, who were often in very long-term situations. It would also reduce the stresses inherent in the caring situation, which were often exacerbated by difficulties in accessing help quickly in a crisis.

The reliability of services was felt to be of key importance to carers, because they feel able to relinquish care – and thus to relax and benefit from a service – only if they have absolute confidence in the substitute care. Good training for staff, and in particular ensuring that they understand the nature of different illnesses, was felt to be an important part of achieving reliability.

Many contributors noted that if services were to be reliable and provide continuity of contact, they had to be sustainable, with a low turnover of staff to ensure consistency and to enable relationships to develop. It was recognised, however, that this could be hard to achieve when services were experiencing recruitment problems or where the resources committed to services were inadequate. Ensuring that services to support carers have secure funding and are part of local strategic planning increases their sustainability, and is therefore likely to improve their effectiveness.

4.4 Integrated and co-ordinated

Carers' issues cut across organisational and professional boundaries, and yet collaboration between agencies can be problematic because they organise their services differently, with different assumptions, objectives and ways of working (Godfrey and Wistow, 1997). Contributors recognised this and highlighted the importance of support for carers being integrated or embedded into mainstream services – whether or not the staff delivering it were employed by the statutory or voluntary sectors. Carers' workers should have a key role in educating their colleagues in working with carers as partners – indeed, if this is achieved, there may be little need for separate carers' services. Ward staff must be aware of carers' needs for information and support, since they are often the first contacts a carer may have after a crisis. Children's services must work closely with adult services if the needs of young carers are to be met. Professionals from statutory organisations should also be willing to link carers into voluntary sector or informal networks which can often complement their own services. A number of contributors expressed regret that professionals seemed reluctant to refer carers to carers' organisations and local support groups – possibly because they were unsure about their quality or how they actually operated.

Support for carers should also be provided by, and co-ordinated between, different agencies. In some areas, health and social care agencies are still perceived as working in isolation from each other. Other public agencies such as housing, the Benefits Agency, education, employment services, youth services and the police are also seen, however, as having a role in recognising and supporting carers. Skilled police, for example, can defuse a violent situation or remove the patient temporarily from the family. Schools can support young carers through pastoral support, personal mentoring and counselling systems, or strategies for addressing non-school attendance.

Section 5 Supporting carers – services and interventions

As discussed in Section 3, there is widespread agreement about the needs of carers of people with mental health problems. The development of services to meet these needs has, however, been very variable. While in some parts of the country support for families has long been recognised as an integral part of mental health care, in others it has only more recently been ‘kick-started’ by a number of important policy changes aimed at carers. The Carers (Recognition and Services) Act (1995) and the Carers and Disabled Children Act (2000) respectively established and then strengthened carers’ rights to an assessment of their own ability to provide care. The National Carers’ Strategy (DoH, 1999a) raised the profile of carers in general and promoted and encouraged the development of support services for carers. Standard 6 of the National Service Framework for Mental Health (DoH, 1999b) emphasised the importance of involving and assessing carers of people with mental health problems, particularly those on CPA. The National Service Framework for Older People (DoH, 2001) also recognised the role of carers of older people with mental health problems and promoted specific support services such as counselling and short breaks.

In spite of these policy initiatives, most areas have taken a pragmatic and incremental approach to meeting the needs of carers, and in some it is acknowledged that services have developed opportunistically in response to new funding streams such as the government’s ring-fenced Carers Special Grant.

5.1 Service delivery issues

5.1.1 Services for the carer – or for the person supported?

Contributors emphasised that support for carers was likely to be most effective when offered as part of a holistic response to the family situation. They highlighted the importance of integrating carer support into local mental health services, rather than developing it as an ‘add-on’ – so that responses to the needs of the person supported and the carer were not seen as separate and discrete.

The importance of integration was stressed, particularly in relation to young carers. In practice, the focus is shifting away from the child to acceptance that intervention must include and enable the parent and other family members. It is now widely acknowledged that too strong a focus on the child can have a negative impact on the parenting capacity of the adult. In one area, young carers have been supported by encouraging their parent(s) to attend parenting courses run by the

CMHT. In another, a school-based project offers support to parents with mental health problems (groups, lunches, IT equipment, adult education etc.) alongside intensive programmes for their children. Some practitioners, however, still take the view that young carers benefit from time away from their families with peers who are in a similar situation. One national organisation hosts a festival for young carers every year.

Areas vary widely in the degree to which they have managed to integrate carer support and assessment into their mainstream mental health services. Though many contributors considered that fundamental changes in mainstream culture could only be achieved long term, it is acknowledged that significant shifts have now been achieved in some areas. In one London borough, which has a fully merged Partnership Executive, all mental health staff are expected to carry out carers' assessments and to offer carer support. To complement this approach, the traditional day services have been given a new role in providing psychosocial and cognitive behavioural training for families. The early onset service also supports families of younger people with mental health service problems.

In some areas carer support has also been integrated into inpatient services. In one mental health trust, staff on the acute ward have been trained to act as 'information signposters' for new carers, while in another a carer support nurse has been appointed. In a third, the consultant psychiatrist holds monthly clinics for carers, inviting each to a separate appointment. His inclusive approach has been transmitted throughout the whole clinical team.

Contributors also cited examples of care managers and care coordinators being given specific training about carers' needs and roles, often delivered at least in part by carers themselves. In some areas all the clinical staff in a particular team have been trained in family intervention techniques. Contributors also cited the Thorn Initiative (www.thorn-initiative.org.uk) as an important influence in disseminating the work of Leff and others on families (for example, Leff and Vaughn 1985) throughout multidisciplinary mental health teams.

5.1.2 Specialist or generic support for carers?

Most contributors took the view that specialist support services for mental health carers were more effective than generic services. As the SPRU review (Perring *et al.*, 1990) highlighted, the challenges facing mental health carers were felt to be significantly different from those facing other groups of carers. Not only was the dynamic between carer and person supported seen as qualitatively different, it was also widely recognised that relationships between carers and mental health professionals could be more complex and difficult. Contributors also acknowledged that, even within the mental health field, carers had very differing needs; for example, the needs of a child caring for a parent with manic depression were likely to be very different from the needs of an adult caring for their elderly parent with dementia. Although carers of people with dementia provide substantial personal care while also coping with changes in behaviour and personality, with other types of mental illness, the actual caring role is seen as less physical, more emotional, more associated with monitoring, and often episodic.

Service providers need to make decisions about specialism versus genericism at a number of levels. Many areas are now appointing specialist carers' support workers in line with government policy (see Section 5.2). Some areas have also decided to address the needs of subgroups of mental health carers separately, by appointing specific carers' support/development workers for carers from black and minority ethnic groups, or by supporting voluntary sector organisations which do so. Some of the contributors questioned this approach, suggesting that the emphasis should instead be on developing the sensitivity of all mainstream services. Examples were cited of areas in which black and minority ethnic carers had been involved in training professionals to improve their understanding of cultural issues. A number of contributors welcomed the newly published good practice guide for people working with black carers (Powell, 2002).

By contrast, where specific young carers' initiatives exist, the current philosophy seems to be to move away from providing specialist schemes for mental health young carers to more generic services for all young carers.

5.2 Responses to Standard 6 of the Mental Health NSF

5.2.1 Carers' assessments

Many authorities have developed – or are developing – their own carers' assessment/'needs review' forms in response to Standard 6 of the National Service Framework for Mental Health. Some areas have based these on the form developed by the National Schizophrenia Fellowship (2000). Others have opted for a much shorter, more simplified version or have developed their own form 'from scratch'. Some areas are broadening out carers' assessments to carers of people on standard (as opposed to enhanced) Care Programme Approach, and to those offering fewer hours of care.

A common approach has been to integrate the carer's assessment as much as possible into the CPA – even if in some areas it is carried out by carers' development workers. Some areas take the view that, unless there are good reasons for a separate carer's assessment, it should normally be part of a holistic assessment of the person supported, or at least undertaken by the same worker.

Many areas are looking for practical solutions to the issues of information sharing and confidentiality discussed in Sections 3.1 and 4.1. In one area, people with mental health problems are invited during the CPA assessment to sign an agreement that clarifies their views as to what information can be shared with the carer. In another, the Care Co-ordinator gives the carer a copy of the care plan if the patient does not agree to share information. Some individual carers and carers' workers are developing legal tools such as 'advance directives' in an attempt to overcome this issue.

5.2.2 Carers' workers

A number of areas have recently appointed specialist mental health carers' workers. Typically these workers take on one of two remits. Carers' *development* workers (or specialist social workers) tend to work within the CPA, their main remit being to implement Standard 6 of the NSF, and often to carry out some or all of the carers' assessments alongside their mental health colleagues. Often they also have a remit to develop services for carers and to act as a resource for colleagues. These workers are usually based within CMHTs or Social Services offices.

In contrast, the main remit of carers' *support* workers (CSWs) – sometimes known as family support workers (FSWs) – is to provide direct support, advocacy and information for individual carers. While some CSWs or FSWs are involved in carers' assessments, they tend to be there to support and advocate for the carer rather than to actually carry out the assessment.

There is a strong view that, even if carers' support workers are not engaged in statutory work, or employed by statutory agencies, they are most effective when based within CMHTs and working alongside statutory mental health workers. Some key informant carers suggested that they were most appropriately based within a primary care setting, because this was where most mental illness was diagnosed and indeed treated. However, this view did not appear to be endorsed by contributors from mental health and social services.

Management arrangements for carers' support workers vary. Some workers are managed by Social Services, while others are managed by an independent carers' or mental health organisation. Some contributors felt that support workers might be more effective if they were employed and managed by an independent organisation, because they were perceived to be freer to offer independent advice or advocacy, and could avoid becoming 'service-led', bureaucratic and constrained by budgetary considerations. Conversely, there was also a view that this could lead to carers' support workers being seen as peripheral and so having less influence on mainstream mental health services.

The Department of Health has recently commissioned the mental health charity Making Space to produce a specification for a mental health carers' support service. The specification was being developed at the same time the scoping study was being carried out and it was delivered in 2002.

5.3 Other support services

Although the pattern, quality and accessibility of services vary enormously across the country, in those areas which have been actively attempting to develop carer support, provision typically includes several of the 'components' described below.

5.3.1 Breaks from caring

The Carers Special Grant (CSG) was introduced in 2000/2001 to support the implementation of the national strategy for carers, Caring about Carers (DoH, 1999a). It made funds available to local authorities to help them develop a wider range of services to give carers a break from their caring responsibilities. A number of contributors expressed frustration with the constraints of the criteria for the CSG, which was seen as too restrictive, and as less relevant to the needs of mental health carers than to other carers. The CSG has been viewed by some as a distraction from the main needs of mental health carers – for example, the need for one-to-one support – and as an irrelevance to the large numbers of mental health carers who do not physically live with the person supported and who therefore may not need respite in the more traditional sense.

In spite of this, the CSG appears to have given a significant boost to the development of short breaks for carers of people with mental health problems. Many areas have found it possible to use the grant creatively, for example to fund individual carers to have a break of their own choosing, to fund home-based respite services, or to pay for a paid worker to spend time with the person supported, doing activities which they enjoy. Others have used a proportion of the CSG to fund young carers' breaks or specific schemes for black and minority ethnic carers.

One scheme for people with dementia enables them and their carers (usually couples) to have a night out together in a social environment. Other approaches include a guesthouse for carers which also hosts weekend courses, and a hotel-type respite facility for people with mental health problems.

5.3.2 Support groups and social events

Many contributors highlighted the value of informal support groups and self-help networks. Support groups take many different forms, though most have a strong social element in addition to their focus on information sharing. It was however stressed that those networks that have flourished and grown had usually needed the support of a paid development worker. These workers had often been employed and managed by national voluntary sector organisations such as Making Space or the National Schizophrenia Fellowship.

However, it was also recognised that not all carers wanted to join support groups, or found them helpful. 'Buddy' systems or telephone networks have been found to offer a useful alternative, because they can give the carer contact with another individual who has been through similar experiences, without the need to join a group.

Social interaction with peers is seen as important for young carers too, though some participants voiced strong concerns that 'special' trips and outings could threaten or undermine family dynamics, and single out these children as 'different'.

5.3.3 Educational interventions

Many areas have commissioned, or are planning to commission, training programmes for mental health carers. These are usually delivered by a combination of health and social care staff, and carers themselves. The model most often cited by contributors was the Carers' Education and Support Programme (CESP), which was developed by the National Schizophrenia Fellowship. Other areas have designed their own courses.

Most programmes appear to focus on educating the carer about the practicalities of caring for a person with a mental illness (including legislation, benefits, carers' rights, medication etc.). One area funds a regular course on rights for local carers, delivered by a highly respected human rights lawyer. Alternative models, however, emphasise the emotional and psychological impacts of caring and deliberately avoid focusing on the person with mental health problems or the illness itself.

Contributors also provided examples of training for carers being provided within secondary care, for example, an acute ward running a short course on depression.

5.3.4 Telephone and computer-based services

Another approach, which has attracted considerable interest, is the provision of a help-line, whether this be a generic help-line for all carers or a specialist one for mental health carers. One national 24-hour help-line has extended its service by developing associated projects to meet the needs of carers who appear to require some continued support and counselling.

There are differing views as to who should staff help-lines. In some areas community psychiatric nurses (CPNs) themselves staff the help-lines, while in others they have trained volunteers to take on this role. Whether generic or specialist, paid or voluntary, it is considered essential that the help-line staff have a real understanding and knowledge of mental illness, including a good knowledge of medication.

A number of contributors made the point that, although help-lines may not be used by large numbers of carers, their existence can be a source of great reassurance to carers. However, some also pointed out that carers do not always find it easy to talk to strangers and that, for this reason, help-lines should not be viewed as an alternative to providing access to one-to-one counsellors.

There is growing awareness of the place of the Internet in disseminating information. Some local areas have piloted this approach for mental health carers. One national children's organisation has developed a website specifically for young carers of adults with mental health problems, while another mental health body promotes coping techniques through its website.

5.3.5 Written information

Although information about the personal situation is felt to be best delivered orally as part of the individual support given by specialist workers, it is also accepted that carers have a need for more general information which can usually be best provided in written form. Information packs for mental health carers have been developed in a number of local areas and by national organisations to address this need. Many local areas and national organisations have also attempted to provide child-friendly information which will be more accessible to young carers. One Social Services Department has, for example, produced a simple leaflet with cartoon illustrations.

Section 6 Effectiveness and cost-effectiveness

Contributors drew on their understanding of the needs of carers, of the principles that should underlie services, and of how the services may be configured and delivered, to construct their views on what constitutes *effectiveness*. However, many admitted to some difficulties in identifying the meaning of – and differences between – effectiveness and cost-effectiveness. Few of the local providers and commissioners had specifically attempted to assess the cost-effectiveness of their services, though one authority had tried to estimate the cost contribution made by its own carers as part of a Best Value exercise (this came to almost £1 billion).

Although the differences between the contributors were not especially significant, professionals from statutory bodies tended to emphasise the role of carers' support services in *reducing demand on services* by both the carer and the person supported. Voluntary sector professionals, and the key informant carers themselves, tended to emphasise the *impacts on the quality of life of the carer and the person supported* – both short and long term.

6.1 Concepts of effectiveness

Overall, contributors tended to conceptualise effectiveness in five main ways, terms of:

- the benefits for the carer
- the benefits for the person supported
- the benefits for the family as a whole
- the impacts on service usage
- the long-term outcomes for society.

6.1.1 Benefits for the carer

Supporting carers is considered effective because this improves their quality of life, reducing stress and preventing the likelihood of their developing their own health problems. The carer is therefore enabled to have greater choice in their situation, whether this be to continue caring or to stop caring. Support is also perceived as empowering carers, helping them to feel in control, so that they can represent their views and use the system effectively (one contributor raised the notion of the 'expert carer' to complement the current policy drive on the 'expert patient'.) Even if some support services are not greatly used (help-lines and support groups were cited), they can be effective if their presence provides reassurance, which may in turn help to protect the carer's emotional health.

In the longer term, support services are seen as effective because they can enable carers to fulfil their potential, for example in education or work. Effectiveness is therefore conceptualised in terms of the degree of normality which can be maintained or attained in the carer's life.

6.1.2 Benefits for the person supported

Supporting the carer was seen as one of the best ways of supporting the person with mental health problems. By involving the carer and listening to them, professionals can understand the person supported better and can provide appropriate and individually tailored support. In this way, the latter is given the best chance of 'getting better' or, if this is not realistic, at least of leading as independent and productive a life as possible. As one contributor put it:

> *Effectiveness is tied up with the recovery of the user. Anything you can do to help the user recover must be effective.*

There was recognition, however, that in some cases effective support to the carer might actually mean enabling or encouraging family members to be less involved so that the person with mental health problems could develop their independence. Support services should therefore aim to encourage care that is 'appropriate' to the patient's needs.

6.1.3 Benefits for the family as a whole

Contributors pointed out that 'care in the community' has brought the 'chaos' of mental illness out of institutions and into the family. It is the family therefore which should be the locus of intervention and support. Some contributors suggested that the key measure of effectiveness should be 'has this support helped the family as a whole?' Support for carers is important because it can help to prevent family breakdown and to maintain or restore caring situations. Effective support empowers parents who have mental health problems so that they can provide adequate and effective parenting to their children. Because many carers now have responsibilities for more than one person – for example, the mother of a son with schizophrenia may also have ageing, dependent parents – support for the carer can have benefits for many members of the extended family.

6.1.4 Impacts on service usage

Contributors suggested that carers' support workers could enable statutory services to target their interventions more effectively (and by implication less expensively) by helping them to identify and address the *real* nature of the family's problems.

Many contributors conceptualised effectiveness of carer support in terms of the impact it was assumed to have on the demand for health and social care services, and also other public services such as the criminal justice system. The 'common sense' view is that supporting carers makes it less likely that either they or those they support will have to fall back on statutory intervention, whether this be from Social Services, primary care or admissions to A & E or the acute psychiatric ward. There was recognition that lack of support, or ineffective support, can lead to family breakdown, necessitating higher levels of statutory care for the person with mental health problems. A number of contributors used the Institute of Actuaries estimates of the 'cost' of informal care (£34 billion) to argue that carers were in effect a resource for society because supporting carers reduced the need for statutory services, which had a cost to society as a whole.

Impacts on service usage relate not only to the person with mental health problems but to the carer as well. It is argued that carers who are effectively supported are less likely to develop health problems of their own which require intervention, or to use services such as primary care inappropriately.

6.1.5 Long-term outcomes for society

Contributors also recognised the long-term benefits to society as a whole of valuing and supporting carers. Effective support is seen as essential to protecting the longer-term contribution of the carer to society, for example by enabling them (if appropriate) to stay in employment and thus benefiting the economy. If not supported in this way, carers may cease to be economically active and may become dependent on State benefits. One contributor summarised the point by stating that cost-effectiveness had to be looked at in relation to 'society's budget' rather than the budgets of individual agencies.

It was also postulated that early and timely support might reduce the longer-term negative impacts of caring on the individual carer. It is known that young carers when unsupported may be unable to reach their potential and make a full contribution to society. Early intervention can avoid the need for, and use of, mental health support at a later stage. However, it was stressed that this must be available early on because, all too often, carers are referred for support only when they have already been damaged by their experience.

From an ethical rather than an economic perspective, effective support for carers was seen as promoting a proper balance between the roles of the carer and the statutory bodies. It was suggested that the assumption common in the research literature – that effectiveness of an intervention is assessed by measuring changes in the carer – should be turned on its head. Instead, effectiveness should be judged by how much attitudes in *services and society itself* are changed.

6.2 Perceptions of cost-effectiveness

Contributors recognised that cost-effectiveness is not the same as cost minimisation – financial prudence should not be equated simplistically with the cheapest way of achieving a particular outcome. Whereas it might be appropriate to explore and promote low-cost options in some areas of support (an example offered was the provision of information via the Internet), contributors stressed that low-cost services might not be cost-effective services. For example, in evaluating a support service it would inappropriate to use only *quantitative* measures such as cost per carer or cost of each hour. The evaluation would also need to assess the *quality* of support provided, even if this were only to a small number of carers. In other words, both costs and effectiveness should be considered.

Many contributors stressed that effective schemes might have a higher cost, because they required skilled, well-trained staff capable of carrying out comprehensive assessments. Effective carer support also required time and often involved home visits, which were more expensive than support provided from the office base. The relative cost-effectiveness of these different services could only be determined by formal economic evaluation.

There were also views as to the relationship between effectiveness and the duration of support input. If support was only available for a short time and was then withdrawn, the service might be cheap but not cost-effective because the value was quickly lost; the carer’s stress remained and might even be exacerbated by their feeling of abandonment. An alternative view was that, if support was too long-term, it might increase dependence on services and thus reduce cost-effectiveness.

Contributors pointed out that, though operational budgets of both voluntary and statutory bodies tend to be planned on a year-by-year basis, carers themselves were usually in very long-term situations and therefore need to be offered solutions which will be effective in the long term. The tradition of short-term funding arrangements for carers’ projects means that the cost-effectiveness of these services can be reduced, because staff have to devote a large proportion of their time to generating more funding. In many areas there is also an expectation that carers’ support workers will spend a proportion of their time representing carers’ issues in planning meetings. Again, this inevitably detracts from their ability to devote time to supporting individual carers.

A number of contributors made the point that many of the elements that had been identified as most important in supporting carers would cost very little to implement. For example, changing attitudes of professionals towards carers might require time and training but this was unlikely to represent a massive input of resources. Professionals also needed to make more effective use of what was already available in their local areas.

6.3 Evaluating effectiveness

Some contributors took the view that a service could be evaluated by measuring take-up, and a high level of referrals and/or self-referrals would indicate an effective service. However, it was noted that a service might be effective in reassuring and supporting carers indirectly even if it were not actually used very much. Help-lines, training courses, crisis services and support groups often fall into this category. It was also noted that success brings its own challenges, because services reached a point when they had to consider how much long-term support they could offer, and whether they needed to refer carers on to other services.

Other contributors, particularly the key informant carers, felt that the effectiveness of services could be evaluated by the positive feedback they received, for example through satisfaction surveys, client evaluation forms, testimonials, letters, or meetings. It was stressed that carers should be involved in designing the questions to be asked, and also that providers had to respond to carers' views and modify services accordingly:

> *Ask your customers, don't tell them … try to deliver as near as you can to what they want, then ask them again.*

A number of contributors suggested that effectiveness should be monitored and measured against performance indicators, such as those developed by the King's Fund (see Appendix E). These were perceived as very valuable because they could help to reduce variations in service quality. However it was pointed out that these were not designed to measure the effectiveness of *mainstream* services in supporting carers.

Another suggestion was that carers should evaluate the effectiveness of their own support packages through CPA. They should monitor their own care plan and know who to complain to if it is not working effectively.

6.3.1 Barriers to evaluating effectiveness

It was acknowledged by many that evaluating the effectiveness of support services could be difficult and time-consuming, and as such was not always a priority for service providers, who might feel they were busy delivering the service. Unfortunately this may be particularly true of those who are developing the most innovative approaches. There is also awareness that services do not work in isolation, and so the more integrated a service, the more difficult it may be to identify those components which are, or are not, effective.

Some areas have, however, been particularly keen to share good practice with others, and have made efforts to have their approaches and schemes formally evaluated by an external agency, often a university department. Others are in the process of being evaluated. One authority has, for example, commissioned an evaluation which includes postal surveys, client interviews and shadowing of support workers. Another area is building up a mailing-list of carers who would be willing to be involved in the evaluation of services, or to be trained to interview other carers about their experience of services. A third is developing an ongoing method of evaluation by incorporating questions about the most and least useful interventions, into the assessment used by the carers' support workers.

Section 7 Current evidence and dissemination

One purpose of the interviews with contributors from the national and local bodies was to identify what further research they felt was needed, either to assist them in their own area of work or to improve support to carers of people with mental health problems more generally by influencing policy and practice. As part of this process, it was important to understand how people used research evidence and its place alongside other sources of evidence. It was also necessary to examine what, if any, services or interventions were perceived to be supported by existing research evidence. These have been briefly detailed at the end of this section. It should be noted, however, that some of these same areas were also highlighted as gaps in research. No attempt has been made to resolve this contradiction and both perspectives are presented in this report.

7.1 Sources of evidence

Those who contributed to the scoping study defined evidence in very broad terms and regarded formal research evidence as only one part of the evidence base. While they recognised the importance of research evidence, most drew on a number of sources of evidence. The only body of carers' research undertaken by an academic unit which was specifically mentioned was the young carers research carried out at the University of Loughborough. However, a few respondents did highlight particular papers or articles that they had found helpful in their work.

Applied research, undertaken by reputable statutory or voluntary bodies, was an important source of evidence for many people, particularly those working in mental health or carers' services at a local level. Examples of this type of evidence included the Social Services Inspectorate reports and work undertaken by Making Space (Weinberg and Huxley, 2000).

At a local level, many of those involved in planning and delivering services drew heavily on both local evaluations of pilot projects or services and consultation with local carers. Indeed, some evidence was seen as credible precisely because it was based on consultation with carers – for example, the London Mental Health Carers' Charter (Carers Advisory Group, 2001) and the good practice guide produced by the Black Carers' Workers' Network (Powell, 2002). Some contributors were very clear about the importance of basing service developments on 'what works for us' and doubted the value of research based on pilot projects which had been carried out in a very particular context or with a highly selected group of carers.

The other important source of evidence was fellow workers. Many contributors highlighted the value of networking with mental health or carers' workers in other areas, in order to pick up ideas and information. Services or initiatives developed in one area often provided an example for others to follow, and there was a real desire for information about 'good practice'.

7.2 The use of evidence

Many contributors, including those working at both a national and a local level, acknowledged that they made relatively limited use of research evidence in their work, other than the findings from local research. This was partly due to the perceived paucity of relevant research evidence. However, there was also a perception that even when research evidence existed, it was hard to find, and was often presented in inaccessible forms (such as lengthy research reports or articles in academic journals). Many of the contributors working locally in health and social care organisations felt frustrated because they wanted to use research evidence but felt that other work pressures left them little time to read research papers. They wanted access to research finding in very accessible forms (such as research summaries or key findings), presented in a manner relevant to the context in which they were working. As one contributor put it:

> *If there is clear research evidence, presented in a clear way, we would use it. We need practical information not long academic reports.*

Where contributors had used research evidence, they had used it in two distinct ways. Many had drawn on research evidence to inform the development of a specific service for carers. Often these services were new or innovative in nature (for example, training and education for carers), as opposed to services which were more common and which were widely regarded as 'a good thing' (such as carers' support groups). A minority said that they used research evidence to inform their general thinking or approach to carers' issues. These contributors were also more likely to apply research evidence from other related fields (psychology and family support, for example). They felt there was scope to use this related research more extensively to inform the development of services to support carers, but recognised that to do this practitioners and managers needed time to read and reflect.

7.3 Improving dissemination

The importance of effective dissemination of research was a strong theme throughout the consultation. As was noted earlier, contributors highlighted the importance of research findings being presented in accessible forms. These included:

- summaries of research and key findings published by universities or research bodies (for example, the Joseph Rowntree Foundation's *Findings*, *Research Works* produced by the Social Policy Research Unit, University of York, *Effectiveness Bulletins* published by the NHS Centre for Review and Dissemination, University of York)

- articles in professional rather than academic journals, in particular widely read journals such as *Community Care*, *Health Service Journal*, and *Mental Health Today*
- research summaries published in magazines produced by national bodies such as Carers UK, and Young Minds.
- the publication of summaries of research alongside policy and implementation guidance.

Most contributors felt these summaries should be brought together on a few well-publicised websites, so that practitioners, planners and managers from all sectors knew where to go to get the latest information. Interestingly, a number of contributors felt that, while the government site www.carers.gov.uk might be an obvious focal point, it was not reaching its full potential and so was not well used.

While the Internet is regarded as an important source of information about research evidence, there was concern that many people, particularly practitioners, did not have easy access to the Internet in their workplace. Many contributors put forward useful suggestions about how dissemination of research findings either in printed form or on the Internet, could be supplemented. In particular, they felt that there was scope to make much greater use of existing national and regional networks, for example the MACA Carers' Workers' Network, the network of Princess Royal Trust for Carers Centres, and the Black Carers' Workers' Network.

In addition, several contributors from the NHS felt that initiatives such as the identification of Beacon sites, the development of Collaboratives, and the new National Institute for Mental Health and its regional development centres could have an important role in both disseminating research findings and encouraging their use in planning, commissioning and delivering services to support carers of people with mental health problems.

Lastly, there was felt to be a place for a good practice guide or resource pack, which would bring together, in an accessible form, both research evidence and practical examples of initiatives or services that have been developed in different parts of the UK. Many contributors felt that this would help to encourage the spread of ideas by offering practical, evidence-based approaches to the development of services for carers. As one local manager explained:

> *We need small ideas which we can adapt and then implement quickly, and which we can see make a difference.*

7.4 Perceptions of research based evidence

Overall, most contributors felt there was relatively little research evidence available about effective support to carers of people with mental health problems. Where services, interventions or models of support were perceived to be supported by research evidence, contributors either noted that they felt there to be a large body of evidence in a particular area, or they noted that what evidence was available was of a high standard. A few contributors questioned the usefulness of some of the research currently available, noting that it was either too narrow or too specific to the context in which it was undertaken.

The areas perceived to be supported by the research evidence fell into three broad categories:

- **Services or interventions to support carers**. These included respite care or breaks from caring, particularly for carers of older people with mental health problems, and carers' support groups. The results of the literature review appear to support this perception in terms of the number of studies in these areas – 36 of the 204 studies included were concerned with breaks from caring and 18 with support groups. However, the evidence in terms of effectiveness is more mixed when effectiveness is assessed using standardised outcome measures. Research using broader qualitative measures suggests that carers do identify positive benefits, and this was reflected in the key informant carers' comments. The benefit of providing good information and advice to carers was also felt to be supported by research evidence, although it was noted that much of the evidence was generic, rather than specific to carers of people with mental health problems.
- **Services or interventions to support the person with mental health problems and their carer/family**. In particular contributors felt that there was good research evidence to support the use of family interventions including family therapy. The literature review clearly suggests this view is correct. However, both the consultation and the literature review highlighted the fact that the evidence supporting this type of intervention tended to be associated with carers of working-age adults, usually with psychotic illness. Many contributors felt that there was much evidence to be found in the wider psychology/psychiatry research literature which could be drawn on when considering effective approaches to support for carers.
- **Aspects of caring or the impact of caring**. In general, the contributors felt there was a significant body of evidence about carers' needs and the impact of caring, including the emotional, physical and financial impact. They also noted that within this broader field, there was felt to be particularly good evidence about the needs of young carers, although a number of contributors noted that there was much less evidence that focused on young carers caring for a parent or sibling with a mental health problem.

The issues raised about the nature of evidence, its availability and application, suggest that while further research into effective ways to support carers of people with mental health problems is needed, it should complement other sources of evidence, including local research and consultation, and good practice exchanged via national and local networks.

Section 8 Gaps in research and suggestions for further research

The consultation with national and local bodies produced a great deal of information about the perceived gaps in research, and generated many valuable suggestions for further research. Not surprisingly, the suggestions put forward reflected the contributors' roles, and the interests of the organisations they represented. Nevertheless, several common themes emerged and a summary of these themes was shared with the key informant carers. They largely endorsed the suggestions put forward by the other contributors, while adding their own ideas and emphasis. This section is intended to reflect the view of all three groups of contributors.

8.1 Service delivery and the effectiveness of interventions

It was clear from the consultation that there was a real desire for research which can inform service delivery and help managers, practitioners and carers assess the effectiveness of service interventions. In terms of service delivery, contributors (particularly managers and planners), frequently noted that they wanted to know *'how best'* to provide certain services (i.e. what modes of delivery were likely to be most effective). Four areas/services were highlighted.

- **Training and education for carers**. In particular, three questions were asked:
  - Which approaches to delivering training are most effective?
  - Which approaches work best for different groups of mental health carers?
  - At what point(s) in the carer's caring 'career' is training and education most beneficial?

  Interestingly, the literature review highlighted similar issues. It shows that a number of studies have examined educational, training and psycho-educational interventions, and that overall, there is evidence to suggest that such interventions are effective. However, further work is needed to address the kinds of questions raised by consultation. Put simply, contributors want to know how and when to provide training and educational interventions to ensure they are most effective.
- **Independent advocacy**. There was general agreement that carers needed access to independent advocacy but many contributors were unsure about the best way to deliver this service. They were also interested in research which could assess whether the demand

for independent advocacy was reduced where carers were more actively involved in decisions about the care of the person they supported.

- **Information**. Again, there was clear recognition that the provision of information was an essential part of supporting carers effectively. Contributors were, however, interested in understanding how best to provide the information required and at what point, in terms of the development of the carer's role and the illness of the supported person.
- **Carers' workers**. Carers' workers' posts are already being developed in many areas of the country, and many contributors were looking for information on what models of provision are being adopted and how effective they appear to be in different service contexts. The Department of Health has recently commissioned Making Space to produce a specification for a carers' support service. This specification may well address many of the questions raised by contributors. However, given the emphasis being placed on the development of these posts as part of the implementation of Standard 6 of the NSF, there may be a place for research which examines the impact and the effectiveness of different models of provision.

More generally, there was felt to be a lack of research evidence available concerning a number of other important aspects of service delivery. These included:

- provision of multi-agency or integrated services to support carers of people with mental health problems.
- balance between specialist mental health carers' service and generic carers' services
- effectiveness of early intervention with carers caring for someone who is in the early stages of their illness.
- improving access to services and in particular increasing take-up by 'hidden carers'.

All three groups of contributors identified the lack of research into the effectiveness and cost-effectiveness of services and interventions to support carers as one the most significant gaps in the evidence base. It was felt that further research in these areas would inform the development of services to support carers and enable those planning or delivering services to use formal research evidence alongside the results of local consultation. However, while there was consensus that this type of research was needed, very few interventions were specifically identified as a priority for investigation. A few contributors noted that they would value evidence about the effectiveness and cost-effectiveness of carers' support groups. There was a perception that, in principle, support groups could offer positive benefits to carers but, as the literature review noted, those developing such services needed to know more about how best to provide them, how they could be encouraged to be less static, and which carers were likely to benefit most from them.

Others wanted comparative research into the effectiveness of different interventions to support carers. Lastly, some contributors felt there was a place for research which specifically examined the link between providing support for carers and the health (including use of health services), ability to cope or quality of life of the person being supported. They recognised that this was only one dimension of effectiveness but felt that evidence in this area might help to change attitudes to carers in mainstream mental health services.

8.2 Carers and mental health services

As was discussed in Section 5, one of the key questions raised during the consultation was whether providing effective support for carers of people with mental health problems was best achieved by changing attitudes, systems and practices within mental health services, or by developing dedicated services to support carers. This debate was also reflected in the suggestions contributors made for further research. Many of the areas they highlighted concerned current service delivery and policy implementation issues. By and large these were not reflected in the literature review which, as required, focused on the effectiveness of specific interventions.

8.2.1 Changing attitudes within mental health services

It was clear that, while contributors felt that the inclusion of a specific standard for carers in the NSF for Mental Health had begun to influence attitudes toward carers in mental health services, much more substantial change was needed. They felt that the important role played by carers in supporting and caring for, or about, people with mental health problems was still not fully recognised, and many professionals continued to see carers as peripheral or even ‘part of the problem’. They wanted research which would inform how attitudes within mental health services could be changed. Several contributors had clearly considered this issue very carefully and highlighted the value of drawing on research from other areas, notably the field of organisational studies. Within this field, work in the areas of change management, the impact of organisational cultures on decision making, and the influence of professions were felt to be particularly relevant.

8.2.2 Information sharing and confidentiality

Many contributors, especially the key informant carers, felt that mental health professionals tended to overemphasise confidentiality and sometimes simply assume that the person with mental health problems would not want information to be shared with their carer. As a result, carers might not be given vital information, and likewise might not have the opportunity to provide information which might be valuable in making decisions about the patient's care. There were felt to be particular barriers to information sharing for certain groups of carers, notably young carers and carers who were not co-resident with the person supported.

It was clear that not only was this a major concern for carers, it was also an issue with which managers and practitioners were struggling at local level. There was felt to be a real need for relatively short-term, practical research into how these barriers to information sharing could be overcome. In particular, contributors wanted to know what approaches had been tried in different parts of the country and the impact they had had. Research into the use of initiatives such as advanced directives and shared confidentiality policies was specifically mentioned (Green, 2001).

8.2.3 Involving carers in decision making

Involving carers in decision making, both at an individual level and at a service/planning level, was clearly seen as an important aspect of supporting carers. Some contributors felt that research was needed into how and when to involve carers in decisions about the care of the person supported, and the effect such involvement had on outcomes for both. This issue is closely linked to information sharing and staff attitudes, and so could be examined as part of a wider piece of work.

A few contributors felt more research was needed into effective ways to involve carers in decision making at a service/planning level. However, others noted that there was already a body of knowledge on this topic, albeit not specific to mental health carers, and that this could usefully be applied in mental health services.

More generally, contributors emphasised the need for research in these areas to involve carers, patients and practitioners, and to examine the issues from all three of these perspectives.

8.2.4 Carer's assessment

Many contributors were either involved in implementing the carer's assessment in mental health services or had been assessed as a carer. There was strong support for research into the implementation and impact of the carer's assessment in mental health services. In particular, contributors wanted relatively quick and practical research, which would address a number of key issues.

First, they wanted to know how the carer's assessment had been implemented in different areas, and within this, what models of assessment were being used. Specifically they wanted research which would examine whether carers' assessments were being undertaken by mainstream mental health workers or dedicated carers' workers, and the impact of these different approaches on the number of assessments undertaken, workloads within mental health teams and relationships between mental health teams and carers. Many contributors also felt the issue of eligibility criteria should be examined, both in terms of how such criteria were being applied and the effect of their use on the number of carers being assessed. It was also suggested that it would be useful to know how many carers one would expect to be assessed.

The key informant carers emphasised that the carer's assessment was about being listened to as an individual, not filling in forms. They wanted research which would not only examine how the carer's assessment had been implemented and the models which appeared to work best, but also research which examined the carer's experience of assessment. As one carer put it:

> *It's not a tick-box exercise. It's got to be prepared carefully. It's got to be done with sensitivity and it's not got to be a little bit on the end of the user's form.*

They also noted that the assessment itself could be an unsettling experience, even when conducted with sensitivity, and so carers did need to see that something positive had been achieved as a result of it. With this in mind, any research in this area would also need to examine the outcome of the assessment for the carer.

8.3 Supporting specific groups of carers

Alongside the research themes and issues described above, many contributors raised the need for research which would enable those planning and delivering services to better understand the needs of certain groups of carers, and so improve the services available to support these carers. Five groups of carers were specifically identified:

- young carers
- black and ethnic minority carers
- carers of people with dual diagnosis
- carers supporting more than one person
- less-common caring situations.

8.3.1 Young carers

There was a strong view that, while good research evidence existed in relation to the needs of young carers in general, relatively little research had examined the needs of children and young people caring for someone, particularly a parent, with mental health problems. This view was endorsed by the literature review, which did not identify any studies concerning interventions with young carers. Several contributors wanted research which could inform how best to support young carers within the family, and on an ongoing basis and, linked to this, how to support parents with mental health problems in their parenting role. There was also felt to be a place for research that could assess the effectiveness of different interventions at different stages in the young person's life. Lastly, it was noted that, while there had been estimates of the number of young carers (of all types) in the population, and the number of adults with mental health problems who had dependent children, there were no national figures for the number of children and young people caring for someone with a mental health problem, which social service departments and health care organisations could use to estimate the levels of need in their areas. Research that could provide this type of data would be welcomed.

8.3.2 Black and ethnic minority carers

Services to support black and ethnic minority carers were felt to be in their infancy, and many contributors noted that this was mirrored by the lack of research into the needs of this group of carers. No studies identified in the scoping study focused specifically on black and minority ethnic carers. The priorities for research highlighted by the contributors included a greater understanding of the way in which different cultures viewed the caring role in mental health, and how care and support were provided in different cultures. There was also interest in research which built on existing, highly regarded guidance, such as the good practice guide for people working with black carers (Powell 2000), to examine further how effective support for black and ethnic minority carers could be provided.

8.3.3 Carers of people with dual diagnosis

Many contributors highlighted the problems faced by carers of people with a dual diagnosis, in particular carers of people with mental health and substance misuse problems, and people with a learning disability and mental health problems. However, the key informant carers also raised the issue of those caring for someone with a mental health problem and significant physical health problems. Little was felt to be known about whether their needs differed significantly from other mental health carers and no contributors were aware of any research evidence about how to support this group of carers most effectively.

8.3.4 Carers supporting more than one person

A few contributors noted that little if any research had been undertaken into the impact of caring for more than one person. Interestingly, around a quarter of the key informant carers who contributed to the study were currently, or had recently been, caring for more than one person. They felt that carers in this situation experienced particular problems, both in terms of coping with their caring responsibilities and in terms of the provision and co-ordination of services to support them.

8.3.5 Less common caring situations

Lastly, a number of contributors noted that much of the available evidence about supporting mental health carers focused on the primary carer, who is usually a spouse, parent, son or daughter, or sibling, often living in the same home or in the same city or area. They felt there was a place for research which took account of less common caring situations, for example caring in a same-sex relationship, caring at a distance, and the support provided to people with mental health problems by networks of friends and/or family rather than one or two primary carers.

8.4 The impact of caring

Contributors felt there was relatively good evidence about the needs of mental health carers. However, many noted that there was little research into the long-term impact of caring for someone with a mental health problem. In particular they wanted to see longitudinal studies, which examined the impact of caring on the carer's physical and mental health, and on their life circumstances and financial situation. There was felt to be value in comparing how caring for someone with a mental health problem differs from caring for someone with a physical disability or physical health problem, and within this how the relationship between the carer and the cared for person might differ for mental health carers. The key informant carers consulted as part of the scoping study also emphasised the importance of recognising that there were significant differences between mental health carers, and research must address this. For example the experience of caring for a son or daughter with schizophrenia is likely be very different from that of caring for a husband or wife with Alzheimer's disease, both in terms of the nature of caring role and the relationship with mental health services.

Several contributors highlighted a particular need for longitudinal research into the impact on children and young people of caring for a parent or sibling with a mental health problem. It was felt that this research should encompass not only the impact on their physical and mental health, in the short and long term (such as the likelihood of young mental health carers experiencing mental health problems themselves in later life), but also the wider impact on their life chances. Such studies would need to examine both the impact on their life as a child or young person (for example, the likelihood of their being taken into care or coming into contact with the juvenile justice system), and the impact on their adult life.

8.5 Types of research

Alongside research into specific services, interventions and service delivery issues, many contributors suggested particular types of research which they felt would be valuable. As noted in Section 8.4, there was clearly felt to be a place for longitudinal research which looked at both the impact of caring and the impact of new policies and systems. However, contributors also wanted relatively short-term, practical research which could directly influence service planning and delivery in the short to medium term.

Again, while recognising the need for research into the effectiveness and cost-effectiveness of interventions, many contributors felt there was a place for rigorous qualitative research. Within this, they particularly wanted to see research which encompassed the experiences and perspectives of carers, people with mental health problems and mental health workers.

Lastly, as noted above, many contributors felt that research into services and support for carers of people with mental health problems could usefully draw on and apply good quality research in other fields. In particular, they highlighted four related fields or areas of research which they felt were relevant:

- organisational studies, and in particular research in the areas of change management, the impact of organisational cultures on decision making, and the influence of professions
- psychological interventions generally and family interventions in particular
- family support, including research in the areas of fostering and child protection
- inter-agency working and the provision of integrated services.

Section 9 Conclusions

The consultation with key stakeholders was viewed as a central part of the scoping study and it did enable the research team to explore a range of different perspectives on the issues under consideration. In particular, the involvement of the key informant carers towards the end of the study provided a valuable ‘sounding-board’ for the emerging findings.

There was a broad consensus among the different stakeholder groups, though the key informant carers expressed the strongest views about the importance of the quality of mainstream mental health services. The contributors from the selected local areas recognised that they had made progress in supporting carers but were in general reluctant to describe their services as ‘good practice’. They appeared only too aware of the limitations of current provision and the constraints in which service development was taking place.

9.1 The development of services to support carers

A common understanding of the broad pattern of services needed to support carers emerged from the discussions with the contributors. They highlighted the need for a range of services which could provide information, support and advice, training and education, and time off from caring. They also emphasised the central importance to carers of effective services to support the person with mental health problems.

Contributors identified and commented on the different ways in which services were attempting to address the support needs of carers for people with mental health problems. Some of these initiatives were in response to Standard 6 of the NSF for Mental Health, for instance local authorities were developing specific carer assessment forms for this group of carers. A common approach was to integrate carers’ assessments as much as possible into the Care Programme Approach (CPA). In many areas, efforts were being made to develop practical solutions to issues relating to information-sharing and the rights of the person supported to confidentiality.

In some areas, specialist mental health carers’ workers had been appointed either as c*arers’ development workers* (or specialist social workers) or *carers’ support workers* (or family support workers). Generally, the main function of the former group was to implement Standard 6 and often involved conducting carers’ assessments alongside mental health colleagues. *Carers’ support workers*, on the other hand, focused on the provision of direct support, advocacy and information for individual carers.

Other support services provided for carers included short breaks from caring (often developed through the Carers Special Grant); support groups and social events; educational and training programmes; telephone and computer-based services; and user-friendly, accessible written information.

It was clear, however, that there was no single blueprint or service model which was regarded as 'ideal' or effective. Indeed, many contributors, particularly local managers and practitioners, and the key informant carers, felt that, if services are to be effective, they had to be tailored to local needs and circumstances. Most areas have taken a pragmatic and incremental approach to developing services to support carers, often influenced by the availability of new funding streams, but also shaped by the geography and socioeconomic make-up of the area and the existing pattern of mental health and voluntary sector services.

Those involved in the consultation emphasised the importance of providing a co-ordinated range of services in order to meet carers' different support needs and to offer them choice. Contributors also stressed that support for carers was likely to be most effective when offered as part of a holistic response to the family situation. They highlighted the importance of integrating carer support into local mental health services, and a number suggested that effective support for carers of people with mental health problems might best be achieved by changing attitudes, systems and practices within mental health services, rather than by developing dedicated services to support carers. These contributors took the view that, although the development of specific carer support services might be a necessary 'stepping stone', there was a risk that areas with these in place could overlook the more important task of integrating carer support and involvement into every aspect of mainstream mental health services.

9.2 Underlying principles of service delivery

The consultation highlighted that, whatever services are developed to support carers, they would only be effective if they were underpinned by certain underlying principles, or if they demonstrated certain key characteristics. Effective support was in fact perceived to be as much about good practice – about the *process* of delivering services – as about the specific types of services provided.

The contributors suggested that services for carers were most effective when they were positive and inclusive, flexible and individualised, accessible and responsive, integrated and co-ordinated.

The importance of effective communication between professionals and carers to achieve a two-way flow of information was particularly stressed.

9.3 Conceptualising and evaluating effectiveness and cost-effectiveness

Contributors conceptualised effectiveness in five main ways. Firstly, they discussed effectiveness in terms of benefits for the carer – by improving their quality of life, reducing stress and health problems – and in the longer term, enabling carers to achieve their full potential. However, effectiveness was also seen in terms of benefits for the person with mental health problems: by supporting and involving carers, professionals could better understand the person supported and provide them with individually tailored support. Support was also seen as bringing benefits for the family as a whole, by helping to prevent family breakdown, by maintaining or restoring caring situations, and, in the case of young carers, by strengthening the parenting capacity of the adult(s).

More broadly, effectiveness was also conceptualised in terms of the impacts on service usage. Supporting carers was seen as effective in that it might reduce demand on health and social care services, as well as other public services such as the criminal justice system. Finally, effective support for carers was seen as essential to protecting the longer-term contribution of carers – especially young carers – to society, for instance by allowing them to remain in the labour market.

Contributors held mixed views about methods to evaluate effectiveness. Some felt that services could be evaluated by measuring utilisation rates, while others – especially key informant carers – felt that the effectiveness of services could be evaluated through satisfaction surveys, client evaluation forms, testimonials, letters or meetings. Some contributors suggested that effectiveness could be measured against performance indicators, for instance those developed by the King’s Fund. Yet another suggestion was that carers should evaluate the effectiveness of their own support packages through the CPA. It was acknowledged, however, that evaluating the effectiveness of support services could be difficult and time-consuming, and consequently was not necessarily prioritised by service providers.

Cost-effectiveness was seen as a complex area which did not necessarily equate to cost minimisation. Contributors felt it was inappropriate to measure only *quantity*, such as cost per carer or cost per hour; any evaluation also needed to assess the *quality* of support provided. There was a feeling that effective schemes could be expensive because of the need for skilled and experienced staff, adequate time and possibly home visits. Another variable related to the relationship between effectiveness and the duration of the intervention. Support that was too short-term might not be cost-effective if benefits were not permanent; alternatively, support that was too long-term could increase dependence on service and in turn affect cost-effectiveness negatively.

Contributors noted that many carers were involved in caring activities for a long time, and therefore sought support that would be effective on a long-term basis. Short-term funding arrangements for many carers’ services had the potential to reduce cost-effectiveness as staff might have to devote time to generating further income.

9.4 Gaps and priorities in research evidence

Overall, contributors to the consultation exercise believed that the knowledge base about effective support for carers for people with mental health problems was sparse. They took the view that, where research on interventions was available, it was of high quality and/or comprised a relatively large body of knowledge. The following three areas were perceived as supported by empirical evidence:

- interventions or services to support carers, including breaks from caring (especially in relation to carers of older people with mental heath problems); support groups; the provision of information and advice
- interventions or services aiming to support the person with the mental health problem as well as the carer/family as a whole
- carers' needs and the emotional, physical and financial impacts of caring.

Some, however, questioned whether available research might be too narrow or specific in context to be useful in a wider or different setting.

Contributors spoke less of gaps in the literature and more of suggestions for further research. In particular, contributors called for further research into the comparative effectiveness of different models of *service delivery and interventions* for carers, focusing on individual interventions such as training and education, independent advocacy, information, carers' workers, and support groups, as well as on multi-agency or integrated services. They suggested that research should focus on what models of provision were being adopted and how effective they were in different service contexts. Further research should explore the balance between specialist mental health carers' services and generic carers' services, the effectiveness of early intervention for carers supporting a person in the early stages of their illness, how to improve access to services, particularly for 'hidden' carers, and the relationship between providing support for carers, and the health, ability to cope or quality of life of the person supported.

Contributors were also keen to see research which could inform how attitudes within mental health services could be changed. They called for short-term, practical research into how barriers to information sharing could be overcome, and into the implementation and impact of carers' assessments. Research on involving carers was also seen as a priority, both in terms of how and when to involve carers in decisions about the care of the person supported, and the effect such involvement might have on outcomes for both parties, and also into effective ways to involve carers in decision making at a service/planning level.

In terms of supporting *specific groups of carers*, contributors raised the need for research into young and young adult carers, black and ethnic minority carers, carers of people with dual diagnosis (in particular carers of people with both mental health and substance misuse problems, a learning disability or significant physical health problems), and carers supporting more than one person. They also suggested that research should explore less common caring situations, for example caring in a same sex relationship, caring at a distance, and the support provided to people with mental health problems by networks of friends and/or family rather than one or two primary carers.

Contributors thought there was a need for research into the long-term *impact* of caring for someone with a mental health problem, in particular longitudinal studies, which would examine the impact of caring on carers' physical and mental health, their life circumstances and financial situation. There was particular interest in such impacts on children and young people who are caring for a parent or sibling with a mental health problem. The contributors also called for comparative work to examine how caring for someone with a mental health problem differs from caring for someone with a physical disability or physical health problem, and within this how the relationship between the carer and the person supported might differ for mental health carers. Research into the experiences of carers involved with different patient groups was also seen as important.

In terms of *research design*, contributors wanted to see both longitudinal research that looked at the impact of caring and the impact of new policies and systems and also relatively short-term, practical research which could directly influence service planning and delivery in the short to medium term. They particularly highlighted the need for rigorous qualitative research that encompassed the experiences and perspectives of carers, people with mental health problems and mental health professionals.

The contributors from the selected local areas stressed that, in planning and delivering services, they used many kinds of knowledge – not just research evidence but also experiential knowledge, awareness of good practice developed in other areas, and lessons from local consultation. They expressed little interest in research based on carefully controlled experiments, but much more in research which suggested how services could work effectively in the real world. Many contributors felt that research into services and support for carers of people with mental health problems could usefully draw on other relevant areas of research. These included organisational studies and, in particular, research in the areas of change management, the impact of organisational cultures on decision making, and the influence of professions; psychosocial interventions generally, and family therapy in particular; family support, including research in the areas of fostering and child protection; and inter-agency working and the provision of integrated services.

Lastly, contributors emphasised the need to further improve the dissemination of existing and future research evidence. They highlighted the importance of research findings being presented in accessible forms. These included the publication of summaries of research and key findings, articles in professional as well as academic journals, more effective use of websites and dissemination through existing national and regional networks.

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Appendix A

Organisations involved in the consultation exercise

National bodies

Statutory sector

Director of NHS Portfolio in Mental Health (Clair Chilvers)

Social Services Inspectorate (Susan Harrison, Tim Birtwisle, Lawrie James)

Department of Health National Carers Strategy (Patience Holland, Rose Cofie)

Department of Health policy manager – mental health (Kathy Billington)

Association of Directors of Social Services (Andrew Cozins)

Voluntary sector

Alzheimer's Concern Ealing (Kulbir Gill)

Barnardo's (Tony Newman)

Carers UK (Diana Whitworth)

The Children's Society (Jenny Franks)

Manic Depression Fellowship (Michelle Rowett)

Mental After Care Association (Geraldine Mahon)

National Black Carer Workers Network / Afiya Trust (Peter Scott-Blackman)

NCH (Pete Andrews)

National Schizophrenia Fellowship (Geoff Lindsay)

Princess Royal Trust for Carers (Peter Tihanyi)

SANE (Amanda Hall)

Sheffield Afro-Caribbean Mental Health Association (Valda Walker)

Young Minds (Peter Wilson)

Also a number of **key individuals** nominated for their specific expertise in the field:

Jo Aldridge (Loughborough University – Young Carers Research Group)

Melanie Henwood (independent policy analyst)

Dr Michael Shotter (child and adolescent psychiatrist)

Michael Bainbridge (development consultant for Mental Health South West)

Dr Dele Oladije (consultant psychiatrist; Carers UK trustee)

Camilla Parker (legal and policy consultant)

Appendix B

Topic guide for interviews with contacts from national bodies

1 Could you briefly describe your role?

Effectiveness of services

2 What services would you consider to be key in providing effective local support to carers of people with mental health problems (e.g. short breaks, emotional support)?

3 What would you consider to be the most important characteristics of individual services (e.g. flexibility, understanding of carers' needs)?

4 With your responses to the previous two questions in mind, can you briefly describe what you think constitutes 'effectiveness' in relation to services to support carers of people with mental health problems?

5 What is your understanding of 'cost-effectiveness' in relation to services to support carers of people with mental health problems?

Research, knowledge and dissemination

6 Do you know of any studies focusing on cost-effectiveness in support for carers of people with mental health problems?

7 In your experience, which types of support for carers of people with mental health problems are backed up by good research evidence/knowledge?

8 What do you think are the main gaps in the research evidence/knowledge about effective types of support for carers of people with mental health problems?

9 What do you think should be the priorities for research in this area? / What further research evidence/knowledge would you find most useful in your work?

10 More generally, what further research do you think would be valuable in enabling both statutory and voluntary organisations to implement Standard 6 of the NSF for Mental Health?

11 Have you any views about what type of research would be most valuable in addressing the gaps in current knowledge?

12 How could the dissemination of research evidence be improved to ensure it reaches and informs those who provide or commission services to support carers of people with mental health problems?

Good practice and local contacts

13 In the course of your work, have you seen/heard/read about any particular example of good practice in supporting carers of people with mental health problems?

14 Do you know if the project/service has been evaluated in any way?

15 Please could you provide us with contact information for the project/service?

16 As part of the Scoping Exercise we also wish to identify a number of agencies (or areas of the country if more than one agency is involved), which have taken significant steps to improve support to carers of people with mental health problems. Could you suggest any Mental Health Trusts, PCG/Ts, HAs, or Social Services Departments which we should contact?

17 During the Scoping Exercise we will also want to talk to a number of carers. Do you know of any carers who, through their involvement in national bodies or networks, or local initiatives and groups, would be able to make a useful contribution to this study?

Any other comments?

Appendix C

Topic guide for interviews with contacts from local bodies

1 Could you briefly describe your role?

Local service developments

2 What services have been developed by your organisation for carers of people with mental health problems? / What services for carers of people with mental health problems have been developed in your area?

Effectiveness of services

3 From your experience, are these services different from or more innovative than services you have seen in other areas/organisations? If yes, why/how?

4 In your view, do the services you have described provide effective support to carers?

5 In your view, do the services you have described provide cost-effective support to carers?

Using research

6 When the services you have described were being planned/commissioned or developed/changed (if interviewee is a service provider), where did you look for ideas, information or evidence about effective approaches to providing support for carers of people with mental health problems?

7 Do you now or have you in the past used research evidence to inform service planning decisions, or the way in which services are delivered?

Research priorities and dissemination

8 What do you think are the main gaps in the research evidence/knowledge about effective types of support for carers of people with mental health problems?

9 What further research evidence/knowledge would you find most useful in your work?

10 More generally, what further research do you think would be valuable in enabling both statutory and voluntary organisations to implement Standard 6 of the NSF for Mental Health?

11 How could the dissemination of research evidence be improved to ensure it reaches and informs those who provide or commission services to support carers of people with mental health problems?

Any other comments?

Appendix D

Group exercise and discussion for key informant carers

The group is asked to imagine that they are members of a multi-agency Carers Strategy Group in an area called 'Borsetshire' (!). The area has an urban centre, but a rural hinterland, and a black and ethnic minority population which is close to the national average.

There is currently a range of services to support carers of people with mental health problems in Borsetshire. These include:

- a 24-hour help-line (for all carers, not specifically those caring for a person with mental health problems) run by the local Carers Centre; there is also an associated website with details of local services, help-lines etc.
- two carers' workers based in a local voluntary sector mental health organisation, whose main remit is to establish and support a number of carer support groups, and to provide advocacy for individual mental health carers
- two statutory carers' workers based in the local Community Mental Health Team; their main remit is to carry out carers' assessments (under Standard 6 of the National Service Framework) and to raise awareness of carers' needs among professional colleagues
- a Carers Education Programme which runs twice a year and has places for 12 carers each time
- a specialist home-based respite care scheme, where paid staff 'sit' with older people with mental health problems (mainly dementia) to enable the carer to have a short break.

The Carers Strategy Group is currently focusing on services for carers of adults with mental health problems (including older people and those of working age). Agencies in the area have a limited budget to spend on these services, and wish to take advice from the Group. However the Group is **not** asked at this stage to worry about the process of commissioning or establishing services. Its remit is as follows:

- to agree the most important **features/characteristics** of support services for mental health carers, both separately and in combination
- to decide on criteria to evaluate the **effectiveness** of existing and future services
- to discuss how to evaluate the **cost-effectiveness** of individual services, and how to compare the cost-effectiveness of different types of services.

Finally, the local agencies have asked the Carers Strategy Group to comment on any **relevant research** (or gaps in research), and to identify any priorities for further research which could be commissioned nationally or locally and which would assist the Group in its work.

Appendix E

Quality standards for local carer support services

(produced by the King's Fund in February 2000)

The following standards are based on carers' views of quality and are broadly supported by carers and managers and practitioners from voluntary, health and local authority services who took part in a wide consultation process.

Many respondents stressed that above all else action is needed by mainstream health, community and social services to deliver good-quality support to disabled, ill and frail people. These services also need to better recognise and respond to carers and ensure carers can get help and substitute care in an emergency, a break from caring and night cover.

The standards are primarily designed for services exclusively aimed at supporting carers, for example: carer centres, carer support projects, carer groups and services designed to offer carers a break, special help or advice.

However, these standards are equally relevant to mainstream health, housing, education, community and social services who will need to address these carer quality standards as well as other quality standards related to the modernisation of health and social services and local government.

It is recommended that as a prerequisite for providing a quality service, all carer support services should demonstrate they meet four essential requirements:

- Carers from all local communities are effectively involved in the organisation
- The service works in partnership with all local agencies
- The service is clear about its principles, aims and how these will be delivered and monitored
- All staff, including volunteers and trustees, are appropriately trained and supported.

It is proposed that any service aiming to provide carers with information, a break, emotional support, support to care and maintain carer's own health or support to have a voice will need to meet the relevant standard and accompanying list of conditions.

The five key standards are:

- *Information:* Any service providing information to carers provides information which is comprehensive, accurate and appropriate, accessible and responsive to individual needs.
- *Providing a break:* Any service offering a break to carers works in partnership with the carer and person being supported, is flexible and gives confidence and can be trusted.
- *Emotional support:* Any service offering emotional support to carers, either on a one-to-one basis or in a group, is sensitive to individual needs, confidential, offers continuity and is accessible to all carers.
- *Support to care and maintain carer's own health:* Any service which supports carers to care and to maintain their own health and well being by offering training, health promotion and personal development opportunities is responsive to individual needs.
- *Having a voice:* Any service which supports carers to have a voice as an individual and/or collectively is accessible to all carers and is able to act in an independent way.

It is proposed these standards for services directed exclusively at carers are monitored through contracting processes. Contracts between the funding organisation and the carer support service should include these standards and evidence for meeting each condition obtained systematically as part of the agreement.

Organisations providing local carer support services should be encouraged to carry out self-audits and continue to develop their own quality assurance schemes in order to deliver these standards.

Recommendations from the consultation for action centrally and locally to put these standards into practice include:

- Support local partnerships between carers, statutory and voluntary organisations to address these standards constructively, ensuring no small voluntary or community organisation is disadvantaged.
- Ensure mainstream services meet these quality standards as well as standards for services to the person being supported.
- Support carers to have a key role in monitoring the quality of services.
- Give priority to ensuring carers from all communities are included.

For further information on the individual standards, please log on to http://www.carers.gov.uk/archives.htm