Services to Support Carers of People with Mental Health Problems

Overview 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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Contents

Acknowledgements 5

**Executive Summary**

Background 6

Objectives of the study 6

Research methods: literature review 7

Research methods: consultation 7

**Key findings** 8

Interventions and services to support carers 8

Effectiveness and cost-effectiveness 9

Research methods 9

**Gaps in the literature** 10

**Recommendations for further research** 11

General approach 11

Research methods 12

Individual interventions relevant to current policy 12

Other research areas 12

Supporting specific groups of carers 13

Cost-effectiveness 13

**Recommendations for dissemination and implementation of research findings** 13
## The Report

### Section 1  Introduction

1.1  Background  
1.2  Aims and objectives of the scoping study  

### Section 2  Literature review: methodology and ‘map’ of results

2.1  Search strategy  
2.2  Study selection  
2.3  Data extraction and synthesis  
2.4  Mapping the results of the literature review  

### Section 3  Consultation exercise

3.1  Consultation with national bodies  
3.2  Consultation with local managers and practitioners  
3.3  Consultation with ‘key informant’ carers  
3.4  Supplementary consultation  
3.5  Analysis  

### Section 4  Interventions and services to support carers

4.1  Type and focus of interventions and services  
4.2  Patterns of service provision  
4.3  Underlying principles of service delivery  

### Section 5  Effectiveness and cost-effectiveness

5.1  Conceptualising and evaluating effectiveness and cost-effectiveness  
5.2  Evidence on the effectiveness and cost-effectiveness of interventions  

### Section 6  Research methods

### Section 7  Gaps in the research
Section 8  Recommendations for further research 40

8.1  General approach 40
8.2  Research methods 41
8.3  Individual interventions relevant to current policy 42
8.4  Other research areas 43
8.5  Supporting specific groups of carers 44
8.6  Cost-effectiveness 44
8.7  Dissemination and implementation of research findings 45

References 46
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Executive Summary

Background

Up to 1.5 million people in Great Britain may be involved in caring for a relative or friend with a mental illness or some form of dementia. Unless the amount of care provided by statutory services increases substantially, it is likely that there will be greater pressure for support to be provided by carers. Recent government policy, including the national strategy for carers and the National Service Frameworks (NSFs) for Mental Health and Older People, puts a high priority on meeting the practical, health, and emotional needs of this particular group of carers.

Objectives of the study

The overall aim of the scoping study was to advise the NHS Service Delivery and Organisation (SDO) Research and Development 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. The five key objectives were:

1. to define what was meant by ‘effectiveness’ and ‘cost-effectiveness’ in relation to services to support the target group, recognising that the major stakeholders will have different perspectives on, and interpretations of, these terms
2. to examine and summarise the evidence from published and grey literature (both UK and international) about effective and cost-effective services to support the target group
3. to ensure that the views of key stakeholders were central to the scoping study and informed its findings and recommendations
4. to draw on the evidence from the literature, and the consultation with relevant stakeholders, to identify the key gaps in existing knowledge and, where possible, to describe how these gaps are affecting development of services
5. to advise SDO on which areas should be a priority for further research, taking particular note of the requirements of the two NSFs, and the concerns and issues raised by different groups of carers or their representatives.

This report draws together key themes that emerged from the two elements to the scoping study: a literature review and a consultation.
Research methods: literature review

The aim of the literature review was to scope the extent and distribution of the literature on the effectiveness and cost-effectiveness of services to support carers of people with mental health problems. Searches were made of key electronic databases and the Internet for studies published between 1985 and 2001. Other search strategies included hand searching, searching websites of key organisations, and contacting librarians of leading mental health organisations. Bibliographies of studies were checked to ensure referenced studies were included. Out of the initial 3867 references generated through the search strategy, some 204 were included in the scoping review. Thirteen studies included an economic evaluation. Relevant data were extracted from each paper and synthesised through a narrative review that included descriptive characteristics, as well as more substantive issues such as effectiveness, cost-effectiveness and gaps in the research.

Research methods: consultation

The consultation involved three groups of stakeholders:
- representatives from national statutory and voluntary bodies (n = 27)
- managers and practitioners from local organisations that had taken significant steps to improve support to carers of people with mental health problems (n = 18)
- 'key informant' carers (n = 19).

The overall aims of the consultation were:
- to explore understandings of effectiveness and cost-effectiveness in relation to services to support carers of people with mental health problems
- to find out what research was seen as useful and/or a priority for future research
- to identify examples of perceived good practice.

In addition, a questionnaire was distributed to delegates at two national conferences, members attending a meeting of a carers’ support workers’ network, and members of a national carers’ organisation.
Key findings

**Interventions and services to support carers**

**Type and focus of interventions**

There were commonalities in the types of interventions and services provided by statutory and voluntary sector services and the evaluation studies of interventions that were included in the literature review. The majority of the studies focused on educational programmes, breaks from caring and family interventions. Locally, organisations were introducing a wider range of breaks for carers, funded through the Carers Special Grant, as well as providing educational and training programmes and support groups and social events. A new development in some areas was the appointment of specialist mental health carers’ workers either as carers’ development workers or carers’ (or family) support workers.

**Patterns of service provision**

Participants in the consultation shared the view that there was no one ‘ideal’ blueprint or service model. There was a belief that if services were to be effective, they should be tailored to local needs and circumstances. Contributors were clear that support for carers was likely to be most effective when offered as part of a holistic response to the family situation.

The literature review included evaluation reports from the USA of very large multi-site, multidimensional approaches to interventions. These studies provided modest evidence to endorse the view of contributors that it is important to provide a co-ordinated range of services to meet carers’ different support needs and to offer carers some choice.

**Underlying principles of service delivery**

Few service delivery issues emerged from the literature review; most studies looked at the effectiveness of specific interventions in terms of outcomes and failed to take account of underlying processes and social context. However, a consensus view emerged from the consultation that, to be effective, services should be underpinned by four underlying principles.

1. **Positive and inclusive**: mental health professionals should have a positive approach to carers, involve them in decision making and recognise them as ‘partners’ or ‘co-experts’.
2. **Flexible and individualised**: services should be person-centred, reflecting the diversity of carers.
3. **Accessible and responsive**: services should be available at all times, including outside ‘office hours’, and able to offer a rapid response.
Integrated and co-ordinated: services should be ‘joined up’; carers’ services should be embedded within mainstream mental health services.

Effectiveness and cost-effectiveness

Participants in the consultation conceptualised effectiveness in terms of benefits for the carers; benefits for the person supported; benefits for the family as a whole; impacts on service usage and long-term outcomes for society. Studies included in the literature review were consistent to a degree, in that as well as assessing outcomes for carers, some also looked at outcomes in relation to care recipients and families as a whole. Contributors had mixed views about how best to evaluate effectiveness. Their suggestions included measures of service utilisation rates, performance indicators, satisfaction surveys and evaluation forms. However, the majority of studies included in the review used standard outcome measures to evaluate the effectiveness of interventions.

As far as cost-effectiveness was concerned, contributors felt it was important to incorporate quality issues relating to the support provided rather than simply to use quantitative measures such as cost per carer or cost per hour.

The literature review found:
- a lack of clear evidence to support any specific intervention for the target group, although almost all studies were able to identify some positive outcomes of services provided
- cost savings reported for a range of interventions, resulting from decreased use of hospital-based care. However, there were methodological weaknesses in all studies with this conclusion.

Research methods

Eighty per cent of studies included in the literature review used quantitative methods, such as randomised and non-randomised controlled trials, before-and-after studies (uncontrolled) or studies collecting post-intervention data. The remaining 20 per cent of studies used mainly mixed or qualitative methods. The majority of studies were experimental or quasi-experimental. Studies with long-term follow-up were in the minority.

Three-quarters of studies used standard outcomes measures to evaluate effectiveness. Carer burden, stress, coping, physical health, emotional well-being, depression and knowledge levels were commonly measured. As far as the 13 studies with an economic aspect were concerned, most studies included health care costs and social services costs. One study valued carer time while two assessed changes in carer earnings.

Overall, the analysis highlighted methodological weaknesses in the studies under review: small sample sizes, problems with attrition; problems relating to the use of control groups; short follow-up periods.
Contributors to the consultation were keen to see short-term, policy-driven research, as well as longer-term, more in-depth policy-related studies. They believed that research-based evidence should complement other sources of knowledge, for example local research and consultation endeavours, and good practice exchanged through national and local networks.

Gaps in the literature

The literature review analysis identified clear gaps in the literature in relation to: carers assessments; care plans; comprehensive packages of care; breaks from caring; the use of telephone help-lines and computer-based interventions; the elements of a multidimensional package that were effective and cost-effective, and in what combination; the relationship between the different stages of an illness and specific interventions.

Two significant gaps in the literature related to services for children and young adult carers, and black and ethnic minority carers. Gaps in relation to services for carers of specific mental illness conditions included acute or chronic severe depression; severe eating, anxiety or sleep disorders; substance abuse.

Contributors talked more in terms of suggestions for further research. In terms of service delivery and interventions for carers, the following areas were suggested:

- individual interventions, including: training and education; independent advocacy; information; carers’ workers; support groups for carers
- comparative research into the effectiveness of different interventions to support carers
- multi-agency or integrated services; 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 the disease trajectory
- the relationship between providing support for carers and the health (including use of health services), ability to cope or quality of life of the person supported
- how to improve access to services, and in particular increase take-up by ‘hidden’ carers.

In terms of the relationship between carers and mental health services, contributors were keen to see:

- research to inform how attitudes within mental health services could be changed
- short-term, practical research into how barriers to information sharing could be overcome
Services to Support Carers of People with Mental Health Problems

- research into how and when to involve carers in decisions about the care recipient’s care, and the effect such involvement might have on outcomes for both parties
- research into effective ways to involve carers in decision making at a service/planning level
- quick and practical research into the implementation and impact of carer assessments.

In terms of supporting specific groups of carers, contributions raised the need for research into:
- young and young adult carers
- black and ethnic minority carers
- carers of people with dual diagnosis
- carers supporting more than one person
- less-common caring situations (for instance, research into caring in a same-sex relationship or caring at a distance).

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

Recommendations for further research

On the basis of the evidence from the literature review and the consultation, the following recommendations are made for commissioning further research concerning carers for people with mental health problems, as detailed below.

General approach

Support for carers of people with mental health problems needs to be offered through flexible packages of services that are tailored to suit the individual carer-care recipient; that are underpinned by key service delivery principles such as inclusiveness, responsiveness and co-ordination; that take account of local contexts. Packages are likely to vary, reflecting diversity of carer experience, patient diagnosis and stage of illness, and differing methods of service delivery. It is important to identify and examine what both carers and care recipients believe is effective in terms of the range of services available and explore how best these can be delivered in order to lead to improved outcomes for both. As well as experimental research, more studies should be undertaken of services and interventions in their ‘natural’ or ‘everyday’
Services to Support Carers of People with Mental Health Problems

health and social care context. Rather than focusing on interventions in isolation, there is merit in examining different components of integrated packages of care to assess their relative effectiveness, while also seeking to identify whether there is any ‘added value’ for carers. Research teams need to be multidisciplinary (embracing both qualitative and quantitative researchers) and should include researchers with a track record of experience in the methodology of study design and outcome evaluation.

Research methods

Current research methods are not always able to address the complex issues involved in providing carers with services. Studies should be commissioned that:

- use more diverse research methods
- adopt more innovative approaches to developing, implementing and assessing interventions
- develop and apply alternative approaches to determining the effectiveness of interventions alongside standard outcome measures
- are powered to detect statistically significant differences in both effectiveness and cost-effectiveness measures
- are longitudinal and capable of testing the effectiveness and cost-effectiveness of interventions and services in the longer term
- are longer-term, not policy driven but policy relevant
- are short-term, focusing on current issues and policy implementation.

Individual interventions relevant to current policy

Individual interventions warranting further research are:

- carers’ assessments
- breaks from caring
- family support
- educational and training programmes
- support groups for carers
- telephone and computer-based technology
- provision of information, advice and independent advocacy.

Other research areas

Other interventions and services worth further investigation are:

- multidimensional packages
- co-ordination of support
- changing attitudes to carers within mental health services
Services to Support Carers of People with Mental Health Problems

- impact of service provision on care recipients.

Supporting specific groups of carers

Research is required focusing on interventions for specific groups of carers, in particular:
- young and young adult carers
- black and ethnic minority carers
- carers in less-common caring situations (for instance, caring in a same-sex relationship; caring at a distance)
- research differentiating between the effectiveness of interventions for: spouse and non-spouse carers; male and female carers; urban and rural carers; working and non-working carers
- research into the effectiveness of services for carers of people with mental health conditions such as: depression; eating disorders; anxiety disorders; substance abuse; and those with a dual diagnosis.

Cost-effectiveness

To address gaps in relation to economic components.
- There is scope for further economic research in all care recipient groups and all interventions, with the possible exception of assertive outreach for patients with severe mental illness.
- It is particularly important that multidimensional packages are evaluated to identify which elements, and in what combination, are cost-effective and for whom.
- Ideally, economic evaluation should be conducted alongside intervention studies, with economic and effectiveness data collected at the same assessment.
- Studies should be powered to detect changes in both effectiveness and cost-effectiveness.

Recommendations for dissemination and implementation of research findings

Efforts should be made to ensure that research findings are more widely available and accessible to potential readers. When commissioning research, adequate funding should be made available; research bids should include this stage of the work in the proposal, with appropriate budget.
Section 1  Introduction

1.1  Background

Mental ill health is very common; at any one time, around one in six people of working age suffer from one form or another of mental illness, most often anxiety or depression (Department of Health (DoH), 1999a). In addition, 10 to 15 per cent of the population aged 65 and over will have depression and approximately 600,000 will have dementia (DoH, 2001). It is estimated that about half those with severe mental illness live with, or are supported by, family and friends (DoH, 1999a); up to 1,500,000 people may be involved in caring for a relative or friend with a mental illness or some form of dementia (figures based on ONS, 2002). It is clear from these figures that carers play a substantial and valuable role in mental health care in this country. Furthermore, there is increasing recognition that carers need effective support if they are to continue to play this vital role without detriment to their own health and well-being, or that of the person they support.

A pioneering review (Perring et al., 1990) undertaken over ten years ago highlighted how caring for someone with mental health problems was different from caring for a person with physical disabilities. Carers of people with mental health problems had been neglected up to that time; for instance, the clinical literature had concentrated on the patient as opposed to the carer. Much of the work that did exist had a strong medical influence, with an emphasis on quantitative methodologies and a bias towards families of people with schizophrenia as opposed to, for example, bipolar disorders and depressive illnesses. The review found that relatively few studies had looked at services from carers’ perspectives. The few that did highlighted the generally low quality and extent of carers’ contacts with services.

Since this review, there have been some important policy changes aimed at carers: the Carers (Recognition and Services) Act (1995); the national strategy for carers, Caring about Carers (DoH, 1999b); the Carers and Disabled Children Act (2000); the National Service Framework (NSF) for Mental Health (DoH, 1999a); and most recently the National Service Framework for Older People (DoH, 2001). All these policy measures emphasise the importance of providing carers with effective practical and emotional support to enable them to continue to care, if they wish to do so.
Given the current emphasis on research-based evidence (DoH, 1997), it is important to find out just what is known about the effectiveness and cost-effectiveness of services for carers of people with mental health problems. The insights provided will assist in the implementation of Standard six and Standard seven in the NSFs for Mental Health and Older People respectively, both of which place a high priority on support for carers. An unintended, but nonetheless useful outcome, is that this sort of information will indicate the progress that has been made in terms of support for carers since Perring and colleagues review (1990).

To this end, the NHS Service Delivery and Organisation Research and Development Programme commissioned a research team led by the Social Policy Research Unit (SPRU) at the University of York to undertake a scoping review on services to support carers of people with mental health problems. The team comprised researchers from SPRU and the primary and community care consultancy Acton.Shapiro.

1.2 Aims and objectives of the scoping study

The overall aim of the 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. Underpinning this aim were five key objectives.

1 To define what is meant by ‘effectiveness’ and ‘cost-effectiveness’ in relation to services to support carers of people with mental health problems, recognising that the major stakeholders will have different perspectives on, and interpretations of, these terms.

2 To examine and summarise 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.

3 To ensure that the views of key stakeholders were central to the scoping study and informed its findings and recommendations.

4 To draw on the evidence from the literature, and the consultation with relevant stakeholders, to identify the key gaps in existing knowledge and, where possible, to describe how these gaps are affecting the development of services.

5 To advise the SDO as to which areas should be a priority for further research, taking particular note of the requirements of the two NSFs, and the concerns and issues raised by different groups of carers or their representatives.

This Overview Report draws together the key themes and issues arising from the study, and identifies priorities for further research. Two accompanying reports contain full details of the complementary components that made up the study: a literature review and a consultation exercise. This report is cross-referenced with both the
Services to Support Carers of People with Mental Health Problems

Consultation Report and the Literature Review Report where necessary for readers interested in fuller information.

The report is organised as follows.

- Sections 2 and 3 discuss the methods adopted for the literature review and consultation respectively.
- Section 4 brings together the findings from both components, first in relation to the types and focus of interventions and services for carers, and secondly in relation to service delivery, including patterns of service provision and the principles which should underpin services to support carers of people with mental health problems.
- Section 5 considers how the effectiveness and cost-effectiveness of services to support carers was conceptualised, both by those who contributed to the consultation and in the literature reviewed. It also includes evidence about the effectiveness and cost-effectiveness of interventions.
- Issues relating to research methods are the focus of Section 6.
- Section 7 reports on gaps in the research identified by the literature review and as perceived by participants in the consultation.
- Finally, Section 8 presents recommendations for further research and development.

Note on terminology

Similar terminology has been used throughout all three reports documenting the study. The term ‘carer’ has been used rather than ‘informal carer’ or ‘care-giver’. Likewise, the terms ‘care recipient’, ‘person supported’, ‘person with a mental health problem’, ‘service user’, or ‘patient’ have been used to refer to the person being cared for.
Section 2 Literature review: methodology and ‘map’ of results

The methods used to scope the literature were designed to identify empirical studies that addressed the central research question: What is known from the existing literature about the effectiveness and cost-effectiveness of services to support carers of people with mental health problems? There is no single way to undertake a scoping study, and the methods used drew on established literature review procedures. However, a definitive component of a scoping study is to ‘map’ or identify the literature that currently exists in the field of interest (Mays et al., 2001) rather than address the issue of quality of individual studies. Thus, the review did not seek the ‘best evidence’ (Slavin, 1995), but instead sought to map the literature and report on relevant studies as a means to identify gaps.

2.1 Search strategy

Relevant studies were defined as any report of research that could be used to inform the development or evaluation of services to support carers for people with mental health problems. The literature search was wide ranging and aimed to identify research that differed in study design, care recipient group, intervention type, site of intervention, or geographical setting. Searches were made of electronic databases, including AMED, ASSI, BNI, Cinah, Cochrane Library, EMBASE, HMIC (King’s Fund Database, HELMIS, Dhdata), Medline, SIGLE, Social Science Citation Index, and Sociological Abstracts. Internet resources used included Caredata, Database of Abstracts of Reviews of Effectiveness (DARE), Health Technology Assessment Database (HTA), and the NHS Economic Evaluations Database (NHS EED).

Other search strategies included: hand searching; searching websites of key organisations (for example, the Department of Health, National Schizophrenia Fellowship, Alzheimer’s Society, Carers UK, The Princess Royal Trust for Carers); contacting librarians of organisations such as the Sainsbury Centre for Mental Health and the Mental Health Foundation. Bibliographies of studies were checked to ensure referenced studies were included.
2.2 Study selection

Studies published between January 1985 and December 2001 were selected for inclusion in the review if they represented a ‘best fit’ with the central research question (see above) and met the following inclusion criteria:

- **study type**: empirical work that evaluated the effectiveness or cost-effectiveness of services to support carers of people with mental health problems
- **intervention type**: any intervention directed towards carers of people with mental health problems, including dementia
- **care recipient group**: any care recipient group comprising individuals 18 years of age and older with any mental health problem
- **carer group**: carers of any age; carers of people with mental health problems.

Studies that were not empirical and not in English were excluded; so, too, were book reviews, commentaries and PhD theses.

Two reviewers identified studies by screening study titles and abstracts, and then by examining the full text of selected studies to decide inclusion. The search generated 3867 references; 204 of these were included in the scoping review, 13 of which included an economic evaluation.

2.3 Data extraction and synthesis

If reported, the following data were extracted from each paper:

- the intervention type, and comparator (if any)
- the study sample
- the care recipient group
- aim(s) of study
- research methods
- the duration of intervention
- outcomes
- the country where the study was set.

Further data extracted only from the economic evaluations included:

- types of costs included
- whether cost data was collected retrospectively or prospectively
• currency used to report findings
• measures of benefits reported
• whether there was a synthesis of costs and benefits.

A narrative synthesis of these data was conducted, which included descriptive characteristics, as well as more substantive issues such as effectiveness and cost-effectiveness. Gaps in the research were also identified.

Fuller details of the methodology adopted can be found in Chapter 2 of the accompanying Literature Review Report.

2.4 Mapping the results of the literature review

Geographical distribution

The majority of the 204 studies included in the review were carried out in the USA (55 per cent). Some 22 per cent of reports derived from the UK. Canada and Australia each accounted for 7 per cent of the studies. Studies from the rest of Europe and the rest of the world accounted for the remainder.

Care recipient group

The majority of interventions were aimed at carers of people with Alzheimer’s disease (AD) or other dementia (70 per cent). The rest were split evenly between people with schizophrenia (15 per cent) and other serious mental illness (15 per cent). Almost half of the studies of carers of people with AD/dementia were carried out in the USA (44 per cent).

Type of intervention

The studies included in the review covered a wide range of interventions and services for carers. To create some order out of this complex and unwieldy material, interventions were classified into 11 different groups of interventions (see Table 2.1) that were meaningful in terms of the aims of the scoping study and current government policy relating to mental health and carers’ issues. The most common intervention related to education of different kinds (36 per cent), followed by breaks from caring (18 per cent).
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<th>Service Type</th>
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<th>Studies with an economic aspect</th>
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**UK studies**

Of the 44 studies set in the UK, 18 targeted carers of Alzheimer’s disease/dementia patients, 14 targeted carers of people with schizophrenia, and the remaining 12 were for carers of people with other serious mental illness. Only one of these 12 was for people with depression or anxiety. The majority (13) of studies described interventions aimed at the family. Educational interventions and breaks from caring accounted for 11 and 8 studies respectively.
Research methods

As Table 2.2 shows, 80 per cent of studies used quantitative methods. Of these, randomised controlled trials (RCTs) accounted for 33 per cent of studies, non-randomised controlled trials for 20 per cent, before-and-after studies (uncontrolled) for 31 per cent, and post-intervention measures for 16 per cent.

The remaining 20 per cent of studies used mainly mixed or qualitative methods. Researchers using mixed methods collected both quantitative and qualitative data using, say, standard outcome measures or a postal survey together with in-depth interviews, focus group work or documentary analysis. Qualitative studies tended to involve in-depth interviews with relatively small numbers of participants.

Less than 20 per cent of the studies included in the review were comparative studies (a very small number of these were RCTs). The vast majority of studies were experimental or quasi-experimental. Those that took place in ‘natural’ settings tended to be of existing support groups for carers or established clinical services. Just over one-quarter of studies included follow-up at three months or over. Longer-term follow-up of two years and over was extremely rare (5 per cent).

Table 2.2 Number and proportion of studies according to type of research (N=204)

<table>
<thead>
<tr>
<th>Type of Research</th>
<th>N</th>
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<tbody>
<tr>
<td>Quantitative methods</td>
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<tr>
<td>• RCTs</td>
<td>53</td>
<td>33</td>
</tr>
<tr>
<td>• before-and-after studies (uncontrolled)</td>
<td>51</td>
<td>31</td>
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<tr>
<td>• non-randomised control trials</td>
<td>33</td>
<td>20</td>
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<tr>
<td>• post-intervention measures</td>
<td>25</td>
<td>16</td>
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<tr>
<td>Mixed or multi-methods</td>
<td>22</td>
<td>11</td>
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<tr>
<td>Qualitative methods</td>
<td>13</td>
<td>6</td>
</tr>
<tr>
<td>Other*</td>
<td>7</td>
<td>3</td>
</tr>
</tbody>
</table>

* e.g. content analysis; secondary data analysis; inadequate description of methods
Measures of effectiveness and cost-effectiveness

Seventy per cent of all the studies included in the review used standard outcome measures as a way to assess the effectiveness of interventions. Carer burden, stress, coping, physical health, emotional well-being, depression and knowledge levels were commonly measured. Alternate, and/or additional, ways to assess the effectiveness of interventions included programme evaluation surveys, satisfaction surveys, service utilisation rates, relapse rates and admissions to institutional care/hospital. Most of the studies with an economic component include health care costs and social services costs. Only one study valued carer time, while two assessed changes in carer earnings.

Fuller details of the extent, distribution, and nature of the studies included in the review can be found in Chapter 3 of the accompanying Literature Review Report.
Section 3 Consultation exercise

This section outlines the methods adopted for the consultation exercise, which involved three groups of stakeholders:

- representatives from national statutory and voluntary bodies (n = 27)
- managers and practitioners from local organisations (n = 18)
- ‘key informant’ carers (n = 19).

3.1 Consultation with national bodies

At a national level, the consultation involved representatives from 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 NSF for Mental Health (8). In addition, the views of a small number of individuals identified as playing a key role in the development of support for this group of carers were sought (5), together with those of people knowledgeable about support for carers from black and ethnic minority groups (3).

The primary purpose of this element of the consultation exercise was to explore understandings of effectiveness and cost-effectiveness in relation to services to support carers of people with mental health problems, to find out what research was seen as useful in people’s work, and to identify examples of perceived good practice.

3.2 Consultation with local managers and practitioners

Interviews were also conducted with a sample of officers from statutory and voluntary agencies in eight different areas of the country that had taken significant steps to improve support to carers of people with mental health problems. The aim of this set of interviews was to ascertain what were seen as the main issues in relation to services and, again, to understand what research would be helpful. The interviews also attempted to develop greater understanding of what evidence about effectiveness and cost-effectiveness would help in decision making in relation to developing and funding services.

All the interviews were carried out on the telephone. A topic guide was sent in advance, and detailed notes were taken during the interview.
3.3 Consultation with ‘key informant’ carers

The third, and last, element of the consultation involved small discussion groups with ‘key informant’ carers – that is, carers who had direct experience of caring for a person with a mental health problem, and who also, through their involvement in national or local bodies or networks, could take a broader perspective on support for carers for people with mental health problems. The aim of the consultation with carers was to validate or cross-check 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.

Discussion groups were held in London and Bristol, attended by seven carers and six carers respectively. Carers taking part had a broad range of personal experience, including caring for a partner, parent or adult child with mental health problems. Two were from ethnic minority groups; one was a former young carer, and one was the father of two children affected by their mother’s mental illness.

A further six carers unable to attend a discussion group took part in telephone interviews.

3.4 Supplementary consultation

In the course of the study, the research team had the opportunity to administer a questionnaire at a national conference on Caring for People with Mental Health Difficulties organised by the Princess Royal Trust for Carers, and also at a meeting of MACA’s ‘Supporting Carers Better’ Network. The questionnaire was later distributed to MACA members unable to attend the network meeting, as well as to members of Carers UK. Over 70 completed questionnaires or letters were received from these sources. The information was useful in identifying key informant carers, areas perceived as developing good practice in carer support, perceived gaps in research, and priorities for future research.

3.5 Analysis

The data obtained from the interviews with representatives from national and local bodies, from the discussion groups and interviews with key informant carers and from the questionnaires, 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.

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, these data 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’. The database was used to inform the research team’s thinking about service structures and service delivery.

Fuller details of the methods adopted can be found in Chapter 2 of the accompanying Consultation Report.
Section 4 Interventions and services to support carers

This section brings together the findings from the literature review and the consultation in relation to the type and focus of interventions for carers. It also summarises the key issues identified, which relate to service delivery, including patterns of service provision and the principles that need to underpin services to support carers of people with mental health problems.

4.1 Type and focus of interventions and services

Contributors to the consultation identified the different ways in which services were attempting to address the support needs of carers for people with mental health problems (see Consultation Report, Section 5.2). Some of these initiatives were in response to Standard six 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). 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). Generally, the main function of the former group was to implement Standard six and often conduct 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 (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.

There was some consistency between the types of interventions and services implemented locally for carers and the interventions reported in the studies included in the review. As shown in Table 2.1, the majority of research studies in the national and international literature focused on educational programmes and breaks from caring. As far as the UK literature only was concerned, the majority focused on interventions aimed at the family as a whole (for instance, interventions drawing on family therapy models, or services provided in the home by, say family support workers), followed by educational interventions (including
training and psychoeducational interventions) and then breaks from caring (including day care; in-home respite care; institutional respite; mixed respite services).

With the exception of those studies looking at family interventions, much of the research included in the review focused on outcomes of interventions for primary carers. Relatively few studies were identified that focused on interventions specifically for: spouse carers; male or female carers; working and non-working carers; residential and non-residential carers. No study was identified that focused specifically on young carers or black and ethnic minority carers, two groups that interviewees recommended should be the focus of more research (see Section 8.3).

4.2 Patterns of service provision

Those who contributed to the consultation had a common understanding of the broad pattern of services needed to support carers. They highlighted the need for a range of services which can provide information, support and advice, training and education, and time off from caring. They also emphasised the central importance of services to effectively support the person with mental health problems.

No single blueprint or service model which was identified was regarded as ‘ideal’ or effective. Indeed, many contributors, particularly local managers and practitioners, and key informant carers felt that if services are to be effective, they must be tailored to local needs and circumstances. In practice, most areas had 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.

Two of the areas involved in the local consultation had taken a more systematic approach to the development of carers’ support services. One local authority had commissioned a voluntary organisation to set up and manage a county-wide network of carers’ support workers. In another area, the local mental health trust and its partner social services department had attached a carers’ development worker and carers’ support worker to every Community Mental Health Team. The development workers were employed by the mental health trust and the support workers by a local voluntary organisation. In addition they had established a carers’ development worker for black and ethnic minority carers.

The literature review identified a number of studies that had examined the effectiveness of multidimensional approaches to caring interventions. One service developed in the USA targeted carers of people with Alzheimer’s disease, offering them a combination of interventions, including community-based services, education and carer support services. Another American study provided support services
such as respite, support groups, educational groups and outreach to families of people with serious mental illness.

Such studies provide valuable information about the effectiveness of offering multiple interventions to specific groups of carers. For instance, generally the studies reported positive outcomes for one aspect or another, but there was little evidence that providing multi-dimensional approaches produced any ‘added value’. The findings of the studies also endorsed the view of those involved in the consultation that it was vital to provide a co-ordinated range of services in order to meet carers’ different support needs and to offer them choice. They do not, however, provide a template for services. As was noted earlier, most contributors to the consultation did not wish to see a single service model but rather wanted evidence which could inform the development of a locally appropriate range of services.

Contributors to the consultation also highlighted the importance of integrating carer support into local mental health services, and questioned 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 separate, dedicated services to support carers.

Again, two areas involved in the local consultation had taken this approach, emphasising the steps they had taken to change thinking and practice towards carers within mainstream mental health services, including integrating carers assessment into the work of Community Mental Health Teams, expecting all mental workers to offer support to carers, and giving day services a new role in providing psychosocial support and cognitive behavioural training for families. Interestingly, both these areas had merged mental health and social services to form Partnership Trusts.

4.3 Underlying principles of service delivery

The consultation also highlighted participants’ convictions that whatever services are developed to support carers, they will only be effective if they are underpinned by certain underlying principles, or if they demonstrate 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 are most effective when they are:

- **positive and inclusive.** Participants emphasised the importance of mental health professionals having a positive attitude to supporting carers, involving them in decisions about the care of the person they support and recognising carers as ‘partners’ or ‘co-experts’. A willingness to share information was seen as central to the relationship between carers and professionals, and many contributors were interested in relatively short-term, practical research which could help them overcome some of the barriers to information sharing.

- **flexible and individualised.** There was a strong view that services should be person-centred, i.e. they should take account of carers’ preferences and their existing relationships and responsibilities. It was also emphasised that carers were not a homogeneous group, and so services should reflect and respond to the diversity of the carer population they serve. Lastly, it was noted that support for carers had to promote independence and be non-stigmatising.

- **accessible and responsive.** These characteristics encompass many different facets of services, but the availability of services outside ‘office hours’ and their ability to respond rapidly to carers were seen as particularly important. Contributors also highlighted the need for services that could offer continuity of contact – not just support in a crisis – and were reliable and sustainable for both the carer and the supported person. Appropriate funding and effective staff training and recruitment were seen as central to achieving this quality of support for carers.

- **integrated and co-ordinated.** Two main themes were highlighted here: the need for support for carers to be provided by and co-ordinated between different agencies, and, again, the importance of carers’ services being embedded in mainstream mental health services.

Few of the studies included in the literature review examined service process and delivery issues. The majority looked at outcomes of discrete interventions in isolation and failed to take account both of the underlying processes and the social context in which the interventions took place. This ‘black box’ approach has been criticised (Fulop *et al*., 2001), and researchers (for instance, Pawson and Tilley, 1997) have proposed revisions to experimental approaches to service evaluation with the aim of taking account of context and processes. The implication of this for evaluating the effectiveness of interventions for carers of people with mental health problems is that issues relating to the design of interventions (for example, that they should be user-focused and individualised), as well as their structure and delivery, need to be incorporated into research designs.
Section 5  Effectiveness and cost-effectiveness

5.1 Conceptualising and evaluating effectiveness and cost-effectiveness

The consultation (Consultation Report, Section 6.1) found that interviewees conceptualised effectiveness in five main ways.

1  Benefits for the carer: supporting carers was considered effective if/when it could improve their quality of life, reduce stress and prevent the likelihood of carers developing health problems themselves. In the longer term, services were seen as effective because they facilitated carers achieving their full potential.

2  Benefits for the person supported: by supporting and involving carers, professionals could in turn better understand the person supported and provide them with individually tailored support.

3  Benefits for the family as a whole: effective services for carers could be a way to help prevent family breakdown and to maintain/restore caring situations.

4  Impacts on service usage: support for carers was viewed as effective if it meant that carers and/or care recipients reduced, maintained or did not increase the levels of support they received from the statutory services.

5  Long-term outcomes for society: 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.

This is fairly consistent with the literature review in the sense that while all the studies were concerned with assessing outcomes for the carer, some also looked at outcomes in relation to both carers and the persons supported. As would be expected, research in the area of family interventions focused on the family unit. However, the studies in the literature review rarely examined the long-term outcomes for society of specific services or interventions.

As far as methods to evaluate effectiveness were concerned, contributors held mixed views (Consultation Report, Section 6.3). Some took the view that services could be evaluated by measuring utilisation rates, for example a high level of (self-) referrals would indicate an effective service. Other contributors – 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
Services to Support Carers of People with Mental Health Problems

CPA. It was acknowledged, however, that evaluating the effectiveness of support services could be difficult and time consuming, and consequently this was not necessarily prioritised by service providers.

In line with comments made by contributors, some studies included in the review did undertake programme evaluation surveys or satisfaction surveys, either in addition to using standard outcome measures or as the main data collection tool. Relatively few studies used small discussion groups. Service utilisation rates were also used as measures. However, nearly three-quarters of all the studies included in the literature review assessed the effectiveness of interventions for carers using standard outcome measures (discussed further in Section 7).

Overall, contributors to the consultation exercise believed that where research on interventions was available it was of high quality and/or comprised a relatively large body of knowledge. With the exception of the three areas listed below, however, contributors believed that the knowledge base about (effective) support was sparse (Consultation Report, Section 7.4). Research was thought to be available on:

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

Table 2.1, which gives the breakdown of review studies according to intervention type, shows that contributors were more or less correct in identifying the areas where research had been undertaken into the effectiveness of interventions.

As far as cost-effectiveness was concerned, individuals taking part in the consultation believed that this was a complex area. Cost-effectiveness was not seen as equivalent to cost minimisation; in other words, it was too simplistic to view financial prudence as the cheapest way of achieving a particular outcome (Consultation Report, section 6.2). 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 have a higher cost arising from 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 services and in turn affect cost-effectiveness negatively.

Contributors noted that many carers were involved in caring activities for a long time, and therefore wanted support that would be effective on
Services to Support Carers of People with Mental Health Problems

a long-term basis. Short-term funding arrangements for many carers’ services was perceived as possibly having the potential to reduce cost-effectiveness because staff might have to devote time to generating further income.

5.2 Evidence on the effectiveness and cost-effectiveness of interventions

Chapter 4 of the Literature Review Report analyses the key interventions and services to support carers. Set out below is a summary of the findings in relation to the effectiveness and cost-effectiveness of the interventions reported.

Overall, there was a lack of strong evidence to support any specific intervention for carers for people with mental health problems, although almost all studies were able to identify some positive outcomes of services provided.

- **Breaks from caring:** there was mixed evidence about the effectiveness of respite breaks for carers. Some studies found no evidence of effectiveness, while others found positive effects in relation to carer burden, carer morale and carer stress. High levels of reported carer satisfaction were not necessarily reflected in improvements in the results of pre- and post-test outcome measures. There was evidence that institutional respite could lead to worsening relationships between carers and persons supported on their return home. Some studies provided tentative evidence that offering carers respite breaks might actually increase the rate of patient institutionalisation.

- **Educational interventions:** the research reviewed reported that provision of educational materials for carers improved carer knowledge, but might not reduce carer burden. Training interventions take many forms and positive effects are reported for certain types of training. Evidence regarding the effectiveness of psychoeducational approaches for carers is diverse and contradictory.

- **Family interventions:** there was evidence to suggest that family therapy might be effective in reducing relapse rates among people with schizophrenia. Other aspects of effectiveness identified included: improvements in patient behaviour, improvements in family relationships, and reductions in family burden.

- **Mutual support and social activity groups:** there was no conclusive evidence about the effectiveness of support groups for carers. There were indications that positive aspects of group involvement included emotional support, shared experience, helping carers to cope with their situation and developing a more positive outlook. Reported carer satisfaction was high.

- **Counselling:** there was some evidence that counselling reduced depression and was successful in reducing role strain. Counselling
might delay or postpone institutionalisation, particularly during the early and middle stages of dementia.

- **Telephone and computer-based services**: evidence regarding the effectiveness of both telephone and computer-based services was limited. Positive effects were reported for telephone networks in relation to depressive symptoms, stress and burden, life satisfaction and use of social support. The long-term benefits were not clear, as peer telephone networks seemed to have greater effectiveness in the short term (three months) than in the longer term (six months).

- **Multidimensional approaches to caring**: the most comprehensive evaluation of a multidimensional approach to caring found small improvements in burden and depression in some of the study sites, but no change when all the sites were combined. Overall, the reported findings of these types of approaches were inconclusive.

- **Other intervention services**: there was only modest evidence relating to the effectiveness of interventions associated with the home or physical environment. The studies reporting on memory clinic support for carers found improved carer well-being and psychosocial health-related quality of life.

As far as cost-effectiveness was concerned, there was some evidence that assertive outreach for patients with severe mental illness was at least as effective as standard inpatient care, and that this could also be cost-effective. Cost savings were reported for a range of interventions, resulting from decreased use of hospital-based care. However, there were methodological weaknesses in all studies with this conclusion.
Section 6 Research methods

The scoping review found that 80 per cent of the studies included were randomised or non-randomised controlled trials, before-and-after studies (uncontrolled) or studies collecting post-intervention data (see Table 2.2). The remaining 20 per cent used mainly mixed methods, or qualitative methods. The vast majority of studies were experimental or quasi-experimental. Those that took place in ‘natural’ settings tended to be of, say, existing support groups for carers or established clinical services. Studies undertaking long-term follow-up were in the minority.

Seventy per cent of studies used standard outcome measures such as the General Health Questionnaire, the Burden Interview, or the Centre for Epidemiological Studies Depression Scale to assess the effectiveness of the intervention being examined. Carer burden, stress, coping, physical health, emotional well-being, depression and knowledge levels were commonly measured. There was minimal use of standard measures focusing on positive dimensions of caring, such as satisfaction. Alternative and/or additional ways of assessing effectiveness included programme evaluation surveys, satisfaction surveys and service utilisation rates. As far as the 13 studies with an economic aspect were concerned, a diverse range of effectiveness measures was reported. Most studies included health care costs and social services costs. However, only one study valued carer time, while two assessed changes in carer earnings.

Questions have been raised about the use of standard outcome measures to judge the effectiveness of an intervention. Bowling (1997), for example, points out that the conceptualisation and measurement of health outcomes are controversial. Most existing indicators reflect a ‘disease’ model where pathological abnormalities are indicated by signs and symptoms. This fails to capture subjective indications of poor health, such as pain and discomfort. Likewise, carers can report high levels of satisfaction with a service, for example a support group, but benefits are not demonstrated through positive/improved outcomes as measured on a standard instrument. A further potential weakness is that standard outcome measures may not be sufficiently sensitive in relation to ‘time horizons’ and the fact that carers’ needs change over time reflecting different stages in the care recipient’s disease trajectory (Literature Review Report, Chapter 6). While not dismissing the use of standard outcome measures, which are a valuable tool in identifying change, it is important to be aware of their limitations.
Recently, there have been calls (Marks and Godfrey, 2000; Gowman and Coote, 2000) to expand the evidence base in health services research from the traditional randomised controlled trial to encompass a wider range of methods. There were examples of the use of qualitative methods to evaluate interventions. For instance, researchers (Pritchard and Dewing, 2001) in the UK used multiple methods within Fourth Generation Methodology (Guba and Lincoln, 1989) to evaluate a dementia care service and approach. Over the 14-week period of this evaluation, data collection included initial orientation; interviews with patients, carers and professionals; self-report questionnaires; dementia care mapping; focus group work; a documentation audit; gathering contextual information; and writing up field notes.

A much smaller UK study (Fisher and Savin-Baden, 2001) conducted individual, in-depth interviews with key stakeholder groups to evaluate an occupational therapy initiative. Interviews were held with the care recipients; their families, where possible; those making referrals to the service, for example consultant psychiatrists; and the occupational therapists responsible for developing and implementing the programme.

The literature review included just one example, from Australia, of a piece of action research (Kilstoff and Chenoweth, 1998), where the results can be fed back to those taking part in the study as the research progresses. According to the researchers:

... the carers’ involvement in the design and evaluation of the study empowered them in many ways, not the least of which was to give them a voice in helping shape the dementia day-care programme offered.

Other studies, albeit few in number, also involved carers in the evaluation and development of interventions. For example, feedback was obtained on an existing educational programme for dementia carers through a telephone survey of past participants and two focus groups comprising family members, presenters and facilitator (Steffen et al., 1999). The information was then used to develop a new programme, which had a new curriculum and format.

Models for evaluating large-scale, multi-site support services have been developed in the USA. For instance, an evaluation (Benson et al., 1996) of a multi-site network of professional family support programmes funded and overseen by the Massachusetts Department of Mental Health was conducted during the first two years of the initiative. During this time, some 647 families had contact with the 12 support programmes, which between them provided respite care, peer support groups, educational workshops, supportive counselling and service linkage. Quantitative data were collected from family members at enrolment and then at regular times throughout the evaluation. These were supplemented by qualitative data, derived from in-depth interviews with support programme staff during site visits.

Overall, the scoping study highlighted recurrent methodological weaknesses in the studies under review: small sample sizes; problems with attrition; problems relating to the use of control groups; short
follow-up periods. Such limitations, often acknowledged by the authors themselves, made the task of judging effectiveness more difficult.

As noted above, many studies were of experimental rather than established services, suggesting that as well as (controlled) experiments, there is also a need for research into the everyday or ‘natural’ context of the intervention. This was endorsed by the contributors to the consultation, who questioned the value of research that was too heavily based on pilot projects or too specific to the context in which it was undertaken.

Although contributors to the consultation were not asked directly about research methods, many of them did comment on the ‘type’ of research they would like to see. In particular they highlighted:

- longitudinal research, capable of examining the impact of caring and the impact of new policies and systems in some depth
- relatively short-term, practical research which could directly influence service planning and delivery in the short to medium term
- rigorous qualitative research that encompassed the experiences and perspectives of carers, people with mental health problems and mental health professionals.

They also felt that research into services and support for carers of people with mental health problems could usefully draw on other relevant areas of research, including:

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

In addition, contributors recommended that in future, research-based evidence should complement other sources of knowledge – for example, local research and consultation endeavours, and good practice exchanged through national and local networks.
Section 7  Gaps in the research

This section details gaps in the research, identified by the literature review and as perceived by contributors to the consultation. Although the literature review was by its very nature highly targeted and structured and the consultation quite broad in comparison, there was a high degree of common ground, both between the two elements of the scoping study and within the different stakeholders taking part in the consultation. Inevitably contributors raised ‘here and now’ issues relating to current policy; not unexpectedly, these were not reflected in the literature review which was retrospective and instrumental. On this basis, it is reasonable to say that policy-related matters emerged more strongly from the consultation, and methodology and research design issues emerged more strongly from the literature review. For fuller details of the discussion that follows, see Chapter 4 of the Literature Review Report and Chapter 8 of the Consultation Report respectively.

The literature review analysis identified clear gaps in the literature regarding the types of interventions studied, especially concerning key policy areas: carers assessments; care plans; comprehensive packages of care; breaks from caring; the use of telephone help-lines and computer-based interventions. More general gaps identified in the review of the literature related to knowing which elements of a multidimensional package, in what combination, were effective and cost-effective, and knowing more about the relationship between the different stages of an illness and specific interventions.

Two significant gaps in terms of services for particular groups of carers related to children and young adult carers, and black and ethnic minority carers. Gaps in relation to specific mental illness conditions included acute or chronic severe depression, severe eating, anxiety or sleep disorders, and substance abuse.

Contributors to the consultation discussed this issue less in terms of gaps in the literature and more in terms of suggestions for further research.

Service delivery and interventions for carers

In terms of service delivery and interventions for carers, the following areas were suggested.

- Training and education: which approaches to delivering training were most effective and which approaches worked best for different groups of mental health carers.
Services to Support Carers of People with Mental Health Problems

- Independent advocacy: what was the best way to deliver this service, and whether demand for independent advocacy was reduced if carers were more actively involved in decisions about the care of the person supported.
- Information: how best to provide information required, and at what point in relation to the development of the carer’s role and the illness of the supported person.
- Carers’ workers: what models of provision were being adopted and how effective they were in different service contexts.
- Multi-agency or integrated services.
- 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, and in particular increase take-up by ‘hidden’ carers.
- The effectiveness and cost-effectiveness of support groups for carers.
- Comparative research into the effectiveness of different interventions to support carers.
- The relationship between providing support for carers, and the health, ability to cope or quality of life of the person supported.

Relationships between carers and mental health services

In terms of the effectiveness of relationships between carers and mental health services, contributors were keen to see:

- research to inform how attitudes within mental health services could be changed
- short-term, practical research into how barriers to information sharing could be overcome
- research into 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
- research into effective ways to involve carers in decision making at a service/planning level
- quick and practical research into the implementation and impact of carers assessments.
Supporting specific groups of carers

In terms of supporting specific groups of carers, contributors raised the need for research into:

- **young and young adult carers**: how best to support young carers within the family on an ongoing basis; how to support parents with mental health problems in their parenting role; how to assess the effectiveness of different interventions for young carers at different stages in their lives; national statistics of the number of children and young people caring for someone with a mental health problem

- **black and ethnic minority carers**: research into the way in which different cultures view the caring role in mental health; how care and support are provided in different cultures

- **carers of people with dual diagnosis**: research into the problems faced by carers of people with a dual diagnosis, in particular carers of people with mental health and substance misuse problems, people with a learning disability and mental health problems, people with a mental health problem and significant physical health problems

- **carers supporting more than one person**: research into the impact of caring for more than one person

- **less-common caring situations**: research into 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.

Impact of caring

In terms of the impact of caring, contributors thought there was a need for the following research.

- The long-term impact of caring for someone with a mental health problem, in particular longitudinal studies, which examine the impact of caring on carers’ physical and mental health, their life circumstances and financial situation.

- 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.

- Longitudinal research into the impact on children and young people of caring for a parent or sibling with a mental health problem, including the wider impact on life chances.
Section 8  Recommendations for further research

On the basis of the evidence from the literature review and the consultation, we recommend that serious consideration be given to commissioning further research and development for services for carers for people with mental health problems as detailed below.

8.1 General approach

Support for carers of people with mental health problems needs to be offered in the form of a flexible package of services that is tailored to suit the individual carer–care recipient dyad; that is underpinned by key principles of service delivery such as inclusiveness, responsiveness and co-ordination; and that takes account of local contexts. The content of these packages will vary, and will reflect the diversity of carer experience in terms of geography, socioeconomic variables, patient diagnosis and stage of illness, as well as differing delivery methods provided by both the statutory, private and voluntary sectors.

A consensual view emerged from the consultation that services and interventions should be tailored to the needs of both individual carers and care recipients; disregarding care recipients can lead to unanticipated outcomes, as well as hindering the full realisation of benefits (Zarit and Leitsch, 2001). On this basis, we feel that it is important to identify and examine what carers, and care recipients, believe is effective in terms of the range of services available and explore how best these can be delivered in order to lead to improved outcomes for both carers and care recipients.

As well as experimental research, more studies should be undertaken of services and interventions in their ‘natural’ or ‘everyday’ health and social care context. We are aware of the tension between local context and the extent to which results can be generalised to other settings, and that there can be a threat to generalisability in that findings are specific to, or dependent on, the particular context in which the study took place. However, this same argument can also be made in relation to experimental studies and the various controls that might be imposed by the researchers in order to boost internal validity or to try to demonstrate causal relationships. From this point of view, then, the results obtained in what may be a quite controlled environment are also difficult to generalise to any settings other than close approximations to the experimental conditions. However, if it is known that the study sample is a representative sample of a known population, say the carer population, then generalisation to that population ought to be possible, according to the rules of statistical inference (Robson, 2002).
In terms of future research commissioning, we are not suggesting that a large number of studies be funded that focus on individual interventions or services for carers. Rather than focusing on interventions in isolation, we believe it would be as, or more, useful to take a holistic view, including looking at services as they are embedded in their natural or local context. This would mean examining different components of integrated packages of care in efforts to assess their relative effectiveness and cost-effectiveness, and at the same time seeking to identify whether there was any ‘added value’ for carers. Research teams would need to be multidisciplinary (embracing both qualitative and quantitative researchers) and should include researchers with a track record of experience in the methodology of study design and outcome evaluation.

### 8.2 Research methods

The combined evidence from the literature review and consultation highlights the complexities involved in delivering interventions and services for carers of people with mental health problems. Current research methods are not always able to address such complex issues, and from that point of view are not always fit for the purpose. A strong case can be made for commissioning studies that:

- use more diverse research methods in order to increase the depth and breadth of data collected and to capture perspectives from a range of key stakeholder groups (including carers/families, persons supported and professionals)
- adopt more innovative approaches to developing, implementing and assessing interventions, including studies that draw on carers’ own particular expertise and involve them in decisions on what outcomes are to be examined and how
- develop, and then apply, alternative approaches to determining the effectiveness of interventions alongside standard outcome measures; this might include, or be complemented by, studies that employ process outcome measures, relating to the structure, delivery and organisation of services
- are longitudinal and capable of testing the effectiveness and cost-effectiveness of interventions and services in the longer term.
Useful studies to examine the more general ‘knowledge generation’ issues as distinct from SDO issues are studies that:

- are longer term, involving more in-depth research, which is not policy-driven but is policy-relevant, in particular research that can examine the impact of policy initiatives on carers
- are short term, and focus on current issues and policy implementation.

8.3 Individual interventions relevant to current policy

The interventions and services detailed below are directly or indirectly relevant to the implementation of the Carers (Recognition and Services) Act 1995, the Carers and Disabled Children Act 2000, the National Strategy for Carers (DoH, 1999b) and Standards 6 and 7 of the National Service Framework for Mental Health (DoH, 1999a) and the National Service Framework for Older People (2001), respectively. The review identified a paucity of studies in some of these areas. There was modest evidence that some of the interventions had benefits for carers; what was not clear was what types of intervention, for which care recipient groups, at what point in the caring and/or illness trajectory, were most effective. Where relevant, further research is needed into the relationship between implementation of the intervention and effects on institutionalisation of the person supported. The interventions warranting further research are:

- carers’ assessments, including: carers’ experience of assessment and its outcomes; the effectiveness of different models of assessment; whether assessments are best undertaken by mainstream mental health workers or dedicated carers’ workers; the impact on workloads and relationships and the application and effect of eligibility criteria
- breaks from caring, including: appropriate models for carers of working-age adults; the provision of in-home respite; the effect of respite on the relationship between the carer and the person supported; the effectiveness and cost-effectiveness of different models of respite care (in-home or in an institution)
- family support, including: interventions for families with children; interventions for carers of people with mental illness other than schizophrenia, particularly carers of people with dementia
- educational and training programmes, including: which approaches or components are most effective; which work best for different groups of carers, and at what point
- support groups for carers, including: which carers are most likely to benefit from them; how groups can be encouraged to be less static; the cost-effectiveness of different models of provision
 telephone and computer-based technology, including: effectiveness; the extent to which telephone and/or computer networks can substitute or supplement other formal and informal support

• provision of information, advice and independent advocacy, including: how best to provide these services, and in what circumstances; and at what point in time.

8.4 Other research areas

Other interventions and services seem relevant and worth further investigation. Consequently, as well as studies examining individual interventions, we would recommend that research is undertaken in the following areas.

• Multidimensional packages, including: identifying which elements in a multidimensional package are effective, in what combination, and for which groups of carers.

• Co-ordination of support, including: research examining the relationship between assessment and the provision of comprehensive, individually tailored packages of support; research into the co-ordination of packages of support across all statutory and voluntary agencies.

• Impact of service provision on care recipients, including: research into 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 supported.

Further valuable research, albeit focusing on more general issues rather than specific SDO concerns, would be to examine attitudes to carers within mental health services, including:

• research to find out how attitudes within mental health services can be changed

• research that draws on other fields of enquiry, notably organisational studies

• research that examines approaches to breaking down barriers to information sharing and improving carer involvement in decision making.
8.5 Supporting specific groups of carers

Research in this area needs to consider both the characteristics and circumstances of the carer and the diagnosis of the care recipient. The study identified a need for research focusing on interventions for specific groups of carers, in particular:

- **young and young adult carers.** As well as the research areas identified for carers of people with mental health problems generally, additional pertinent fields of inquiry include: the effectiveness of young carers projects, especially for young people who are involved in caring for relatives with mental health problems; appropriate service provision to support young carers, which at the same time will help them remain within the family environment; effective support for the family as a whole, provided on an ongoing basis rather than intermittently to address a crisis that has occurred.

- **black and ethnic minority carers.** The previous research areas identified for carers of people with mental health problems are relevant, but in addition research examining ‘what works’ for different minority groups; how mainstream services can strengthen their sensitivity and responses to different cultures; how best to utilise/exploit existing good practice

- **carers supporting more than one person**

- **carers in less-common caring situations** (for instance, caring in a same-sex relationship; caring at a distance).

In addition, research is required which differentiates between the effectiveness of interventions for: spouse and non-spouse carers; male and female carers; urban and rural carers; and working and non-working carers.

There is also a need for research that examines the effectiveness of services for carers of people with mental health conditions such as depression, eating disorders, anxiety disorders, substance abuse, and of those with a dual diagnosis.

8.6 Cost-effectiveness

Very few studies contained an economic component. To address this gap:

- there is scope for further economic research in all care recipient groups and all interventions, with the possible exception of assertive outreach for patients with severe mental illness

- it is particularly important that multidimensional packages are evaluated to identify which elements, and in what combination, are cost-effective and for whom
• ideally, economic evaluation should be conducted alongside intervention studies, with economic and effectiveness data collected at the same assessment\(^1\)

• studies should be powered to detect changes in both effectiveness and cost-effectiveness.

### 8.7 Dissemination and implementation of research findings

We are aware that the SDO Programme is actively involved in communicating the results of the research it has commissioned, thus supplementing dissemination by the researchers themselves. In the light of comments made by contributors to the consultation exercise, we recommend that continued efforts be made to improve the dissemination and implementation of existing and future research evidence. In particular, those commissioning research in this field should explore ways in which research findings can be presented in accessible forms, including 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.

When commissioning research, it is important to ensure that sufficient funding is made available for dissemination and implementation, and that research proposals include this stage of the work, with appropriate budget.

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\(^1\) See, for example, a study recently commissioned by the NHS R&D Health Technology Assessment Programme: ‘Does befriending by trained lay workers improve psychological well-being and quality of life for carers of people with dementia, and at what cost?: a randomised controlled trial’ (project code: 99/34/07). The study was due to start in January 2002, with an estimated publication date of late 2007. For further details see: www.hta.nhsweb.nhs.uk/projects/993407.htm.
References


Kilstoff, K. and Chenoweth, L. 1998. New approaches to health and well-being for dementia day-care clients, family carers and day-care staff. International Journal of Nursing Practice 4: 70–83


Services to Support Carers of People with Mental Health Problems


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