

# Briefing Paper



## Services to support carers of people with mental health problems

### Who cares for the carers?

Up to one and a half 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 (DH, 1999a)

and the National Service Frameworks (NSFs) for Mental Health and for Older People (DH, 1999b, 2001), puts a high priority on meeting the practical, health, and emotional needs of this particular group of carers. Accordingly, it is important for local service managers to assess available evidence for what works in this area so that resources can be targeted at those forms of support that are likely to be more effective as well as more valued by carers themselves.

This paper summarises findings of a review of research evidence and current service provision of support of carers of people with mental health problems (Arksey *et al.*, 2002). Research consisting of (i) a literature review and (ii) a consultation exercise was carried out between October 2001 and March 2002. The research was commissioned by the National Co-ordinating Centre for NHS Service Delivery and Organisation Research and Development (NCCSDO). (See also 'About the study', page 6.)

# Key Findings



## What are the interventions and services to support carers?

### **Type and focus of interventions**

Research showed that similar types of interventions and services for carers are currently provided by both statutory and voluntary sector services. As far as the UK only was concerned, most focused on the following in order:

- **Working directly with families as a whole** – including interventions drawing on family therapy models, or services provided in the home by, say, family support workers
- **Educational programmes** – including training and psycho-educational interventions
- **Breaks from caring** – including day care, in-home respite care, institutional respite and mixed respite services.

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**

Those consulted shared the view that there was **no single 'ideal' blueprint or service model**. They were also clear that support for carers was likely to be most effective when offered as part of a response to the family situation as a whole, and tailored to local needs and circumstances.

### **Examples of partnership work**

One local authority had commissioned a voluntary organisation to set up and manage a countywide 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.

Evaluation reports, mainly from the US, of very large multi-site, multi-dimensional approaches, provided modest evidence to endorse the view that it is important to provide a coordinated range of services to meet carers' different support needs and to offer carers some choice.

### **Principles for how services should be delivered**

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 the wider circumstances affecting people's lives. However, a consensus view emerged from the consultation that to be effective, services should be underpinned by four principles. They should be:

- **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'
- **Flexible and individualised** – services should be person-centred, reflecting the diversity of carers rather than being picked off a menu of what happens to be available locally
- **Accessible and responsive** – services should be available at all times, including outside office hours, and able to offer a rapid response
- **Integrated and coordinated** – services should be 'joined up'; carers' services should be embedded within mainstream mental health services.

# Gaps in Research



“We don’t need to know everything, but we do need to know some things, especially if the person is living under our roof.” Carer

## **Confidentiality**

Efforts were being made to develop practical solutions to issues relating to the rights of the person supported to confidentiality. Many contributors, including local practitioners/managers and carers, felt that confidentiality is often over emphasised by mental health professionals. Carers may not get given information which is vital to their caring role, and which may be necessary for their own protection, or for the safety of others.

## **What is meant by effectiveness and cost-effectiveness?**

Those consulted thought of effectiveness in terms of:

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

Some studies also assessed benefits for carers alongside outcomes in relation to those receiving care and families as a whole. Contributors had mixed views about how best to evaluate **effectiveness**. Their suggestions included measuring the extent to which services are used and how services perform, satisfaction surveys and evaluation forms. However, most studies used standard outcome measures to evaluate effectiveness of interventions, e.g. measuring levels of carer burden and stress.

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

There was 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 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.

A strong message from the review is that the knowledge base about effective support for carers of people with mental health problems is sparse. The overall view of contributors chimed with this message. There are now some very important questions to be addressed by further research. The review identified the following gaps in research:

- carers’ assessments and care plans
- comprehensive ‘packages’ of care (see ‘General approach’, page 5)
- breaks from caring
- use of telephone helplines and computer-based interventions
- which elements of a multi-dimensional package, in what combination, are effective and cost-effective
- relationship between different stages of an illness and specific interventions.

Two significant gaps in the literature were: services for **children and young adult carers**; and **black and ethnic minority carers**.

Contributors talked more in terms of suggestions for further research, as follows.

## **Service delivery and interventions for carers.**

The following areas were suggested:

- individual interventions, including: training and education; independent advocacy; information; carers’ workers; and 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
- effectiveness of early intervention for carers supporting a person in the early stages of mental illness

- 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.

**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
- research into how and when to involve carers in decisions about the care recipient's care, and the effect such involvement might have on 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.**

Contributors raised the need for research into:

- young and young adult carers
- black and ethnic minority carers
- carers of people with dual diagnosis, i.e. those with a mental health and a drug and/or alcohol problem
- carers supporting more than one person
- less common caring situations, e.g. research into caring in a same-sex relationship or caring at a distance.

**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.

Contributors 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. Equally, methods used in research and for assessing the quality of services matter as much to carers as they do to researchers and managers. Many stressed that carers should be involved in designing the questions to be asked, and also that providers must respond to carers' views and modify services accordingly.

“Ask your customers, don't tell them ... try and deliver as near as you can to what they want, then ask them again.” Carer



# Further Research *Recommendations*



## 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 and care recipient
- underpinned by key service delivery principles such as being inclusive, responsive and coordinated
- adaptable to local contexts.

Packages are likely to vary, reflecting diversity of carer experience, patient diagnosis and stage of illness, and differing methods of service delivery. As well as experimental research, more studies should be undertaken of services and interventions in their 'natural' or 'everyday' health and social care context. Rather than focusing on interventions in isolation, different components of integrated packages of care should be examined to assess their relative effectiveness, while also seeking to identify whether there is any 'added value' for carers. Research teams need to be multi-disciplinary and should include researchers with experience in the methodology of study design and outcome evaluation.

## Research methods

Studies should be commissioned that:

- use more diverse and innovative research methods
- 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

A number of individual interventions appear to have no evidence base, not least carers' assessments which carers have a right to request under current legislation. Assessment itself can be an unsettling experience, even when conducted with sensitivity, and so carers need to see that something positive has been achieved as a result of the assessment. With this in mind, any research in this area would also need to examine the outcome of the assessment for the carer.

## Disseminating and implementing research findings

Those working locally in mental health are keen to base decisions on evidence but work pressures leave them little time to read academic papers. Many want access to findings presented in terms and language relevant to the contexts in which they work. The same goes for many carers and care recipients. Access could include 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.

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

"We need small ideas that we can adapt and implement quickly, and which we can see make a difference."

Local health and social care managers

## About the Study

The aims of the study were to summarise available research evidence, to identify key gaps in existing knowledge and to identify priorities for further research in the area of services to support carers.

The literature review examined and summarised evidence from published and unpublished literature (both UK and international) between 1985 and 2001 about effective and cost-effective services to support carers. In addition, a consultation exercise was carried out by group discussions and telephone interviews and explored the following:

- people's understandings of effectiveness and cost-effectiveness in relation to services to support carers of people with mental health problems
- what research was seen as useful and/or a priority for future research
- examples of perceived good practice.

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 outcome measures to evaluate effectiveness. As far as the 13 studies with an economic aspect were concerned, most studies included health care costs and social services costs.

Overall, the analysis highlighted methodological weaknesses in the studies under review: small sample sizes, problems with follow up; problems relating to the use of control groups; and short follow-up periods.

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); and 'key informant' carers (n=19). 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.

### References

- Arksey, H., O'Malley, L., Baldwin, S., Harris, J., Mason, A., Newbrunner, E. and Hare, P. 2002. *Overview Report: Services to Support Carers of People with Mental Health Problems*. University of York (Social Policy Research Unit & Centre for Health Economics) and Acton.Shapiro
- Department of Health (DH) 1999a. *Caring about Carers: A national strategy for Carers*. London: Department of Health. [www.doh.gov.uk/carers.htm](http://www.doh.gov.uk/carers.htm)
- Department of Health (DH) 1999b. *National Service Framework for Mental Health*. London: Department of Health. [www.doh.gov.uk/nsf/mentalhealth.htm](http://www.doh.gov.uk/nsf/mentalhealth.htm)
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## Further Information

Three related publications on services to support carers of people with mental health problems were commissioned by the NHS Service Delivery and Organisation (SDO) R & D Programme.

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**Literature Review Report: Services to Support Carers of People with Mental Health Problems** (July 2002)

Hilary Arksey, Lisa O'Malley, Sally Baldwin and Jennifer Harris (Social Policy Research Unit); and Anne Mason (Centre for Health Economics), University of York. Searches: Su Golder (NHS Centre for Reviews and Dissemination), University of York

A 158-page survey and analysis of over 200 research studies

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**Consultation Report: Services to Support Carers of People with Mental Health Problems** (July 2002)

Elizabeth Newbrunner and Philippa Hare, Acton.Shapiro

A 56-page report of the consultation exercise

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**Overview Report: Services to Support Carers of People with Mental Health Problems** (July 2002)

Hilary Arksey, Lisa O'Malley, Sally Baldwin and Jennifer Harris (Social Policy Research Unit) and Anne Mason (Centre for Health Economics), University of York; and Elizabeth Newbrunner and Philippa Hare, Acton.Shapiro

A 36-page summary of the main findings

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All three documents, plus this briefing paper and details of current and future research in this field, can be downloaded at [www.sdo.lshtm.ac.uk/mentalhealthcarers.htm](http://www.sdo.lshtm.ac.uk/mentalhealthcarers.htm)

### About the SDO Programme

The SDO R & D Programme is a national research programme managed by the National Co-ordinating Centre for NHS Service Delivery and Organisation Research and Development (NCCSDO) under contract from the Department of Health's R & D Division.

For further information about the NCCSDO or the SDO Programme visit our website at [www.sdo.lshtm.ac.uk](http://www.sdo.lshtm.ac.uk) or contact:



National Co-ordinating Centre for NHS Service Delivery and Organisation R & D

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This document was published by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) research programme, managed by the London School of Hygiene & Tropical Medicine.

The management of the Service Delivery and Organisation (SDO) programme has now transferred to the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton. Prior to April 2009, NETSCC had no involvement in the commissioning or production of this document and therefore we may not be able to comment on the background or technical detail of this document. Should you have any queries please contact [sdo@southampton.ac.uk](mailto:sdo@southampton.ac.uk).