



Developing services for carers and families of people with mental illness





My name is Daniel Monk and I am 34 years of age. I live in a Making Space supported accommodation scheme in Bolton. I have been interested in art for a long time and have completed a number of art courses. I have donated this piece of work called “The Eruption of time” in which I feel I expressed the way I was feeling at the time I painted it. I hope you enjoy it.

Making Space exists to help all those affected by schizophrenia and other forms of serious and enduring mental illness. It is a charity run by people who have a direct and often personal experience of this. It is inclusive in its approach, embracing the needs of sufferers, carers and families.

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1. Introduction

1.1 Scope and purpose

The aim of this document is to help local mental health services develop support services for carers of people with mental health problems. It contains guidance on developing and sustaining mental health carer support services and also includes a sample job description for carer support workers. The guidance should be read in conjunction with Standard Six (Caring for Carers) of the Mental Health National Service Framework (MHNSF)¹ and guidance on implementation of the Carers and Disabled Children Act 2000².

Implementation of this guidance is the responsibility of commissioners and providers of health and social care mental health services. Primary Care Trusts also have a vital role to play in identifying and supporting carers of people with mental health problems.

Although Standard Six of the MHNSF and this guidance are aimed primarily at carers of people with severe mental health problems on the Care Programme Approach (CPA)^{*3}, it is acknowledged that many carers provide a significant amount of care to people with mental health problems who are not on CPA. The principles outlined in this guidance will also have relevance to this wider group.

1.2 Background

The Carers (Recognition and Services) Act 1995 and the Carers and Disabled Children Act 2000 established and strengthened carers' rights to an assessment of their needs in regard to the sustainability of their role where they provide (or intend to provide) substantial care on a regular basis. The National Strategy for Carers *Caring about Carers*⁴ gave further recognition to the key role carers play in supporting individuals in the community. The Carers Grant was established to support the implementation of the strategy.

All of these initiatives cover carers of people with mental health problems, although Social Services Inspectorate (SSI)⁵ reports showed that carers of people with mental health problems were not always getting access to these resources.

The MHNSF makes it clear that addressing the needs of carers of people with severe mental illness is one of the key standards that health and social care services must address to ensure the development of a modern mental health service.

Carers provide invaluable support to the people they care for. Statutory services should acknowledge this and provide the support and services carers need to continue caring and for their own health needs.

Much is being done across the country and there are already many successful carer support schemes in the statutory and voluntary sectors. Carer support services and workers are not new and there are numerous examples of existing positive practice around the country. Rethink, for example, run successful

* Currently around 600,000 people are on CPA, including 100,000 on enhanced CPA.

support group programmes in many areas and Making Space has carer support workers across a large part of the North of England. Hampshire Social Services have a team of carers' workers developing support groups, providing advocacy and carrying out carers' assessments. A small number of other positive practice examples are highlighted throughout this document.

But we also know that in many areas carer support services are patchy and carers report frustrations at the lack of services, or even acknowledgement of the legitimacy of their involvement in caring.

We want to ensure that progress is maintained, and that services across the country continue to develop to the standard set out in the MHNSF. To help further these aims, the NHS Plan⁶ set out a commitment that services would provide an additional 700 carer support workers by 2004 to increase the breaks available for carers, and to strengthen carer support networks. These carer support workers are intended to provide additional support for carers of people on CPA. Their work is described later in this document.

1.3 Evidence base and research

In producing this guidance we acknowledge that generally there is a lack of clear evidence to support the effectiveness of any specific service configuration for carers of people with mental health problems. However, studies have been able to identify some positive outcomes for carers and service users when carer support services are provided, and this work has informed this guidance (Social Policy Research Unit (SPRU)⁷). Also, there is extensive evidence in relation to a variety of ways in which carers of people with serious mental health problems can be helped, eg psycho-educational approaches, family support groups, multi-family groups, etc.

This guidance, and the SPRU research, has been informed by talking to carers and families and learning from existing services that are currently providing carer-focused services. It is known that carers want services that are accessible, responsive and individually tailored to their needs⁸.

Although there is currently no identifiable ideal single blueprint or service model which could be regarded as ideal or effective, if services are to be effective they must be adapted to local needs and circumstances. Local mental health services need to provide a range of co-ordinated services to meet carers' support needs and to offer them choice.

The Department of Health is currently commissioning a range of research projects that will help to strengthen the evidence base around carer support services.

The National Institute for Clinical Excellence (NICE) guidelines on the management of symptoms and experiences of schizophrenia in primary and secondary care are considering the effectiveness of family interventions. The final guidelines are expected in December 2002 and will be posted on www.nice.org.uk

The National Institute for Mental Health (England)⁹, advised by its user and carer expert group, is also working to develop mental health services for users and carers. This includes:

- the promotion of effective mental health services;
- monitoring the effectiveness of mental health services; and
- researching methods of identifying and measuring desired outcomes for service users and carers.

1.4 Definitions

Carer The term 'carer' has been used throughout the document rather than 'informal carer' or 'care-giver'. Where someone giving 'care' is a paid or voluntary worker this has been specified eg ;'carer support worker', 'care co-ordinator'.

Person being cared for A variety of terms such as 'person supported', 'person with mental health problem', 'someone with a mental illness', or 'service user' have been used to refer to the person being cared for.

Within these definitions we should also acknowledge the reciprocal nature of the caring relationship.

Carer support worker The term 'carer support worker' is used throughout to describe health or social care professionals who provide specialised or specialist support to carers of people with mental health problems. A sample job description is set out at Annex A. Some services may currently include descriptions such as 'carer development workers' or 'family support workers'.

2. Principles of a carer support service

2.1 Who is the service for?

The service is for carers of people with mental illness. In this section, a carer is defined as a friend or relative who is involved in caring for a person with a severe mental illness. To be regarded as a carer, a person does not have to live in the same household as the person he or she supports. Family members who do not undertake the main caring role may also benefit from support.

Carers of people with mental illness may be difficult to identify and support (also see section on black and minority ethnic carers and young carers). Their role may be less visible to those outside the family or community and this, together with the stigma associated with mental illness, means that they can fail to access services that might help them.

Carers of people with a mental illness, unlike other carers, may not be involved in active caring continuously. Their role may be relatively unobtrusive when the person they support is well, and so it may not be recognised by mental health agencies. There are a significant number of men as well as women carers, and a sizeable number of users of mental health services are themselves carers. It is important, therefore, that local mental health services attempt to identify and make contact with all carers.

Effective support for carers is both an essential and crucial part of any treatment or care plan for a person with a mental illness. In the vast majority of cases, carers are taking the primary responsibility of care for the person supported. The Princess Royal Trust for Carers estimate that 42% of carers are providing care for between 1 and 9 hours per week, whilst 31% care for 50 hours or more¹⁰.

2.2 What is it intended to achieve?

Mental illness can have a major impact on carers, families and friends as well as on the person with the illness. It may cause social and financial disruption and restrict educational and employment opportunities for both carer and the person supported. Those who take on a caring role may have to completely re-structure their lives to provide care for the carer and person supported. The demands of caring can also affect the physical and emotional health of the carers¹¹.

Stigma, poor availability of information, difficulties in diagnosis of mental illness combined with the quality of local mental health services can all have a bearing on when or whether a carer may seek help. Carers of people with a mental illness can experience very long delays from the point of diagnosis of the person supported before receiving any help for him or herself. 65% of people caring for someone with a mental illness say that they receive no support whatsoever¹².

Engagement of carers at, or as soon as possible after, the first episode of illness will be particularly beneficial in improving the long term prospects of those involved¹³, as this is often when carers have their first contact with mental health services and need information. Given that family members have a recent history of coping with and understanding the problems of the illness, they may possibly be more open to accepting advice at this point¹⁴.

A high proportion of carers feel that the key determinant in their own experience as a carer is the quality of support available for the person supported. Put another way, it is the quality of the mainstream mental health services that may have the most significant impact on the carer's quality of life¹⁵. The opposite is of course also true – the support received by a carer may well have a significant influence on the person supported and their illness.

So, in supporting carers, services should aim to:

- recognise the valuable role carers have and the stresses that caring can bring;
- provide timely support for them in this role – or help if they can no longer carry out all or part of the role;
- ensure participation of carers in planning and developing services so that they can be more effective and suited to carers needs;

And thus ultimately aim to ensure better outcomes for carers and service users.

2.3 What will it do?

If support services for carers are to be effective, they should aim to empower carers as much as support them. There needs to be a range of services available, which take account of the needs and wishes of carers, without making assumptions about these.

- support and advice, including advocacy;
- information;
- breaks;
- access to appropriate interventions, including training.

These are covered more fully in the section on provision of services to carers.

2.4 Underlying principles for service delivery

For services to be effective developments should be underpinned by four underlying principles:

- *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 diversity of carers;
- *Accessible and responsive:* services should be available at all times, including outside 'office hours' and be able to offer a rapid response;
- *Integrated and co-ordinated:* services should be 'joined-up', carers' services should be embedded into mainstream services (SPRU)¹⁶.

3. Commissioning and planning carer support services

3.1 Developing and improving services

Support for carers of people with a mental illness has historically been of variable quality. This is starting to change, a number of areas now have carer support services and workers who work exclusively with those carers, and more are expected to follow. The NHS Plan makes a commitment to provide an extra 700 such workers across the country to complement those already in place.

The resources for the additional carer support workers will be made available through NHS mental health funding allocations. It will be for commissioners to decide how best to allocate these resources locally. Strategic health authorities will wish to have an overview of progress towards achieving NHS Plan commitments for these additional workers. The number of mental health carer support workers employed should be included in local mental health service mapping.

The additional 700 carer support workers nationally translates to 14 additional workers per million population. This will range from 1–2 workers for small primary care trusts to 5–6 workers for the largest primary care trust areas OR if the worker is based in the Community Mental Health Team (CMHT), up to 1 additional worker per CMHT.

To ensure that these new and additional resources meet their requirements, carers should ideally be involved in the creation of these services. Services to carers should be designed and delivered in a way which promote autonomy, empowerment and choice.

Carers of those with mental health problems are a diverse group, and the stresses they may experience are influenced by a range of factors such as the nature, extent and timing of any problems, their relative's experiences, their own coping skills and resources and other stresses they may be experiencing in their lives at that time.

It is unlikely, therefore, that any single intervention or service will be identified to meet all the needs of all carers at all points in time. Carers will need different types of support and interventions at different times. Local services should provide a range of options for carers. Mental health services will need to ensure that this range of service provision, including the number of mental health carer support workers employed, is included in local mental health service mapping.

Carers living in rural areas can be particularly isolated. Commissioners in these areas will need to consider how best to organise and deploy carer support to ensure it can be accessed across a wide geographical area.

Positive practice example

Rural carers have been found by COOL – Carers One to One Links – in South Devon. In two years a mailing list of over 200 caring families has been built up, with carers using the phone to support each other.

Contact: Claudia Benzies telephone 01803 712669

Research shows that where carers have reported negative experiences with statutory services, there is a need to take a fresh approach in developing these services so that they will not be seen as ‘more of the same’¹⁷. Often, when carers have had negative experiences of services and professionals it can be difficult to build trust and good communications. These histories and experiences should be understood by services.

3.2 Specialist or generic?

The opinion emerging from research of carers’ views is that a majority feel that specialist, as opposed to generic services are more desirable and appropriate for carers of people with a mental illness¹⁸. This is because the caring task and challenges facing a carer of someone with a mental illness is different from other carers. The caring task has less emphasis on physical care and is likely to be focused more on supervision, befriending and (at times) coping with the behaviour of the person supported.

Many Social Services Departments are devising generic carers’ strategies and there are an increasing number of local carers’ centres. If support for carers of people with mental illness is located within a generic carers’ centre, and many already are, services should ensure that they are relevant and accessible to carers of people with mental health problems. At present many carers say they are not. Mental health carer support workers can play a part in helping generic services develop to support carers of people with mental health problems.

3.3 Operating and referring protocols

Carer support services should be viewed as complementary to existing services and part of the overall local system of mental health and social care provision. They will need operating and referring protocols that are agreed with all relevant agencies. This should, amongst other things, cover:

- the scope of the service (i.e.who is it for?);
- how to access the service;
- the linkages between the service and local mental health care co-ordinator and the cared for person’s care plan;
- the role of the service in helping carers to access short breaks;
- an optimum workload for carer support workers, as experience has shown that newly appointed workers quickly build up heavy workloads.

3.4 Evaluating the impact and success of carer support services

It is important at the outset to have some measures to assess the impact and effectiveness of carer support services. Evaluation can be a complex process and many factors need to be considered, including:

- involving various stakeholders including carers, service users and professionals;
- considering the different needs and circumstances of carers;
- understanding the diversity of carer experience;
- some understanding of how interventions work and why,
- and a more open approach to the measurement of outcomes¹⁹.

Evaluation should not only focus on effectiveness and outcomes but also on how the resources allocated for carer support match the level of identified need for the service, as carer support workers are likely to identify high levels of demand. Carers themselves should have a central role in evaluating the effectiveness of local services.

Carers should be fully involved in evaluation. This should include not just the design of the evaluation but might also involve training carers in interviewing skills so that they can undertake qualitative research with people who have used the service.

Positive practice example

Suffolk Carers Mental Health Project provides a countywide service for carers enabling them to access one to one and group support, advocacy and information. Working with partners in social care, the project also provides training for carers and service users to enable them to participate in the training of mental health workers from both the voluntary and statutory sector. This training also enables carers to participate more fully in consultation and evaluation of mental health services.

Contact: Sue Allison, Carers Mental Health Project Manager, telephone 01473 408031

The Department of Health is developing guidance on the measurement of outcomes, which includes measures of morbidity, user satisfaction, carer satisfaction and quality of life (the Outcomes Project). The aim of this work is to learn about how to establish routine outcome assessment in adult mental health services. The carer outcome assessment element is being provided by the use of Carer CUES (Carers and Users Expectations of Services) which is being further developed for piloting within the Outcomes Project. The report of the evaluation of the pilot work will be available in March 2003, and the national roll out will start from 1st April 2003, when a comprehensive pack of information and advice will be available.

4. Identification and assessment of carers

4.1 Identifying Carers

Rather than having leaflets to hand out, one GP Practice in East Devon holds the contact details for the local carers' worker on the surgery intranet. When a GP realises a patient is a carer s/he just prints off the contact details with a recommendation to ring the number and get in touch with other carers.

GPs and primary care staff have a crucial role in helping to identify carers of people with mental health problems. Since October 1999, GP computer systems have been required to include a field where the details of carers could be entered in patient records. GPs are prompted to ask for carer details as part of the registration details of patients. As the systematic use of these systems develops links and protocols between primary care and mental health carer support services will aid information sharing.

Positive practice example

Fareham and Gosport Rethink Carers' Group have worked with local mental health services to ensure that when a patient is admitted to an acute ward, a member of staff is available to talk to the carer and provide them with an information sheet that has details of when the Carers' Group meets and contact numbers for other carers. When the patient is discharged the carer is referred to one of the five Carers' Group in this locality.

Contact: Heather Watts, Group Co-ordinator telephone 01329 846679

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Use of the word 'carer' should be carefully considered when aiming to raise awareness of services and support available to families and friends of people with mental health problems. In particular, when working with service users and families from black and minority ethnic groups the idea of 'carer' is sometimes better replaced with an appreciation of the role of kinship networks and extended families.

4.2 Assessing Carers' Needs

Assessment is the gateway to carers receiving help. It should ideally take place as soon as possible after the first onset of the illness of the person supported. The assessment is the responsibility of the statutory services to arrange, usually through the local care co-ordinator, but arrangements will vary locally. Assessment is not the responsibility of the carer support worker.

Many carers report experiencing lengthy delays before receiving assessments, and subsequently services, others report being unable to access services where the person supported is not subject to CPA. Agencies should not limit carer support to those who care for someone who is subject to CPA, as other carers may also provide regular and substantial support to someone with a mental health problem.

Agencies should, wherever possible, work together to ensure that a carer has one assessment which will enable them to access all services. It is particularly important to ensure that the carer's own GP is aware of, and participates in, the assessment and the potential support services available. Services are reminded that a carer can receive an assessment of their own needs even if the person they care for is not receiving, or has refused, services him or herself and the local council is satisfied that this person is someone who is eligible for community care services.

The experience and needs of carers of people with a mental illness differ in some key respects from other carers. There may be less emphasis on physical care and more on the emotional support, supervision, dealing with bureaucracy, advocacy and, at times, managing the behaviour of the person supported. Services should recognise the reciprocal nature of caring and that the relationships between carers and service users can be complex and can change.

4.3 Carer's support plan

The MHNSF Standard Six Caring for Carers provides guidance on the content of carers' support plans.

The outcome of a carer's assessment should be the production of a focused support plan outlining who will take responsibility for particular services and what outcomes will be achieved. This should contain appropriate timescales for the delivery of services, and should be agreed with the carer. The plan should be sensitive to the carer's race, culture, religion, disability, age, gender and sexual orientation. It should be made available in a format accessible to the carer (language and medium).

The support plan should ensure that the carer understands where to access services, including crisis and out of hour access information. The plan should have 24-hour, 7 day a week contact numbers. Carer assessments should, where possible, be linked with the CPA plan of the person supported, and should include pre-crisis and contingency planning arrangements.

4.4 Addressing the different needs of carers and service users

Support for carers should focus primarily on their support needs but should also take account of the circumstances of the person supported and wider family and social circumstances. Carers sometimes report feeling excluded from expressing their views or being listened to when the supported person refuses to permit their involvement with the statutory services, e.g. attending care planning meetings.

Disagreements between carers and the person they care for happen from time to time, as in all families. Even where there is disagreement between a carer and the person supported, services should work towards involving the carer as far as is practical. Conflict should not be a barrier to carer involvement, carers still need information and other services in these situations. Carer support workers can often play a valuable part in resolving disagreements of this kind, and in working with statutory services and the parties concerned in an attempt to achieve some form of workable compromise.

The respective views of carers and the person supported are sometimes perceived by agencies as being divergent or in conflict. This may be an accurate perception, although perceptions can be distorted because mental health professionals may have more contact with carers at the point of crisis when tensions and emotions are running high. This may not always be an accurate reflection of relationships. Family relationships may also be under strain due to the prolonged impact of living with the illness of the person supported.

Positive practice examples

The Supporting Carers Better Network is a network across the whole of England, for 'People Supporting Carers in Mental Health'. It is facilitated by the Mental After Care Association (MACA), and includes people working for and with carers in both statutory and voluntary organisations, and also volunteers – e.g in groups or local implementation.

It is both a list of services for mental health carers, and a forum for the exchange of information and research, and the sharing of skills and good practice. It also connects relatively small numbers of people in each area into a substantial national network.

Membership of the Network is free. For more information or to join, contact Phil Partridge, MACA South, 94b High St, Epsom KT19 8BJ – telephone 01372 722 970, fax 01372 722 980, email: philip-partridge-south@maca.org.uk

Family Group Conference (FGC) in mental health is a unique initiative to empower service users and their families to make plans about how they want to be supported. The approach has been piloted and evaluated by the North Essex Mental Health Partnership NHS Trust. FGC is primarily aimed at empowering the service user to make decisions about their needs as part of the care planning process. Central to the approach is the belief that carers and the wider extended family, including close friends, are a valuable source of knowledge and understanding, and have the right to be included in the decision making process. Through the FGC process carers are provided with information on their relatives mental health problems, treatments and services available which allows them to formulate a 'family plan' in partnership with the provision of mental health services.

Contact: Linda Flynn, Service Manager, telephone 01245 318606, email Linda.flynn@nemhpt.nhs.uk

5. Provision of services to carers

5.1 Supporting and advising carers

Most carers at some point will require support and advice of some form or other. The nature of this will vary from carer to carer. Some may only need sign-posting to various services either for themselves or the person they support. Others may need emotional support or counselling, while some carers may need advocacy for brief or sustained periods. It is important that support services avoid a prescriptive approach based on generalised assumptions about carers.

Support groups for carers play a vital role for carers in many areas, and take many different forms. They often demonstrate to carers that they are not on their own, and often have a 'campaigning dimension' which can be effective in informing and improving local services. Some carer groups organise social outings and events. Carer support services and workers should assist this self-help and mutual support work, and avoid undermining or cutting across it.

Carer support workers can also offer individual support to carers through home visits and ongoing contact. Some carers report that being able to access someone who is there 'for them', as distinct from the person they support, can be very valuable.

Carer support workers can signpost specialist forms of support, some of which focus on family intervention e.g. psycho-social interventions.

5.2 Providing information

Carers highlight information as being one of the most crucial areas, enabling them to understand the illness of the person supported, its prognosis and possible effects. The information needed by most carers falls into two main categories:

- specific information about the person they are caring for e.g. their illness, the medication being used and its effects etc;
- more general information on a wide range of issues, such as research into the effectiveness of treatments, alternative therapies, legislation, benefits, rights for both service users and carers and of course local services and their availability.

The carer and the person cared for have the right to expect that information either provides will not be shared with other people without their consent. But issues around 'confidentiality' should not be used as a reason for not listening to carers, nor for not discussing fully with service users the need for carers to receive information so that they can continue to support them. Carers should be given sufficient information, in a way they can readily understand, to help them provide care effectively.

Information packs for carers can be very helpful, particularly at the first episode of illness. A number of high quality information packs for carers are produced by the mental health charities, a number of local statutory services have also produced their own packs.

Positive practice examples

MACA have produced an information booklet for people who support people with mental health needs to ensure that these carers get the support they need. It is available by calling **01706 644027**.

Making Space have information on a wide range of subjects for both carers and the people they care for. They are available free of charge by calling **01925 571680**.

The Carer's Advisory Group for Mental Health in London, sponsored by the Department of Health produced a Charter and workbooks to acknowledge the crucial role of carers and ensure that their needs are met. Copies of all documents are available by phoning **020 7725 5300** or by logging on to the virtual website – www.virtuall.org

New carers can obtain a high quality resource pack from **Rethink** by calling **020 8547 9221**.

Sandwell Primary Care Trusts have produced a mental health information pack to provide useful information for carers of people who have a mental illness. Details are available by calling **0121 500 1625**.

The Department of Health in association with Rethink has produced a leaflet 'Commitment to Carers' which details for carers what they should expect from their local mental health services. Copies can be obtained from Rethink on 020 8547 9221.

5.3 Ensuring breaks from caring

The Government's promotion of carer breaks, and the resources allocated to support this, is now well established. Break programmes now operate in all areas of the country. Although carer break programmes are widely available, there is still some evidence to suggest that carers of people with a mental illness may have difficulty in accessing these, compared with other carers.

Carer support services and workers will play a key role in making sure that carers are made aware of opportunities for breaks. Services for carers of people with a mental illness should access resources available through the Carers Grant. Some local services have ensured equitable access to breaks for carers of people by allocating a proportion of the Carers' Grant to this group. The Princess Royal Trust estimates that 18% of all carers care for someone with mental health problems²⁰.

The range of breaks available is now wide in scope and imagination. Some are designed exclusively for carers of people with mental illness, but there are many good 'generic' breaks schemes and programmes available. Some carers and service users prefer a 'joint break' and these are now becoming available.

5.4 Psycho-social interventions

Psycho-social interventions (PSI) are becoming increasingly available both to individuals who have been diagnosed with a mental illness and their families. In family therapy, for example, people identify the triggers for symptoms associated with schizophrenia to enable them to manage the illness more effectively. PSI and associated interventions need to be provided by practitioners with appropriate training, and are usually provided in conjunction with other forms of treatment.

Overall there is good evidence that family interventions improve outcomes for people with schizophrenia living with, or having close contact with, their family. However, the majority of families do not receive this type of help.

In a research study in the North West of England, carers of outpatients diagnosed with schizophrenia were randomly allocated to receive either family support alone or in combination with systematic psychosocial interventions. The study had a good outcome for family treated patients in terms of relapse reduction and there was a significant reduction in identified carer's needs²¹.

Positive practice example

Meriden: The West Midlands Family Programme

Established in 1998, its key aims are:

- to increase awareness of the needs of families within mental health services and to ensure that families become “visible” to professionals;
- to ensure that services which are sensitive to the needs of families are delivered at whichever point families come into contact with the service;
- to ensure that families receive those interventions which are effective and evidence-based in addition to more general support and help in coping with situations in which they find themselves.

Two main methods have been used to achieve these aims:

- a cascade system of training whereby professionals from all disciplines are trained as therapists in family work, and then as trainers to deliver training within their own Trust and Social Services areas;
- on-going work with managers at all levels in services to identify obstacles to change, and implementation of family work. Implementation is reviewed continually, and additional ad hoc support is offered where necessary.

All 16 Trusts within the West Midlands Region are involved in the programme covering a population of 5million, both urban and rural areas.

Contact: Dr Grainne Fadden, Manager telephone 0121 623 5866

NICE guidelines on the management of symptoms and experiences of schizophrenia in primary and secondary care, to be published in December 2002, will consider the effectiveness of family interventions.

6. Specific groups of carers

6.1 Carers from black and minority ethnic communities

It is not known how many black and minority ethnic carers there are in Britain, but those already known to services are highly likely to be a significant underestimate of the actual numbers. Carer support services need to be accessible and sensitive to the needs of carers from all parts of the community.

Services need to be sensitive to different cultural models. In particular, the idea of 'carers' is sometimes better replaced with an appreciation of the role of kinship networks and extended families.

Much has been written about the impact of racism in the mental health system and it need not be repeated here. The impact of this on carers is just as powerful as on the person who has been diagnosed with a mental illness.

Workers supporting carers should be recruited to reflect the racial, religious and cultural make up of the areas in which they are working.

Because carers from some minority groups can be particularly isolated, some thought needs to be given as to how they can access services. Many areas and organisations employ workers who work exclusively with certain minority groups. There is also growing evidence and awareness about the mental health problems of asylum seekers, and the needs of carers in these groups need to be considered.

The need for effective and accessible translation and interpretation services is another essential component of carer support with people whose first language is not English. It is not acceptable to involve family members in translating for their relatives at outpatient, GP appointments or in other meetings with mental health professionals.

Information about services for carers should be published in languages that ensure it will be accessible to all members of local communities who may use them. Use of other media (tapes, video, radio etc) should also be considered.

6.2 Young carers

There is evidence to suggest that the person with mental illness supported by a young carer is less likely to be receiving treatment and support in their own right, compared to the person supported by an adult carer.

Assistance to young carers needs to avoid, however unintentionally, reinforcing the role of the child or the young person as a carer. Interventions to help support the family as a whole and promote the parenting role of adults are more likely to be helpful and ensure that a child's welfare or development is not impaired.

It is important that local carer support strategies consider how young carers are to be identified and supported, be this by the carer support service or by a separate service.

Positive practice example

Through its Young Carers' Initiative, the Children's Society has developed a database of over 300 young carers' projects throughout the country. For more on developing services for young carers or to register your young carers' project on this Department of Health funded database ring 01962 711511 or go to www.childrengsociety.org.uk/youngcarers

7. Carer support workers

Carer support services and workers are not new and there are numerous examples of existing good practice around the country. Typically, carer support workers carry the dual roles of ensuring that carers receive direct support and help and also of working with carers to empower them to ensure they have real influence in shaping mental health services.

It is not intended that carer support workers carry out carer assessments. Resources for the additional 700 carer support workers in particular are designed to increase service provision to carers so that they receive more support and breaks.

Carer support workers will help to identify carers and make links between services to ensure that services are provided to meet assessed needs. They will work with existing carer services and help them to become more accessible to carers of people with mental health problems (particularly when these services are set within generic carer services). The additional workers should work alongside and enhance existing services and initiatives.

The location of carer support workers will have a significant bearing on their usage and effectiveness. Locating them in community mental health teams (CMHTs), working alongside community psychiatric nurses, approved social workers and psychiatrists will enable them to link effectively and quickly to the local mental health network. This arrangement also automatically offer CMHTs a 'carers' dimension' and demonstrates a model of collaborative working.

However, whilst locating carer support workers in CMHTs may make sense logistically, it is important that they are seen by carers as having a degree of independence from statutory services. The consensus view from carers themselves is that carer support workers will be more effectively managed by an organisation that is seen as being independent of the statutory services²². Carers generally perceive this as freeing the carer support worker to offer independent advice and advocacy.

Above all, carer support workers need to be located in settings where they are visible and accessible to both carers and referring agencies.

The skills, knowledge and experience of carer support workers will obviously vary according to the way in which agencies want the role to operate in a particular area. Generally speaking, however, these workers will need to be competent in the following areas:

- awareness [and experience] of caring;
- knowledge about mental illness;
- understanding of The Mental Health Act and National Service Framework for Mental Health;
- liaison and networking skills;
- advocacy skills.

A sample job description for a carer support worker is set out at Annex A. There may be merit in considering employing people with direct experience of caring as carer support workers.

Carer Support Workers are likely to be recruited from a variety of backgrounds. It is important that their training and development needs are considered at the point they are recruited, and as part of mental health services training development plans as a whole.

8. Conclusion

Much of what is contained in this guidance will not be new to those services that are already providing good support services to carers of people with mental health problems. What is needed now is for all services to reach these standards.

We know that carers play a vital role in helping to support users of mental health services and those with mental health problems not in touch with services. Providing help, support and advice to carers can be one of the best ways of helping people with mental health problems. Support for carers must be mainstreamed into the activities of all health and social care mental health services. It is hoped that this document will help achieve this.

Commissioners will need to direct additional resources to recruit and train carer support workers to meet NHS Plan commitments. How these workers will be deployed is for local commissioners and providers to determine, guided by the contents of this document, and depending on the current level of service provision.

Those planning, commissioning and providing services are reminded that this guidance should be read in conjunction with the Mental Health National Service Framework Standard Six and guidance issued on implementation of the Carers and Disabled Children Act. Annex B to this guidance also provides a list of useful resources for further reference.

Annex A

Sample Job Description

JOB TITLE:	CARER SUPPORT WORKER
ACCOUNTABLE TO:	For local determination
WORKING HOURS:	These will need to be flexible to accommodate the requirements of the job. This will include some evening and weekend work.
LOCATION:	In CMHT, Carers Centre, GP surgery, voluntary sector agency, (for local determination)

MAIN PURPOSE OF THE JOB:

To provide information, advice, support and information about breaks for carers and other family members of people with a mental illness. To promote and enable service provision and social inclusion for carers in line with current national policy objectives, particularly Standard Six of the National Service Framework. To work with carers in a way which promotes their active involvement and participation in developing and improving local mental health services. The worker(s) will work in close liaison with colleagues in statutory mental health services and primary care.

KEY TASKS:

1. Provide practical and emotional support to carers. This will be achieved in various ways, but particularly by providing individual contact with carers and by the support and development of local groups.
2. Play an important role in helping local statutory services to estimate the numbers of carers in their area and to identify and make contact with them.
3. Provide information to carers about mental illness, treatments, and to signpost carers to other information about specialist forms of help such as psycho-social interventions, etc
4. Provide information to carers about local mental health services (including crisis and 24hr provision), and how to access them.
5. Support and develop carer groups.
6. Provide carers with information about carer breaks.
7. Facilitate the involvement of carers in the local mental health development and planning system to ensure their active participation and influence in modernising local services.
8. Provide advocacy to carers where appropriate.

Annex B

Information Sources for further reference

- Aitchison K.J., Meehan K., Murray R.M.* (1999) First Episode Psychosis.
- Banks P.* (Kings Fund) (1999) Carer Support. Time for a Change of Direction?
- Banks P., Roberts E.* Kings Fund. (2000) More Breaks for Carers?
- Becker S., Aldridge J., Dearden C.* (1998) Young Carers and Their Families.
- Butterworth R.* (2001) Confidentiality. (Presentation).
- Carers National Association.* (2001) Primary Support to Carers. Practice Briefing.
- Department of Health* (2000) Black Carers Manifesto.
- Department of Health* (2001) A Commitment to Carers (National Schizophrenia Fellowship).
- Department of Health* (2001) The Journey To Recovery – The Governments vision for mental health.
- Kings Fund.* (2000) Quality Standards for Local Carer Support Services.
- Lyons A.* (2000) Marginalised Carers Project (North Tyneside Carers Centre) final Report.
- Northern Rock Foundation.* (1999) Reviewing the Grants Programme for Carers.
- National Schizophrenia Fellowship.* (1999) Carers Education and Support Programme.
- Pickard, L.* Carer Break or Carer Blind? Policies for informal carers in the UK. *Social Policy and Administration* 35 (4): 441-458.
- Ramsay R., Gerada C., et al.* (2001) Mental Illness. A handbook for carers.
- Scottish Development Centre for Mental Health.* (2001) Route Map to User and Carer Participation. Part 4. Influencing the Planning of Mental Health Services.
- Shah R., Hatton C.* (Barnardos) (1999) Caring Alone; Young Carers in South Asian Communities.
- The Royal College of Psychiatrists.* (1999) Mental Health and Growing Up, Second Edition, Parental Mental Illness – the problems for children.
- Yee L., Blunden R.* (Kings Fund). (1995) General Practice and Carers: Scope for change?

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Lancashire Gujarat Health Users Forum.

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Rethink (formerly The National Schizophrenia Fellowship)

Salford Carers' Centre

The Avondale Unit Academic Library, Preston

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References

- 1 Department of Health. *National service framework mental health*. London: HMSO, 1999.
- 2 Department of Health. *Carers and Disabled Children Act 2000*. London: Department of Health, 2000.
- 3 Department of Health. *Effective care co-ordination in mental health services – Modernising the Care Programme Approach*. A policy booklet. London: Department of Health, 1999.
- 4 Department of Health. *Caring about Carers: A National Strategy for Carers*. London: Department of Health 1999.
- 5 Department of Health. *A Matter of Chance for Carers? – Inspection of local support for carers*. London: Department of Health, 1998
- 6 Department of Health. *The NHS Plan: a plan for investment: a plan for reform*. London: HMSO, 2000
- 7 Arksey, H., O'Malley, L., Baldwin, S., Harris, J., Mason, A., Newbronner, E, and Hare, P. 2002. *Services to Support Carers of People with Mental Health Problems*. University of York (Social Policy Research Unit & Centre for Health Economics) and Acton.Shapiro.
- 8 Nichols, E. *Implementing an outcomes approach in carer assessment and review*. In Qureshi, H (ed). *Outcomes in Social Care Practice 2001*. University of York (Social Policy Research Unit & Centre for Health Economics). 2001.
- 9 National Institute for Mental Health in England. *First year strategy for NIMHE – Meeting the implementation challenge in mental health*. London: NIMHE, 2002.
- 10 The Princess Royal Trust for Carers. *Key findings on mental Health research*. London: Princess Royal Trust for Carers, 2000.
- 11 Weinberg A, Huxley P. *An evaluation of the impact of voluntary sector family support workers on the quality of life of carers of schizophrenia sufferers*. *Journal of Mental Health*. 2000; 95: 495-503.
- 12 The Princess Royal Trust for Carers. *Key findings on mental Health research*. London: Princess Royal Trust for Carers, 2000.
- 13 Goldstein M.J., Rodnick E.H.et al. *Drug and family therapy in the aftercare of acute schizophrenia*. *Archives of General Psychiatry*. 1978; 35: 1169-77
- 14 Barrowclough C, TARRIER N. et al. *British Journal of Psychiatry*. 1999 June; 174(6) 505-11.
- 15 Arksey, H., O'Malley, L., Baldwin, S., Harris, J., Mason, A., Newbronner, E,
16 and Hare P. 2002. *Services to Support Carers of People with Mental Health
17 Problems*. University of York (Social Policy Research Unit & Centre for Health
18 Economics) and Acton.Shapiro.
- 19 As above.
- 20 The Princess Royal Trust for Carers. *Key findings on Mental Health Research*. London: Princess Royal Trust for Carers, 2000.
- 21 Barrowclough C, TARRIER N. et al. *British Journal of Psychiatry*. 1999 June; 174(6) 505-11.
- 22 Arksey, H., O'Malley, L., Baldwin, S., Harris, J., Mason, A., Newbronner, E, and Hare P. 2002. *Services to Support Carers of People with Mental Health Problems*. University of York (Social Policy Research Unit & Centre for Health Economics) and Acton.Shapiro.



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