

---

# **Scoping exercise to inform the development of a National Mental Health Carer Support Curriculum**

---



**Supporting (MH) Carers Better Network**



---

Funded by the  
Department of Health

Alan Simpson, Senior Research Fellow

Lisa Benn, Research Assistant

July 2007  
Department of Mental Health and  
Learning Disability  
City University  
London E1 2EA



## Contacts

Dr Alan Simpson  
City University  
Department of Mental Health and Learning Disability  
Philpot Street  
London E1 2EA

Tel: 0207 040 5937  
Email: [A.Simpson@city.ac.uk](mailto:A.Simpson@city.ac.uk)  
Website: [www.citypsych.com](http://www.citypsych.com)

Tom Gourlay  
Area Manager, Together  
Carisbrooke House  
Stockleigh Road  
St Leonards-on-Sea  
East Sussex  
TN38 0JP

Tel: 07778 659293  
Email: [tom-gourlay@together-uk.org](mailto:tom-gourlay@together-uk.org)  
Website: [www.together-uk.org](http://www.together-uk.org)

Sally Davey  
Acting Coordinator  
Supporting (MH) Carers Better Network  
St Barnabas Church  
Temple Road  
Epsom  
Surrey  
KT19 8HA

Tel: 01372 721518  
Email: [sallyanne-davey@together-uk.org](mailto:sallyanne-davey@together-uk.org)  
Website: <http://www.scbnetwork.org/>

## **CONTENTS**

Appreciation	5
Acknowledgements	6
Executive Summary	7
The Project	10
Introduction	10
Policy Background	11
Aims and Objectives	15
Methods and Procedures	15
Literature Review	15
Focus Groups	16
Survey	17
Ethics	18
Data Analysis	19
Results: Literature Review	19
The Impact of Caring	20
Services to Support Mental Health Carers	23
Sharing Information and Confidentiality	26
Evidence for family interventions	28
Effectiveness of family interventions	31
Family interventions: Education, training and implementation	33
Meriden West Midlands Family Programme	39
Somerset Family Intervention in Psychosis Service, Strategy and Training Programme	39
Training in carer support	43
Carer involvement in education and training	46
Results: Focus Groups: Participants' Experiences	49
Recognition of families and the carer's role	50
Identification and recording of carers	50
Complexities of family work	52
Working in partnership?	53

## Mental Health Carers' Curriculum Report 2007

Obtaining information	54
Attitudes and communication skills	56
Confidentiality	56
Support	58
Assessments of carers' needs	58
Culture, ethnicity and gender	60
Results: Focus Groups: Recommendations for Training	61
Communication skills and information	62
Timing and level of training	66
Challenging the system	68
Carers' involvement in training	68
Carer Support Workers and training needs	70
Results: Survey	72
Type and level of training provision	72
Carers' involvement in training	73
Cultural issues	73
Achievements	74
Difficulties	74
Assessments	75
Evaluation	75
Recommendations	76
Education and training	76
Key strategies to help establish, develop and maintain family-friendly services and support mental health carers	77
References	81
Appendices	93

## APPRECIATION

Researchers at City University, London were commissioned by the Supporting Carers Better Network to identify what needs to be included in the education and training of mental health staff and carer support workers to address the needs of mental health carers. This will be used to inform the development of a nationally-accredited curriculum and training modules.

The Research Team would like to thank:

All the carers, carer support workers, service users, mental health workers, trainers and educators who participated in or helped organise focus groups or responded to the survey for the Mental Health Carers' Curriculum Project.

Maria Tziggili for her help with the focus groups.

Robbie Simpson for collating the survey responses.

Colleagues and members of the research team in the Department of Mental Health & Learning Disability at City University.

The Supporting (Mental Health) Carers Better Network is a project of Together: Working for Wellbeing, a national charity.

<http://www.scbnetwork.org/>

## ACKNOWLEDGEMENTS

We would also like to acknowledge the members of the Expert Steering Group, who supported and encouraged the project and provided superb advice and information throughout.

Geoff Brennan	Nurse Consultant, Berkshire Healthcare NHS Foundation Trust
Monica Clarke	Patient/Carer Advisor, NHS Clinical Governance Support Team
Jenny Cobb	Lecturer, Child & Adolescent Mental Health, City University
Jeanette Copperman	Senior Lecturer, Social Work, City University
Dominic Dowell	rethink severe mental illness
Danë Goodsman	Senior Lecturer, Interprofessional Education, City University
Drew Linden	The Princess Royal Trust for Carers
Soo Moore	Senior Lecturer, Mental Health of Older People, City University
Phil Partridge	Co-ordinator, Supporting Carers Better Network
Scott Reeves	Associate Professor, Interprofessional Education, University Toronto, Canada
Peter Reynolds	Service User and Carer
Lyn Shore	Carer Services Development Worker, Kent & Medway NHS & Social Care Partnership Trust
Rachel Thompson	Admiral Nurse/for dementia
Georgina Wakefield	Carer and Independent Trainer

## **EXECUTIVE SUMMARY**

### **BACKGROUND**

Providing care for a friend or relative with mental health problems can have significant impacts on family life and finances, on work and career opportunities, on friendships and social relations, and on personal health and wellbeing. There is now an extensive range of legislation, official policies and implementation guidelines that make clear both the statutory requirement and expectation that mental health staff should consider and address the needs of mental health carers. Despite this, support for mental health carers remains low.

### **AIMS AND OBJECTIVES**

The aim of the project was to inform the development of a national mental health carer support curriculum and training modules. The key objectives were to:

- 1) Identify the education and training needs of mental health professionals, including carer support workers and related roles, in relation to improving the support provided to mental health carers;
- 2) Identify and describe existing education and training provision; and
- 3) Recommend the content and delivery of a national mental health carers' curriculum and training modules.

### **METHODS**

Three methods were employed:

- 1) A Literature Review.
- 2) Focus groups with various stakeholders to identify content and design of education and training that will enable staff to address mental health carers' needs and perspectives across a range of disciplines and roles.
- 3) A Survey of organisations providing health and social care education to identify existing pre-registration and post-qualifying education and training.

The results from the literature review, focus groups and survey are reviewed. A process of triangulation allowed the results from each method to inform the other and this synthesis informs the following recommendations.

## **RECOMMENDATIONS**

The findings from this study provide a strong argument that a wide-ranging and comprehensive education and training programme is required in order to enable mental health staff to inform, involve and support families and carers of people with mental health problems.

Education on the importance of working in partnership with families should be provided to all mental health students and trainees throughout their pre-registration professional education. This education should be supplemented with visits to and placements with families, carer support workers and carers' centres and organisations.

Continuing professional development and post-registration training should then be utilised to ensure that the mental health workforce is able and motivated to ensure that all mental health services are family-friendly and sensitive to the needs of families and carers, and able to provide intensive family work and interventions to those that require it. This requires three different but interlinked levels of training.

Level one requires that *all* staff (clinical, managerial and administrative) obtain an awareness of the experiences and needs of carers and families and of what family work involves, in order to facilitate carer and family-friendly practices and to recognise the need for carer support and family work, to discuss it with carers and families and make appropriate referrals. Information about local carer support services should also be provided and partnership working between mainstream mental health staff and Carer Support Workers and carers' organisations should be actively encouraged and supported. This level of training can be provided through staff induction programmes, work place training and regular updates.

Level two requires that smaller numbers of clinical staff across all services and teams should be trained to provide expert family work and psychosocial interventions to those that require them. Training should be supplemented with regular supervision, appropriate work placements, job shadowing and re-organisation of work practices so that knowledge and skills in family work are supported, encouraged, developed and implemented.

Level three requires that within each team or service area, a suitable number of staff are trained and supported to provide ongoing supervision, training and support of staff providing family work and interventions.

All education and training provision needs to address the development and confident delivery of communication skills and information sharing identified within this report as important in supporting mental health carers.

All education and training should also be informed by the 10 Essential Shared Capabilities.

Carer Support Workers need to be able to access a structured programme of continuous development and support that builds on their existing knowledge and expertise with the contents and delivery informed by the findings in this report.

Carers, carer trainers, carers' organisations, carer support workers and service users should be involved throughout the design, delivery and evaluation of all education and training aimed at improving services for carers.

In order for such a programme of education and training to be effective, the findings in this report strongly indicate that any training programme to improve the support of families and mental health carers needs to form part of a comprehensive organisational structure and strategy that includes explicit support throughout all levels of health and social care organisations.

Consequently, we have drawn on the experiences and recommendations of successful programmes and projects to identify key factors that help establish, develop and maintain family-focused services and greater support for carers.

These factors include the establishment of a service users and carers forum; appointment of a credible, skilled person to lead developments; identification of family work and carers 'champions'; preparation and support of senior and middle managers; establishment of a steering group and strategy; appraising work priorities and organisation; and the establishment of good links and partnerships between different service areas, carer support workers and carers' organisations.

Training also needs to target GPs and primary health care teams, so that staff are aware of family and early intervention services for people with mental health problems and their families and carers.

Education in schools and amongst the wider public is required to challenge stigma and discrimination faced by people with mental illness and their families.

## **The Mental Health Carers' Curriculum Project**

### **INTRODUCTION**

An estimated 40-50% of almost six million carers in the UK provide care for another family member or friend with a mental health problem (Office for National Statistics 2003). Of these, about 11% care for people with dementia, 14% with learning disabilities or autism, 7% for people with psychosis, schizophrenia or depression, and 8% of those with both mental and physical illness (Keeley & Clarke, 2002). There are estimates of up to 175,000 young carers under the age of 16, most of them unsupported (Cooklin 2007, Aldridge & Becker 2003).

A 'carer' is defined in the Carers Recognition and Services Act 1995 as 'someone who provides, or intends to provide regular and substantial support to a friend, partner or relative with a physical or mental disability'. This is the definition chosen by SCBN. However, others have challenged this somewhat limited definition, as the emphasis on 'regular and substantial' excludes those who provide slightly lower levels of practical and emotional support but who still require and benefit from information, involvement and support.

A young carer is a child or young person under the age of 18, carrying out significant caring tasks and assuming a level of responsibility for another person that normally would be undertaken by an adult (Cormac & Tihanyi 2006). An excellent summary of research into the lives of young carers and interventions that help has been produced by Social Care Institute for Excellence (SCIE 2005).

The term 'carer' is also not without difficulties as many people do not recognise or accept this terminology as it does not necessarily reflect the nature of the relationships amongst family members or with friends. Many carers object to this label because it implies that they did not 'care' before the person became ill or that it unhelpfully 'professionalises' their relationship. Others do not recognise the carer role at all and identify solely with their relationship roles, whilst for others the focus should remain on the service user (rethink 2003b). These and many other challenges will face the mental health professional attempting to engage and work alongside service users and their informal carers.

The relationship between the person using mental health services and the carer is unique and complex. It is rich and valuable but can also be tense and fraught. Whatever it is, it cannot be ignored in any process of recovery toward a full and meaningful life for someone living with a severe mental illness. (rethink 2003b)

## **POLICY BACKGROUND**

There is now an extensive range of legislation, official policies and implementation guidelines that make clear both the statutory requirement and expectation that mental health staff should consider and address the needs of mental health carers.

Table 1 provides a brief summary of recent legislation that impact on carers. Table 2 provides a summary of some of the key policies relating to mental health carers.

It is now recognised that carers play a key part in the lives of many people with mental health difficulties and the demand is that support for carers be made an integral part of service delivery.

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. (DH 2002: p23)

Carers are now legally entitled to a formal assessment of their physical and mental health needs: what is available, the help they are receiving, the care being provided, including consideration of work, training, leisure and other opportunities. For mental health carers, this was augmented by Standard 6 of the National Service Framework for Mental Health (DH 1999), which recommends that carers' receive a written care plan, implemented in consultation with them (see Tables 1 & 2).

Numerous national guidelines on 'good practice' recommend greater involvement and attention to the needs of families and carers. These include the National Institute for Clinical Excellence (NICE) guidelines on schizophrenia, dementia, eating disorders and depression and mental health policy implementation guidelines on community mental health teams, acute inpatient units, low secure and psychiatric intensive care units, produced by the Department of Health.

Primary healthcare staff are also in an excellent position to identify and maintain a register of mental health carers, including young carers and Black and minority ethnic carers often overlooked, and ensure their health and social care needs are addressed (Hare 2004). Best practice guidelines for GPs and primary care services have now been produced by The Princess Royal Trust for Carers in partnership with the Royal College of General Practitioners (Clarke & Riley 2006).

However, as will be shown, there is evidence that suggests that although progress is being made there is still some considerable way to go before the consideration, involvement and support of families and carers becomes a core component of high quality, effective mental health care (Hervey & Ramsay 2004).

<b>TABLE 1: RELEVANT CARERS LEGISLATION</b>	
The Carers (Recognition and Services) Act 1995	People who provide 'substantial care on a regular basis' have the right to request an assessment of what they need, what is available, the help they are receiving and the care provided from social services. Includes carers of all ages, including children.
The Carers & Disabled Children Act 2000	Ensures access to services for carers in their own right. Local authorities' remit to offer support to carers but types and level of services not specified.
The Health and Social Care Act 2011 (Section 11)	Requires strategic health authorities, primary care trusts and national health services to involve and consult patients and the public about carers' issues.
The National Health Service Reform and Health Care Professionals Act 2002	The Commission for Patient and Public Involvement in Health required to set-up forums and independent complaints and advocacy services for patients and carers.
The Community Care (Delayed Discharges etc) Act 2003	Gives carers the right to have own assessment and to request home visit to assess needs before patient can be discharged from hospital.
The Carers (Equal Opportunities) Act 2004	Aims to enhance the opportunities of carers. Assessments to include the consideration of work, training, leisure needs and opportunities. Facilitates inter-agency co-operation (housing, health, social care and education) in planning and delivery of care services for carers and those they care for. Requires local health services to cooperate with local authorities in providing support to carers.

<b>TABLE 2: SELECTED NATIONAL POLICIES ON MENTAL HEALTH CARERS</b>	
<p>National Service Framework for Mental Health. (1999) London, DH.</p>	<p>Standard 6: Caring about Carers                      All carers who are providing regular and substantial care to a service user on enhanced CPA are entitled to an assessment and their own care plan.                      10 key action points:                      1) Identify carers of people with mental health problems                      2) Provide carers with the information they need to in order to help them provide care                      3) Listen to what carers have to say                      4) Consider whether carers are providing regular and substantial care                      5) Assess carers' needs                      6) Co-ordinate with carer, service user and other agencies to meet standard 6                      7) Carer's plan                      8) Review at least annually                      9) Consult with carers about the service they receive                      10) Involve carers in the planning and development of services</p>
<p>National Strategy for Carers: Caring about Carers. (1999) London, DH.</p>	<p>Contains eight sections on the needs of carers, including a chapter on young carers. Looks at how to better identify and meet the needs of carers. Three strategic elements: information (new charter about what can be expected from housing, health and social care, helpline), support (carer involvement in planning, service provision, delivery and evaluation) and care (carers' own health &amp; wellbeing, take a break etc). Recognises the diversity of carer's needs, but identifies a range key issues which are important to the support of carers, including: receipt of reliable and satisfactory services, time off, freedom from isolation, emotional support, information and advice (about the condition of the person they care for but also about their own coping, and the availability of services and benefits), and recognition for the contribution they make and the expertise they have. More effective and respectful partnerships are needed and carers should be involved in discussions about their own support and the support provided to the person they care for.</p>
<p>The NHS Plan: a plan for investment, a plan for reform. (2000) London, DH.</p>	<p>Includes the core principle that the NHS will shape its services around the needs and preferences of individual patients, their families and their carers; developing partnerships and co-operation between patients, their carers and families and NHS staff. Pledged to provide 700 carers' support workers, increase the breaks available for carers and to strengthen carer support networks. Specific mention of carers of older people.</p>
<p>The Capable Practitioner: A framework and list of the practitioner capabilities required to implement the National Service Framework for Mental Health. (2001). London, SCMH.</p>	<p>Identifies values, attitudes and knowledge required and specific capabilities for communicating with, listening to and educating service users, carers and families. Includes the ability to work in partnership with families and carers in all aspects of care planning, delivery and review, and to help carers access and make use of local support services. Other capabilities include collaborating with agencies, users and families to help them maintain their quality of life.</p>

<b>TABLE 2: SELECTED NATIONAL POLICIES ON MENTAL HEALTH CARERS (Continued)</b>	
National Service Framework for Older People. (2001) London, DH.	Builds on core principles in NHS Plan and includes Standard 7 Mental health in older people; Older people who have mental health problems have access to integrated mental health services, provided by the NHS and councils to ensure effective diagnosis, treatment and support, for them and for their carers. Good information is also essential for carers and enables them to become partners in the provision of care, and supports them in best helping the person they are caring for. Subject to the consent of the older person, carers need information and advice about the health or condition of the person they are caring for, what they can do, and the services available.
Developing services for carers and families of people with mental illness. (2002) London, DH.	Provides guidance for the implementation of Standard 6 of the NSFMH. Services should be: 1) Positive & inclusive – carers as partners/co-experts 2) Flexible & individualised – person-centred, reflecting diversity of carers 3) Accessible and responsive – rapid response, flexible time 4) Integrated and co-ordinated – carers services embedded within mainstream mental health services Contains guidance on developing and sustaining mental health carer support services; outlines aims, development, provision and evaluation of carer support services.
National Service Framework for Children, Young people and maternity services. (2004) London, DH.	All children and young people and their parents or carers require access to information and supportive environments to ensure that the child or young person's mental health is promoted. Recognises that untreated mental health problems create distress not only in the children and young people, but also for their families and carers, continuing into adult life and affecting the next generation.
Every Child Matters: Change for Children (2004) London: HMSO.	Parents, carers and families are the most important influence on outcomes for children and young people. The Every Child Matters: Change for Children programme aims to ensure that support for parents and carers becomes routine, particularly at key points in a child or young person's life.
The Ten Essential Shared Capabilities - A Framework for the whole of the Mental Health Workforce (2004). London, NIMHE.	Recognising the needs of carers and families is highlighted throughout the 10 capabilities, specifically on working in partnership. Acknowledges the part that families and carers play in the service users' support network and the need to engage them as partners in care. Stresses the need to practise ethically, respect diversity, challenge inequality, identify users' and carers' needs and strengths, promote safety and positive risk-taking, and to work positively with any tensions created by conflicts of interest or aspiration that may arise between the partners in care.
Our health, our care, our say: White Paper. (2006) London, DH.	Recognises the role and needs of carers and pledges help including: better information, emergency respite care, expert carers programme & direct payments.
From Values to action: the Chief Nursing Officers Review of Mental Health Nursing. (2006) London, DH.	Highlights the building and maintaining of inter-personal relationships with users and carers as crucial to successful mental health nursing practice. Highlights that confidentiality can raise difficulties for carers, but notes it does not preclude listening to carers or giving advice or information which is not directly concerning the user.

## **THE PROJECT: AIMS AND OBJECTIVES**

The aim of the project was to inform the development of a national mental health carer support curriculum and training modules. The key objectives were to:

- 1) Identify the education and training needs of mental health professionals, including carer support workers and related roles, in relation to improving the support provided to mental health carers;
- 2) Identify and describe existing education and training provision; and
- 3) Recommend the content and delivery of a national mental health carers' curriculum and training modules.

## **METHODS AND PROCEDURE**

There were three components to the project:

- 1) A Literature Review.
2. Focus groups with various stakeholders to identify content and design of education and training that will address mental health carers' needs and perspectives across a range of disciplines and roles.
3. A Survey of organisations providing health and social care education to identify existing pre-registration and post-qualifying education and training.

### **Literature Review**

The literature review was designed to identify publications that:

- a) Identified mental health carers' priorities for education and training;
- b) Provided information about existing training around carers' issues;
- c) Evaluated mental health carer-focused health and social care education and training; and
- d) Evaluated or provided guidelines for mental health carer involvement in education and training.

The review incorporated searches of several bibliographic databases: Embase, British Nursing Index, MedLine, PsychInfo, IBSS, CINAHL and EBM Reviews, between 1990 and October 2006. Searches were performed using key terms developed from the review aims and following preliminary reading. Key search terms included 'family interventions', 'psychosocial interventions', 'carer training', 'carer education', 'carer curriculum', 'carer teaching', 'carer involvement' and 'carer support' (plus truncations of the word carer). The search was limited to mental health carers for reasons of brevity.

The literature comprised empirical research, literature reviews, first person narrative accounts and expert opinion and other grey, non-empirical literature. In addition, key carer organisations and health and social care websites, reports, policies, guidance documents and published reading lists on user and carer involvement were also examined and relevant articles obtained. Further articles were later identified through a process of snowballing, whereby relevant citations from the products of the searches were followed up. Attendance at a 'Working with Families' conference (Meriden 2007) led to further literature being identified.

## **Focus Groups**

We aimed to run nine focus groups with various stakeholders in order to obtain a range of perspectives:

- 3 x Focus Groups with carers and representatives (including BME carers, young carers and carers of older people);
- 2 x Focus Groups with mental health professionals including nurses, psychiatrists, occupational therapists, social workers and managers;
- 2 x Focus Groups with workers in carers' assessment, carers' support, carer involvement/development workers and carers' advocates, etc;
- 2 x Focus groups with service users and user representatives.

Planning, conduct and analysis of the focus groups followed discussions with the Expert Steering Group and consideration of relevant literature (Curtis and Redmond 2007). Recruitment was through nationwide membership of the Supporting Carers Better Network (SCBN), which includes carers, a range of staff working directly in support of mental health carers and for carers' organisations, mental health professionals, independent carer trainers and service users.

An advertisement, inviting people to take part in the focus groups was posted on the SCBN website and was emailed to all members of the network (see Appendix 1). Interested parties were asked to contact the research team, who then emailed or posted out an official invitation to participate, a detailed information sheet and consent form (Appendices 2, 3 & 4). Further direct communication with interested parties then took place by email and telephone as attempts were made to arrange suitable dates, times and venues for the maximum number of people. The invitation was to take part in focus groups at City University in London or for the project team to visit existing groups or organisations and conduct focus groups there. Carers and service users would be paid £10 on the day for their participation and up to £10 towards travel costs.

The focus group interview schedule was designed by the research team in consultation with the Expert Steering Group (Appendix 5). The questions were designed to elicit personal experiences of caring/carers and working with carers, necessary staff knowledge, skills & values to meet carers' needs, the barriers to achieving this, and training content and delivery process. A self-completion postal version of the focus group interview schedule (Appendix 6)

was later developed and emailed or posted to a number of carers' groups that could not attend or organise focus group meetings within the timeframe but who were keen to contribute their views.

The focus groups consisted lasted a total of two hours and at each group, refreshments were available. AS facilitated each group, explained the purpose of the group and discussed issues of confidentiality, anonymity and sensitivity. AS and LB ensured that each participant signed a consent form. LB and another research assistant (MT) took notes throughout the meetings and MT dealt with any domestic or other matters that arose. With the participants' agreement, the groups were digitally recorded, which allowed us to check notes against the recording to ensure accuracy and completeness.

The first 20 to 30 minutes was designed to provide participants with a space to 'offload' some of their more negative and critical thoughts and experiences. After this, participants were encouraged to consider and discuss the topics on the schedule with the facilitator attempting to allow free-flowing discussion whilst ensuring all topics were discussed. In the last 15 minutes, people were invited to reflect on the session and to identify a negative experience they would like to 'leave in the room if they could' and a positive one they would like to 'take with them' from the day. This served to help people who had been speaking about or listening to highly emotional issues to find some sort of composure before leaving and appeared to be appreciated.

## **Survey**

An email questionnaire survey of universities and other organisations providing health and social care education was conducted to identify existing pre-registration and post-qualifying education and training that focuses on working with mental health carers.

The survey questionnaire (see Appendix 7) was developed by the research team in consultation with the members of the Expert Steering Group. It was also informed by the continuous quality improvement tool for mental health education and training and a previous mapping exercise of university-accredited, post-qualifying training and education for mental health professionals (Brooker et al 2002; 2005; Workforce Action Team 2001). The tool itself was not suitable for this study given the severe time limitations.

The questionnaire was emailed with an accompanying explanatory letter to relevant networks and organisations identified by the research team and the Expert Steering Group (see Table 4). Information was requested concerning aims and objectives of programmes, educational level and target population, aspects particularly proud of, difficulties faced, level of carer involvement, addressing of cultural issues, funding source and period, accreditation, assessment of skills/competencies, and planned changes or new programmes.

**TABLE 3: NETWORKS AND ORGANISATIONS SURVEYED**

- The mental health higher education (mhhe) project: a collaboration between four network centres of the Higher Education Academy involved in mental health education, including social policy and social work, health sciences and practice, psychology and medicine;
- Mental Health Nurse Academics (UK): a network of UK Higher Education Institutions engaged in mental health nursing education;
- Centres for Excellence in Teaching and Learning (Health and Social Care) at Birmingham and Middlesex universities;
- Centre for Clinical and Academic Workforce Innovation (includes mental health team focusing on implementation of 10 Essential Shared Capabilities)
- Supporting Carers Better Network (includes charities, voluntary organisations and independent carer trainers) and members of the Expert Steering Group
- National Centre for Work Based Learning Partnerships (NCWBLP)
- Association of Directors of Social Services
- Royal College of Psychiatrists Training Unit
- Network of Thorn/Psychosocial Interventions trainers
- CSIP(NIMHE) National Carer Lead
- CSIP(NIMHE) Service User and Carer Involvement Lead
- CSIP(NIMHE) Workforce Lead
- SCIE (Social Care Institute for Excellence)
- Community Mental Health Nurse Education and Practice

## **Ethics**

The project received ethical approval from East London and The City Health Authority Local Research Ethics Committee 3 (Ref: 06/Q0605/105) on 28<sup>th</sup> September 2006. All focus group participants gave written informed consent to participate and were guaranteed anonymity.

## Data analysis

There is an extensive literature on the use of family interventions with relatives of people with mental illness (mostly psychosis and schizophrenia) and in the training of staff to provide such interventions. This literature provides rich evidence supporting the involvement and support of carers in the care and treatment of people with mental illness. Given the limitations of this project, it has been necessary to focus on identifying key reviews and seminal papers within this extensive literature. There is much less literature on providing support to carers.

All identified reports and papers were read and key topic headings identified and used to sort the literature. Key data were then extracted and collated and common themes identified.

Notes taken during the focus groups were checked against the digital recordings and were then typed and imported into QSR N6 qualitative data analysis software to aid analysis. Themes and categories were identified and coded and subsequently mapped onto a MS Excel spreadsheet and compared with the findings of the literature review. Similarities and differences were identified and have informed the recommendations.

Data from the questionnaire survey responses detailing carer-focused educational and training programmes were charted onto a matrix using MS Excel which allowed identification of commonalities and differences.

The results from the literature review, focus groups and survey are detailed below. A process of triangulation allowed the results from each method to inform the other and it will be seen that there was a large overlap between key elements of the literature review and responses to the survey of current training provision. This synthesis gave us confidence that we were identifying the relevant information and provided us with a clear idea of the recommendations we would be making.

## RESULTS: LITERATURE REVIEW

The literature has been organised under the following headings:

- a) The impact of caring
- b) Services to support carers of people with mental health problems
- c) Sharing information and confidentiality
- d) Evidence for family interventions
- e) Effectiveness of family interventions
- f) Family interventions: education, training and implementation
- g) The Meriden West Midlands Family Programme
- h) The Somerset Family Interventions in Psychosis Service, Strategy and Training Programme
- i) Training in carer support
- j) Carer involvement in education and training

### **a) The impact of caring**

Being a carer for someone with physical or mental health problems is often referred to in solely negative terms of the carers' 'burden' (Huang & Slevin 1999, Papastavrou et al 2007). But being a carer to a close relative or friend can also provide positive experiences and elicit enormous personal rewards.

Underpinning the caring role may be life-long love and friendship, together with an acceptance of the duty to provide care. Carers can derive satisfaction and a sense of wellbeing from their caring role, receive love and affection from the care recipient, gain a sense of achievement from developing personal attributes of patience and tolerance, and gain satisfaction from meeting cultural or religious expectations. (Cormac & Tihanyi 2006: p162)

Undoubtedly though, becoming a carer can have significant impacts on family life and finances, on work and career opportunities, on friendships and social relations, and on personal health and wellbeing compared with the general population (Singleton et al 2002). There are now numerous reports and research papers that illustrate the often negative impacts of being a carer and there is no need to rehearse those in great detail. Suffice to say that various studies have found that significant proportions of carers face physical and mental health problems that include stress and tension, anxiety, depression, disturbed sleep, back injuries and hypertension. Many also feel mentally, emotionally and physically drained, frustrated, angry, guilty and lonely and express sadness for the care recipient (Cormac & Tihanyi 2006).

At any stage of the caring role, carers can feel trapped, resentful, angry or upset and excluded from society. ... Carers can grieve over the loss of the 'person they knew' or 'what might have been' and the loss of mutual support and reciprocity in their relationship with the care recipient. (Cormac & Tihanyi 2006: p164)

Carers of people with dementia and mental health problems can face a 'double whammy' as they are more likely to be in poorer physical and mental health (Princess Royal Trust for Carers 2004) and also have to face-up to the added stigma and challenges associated with mental illness. Families often have problems coping with behaviour linked with mental disorder, such as social withdrawal, restlessness and pacing, frequent demands, nocturnal disturbances, bizarre or unusual behaviour, and suicide attempts (Perring et al 2002). Mental health carers often also have to face verbal and physical aggression and take financial responsibility, dealing with benefits and other practical issues such as housing (The Princess Royal Trust for Carers 2004). Tensions often lead to family or marital discord and caring for a spouse or partner can create complex role changes and ambiguity within relationships (Stubbings 2006). Children and young people living with a parent or sibling with mental illness often face enormous difficulties that can impact on their lives, education and development and many become carers themselves (Aldridge & Becker 2003). Around 30% of young carers provide care for people with mental health problems (Dearden & Becker 2004). However, their role and needs are often overlooked with staff training rarely considering young carers (Watson 1999).

Families and carers tend to go through different stages and responses to the ambiguity, realisation and impact of a family member developing mental

health problems. Various descriptions or models of the different stages that carers often pass through have been described by Pearlin (1990), Nolan et al (1996), Mohr et al (2000) and Rose et al (2002). Oyeboode (2003) provides an extremely useful review of the stressors faced by carers, the coping strategies that can mediate the impact of caring and scales for measuring carer stress and coping.

A review of studies exploring service users' and carers' views of mental health nurses identified that across all service settings carers perceive a universal lack of information and inadequate involvement in the planning of care (Bee et al 2005). They also reported that friends and relatives of users of mental health services are likely to have many emotional and psychosocial needs of their own. Despite carers expecting mental health nurses to assist with these issues, the evidence suggests that such input rarely occurs. Bee et al (2005) suggest the need for more formal procedures to improve nurse collaboration with the friends and family of service users, who should be provided with adequate information and experience regular and frequent involvement in the planning and evaluation of care. Mental health nurses should also be trained and encouraged to recognise and deal with symptoms of psychological ill health amongst carers.

One of the greatest concerns for carers is what will happen to the person they care for if they die or can't cope (Rose et al 2006). A survey of over 1,000 carers conducted for The Princess Royal Trust for Carers (2004) found that after worries about future care and financial security, carers were concerned that the person they care for would self-harm or attempt suicide (47%). Almost half (47%) did not know how to react in certain situations and 40% did not know how to deal psychologically with the person. 27% admitted they had thought about harming the person. Nearly half (48%) indicated that professionals do not spend sufficient time listening to the views of carers and 41% do not know where to go to get more help.

It has been reported that as many as 65% of carers of people with mental health problems receive no support at all (Keeley & Clarke, 2002). This is extremely concerning as studies suggest that carers suffer prolonged psychological distress (Brown & Birtwistle 1998) but that comprehensive support can mitigate mental and physical health problems amongst carers (Falloon et al 1993). A postal survey of over 1,400 mental health carers conducted by rethink suggests that carers who are involved and supported by mental health services have a better experience and are more effective carers than those who are uninvolved and lack access to support and information (Pinfold & Corry 2003a). Those carers with the most information about their role and the diagnosis of the person they support, report fewer adverse effects than new carers and those with little information. Having a choice over whether to continue providing care and support is also important but 50% of carers feel they never have any choice, with 80% uncertain or sure that health and social care services would be able to provide support and care if they were no longer able to be involved. A lack of choice over caring responsibilities is related to increased levels of mental health problems and financial pressures among carers (Pinfold & Corry 2003a).

Carers who receive timely information, are in contact with professionals, feel involved, valued and respected and have their own needs assessed and met, experience fewer and less severe adverse effects to their own mental and physical health, family relationships, finances and careers and have more time for their own leisure pursuits. (Pinfold & Corry 2003a: p5).

Other results from the rethink survey found that just under half of carers reported that standards of mental health care for carers (47%) and users (49%) had improved in the previous three years, although less so in London. Yet services such as respite or breaks for carers were still unusual. Whilst 92% wanted contact with professionals, fewer than half (49%) had regular contact though only 8% said the person they cared for prevented them having access to professionals. Over half the service users (55%) always and 37% sometimes allowed the carer to have access to mental health staff.

More positively, of those who did have contact with staff, two-thirds (67%) always or mostly felt valued for their skills by staff and 55% felt that staff regularly took account of their opinions. Issues of confidentiality were cited as a barrier by 37%. The quality of care staff was mentioned by 11%, with concerns expressed over training, empathy and listening skills and 10% feeling carers were not taken seriously or valued. A quarter of respondents (25%) complained of not receiving any information to help them on issues that included medication, specific mental health problems, new treatments, local services and coping strategies.

As outlined in the policy section above, carers have a right to ask for their own needs to be recognised by a local authority through a Carers' Assessment to identify carer's needs and make recommendations on how these can be addressed and the carer supported. In Pinfold and Corry's (2003a) survey of over 1,400 mental health carers in contact with rethink, 62% of carers knew that that they could ask for an assessment but only one in four carers had been assessed. In addition, there were wide variations between regions. A third of carers said that after their carers' assessment none of the health and social care needs identified were being addressed – even up to 12 months later. The picture with more isolated carers not in contact with support networks is likely to be even worse.

The snapshot provided above suggests that there have been undoubted improvements for the estimated 1.5 million mental health carers, with more carers than ever before involved in one-to-one care and sometimes in the planning of mental health services. But those providing care for friends or family members with a mental illness are still likely to experience deterioration in their own mental and physical health, reduced finances and career prospects, strained family relationships and lost leisure. There also remain regional variations in the availability of information, help and support, with the legal right to an assessment of their needs still failing to ensure that carers' complex needs are met. Pockets of good practice for supporting carers are emerging but the challenge is to see these vital supports and services extended to all (Pinfold & Corry 2003a).

## **b) Services to support carers of people with mental health problems**

The National Co-ordinating Centre for NHS Service Delivery and Organisation (SDO) commissioned a review of the research evidence and current service provision of support for carers of people with mental health problems, which led to the publication of three reports and a briefing paper (Arksey et al 2002a, Newbronner & Hare, 2002, Arksey et al 2002b, SDO 2002).

In the UK, three types of interventions and services for carers were identified: interventions with whole families, including family therapies and family support workers; educational programmes, including training and psycho-educational interventions; and breaks from caring, including day care and various forms of respite care (SDO 2002). A new development was the appointment of mental health carers' support or development workers.

### **FIGURE 1: CARER SUPPORT WORKERS**

Carers support workers have been developed to target the specific needs of carers. The role may include one or more of the following functions:

- 1) Providing assessment of carers needs;
- 2) Providing services to carers e.g. short-term support, support at CPA meetings, respite care;
- 3) Developing networks to support carers to be involved in service planning and evaluation.

Carer support workers may be employed by PCTs, NHS Trusts, Social Services or the voluntary sector. They are likely to be non-professionally affiliated i.e. trained but unqualified. This may not be the case if their function is assessment of carers' needs.

An extensive study on information sharing found that where carer support workers had been employed to work with carers and carry out carers' assessments, the tendency for mainstream mental health staff to sideline carers and not work with them in partnership was further compounded. In most cases, this is because carer support workers are positioned outside the multidisciplinary team, so conducting carers' assessments and addressing carers' needs is not embedded within the mental health teams (Rapaport et al 2006).

It was acknowledged that the evidence base about effective support for carers is sparse, with the needs of children and young carers and black and ethnic minority carers particularly lacking. Contributors were particularly keen to see research into how attitudes within mental health services could be changed; how barriers to information sharing could be overcome; how and when to involve carers in decisions about care; the effect of such involvement on carers and users; effective ways to involve carers in service planning; and the implementation and impact of carers' assessments.

The report identified particular difficulties around sharing information with carers and that the issue of confidentiality was often over-emphasised by mental health professionals and prevented carers from receiving information

vital to their caring role. This led the SDO to commission further research around the issue of confidentiality, which we shall explore next, following brief summaries of various supports available to mental health carers.

### **FIGURE 2: SUPPORT FOR MENTAL HEALTH CARERS**

The majority of support for carers of people with both physical and mental health difficulties is provided by voluntary or charitable sector organisations. These groups provide carers' centres, local support services, information, advice, education and training, and opportunities for recreation and social activities. They also enable carers' views to be heard and recognised. Many also seek to inform and influence policy makers, service providers and health and social care professionals. A list of useful organisations can be found in Cormac and Tihanyi (2006: p170).

Information can also be obtained from the Supporting Carers Better Network website <http://www.scbnetwork.org/index.cfm>

### **FIGURE 3: PARTNERS IN CARE**

The Royal College of Psychiatrists and The Princess Royal Trust for Carers mounted a joint campaign from January 2004 to June 2005 to highlight the problems faced by carers of people with different mental health problems and learning disabilities.

Information, leaflets, presentations and useful checklists for carers and psychiatrists can be downloaded from their website:

<http://www.rcpsych.ac.uk/campaigns/partnersincare.aspx>

### **FIGURE 4: SELF-HELP GROUPS FOR CARERS**

The only published study of a self-help group for carers, found that most members had joined because of the 'failure' of existing support networks to cope with or adjust to the carer's needs (Munn-Giddings 2006).

Carers gained a number of things from membership of the group that included empathy, emotional information, experiential knowledge and practical information based on a core value of reciprocity through peer support. The relationships built between peers were highly valued and were often described as 'comradeship and friendships', with members knowing they could call on one another if required.

Carers spoke of the lack of understanding amongst professionals of the complexity and demands of their caring role and of their loss of trust in services to support them or meet their needs. They also spoke of not having to 'put on a front' for professional staff and show they were coping. Munn-Giddings (2006) argues that it is the peer support that sets self-help groups apart from professionally-supported groups, as it provides an additional 'space' that enables members to transcend their traditional role as a 'carers' and safely express their emotions.

### **FIGURE 5: NEW DEAL FOR CARERS**

A programme of work outlined in the Department of Health's (DH) 2006 White Paper 'Our Health, Our Care, Our Say', includes a revision of the Prime Minister's 1999 Carers Strategy, setting up a help/advice line, provision of cover in emergencies and an expert carers programme.

Full details on the DH website:

<http://www.dh.gov.uk/en/Policyandguidance/Organisationpolicy/Healthreform/NewDealforCarers/index.htm>

### **FIGURE 6: NEW WEBSITE FOR MENTAL HEALTH CARERS**

A new website has been established by the Institute of Psychiatry, King's College London, the South London and Maudsley NHS Trust and Rethink. It provides information for friends, family and carers providing support to anyone experiencing mental illness and includes details of mental health carer support groups around the country:

<http://www.mentalhealthcare.org.uk/>

### **FIGURE 7: TRAINING FOR MENTAL HEALTH CARERS**

This report will not focus on education and training provided for mental health carers, but it is worth mentioning several successful programmes that do.

The Carers Education Training Programme (CETP) is an 11-session comprehensive programme aimed at carers of people with a mental illness, co-led by carers and developed in consultation with carers, psychiatrists and rethink.

CETP was developed by rethink through an amalgamation of two previous programmes, Carers Education and Support Project (CESP) and Family Education and Training Programme (FETP) and is accredited by the Open College Network.

The aim of this programme is to inform, support and empower relatives and carers and also provides training to professional staff and carer trainers. The programmes are provided regionally, with CD-Roms and carers' manuals provided by rethink. See: [http://www.rethink.org/how\\_we\\_can\\_help/our\\_services/carers\\_support.html](http://www.rethink.org/how_we_can_help/our_services/carers_support.html)

Other training packages for unpaid carers are available online, including courses on personal development provided by City and Guilds, a provider of vocational qualifications in the UK. See: [www.cityandguilds.com/](http://www.cityandguilds.com/)

The European Federation of Associations of Families of People with Mental Illness (EUFAMI) provides training for carers and service users in 12 European languages. See: [www.eufami.org/prospect/](http://www.eufami.org/prospect/)

### **c) Sharing information and confidentiality**

Information has been frequently highlighted as one of the most crucial aspects of support, enabling carers to understand the illness and its effects, and empowering them to make choices (Newbrunner & Hare 2002). Carers need two types of information: specific information and updates about the person they care for, their illness and treatment; and more general information on a wide range of issues that include effectiveness of treatments, prognosis, potential risks, coping techniques, legislation, benefits, carers' rights and the services that are available and how to access them (SCMH 1999, Newbrunner & Hare 2002, Pinner & Bouman 2003).

But there can often be conflict between the agendas of users and carers (Goodwin & Happell 2006) and patient confidentiality can create an obstacle to providing even basic information to family members and carers (Furlong & Leggatt 1996, SDO 2002). In some situations, service users may not consent to sharing information with carers. In others, staff concerns to maintain patient confidentiality are adhered to without consideration or discussion with the parties involved. However, carers require access to relevant information to support them in their role (Szmukler & Bloch 1997).

The large study commissioned by the SDO and conducted by Pinfold et al (2004), aimed to identify effective ways to involve carers in information sharing and involved a review of policy documents, a survey of current practice, focus groups, workshops and interviews with users, carers and mental health professionals. There are extensive findings from the study, which are summarised in a briefing paper (SDO 2006) (see Table 3). Issues around confidentiality and information sharing must form an integral part of any future training of mental health professionals.

Pinfold's (2004) research findings are discussed in a podcast, available to download at <http://www.sdo.lshtm.ac.uk/160podcast.html>.

This study also produced recommendations and a best practice framework that inform clinical practice when service users withhold consent to share information with their carer (Slade et al 2007).

A leaflet on sharing information and patient confidentiality is also available from the Royal College of Psychiatrists (2004) and can be downloaded at <http://www.rcpsych.ac.uk/PDF/Carersandconfidentiality.pdf>.

More general advice on good psychiatric practice in relation to confidentiality and information sharing is also available (Royal College of Psychiatrists 2006) <http://www.rcpsych.ac.uk/publications/collegereports/cr/cr133.aspx>.

**TABLE 3: SHARING MENTAL HEALTH INFORMATION WITH CARERS\***

Carers play an important role in many service users lives and their knowledge and expertise are an enormous resource for mental health services.

Providing carers with information to support their role can improve outcomes for both service users and carers.

There is a need for a 'cultural shift' within the mental health system to recognise the importance and value of the carer's role.

Carers fear being denied access to important information and are concerned that their confidences will be broken.

Professionals have difficulties in identifying the appropriate carer in order to share or acquire relevant information.

Highly complex issues influence how, when and why information can be shared. There is no single 'blueprint' for good practice.

Effective information-sharing strategies to improve the quality of care can be developed. Service users, carers and professionals should all be involved in generating such strategies.

Information-sharing strategies can be tailored to people's individual needs and requires professionals to make carefully weighted judgements.

Professionals need training to help them understand the roles of carers and to work with carers effectively.

Information can be classified into three types: general information; personal information; and personal-sensitive information. Decisions around appropriate information sharing with carers should take account of the type of information being sought or shared, and what the carer knows already.

While the majority of service users might agree to the sharing of personal information with carers, some do not. It is therefore not helpful to involve carers uncritically. The context of care and user-carer relationships must be discussed and considered.

Carers and professionals should always seek the service user's consent to share personal and personal-sensitive information and staff should document the user's responses. Consent or non-consent to information-sharing can be re-negotiated, changed and updated.

If confidentiality needs to be breached, the professional should normally explain this to the service user and carer in order to address the needs of both parties.

\*Adapted from SDO (2006).

#### **d) Evidence for family interventions**

There is now an extensive literature that supports the involvement of carers in the care or treatment of people with mental illness. This is generally described under the heading 'family interventions', 'psychosocial interventions', 'family work' or 'family therapy' with the emphasis most often on providing interventions and support to family carers with the aim of reducing relapse in the person identified as the patient or service user. Much less often is the focus on the needs of family members and other carers in their own right.

Equally, the vast majority of literature concerns carers of people with what is termed *severe mental illness*, most often schizophrenia and sometimes other psychoses such as bipolar disorder. Far less attention has been given to carers of people with other mental health difficulties including depression, dementia or personality disorders. Given the wealth of research and publications available on family interventions, the review draws on systematic reviews of research and seminal papers, where these are available.

Over the last 30 years, there has been a major development in the use of family interventions in the management of schizophrenia. Studies suggested that stressful factors in the family were associated with higher levels of relapse (Fadden 1998). In particular, people with schizophrenia were more likely to relapse when they returned to families with higher levels of what was termed, 'Expressed Emotion' (EE), which was characterised by higher levels of criticism, emotional over-involvement or hostility (Leff & Vaughn 1985).

There are now robust findings that suggest that even when on medication, people with schizophrenia have a 50% rate of relapse within nine months of returning to a family with high EE compared with 20% in those families with low EE. And it's not just families. Mental health staff can also exhibit high EE (Kuipers 2006).

Research studies designed to help better understand 'expressed emotion' and the processes involved in relation to family interactions, coping strategies and relapse continue to produce interesting results. The factors influencing the development of EE are still unclear but may be linked with the carers' appraisal of loss and may be an adaptive reaction to that perceived loss (Patterson et al 2005). Ways of coping are influenced by family's perceptions of the situation with their relative and avoidance coping is strongly associated with burden, distress and high EE (Sczufca & Kuipers 1999). Avoidance strategies seem to be less effective in regulating the distress of being a carer and problem-focused strategies may benefit both the family and the service user (Sczufca & Kuipers 1999). However, Bhugra & McKenzie (2003) have summarised studies of expressed emotion in non-Western cultures and suggest the findings are less solid with cultural variation in the degree and type of EE. Normative levels of EE and their impact on illness may be influenced by cultural dynamics that need to be considered. For example, Wong (2000) describes the cultural issues experienced by carers who hold traditional Chinese values and beliefs that affect their family expectations and obligations.

Informed by studies in 'expressed emotion' and a vulnerability-stress model (Zubin & Spring 1977), several psychosocial interventions have been developed that involve education, support and management to reduce expressed emotion within families (Pharoah et al 2006). The aim is to help families understand the illness and see the symptoms and behaviours as due to the illness rather than 'awkward behaviours' that the relative can easily control. Coaching is given, where required, to improve the family's ability to solve problems, deal with stressors and cope by encouraging clear communication which, as understanding increases, decreases tension and improves the quality of family life (Smith & Velleman 2002). Fadden (1998) has summarised the core components of family interventions (see Table 4).

**TABLE 4: CORE COMPONENTS OF FAMILY INTERVENTIONS\***

Establish a collaborative working relationship with all family members, including the identified service user

A positive, non-blaming attitude by the staff member/therapist

Share information about the disorder, cause, prognosis, symptoms etc

Service user and family members seen as experts with helpful knowledge to share

Interventions have emphasis on finding practical solutions to day-to-day problems

Assist family members to acquire a range of coping skills to help them deal with difficulties faced when a family member has a mental illness

Simpler, more practical issues selected first, building up to more emotive topics such as the management of disruptive behaviour or desire for independence

Focus of attention balanced amongst family members with aim to ensure no member feels 'scapegoated'

Emphasis on communication and learning more constructive, positive methods of interacting and pay attention to good things that happen

Make requests of each other in a direct, clear manner rather than less effective styles that have developed

Participants encouraged to find ways of expressing more difficult feelings such as anger, irritation and disappointment

New skills are practiced in sessions with family members and therapists giving feedback encouraging positive change

Family and individual goals are identified and encouraged

\*Adapted from Fadden (1998)

These psychosocial interventions are often termed 'behavioural family interventions', with the emphasis on 'psycho-education' and 'family-management'. However, since the mid-1950s there have been a number of phases and developments in family interventions for schizophrenia, which have been well summarised in papers by Mohr et al (2000) and Bertrando (2006), with the key phases reproduced in Table 5.

Sadly, there was often little engagement and some tension between advocates of behavioural psychoeducational and systemic family therapy interventions (Johnstone 1993, Leff & Vaughan 1994, Keen 2003). However, Frank Burbach, a clinical psychologist from Somerset where systems-theory based family therapy with schizophrenic families has been developed since 1980, attempted to begin a process of bridge-building in an excellent review of the issues (Burbach 1996). Bertrando (2006) suggests that we are probably now in a new, 'integrative' stage of family interventions, with the different approaches to family dynamics being 'bridged and blended', in order to give more effective help to all members of families with schizophrenia, as reflected in recent papers by the likes of Fadden (2006), Burbach and Stanbridge (2006).

**TABLE 5: PHASES OF FAMILY INTERVENTION FOR SCHIZOPHRENIA\***

**Phase 1: Conjoint family therapy (1955-1965)** – family interventions aimed at modifying family communication patterns, implying the possibility of a definitive resolution of psychopathology.

**Phase 2: Antipsychiatry (1965-1975)** – a philosophy of psychiatry, which considered schizophrenia as an epiphenomenon of the distortions of Western society, with family therapy raising awareness of this.

**Phase 3: Milan systemic therapy (1975-1985)** – the systemic model aimed to help people with schizophrenia recognise their position within the family and other systems, giving all family members a new sense of their relationships.

**Phase 4: Psychoeducation (1985-2005)** – Schizophrenia usually conceived as a biologically determined disorder, with psychoeducation aiming to help family members cope with problems brought about by the illness, eliciting consensus towards psychiatric treatments such as medication and rehabilitation.

**Phase 5: Integrative phase (2006 - )** New phase of family interventions developing now, merging different approaches to family dynamics in order to give more effective help to all members of families with schizophrenia.

\*Adapted from Bertrando (2006)

### **e) Effectiveness of family interventions**

A Cochrane Review is a systematic summary of reliable evidence of the benefits and risks of healthcare. Cochrane Reviews are often seen as the best review of the research available as they employ strict criteria when considering the value of research studies. They are intended to help people make practical decisions about healthcare interventions.

The most recent Cochrane Review of family interventions for people with schizophrenia or schizophrenia-like illnesses, reported on 43 studies involving over 4,000 patients in community settings in Europe, Asia and North America (Pharoah et al 2006). After considering the various criteria and measures used and the relatively poor quality of data reported in some studies, the authors drew their findings. The main results were that family interventions may decrease the frequency of relapse, may reduce hospital admissions and may encourage compliance with medication although not the tendency of individuals and families to drop out of care. It may improve general social impairment and the levels of expressed emotion within families. Family interventions did not appear to impact on suicides. The authors noted that few studies measured the impact of family interventions on members of the family other than the identified patient.

In conclusion, the authors did not feel the results were strong enough to be confident of the effects of family interventions and wished to see more studies of interventions that were applicable to routine care. In considering the implications for practice and in particular for people with schizophrenia and their families, they suggested the main benefits of family interventions were a likely increase in patients consistently taking their medication and a decrease in the risk of relapse and re-hospitalisation. Family life may also become less burdensome and tense. However, for this 'moderately certain' gain, the service user and their family would need to commit a significant amount of time working with services – and that would then depend on high-quality family services and interventions being available within local psychiatric services (Pharoah et al 2006).

In the UK, the National Institute for Clinical Evidence (NICE) independently evaluates the available evidence for treatments and interventions for a wide range of physical and mental health problems and provides guidance for clinicians and service providers. The NICE Guidelines on Schizophrenia (NICE 2003) drew heavily on earlier Cochrane Reviews of evidence concerning numerous treatments and interventions for schizophrenia and decided there *was* sufficient evidence of the benefits of family interventions:

There is strong evidence that family interventions improve the outcomes for people with schizophrenia living with (or having close contact with) their family, most notably in reducing the relapse rate both during treatment and for up to 15 months after treatment has ended. Family interventions are also effective in reducing relapse rates in those who have recently relapsed, and in those who remain

symptomatic after resolution of an acute episode. The benefits are most marked if treatment is provided over a period of more than 6 months or for more than ten planned sessions, and if the service user is included in the family sessions. Treatment with family interventions may be less acceptable when delivered as a multi-family group intervention. (NICE 2003, p107-8).

There was weaker evidence that such interventions were likely to be cost effective, mainly because of the reduction in relapse and the use of expensive hospitalisation. There was insufficient evidence to know if suicide rates are altered by family interventions.

In conclusion, NICE recommended that family interventions should be available to the families of people with schizophrenia who are living with or are in close contact with the service user; where people with schizophrenia have recently relapsed, are considered at risk of relapse, or have persisting symptoms. The duration of the family intervention programme should normally be longer than six months and should include more than 10 sessions of treatment. Where possible, the service user should be included in the family intervention sessions, as doing so significantly improves the outcome.

As importantly, NICE recommend that carers should be engaged with and involved from the very start of a service users' contact with mental health services, provided with accessible information and offered appropriate support (see Table 6). The recommendations provide suggestions of good clinical practice no matter what the diagnosis.

Family interventions have also been found to be cost effective (Knapp 2000) and are recommended by leading clinical research teams including the Schizophrenia Patient Outcomes Research Team (PORT) (Lehman et al 2004). The World Fellowship for Schizophrenia and Allied Disorders (2007), a global organization dedicated to 'lightening the burden of schizophrenia and allied disorders for sufferers and their families', has produced useful principles and guidelines for working with families as 'partners in care'.

Recent publications have explored the use of family interventions in some of the most prevalent mental disorders, including anxiety disorders, eating disorders, childhood mental difficulties and substance misuse (Sartorius et al 2005); dual diagnosis (Drake & Mueser 2000, Sheils & Rolfe 2000); and dementia care (Michon et al 2005, Rogerson 2006). The use of family interventions in different clinical settings has also been explored, including acute inpatient units (Baguley & Dulson 2004, Jones et al 2005), medium secure units (Geelan & Nickford 1999) and high-secure forensic hospitals (Walker 2004). Family interventions are an important component of early intervention services for psychosis (Addington et al 2005, Pinfold et al 2007) and Sin et al (2007) have outlined inclusive care pathways and innovate services for carers of people with early onset psychosis. However, staff working with families of people experiencing first episode psychosis may require a modified training that addresses the specific subtleties and needs of this client group (Singh et al 2003, Brabban & Kelly, 2006, Askey et al 2007).

**TABLE 6: WORKING IN PARTNERSHIP WITH SERVICE USERS AND CARERS\***

Health professionals involved in the routine treatment and management of schizophrenia should take time to build a supportive and empathic relationship with service users and carers; this should be regarded as an essential element of the routine care offered.

The families of people with schizophrenia often play an essential part in the treatment and care of their relative, and with the right support and help can positively promote recovery.

Clear and intelligible information should be made available to service users and their families about schizophrenia and its possible causes, and about the possible role families can have in promoting recovery and reducing relapse.

Health professionals should provide accessible information about schizophrenia and its treatment to service users and carers; this should be considered an essential part of the routine treatment and management of schizophrenia.

In addition to the provision of good-quality information, families and carers should be offered the opportunity to participate in family or carer support programmes, where these exist.

When talking to service users and carers, health professionals should avoid using clinical language, or at least keep it to a minimum. Where clinical language is used, service users and carers should have access to written explanations. All services should provide written material in the language of the service user, and interpreters should be sought for people who have difficulty in speaking English.

\*Adapted from key recommendations on schizophrenia (NICE 2003, p36).

Family interventions have also been considered in relation to the growing focus of 'recovery' in mental health. Many characteristics of family interventions are consistent with the recovery approach (NIMHE 2005), with their emphasis on being community-based, achieving personally relevant goals, instilling hope and improving natural supports. Suggestions are made to develop family interventions further within a recovery framework (Glynn et al 2006).

**f) Family interventions: education, training and implementation**

A survey of 11 community mental health teams (CMHTs) in one inner London borough found that whilst a high proportion (81%) of 257 service users had contact with family or carers and that in over a third (37%) of cases care co-ordinators had been in contact with carers, very few families had received an assessments of carers' needs (7%) or family interventions (5%) (Krupnik et al 2005).

Despite the evidence that family interventions can have a beneficial impact, they are still not routinely available to mental health service users, their families and carers. Part of the difficulty is that too few mental health staff have been trained to provide them, yet there is considerable evidence that a range of clinicians can be successfully trained to provide effective family interventions and other psychosocial interventions (PSI) such as cognitive behavioural therapy (CBT) (Tarrier et al 1999). There is also evidence that family interventions are not effective when offered by clinicians who have not received appropriate training or when supervision is not subsequently provided (Fadden 2006).

Brooker (2001) has provided a useful overview of the development and evaluation of training in PSI. Since the early 1990s, the number of PSI training programmes has doubled year on year, particularly through the funding and development of the Thorn Initiative training courses (O'Carroll et al 2004), but overall numbers of the national workforce accessing such training remains low and is almost non-existent in some areas of the country.

Brooker and Brabban (2004, 2006) have conducted a comprehensive review of all studies that have evaluated training in psychosocial interventions between 1990 and 2003 and identified 37 papers, the majority of which evaluated training in family interventions or generic PSI training. We will draw out from that study the key points relevant to the training and implementation of family interventions. Brooker and Brabban (2006) identified a wide variety of evaluated PSI courses, which they classified under three main headings:

- i) higher education accredited courses at undergraduate level
- ii) higher education accredited courses at postgraduate level
- iii) shorter programmes often run 'in-house' within mental health services

The focus of PSI programmes could also be classified under three headings:

- i) family interventions
- ii) individual psychological interventions
- iii) broader generic courses (that often include both family and individual psychological interventions)

The programmes most often evaluated were generic courses across all levels, with most studies focused on whether trainees can implement their new skills in real-world practice settings. Although there are relatively few evaluations given the number of courses and even fewer well funded, large scale studies, PSI training is better evaluated than most other post-qualifying training programmes (Bailey et al 2003).

Overall, trainees tended to be satisfied with their training but, when evaluated, less satisfied with the supervision provided in the workplace. PSI training appeared to have a positive effect on the attitudes and beliefs that trainees held about psychotic conditions, about service users and about available

psychosocial interventions to help users and carers. Although different measures were used making comparison difficult, acquisition of specific knowledge tended to improve although it is unclear how long newly acquired knowledge was retained. On the whole trainees developed targeted skills, although the variety and limited forms of measurement made it difficult to determine the level of expertise achieved. The small number of studies that attempted to measure post-training skills reported moderate scores. Those staff with better prior skills and academic qualifications and who attended regularly may gain most from PSI training.

Brooker and Brabban (2006) identified the commonly reported barriers to the provision of family work and factors that facilitated implementation (see Table 7) and stressed that several studies point to the importance of organisational ownership of the implementation of PSI through steering groups involving senior managers.

Benefits to service users and carers have been found in the majority of studies, although too few studies (n=4) examined outcomes for carers. More research is required to explore the impact of PSI and particularly family interventions from the relative's experience. It is worth mentioning that there has been some criticism of the limitations inherent in evaluations of PSI training, in particular the tendency to focus on outcomes valued by services and professionals rather than service users and carers. Attempts to identify carers' perspectives on outcomes found that carers most valued improvements in relationships and communication, but that this centred on the carer-worker relationship, rather than the user-worker relationship. In particular, carers wanted to be recognised as part of the healthcare team (Forrest & Masters 2004). When Forrest et al (2004) conducted a stakeholder evaluation on five PSI training course they encountered some resistance amongst the professional trainees to the involvement of users in appraising the impact of the training on their work and failed to involve carers at all.

<b>TABLE 7: FACTORS IMPACTING ON IMPLEMENTATION OF FAMILY INTERVENTIONS*</b>	
Barriers to implementation	Allocation of time in the service Problems of integration with the existing caseload Availability of families
Factors facilitating implementation	Critical number of staff trained in team Access to high quality supervision Having time to do the work Possessing enough skill to apply the intervention flexibly
*Adapted from Brooker and Brabban (2006)	

Neither the length nor type of training appeared to be an important factor in determining outcomes, so it was difficult to determine the essential ingredients of a successful training programme. It was also difficult to assess the level of skills that have been acquired, given the paucity of standardised measures or rigorous methods employed, so no conclusions could be drawn on the type or

length of training required to achieve any specific level of expertise. The authors also pointed out that despite the 'policy imperatives and the rhetoric', few mental health professionals have received any training in PSI or family interventions.

Brooker and Brabban (2006) consider the implications for the commissioning and provision of PSI training programmes within the NHS. They suggest that the commissioning process will want to take into account, probably at the strategic health authority workforce development planning level, the plans each mental health provider has for training the workforce, whilst considering the different levels of training required to successfully implement psychosocial interventions. They suggest three levels of training provision:

- 1) All mental health professionals trained to at least an introductory level, often on courses run in-house;
- 2) A smaller number on longer undergraduate programmes; and
- 3) A small minority trained to expert level, able to provide expert supervision to others.

The need for staff with differing levels of competence within teams and organisations will be developed later. But importantly, a 'critical mass' of any organisations' workforce needs to share, understand and work to the attitudes and beliefs that underpin the adoption of psychosocial interventions, particularly the involvement of families and carers, and a recovery model of serious mental health problems. Numerous studies have shown that individuals trained in family interventions find it very difficult to maintain their interest and to implement their newly developed skills in the workplace because of high caseloads and other work pressures, lack of supervision and protected time for family work (Brooker and Brabban 2006).

A follow-up study of 141 psychosocial intervention trainees and their service managers in Sheffield and London, with an 82% response rate (Brooker et al 2004), suggested that the PSI training may not have equipped trainees with formal technical skills in cognitive behavioural therapy and family work but did provide them with proficiency to work effectively within a case management model, convey 'therapeutic optimism', enable users to meet their own goals, help them develop better coping strategies, and use 'stress vulnerability' and formal outcome measures in a structured way. Whilst the clinicians and managers reported that PSI training had a positive impact on the development of services, addressing issues around caseload size, team support and organisational factors such as the existence of an implementation plan and a training strategy, are crucial in ensuring that skills are implemented in practice. A more detailed consideration of the implementation of family work in this group, found trainees working with an average of just one family per year. Although there were wide variations, the vast majority of trainees (51/78 65%) worked with very few or no families at all since completing training.

Earlier studies of staff that had received training in behavioural family interventions reported similarly low numbers of families being seen by therapists subsequent to training (Fadden 1997). Small numbers of staff do

manage to work with a large number of families but do not appear to represent any particular profession or clinical area. Difficulties faced in implementing family work included being unable to find 'suitable' families, insufficient time because of time required or out-of-hours working, difficulty engaging or motivating families. In-patient staff faced particular difficulties. Working in community teams and in teams with higher numbers of staff trained in family interventions increased the likelihood of implementation. Other studies have shown that where whole teams or area services provide family interventions, implementation of the approach tends to be much higher (Brooker 2001). In-house training programmes within NHS Trusts have also been found to be particularly effective where there are organisational and managerial supports and encouragements in place (Milne et al 2001). Offering family interventions to all families with a serious mental illness, rather than just those with a family member with schizophrenia, also helps establish a family-focused culture within mental health services (Hughes et al 1996). However, Fadden (2006) has identified certain complexities and contradictions in aspects of family work which make it imperative that informed, skilled practitioners are available to ensure work with families and carers provides benefits rather than harm.

Fadden (2006) suggests that the delivery of family interventions is determined by a complex interaction of numerous factors involving users and families, mental health professionals and organisations. First, service users, families and carers are unlikely to be aware that such services exist, even where they do. Other families may fear being seen as trouble makers if they request family services. For professionals, the move from providing a service focused on the individual to one focused on families is a difficult transition, with the majority of staff not usually trained in family work. Basic mental health training may also fail to adequately equip many staff with the basic counselling and therapeutic tools that underpins family interventions, so staff struggle to adopt new skills around family engagement and interventions.

Grainne Fadden (2006) has identified the knowledge, skills and attitudes necessary for working with families. These are shown in Table 8 with a few additional suggestions made by Frank Burbach (2007) at a 'Working with Families' conference organised by Fadden.

Finally, Fadden (2006) goes on to suggest that organisational factors still make the implementation of family interventions difficult. Findings from numerous studies show that most family work is carried out by a relatively small number of highly motivated individuals. Others, as outlined earlier, find that organisations rarely facilitate family work. The focus of clinical practice tends to remain on the individual patient, rather than the user within their family and social context, and the priorities of mental health services are determined by targets, budgets and the development of new services with less attention given to the therapeutic approaches employed.

**TABLE 8: SKILLS, KNOWLEDGE AND ATTITUDES NEEDED FOR FAMILY WORK\***

- Positive, understanding attitude towards families
- Ability to use Rogerian principles (e.g. empathy, positive regard, listening and reflecting skills)
- Ability to engage with families
- Awareness of transference and counter-transference issues
- Good communication skills
- Experience of group work
- Ability to involve all family members equally in sessions
- Confidence in handling conflict
- Dealing with complex issues such as conflicts around confidentiality
- Understanding of normal family development
- Knowledge of family systems and how they function
- Awareness of biological theories of mental health difficulties
- Knowledge of the key components of psychoeducational family interventions
- Skills in applying components of family work
- Behavioural and cognitive skills
- Familiarity with policies relating to families
- Openness to reflecting on own practice
- Willingness to use supervision
  
- \*\*Understand family systems and how they evolve
- \*\*Explore unhelpful patterns of interaction in which all family have been caught up despite their best intentions
- \*\*Enable conversations in which each member feels their strengths and perspectives are heard and respected

\*Adapted from Fadden (2006) and \*\*Burbach (2007)

A comparison of staff working in community mental health teams (CMHTs) and a new early intervention service suggested that staff in both services displayed 'considerable sophistication' in their understanding of the impact of mental illness on families and of carers' needs but that workload within CMHTs precluded any involvement with families (Slade et al 2003). High rates of staff-turnover and changes in management also militate against the long-term impact of training sessions (McCann & Bowers, 2005) and numerous other organisational and structural barriers to bringing about change also exist in NHS work environments faced with constant and unrelenting pressures (Jones & Scannell 2002, Brennan et al 2006).

Any training programme aimed at improving the involvement and support of mental health carers is going to have to address this complex web of factors that tends to limit the implementation of knowledge and skills obtained through training and impede the development of family interventions and family-focused services.

The next section of this literature review will draw on two systematic but different training programmes that have attempted to do just this; The Meriden West Midlands Family Programme and the Somerset Family Interventions in Psychosis Service. Each programme will be briefly outlined and then, drawing from these and other relevant studies, key strategies will be identified that help establish, develop and help maintain family-focused practices and family intervention services.

#### **g) The Meriden West Midlands Family Programme**

The Meriden Programme was established in 1998 with the aim of ensuring that mental health services were sensitive to the needs of families and that evidence-based family interventions were available to families in the West Midlands, covering a multicultural population of 5.5 million in urban and rural areas. The programme has been described in detail (Fadden & Birchwood 2002, Fadden et al 2004, [www.meridenfamilyprogramme.com](http://www.meridenfamilyprogramme.com)).

The programme employed a coherent combination of staff training based on the PSI family management approach outlined above, ongoing supervision and an extensive range of organisational strategies (Fadden 2006). Funding of around half a million pounds over six years was provided through regional training monies.

Staff who receive a comprehensive training programme then go on to train and supervise other staff within their services. Most recent figures show that over 2,000 people have been trained to deliver family work over the last seven years and there are currently over 120 trainers/supervisors working across 13 participating organisations (Fadden 2006). A UK survey of carers carried out by rethink in 2003, found that services for carers in the West Midlands had improved and the highest proportion of carers reported that they had received sufficient information on their relative's difficulties (Pinfold & Corry 2003b). A small in-depth study of 10 families that received behavioural family therapy under the Meriden programme reported high levels of satisfaction with the intervention, reductions in stress levels and carer burden in the families, enhanced communication skills and a positive sense of empowerment (Campbell 2004). The majority of families viewed mental health professionals and services more favourably compared to their previous experiences.

#### **h) The Somerset Family Interventions in Psychosis Service, Strategy and Training Programme**

Between 1996 and 2001, a Trust-wide family intervention or family support service was established in each of four service sectors covered by Somerset Partnership NHS and Social Care Trust (Burbach & Stanbridge 2006). The Somerset programme involved a comprehensive programme of multi-professional training and a strategy to enhance working partnerships with families and carers throughout all mainstream services. It also integrated systemic and psychoeducational approaches to family work.

Each of the four service areas covers a largely rural population of between 110,000 and 140,000 people and now contains a Family Support Service of around eight members from a variety of disciplines drawn from a range of inpatient and community teams, each providing at least half a day a week to the family service. Such an arrangement promotes integration between each clinical team and with the family support service.

The Family Support Service meets monthly for peer supervision and reviews and one member co-ordinates referrals and related audit work. The service is available to people in regular contact with their family members or significant others (carers) who are experiencing psychotic symptoms with an emphasis on early intervention. The main aim is to improve outcomes and quality of life for all family members. Detailed descriptions of the interventions employed and service evaluation are available in Burbach & Stanbridge (1998, 2006). Early indications suggest the service is well regarded by families, with satisfaction related to families' needs being met (e.g. coping with symptoms, problem-solving, improved communication in the family, better liaison with services), developing new perspectives and being listened to in the context of an empathic, non-judgemental therapeutic relationship (Stanbridge et al 2003).

Alongside developing the Family Support Service teams, a one-year individual skills-based university-accredited degree/diploma-level training course was provided to multi-disciplinary staff in their workplace. The course consists of three modules and integrates systemic family therapy and behavioural family management approaches (see Table 9).

<b>TABLE 9: THE SOMERSET FAMILY INTERVENTIONS (RESEARCH, SKILLS, THEORY) IN PSYCHOSIS (FIRST) MODULE CONTENT*</b>	
Module 1	Covers systemic theory, research and basic practice skills. Systems thinking, the importance of context, and the way in which problems arise/are maintained are introduced from a 'cognitive-interactional' perspective. The family life cycle, family beliefs/narratives, the individual's/caregivers' experience of psychosis and the stress-vulnerability model are also introduced. Appropriate clinical skills are developed through role play.
Module 2	Critically examines the systemic therapy and cognitive-behavioural psychoeducational family interventions approaches to psychosis and further develops their integration. Theory and research about early interventions, ethical issues and risk are also examined. Behavioural family therapy, systemic interviewing, and formulation skills are developed in role play and in supervised work with families, midway through the module.
Module 3	Further develops clinical skills through direct supervision and considers their application in the service context. Cognitive-behavioural therapy techniques for psychosis (hallucinations, delusions, negative symptoms) are introduced. Further systemic theory and skills, narrative approaches and relapse prevention strategies are also introduced.
*Adapted from Burbach & Stanbridge (2006)	

An evaluation with 15 therapists that had completed the FIRST training reported an increase in the number of families worked with compared to other studies (although the average numbers still seemed fairly low) and fewer difficulties in implementing the approach (Bailey et al 2003). The main areas of difficulty continued to be insufficient time and integration with caseload and other responsibilities, though tailoring the approach to needs of clients and families and accessing supervision were not problems, in contrast to other studies.

Like the Meriden Programme, in Somerset there was a strategic focus on influencing management and the wider clinical culture to ensure family-friendly services and that family intervention services are routinely integrated into treatment. A key emphasis was on the Trust adopting a strategy to enhance working partnerships with carers and families and training staff throughout the Trust in awareness and basic family inclusive skills (Stanbridge and Burbach 2004). Key initiatives are outlined in Table 10.

<b>TABLE 10: KEY INITIATIVES IN DEVELOPING FAMILY INCLUSIVE SERVICES*</b>	
Family-friendly facilities	Ensure that mental health facilities are friendly to visit and that staff welcome relatives, friends and carers. Provide appropriate facilities such as visiting rooms that offer privacy and are child-friendly. This may provide major challenges to many services.
Involvement in assessment	Staff required to make contact with families and carers during initial stage of engagement with users unless a good reason not to do so. This may include involving carers in the initial assessment interviews. This aids the identification of social networks, facilitates treatment interventions which consider the user in the context of his or her relationships, and allows appropriate referrals for more intensive family work when required. Even when not appropriate to meet directly with relatives, it is both possible and desirable to include a family perspective when working with individuals. Providing general information to families and contact details of local carer support workers and organisations is also desirable.
Whole system approach	In order to meet the needs of the whole family, it is important to encourage a more joined-up approach with close working between colleagues in a range of health and social care agencies, including child and adolescent services, older adults' services primary care, social services, education and voluntary organisations. In particular, there needs to be greater consideration of the needs of children and adolescents, the impact family mental illness may have on their own mental and physical health and the needs of children who become carers. Adults caring for young people with mental health problems may also need greater consideration.
*Adapted from Stanbridge & Burbach (2004)	

The training programme aimed at staff across the Trust in Somerset aimed to introduce a family-systemic perspective throughout the service and all community and inpatient teams so that considering and working with families becomes a mainstream activity. Stanbridge & Burbach (2004) suggest a whole teams training approach shaped to the particular needs and interests of the team to maximise impact. Like Meriden, the focus is on attitudes and awareness, in order to counter common misapprehensions, and skills.

Different staff will require varying levels of knowledge and skills dependent on their role and responsibilities. For many, an awareness of issues facing families and carers, alongside information on how to access further help and support, may be sufficient. For others with more direct, therapeutic contact with individuals and their families, developed skills in conducting family meetings and providing family interventions are required. Table 11 illustrates the suggested content for different levels of training.

<b>TABLE 11: LEVELS OF COMPETENCE IN FAMILY WORK*</b>	
Level 1	An awareness of the experiences and needs of carers and families and of what family work involves, in order to facilitate carer and family-friendly practices and to recognise the need for carer support and family work, to discuss it with carers and families and make appropriate referrals. Information about local carer support services should also be provided. This competence can be achieved by attending presentations or by receiving awareness-raising courses, which should both include input from carers and families, carer support workers and family workers. Such training should be made available on a regular basis to all existing staff, including managerial and administrative workers, and should form a core component of any staff and student induction programmes.
Level 2	As above, plus an ability to offer family interventions. This will be achieved through attending formal training courses, by working alongside skilled family workers and through ongoing supervision and support. All community, inpatient and specialist teams should aim to contain a reasonable number of multidisciplinary staff trained and competent in the provision of family interventions.
Level 3	As above, plus an ability to teach family work skills and offer clinical supervision. This will be appropriate for clinicians who wish to become specialist or advanced practitioners in family work and will be achieved by attending formal training courses such as the Thorn or Meriden programmes. Such clinicians are likely to provide training and supervision across a number of clinical teams and areas.
* Adapted from Fadden (2006) & Burbach and Stanbridge (2006)	

Key strategies that have been successfully implemented in the Meriden and Somerset programmes and other centres to help establish, develop and maintain family-focused services and to ensure that any training programme is effective are outlined in the recommendations section of this report.

### **i) Training in carer support**

In considering why implementation of family interventions has tended to be poor, Mairs and Bradshaw (2005) reviewed six English–language studies that specifically attempted to evaluate rates of implementation by mental health professionals following training. While pointing out a number of methodological weaknesses to these studies, they focused on the considerable difficulties commonly reported in recruiting and engaging families. The reasons cited for not wanting to take part included patient objection, caregivers being too busy, caregivers requesting practical help not support or not being interested. Yet, paradoxically, family intervention programmes appear to provide the very things requested in surveys of carers – information and education about schizophrenia, its aetiology, course, symptoms, treatment and management and local service provision. Stress management and/or problem solving strategies, relapse prevention planning and strategies to enhance the functioning of the person with schizophrenia.

Mairs and Bradshaw (2005) go on to suggest that what carers do not ask for is prolonged and regular contact with mental health professionals and that family interventions tend to be an intensive intervention requiring considerable investment of time and energy on the part of the user and their caregivers. This factor and the variable success rate of family interventions, with the Cochrane systematic review by Pharoah et al (2004) suggesting that six or seven families must participate in family interventions to prevent one relapse (although there may well be other gains along the way), may be part of the reason so few families are willing to take part. They suggest that shorter carer-led family psycho-education groups, as developed in the USA (Dixon et al 2004), may be more effective, although the impact on users of such programmes has yet to be evaluated. This is supported to some extent by the experiences in an early intervention service which suggested that in families that welcomed input, only a small proportion required intensive family work. Most wanted a single point of contact, low level support, information and psychoeducation (Slade et al 2003).

It should also be clear from the above, that the major focus of psycho-educational family interventions is on reducing relapse amongst people with mental illness, particularly psychosis. Whilst it is intended that these interventions will benefit family members and relieve some of the stress and help family members develop new coping skills, they are not intended to provide direct support to carers.

In Scotland, clinical standards have been set for the professional support of carers of people diagnosed with schizophrenia, yet there is a lack of robust evidence on the most effective means of providing that support (Gall et al 2003). Mental health professionals often interact with carers solely in relation to the needs of the identified patient and as such carers' emotional, psychological and practical support needs are often overlooked (Walker & Dewer 2001, Bee et al 2005). Both Hatfield (1997) and Simpson (1999) have suggested that staff need to work collaboratively or in an empowering alliance with carers, whilst respecting their unique perspectives.

Gall et al (2001, 2003) have described and evaluated a post-registration training course aimed at mental health nurses working in community, day hospital and inpatient settings. The accredited course ran one day a week over 12 weeks and was taught by carers, a member of the National Schizophrenia Fellowship (Scotland) and nursing lecturers. The content of the programme included exposure to carers' real life experiences and focused on five key practice outcomes:

- Working collaboratively with carers;
- Utilizing a carer-focused approach;
- Acknowledging and supporting the carer's role;
- Helping carers identify their needs; and
- Accessing appropriate resources to meet the identified needs.

Interventions with carers that followed the training comprised up to 12 support sessions, a carer assessment and intervention. A care history was taken followed by an assessment of the carer's needs that included practical care needs, educational needs, coping and managing, and satisfaction with caring. Resources to meet those needs were then explored, identified and discussed. Action plans were established and agreed collaboratively, building on the carer's strengths and abilities in meeting those needs, whilst identifying those aspects requiring additional help. Assessments and action plans were jointly recorded and reviewed.

The evaluation involving 10 nurses and just nine carers found that nurses worked more collaboratively with the carers, listening to and acknowledging the carers' perspective, helping them communicate openly, acknowledging the expertise of the carer and adopting an expert-to-expert approach with the carer (Gall et al 2003). They were also able to focus on and address the needs of the carers rather than solely the patient and were able to provide support and information and act as advocates. The nurses were also more aware of carer support services and how carers could access them. However, the nurses did face difficulties. These included discomfort at hearing carers' negative experiences of health services, dealing with carers' own mental health or substance misuse problems, and facing interfamily conflicts or social isolation. Some inpatient-based nurses found the transition to community work difficult. Those nurses who accessed clinical supervision, found it beneficial and more able to cope with conflicts.

Interviews with carers confirmed the generally positive picture, with the carers welcoming the nurses' abilities in communicating, working collaboratively and in a carer-focused way. The interactions with the carers were reported to be different than those usually experienced with mental health professionals; their caring role and expertise was acknowledged and they felt more supported with numerous needs identified and addressed. Some needs though, such as providing assurance concerning the care of the family member should the carer die, remained unmet.

These results are hugely encouraging, albeit from a very limited study. A relatively short training course appeared to increase the ability of mental health nurses to engage with and work collaboratively and supportively with carers. Gall et al (2003) make several recommendations for future training on the basis of this study:

- Training should reflect carers' needs and prepare staff for the practice change that is required to meet those needs;
- Staff with community experience may be best suited to future training programmes;
- Staff should receive adequate clinical supervision when working with carers;
- Parameters and limitations of the work with carers should be explored and acknowledged during training and in clinical supervision.

To our knowledge this is the only study published of training in carer support. Clearly more such training initiatives and high quality research evaluations are required and could be linked with the training and evaluation of Carer Support Worker roles, which appear to cover similar territory but have not yet, to our knowledge, received any form of evaluation.

An innovative approach aimed at developing mental health nurses' understanding of the needs of carers and their role in achieving positive outcomes for users has been developed by Cleary and Freeman (2006) in Australia. They produced self-directed learning programme, designed to enable nurses to learn within the constraints on their time through work and personal commitments. Self-directed learning is based on adult education principles, with the learner taking responsibility for their learning whilst pursuing objectives based on their needs and those of the organisation. One way of demonstrating the knowledge and skills acquired is through a learning portfolio, in which the learner documents their achievements and accomplishments with the specific focus of continuing professional development and self-growth. Such approaches to learning have been found to be very effective in developing clinical leadership skills.

The aims of the programme included increasing nurses' understanding of carer issues and needs, fostering the development and evaluation of strategies to enhance carer involvement, encouraging the pursuit of knowledge and experience in the area of carer participation and project development (Cleary & Freeman 2006). Specially designed workbooks, entitled 'Improving carer involvement: A clinical leadership approach', was developed and included exercises on carers' concerns and ways to enhance partnerships, communicating and collaborating with carers, understanding barriers to care involvement and ways of overcoming them, and how to obtain appropriate support for carers.

Although the evaluation of the initial programme was completed by only a small number of nurses, there were strong indications that the approach had a positive impact on nurses' understanding of carers' needs and related issues and their ability to develop clinical practice around carer involvement.

However, the authors point out the time intensive nature of running the programme and supporting the nurses to develop their portfolios. Further research would be required to explore the potential benefits of self-directed learning and its impact on practice.

#### **j) Carer involvement in education and training**

Over the last 25 years there has been a shift in healthcare policies that has seen greater involvement of patients or service users, and to some extent carers, in the design, delivery and evaluation of health and social care provision (Simpson & House 2002, 2003). Over a similar period there have been calls for and examples of greater involvement of users and carers in designing and delivering training programmes for health and social care professionals (Repper & Breeze 2004). This has included doctors (GMC 1993), social workers (Beresford 1994, Levin 2004, Molyneux & Irvine 2004), nurses (ENB 1996), psychologists (Harper et al 2003, Curle & Mitchell 2004) and mental health nurses (SCMH 1999, Simpson 1999, DH 2006). In 2005, it became mandatory for psychiatric trainees to receive training directly from people who experience mental health problems and their carers (Fadden et al 2005).

Reasons for involving consumers in education include the demands from users and carers themselves; to increase the power, control and influence of people on the receiving end of services; to challenge entrenched perceptions and attitudes of healthcare and education professionals; to challenge the hierarchies and paternalism that create barriers in services; and to improve clinical standards and service delivery, making them more responsive to users and carers (Lathlean et al 2006). Users and carers often acquire a knowledge base of immediate relevance to practice that can be different from that being taught to professionals (Ahuja & Williams 2005). Involvement may also empower those individuals that become involved and aid their well-being, self-confidence and self-worth (Simpson et al in press).

Personal testimony training by people with direct experience of caring can provide a passionate, moving and persuasive account of the needs of carers and why they need to be considered and seen as potential collaborators by professional workers (Butterworth & Livingston 1999, Turner et al 2000). As well as face-to face training and consultation, carer trainers have used methods such as poetry, books and videos to get across their message (Wakefield 2007) and published on the tensions that can arise when carers challenge the expertise of professional staff or advocate for innovative ways of working (Clarke 2005a, 2005b, 2006).

Such personal accounts are remarkable and memorable for the power of their testimony and are frequently cited as the most profound, valuable and insightful parts of training received (Forrest et al 2004). But, increasingly, carer trainers are being asked to combine accounts of their personal experiences with input on research, policy and practice issues around carers; to combine awareness-raising with knowledge, skills and values developed to meet specific criteria and practice development objectives (Lynn Shore,

personal communication). Nonetheless, carers' accounts are an important part of staff training and involvement of carers and families should be a core component of any training programme.

Alongside such approaches, a range of methods can be employed to enable the direct and indirect involvement of users and carers and ensure their input into curriculum and module development, teaching, student recruitment, student assessment, educational audit and research (Le Var 2002, Masters et al 2002, Levin 2004, Tew et al 2004, Simpson 2006). But there are also numerous difficulties and challenges that need to be considered and engaged with to make involvement meaningful and effective (Manthorpe 2000, Tew et al 2004, Ahuja & Williams 2005, Simpson 2006, Hayward & Harding 2006).

Joint strategies on increasing user and carer involvement have been developed between education and service providers (Trent SHA 2005), guidelines on involving users and carers produced (Tew et al 2004) and tools designed to audit developments in higher education and inform the commissioning education programmes (NCMH 2003, Tew et al 2004). These include adaptations of Goss and Millar's (1995) 'ladder of participation', which identifies five levels of involvement includes five from 'no involvement' through increasing levels of involvement to full 'partnership' (also used in our survey - see Appendix 7).

However, when Repper & Breeze (2004) reviewed the literature on user and carer involvement in education and training they found only two studies that evaluated the involvement of carers and only one of those concerned mental health. Soliman and Butterworth (1998) described the involvement of a group of carers in the professional education of social workers, nurses and doctors in dementia care. Livingston & Cooper (2004) confirm the lack of carer involvement, whilst summarising some of the benefits and challenges in developing consumer involvement in training.

A review of education and training provision for the mental health workforce highlighted the continuing lack of focus on carers in post-qualifying training. Brooker et al (2002) obtained detailed information on 292 of 313 (93%) training courses accredited by universities for qualified health professionals targeted for work with people with serious mental illness. They found large variation across regions but training in PSI made up a third (34%) of all relevant training programmes, although 'risk management' is projected to become the most commonly provided training. In general, attendance on post-qualifying training courses amongst mental health staff is very low with even fewer attending interprofessional training. High attendance on PSI courses in the West Midlands reflected the success of the Meriden programme.

In a later study, 15 out of 28 (53.5%) NHS Workforce Development Confederations (WDCs) in England took part in a project that rated 29 educational programmes including 6 pre-qualifying programmes (mental health nursing and social work), 6 new graduate mental health worker programmes and a range of 17 post-qualifying programmes including 3 PSI training and one specific course on carers (Brooker & Curran 2006). Whilst

finding that overall the majority of programmes involved service users in a meaningful way, courses were far less likely to engage with carers, especially at pre-registration level. However, the majority of education and training programmes in PSI and family interventions outlined earlier, including the Thorn, Meriden and Somerset programmes, all make a point of involving carers and family members in the design and delivery of that training.

Cleary et al (2006) propose that strategies aimed at maximise understanding of the carer's role and the changes in practice required, should provide for greater use of carer consultants working alongside practitioners, educators and trainers. They suggest that carers' involvement in education should start at the under-graduate or pre-registration level so that health care providers are made aware, from the earliest stage, that the caring role is recognised, valued and integrated with other service components. Early involvement also helps shift staff attitudes and minimises the possibility of overlooking the role of the carer. However, Cleary et al (2006) also point out the importance of not further over-burdening carers and sensitive, creative ways of working with carers, carer consultants and carers' representatives must be found.

Carers may be reluctant to participate if previous experiences have proved fruitless (Lammers & Happell 2004) and academic and clinical staff may be resistant or cynical regarding carer involvement unless issues of tokenism, representativeness and work overload are addressed. Such issues and those around remuneration of consumer participants have been well articulated elsewhere (Crawford & Davies 1998, Tew et al 2004, Cleary et al 2006, Simpson 2006), so do not need to be rehearsed here, but need to be part of a wider organisational strategy addressing user and carer involvement.

**RESULTS: FOCUS GROUP**

Over 100 people responded to the advertisement, expressing an interest in taking part in a focus group. Organising dates and times that were convenient for sufficient numbers of people proved difficult, particularly as we had less than three months in which to fit them. Several attempts were made to organise focus groups in parts of the north of England and in the Midlands, some of which involved BME carers' groups. Unfortunately, most organisations already had other speakers or topics lined up and were unable to accommodate us within the timeframe. Other people could not attend any of the dates on offer in London or would not attend because the amount of remuneration on offer was insufficient. Others agreed to attend but failed to turn up on the day. Unfortunately, there were few responses from mental health staff and extending the advertisement to wider staff networks were equally unproductive.

Despite these difficulties, seven extremely productive focus groups took place, involving a total of 47 people (Table 12). It did not seem appropriate to request demographic details of participants, but there was a mix of gender and ages and people from various minority ethnic communities. Three completed postal questionnaires were also returned (one from a carer, one from a carer/CSW, and one from a carer/CSW on behalf of a support group of 20 carers and two CSWs).

Although the groups were organised around specific roles, e.g. carer, or carer support worker, in reality many participants crossed such boundaries with many carer support workers or NHS managers being carers themselves, and both carers and service users having experience 'both sides of the fence'.

<b>TABLE 12: FOCUS GROUP PARTICIPANTS</b>		
<b>Participants</b>	<b>Location</b>	<b>Number</b>
Carers	Reading	8
Carers	London	8
Carers	London	4
Carer Support Workers	Aylesbury	7
Carer Support Workers	London	7
Service Users	London	8
NHS Carers' Leads/Managers	London	6
<b>Total focus group participants</b>		<b>47</b>
Postal respondents		3
<b>Total</b>		<b>50</b>

Notes from the seven focus groups and the three written responses were read and coded to identify common themes and extracts that illustrated those themes, which were then collated in a tabulated format. These themes and

extracts were then read and re-read whereby it was recognised that the views expressed within the different groups built on and complemented one another. No group produced topics or issues out of step with the others and some views expressed by CSWs and Carer's Leads provided a deeper understanding or explanation of issues raised by carers.

### **Participants' Experiences: Recognition of families and the carer's role**

Many participants spoke of their desire that staff recognise the importance of family ties, of the need to see the service user in the context of their family and friends and to show understanding and empathy.

Try to see mental health carers and service users as part of a whole and normal family scene – not as somehow outside everyday society or experience – all of us suffer the same human condition in varying degrees and are *always* worthy of the respect and treatment we would expect for ourselves. (Carer/CSW)

Carers also wanted their own role and expertise as carers in providing 'continuity of care' to be recognised, valued and appreciated and for there to be a holistic appreciation of care givers and consideration of their "quality of life" and their "life outside of caring".

Caring and treatment is seen purely from a medical viewpoint and neither the service user or his carers are seen holistically. (Carer/CSW)

How many members of the mental health team would want to work out there on their own with no team around them. You can go home at five o'clock. (CSW)

At times, staff could be quite belittling and fail to recognise the true level of the carer's involvement and the level of impact on their lives.

I don't think staff have any idea what it is like [for carers]. I would like staff to acknowledge that it is stressful... staff's response could have been more human, more understanding. (Carer)

Many staff do not recognise the distress caused in a family by mental illness. (CSW)

Some CSWs mentioned that there tended to be myths around working with families, including not working with families unless you were providing structured family therapy. It was suggested that even amongst people trained in psycho-social interventions there were different views held, and some understood that working with families was a part of everyone's role while others did not.

### **Participants' Experiences: Identifying and recording the carer**

The terminology of 'carer' could make the identification of carers more difficult, with the term 'carer' rarely used or recognised and family members not realising that they could be classed as a 'carer'. A Carers' Leads said that most carers when asked, focus upon the quality of the services the person they care for receives and find it hard to think about themselves. Some carers

spoke of feeling frightened of seeking help and wanted staff to recognise that they might need encouragement and support in doing so.

Frightened to get help... another avenue where you don't know what's at the end.  
(Carer)

It is also difficult when there are many carers in a family and there are challenges in identifying different and multiple roles. Many carers, especially those in their 50s or 60s, often had several caring roles, with ageing parents as well as teenage or adult offspring requiring their help.

Yet it is important to know how to identify a carer and to get carers to recognise the impact their caring role has upon them. And once identified, it is crucial that information on carers is recorded and staff need to think how that information can be retrieved. It needs to be built into care planning systems in an immediately visible place.

For some people, including in some Black and minority ethnic (BME) families, being described as a carer was actually insulting, as they saw themselves primarily as a mother/father/brother/sister doing what any one would do for a family member in need. It was suggested that work should be done with staff on the type of vocabulary used.

Call it supporting someone rather than caring... More in tune with the way they think of themselves. (CSW)

Families don't identify with the term carer... [they say] I am a husband, mother....  
(CSW)

It's hard for anyone with a mental illness to like the term carer. (CSW)

Identifying the carer was particularly difficult when children or young people were caring for mentally ill relatives, often parents. Staff tended to think of carers as adults and made assumptions which meant that young carers were frequently overlooked. Identifying a child as a carer may provoke contradictory reactions.

Young carers may be happy to be identified as carers but their parent may not... they feel it is a criticism of them. (CSW)

Once identified as a young carer, children need information as well. Too often young carers are sidelined until there is another crisis. Staff frequently underestimate the amount of support the child provides.

You need them in the loop all the way not just at crisis point. (CSW)

Young carers need reassurance that it's not their fault; it's not likely to happen to them; what they can do to help; and what is going to happen next. Equally, it is important to include the child in developing care plans and contingency plans, so that they understand and can be reassured.

## **Participants' Experiences: Complexities of family work**

Carers' Leads recognised that for many staff there was an anxiety and resistance about working with families and carers because of the perceived difficulties, such as the complex psychological processes in families and how to manage these. Staff often don't want to work with carers identified as 'emotional' or 'high expressed emotion' and required training in how to work with carers experiencing extreme anger and guilt.

A 20 minute interview went into 90 minutes psychotherapeutic interaction. (Carers' Lead)

CSWs agreed. Often, staff do not want to or do not feel able to deal with the relationships in the family, as they can be "difficult, messy... not my business. Not what I took the job for". Older carers often had fears about what would happen if and when they die and too often staff were not prepared to talk with them about this, perhaps fearful or uncomfortable about discussing such sensitive issues. But staff could put carers' minds at rest by helping them make contingency plans or develop advanced directives. CSWs and Carers' Leads thought that most staff had all the skills to support carers – it is about gaining the confidence and being provided with support themselves.

They see carers as a completely new animal, [but] you've got people skills – just transfer them. (CSW)

This relates to the amount of support and supervision they [staff] get. (Carers' Lead)

Current training doesn't deal with these issues, it encourages staff to filter carers and families out and by directing people straight to a carers' centre or carer support worker these complexities are reduced or avoided.

A number of CSWs mentioned that carers required help in negotiating the provision of care for their relative, particularly if services crossed health and social care boundaries or if the person had a dual diagnosis of learning disabilities of substance misuse and mental, illness. In such cases care was often not well co-ordinated and "they spend all of their time shuttling back and forth".

No-one will take ownership if there is a dual diagnosis. (CSW)

CSWs also remarked that carers often found it difficult to obtain help when they wanted to reduce the level of their caring role. Carers are often asked if they want to continue caring but as soon as they say they need help, this is ignored. But if service users express a desire for a carer to reduce their role this tends to be listened to and acted on. Carers learn that the only way to reduce care is to say that they are stopping altogether, then after services are put in place "they get back on board" (CSW).

Some things they [staff] seem to hear very loudly and others not at all. (CSW)

Some CSWs mentioned that some service users abused carers and that people's tolerance of undesirable behaviour tends to be higher when mental health problems are involved. Staff tend to accept that carers will be subject to abuse, but we "shouldn't be accepting it for carers when we wouldn't accept it for ourselves or others" (CSW) and dealing with such challenging issues needs to be included.

Carer-user relationships may change as an individual recovers and in such a situation the carer sometimes finds the change in their role and relationship difficult. There is also a need to provide transitional support to carers when their caring role *is* reduced at the request of the patient. Staff require the skills to help people negotiate these transitional stages as there is an emotional impact on the family. They also need to consider appropriate timing for ending the support of carers as there is a perceived tendency to discharge carers as quickly as possible, described by one CSW as a "hand washing policy".

### **Participants' Experiences: Working in partnership?**

Issues around communication predominated for carers. Not being heard or listened to were common complaints, with few staff seeming to involve families and carers or working with them as 'part of the team'. Several carers spoke of trying to provide helpful information and even of asking staff if they could "work alongside" them in caring for their relative only to be patronised and ignored.

Doctors just stared at me and didn't take any notes. (Carer)

This same carer described feeling very angry when, after his son had assaulted him several times, the psychiatrist said it was "not unpredictable your son would assault you", while he had never been warned of such a possibility. Another carer wrote to her son's psychiatrist outlining examples of her son's potentially dangerous behaviour but did not receive a response. Care Support Workers (CSWs) spoke of carers not getting return phone calls when they tried to speak with mental health staff.

One carer spoke of her frustration at being denied a face-to face meeting with their son's psychiatrist, despite the fact that just such a right was espoused in the carers' booklet they were given. Another, whose son was suspected of developing psychosis whilst at university, was astonished that the medical practice did not request any historical or background information about family mental illness. Attempts to consult with staff sometimes led to derogatory statements being made about them. One psychiatrist wrote that a mother was "anti-doctors", which she felt was grossly inaccurate and unfair.

Others spoke of difficulties with their GPs, including when they had concerns about potential side-effects of the medication their son was on. Carers felt they were "treated with arrogance", with one person saying the GP was "patronising... I could have smacked him". Others described times where their awareness of a looming relapse or other concerns were not taken seriously or simply dismissed.

The CSWs agreed that a key challenge was getting staff to take a more responsive stance when carers express concerns about a relative's deteriorating health. Some suggested there was an element of 'competition' between carers and staff, as carers were often accurate at predicting relapses as they know the service user best. This tends to expose staff limitations, so that too often carers were not listened to "until it hits a crisis".

Sometimes professionals do not listen, especially when carers note that situations are getting worse for the user. They try to ignore the bad news for too long. (CSW)

Other carers spoke of poor, dismissive or even rude attitudes shown by various staff. One participant was told that she "wanted her son ill". Highly judgemental and blaming attitudes towards families and carers still seemed to exist, with medical staff most often cited as at fault in this regard.

My relationship with my son was described as 'almost incestuous'... very hurtful.  
(Carer)

CSWs spoke of carers feeling intimidated by staff if they made a complaint about the care their family member was receiving and often feared that they would make things worse for the vulnerable person they care for. Participants argued strongly that staff needed to recognise that carers are an asset and potentially part of the team providing care and support to the service user. At present they are too often seen as "other".

Staff need to recognise the expertise of carers and the importance of their involvement in care plans and discharge plans. They should be respected for their contribution. (CSW).

This viewpoint was amplified by Carers' Leads who recognised that by helping the carer, staff would often reduce their own workload with the service user. Instead, they tended to see the carer as an additional workload, rather than a help. There was also need for greater understanding of the financial savings obtained through greater support of families and carers.

It was recognised by almost everyone that most staff are faced with enormous pressures on work load and insufficient time. As a result, building relationships with carers and considering and responding to their needs was not seen as a priority. The CSWs were happy to work alongside other staff, acting as mediators to help them establish relationships, but felt that overall there needed to be a change of culture in mental health services so that staff recognised the benefits and advantages of working with families and carers.

### **Participants' Experiences: Obtaining information**

Being provided with useful information about the service user's condition and what the services were trying to do was identified as important. Frequently, carers were not provided with information, but when they were it was greatly appreciated.

They told us what they did know and what they didn't... that was helpful. (Carer)

Often, the relative or friend with the illness is unable rather than unwilling to provide carers with meaningful information themselves. At such times, it is greatly appreciated by families when mental health staff take the time to explain what is happening. Some carers recognised that there had been changes and that staff were beginning to provide more information and sometimes negotiating care. One carer spoke warmly of her son's psychiatrist who was happy to communicate with the carer by email. Another spoke of how her life had changed when a new GP took over and immediately engaged with the family.

The CPN now talks to us, didn't use to... when he first came to see our son, the CPN just said hello and goodbye and no other information. (Carer)

The first 10 years my GP didn't understand... but our current GP is really brilliant... she's trying everything. (Carer)

One carer discussed the sectioning of her daughter and how the staff had failed to talk to her throughout the sectioning process, despite the episode being incredibly frightening for both her and her daughter. Another said that she had been asked to sign sectioning papers without being told about the meaning and powers of a section under the Mental Health Act. One mother felt she had been tricked by a social worker who spoke with her in the kitchen whilst her son was sectioned and forcibly removed in another room.

A big issue concerned the lack of consistency – both consistency in the information provided to carers and users and consistency in approach between different staff and different professions. Some carers felt that staff were insufficiently aware of relevant legislation, policies and guidelines, which seemed to contribute to a lack of consistency. CSWs mentioned that often there was little consistency between different professions, with social workers and CPNs for example, providing different viewpoints and approaches to providing services and liaising with agencies. On inpatient wards, too often staff did not appear to know anything when asked questions and carers wondered why they had not had a hand over or read something about the patient. There were also concerns expressed about the apparent failure of staff to communicate with each other. Doctors did not appear to pass information to one another.

No continuity of staff approach – shouldn't they read a report? (Carer)

Staff consistency was not helped by frequent staff changes and use of agency staff.

Every time we go we someone different. (Carer)

CSWs said that it was difficult to provide meaningful support to families if there was not continuity of staff; the situation is maintained, but no real therapeutic relationship takes place. Constantly changing staff makes people very unhappy and carers "lose faith in the staff and the system." Being given a named person to contact or identifying someone that carers can liaise with would help overcome these difficulties.

Sudden, unannounced changes in service planning or delivery could also have a big impact on the care and support being provided to a relative and have a knock-on effect for families, but this was rarely discussed with carers. Common-place practices such as sending appointment letters to users only when the user has indicated that they wish the carer to accompany them, made it less likely that the carer would know the details and maintain their involvement.

Understand the 'tightrope' that carers are treading between communication with the services and their 'cared-for'. (Carer)

Staff need to be able to sign post and inform carers about carer support services. Some carers spoke positively about carers' packs they had been given with information about conditions, medications, glossary of terminology, ward/service information, carer support services etc.

I got information from the ward about a carers group on the notice board. (Carer)

They [staff] need a good understanding of what's available, mental health and otherwise. They would know this if they came to a carers' training session. (Carers' Leads)

### **Participants' Experiences: Attitudes and communication skills**

Often, simple basic communication skills and common courtesies were lacking – people failing to say who they are on the telephone, or regularly walking past family members on acute wards and not even saying hello or passing the time of day. Some had even been asked why they kept turning up on the ward – in one case even though their son could not speak English.

They need to understand how upsetting it is first time on an inpatient ward. (Carer)

CSWs also spoke of poor attitudes amongst many ward staff who often appeared to ignore carers and rarely proactively offered information or support.

They don't speak to carers and CSWs... feel as though you shouldn't be there. (CSW)

They [staff] sit there in silence and you have to go and engage them to get information. (CSW)

But sometimes, it was also necessary for staff to help families understand "that there is a problem", that the family member has a mental illness. At times this can be difficult, not least because of the level of stigma attached to mental illness. The CSWs saw their role as central to this, providing support to someone through all the emotions, "practicalities and emotionality... because things will never be the same as they have before" (CSW).

Sometimes carers were provided with copies of CPA care plans and on occasions CPNs had even sat down and explained the care plan to them. However, care plans were often hand written and sometimes illegible. Explanations provided verbally were quickly forgotten. Carers suggested that care plans should be typed clearly. One carer described how having "information written down about what had been agreed between the GP and the psychiatrist was very helpful".

### **Participants' Experiences: Confidentiality**

Issues around sharing information and confidentiality were a common theme in the focus groups. Examples included a mother who called for an ambulance after her daughter came and told her in the middle of the night that she had taken an overdose. When later she rang the A&E department, the staff would not even tell her if her daughter was still there or had been admitted to hospital.

Need definite guidelines on confidentiality. (Carer)

There is a basic package of information needed on the law and confidentiality. It is ingrained wrongly in adult services, probably at all levels. (Carer)

CSWs spoke of a overall lack of clarity and frequent cases where the user has been admitted but the family not told and the family have gone out looking for their relative.

When you don't tell carers basic information they assume the worst, which creates more anxiety and makes you seem evasive. (CSW)

It can be difficult if the worker is trying to build a trusting relationship with a carer to then say that the user doesn't want them to know something. And it works both ways, where the carers want and appreciate confidentiality where they do not want the user-relative to know some things they are saying. Staff need training and help to learning how to manage conflicts between carers and service users.

Reflecting the work by Pinfold et al (2002), CSWs stressed that there are differences between personal, sensitive and general information and that "staff could unpick things better". Additionally, service users can make a decision about the sharing of information at one point in time but this is often not addressed again and "lasts forever".

There is not enough negotiating or revisiting. (CSW)

In contrast, we had one report of very good relations in a local Child and Adolescent (CAMHS) unit, with family carers given the opportunity to speak with medical staff in confidence and being offered helpful advice on dealing with particular situations. But, it was suggested that problems can be created around confidentiality when young people are transferred from the care of CAMHS to adult services, if things are not communicated accurately and carefully. Staff need to understand issues around data protection, mental

competence and the so-called Fraser Guidelines on providing advice and healthcare to young people (NHS Scotland 2007).

One Carers' Lead suggested that confidentiality was often used as an excuse, or "a cop-out". The issue of confidentiality was contrasted for physical and mental health, with the suggestion that less is revealed in a mental health context. It needed to be recognised that there are different levels of confidentiality and different rules and procedures needed to be adopted.

### **Participants' Experiences: Support**

Experiences of being provided with or accessing support varied. Some spoke of mental health staff being incredibly supportive:

The CPN, psychiatrist, psychologist are all very supportive. (Carer)

However, far more common were stories of struggling alone for as long as 20 years with little or no support offered and no information provided about support networks that might have been available. People described years of battling to work out how best to cope with incredibly demanding behaviours and situations, of being frightened and even facing physical and mental abuse.

I dealt with this nightmare single handedly for three years... had to do my own research... (Carer)

One mother was told by a member of staff that it was her fault that she had received no help from services, despite the fact that she had asked for help on many occasions.

Frequently, carers spoke of their surprise and relief when, often through their own efforts, they became aware of a local carers' group or organisation. Some felt the support offered to people providing support for people with physical ailments was easier to access. Many said that not only had they been unaware of support groups for carers, but that even when they found out about them they did not immediately think they would be of much relevance or use to them. However, frequently, attendance at carer support centres and groups had been a "life saver", providing a "mixture of information and relaxation", "skills to help in their caring role" and taking away "the feeling of isolation". Some carers had attended educational courses for carers, provided at the carers' centres, and these had improved things enormously.

### **Participants' Experiences: Assessments of Carers' Needs**

Discussion by carers and CSWs of carers' assessments provided a wealth of evidence to suggest that far too often these assessments were not taking place, or that they were being undertaken poorly, or that the needs identified were frequently not addressed. The vast majority of assessments led to no provision of services or changes in the carer's situation or even feedback to the carer. For carers, there is "huge frustration when they are offered something and nothing comes of it" (CSW).

I discussed respite with the social worker but no action. (Carer)

Page after page of stuff... vanished into a black hole. (Carer)

Never heard about it again. (Carer)

No point doing them if you are not going to follow them up. (Carer)

A small number had received input following an assessment, including provision of respite care, and this was appreciated. The importance of carers' assessments was recognised, with one carer describing them as "the gatekeepers" to services. Carers' Leads and CSWs said there was a need for many staff to recognise their own responsibilities in facilitating support for carers. At one induction training where the CSW gave a presentation about carers and carers' assessments, she said people "looked surprised" that this was part of their role.

One manager thought she didn't need to do [assessments]; that it was not in her remit. (Carers' Lead)

Too often though, it appeared that carers' assessments were seen largely as a 'paper exercise' and received cursory attention as a legal and policy requirement, with little serious attention to delivery. Lots of care co-ordinators send out carers' assessment in the post! Paradoxically, it was suggested by CSWs that those staff that do complete carers' assessments learn a lot and find it useful.

Some Carers' Leads said that staff avoided completing carers' assessments because they fear that it will open up all this painful history which then takes a long time to deal with. Others were aware of the gaps in services and the limits on what could be offered. The CSWs stressed that it is about being honest and explaining that they can not guarantee that support or other services can be provided. Too often staff avoid telling the truth but carers appreciate an honest explanation of the situation and of the limitations, even if those are disappointing.

Some CSWs suggested that the terminology of carer's assessment put many carers off and that people assume they are going to be judged for their 'caring'; that it is an assessment of how well they are caring for the person.

You need to tell them it's an assessment of their needs not them. (CSW)

However, some said that 'in reality' carers *are* judged and they hear many staff dismissively label family members as "high EE [expressed emotion] or over involved", suggested that the use of such terminology from the psychosocial interventions literature can be seen as derogatory labelling and perhaps needs to be better explained or used more sensitively.

There was some suggestion that given the complexity and time involved, it would better if there was one point of contact, such as a CSW, who would listen to the carer's experience and record this on the Assessments of Carers

Needs, in order to help “reduce the carer’s distress and save time for everyone concerned”. Others argued that when assessments were left solely in the hands of the CSWs, it tended to maintain the tendency of mainstream mental health staff to ignore carers and remain unaware of their situation and needs. Most preferred the encouragement of joint working on assessments.

Staff need to be trained and encouraged to routinely offer carers’ assessments as part of integrated CPA care planning and offer regular reviews. But there also needs to be an awareness of ‘hidden carers’, where the relative with mental illness is maintained by their GP and the carers tend not to be identified, not routinely offered assessments of their needs, or are assessed using the inappropriate type of assessment form, which excludes ‘functional mental health’.

### **Participants’ Experiences: Culture, ethnicity and gender**

There was a general agreement amongst carers that many of the issues facing carers were faced by Black and minority ethnic (BME) carers as well, but in addition they faced particular issues or difficulties that needed consideration. There was a common concern that BME carers were even more likely to be stigmatised and excluded from society.

There were a number of descriptions of certain assumptions being made about the ability, preparedness or willingness of members of BME communities to provide care for a family member with mental illness. These were often based on stereotyped beliefs about particular communities or gender roles within those communities. Some BME carers felt they could not win – it was either assumed that they would provide all the care for their family member or they were seen as ‘scroungers’ for asking for financial or practical support. Some carers felt they had experienced explicit and implicit racism from staff within mental health services, with a lack of consideration and respect commonplace.

When Asian families ask for help they are viewed as taking too much, because it is assumed they have the support of a large family. Some would say they are coning the system – bloody cheek! (Carer)

A Somali woman and her daughter provided particularly disturbing testimony about the callous way they had been treated and the lack of help they had been provided despite trying to care for a confused, psychotic man who was doubly incontinent. Both this family and an Iranian family described how, when their relative was admitted to a psychiatric hospital, they were perceived as “over involved”. The Iranian family had said, “There is a Western tradition that caring ends at the door of the hospital.”

Others spoke of traumatic experiences where inadequate translation services had not considered important cultural, political and language issues based on regional differences and tensions in their home country, which caused huge distress and communication failures.

CSWs who worked with a lot of carers from BME communities said there is a need for staff to be aware of and sensitive to different cultural belief systems that impact on understandings of mental illness.

...understand and respect people's religious beliefs... different beliefs, understanding of mental illness, rather than imposing a model. (CSW)

The CSWs recognised many of the difficulties faced by BME carers and in many instances spoke with even greater passion about the issue. Many BME families have problems articulating their needs and in the Black African Caribbean community, they suggested, it is even more difficult to get the role of the carer recognised. Many wouldn't identify with the role of carer and wouldn't ask for help from outside. Issues around services for carers that do not speak English are a particular issue, with many such carers unaware they have the right to an assessment of their needs.

70% carers don't speak English... and often don't get an interpreter. (CSW)

Illustrating the complexity of the situation, some CSWs said that whilst staff shouldn't pre-judge the situation, it was important they had some awareness of potential issues, for example in more male dominated cultures a husband who interprets for his wife may re-interpret her account. In contrast, a Carers' Lead said that there also assumptions that in Asian families the daughters would be "dumped with the role".

The CSWs also mentioned that mental health staff often made presumptions on the basis of gender, frequently just assuming the woman in the house would act as a carer. One CSW quoted a psychiatrist who said, in front of the CSW to a woman whose husband was seriously ill, "may I remind you of your wedding vows". A Carers' Lead said that, in reality, most carers *are* women who mostly care for men. The mental health system is a mainly male environment so trying to stand up and be empowered is very difficult. Complaints are more likely to come from male carers "who take the system on".

### **Recommendations for training: Communication skills & information**

Participants' views on the communication skills and types of information and support that staff need to be able to provide carers with are summarised in Table 13.

**TABLE 13: RECOMMENDATIONS FOR STAFF TRAINING FROM THE FOCUS GROUPS**

<b>Recommendation</b>	<b>Examples</b>
Consider language and vocabulary used	<p>Terminology can be confusing or meaningless, e.g. crisis, associates, locum, absconding, CPA</p> <p>Carers overhear staff and students using stigmatising language, e.g. 'mad house'</p>
Consider different needs of people caring for someone admitted for first time, someone in crisis, an experienced carer, etc., and check that they have understood.	<p>"Carers often say 'I wish they had told me this and that' but often they don't cope with receiving information and retaining it at times of stress." (CSW)</p> <p>"Spend some time with them and make sure they understand." (Service User).</p> <p>"Too often carers are faced with 'information overload' early on in the caring process, but then receive little later on." (Carers' Lead)</p> <p>"Consistency of information between what is told to user and carer." (User)</p>
Use a variety of methods to provide information.	<p>Carers suggested face-to-face verbal (and repeated); written – leaflets, checklists, booklets, etc; online/websites/TV; through carer organisations and groups.</p> <p>Local 'carers' information packs that includes both general and specific information detailing local services</p>
Consider the nature of the language used when presenting information.	<p>Carers say many staff need to be taught how to give information, the way and style in which it is presented, the body language that accompanies it, etc (e.g. not looking fed-up or impatient).</p> <p>"Not about doing unto but informing people... then carers can make their own choices." (CSW)</p>

<b>TABLE 13: RECOMMENDATIONS FOR STAFF TRAINING FROM THE FOCUS GROUPS (CONTINUED)</b>	
<b>Recommendation</b>	<b>Examples</b>
Families and carers require different types of information.	<p>Basic information on how the services run, who to contact locally for help/support etc.</p> <p>Accessible information about causes, genetics, symptoms and course of mental illnesses.</p> <p>Best treatments and approaches for users, including medical, psychological, psycho-social, recovery, relapse prevention, etc.</p> <p>Family interventions and what the family can do to help: "If there is the potential for bizarre or risky behaviour on the part of the user, then the relative should be informed beforehand." (User)</p> <p>Widening social circle for users, including work and productive activities.</p> <p>Promoting good physical and mental health for carers.</p> <p>Supports available for carers.</p> <p>Carers' legal rights (e.g. to an assessment, nearest relative, etc) and carers' policies.</p>
Empathy and understanding	<p>"Understanding the carer's journey - from not knowing there's a problem, to identifying and labelling the problem, to acceptance, which is often associated with depression." (CSW)</p> <p>"Understanding that the carer has a great deal of personal interest/ involvement invested in their caring role, e.g. ... <i>raison d'être</i>; co-dependency, loss of career and prospects." (Carer)</p> <p>"Some carers are keen to become involved, some are terrified." (CSW)</p>
Good manners	<p>"Common courtesy goes a very long way." (CSW)</p>

<b>TABLE 13: RECOMMENDATIONS FOR STAFF TRAINING FROM THE FOCUS GROUPS (CONTINUED)</b>	
<b>Recommendation</b>	<b>Examples</b>
Listening skills and receptive communication	<p>“Really listening to what the carer is saying.” (CSW)</p> <p>“Stop trying to find solutions. Just listen.” (CSW)</p> <p>“Client focused listening, i.e. open to the carer’s story/perspective to give a rounded picture of domestic experiences.” (Carer/CSW)</p> <p>“[The CSW] stays quiet and just lets me talk... doesn’t dismiss my point of view.” (Carer)</p>
Sensitive sharing of information and confidentiality	<p>“Certain things that the user doesn’t want the carer to know.” (CSW)</p> <p>“Being careful as to how conversations with carers/parents are reported back to the service user, e.g. not ‘your mum says you have been behaving in a strange way’ but perhaps ‘your mum has been a bit worried about you. Do you know what she is worried about?’” (Carer)</p> <p>“How to manage conflicts between carers and service users.” (CSW)</p>
Positive suggestions	<p>“To realise that if a suggestion is made in a positive way, it is more likely to be accepted, e.g. ‘We usually find it helpful for parents/carers to join in the CPA meeting/outpatient appointment... Are you happy for your parents to come along?’” (Carer)</p>
Not undermining carers	<p>“If it seems that the carer is being over-protective or unhelpful in some way, discuss this with them alone and give the carer a chance to explain why they have done something – perhaps there is a reason the professionals do not know about. It is very easy to upset a relationship between a user and a carer.” (Carer)</p>

<b>TABLE 13: RECOMMENDATIONS FOR STAFF TRAINING FROM THE FOCUS GROUPS (CONTINUED)</b>	
<b>Recommendation</b>	<b>Examples</b>
Non-blaming	<p>“There is a culture of blaming the family.” (CSW)</p> <p>“An ability to make carers feel relaxed and not continually judged.” (Carer)</p> <p>“Sympathetic.” (User)</p>
Honesty	<p>“They would like nurses to admit that they don’t know the answer”. (User)</p> <p>“Keep promises”. (User)</p>
Feedback and updates	<p>“Feedback to carers the progress that users are making (e.g. reducing medication) to help them come to terms with the idea of the person recovering.” (User)</p> <p>“Regularly provide feedback and information”.(User)</p> <p>“Carers need to know that staff will monitor the situation; that relatives can seek their advice and support, go away and then return in the future to discuss progress, issues or problems.” (User)</p>
Partnership working	<p>“Learn about working with someone genuinely. Partnership is not a glib word.” (Carers’ Lead)</p> <p>“Lots of workers have got empathy. There’s a difference between empathy and working well with carers.” (Carers Lead)</p> <p>“How to work in group situations with other professionals.” (CSW)</p>
Coping Skills	<p>“Staff should be able to help carers discuss practical problems and develop their coping skills.” (CSWs)</p> <p>“How to deal with certain situations and behaviours. How to get help if the service user doesn’t want to.” (Carer)</p> <p>“Advice on how to talk to someone who’s mentally ill – “share a bit of that knowledge” (Carer).</p>

## **Recommendations for training: Timing and level of training**

In all focus groups there was a strongly held belief that education and training around working with families and carers needed to be included right from the very beginning of people's professional training, pre-registration. Then, the concept of working in partnership with carers needs to be threaded throughout the whole of staff inductions and ongoing professional development programmes, with an appreciation of carers' 'careers' and how their role and needs for information, support and so on, changes and develops over the years.

From year one. (Carer)

Put a face to the word carer. (Carer)

If you don't say it early enough on, it doesn't become embedded. (CSW)

Should be all the way through [their training]. (Carer)

Once an idea has been formulated, it is difficult to change it. It's important to create a mindset from the beginning. (User)

Staff have been told that service users and the "core focus" of their work, so there needs to be a recognition that service provision had to shift from treating people as separate individuals to recognising that they existed as part of a family and social network.

Not treating an individual... treating the family. (Carer)

Carers training should be pushed more; it's obviously not being pushed that much. (Carers' Lead).

Participants agreed that working with carers should be integral to initial education and training, to ensure that staff didn't think they could just choose not to do it. It would also mean that staff who got the right message at the beginning would take that message with them as they progressed through their career and the mental health system. But staff that have been in post for long periods of time should not be forgotten.

There is a big need to change attitudes of staff who have been in post for a long time and will probably be very resistant to even thinking about any of these ideas. (Carer)

Working with carers should be embedded in existing programmes and courses and not just provided as a separate module. There should be carers' components in every aspect of training. Carers' Leads wanted to see interprofessional training for all health and social care staff, doing it together. CSWs said that staff require updates once a year so that they are reminded of their duties and responsibilities and can catch up with what the CSWs and other carer support services can offer.

Many CSWs had organised and provided training for staff but most often this was poorly attended or even not attended at all. Carers' leads similarly

reported training events being organised and then cancelled due to lack of interest. Even when made mandatory, attendance is not enforced and attendance is low.

Staff are resistant to training and I don't know how to make it more appealing.  
(Carers' Lead)

Others spoke of carers' issues only recently being included in staff induction programmes but also of the carer's input being "whittled down to a five minute slot". At one university a post-registration module on user and carer perspectives was developed but not taken up.

Institutions don't want to let go of other curriculum items. (Lecturer/Carers' Lead)

Some CSWs suggested the need to incorporate family work into other training, such as the care programme approach, or offering some sort of incentive to increase attendance and awareness. Some thought that training on working with carers should be mandatory for all staff. Managers should also be required to attend training "because they effect the changes".

Include those at the top who make the decision. (Carers' Lead)

Visits to carer support workers and carers' centres were recommended for all staff and during pre-registration training of health and social care students. Linked to this idea was the suggestion that there needed to be an emphasis on an "experiential approach versus facts and figures" and care should be taken not to overload the curriculum with information. Above all, any education or training needs to be emotionally engaging.

If we don't engage them emotionally... it's not surprising people don't attend training.  
(Carers' Lead)

It needs a lot of group discussion, and probably repeated re-visiting the ideas to see what has happened after people have tried to behave differently. (Carer)

Perhaps looking at different scenarios and seeing how different approaches can affect the outcome. (Carer)

Training in carrying out and implementing carers' assessments should be provided, followed by regular reviews to check staff are doing them. Include opportunities for staff to watch carers' assessments being completed by experienced CSWs and to illustrate how they are already doing a lot of the work involved in assessments but are not formalising it. Provide opportunities for staff to co-work cases with CSWs, especially the more complex cases.

Some carers had very distressing tales of family members and themselves being targeted for bullying, abuse, and even physical attacks and said that addressing issues of stigma and discrimination against people and families with mental illness should be addressed in schools.

Interestingly, some of the service users also raised the issue of stigma in relation to mental illness, but wanted families to understand the issue, the

frequency of mental health difficulties in the general public and that mental health issues can be short-term. This perhaps relates to the need for staff to develop skills in negotiating potential tensions within families, particularly as the patient-carer relationship changes, and to embed training on working with families with a recovery model or approach.

### **Recommendations for training: Changing systems**

Carers' leads reported that management and existing systems did not encourage staff to provide carers with information and support and there needed to be structural changes made to bring about significant change.

It needs to come from the top; unless it's integral to internal systems and policies it won't get done. (Carers Lead)

Incorporate into manager's job descriptions a requirement to supervise work with families and carers. (Carer)

Staff need to know they are accountable for their practices and will be held responsible if they do not involve carers and this message needs to be included in the training. But CSWs also stressed that good training and education should allay fears, "so they know they are not on their own" (CSW). Training should educate staff to realise that support from CSWs and carers' organisations is available and that they can refer on for help or expert advice when necessary. Staff also needed to be provided with ongoing supervision and training in providing supervision for others.

CSWs attached to voluntary organisations felt that they were often "looked down upon" and that staff training should include explicit recognition that they belong to professional organisations and have something useful to contribute.

### **Carers' involvement in training**

There was widespread agreement that student education, staff training provision and inductions should all incorporate the views and experiences of carers and carers themselves, or trained carer trainers, should be central to any training provision. One carer said it helps carers be seen as people not a "problem entity". It helps break down stereotypes of "cool distant fathers and over-involved mothers".

Putting a face to the word carer. (Carer)

Involving carers raises people's consciousness. (Carers' Lead)

Using carers, carer support agencies/workers and service users, who have been trained themselves to talk to professionals as the trainers. (Carer)

Some people in the focus groups had been involved in training or in speaking to groups of professional workers, either within Trusts or at conferences, and reported varying experiences which they felt should inform the design of training.

Carers who had been asked to speak to large rooms or lecture theatres of 100 or more people felt this was inappropriate and that it prevented meaningful discussion from taking place. One carer who spoke to a range of professionals about his experience caring for his son, said the staff were taken aback at what they heard but he felt the language they used in response was designed to "distance and protect themselves", at the expense of excluding him.

It was important that the right environment was used to facilitate training. One example was given of a useful training technique used in social work training, where carers were involved via shared discussions and reflection sessions with social work students. Students presented an issue or case example and sought carers' opinions and in turn responded to these. The interactions and discussion helped people understand each others positions and also some of the dilemmas and counter-pressures faced.

It was better than sitting there quietly as a carer talked up front in a lecture theatre for 30 minutes. (Carer)

Both carers and service users suggested the involvement of both users and carers in training, including the use of role play, with carers, users and staff swapping roles to understand each other's position.

Shared user and carer involvement in training. (Carer)

Visually, a carer and staff and patient together. (User)

Involve carers and users – summarise how carers feel. (User)

Others suggested drawing upon staff's own experiences – many have dual roles and are carers themselves, of children, elderly or disabled relatives. Participants also recommended using carers' written accounts of caring, but also audio tapes, podcasts, videos, DVDs, video diaries, films, etc. Videos of families can be used to lead discussions about why things happen they way they do. At least two carers' groups, in Hertfordshire and Newham, had made videos for educating and training staff. Such methods were thought particularly useful when discussing young or elderly carers who may have difficulties attending training sessions in person. One CSW had developed a DVD about young carers.

Some carers suggested that staff should be required to spend time living with a family to see what it is like for the users and the carers – to "walk a mile in their shoes". Others suggested student placements at carers' centres and with carer's groups and organisations. In some areas, where staff had attended and taken part in carers' groups, they listened to and learnt from each other.

Students should be allocated to a carer... should know how to cope. (Carer)

Spend time with the family (Carer)

Some of the CSWs made an interesting observation that it often appeared that carers did not have much positive to say. One said "Carers have long

memories". Often, because carers have faced difficulties and faced exclusion for so long, when they did get a chance to offer their opinions it often felt as though they had saved up many years of grievances and were determined to pour them all out. This was clearly the result of their enormous frustrations but tended to put-off staff from working with them or attending training that involved carers. This aspect needed to be carefully managed in order to ensure training was constructive.

CSWs generally thought that training was most effective when it involved local carers. Some others thought that there were advantages in involving carers from other geographical areas so there was less risk of a conflict of interests. Former carers "with a world of experience to share" could also help provide training and their involvement "might help create purpose to their caring experience" (CSW).

There was some concern that too often the same carers "get wheeled out again and again" and this might lessen the importance of the message. Carer trainers can encourage other carers to speak out but, on the flip side, if they appear very competent this can put others off. Some people in the Carers' Lead focus group said that some of the carers brought in to speak had been "out of date" and were talking about a level of service provision from many years ago. They recognised that there could be a difficulty in recruiting carers in the midst of caring for someone to contribute to service development and training but needed to ensure the carer's views were relevant and topical. Carers also needed to be adequately prepared and supported in any training role.

Carers need support to deliver, to get involved in training. (Carers' Lead)

There also needs to be widespread involvement of carers in all aspects of service and educational organisations, e.g. exam boards, audit/monitoring committees, steering groups, Trust boards, University committees.

### **Carer Support Workers**

There are still too few CSWs and too little investment in such roles and in supporting carers. All of the CSWs in the focus groups worked alone and very few of them had much contact with other CSWs. For the vast majority, this was the first time they had been brought together as a group to discuss their experiences.

It's the idea that one person can do it all. (CSW)

It goes hand in hand with recognising carers. (CSW)

CSWs were concerned that there had been little planning or strategic thought about their roles and what they were required to do. It was evident that service managers did not understand what they wanted the CSW service to do or how to measure it.

You have to say to carers 'no you are not an afterthought' when your own role is an afterthought. (CSW)

Things make you feel this is just lip service. (CSW)

Carers' Leads and others also spoke about the limitations placed on carers' services and CSWs, who were often not funded to work with people no longer in an active caring role, providing direct physical or psychological support. This often raised tensions when an 'ex-carer' required support in coming to terms with their changed role.

### CSW Training needs

In the focus groups, the CSWs came across as a very impressive, articulate, capable and thoughtful group of women (they were all women). They appeared to have a clear grasp of their own role, despite having had to develop that role themselves. This current batch of CSWs appeared to be made up of a group of passionate, determined women who were strong supporters of and advocates for families and carers. Nonetheless, they were easily able to identify a vast range of issues on which they would benefit from receiving training (See Table 14).

Mediation	Counselling skills
Listening skills	Conflict resolution
Risk management	Break-away techniques
Lone working and personal safety	Medication
Complaints procedure	Managing endings
Family work	Legislation
Presentation and staff training skills	Mental health/illness
Child protection issues	Mental capacity
Note taking	Managing groups
Food handling (for meetings & groups)	

CSWs need training that is ongoing with built-in supervision and more than single workshops, so they can build their confidence to implement the things they are learning. CSW training also needs to build on the considerable knowledge and experience they have already.

The best kind of training is where there has been learning but they recognise you have many of the skills already. (CSW)

Some would also welcome opportunities to shadow CPNs, social workers, case managers and to receive an induction within mental health settings. One of the Carers' Leads welcomed the idea of training for CSWs, including in the voluntary sector, and suggested CSWs often had a lack of "theoretical background".

## **RESULTS: SURVEY**

There were 54 responses to the survey of organisations providing health and social care education. Approximately, a third of all responses came from each of the NHS (20/54, 37%) university (19/54, 35%) and voluntary sectors (15/54, 26%). Some organisations submitted multiple responses for different courses or modules. A small number of courses or modules were being finalised with planned start dates in 2007 or 2008. Six responses concerned training (or related initiatives such as user and carer forums), targeted at carers and/or service users, including specific training for BME carers

### **Type and level of training provision**

The main type and level of training detailed in the responses received concerned the provision of staff induction programmes and/or short workplace training sessions (18/54). Such sessions included half-day to two-day courses or formed components of other training provision, including the Care Programme Approach.

One Trust, Central and North West London Mental Health Trust (CNWL), provides a range of in-house training with a carer focus: Carers Assessments and CPA, Working with Carers, Information Sharing and Confidentiality, and Carer Involvement (specifically aimed at Senior House Officers). They are also developing a Carers and CNWL package for staff inductions. Other courses on Needs Assessments and Patient Advice and Liaison include a carers' component. They are currently working with a university to develop and introduce a module with a carers' focus, incorporating all of the above.

More extensive workplace training, including programmes targeting specific clinical teams or areas including inpatient units, were outlined in just six responses. These included comprehensive outlines of the Somerset Partnership Trust's 'Working with families and carers' staff training package, and the West Midlands' Meriden Family Work Programme that were both described in the literature review. The Somerset programme included three-day training targeted at particular teams and specialities including all acute inpatient units; crisis resolution/home treatment teams; the eating disorders core team and link workers; older adult inpatient teams; and multi-professional community mental health teams. Input on the medical training programme was scheduled for February 2007. The Meriden programme includes various courses ranging from awareness sessions through to training of trainers; afternoon sessions, five-day therapy training programmes, and three-day carer training programmes.

The second and third largest categories of training provision focused on the pre- and post-registration education of mental health professionals, including nurses, social workers, occupational therapists, psychologists and medical students. Pre-registration education was identified in 12/54 responses; post-registration/continuing professional development courses and modules were outlined in 13/54 responses and included training in psychosocial interventions. The majority consisted of relatively new attempts to introduce topics

around recognising the role of carers, understanding relevant legislation and policies and working with carers. Despite the focus of the survey, some responses provided very little evidence of training that specifically addressed the needs of families and carers. Four responses concerned courses at certificate/NVQ/ foundation degree level.

### **Carer involvement**

On the issue of carer involvement in training provision, three respondents acknowledged little or no carer involvement whilst six others failed to respond to this question. The mean average score for carer involvement was 3.6, which equates to a growing level of carer involvement in module planning, delivery, student selection and so on, moving towards regular collaboration with carers. Most involvement seemed to involve input into the planning of the design and content of training and contributions from carers about their personal experiences. Some plans for increased carer involvement were identified. Three courses were identified as 'carer owned or controlled'.

The University of Central Lancashire's Comensus Project is a rare example (<http://www.uclan.ac.uk/facs/health/comensus/index.htm>) of an attempt to support a range of service user and carer involvement in the recruitment of students and the planning, delivery and evaluation of courses across the faculty of health. This included carer input into formal pre- and post-registration education and training of nursing practitioners to work with families of people with mental health problems within a broad context of psychosocial approaches.

Where involved, the vast majority of carers appeared to be paid for their time and expenses, either at set rates of £25-30 plus travel costs, or at visiting lecturer rates. Some organisations had negotiated special arrangements with carer organisations or local community groups. A small number of respondents admitted that carers were not reimbursed for their time and efforts. Additional support and preparation for teaching and training contributions were made available at a minority of centres.

Involvement of carers was sometimes frustrated by difficulties in securing payment from organisations or the restrictions placed on carers by the benefits system. Carers were also affected by unplanned illness of those they care for or themselves.

### **Cultural issues**

The overwhelming majority reported that issues of culture and ethnicity were addressed as core topics within training on working with carers and families. Plentiful examples were provided, including involvement of Black and minority ethnic (BME) carers, development of DVD/videos on the experiences of BME carers, arranging meetings and events at the premises of local BME groups and threading relevant topics throughout the training. Many had established working relationship with local organisations and support centres for BME

carers, although some reported difficulties in recruiting BME carers to participate in training.

### **Achievements**

Participants were asked to identify things of which they were particularly proud. Many identified the simple fact that they had managed to establish a focus on the needs of carers as a considerable triumph given the previous absence of such issues. For many they were amply rewarded by the enthusiastic evaluations by students and staff. Others wrote positively of carer involvement and of collaborative partnerships between practitioners, educationalists and local carers and carers' organisations.

A small number of respondents identified constructive changes in clinical practice and service arrangements. This included increases in the number of carers' assessments being completed; increased referrals to the carers' centre from CMHT staff; voluntary sector partnerships with mental health teams; joint carer and service provider working parties on carers' issues; establishing a local Carers Action Group which has health workers involved working closely with carers; and supported representation of carers on commissioning boards.

### **Difficulties**

Aside from challenges faced involving carers in training, other difficulties encountered could be grouped under three key headings: staff involvement in training, conducting the training, and implementation of training in practice.

Respondents commented on difficulties obtaining management support to make staff available for training, especially on inpatient units and where staff worked shifts. This was exacerbated in areas with staff shortages. Difficulties persuading managers and medical staff to attend training were highlighted by several respondents. Funding for training was sometimes limited and was further eroded by recent cutbacks within the NHS.

Other difficulties included the challenges associated with introducing a new, family or carer-oriented approach to care in the prevailing individually-based culture of the NHS. Some trainers identified difficulties with staff discomfort or resistance to learning about and working with carers. Some professionals viewed working with carers as an additional burden and did not welcome encouragement to communicating with and involve carers. In one area, the trainers reported that ward staff found the course challenging as they tended to be least experienced and primarily focused on the needs of the patients and viewed carers as a problem. Ward staff also struggled with balancing issues round providing general information to carers and maintaining patient confidentiality. They also generally did not cope well with hearing the powerful, personal experience of carers or with constructive criticism.

One respondent outlined a number of challenges faced that resulted from working with differences. This included differences between statutory

services and voluntary services; different points of views within teams; and different models of disability between agencies and professions. Trainers and training participants also faced differences between what feels appropriate in terms of treatment of the patient and what the carer requires. Pitching training at the various levels of staff knowledge within multi-agency and multi-disciplinary groups was also seen as difficult by some, as was including management with frontline staff.

Implementation in practice of new skills learned through training was often hampered by managerial and organisational resistance and, at times, by high staff turnover and vacancies. Lack of appropriate supervision and ongoing support could also prove challenging.

There was acknowledgement by some respondents that developing new training initiatives can take some considerable time and commitment in order to mould participating carers, users, academic and clinical staff into building capacity, confidence and preparedness to take on and support such work.

### **Assessments**

Methods of assessment identified for training participants varied enormously. Workplace training included pre- and post-training quizzes, questionnaires and surveys, general monitoring of performance by managers, identifying specific projects to take forward in consultation with managers and supervisors, team action plans, audits of workplace practices and surveys of families and visitors.

Training provision within university-based pre-registration programmes is assessed in keeping with the diverse competencies required by various professional bodies and the Quality Assurance Agency for higher education (QAA). Fitness for purpose and practice are assessed through successful completion of practice placements and assessment by practice mentors. Post-registration, continuing professional development employs a mix of written assessments and more practice based formats including practice portfolios, case studies and supervisor reports. Training in psychosocial interventions, including family work, tends to employ assessment via video or audio recorded interviews or therapy sessions, rated using criteria for specific competencies.

### **Evaluation**

When evaluated by students, most respondents claimed that courses were well-regarded with carer involvement especially valued. However, there are very few rigorous evaluations of training programmes and no comprehensive studies of the impact of training courses on practice. Several respondents identified new developments and modifications to existing training taking place, some based on feedback to current provision.

## **CONCLUSION AND RECOMMENDATIONS**

### **Education and training**

The findings from this study provide a strong argument that a wide-ranging and comprehensive education and training programme is required in order to enable mental health staff to inform, involve and support families and carers of people with mental health problems.

Education on the importance of working in partnership with families should be provided to all mental health students and trainees throughout their pre-registration professional education. This education should be supplemented with visits to and placements with families, carer support workers and carers' centres and organisations.

Continuing professional development and post-registration training should then be utilised to ensure that the mental health workforce is able and motivated to ensure that mental health services are family-friendly and sensitive to the needs of families and carers, and able to provide intensive family work and interventions to those that require it. This requires three different but interlinked levels of training.

Level one requires that *all* staff (clinical, managerial and administrative) obtain an awareness of the experiences and needs of carers and families and of what family work involves, in order to facilitate carer and family-friendly practices and to recognise the need for carer support and family work, to discuss it with carers and families and make appropriate referrals. Information about local carer support services should also be provided and partnership working between mainstream mental health staff and Carer Support Workers and carers' organisations should be actively encouraged and supported. This level of training can be provided through staff induction programmes, workplace training and regular updates.

Level two requires that smaller numbers of clinical staff across all services and teams should be trained to provide expert family work and psychosocial interventions to those that require them. Training should be supplemented with regular supervision, appropriate work placements, job shadowing and re-organisation of work practices so that knowledge and skills in family work are supported, encouraged, developed and implemented.

Level three requires that within each team or service area, a suitable number of staff are trained and supported to provide ongoing supervision, training and support of staff providing family work and interventions.

All education and training provision needs to address the development and confident delivery of communication skills and information sharing identified within this report as important in supporting mental health carers.

All education and training should also be informed by the 10 Essential Shared Capabilities.

Carer Support Workers need to be able to access a structured programme of continuous development and support that builds on their existing knowledge and expertise with the contents and delivery of training informed by the findings in this report.

Carers, carer trainers, carers' organisations, carer support workers and service users should be involved throughout the design, delivery and evaluation of all education and training aimed at improving services for carers.

Training also needs to target GPs and primary health care teams, so that staff are aware of family and early intervention services for people with mental health problems and their families and carers.

Education in schools and amongst the wider public is required to challenge stigma and discrimination faced by people with mental illness and their families.

In order for such a programme of education and training to be effective, the findings in this report strongly indicate that any training programme to improve the support of families and mental health carers needs to form part of a comprehensive organisational structure and strategy that includes explicit support throughout all levels of health and social care organisations. There is considerable evidence elsewhere that even where there is strong research evidence for the efficacy of a particular intervention and even overwhelming agreement that such an intervention is desirable, it does not mean the practice will be widely implemented (Torrey et al 2001).

Consequently, we have drawn on the experiences and recommendations of the successful Meriden and Somerset programmes outlined earlier and other relevant projects to identify the key factors in bringing about family-friendly services and greater support for carers.

### **Key strategies to help establish, develop and maintain family-focused services and support for carers**

#### **i) Establish a service users and carers forum**

Service users and carers need a forum where they can feedback challenging views of services, and identify key issues and advocate safely in order to have their needs met. This empowers service recipients to work with professionals and managers to bring about constructive improvements to services (Cleary et al 2006). Forum members can participate actively in services, on committees, writing position papers and contribute to the training of staff. The Meriden programme includes input from family members in all of their courses (Fadden 2006). Such involvement of users and carers helps increase awareness amongst staff of the needs of families and enables providers and recipients to work together to bring about positive change. Such forums have been used in education institutions as well as health services with members acting as 'culture carriers' (Lathlean et al 2006).

## **ii) Appoint a credible, suitably skilled person to lead developments**

Appointing the right person to take the lead on developing and implementing a programme of family-focused training and establishing family-focused services is important. The person needs to have credibility amongst senior and middle managers and respect amongst clinicians. They need to have family work skills and experience themselves and the professional, personal and interpersonal skills and qualities to effect a culture change and the abilities to write policies and oversee practice development (Stanbridge & Burbach 2004, Fadden 2006).

## **iii) Provide staff training and supervision**

Mental health staff require targeted education and training in order to obtain and nurture the knowledge, attitudes and skills required to work effectively with families and service users. The broad content of such training has been outlined earlier in this report. Several authors have suggested that mental health teams need to include staff with differing, staged levels of training from a basic introduction through family interventions skills to higher level family work and supervision skills. A basic level of training for all in the needs of families and carers, what family work involves and why it is important, helps establish an all-round family-friendly service and provides greater support to those staff providing interventions. It also increases the relevance of referrals for family work (Fadden 2006).

In order to build their confidence and expertise in working with families, staff also need to access ongoing skilled supervision. Group supervision can be a more cost effective use of skilled supervisors and also provides a useful forum for sharing ideas and providing peer support and encouragement. Another good way of developing staff skills is to encourage newly trained staff to co-work with more experienced family worker. Being able to work with families as soon as training is completed is important in developing new skills, as is being able to link up with or work alongside other clinicians trying to implement family work so that difficulties and barriers can be shared and overcome. Fadden (2006) also stresses the importance of providing positive feedback and appreciation to staff undertaking family work in order that they feel acknowledged, valued and rewarded. Staff also need to know that time required to work with families is facilitated or protected within existing caseloads.

## **iv) Identify family work 'champions'**

Identifying clinicians who act within their workplace and organisation to promote training and champion the development of family work and the needs of carers has proved very effective within the Meriden programme and in North Somerset, Avon and Wiltshire (Smith & Velleman 2002).

### **v) Prepare managers and organisations**

It is clear from numerous evaluations of PSI/family work training that the implementation of family work is only widely successful where local managers and organisations are involved in and signed up to the development of family-focussed services. And, as Fadden (2006) makes clear, this takes time and persistence and consistent involvement of committed people championing the cause. This is particularly the case now, given that over the last 10 years, the NHS has faced enormous upheaval, restructuring and demands on commissioners, managers and clinicians so that any new demands are often met with understandable weariness and resistance. Smith & Velleman (2002) have also stressed that many senior managers may retain negative beliefs about families from earlier models of family work that they encountered in their clinical careers, so need to be educated into the newer, more constructive ways of thinking.

### **vi) Obtain backing and commitment at senior levels**

A solid relationship must be established with senior management and those charged with the strategic implementation of family work and related training programmes must be at a sufficiently senior level to relate to and obtain backing from other senior managers. Presenting clear, concise information about the evidence base for family work, outlining the current gap between policy requirements and local service provision alongside a costed plan for implementation can help establish Trust Board backing. Maintaining an interest can be achieved by providing regular progress reports to the Trust Board and managers. Reports can include evidence of number of staff trained, range of professions involved, number of families supported, and feedback from carers (Smith & Velleman 2002). Kelly and Newstead (2004) have also outlined how taking up opportunities to present and discuss the benefits of family work with users, carers and professional groups and to make maximum use of Trust magazines and other news outlets to promote new services have been key elements in establishing and maintaining a new family intervention service in routine practice in Dorset.

Fadden (2006) notes that the NHS is marked by constant changes in senior personnel so it is important to keep in touch with these changes and convince new post-holders of the importance of family work. Trust-wide policies around family work and training provide additional top-level support for developments and should be identified in Trust plans and priorities, in annual reports and in discussions with commissioners and planners. Auditing of the delivery of family work provides a useful means of monitoring and reporting on successes and identifying areas for further attention. Existing clinical governance structures, acute care forums and monitoring of the care programme approach can all be involved in monitoring the development of family work and carer involvement.

### **vii) Establish a steering group and strategy**

Establishing a steering group to plan and oversee the implementation of family work is very helpful. Representatives of senior management and key clinical areas and services should work alongside service user and family and carer representatives, specialist carers' agencies and expert educators and trainers to draw up a detailed strategy and implementation plan, with identified target achievements and dates and named people and responsibilities (Stanbridge & Burbach 2004, Fadden 2006). Job descriptions should be amended to emphasise the commitment to working with families and presentations on family work should be included in staff inductions, preceptorship, mentoring, development programmes and staff appraisals and supervision (Fadden 2006).

### **viii) Target middle managers and work prioritisation**

Training and support with team managers is also important as these people are involved in establishing team priorities, caseload management, work allocation and out-of-hours working, so are central to overcoming some of the most common barriers to successful implementation. Fadden (2006) describes helping managers clarify their own role in terms of leadership and creating an ethos and culture that supports the delivery of services to families. Helping managers to establish and implement training strategies to develop carer-focused services specific areas such as inpatient units, can also prove useful (Thurston et al 2003).

### **ix) Establish links between teams and organisations**

Being able to provide the appropriate level of information, support and interventions to carers and families at the right time is an important part of providing an effective service. Close links between inpatient services and community teams helps ensure that family work is provided at the right time and helps families understand the roles of various teams and clinicians (Fadden 2006). Good links with carer support workers and local voluntary agencies providing support, advice and information to carers is crucial.

## REFERENCES

- Addington, J., McCleery, A. & Addington, D. (2005) Three year outcome of family work in an early psychosis program. *Schizophrenia Research*, 79, 1, 107-116.
- Ahuja, A. S. & Williams, R. (2005) Involving patients and their carers in educating and training practitioners. *Current Opinion in Psychiatry*, 18, 374-380.
- Aldridge, J. & Becker, S. (2003) *Children caring for parents with mental illness*. Bristol: The Policy Press.
- Arksey, H. et al (2002a) *Literature Review Report: Services to support carers of people with mental health problems*. London: NCCSDO.
- Arksey, H. et al (2002b) *Overview Report: Services to support carers of people with mental health problems*. London: NCCSDO.
- Askey, R., Gamble, C. & Gray, R. (2007) Family work in first-onset psychosis: a literature review. *Journal of Psychiatric and Mental Health Nursing*, 14, 4, 356-365.
- Bailey, D., Carpenter, J. & Rogers, H. (2003) *Expert Paper on Post Qualifying Mental Health Training*. London: Department of Health.
- Bailey, R., Burbach, F. & Lea, S.J. (2003) The ability of staff trained in family interventions to implement the approach in routine clinical practice. *Journal of Mental Health*, 12, 2, 131-141.
- Baguley, I. & Dulson, J. (2004) Psychosocial interventions. In Harrison, M. (Ed) et al; *Acute mental health nursing; from acute concerns to the capable practitioner*. London; Sage. Pp198-217.
- Bee, P., Lovell, K., Playle, J., Barnes, P., Gray, R. & Keeley, P. (2005) Service User and Carer Views of UK NHS Registered Mental Health Nurses: A Review of the Literature.  
[www.nursing.manchester.ac.uk/projects/mentalhealthreview/usercarerviewsfinalreport.pdf](http://www.nursing.manchester.ac.uk/projects/mentalhealthreview/usercarerviewsfinalreport.pdf)
- Beresford, P. (1994) *Changing the Culture: Involving Service Users in Social Work Education*. London, CCETSW.
- Bertrando, P. (2006) The evolution of family interventions for schizophrenia. A tribute to Gianfranco Cecchin. *Journal of Family Therapy*, 28, 4-22.
- Bhugra, D. & McKenzie, K. (2003) Expressed emotion across cultures. *Advances in Psychiatric Treatment*, 9, 342-348.
- Brabban, A. & Kelly, M. (2006) *Training in Psychosocial Interventions within Early Intervention Teams: A National Survey*. London: NIMHE/CSIP National PSI Implementation Group.

Brennan, G., Flood, C. & Bowers, L. (2006) Constraints and blocks to change and improvement on acute psychiatric wards – lessons from the City Nurses project. *Journal of Psychiatric and Mental Health Nursing*, 13, 475-482

Brooker, C. (2001) A decade of evidence-based training for work with people with serious mental health problems: Progress in the development of psychosocial interventions. *Journal of Mental Health*, 10, 1, 17-31.

Brooker, C. & Brabban, A. (2006) Effective training in psychosocial interventions for work with people with serious mental health problems. *The Mental Health Review*, 11, 2, 7-14.

Brooker, C. & Brabban, A. (2004) *Measured Success: A Scoping Review of Evaluated Psychosocial Interventions Training for Work with People with Serious Mental Health Problems*. NIMHE/Trent WDC.

Brooker, C. & Curran, J. (2006) The National Continuous Quality Improvement Tool for Mental Health Education: Results of targeted and supported implementation in England. *Journal of Interprofessional Care*, 20, 3, 276 – 289.

Brooker, C., Curran, J., James, A. & Readhead, E. (2005) Developing and piloting an audit tool for mental health education and training: The National Mental Health Education Continuous Quality Improvement Tool. *Journal of Interprofessional Care*, 19, 3, 280-293.

Brooker, C., Gournay, K., O'Halloran, P., Bailey, D. & Saul, C. (2002) Mapping training to support the implementation of the National Service Framework for Mental Health. *Journal of Mental Health*, 11, 1, 103-116.

Brooker, C., Saul, C., Robinson, J., King, J. & Dudley, M. (2003) Is training in psychosocial interventions worthwhile? Report of a psychosocial interventions trainee follow-up study. *International Journal of Nursing Studies*, 40, 731-747.

Brown, S. & Birtwistle, J. (1998) People with schizophrenia and their families: Fifteen-year outcome. *British Journal of Psychiatry*, 173, 139-144.

Burbach, F. (2007) Somerset's Family Intervention Service. Presentation at *Working with Families: Developing Caring Partnerships Conference*. Stratford-upon-Avon: Meriden.

Burbach, F. (1996) Family-based intervention in psychosis – an overview of and comparison between family therapy and family management approaches. *Journal of Mental Health*, 5, 2, 111-134.

Burbach, F. & Stanbridge, R. (1998) A family intervention in psychosis service integrating the systemic and family management approaches. *Journal of Family Therapy*, 20, 311-325.

- Burbach, F. & Stanbridge, R. (2006) Somerset's family interventions in psychosis service: an update. *Journal of Family Therapy*, 28, 39-57.
- Butterworth, M. & Livingston, G. (1999) Medical student education: The role of caregivers and families. *Psychiatric Bulletin*, 23, 549-550.
- Clarke, C. (2005a) A carer's experience of the mental health system. In Joseph, S. & Worsley, R. (Eds) *Person-Centred Psychopathology: A positive psychology of mental health*. Ross-on-Wye: PCCS Books. pp 9-20.
- Clarke, C. (2005b) Prouty's Contact Work: A carer's perspective. *Mental Health Practice*, 9, 1, 24-27.
- Clarke, C. (2006) Relating with professionals. *Journal of Psychiatric and Mental Health Nursing*, 13, 522-526.
- Clarke, M., & Riley, S. (2006) *Best practice, better practices: a new deal for carers in primary care*. London: The Princess Royal Trust for Carers.  
<http://www.carers.org/professionals/articles/carers-in-practice-rcgp,1792,PR.html>
- Cleary, M. & Freeman, A. (2006) Enhancing nurse carer partnerships: A self-directed learning approach. *Nurse Education in Practice*, 6, 224-231.
- Cleary, M., Freeman, A. & Walter, G. (2006) Carer participation in mental health service delivery. *International Journal of Mental Health*, 15, 189-194.
- Cooklin, A. (2007) *Being Seen and Heard: the needs of children of parents with mental illness. Video/DVD Training Pack for Professionals*. London: Royal College of Psychiatrists.
- Cormac, I. & Tihanyi, P. (2006) Meeting the mental and physical healthcare needs of carers. *Advances in Psychiatric Treatment*, 12, 162-172.
- Crawford, M. & Davies, S. (1998) Involvement of users and carers in the training of psychiatrists: making it happen. *Psychiatric Bulletin*, 22, 42-43.
- Curle, C. & Mitchell, A. (2004) Hand in hand: user and carer involvement in training clinical psychologists. *Clinical Psychology*, 33, 12-15.
- Curtis, E. & Redmond, R. (2007) Focus groups in nursing research. *Nurse Researcher*, 14, 2, 25 – 37.
- Dearden, C. & Becker, S. (2004) *Young carers in the UK: the 2004 report*. London: Carers UK/The Children's Society.
- DH (2002) *Developing services for carers and families of people with mental illness*. London: Department of Health.
- DH (2006) *From values to action: The Chief Nursing Officer's review of mental health nursing*. London, Department of Health.

- Drake, R.E. & Mueser, K.T. (2000) Psychosocial approaches to dual diagnosis. *Schizophrenia Bulletin*, 26, 1, 105-118.
- ENB. (1996) *Learning From Each Other*. London, English National Board.
- Fadden, G. (1997) Implementation of family interventions in routine clinical practice following staff training programs: A major cause for concern. *Journal of Mental Health*, 6, 6, 599-612.
- Fadden, G. (1998) Family intervention in psychosis. *Journal of Mental Health*, 7, 2, 115-122.
- Fadden, G. (2006) Training and disseminating family interventions for schizophrenia: developing family intervention skills with multi-disciplinary groups. *Journal of Family Therapy*, 28, 23-38.
- Fadden, G. & Birchwood, M. (2002) British models for expanding family psychoeducation in routine practice. In H. P. Lefley and D. L. Johnson (Eds) *Family Interventions in Mental Illness: International Perspectives*. Westport, CT: Praeger.
- Fadden, G., Birchwood, M., Jackson, C. & Holsgrove, G. (2004) Psychological therapies: implementation in early intervention services. In P. McGorry and J. Gleeson (Eds) *Psychological Interventions in Early Psychosis: A Practical Treatment Handbook*. Chichester: John Wiley.
- Fadden, G., Shooter, M. & Holsgrove, G. (2005) Involving carers and service users in the training of psychiatrists. *Psychiatric Bulletin*, 29, 7, 270-274.
- Falloon, I.R.H., Graham-Hole, V. & Woodroffe, R. (1993) Stress and health of informal carers of people with chronic mental disorders. *Journal of Mental Health*, 2, 165-173.
- Forrest, S. & Masters, H. (2004) Evaluating the impact of training in psychosocial interventions: a stakeholder approach – part I. *Journal of Psychiatric and Mental Health Nursing*, 11, 194-201.
- Forrest, S., Masters, H. & Milne, V. (2004) Evaluating the impact of training in psychosocial interventions: a stakeholder approach – part II. *Journal of Psychiatric and Mental Health Nursing*, 11, 194-201.
- Furlong, M. & Leggatt, M. (1996) Reconciling the patients right to confidentiality and the family's need to know. *Australian and New Zealand Journal of Psychiatry*, 30, 614-622.
- Gall, S.H., Atkinson, J., Elliott, L. & Johansen, R. (2003) Supporting carers of people diagnosed with schizophrenia: evaluating change in nursing practice following training. *Journal of Advanced Nursing*, 41, 3, 295-305.

Gall, S.H., Elliott, L., Atkinson, J. & Johansen, R. (2001) Training nurses to support carers of relatives with schizophrenia. *British Journal of Nursing*, 10, 238-241.

Geelan, S. & Nickford, C. (1999) A survey of the use of family therapy in medium secure units in England and Wales. *Journal of Forensic Psychiatry*, 10, 2, 317-324.

Glynn, S.M., Cohen, A.N., Amy, N., Dixon, L.B. & Niv, N. (2006) The Potential Impact of the Recovery Movement on Family Interventions for Schizophrenia: Opportunities and Obstacles. *Schizophrenia Bulletin*, 32, 3, 451-463.

GMC (1993) *Tomorrow's Doctors: Recommendations on Undergraduate Medical Education*. London: General Medical Council.

Goodwin, V. & Happell, B. (2006) Conflicting agendas between consumers and carers: The perspectives of carers and nurses. *International Journal of Mental Health Nursing*, 15, 135-143.

Goss, S. & Miller, C. (1995) *From Margin to Mainstream: Developing User and Carer Centred Community Care*. York: Joseph Rowntree Foundation.

Hare, P. (2004) Keeping carers healthy: the role of community nurses and colleagues. *British Journal of Nursing*, 9, 155-159.

Harper, D., Goodbody, L. and Steen, L. (2003) Involving service users in clinical psychology training. *Clinical Psychology*, 21, 14-19.

Hatfield, A.B. (1997) Working collaboratively with carers. *Social Work in Health Care*, 25, 75-85.

Hayward, M. & Harding, E. (2006) User and carer involvement in clinical psychology training: Views from Buxton. *Clinical Psychology Forum*, 157, 3-7.

Hope, R. (2004) *The Ten Essential Shared Capabilities: A framework for the whole of the mental health workforce*. London: NIMHE.

Huang, M-C. & Slevin, E. (1999) The experiences of carers who live with someone who has schizophrenia: a review of the literature. *Mental Health Care*, 3, 3, 89-93.

Hughes, I., Hailwood, R., Abbati-Yeoman, J. & Budd, R. (1996) Developing a family intervention service for serious mental illness: Clinical observations and experiences. *Journal of Mental Health*, 5, 145-159.

Jones, M., Lancashire, S. & Bennett, J. (2005) Supporting the application of psychosocial interventions in adult inpatient services. *Mental Health Practice*, 9, 5, 42-45.

Jones, A. & Scannell, T. (2002) Research and organizational issues for the implementation of family work in community psychiatric services. *Journal of Advanced Nursing*, 38, 2, 171-179.

- Johnstone, L. (1993) Family management in schizophrenia: it's assumptions and contradictions. *Journal of Mental Health*, 2, 3, 253-269.
- Keeley, B. & Clarke, M. (2002) *Carers Speak Out project. Report on findings and recommendations*. London: Princess Royal Trust.
- Keen, T. (2003) Behavioural Family Interventions and Family Therapy. In Simpson, A. (Ed) *Keen On: Selected contributions by Tom Keen to the Psychiatric Nursing Email Discussion List (1999 – 2002)*. p16.  
[http://www.citypsych.com/docs/Keen\\_on.pdf](http://www.citypsych.com/docs/Keen_on.pdf)
- Kelly, M. & Newstead, L. (2004) Family Intervention in routine practice: it is possible! *Journal of Psychiatric and Mental Health Nursing*, 11, 64-72.
- Knapp, M. (2000) Schizophrenia cost and treatment cost-effectiveness. *Acta Psychiatrica Scandinavica, Supplement*, 102, 407, s15-s18.
- Krupnik, Y., Pilling, S., Killaspy, H. & Dalton, J. (2005) A study of family contact with clients and staff of community mental health teams. *Psychological Bulletin*, 29, 174-176.
- Lammers, J. & Happell, B. (2004) Research involving mental health consumers and carers: A reference group approach. *International Journal of Mental Health Nursing*, 13, 262-266.
- Lathlean, J., Burgess, A., Coldham, T., Gibson, C., Herbert, L., Levett-Jones, T., Simons, L. & Tee, S. (2006) Experiences of service user and carer participation in health care education. *Nurse Education Today*, 6, 424-429.
- Leff, J. & Vaughan, C. (1994) Critics of family management in schizophrenia: their assumptions and contradictions. *Journal of Mental Health* 3, 1, 115-116.
- Leff, J. & Vaughn, C. (1985) *Expressed Emotion in Families*. New York: Guilford.
- Lehman, A.F. et al (2004) The Schizophrenia Patient Outcomes Research Team (PORT): Updated Treatment Recommendations 2003. *Schizophrenia Bulletin*, 30, 2, 193-217.
- Lester H., Tait, L., Khera, A., Birchwood, M., Freemantle, N. & Patterson, P. (2005) The development and implementation of an educational intervention on first episode psychosis for primary care. *Medical Education*, 39, 10, 1006-1014.
- Le Var, R. M. H. (2002) Patient involvement in education for enhanced quality of care. *International Nursing Review*, 49, 219-225.
- Mairs, H. & Bradshaw, T. (2005) Implementing family intervention following training: what can the matter be? *Journal of Psychiatric and Mental Health Nursing*, 12, 488-494.

Manthorpe, J. (2000) Developing carers' contributions to social work training. *Social Work Education*, 19, 1, 19-27.

Masters, H., Forrest, S., Harley, A., Hunter, M. & Brown, N. (2002) Involving mental health service users and carers in curriculum development: moving beyond 'class-room' involvement. *Journal of Psychiatric and Mental Health Nursing*, 9, 309-316.

McCann, E. & Bowers, L. (2005) Training in cognitive behavioural interventions on acute psychiatric inpatient wards, *Journal of Psychiatric and Mental Health Nursing*, 12, 2, 215-222.

Meriden (2007) Working with Families: Developing Caring Partnerships conference. Stratford-upon-Avon: Meriden West Midlands Family Programme.  
<http://www.meridenfamilyprogramme.com/>

Michon, A., Weber, K., Rudhard-Thamazic, V. & Giannakopoulos, P. (2005) Dynamic processes of family burden in dementia caregiving: A new field for psychotherapeutic interventions. *Psychogeriatrics*, 5, 2, 48-54.

Milne, D., Dudley, M., Repper, D. & Milne, J. (2001) Managers' perceived contributions to the transfer of psychosocial interventions training. *Psychiatric Rehabilitation Skills*, 5, 3, 387-402.

Mohr, W.K., Lafuze, J.E. & Mohr, B.D. (2000) Opening Caregiver Minds: National Alliance for the Mentally Ill's (NAMI) Provider Education Program. *Archives of Psychiatric Nursing*, 15, 5, 235-243.

Molyneux, J. & Irvine, J. (2004) Service user and carer involvement in social work training: a long and winding road? *Social Work Education*, 23, 3, 293-308.

Munn-Giddings, C. (2006) Self-help groups as mutual support: What do carers value? *Health and Social Care in the Community*, 15, 1, 26-34.

NCMH (2003) *National Continuous Quality Improvement Tool for Mental Health Education*. Durham: NCMH.

Newbronner, E. & Hare, P. (2002) *Consultation Report: Services to support carers of people with mental health problems*. London: NCCSDO.

NIMHE (2005) Guiding Statement on Recovery. London, NIMHE.  
<http://www.psychminded.co.uk/news/news2005/feb05/nimherecovstatement.pdf>

NICE (2003) *Schizophrenia: Full national clinical guideline on core interventions in primary and secondary care*. London, The Royal College of Psychiatrists & The British Psychological Society.

Nolan, M., Grant, C. & Keady, J. (1996) *Understanding Family Care*. Buckingham: Open University Press.

O'Carroll, M., Rayner, L. & Young, N. (2004) Education and training in psychosocial interventions: a survey of Thorn Initiative course leaders. *Journal of Psychiatric and Mental Health Nursing*, 11, 602-607.

Office for National Statistics (2003) *Census 2001. National report for England and Wales*. London: The Stationery Office.

Oyebode, J. (2003) Assessment of carers' psychological needs. *Advances in Psychiatric Treatment*, 9, 45-53.

Papastavrou, E., Kalkerinou, A., Papacostas, S.S., Tsangari, H. & Sourtzi, P. (2007) Caring for a relative with dementia: family caregiver burden. *Journal of Advanced Nursing, online – to complete*.

Patterson, P., Birchwood, M. & Cochrane, R. (2005) Expressed emotion as an adaptation to loss: Prospective study in first-year psychosis. *British Journal of Psychiatry*, 187 (suppl. 48), s59-s64.

Pearlin, L. I., Mullan, J.T. & Semple, S.J. (1990) Caregiving and the stress process: an overview of concepts and their measures. *Gerontologist*, 30, 583-594.

Perring, C., Twigg, L. & Atkin, K. (1992) *Families caring for people diagnosed as mentally ill: the literature re-examined*. London: The Stationery Office.

Pharoah, F., Mari, J., Rathbone, J. & Wong, W. (2006) Family intervention for schizophrenia. *Cochrane Database of Systematic Reviews*, Issue 4, Art. No.: CD000088. DOI: 10.1002/14651858.pub2.

Pinfold, V. & Corry, P. (2003a) *Under pressure: The impact of caring on people supporting family members or friends with mental health problems*. London: rethink severe mental illness.

Pinfold, V. & Corry, P. (2003b) *Who cares? The experiences of mental health carers accessing services and information*. London: rethink severe mental illness.

Pinfold, V., Farmer, P., Rapaport, J., Bellringer, S., Huxley, P., Murray, J., Banerjee, S., Slade, M., Kuipers, E., Bhugra, D. & Waitere, S. (2004) *Positive and Inclusive? Effective ways for professionals to involve carers in information sharing. Report to the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO)*. London: SDO.  
<http://www.sdo.lshtm.ac.uk/files/project/54-final-report.pdf>

Pinfold, V., Smith, J. & Shiers, D. (2007) Audit of early intervention in psychosis service development in England in 2005. *Psychiatric Bulletin*, 31, 7-10.

Pinner, G. & Bouman, W. P. (2003) What should we tell people about dementia? *Advances in Psychiatric Treatment*, 9, 335-341.

Rapaport, J., Bellringer, S., Pinfold, V. & Huxley, P. (2006) Carers and confidentiality in mental health care: considering the role of the carer's assessment: a

study of service users', carers' and practitioners' views. *Health and Social Care in the Community*, 14, 4, 357-365.

Repper, J. & Breeze, J. (2004) *A Review of the Literature on User and Carer Involvement in the Training and Education of Health Professionals*. Sheffield: Sheffield Health and Social Care Research Consortium.

Rogerson, H. (2006) Family work with people with dementia. *Nursing Older People*, 18, 7, 28-31.

Rose, L.E., Mallinson, R.K. & Gerson, L.D. (2006) Mastery, burden and areas of concern among family caregivers of mentally ill patients. *Archives of Psychiatric Nursing*, 20, 1, 41-51.

Rose, L., Mallinson, R.K. & Walton-Moss, B. (2002) A grounded theory of families responding to mental illness. *Western Journal of Nursing Research*, 24, 516-36.

Royal College of Psychiatrists (2004) Carers and Confidentiality in Mental Health: Issues involved in information-sharing. London: Royal College of Psychiatrists.  
<http://www.rcpsych.ac.uk/PDF/Carersandconfidentiality.pdf>

Royal College of Psychiatrists (2006) Good Psychiatric Practice: Confidentiality and Information Sharing. London: Royal College of Psychiatrists.  
<http://www.rcpsych.ac.uk/publications/collegereports/cr/cr133.aspx>

Sartorius, N. (Ed)., Leff, J., Lopez-Ibor, J.J., Maj, M. & Akasha, A.(2005) *Families and mental disorders: From burden to empowerment*. New York: John Wiley & Sons Ltd.

Scazufca, M. & Kuipers, E. (1999) Coping strategies in relatives of people with schizophrenia before and after psychiatric admission. *British Journal of Psychiatry*, 174, 154-158.

SCIE (2005) Research briefing 11: The health and well-being of young carers. London: Social Care Institute for Excellence.  
<http://www.scie.org.uk/publications/briefings/briefing11/index.asp#user>

SCMH (1999) *Pulling Together: Future roles and training of mental health staff*. London: Sainsbury Centre for Mental Health.

SDO (2002) Briefing Paper: *Services to support carers of people with mental health problems*. London: NCCSDO.

SDO (2006) Briefing Paper: *Sharing mental health information with carers: pointers to good practice for service providers*. London: NCCSDO.

Sheils, R. & Rolfe, T.J. (2000) Towards an integrated approach to a family intervention for co-occurring substance abuse and schizophrenia. *Australian and New Zealand Journal of Family Therapy*, 21, 2, 81-87.

Simpson, A. (1999) Creating alliances: the views of users and carers on the education and training needs of mental health nurses. *Journal of Psychiatric and Mental Health Nursing*, 6, 347-356.

Simpson, A. (2006) Involving service users and carers in the education of mental health nurses. *Mental Health Practice*, 10, 4, 20-24.

Simpson, A., Reynolds, L., Light, I. & Attenborough, J. (in press) Talking with the Experts: Evaluation of an online discussion forum with mental health service users and student nurses. *Nurse Education in Practice*.

Simpson, E.L. & House, A.O. (2002) Involving user in the delivery and evaluation of mental health services: systematic review. *BMJ*, 325, 1265.

Simpson, E.L. & House, A.O. (2003) User and carer involvement in mental health services: from rhetoric to science. *British Journal of Psychiatry*, 183, 89-91.

Sin, J., Moone, N. & Newell, J. (2007) Developing services for the carers of young adults with early-onset psychosis – implementing evidence-based practice on psycho-educational family intervention. *Journal of Psychiatric and Mental Health Nursing*, 14, 282-290.

Singh, S., Wright, C., Joyce, E., Barnes, T. & Burns, T. (2003) Developing early intervention services in the NHS: a survey to guide workforce and training needs. *Psychiatric Bulletin*, 27, 254-258.

Singleton, N., Aye Maung, N., Cowie, A., Sparks, J., Bumpsted, R. & Meltzer, H. (2002) *Mental health of carers*. London: The Stationery Office.

Slade, M., Holloway, F. & Kuipers, E. (2003) Skills development and family interventions in an early psychosis service. *Journal of Mental Health*, 12, 4, 405-415.

Slade, M., Pinfold, V., Rapaport, J., Bellringer, S., Banerjee, S., Kuipers, E. & Huxley, P. (2007) Best practice when service users do not consent to sharing information with carers: National multi-method study. *British Journal of Psychiatry*, 190, 148-155.

Smith, G. & Velleman, R. (2002) Maintaining a family work for psychosis service by recognising and addressing the barriers to implementation. *Journal of Mental Health*, 11, 5, 471-479.

Soliman, A. & Butterworth, M. (1998) Why carers need to educate professionals. *Journal of Dementia Care*, 6, 26-27.

Stanbridge, R.I. & Burbach, F. R. (2004) Enhancing working partnerships with carers and families: a strategy and associated training programme. *The Mental Health Review*, 9, 32-37.

Stanbridge, R. I., Burbach, F.R., Lucas, A. S. & Carter, K. (2003) A study of families' satisfaction with a family interventions in psychosis service in Somerset. *Journal of Family Therapy*, 25, 181-204.

Stubbings, R. (2006) *Caregiving Partners: Managing role change in dementia*. London: City University Department of Mental Health & Learning Disability Mental Health Seminar.

Szmukler, G. & Bloch, S. (1997) Family involvement in the care of people with psychoses: an ethical argument. *British Journal of Psychiatry*, 171, 401-405.

Tarrier, N., Barrowclough, C., Haddock, G. & McGovern, J. (1999) The dissemination of innovative cognitive-behavioural psychosocial treatments for schizophrenia. *Journal of Mental Health*, 8, 6, 569-582.

Tew, J., Gell, C. & Foster, S. (2004) *Learning from Experience: involving service users and carers in mental health education and training*. York: Mental Health in Higher Education/NIMHE West Midlands/Trent WDC.

The Princess Royal Trust for Carers (2004) *Carers' Health Survey*. London: The Princess Royal Trust for Carers.

Thurston, S., Rimmer, S., Flynn, S. & Sandwells, S. (2003) Developing a training framework for carer inclusion in acute inpatient care. *Mental Health Practice*, 7, 2, 12-15.

Torrey, W.C., Drake, R.E., Dixon, L., Burns, B.J., Flynn, L., Rush, A.J., Clark, R.E. & Klatzker, D. (2001) Implementing evidence-based practices for persons with severe mental illnesses. *Psychiatric Services*, 52, 1, 45-50.

Trent SHA (2005) *Principles for Practice: involving service users and carers in health care education and training*. Mansfield, Trent Strategic Health Authority.

Turner, P., Sheldon, F., Coles, C., Mountford, B., Hillier, R., Radway, P. & Wee, B. (2000) Listening to and learning from the family carer's story: an innovative approach in interprofessional education. *Journal of Interprofessional Care*, 14, 4, 387-395.

Walker, H. (2004) Using psychosocial interventions within a high-security hospital. *Nursing Times*, 100, 31, 36-9.

Walker, E. & Dewar, B.J. (2001) How do we facilitate carer's involvement in decision making? *Journal of Advanced Nursing*, 34, 329-337.

Watson, S. (1999) Meeting the needs of young carers. *Nursing Standard*, 13, 3, 37-40.

Wong, D.F.K. (2000) Stress factors and mental health of carers with relatives suffering from schizophrenia in Hong Kong: implications for culturally sensitive practices. *British Journal of Psychiatry*, 30, 365-382.

Workforce Action Team (2001) *Mental Health National Service Framework and the NHS Plan: Workforce Planning, education and training underpinning programme for adult mental health services. Final Report*. London, Department of Health.

World Fellowship for Schizophrenia and Allied Disorders (2007) *Families as Partners in Care (FPC) Goals and Principles*. Accessed on 29/05/2007 at <http://www.world-schizophrenia.org/activities/fpc/principles.html>

Zubin, J. & Spring, B. (1977) Vulnerability - a new view of schizophrenia. *Journal of Abnormal Psychology*, 86, 103-126.

**St Bartholomew School of Nursing & Midwifery**

**APPENDIX 1: Advertisement for Recruitment of Participants**

Dr Alan Simpson  
Senior Research Fellow

**Scoping Research to Inform the Development of a  
'National (Mental Health) Carer Support Curriculum'  
for People Supporting Friends-and-Family Carers in Mental Health**

Philpot Street  
Whitechapel  
London E1 2EA  
T +44 (0)20 7040 5937  
F +44 (0)20 7040 5811  
A.Simpson@city.ac.uk

Researchers at City University, London are working with the Supporting Carers Better Network to identify what needs to be included in the education and training of mental health staff and carer support workers to address the needs of mental health carers. This will be used to inform the development of a nationally-accredited curriculum and training modules.

[www.city.ac.uk/barts](http://www.city.ac.uk/barts)

If you are a mental health carer, a carer support worker or advocate, a mental health professional or a mental health service user (patient), you may wish to participate in a focus group to discuss with others what you would like to see included in education and training about the needs of mental health carers.

We will be running up to 10 focus groups. There will be three or four groups for carers, two for carer support workers, two for mental health professionals and two for service users.

The focus groups will take place at City University in London or we may also arrange to attend existing carer support groups. Each group will last a total of two hours. If you agree to take part, full details about the venue, date and time of groups will be provided. Carers and service users will be paid £10 on the day for their participation.

Whether or not you choose to take part in this study will not impact in any way on your care, treatment, support or employment. You may choose to withdraw your participation at any time.

If you think you might like to take part and would like to know more, please contact either Alan Simpson or Lisa Benn.

Alan is the Principal Investigator on the project and is an experienced researcher, a qualified mental health nurse and counsellor who has conducted previous research with carers, service users and mental health staff. Lisa Benn is the Research Assistant for the project and will be helping Alan facilitate the focus groups. Lisa is a psychologist and has several years clinical and research experience in mental health.

Once you have contacted us, we will then send you detailed information about the purpose and nature of the study, details of the venue and travel directions. We will also send you a consent form to complete and return if you wish to take part. Places in the focus groups will be allocated on a first come first served basis, due to the limited number of places available.

If you would like more information please contact:

Dr Alan Simpson on:

Email: [A.Simpson@city.ac.uk](mailto:A.Simpson@city.ac.uk) or telephone: 020 7040 5937

Lisa Benn on:

Email: [Lisa.Benn.1@city.ac.uk](mailto:Lisa.Benn.1@city.ac.uk) or telephone: 020 7040 5823

**St Bartholomew School of Nursing & Midwifery**

**APPENDIX 2**

Dr Alan Simpson  
Senior Research Fellow

Philpot Street  
Whitechapel  
London E1 2EA  
T +44 (0)20 7040 5937  
F +44 (0)20 7040 5811  
A.Simpson@city.ac.uk

www.city.ac.uk/barts

**LETTER OF INVITATION**

Centre Number:           :  
Study Number:  
Participant Identification Number:

**Title of Project: Research to inform a mental health carers' curriculum**

Dear NAME,

Thank you for contacting us to express an interest in taking part in a research study that was advertised on the Supporting Carers Better Network.

Researchers at City University, London are working with the Supporting Carers Better Network to identify what needs to be included in the education and training of mental health staff and carer support workers to address the needs of mental health carers. This will be used to inform the development of a nationally-accredited curriculum and training modules.

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. An information sheet and two copies of a consent form are enclosed with this letter.

Please take time to read the information carefully to decide whether or not you wish to take part. Talk to others about the study if you wish.

You may contact me, Alan Simpson, on 020 7040 5937 or email [A.simpson@city.ac.uk](mailto:A.simpson@city.ac.uk) if you have any questions.

You are free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care or support you receive or your employment.

Yours sincerely,

Dr Alan Simpson  
Senior Research Fellow

Tel: 020 7040 5937  
Email: [A.Simpson@city.ac.uk](mailto:A.Simpson@city.ac.uk)

**St Bartholomew School of Nursing & Midwifery**

**APPENDIX 3**

**Participant Information Sheet v1**

Research Ethics Committee Ref: 06/Q0605/105

**Research to inform a mental health carers' curriculum**

Dr Alan Simpson  
Senior Research Fellow

Philpot Street  
Whitechapel  
London E1 2EA  
T +44 (0)20 7040 5937  
F +44 (0)20 7040 5811  
A.Simpson@city.ac.uk

[www.city.ac.uk/barts](http://www.city.ac.uk/barts)

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish.

- Part 1 tells you the purpose of this study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the conduct of the study.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

**Part 1**

**What is the purpose of the study?**

Despite numerous policy developments, the mental health workforce remains frequently unaware of the role that carers play in the care of people in mental distress, of how often carers are excluded from assessments, care planning and aftercare arrangements, and how carers' multiple needs are overlooked. Reviews of education and training provision for the mental health workforce highlight the continuing lack of carer focus and involvement.

Researchers at City University, London are working with the Supporting Carers Better Network to identify what needs to be included in the education and training of mental health staff and carer support workers to address the needs of mental health carers. This will be used to inform the development of a nationally-accredited curriculum and training modules.

**Why have I been chosen?**

We are inviting mental health carers, carer support workers or advocates, mental health professionals and mental health service users that are members of the Supporting Carers Better Network to take part.

**Do I have to take part?**

No. It is up to you to decide whether or not to take part. If you do, you can keep this information sheet and will be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care or support you receive or employment.

**What will happen to me if I take part?**

We will be running nine focus groups. There will be three groups for carers, two for carer support workers, two for mental health professionals and two for service users.

You are invited to participate in a focus group to discuss with others what you would like to see included in education and training about the needs of mental health carers. Each group will be facilitated by an experienced researcher.

Notes will be taken during focus groups but all views expressed will be recorded anonymously. No names or other identifying information will be used.

All of the focus groups will take place at City University in London during October and November 2006 and will last two hours including time for introductions and 'good-byes'. If you agree to take part, full details about the venue, date and time of groups will be provided. Carers and service users will be paid £10 on the day for their participation to help defer any travel costs.

**What are the possible disadvantages and risks of taking part?**

We do not believe that participation in this study carries any risks. However, it is possible that discussion of sensitive or upsetting issues may cause some distress. Experienced, trained mental health staff will be on hand to provide comfort and support should the need arise and contact details of someone to speak to at a later date if required will also be provided.

**What happens after the study stops?**

The study will run until the end of December 2006. Final reports will be sent to all participants that would like a copy. The findings in the report will inform the development of a nationally-accredited curriculum and training modules for mental health staff and carer support workers.

**What if there is a problem?**

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

**Will my taking part in the study be kept confidential?**

Yes. All the information about your participation in this study will be kept confidential. The details are included in Part 2.

**Contact Details:**

Researcher: Dr Alan Simpson  
Email: [A.Simpson@city.ac.uk](mailto:A.Simpson@city.ac.uk)  
Telephone: 020 7040 5937

*This completes Part 1 of the Information Sheet.*

*If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.*

## Part 2

### ***What will happen if I don't want to carry on with the study?***

You are free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care or support you receive or employment. Any data collected prior to your withdrawal will not be used in the study.

### **What if there is a problem?**

Complaints: If you have a concern about any aspect of this study, you should ask to speak with the researcher Dr Alan Simpson, who will do his best to answer your questions (Telephone: 020 7040 5937). If you remain unhappy and wish to complain formally, you can do this through City University. Please contact:

Dr Naomi Hammond, City University Ethics Committee Secretary  
Telephone: 020 7040 8106

Harm: It is very unlikely that this study will cause any harm. However, City University has extensive insurance cover with suitable indemnity concerning negligent harm. This insurance cover includes Employers and Public Liability. City University also has insurance policies arranged for No Fault Compensation cover. For further information, please contact:

Ms Aquila Muir, Research Administrator  
Telephone: 020 7040 5783  
Email: [a.muir@city.ac.uk](mailto:a.muir@city.ac.uk)

### **Will my taking part in this study be kept confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential. Storage of identifying details (names and contact details) of participants will be stored securely on City University password protected computer systems or in locked cabinets.

Written notes will be taken at the focus groups. These will be typed up as transcripts. All transcripts from the focus groups will be made anonymous before storage on computer. No names or identifying information will be used in reports, publications or presentations. Only members of the research team will have access to identifiable data. Data discussed with members of the Expert Steering Group will be anonymous.

University procedures for handling, processing, storage and destruction of data (information) are compliant with the Data Protection Act 1998.

### **What will happen to the results of the research study?**

A report at the end of the study will be submitted to the sponsors, *Supporting Carers Better Network*. The report will be available for download from the website of *Supporting Carers Better Network* and the research project website to be established at [www.citypsych.com](http://www.citypsych.com). Paper copies will be available from Dr Alan Simpson on request. Shorter reports may also be published in professional journals or presented at conferences. No individuals will be identified in any of these reports.

### **Who is organising and funding the research?**

The research is being organised and conducted by City University. It is funded by *Supporting Carers Better Network*, part of *Together*, a national charity.

**Who has reviewed the study?**

This study was given a favourable ethical opinion for conduct in City University by the East London and the City Research Ethics Committee in September 2006.

**Information sheet and consent forms**

You may keep this information sheet.

If you have now decided that you wish to take part in this study, please sign both copies of the consent form enclosed and return them in the stamped, addressed envelope enclosed.

We will sign and return one copy for you to keep for your records.

**Thank you for considering taking part in this study and taking time to read this sheet.**

**St Bartholomew School of Nursing & Midwifery**

**APPENDIX 4**

Dr Alan Simpson  
Senior Research Fellow

Philpot Street  
Whitechapel  
London E1 2EA  
T +44 (0)20 7040 5937  
F +44 (0)20 7040 5811  
A.Simpson@city.ac.uk

www.city.ac.uk/barts

**CONSENT FORM**

Centre Number:  
Study Number:  
Participant Identification Number:

**Title of Project: Research to inform a mental health carers' curriculum**

Name of Researcher: Dr Alan Simpson

**Please initial box**

1. I confirm that I have read and understand the information sheet dated 17.07.06  (version 1)  
for the above study. I have had the opportunity to consider the  
information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at  any  
time without giving any reason, without my medical care or legal rights being affected.
3. I understand that data collected during the study, may be looked at by   
responsible individuals from City University and from regulatory authorities. I give  
permission for these individuals to have access to my records.
4. I agree to take part in the above study.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Person taking consent  
(if different from researcher)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

When completed, 1 for participant; 1 for researcher site file.

**St Bartholomew School of Nursing & Midwifery**

**APPENDIX 5**

**Focus Group Interview Schedule (Outline)**

**Research to inform a mental health carers' curriculum**

Dr Alan Simpson  
Senior Research Fellow

Philpot Street  
Whitechapel  
London E1 2EA  
T +44 (0)20 7040 5937  
F +44 (0)20 7040 5811  
A.Simpson@city.ac.uk

[www.city.ac.uk/barts](http://www.city.ac.uk/barts)

**Introductions (10 minutes)**

Introduce ourselves

Briefly outline the project and the purpose of the focus groups today. Explain what we will be doing (facilitator and recorder). Collate views from this and other groups.

Ask each person to introduce themselves.

**Question 1: (Blocks and barriers) (Acts as warm-up & offload time) (20 mins)**

Staff - What are your experiences of the difficulties of working effectively with carers? What stops it happening?

Carers – What are your experiences of being heard, involved and supported as a carer?

**Question 2: (Knowledge, skills and abilities) (10 mins)**

All - What knowledge, skills and abilities do you think mental health staff need to work effectively with carers? (Include cultural sensitivity and competencies)

**Question 3: (Values and attitudes) (10 mins)**

All - What about the values and attitudes that staff have? What behaviours or qualities do staff require to work well with carers? What negative values or attitudes have you encountered? (Include cultural sensitivity & competencies)

**Question 4: (Content) (20 mins)**

So, given all the above and thinking about the work of mental health staff and carer support workers, what do you think needs to be included in their education and training to enable them/you to work more effectively with carers of people with mental health difficulties?

**Question 5: (Education & training; delivery & accreditation) (20 mins)**

What is the best way for staff to learn about the things you have identified? What works well or is less useful? What would be the best way to provide such training?

**Question 6: (Carer involvement) (10 mins)**

Would you like to see carers, carer organisations and/or independent carer trainers involved in designing and delivering that education/training programme? What sort of involvement should carers have?

**Question 7: (Levels) (5 mins)**

The education or training will be for mental health staff including nurses, doctors, social workers, occupational therapists and support workers. It will also be for carer support workers and carer assessment workers.

Do you think everybody should receive the same education and training or do people in different jobs need different types or levels of education and training? How could we evaluate and reward their learning?

**Warm-down and thank-you (15 minutes)**

Thank everyone for taking part

Ask each person to say **one thing negative** they have heard today they would happily leave in the room when they leave and **one thing positive** they cheerfully will take with them.

End.

Total 120 minutes

## St Bartholomew School of Nursing &amp; Midwifery

## APPENDIX 6

## Focus Group Postal Questionnaire

## Research to inform a mental health carers' curriculum

Despite numerous policy developments, the mental health workforce remains frequently unaware of the role that carers play in the care of people in mental distress, of how often carers are excluded from assessments, care planning and aftercare arrangements, and how carers' multiple needs are overlooked. Reviews of education and training provision for the mental health workforce highlight the continuing lack of carer focus and involvement.

Researchers at City University, London are working with the Supporting Carers Better Network to identify what needs to be included in the **education and training of mental health staff and carer support workers** to address the needs of mental health carers. This will be used to inform the development of a nationally-accredited curriculum and training modules.

Your group has kindly offered to discuss and identify what you think are the priorities for inclusion in that education and training.

The following questionnaire contains seven topic areas that we would like you to discuss. We would like you as a group to identify the things that you think are most important and write or type them on this form and send it back to us at the address below. **Please complete just one form for your group.**

Obviously there is a lot that can be said about each of these topics but please do not send us any additional sheets of paper or information, as we have very limited time in which to collate and analyse all of the views and priorities from this and other groups across the country.

Please enter details of your group and the number of people consulted on the final page of the questionnaire.

Then send your completed questionnaire to either name and the address below by **Friday 1<sup>st</sup> December 2006.**

We will send you a copy of the final report when it is ready – probably in February 2007. Thank you for your help with this.

Dr Alan Simpson  
Senior Research Fellow  
020 7040 5937  
[A.Simpson@city.ac.uk](mailto:A.Simpson@city.ac.uk)

Ms Lisa Benn  
Research Assistant  
020 7040 5823  
[Lisa.Benn.1@city.ac.uk](mailto:Lisa.Benn.1@city.ac.uk)

City University  
St Bartholomew School of Nursing & Midwifery  
Philpot Street  
Whitechapel  
London E1 2EA

**Question 1: (Blocks and barriers)**

Carers – What are your experiences of being heard, involved and supported as a carer of someone with mental health problems?

**Question 2: (Knowledge, skills and abilities)**

What knowledge, skills and abilities do you think mental health staff require to work effectively with carers?

**Question 3: (Values and attitudes)**

What about the values and attitudes that staff have? What behaviours or qualities do staff require to work well with carers?

**Question 4: (Content)**

So, given all the above and thinking about the work of mental health staff and carer support workers, what do you think needs to be included in their education and training to enable them to work more effectively with carers of people with mental health difficulties?

**Question 5: (Education & training; delivery & accreditation)**

What is the best way for staff to learn about the things you have identified? What works well or is less useful? What would be the best way to provide such training?

**Question 6: (Carer involvement)**

Would you like to see carers, carer organisations and/or independent carer trainers involved in designing and delivering that education/training programme? What sort of involvement should carers have?

**Question 7: (Levels)**

The education or training will be for mental health staff including nurses, doctors, social workers, occupational therapists and support workers. It will also be for carer support workers and carer assessment workers.

Do you think everybody should receive the same education and training or do people in different jobs need different types or levels of education and training? How could we evaluate and reward their learning?

**Thank-you to everybody for taking part.**

PLEASE COMPLETE THE FOLLOWING:

**Meeting or Group Type/Name (e.g. Melthorpe Carers Support Group)**

---

**Number of people consulted (e.g. 8 carers, 2 carer support workers)**

---

## St Bartholomew School of Nursing &amp; Midwifery

## APPENDIX 7

## NATIONAL MENTAL HEALTH CARERS CURRICULUM SURVEY

The Supporting Carers Better Network\* has commissioned researchers at City University, London to identify what needs to be included in the **education and training of mental health staff and carer support workers** to improve the support provided to mental health carers. This will be used to inform the development of nationally-accredited curriculum and training modules.

We have conducted a literature review and focus groups with numerous stakeholders to identify suggestions for the content, design and delivery of future education and training. Now, we hope to identify examples of good practice, innovative approaches and successful education and/or training that address working with mental health carers that is already being provided to professional mental health staff or support workers. We are also interested in any particular difficulties faced.

This survey questionnaire is being sent to educators and trainers at higher education institutions, various charitable and voluntary organisations, health and social care organisations and independent carer trainers.

We would be extremely grateful if you could complete this survey for any programmes or courses you think are relevant.

- Complete several questionnaires for different courses or modules if you wish.
- Adapt the form or add sections if you think there is information we should know that has not been requested or skip sections if they are not relevant to you.

**Please contact us by email or telephone if you have any queries or would prefer to complete the questionnaire with us over the phone.**

We recognise that you will have many demands on your time but hope you can spare a few minutes to complete as much of the questionnaire as possible. Please forward this questionnaire to any colleagues you think would be interested.

**Please return completed questionnaires by Monday 18<sup>th</sup> December 2006 by email or post to:**

Dr Alan Simpson  
Senior Research Fellow  
020 7040 5937

[A.Simpson@city.ac.uk](mailto:A.Simpson@city.ac.uk)  
[www.citypsych.com](http://www.citypsych.com)

OR Ms Lisa Benn  
Research Assistant  
020 7040 5823

[Lisa.Benn.1@city.ac.uk](mailto:Lisa.Benn.1@city.ac.uk)

City University  
St Bartholomew School of Nursing & Midwifery  
Philpot Street  
London E1 2EA

We will send you a copy of the final report when it is ready – probably in February 2007. Thank you for your help with this.

**Please complete the questionnaire below. Thank you.**

\*The Supporting (Mental Health) Carers Better Network is run by the national charity Together to support all people supporting carers in mental health. See: <http://www.scbnetwork.org/>

- 1. Your name:**
- 2. Your organisation:**
- 3. Your contact details:**
- 4. Title of course/module/programme:**
- 5. Educational level (induction, team-building, workplace learning, certificate, pre-registration diploma or degree, post-graduate, etc):**
- 6. Who the course is targeted at (e.g. nurses, support workers, medical students):**
- 7. Please tell us about the aims and content:**
- 8. Anything you are particularly proud of:**
- 9. Any particular difficulties faced:**
- 10. Level of carer involvement (Please rate using scale below and add any comments):**

Level 1: NO involvement

Level 2: Limited involvement: Carers give the odd lecture etc. but they have no opportunity to shape curriculum content etc.

Level 3: Growing involvement: Carers contributing to at least 2 of the following: module planning, delivery, student selection, assessment, management or evaluation.

Level 4: Collaboration: Carers involved in at least 3 of the level 2 activities.

Level 5: Partnership: Carers and teaching staff work together systematically and strategically across all areas.

Level 6: Carer owned: Carer(s) 'own', plan and deliver course.

- 11. Are carers who get involved supported, remunerated, reimbursed for travel, childcare and other carer activity, respite, etc? If so, how?**
- 12. Are cultural issues relevant to carers addressed and if so, how?**
- 13. Funding source/period (and amount if possible)?**
- 14. Assessment of knowledge, skills, competencies (what and how?)**
- 15. Success of course (popularity, applications, evaluations):**
- 16. Planned changes or new programmes:**
- 17. Anything else you want to tell us:**

Please send us any course details or materials if you would like to do so. We will send you a copy of the final report in the spring of 2007.

**Thank you very much for your help.**

