Supporting carers for people with mental health problems: needs assessment to service provision

Final report to the Big Lottery Fund

C.A. Robinson[1], D. Seddon[1], A. Krayer[1], Y. Tommis[1], A. Roberts[2,] B. Gray

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[1]CARES, School of Social Sciences, Bangor University
[2]Crossroads Care, Wales

Executive summary

Policy and practice guidance advocates the involvement of carers who look after someone with mental health problems in care decisions and treatments. However, research suggests that carers are still experiencing social and personal exclusion and often feel ignored by services (e.g., Askey, *et al*., 2009; Lyons *et al*., 2009; Pinfold & Corry, 2003). Thus, the overall purpose of the research described here was to provide an evidence base to inform the development of effective and inclusive services which facilitate the social inclusion of carers for people with mental health problems. There were five key research aims:

- To describe the *strategic* arrangements to support carers for people with mental health problems across Wales
- To identify the needs and note the services responses to those needs of a broadly representative sample of carers for people with mental health problems.
- To identify factors which hinder and factors which facilitate the social inclusion of carers for people with mental health problems
- To highlight, from a number of different stakeholder perspectives, the ways in which carers for people with mental health problems can be supported to play a full part in economic, social and community activities
- To inform the planning, development and implementation of services to support carers for people with mental health problems

Adopting a multi-method approach, we collected initial survey data from eighty-one carers and subsequently conducted in-depth interviews with seventy-six members of staff and thirty-six carers. Twelve carers were re-interviewed approximately seven months later.

Findings

Findings from the current study highlight that there is still a gap between policy guidance and current practice in relation to carers. Becoming a carer for someone with mental health problems affects the life course and can dramatically change expectations. Caring for someone with mental health problems has a ripple effect on all aspects of a carer's life such as family relationships, physical and mental health, the ability to form and maintain friendships, being able to undertake paid employment and financial expectations. In order to cope, professional support for carers is important and low perceived control over and involvement in service provision and treatment can increase feelings of stress and helplessness. From the perspective of carers, disregard of their expertise by health and social care professionals may impede recovery of care-recipients. Overall, the implications of carers' social exclusion need to be

comprehensively addressed by social care, health and voluntary professionals as well as planners and policy makers in a holistic manner. Of importance is the recognition that carers all undertake individual journeys and have differing needs at different times.

Key implications for policy and practice

- There needs to be a debate about the meaning of mental health and illness, notions of recovery and underlying values and approaches in the practice and political arenas.

- Government needs to ensure that professionals work towards the vision for carers set-out in the Carers Strategies (Department of Health, 2008; Welsh Assembly Governmnet, 2008), such as recognition of carers as experts with access to integrated and personalised services.

- Government needs to ensure that legislation and policies unambiguously set out carer's right to information and promote a clear-cut framework for sharing information such as those developed by Pinfold *et al*. (2004) and Slade *et al*. (2007).

- Comprehensive education and training about carers' rights and issues around confidentiality and inclusion of carers should be provided at all levels of mental health service provision, including at primary care level; Benn and Simpson's (2007) three stage model is a good example.

- Professionals should aim to develop a relationship with carers and care-recipients based on mutual respect and dignity; use of models such as the *therapeutic quadrangle* (*Nolan et al.*, 2008) and *the triangle of care* would be helpful in this respect (Princess Royal Trust for Carers with the National Mental Health Development Unit, 2010)

- Responsibilities for conducting carer assessments needs to be clearly defined and appropriate training needs to be offered to staff to conduct these in an empathic and sensitive manner.

- The type and range of services offered need to be sensitive to individual' needs; given the significant distress associated with caring, resources and programmes need to be developed and implemented to assist carers in acquiring skills and information necessary to manage caring demands.

- Issues around social exclusion of carers need to be addressed at policy and practice level; for example:

  o Tax and benefit systems should facilitate carers' participation in employment.

- o More widespread implementation and evaluation of anti-stigma campaigns (such as '*time to change*'; http://www.time-to-change.org.uk) with particular groups including school children, police, and health and social care staff.

- For carers to have access to interventions or services that are relevant to them such as family therapy, counselling, respite, access to carer support groups or independent advocacy.

- Timely support for carers with a recognition that needs might change over the caring journey.

Summary carer recommendations

- Recognition of carers – tackle issues of confidentiality and inclusion of carers in the CPA

- Access for carers to financial support and free legal advice/ independent advocacy

- Appropriate respite

- Training and comprehensive information for carers

- Improved communication between services **and** between services and carers

- Raising awareness of mental health issues in the wider community

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Chapter 1: Introduction and background

Introduction

Family carers for people with mental health problems have until recently been neglected by empirical research, which has traditionally focused on the experiences of carers for older people, in particular, carers for older people with dementia. However, recent policy initiatives, such as the Carers Strategies in England and Wales (Department of Health, 1999, 2008; Welsh Assembly Government, 2000, 2007), as well as legislation underpinning the assessment of carer need (Carers Recognition and Services Act 1995; Carers and Disabled Children Act 2000; Carers Equal Opportunities Act 2004) have not only emphasised the importance of addressing carers' needs per se, but have specifically highlighted the needs of family carers for people with mental health problems. For example, Standard Six of the National Service Framework for Mental Health (Department of Health, 1999) is *Caring About Carers.*

However, despite the raft of policy and guidance documents advocating the involvement of carers who look after someone with mental health problems in care decisions and treatments, research suggests that carers are still experiencing social and personal exclusion and often feel ignored by services (e.g., Askey, *et al*., 2009; Lyons *et al*., 2009; Pinfold & Corry, 2003). Thus, the overall purpose of the research described here was to provide an evidence base to inform the development of effective and inclusive services which facilitate the social inclusion of carers for people with mental health problems. There were five key research aims:

- To describe the *strategic* arrangements to support carers for people with mental health problems across Wales
- To identify the needs and note the services responses to those needs of a broadly representative sample of carers for people with mental health problems.
- To identify factors which hinder and factors which facilitate the social inclusion of carers for people with mental health problems
- To highlight, from a number of different stakeholder perspectives, the ways in which carers for people with mental health problems can be supported to play a full part in economic, social and community activities
- To inform the planning, development and implementation of services to support carers for people with mental health problems

Background

Supporting someone with mental health problems: carer experiences

The policy emphasis on supporting carers for people with mental health problems highlights the importance of understanding their experiences and emotions, as well as developing interventions to address their needs and promote their social inclusion. According to Arksey (2002, 2003), carers for people with mental health problems go through a variety of often difficult and conflicting emotions, involving frustration, despair and isolation, as well as happiness, satisfaction and relief when things are going well. Caring for people with mental health problems can generate fear, disbelief, guilt and chaos, which are controlled through information, optimism, routine living and social expectation (James, 1989). In many cases, difficult and profoundly troubling feelings leave family carers with the frightening prospect that they are isolated and alone. They can often feel guilty even about minor things, such as asking others (including family members, neighbours, friends or professionals) for help (Arksey 2002, 2003; Ashworth & Baker, 2000; Barnett & Parker, 1998). The ways in which professionals manage the difficult emotions presented by carers remains relatively unexplored. The research reported here goes some way to addressing this gap by considering professional understanding of carers' emotions and exploring the challenging emotions that professionals suggest are associated with caring for a family member with mental health problems.

Compared with carers from other groups, carers for people with mental health problems are thought to be especially susceptible to feelings of stigma and can feel marginalised. They often avoid contact with friends, neighbours and professionals because they have deeply embedded feelings of embarrassment, shame and fear of associative stigma (Arksey 2002, 2003; Byrne, 2001; Carson & Manchershaw, 1992; Magliano *et al.,* 2005; Ostman & Kjellin, 2002). The types and patterns of exclusion that carers experience are relatively undocumented. Similarly, the practices and interventions that staff develop to tackle exclusion also remain relatively unexplored, despite the fact that promoting social inclusion is high on the policy agenda, alongside the delivery of personalized services that support carers *in* and *beyond* their caring role (Department of Health, 1999, 2008).

By way of contrast, research suggests that there is satisfaction and emotional reward in caring for a family member with mental health issues and sustaining a comfortable, loving and caring relationship. Seeing someone go through recovery, recuperate, learn to cope with difficulties such as hearing voices and start a life afresh in the community is arguably a major reward for carers and also for professionals (Arksey, 2002, 2003; Chang & Horrocks ,2006; Coleman & Smith, 2007; Pinfold *et al*., 2004). Conceptual models of caregiving have captured the dynamic, multi-dimensional nature of carer experiences (Nolan *et al.,* 2003) as well as the complexity and mutuality of caring relationships (Forbat, 2005).

Supporting a parent or sibling with mental health problems: the experiences of young carers

According to recent studies, growing numbers of children, described in the literature as young carers, are taking up the responsibilities of caring for parents with serious mental health problems (Aldridge, 2006; Aldridge & Becker, 2003; Becker, 2004). The 2001 Census estimates that there are around 175,000 young carers in the United Kingdom; young carers are defined as being under the age of 18 whose lives are affected by the care needs of another person who has a disability or long term illness. Twenty-nine percent of all young carers are providing care for someone with a mental health problem (Dearden & Becker, 2004). Young carers provide, or help to provide, care and support to that person and take on a level of responsibility usually associated with an adult. The person they care for is usually a parent or sibling (Aldridge, 2006; Aldridge & Becker, 2003; Becker, 2004). In addition to practical care, these young carers are involved in providing emotional help such as crisis support or ongoing support when parents undergo significant downturns in their mental health. They are on-hand to assess and monitor the emotional health and well-being of their parents and often administer medication at designated times (Aldridge, 2006; Aldridge & Becker, 2003). Recently, the experiences and support needs of young carers have been highlighted by campaign groups such as Rethink, The Children's Society and Carers UK (Aldridge, 2006). Much contemporary research has been informed by qualitative approaches that have highlighted the needs of families when parents have a mental illness (Aldridge, 2006; Aldridge & Becker, 2003; Gray, 2003). Evidence suggests that young carers are seldom consulted about health and social care provision and there is a shortage of consistent plans for multidisciplinary training or partnership working to support these children and their families (Corlyon *et al.,* 2001; Underdown, 2002).

Engaging with services and seeking support – policy context

The Carers Strategies in England and Wales acknowledge the contribution that carers make to supporting people with mental health problems. They aim to:

- Empower carers by giving them greater control over the range, nature and timing of services.
- Mobilise community support to carers.
- Respond to the diversity of care-giving contexts.

Five priority action areas underpin the Strategies, which were launched in 1999 and up-dated in 2008 in England and launched in 2000 and subsequently updated in 2007 in Wales. These relate to: care for carers; information; local support; young carers; and, carers and employment. The *Strategies* promise that carers will be better supported via the provision of new services and in 2000 Carers Special Grant money was made available to encourage innovation in providing flexible services to carers. Originally available for three years and subsequently extended until 2005/2006 in Wales, this money has now been incorporated into the Revenue Support Grant to Local Authorities. New sources of funding have been made available via the Mental Health Carers Grant, which was introduced in Wales in 2006 to develop support for carers for people with mental health problems. Similar initiatives have been introduced in England to provide short-term emergency respite for carers. Notwithstanding the increased policy commitment to supporting carers and the introduction of specific pump-priming monies for those looking after people with mental health problems, evidence suggests that the lack of significant investment in social care services makes it difficult to translate this commitment into practice (Hudson & Henwood, 2008).

Taking stock of the progress achieved to date, as well as legislative changes relating to carer assessment, the *Carers Strategy for Wales Action Plan (*Welsh Assembly Government, 2007) outlines the vision for a revised Carers Strategy that delivers measurable improvements to carers' lives. Key objectives include ensuring that carers:

- Are not disadvantaged because of their caring responsibilities.
- Are listened to.
- Maintain as normal a life as possible outside of their caring role.
- Have timely access to a carer assessment and to services.

These objectives reflect the Welsh Assembly Government's strategic direction for health and social care (Welsh Assembly Government,

2005; 2007b), namely, to develop outcome-focused provision that encourages independence and choice. The Welsh Assembly Government worked alongside the Department of Health to develop a new ten-year UK Strategy for carer support (Department of Health, 2008). Whilst it is committed to developing a revised Wales Strategy, the timescales for development and implementation are unclear.

Engaging with services and seeking support – carer experiences

Clarke *et al.,* (2006) suggest that carers of all ages have been activated, empowered, 'responsibilised' but also abandoned. Many feel at a loss as to what to do in caring for someone with mental health problems and lack vital information and necessary training to provide adequate support (Pinfold *et al.,* 2004). Seedhouse (2000) lays the foundations of a holistic approach by taking into account the basic emotional, ethical and human dimensions of care. People are not only physical beings but have complex mental and emotional lives. Caring for carers in mental health provides a prime example of the importance of engaging emotions. For example, the study of Taggart *et al.,* (2000) shows the success of professionals when they engage the emotions of families, helping people to 'feel human again'.

Collaboration between carers and professionals is essential; evidence points to the importance of close and consistent liaison with carers from the point of first contact with services as well as the necessity of taking carers' own beliefs and requirements into account in offering services, if subsequent relationships are to achieve the desired level of collaboration (Repper *et al.,* 2006).

Services to carers are not defined in legislation; however, organizations are encouraged to provide services that help to maintain carer health and well-being. This requires innovation at strategic and practice levels. It also requires practitioners to distinguish outcomes from needs and services. Research suggests that support is often inconsistent with carer-defined outcomes and needs and highlights the potential for improvement, both in terms of access to services and their scope (Thompson *et al.,* 2007). Variation in access to services across the UK, and indeed across Europe, is well documented (Hudson & Henwood, 2008; Lamura *et al.,* 2008). Despite the introduction of Fair Access to Care Guidelines, which seek to increase consistency and transparency, there remain differences in the way eligibility criteria for social care services are applied (Hudson & Henwood, 2008). Also, variations in professional judgment (for example, whether to meet eligible needs through community care services or specific carer services), as well

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as Local Authority discretion to determine social care budgets lead to differences in the availability and types of provision (Welsh Assembly Government, 2007a; Care and Social Services Inspectorate Wales, 2008; Hudson & Henwood, 2008). Evidence suggests that carer support continues to be shaped by a service-led approach that offers traditional social care services, such as help with personal care tasks, but because of increasingly tight eligibility criteria can fail to support other needs (Hudson & Henwood, 2008), such as help with the emotional aspects of caring for someone with a mental health problem.

Confidentiality and smokescreens

Information is one of three priority action areas underpinning the Carers Strategies in England and Wales, alongside support and care. Carers for people with mental health problems often find obtaining relevant information very difficult; many report that 'confidentiality smokescreens' make matters worse, preventing carers from understanding and learning important information about the issues they and the individual with mental health problems are facing and how best to deal with the challenges of caring, especially in times of crisis (Hervey & Ramsay 2004; Rapaport *et al.,* 2006; Repper *et al.,* 2006). According to Repper *et al.,* (2006), carers frequently report that confidentiality smokescreens result in a lack of dialogue with professionals and shortcomings in information sharing; carers are often kept 'outside the loop' but expected to keep on caring however challenging their circumstances. The authors go on to suggest that many carers feel that they are undervalued and treated unequally, as professionals often want information about service users' problems, but give little or no information in return. Because of confidentiality smokescreens, carers may not be given information, which is vital to their caring role, and which may be necessary for their own protection, for the management of risk, or for the safety of others. This can induce feelings of isolation, anxiety and resentment. The potential to lead to a culture of blame between the carer and person with mental health problems is noted (NSF (Scotland) 2000; Arksey 2002, 2003; Pinfold *et al.,* 2004; Repper *et al.,* 2006).

Whilst carers have the capacity to be 'experts' in mental health care and have experiential-based knowledge to inform effective care plans, evidence suggests that carers are often excluded from decision-making (Repper *et al*., 2006). Health and social care professionals often claim that they are unable to keep carers informed about progress and plans (even when these include discharge to live with carers) because of the need to respect confidentiality. They also often report lacking time and resources to involve carers and meet their needs. These needs include:

recognition and respect; information, advice and encouragement; involvement in care planning; and, effective access to the care team, not only to seek advice, but to convey information (Repper *et al.,* 2006). Deficits in professional training and conceptual ambiguities about the carer role have created uncertainties for professionals in their relationships with carers, particularly in regard to issues involving confidentiality and information sharing. There is agreement that professionals should receive specific training in: assessing carer need; managing conflicting views, legal rights and confidentiality issues; assisting carers in managing difficult behaviour; and, accessing local resources. Many studies propose that some training should be provided by carers themselves (Arksey 2002, 2003; Machin 2004; Pinfold *et al.,* 2004; Rapaport *et al.,* 2006; Repper *et al*., 2006; Scourfield 2005).

Chapter 2: Method

Introduction

Adopting a multi-method approach we collected initial survey data from carers and subsequently conducted in-depth interviews with strategic and operational members of staff and carers. All participants received a study pack including a letter of invitation and a study information sheet (Appendix A). The study was approved by the Wales Multi-Centre Research Ethics Committee and the Association of Directors of Social Services.

Survey

A questionnaire (Appendix B) was sent out on behalf of the research team through carer organisations such as Crossroads, the Princess Royal Trust for Carers and Hafal (a voluntary organisation in Wales that supports people with mental health problems and their families). Eighty-one carers completed and returned a questionnaire. The questionnaire was designed to explore the needs and experiences of carers caring for someone with mental health problems. Areas covered in the questionnaire included carer characteristics, caring arrangements, caring experience and measures of functioning health and well-being (SF12 v2, Ware et al., 2002). Table 2.1. shows the characteristics of the survey respondents.

Table 2.1 Characteristics of survey respondents (N = 81)

		n (%)
Gender		
(N = 81)	Male	25 (30.9)
	Female	56 (69.1)
Care-recipient		
(n = 80)	Child	35 (43.8)
	Husband/wife/partner	29 (36.2)
	Parent/parent-in-law	13 (16.2)
	Other	2 (2.5)
	Friend/Neighbour	1 (1.2)
Main diagnosis		
(n = 77)	No diagnosis	5 (6.5)
	Schizophrenia	22 (28.6)
	Bi-polar	14 (18.2)
	Multiple	14 (18.2)
	Other	8 (10.4)
	Depression	7 (9.1)
	Psychosis	3 (3.9)
	Anxiety	2 (2.6)
	Paranoia	2 (2.6)
Employment status		
(n = 80)	Retired	29 (36.2)
	Unavailable for work due to caring responsibilities	16 (20.0)
	Employed/Self-employed part-time	11 (13.8)
	Employed/Self employed full-time	10 (12.5)
	Voluntary work	5 (6.2)
	Unavailable for work due to own health problems	5 (6.2)
	Unemployed	4 (5.0)
Hours caring per week	1 – 19 hours	19 (24.1)
(n = 79)	20 – 49 hours	24 (30.4)
	50 hours or more	36 (45.6)
Live with		
(n = 80)	Yes	50 (62.5)
	No	30 (37.5)
Age	Mean (SD)	55.0 (14.1)
(n = 80)	Range	18 – 80 yrs

Interviews with strategic and operational staff

Interviews with strategic staff

Interview sample

Sixty-four members of staff were interviewed (Appendix C, interview schedule); the sample was drawn from planning and management in: community psychiatric nursing; discharge liaison; social services; primary care; acute mental health care provision; and, key voluntary sector agencies. A breakdown of the sample by employing organisation is provided in Table 2.2.

Table 2.2 Staff sample by employing organisation

Employing organisation	Total number of staff interviewed
Local Authority Social Services Department	30
Local Health Board	15
Voluntary Sector	9
NHS Secondary Care	8
NHS - Primary Care	2

Strategic staff were nominated by the Director or Chief Executive of their organisation because of their first-hand experience of planning or managing services that help to support people with mental health problems and their carers. Strategic staff served city, town and rural areas across Wales.

Areas of interest

The purpose of the interviews was to gather information about local services and collaborative arrangements between local authorities, the health service and the voluntary sector. Interviews were framed by a topic guide, which helped to keep discussions focused but at the same time allowed individual perspectives and viewpoints to surface. In developing the topic guide we drew on the most recent research, policy and practice literature that considers the experiences and support needs of carers. The areas of substantive interest addressed in the telephone interviews with strategic staff included:
- Exploration of the challenges facing carers for people with a mental health problem as perceived by staff
- Defining professional roles and responsibilities in relation to carers for people with a mental health problem

- Planning a local approach to working with carers for people with a mental health problem and their care recipient
- Awareness of the challenges faced by carers for people with a mental health problem
- Training and information needs for carers for people with a mental health problem
- Arranging, providing and co-ordinating support to carers for people with a mental health problem and their care recipient
- Strengths and weaknesses of current service provision and priority areas for future development
- Identification and implementation of good practice
- Carers' unmet needs for help and how these can be addressed

A participant information sheet and summary of the interview topic guide was sent to staff prior to the interview to ensure that the interviews were focused.

Interviews with operational staff

Interview sample

We completed in-depth semi-structured telephone interviews with twelve practitioners involved in supporting carers for people with mental health problems living in North Wales (interview schedule Appendix D). Individuals were nominated by the Chief Executive or Director of their organisation because of their practice-based experience. They worked in the statutory and voluntary sectors, including Crossroads (=5), Princess Royal Trust for Carers (n=2) and Community Mental Health Teams (n=5).

Areas of interest

The interviews with practitioners augmented some of the areas of interest addressed in the work with strategic staff and included:
- Identifying carers for people with mental health problems
- Perceptions of the challenges faces by carers for people with mental health problems
- Defining professional roles and responsibilities in relation to carers for people with a mental health problem and their families
- Planning a local approach to working with carers for people with mental health problems and their families and making information available to them
- Interpreting current guidelines and protocols, including the National Service Framework, the Mental Health Act and the Mental Health Strategy in Wales
- Impact of the Carers and Disabled Children Act
- Establishing relationships with carers and their families, discussing the caring role and identifying their needs

- Arranging, providing and co-ordinating support to carers for people with mental health problems
- Working at a multidisciplinary level
- Strengths and weaknesses of current service provision, models of service delivery and priority areas for development
- Examples of good and innovative practice
- Involving carers in the assessment, care planning and review processes and enabling them to shape the future direction of services
- Staff training and support needs relating to carers for people with mental health problems
- Unmet need of carers for people with mental health problems and how these might be met

As with the strategic staff interviews, a participant information sheet and summary of the interview topic guide was sent to practitioners prior to the interview.

Interviews with carers

Interview sample

A sub-sample of fifty-one carers who responded to the postal questionnaire and indicated their willingness to be interviewed was identified. We sent a letter of invitation, information sheet and consent form to these individuals. We achieved an interview sample of thirty-six carers. Follow-up interviews were completed with twelve of these. A break-down of the sample can be found in Table 2.3.

Participants were recruited from across Wales and were drawn from urban and rural areas.

Table 2.3 Characteristics of carers interviewed (N = 36)

		n (%)
Gender		
	Male	9 (25.0)
	Female	27 (75.5)
Care-recipient		
	Child	19 (52.8)
	Husband/wife/partner	13 (36.1)
	Parent/parent-in-law	3 (8.3)
	Other	1 (2.8)
Main diagnosis		
	No diagnosis	4 (11.1)
	Schizophrenia	14 (38.9)
	Bi-polar	6 (16.7)
	Depression	3 (8.3)
	Other	3 (8.3)
	Paranoia	2 (5.6)
	Multiple	2 (5.6)
	Psychosis	1 (2.8)
	Anxiety	1 (2.8)
Employment status		
	Retired	14 (38.9)
	Employed/Self employed full-time	7 (19.4)
	Unavailable for work due to caring responsibilities	7 (19.4)
	Employed/ Self employed part-time	5 (13.9)
	Voluntary work	2 (5.6)
	Unavailable for work due to own health problems	1 (2.8)
Hours caring		
	1 – 19 hours	9 (25.0)
	20 – 49 hours	10 (27.8)
	50 hours or more	16 (44.4)
	Missing	1 (2.8)
Live with		
	Yes	22 (61.1)
	No	14 (38.9)
Age	Mean (SD)	55.9 (10.0)
	Range	37 – 79 yrs

Interview approach

The interviews used a narrative approach and stories were elicited using the biographical narrative interview method (BNIM) approach by Wengraff (2001; 2009). Narrative approaches have been shown to be very effective with vulnerable groups and for exploring sensitive topics (see for example, Brannen *et al*., 2007; Holloway & Freshwater, 2007; Rapport *et al.*, 2010). Interviews took place in carers' homes and visits lasted between 1 to 3 hours.

Each interview was conducted in three phases: in the first phase a generative question was asked to elicit a narrative, in the second phase, the interviewer asked questions to clarify and/or extend issues raised in the narrative and in the last phase specific questions around barriers to services and suggestions for improvement were asked (see Appendix E). The generative question to initiate an uninterrupted narration was: *"Please tell me the story of your life from when you started to move towards becoming a carer up to now, including all the events and experiences that have been important to you personally."*

We aimed to recruit a number of carer and cared-recipient pairs to ascertain their perspectives on service provision. The interviewer left a pack for the care-recipient with the interviewee where appropriate. It became clear in some instances that it would be unsuitable to aim to recruit a cared-recipient person for a range of reasons, such as that the cared-recipient was currently in hospital or the carer did not want to inform the cared-recipient that they had participated in an interview. None of the cared-recipients responded to the invitations in the study pack. We then tried to recruit individuals with mental health problems through a range of strategies such as involving voluntary organisations, but were unable to recruit. In view of these problems we decided to interview more carers than originally planned and re-interviewed twelve carers about five months later to follow-up areas of interest identified in the interview analysis and talk about any changes in their circumstances (see Appendix F).

Data management and analysis

Survey data

Survey responses were entered into SPSS 16 and a descriptive analysis conducted. Results from the survey are included in Chapter 4: Findings from carer interviews.

Interview data

Where permission was given, interviews were recorded and transcribed. Notes were made during all the interviews and served as a back-up to the MP3 recordings. The resulting qualitative data was entered and analysed using the software package NVivo 8.

Operational and strategic staff interviews were read in detail to establish familiarity with the data. A series of codes (free nodes) was developed inductively to encapsulate emerging themes. Key themes were refined in team discussions about node definitions. Detailed analysis focused on the identification of communalities and contrasts between interviews and between operational and strategic staff (Pope, Ziebland & Mays, 2000).

For the carer interviews, the focus of the analysis was on the lived experiences of individuals over time, with a focus on processes and changes. Consequently, we produced a chronological summary of each interview to represent the lived life and all the events mentioned but the interviewees, but also broke transcripts down into units of analysis, e.g., a specific incidence like hospitalisation (Wengraff, 2001). Specific themes were developed through reading the transcripts as a whole and the units of analysis. As the interviews produced a large volume of data, coding was done using annotations and memos. Themes were developed in-depth across interviews through comparisons and the identification of patterns. This allowed us to develop an understanding of the experiences of individual interviewees over time and compare those across interviewees.

Project Reference Group

It is now widely accepted that people have a right to be consulted about and involved in research that affect them; this reflects the drive to empower people to speak out on issues that matter most to them and to influence research outcomes that have a direct impact on their lives.

A Project Reference Group (PRG) was established with the explicit aim of involving carers and people with mental health problems in the research process. The PRG comprised carers, people with mental health problems and representatives from the statutory and independent sectors. Members were recruited from a broad range of organisations in Wales, including Crossroads Care Wales, Mind and Hafal. An information Sheet was sent to members that explained the purpose of the study, as well as the importance and likely the nature of their involvement in the research process and the resources available to facilitate this. Half day meetings were

convened in accessible venues and begun with lunch. Members of the group were invited to comment on:

- The content and presentation of draft interview protocols
- The preliminary analysis of research data, for example, the interpretation of emerging findings
- Policy and practice implications

Input from PRG members helped to ensure that the research addressed issues that are most important to carers and people with mental health problems and that subsequent policy and practice recommendations were sensitive and responsive to their needs.

Resourcing working partnerships to enable participation and involvement costs is important; in line with principles of good practice (Oliver *et al*., 2004), members travelling expenses were paid. Where respite care costs were incurred, these were reimbursed.

Chapter 3: Findings from interviews with managers and practitioners

Introduction

This chapter presents key findings from the interviews with managers and practitioners. We consider issues relating to confidentiality and the sharing of information with carers, as well as carer emotions, patterns of exclusion amongst carers and the challenges facing young carers who are involved in supporting a parent with mental health problems.

The findings presented here do not reflect the full scope of the data but encapsulate a number of important areas of interest arising from our analyses. Further findings will be reported in papers for peer review and professional journals. We have used quotes from staff to illustrate the findings. The notation below each quote indicates the unique identification number given to the interviewee.

Confidentiality smokescreens: barriers to effective information sharing

Previous research has highlighted the need for a shift in organisational culture to address professional attitudes towards carers, from one of doing things 'for' or 'to' people, to one of working 'with' them and engaging with them as experts (Nolan *et al.,* 2006; Rapaport *et al.* 2006). Our findings suggest that all too often professionals hide behind confidentiality smokescreens and refuse to share or disclose much needed information to carers. Both managers and practitioners suggested that confidentiality barriers and lack of information flow between professionals and carers mean that many carers experience services as paternalistic and disempowering. Barriers erected because of confidentiality limit participation and dialogue between carers, the people that they care for and professionals.

Managers and practitioners highlighted a number of issues relating to confidentiality and the sharing of information with carers and suggested that confidentiality smokescreens create a 'wall of silence'. They conceded that this negatively affects carers' involvement with services, limits the information to which carers have access and adversely impacts upon the knowledge which carers require in order to provide care:

> *Psychiatrists used to say that whatever was said was just between their patient and them. The carer wasn't allowed to*

be involved. Confidentiality has long been a problem for carers. They keep getting told they can't participate.
CFC3.5 Mental Health Nurse Manager

It's very, very difficult for carers in the way we as a service work. Because of confidentiality, we are not always free to discuss whatever is going on with the carers and I feel sometimes that they are left out too much. We have to look at the mass resource as well and involve them as much as possible. It's very difficult for carers and very often they are left in the dark, even though they are the people that spend 24 hours with the service user.
CFC13.5 Senior Social Worker

There's also this issue: 'Well, I can't break confidentiality. I'm there for the service user, not the carer or parent' and 'the service user didn't want me to tell the carer'. Services are very much focused on the service user and their needs.
CFC27.5 GP

It's quite confidential, you don't want to be going and talking about someone's illnesses….. And, you know, you need to know as much as information of their illness and, you know, their needs but it's very difficult because of the confidentiality with sharing the information and protecting the person with mental … who's got the mental health illness, is how much information they'll share with us and can be shared.
CFC 4.6 Practitioner, Voluntary Organisation

According to managers and practitioners, frontline practitioners are prone to hide behind confidentiality and may sometimes use confidentiality issues as a reason to withhold information from carers. We found only limited evidence of practitioners acting as intermediaries to promote discussion between carers and service users concerning issues of confidentiality and appropriate information sharing. In many cases, confidentiality smokescreens, poor information sharing and lack of dialogue result in professionals not identifying people as carers:

It's been quite tricky because I think certainly in the field of mental health, there seems to be a huge issue around confidentiality. And people think I can hide a little bit behind confidentiality and people will say 'I don't want you to talk to my carer', and some professionals have taken that as a reason not to then go and engage with the carer. This means that some professionals haven't identified people as being

carers. If service users are not giving their consent they just withhold information.
CFC3.5 Mental Health Nurse Manager

Carers are often cited in the research literature as 'experts' in care who help in providing holistic and effective packages of support that contribute to the best management of mental health problems; carers have detailed knowledge of the service user which is vital in producing effective care plans. By working *with* carers in partnership, it is possible for health and social care practitioners across the statutory and independent sectors to build up a fuller picture of service users' lives, to understand their needs more holistically and to be able to assess their preferred options for care and future management (Nolan *et al*. 1996, Repper *et al.* 2006). Conversely, many carers report that they are viewed by services as 'troublemakers' or as 'part of the problem' rather than 'part of the solution' (Arksey 2002, 2003, Repper *et al*. 2006). Because of confidentiality barriers, carers are ostracized and left out of the loop of information sharing. Carers are not only told that they cannot have information because of confidentiality issues, but are also unable to communicate vital information that would give professionals a more well rounded picture of the service user's illness and the challenges of care. Reflecting on these difficulties, managers and practitioners reported:

> *Quite often, people will go and see the psychiatrist for the three monthly appointment and say: 'Yeah, yeah, everything is absolutely fine!' And the carer is sitting at home and everything really isn't absolutely fine. Because of the confidentiality thing that professionals hide behind, quite often the carer feels that the provider of services don't get the full picture.*
> *CFC52.5 Mental Health Nurse Manager*

> *[….] the confidentiality is something that we, you know, there's not really a way round it in a way.*
> *CFC31.6 Social Worker*

Both managers and practitioners conceded that in clinics, meetings and case reviews, service users are seen as the priority, while the rights and needs of the carers are a secondary and less important concern:

> *Your first duty is towards the client.*
> *CFC30.6 Social Worker*

> *We don't often get situations when we would talk to the carers individually because obviously I think you know there's issues of confidentiality again.*
> *CFC31.6 Social Worker*

> *But they do feel isolated 'cause they're not part, you know, even if they're looking after them, if you had somebody with cancer, you'd be taking them to the cancer treatment centre and you'd be in with the consultation with the consultant wouldn't you or the specialist [….] but you're not involved, as the carer of mental health people, you're not involved, er, and it – it is so frustrating.*
> *CFC32.6 Field Officer Voluntary Organisation*

Carers are not only a disadvantaged and largely invisible group in society, but also, it seems, may be neglected by professionals in practice. Rather than being positive and inclusive of carers, managers and practitioners interpret confidentiality in terms of a possible conflict of interests between the carer and service user as well as a thorny legal and ethical dilemma:

> *We have case reviews which carers are fairly routinely asked to attend. But the patient is always given the option. If the patient says, 'I don't want the carer there', we will respect that and not have the carer there. So, there's a bit of a conflict there. There's doctor/patient issue as well.*
> *CFC64.5 Senior Social Worker*

> *We do try and talk to carers, but sometimes carers are not exactly in the best interests of the patients. Sometimes, there's a conflict. You get the odd carer that really wants to control the person and, you know, you've got a parent ringing up and the child is forty.*
> *CFC59.5 GP*

Although the merits of confidentiality, disclosure and information sharing vary from case to case, carers are often perceived as over-involved and an obstacle between the service user and professional.

According to Pinfold *et al.* (2004), there is ambiguity and a lack of clarity in policy as well as a lack of guidance in professional training involving confidentiality and information sharing. Because of ambiguity in an array of policy documents and shortcomings in training, practitioners report receiving poor guidance and minimal support on methods to discuss confidentiality and information sharing with carers and service users. As a consequence, this leaves practitioners to wrestle with the difficult legal, ethical and practical

dilemmas of confidentiality and disclosure of information. Under these circumstances, and with the fear of legal or disciplinary action as well as the need to keep the trust of the service user, it is perhaps little wonder that professionals often refuse to share information and find it easier and safer to say nothing. Managers and practitioners both highlighted this dilemma when discussing carer assessments:

One of the issues that's come up is carers' assessments and confidentiality, and I know this is an issue right across the board. If a service user identifies that they don't want their carer, partner, wife, husband, whoever, to be aware or involved, where do you get to the point where you involve the carer for the carer's assessment, recognizing the duty to offer a carers' assessment to a carer? I think there is a conflict of issues of legislation that we need to get resolved. If somebody clearly states, for example, 'I don't want my wife to know what my current situation is', but the wife is putting a lot of care into that support, where do we draw the line? That's something the practitioners are asking more and more. It's becoming an issue all the time, because somebody like me's asking: 'why aren't you offering carers' assessments?'
CFC36.5 Director of Social Services

Yeah I mean confidentiality, if the service user doesn't want you to speak to their carer [….] then we can't, although we're still obliged to offer them the carer's assessment [….] it just … means you have to, you know, you just have to be very, very mindful not to break – not to break confidentiality and I'd never talk to you without actually giving away any confidential information… Um, so you can still complete an assessment and pass them on, but – but, yeah, you know, you need to be very, very mindful of confidentiality. Er, I personally, if I was going to be talking to a carer about a service user, I would prefer the service user to be present.
CFC35.6 Community Psychiatric Nurse

According to Rapaport *et al*. (2006), while the majority of initiatives support the case for disclosure and information sharing, policies and practice are generally more guarded. There is a general lack of confidence among practitioners in sharing information with carers. Managers recognize that, as a result of confidentiality smokescreens and being kept out of the health and social care loop, carers experience feelings of disempowerment, anger and isolation:

Carers get very angry and think that professionals are being unhelpful. So, there's all those feelings, of isolation, anger,

stigma and resentment. Carers have traditionally been left out.
CFC23.5 Manager, Voluntary Organisation

Confidentiality and risk management

Although managers and practitioners were reticent about information sharing and sometimes tended to erect confidentiality smokescreens in everyday practice, nearly all agreed that sharing information was vital in cases involving risk management, the safety of service users and carers and for carers in crisis. Under these circumstances, it was considered important to involve the carer:

> *We have talked to a number of carers where the person they are looking after has given quite clear and explicit permission for the psychiatrist or other mental health professionals to discuss their condition and their treatment with the family, and that has been ignored and that has actually put family members at risk because, you know, the case that I am thinking of was somebody who knew themselves when they weren't ill that they had a tendency to be violent when they were ill, and they were concerned that they might do something.*
> *CFC35.5 Team Manager, Social Work*

> *There are people who share very much what's going on with their carers and they'll be seen together and it's very much shared care, really. But there are others who don't want their mental health being talked about by anyone else. It's difficult to manage risk then. You're not allowed to tell anyone anything which can keep things safe.*
> *CFC25.5 Team Manager, Social Work*

Information can only be shared with the carer without the service user's consent in cases of, for instance, the prevention of serious crime or when the public interest in disclosure outweighs the public interest in maintaining confidentiality. Disclosure may avert or reduce a real risk of serious harm to individuals (including the user and carer) or the public generally (Machin 2004, Szmukler 2006). Research has highlighted that health and social risks may be better managed by timely access to crisis services, but many carers report difficulty in accessing services and crisis prevention when most needed or out of hours (Rethink 2003). Evidence suggests that if carers have knowledge and understanding of risk management and crisis plans, they can often persuade the service user to follow them or seek help earlier (Partners in Care 2006). Clinicians may also have a 'duty of care' over and above that of the patient, which

might well involve carers in information sharing (Szmukler 2006). The Confidentiality in Mental Health Report (2006) suggests that negotiating confidentiality barriers and information sharing is of vital importance to carers. Carers should be facilitated to share information with professionals, such as acts or threats of harm to themselves or others, abnormal behaviours, suicidal thoughts as well as positive milestones. Professionals should listen to carers' concerns in order to weigh up risk management plans to prevent tragedies that have occurred in the past. Reith (1998) suggests that the key tasks for agencies are to engage families in the care plan, explain mental illness, and involve them in the risk assessment within the frame of balancing the rights of the individual with responsibilities towards the family and wider community. Having said this, some practitioners are still uncertain how far they can involve carers, even in scenarios of risk, possible harm and safety.

Examples of good practice

Examples of good practice included the distribution of specially written leaflets for carers and professionals on confidentiality and information sharing; consciousness raising on confidentiality and carer issues; the facilitation by professionals of carers to support groups, where carers could establish peer friendships, discuss coping strategies and share general non-confidential information about mental illness, medication, odd behaviours, etc.; highlighting that carers have rights to information and support, particularly to a carer assessment; utilizing GP surgeries to identify, information share and care for carers. GP surgeries were said to act as a point of early identification of carers and an equally early point to broach the issue of consent to information share; and, finally, for professionals to act as intermediaries and negotiate confidentiality barriers and information sharing, seeing carers as part of the support package.

The negotiation of advance agreements, statements or directives, when service users were stable, had the capacity to consent and had insight into their mental health problem, was integral to treatment plans and information sharing with carers during times of illness. Sharing information about medication and side effects was seen to be particularly important. According to two managers:

> *I know there's confidentiality, but carers need to know what medication the person with mental health problems is taking, what the results can be and it's empowering the carer.*
> *CFC16.5 Mental Health Service Manager*
>
> *Many of the difficulties that carers find is that the professionals will not share information with them. We've got*

a number of mental health nurses who have told carers: 'I can't tell you what the side effects of the medication are because they're confidential', which is absolute drivel. But what it means then is that the carers are saying: 'Look, I can see my son is starting to grow breasts, or my daughter's periods have stopped, but I don't know why'. We're able to go then and say: 'No, actually that is part and parcel of the medication that they're on, but this is how, perhaps, you can help them and ask for a different type of medication'.
CFC41.5 Mental Health Nurse Manager

Improvements in information sharing about medication and side effects might facilitate significantly greater family, community and service system empowerment, which might also enhance carers' ability to advocate for better care and result in more appropriate treatment for service users (Dixon *et al*. 2001). Professionals also have to recognise that carers have support needs of their own and have basic rights, such as the right to a carer assessment:

The issue of confidentiality is important. Sometimes, the person with the illness doesn't want to share everything with the carer, but I think it's also being that this is the way the relationship is, that carers are fully involved in the process. It's recognizing that carers also need support and have rights to things such as a carers' assessment.
CFC48.5 Director of Mental Health Advocacy Group

The carer's assessment provides opportunities to assess the carer's needs, motivation, and ability to understand the situation, and the quality of the relationship between the service user and carer in the long term. Information sharing about how to help the service user, for example, to manage risk or avoid hospital admission, emerges from the carer's side of the picture. The carer's assessment may provide crucial information about the service user's behaviour, mental capacity and degree of insight as well as who to contact in times of crisis. Unfortunately, a barrier to this is that carer's assessments are not sufficiently embedded within the workings of community mental health services and, across Wales, the number of carer assessments remains low (Seddon *et al.,* 2007). GP surgeries are vital to the early identification of carers and an initial context in which to broach issues involving confidentiality. According to one manager:

We have pilot GP's surgeries that are piloting a carer's registration scheme, so that whenever they come to visit the practice the doctor is aware that they are a carer and the person they are caring for can give written consent to

information being shared with the carer, if the service user agrees to this. That would help the carer make it easier to care medically for the person they look after and helps the GP understand the pressures carers are under.
CFC7.5 Director of Mental Health Services

Raising the consciousness of carer and confidentiality issues in GP surgeries and primary care is important for several reasons: first, GP surgeries are vital to the initial identification and early filtering of carers and users to secondary services; second, the GP practice is a safe and familiar context in which to discuss the challenges of care and confidentiality issues; third, many carers report that GPs listen to service users and not to them; and fourth, the majority of carers believe that GPs are unaware of their needs.

As in recent studies (Pinfold *et al*. 2004, Partners in Care 2006, Rapaport *et al*. 2006), the negotiation of advance agreements, statements or directives was particularly important. Service users who were stable and had more insight were more likely to understand the need for sharing information with their carer. Advance agreements allowed service users to plan, when they were well, what they would like to happen in the event of them becoming unwell and to specify to whom information could be shared.

Training in confidentiality, information sharing, carer rights and assessment

The need for professional training emerged as a key theme. Professional training on confidentiality and carer issues was frequently cited as an important component of good information-sharing practice.

However, shortcomings in professional training and ambiguities about carer rights, the carer role and especially carer assessment were reported by participants to create uncertainties for practitioners in their relationships with carers, particularly in regard to issues involving confidentiality and information sharing. Echoing recent studies, several of the interviewed professionals suggested that some training should be provided by carers themselves, which would place a high value on the experiences of carers as well as seeing carers as an integral part of the support package (Arksey 2002, 2003, Machin 2004, Pinfold *et al*. 2004, Rapaport *et al*. 2006). The majority of professionals also reported, though, that they had limited time and resources with which to address carer issues in general and more specifically as regards training on confidentiality, particularly when run by carers. For professionals, training by carers was an ideal to be aspired to rather than a reality

in practice. Carers' rights and assessment emerged as two interlinked themes:

> *It's partly the training and instructions professionals get on confidentiality. Somehow they're putting confidentiality as a priority above the rights of the carer.*
> *CFC48.5 Director of Mental Health Advocacy Group*

> *What we've got is this conflict between the carers' assessment and confidentiality and I think that's something we've realised. We're going to have to go through our legal department to clarify it and put some training on what sounds very clear.*
> *CFC25.5 Team Manager, Social Work*

Professionals required training on the rights of carers and particularly the rights of carers to a separate assessment of their needs. Many professionals said they felt uncertain about balancing the confidentiality of the service user with an assessment of the carer's need. Professionals found policy, law and practice ambiguous on this matter, and were confused about how far to involve carers in information sharing and whether an assessment of carer need would contravene their duty of confidentiality to the service user. This is a major finding, as carer assessments have been suggested in recent studies to facilitate carer involvement and information sharing (Arksey 2002, 2003, Pinfold *et al*. 2004, Rapaport *et al.* 2006). Confusion about carer rights, entitlements and carer assessment could possibly limit their scope, role and effectiveness in practice as well as perhaps explaining why there is a shortfall of carer assessments offered to carers. Fourteen of the managers we spoke to had not heard of carer assessments and were unaware of Standard Six of the National Service Framework relating to carer support. Lack of awareness of carer rights and especially the right to assessment could impede effective and holistic information sharing as well as creating distance and confidentiality barriers between professionals, carers and service users.

An emotive subject: insights from social, voluntary and healthcare professionals into the feelings of family carers for people with mental health problems

We explore the challenging emotions of family carers of people with mental health problems from the perspectives of managers and practitioners. Topics illustrate professional understanding of aspects of carers' emotions and the severe challenges, including isolation, stigma, alienation, worries about diagnosis, and even notions of life and death, which family carers go through in their daily lives. Transitions in caring, particularly the end of the caring role, is a

major gap in professional practice and research that needs to be filled.

The spectrum of family carers' emotions

Managers and practitioners understand that family carers may go through complex and multifarious emotions associated with the unpredictability and uncertainty of caring for a family member with mental health problems. They reported a spectrum of emotions involved in caring for a family member with mental health difficulties. Challenging and sometimes negative emotions associated with family caring were mentioned more frequently than positive emotions:

> *Carers experience anger, frustration, guilt, shame – usually negative ones, I think.*
> *CFC35.5 Senior Social Worker*

> *Having been a carer myself, we go through guilt, despair, happiness, worry, anxiety, grief, the whole range of emotions, it can all be applied.*
> *CFC60.5: Director of Voluntary Organisation*

> *Like sometimes they feel there's no way out [….]there's no way out of it, it's, something they have to live with, the challenges and how they're going to be that day when they wake up, are they going to be in a good mood or a bad mood.*
> *CFC6.6 Area Manager, Voluntary Organisation*

> *I think there's also, you know, it's very, you know, if somebody is like very depressed for example, you know, they may be at risk of suicide and you know the stress of caring for somebody who – who may be at risk of suicide is tremendous really.*
> *CFC35.6 Community Psychiatric Nurse*

Caring for people with mental health problems is largely conceived of by managers and practitioners alike as a negative experience, albeit with occasional rewards and carer satisfaction. Family carers were said to go through many highly troubling feelings, including guilt, helplessness, anger, despair, frustration, isolation, anxiety, disempowerment, loneliness, shame, depression, desperation, denial, stress, and believing that they have no future:

> *I think people end up feeling quite angry and then guilty about that anger, you know it's, it doesn't elicit sympathy in*

the same way as you know seeing somebody with a broken leg or something.
CFC36.6 Occupational Therapist

… you can't arrange anything, you know, you can't arrange a holiday, you can't arrange, you can't do any forward planning … because you never know what their state of mind is going to be.
CFC32.6 Field Officer Voluntary Organisation

With reference to positive emotions, some practitioners reported that family carers also experienced rewarding feelings from their caring role, such as satisfaction and pleasure when 'things are going well', and they can see improvement in the person with mental health problems. According to some practitioners, there is a great deal of satisfaction in caring for a family member with mental health problems and sustaining a caring, comfortable and loving relationship:

I think some, some of the people I've worked with have found that their relationship has got deeper, better in some ways. Particularly as the person's begun to recover and they, you know they've been through this together and come out the other side and maybe that's all and I think it's extremely wearing otherwise.
CFC36.6 Occupational Therapist

Seeing someone recuperate and maintain stable community tenure is arguably a major reward both for family carers and the professionals involved.

Carers were also reported to experience more than one emotion at a time, which could lead to emotional conflicts that could in turn lead to long-term feelings of insecurity and ambiguity towards the care-recipient. The following extracts reflect the spectrum of emotions perceived to be involved in the role of family caring in mental health:

Carers experience every emotion going probably: guilt, frustration, anger, love, happiness; everything, all spectrums and more than one at each time. Things are very difficult and people should not feel guilty about needing a break and try to help people work through that.
CFC62.5 Senior Social Worker

Carers experience everything from frustration, hating the person they are living with, to wanting to escape the

situation. There's a conflict undoubtedly psychologically between the fact that you do care for the person that you are caring for but the frustration that you can't do anything for them.
CFC17.5 Senior Social Worker

Feelings of guilt, psychosocial isolation and stigma

Common themes in the entirety of the manager and practitioner data sets relate to feelings of guilt and isolation:

They've got nobody to turn to, you know, you've got no sleep and you know they could be ranting or raving or what have you, um, if they're not sleep… you know, drink is a problem with some, er, you know, and you're trying to placate and you don't want to call the police obviously, so it's an embarrassing situation, you don't want to go down that road … but if there was somebody there that you could just pick up the phone and talk to.
CFC32.6 Field Officer Voluntary Organisation

According to interviewees, an accompanying feeling of guilt was pervasive when carers asked others, be they relatives, neighbours or professionals, for support, such as carer breaks. Several other studies have confirmed this, suggesting that family carers' relationships with mental health professionals engender feelings of guilt, especially when asking for assistance, and can also lead to feelings of stigma (Lefley 1987, 1996; Pejlert 2001; Wahl, 1999; Winefield & Burnett, 1996). Feelings of isolation were identified as a major problem:

I imagine that it can be a very lonely job and a job where you feel entirely unsupported and very much on your own. I would think the sense of isolation that you must feel because, depending on how debilitated the person is that you're caring for, will also impinge on how much you can get out yourself and actually get away from that situation of being a carer and become a, if you like, a different human being, a human being that's not a carer. So I always think that loneliness and isolation will be quite major emotions in a carer's life.
CFC42.5 Senior Social Worker

Being a family carer limits the possibilities and opportunities that are available in society; it can result in a person being trapped and isolated in the caring role. Research has highlighted that the effect of mental illness on carers can be felt across a broad spectrum of family life, including employment, income, education, leisure, children, family health, and relationships with extended family,

friends and neighbours (Clausen & Yarrow, 1955; Grad & Sainsbury 1968, McCausland 1987, Maurin & Boyd 1990, Magliano *et al*. 2005). A common and recurring theme in the data was the psychosocial isolation of carers in rural or remote areas where a lack of supportive social networks, difficulties in providing and accessing comprehensive professional support and poor transport combined to compound feelings of isolation and marginalization:

> *[….] especially in the rural areas there's very little help really. Very little support.*
> *CFC3.6 Area Manager Voluntary Organisation*

Feelings of embarrassment, stigma and fear of a small community's reactions to mental illness were touched on in many of the interviews with managers and practitioners. Combined together these feelings were reported as putting people off accessing services:

> *The stigma associated to mental health as well because you have the close-knit communities where people don't talk about it. I'm told there's greater stigma in rural communities and that causes access problems in that people don't want to be seen going to a service in their village.*
> *CFC22.5 Senior Social Worker*

This also meant that carers remained a hidden and largely invisible population:

> *Because of their isolation they're not very visible in the community.*
> *CFC59.5 General Practitioner*

The process by which family members and carers are stigmatized by association with another stigmatized person has been termed as 'courtesy' (Goffman 1963) or 'associative' stigma (Byrne, 2001; Mehta & Farina, 1988; Phelan *et al*., 1998; Sommer, 1990; Struening *et al.,* 2001). In Carson and Manchershaw's (1992) study, family carers described avoiding contact with neighbours, friends and professionals through embarrassment, shame and fear of stigma. In addition, Ostman and Kjellin (2002) noted that relatives who acted as carers had deep-seated feelings of inferiority to staff, which may be an explanation for low levels of cooperation between relatives and professionals as well as entailing problems with access to appropriate services. Several studies have found that carers' relationships with social care and mental health professionals engender feelings of guilt which can affect the severity of stigma

(Lefley, 1987, 1996; Pejlert, 2001; Wahl, 1999; Winefield & Burnett, 1996). A central issue was associative stigma:

> *I think one of the biggest challenges is stigma. If you're a carer for a disabled child, if you're a carer for somebody with a learning disability, if you're a carer for someone with cancer, the instinctive reaction is 'Oh, you must be an angel, you're having to deal with that, poor thing', you know, it's a tragedy. With mental illness there's still the stigma of: 'Hold on, is it catching?' It's the fault of the carers that the individual has a mental illness.*
> *CFC37.5 Mental Health Nurse*

> *Because it's totally a different time of caring role they're dealing with isn't it? [….] Totally different to somebody who's had a stroke and sitting in the corner, you know [….], there is a stigma, you know, you can't talk to neighbours about it, they don't understand, it's not, it's totally … you don't get the same sympathy do you [….] full stop, you don't get the same sympathy because people don't understand it.*
> *CFC32.6 Field Officer Voluntary Organisation*

Coming to terms with the caring role

Coming to terms with the caring role in the family may be a difficult, protracted and painful process. Initially, many family members may not identify themselves as carers. After all, as Repper *et al*. (2006) ask, when do the responsibilities associated with being a parent, a spouse or a sibling end and the caring role begin? According to Peternelj-Taylor and Hartley (1993), feelings of helplessness can entrench feelings of social exclusion and marginalisation, resulting in family carers feeling isolated in their role and trapped in the family home. Pinfold *et al*. (2004) and Arksey (2002, 2003) suggest that carers coming to terms with their caring role have clear needs of their own for information, support and help with coping with an unfamiliar range of problems. Health and social care services should be aware of these needs, especially family carers' emotional needs, as suggested in recent research and established policy legislation (Arksey, 2002, 2003; Department of Health, 1999; HM Government, 1999, 2004; Pinfold *et al*., 2004; Repper *et al*., 2006; Tennakoon *et al*., 2000;). The managers and practitioners that we interviewed reported a huge emotional drain on family carers coming to terms with their difficult role. In addition, they suggested that family carers are initially at a loss, sometimes in shock and are prone to ask irresolvable questions such as 'why has this happened?' and 'why me?' Coming to terms with the caring role involves a steep and often unsupported learning curve that requires considerable emotional adjustment:

> *If you're talking about the parents of an 18-year-old who's developed a psychotic illness, it being the first episode, there's a huge learning curve for them. Again there's a huge emotional adjustment they need to make to their child who they had all these aspirations for who suddenly it looks like they'll have to change their views on what that person's able to achieve and learning to cope with the professional services.*
> *CFC13.5: Senior Social Worker*

Changes in the care recipient's behaviour and personality, either due to mental health problems or side-effects from medication, also affect carers and can lead to family carers feeling isolated and alienated even from their loved one for whom they care:

> *Sometimes it's not easy to care for somebody who is perhaps not the person who you married or the person that you've known for a long time because the illness, or whatever's happened to them, changes them. So they often feel guilty, they often feel, 'I wish I wasn't doing this'.*
> *CFC52.5 Mental Health Nurse Manager*

> *It's hard to accept really, you know that's been my experience – it's hard to accept that the person that they love has changed, has got the onset of mental illness.*
> *CFC60.5 Director of Voluntary Organisation*

Another major issue for carers is coming to terms with and understanding the meaning of diagnosis. Pejlert (2001) found that diagnosis was never mentioned in the narratives of her research participants. The disease was never mentioned in terms of a diagnosis; rather, more anodyne terminology was used with expressions such as 'illness', 'disabled', 'something s/he has to take medicine for', indicating that the diagnosis was loaded with negative meaning. Odd behaviour of care-recipients was thought of as difficult to understand and shameful for family carers. For the staff participating in this study, diagnosis was also perceived to be imbued with challenging emotions such as fear, anger, and denial:

> *We've got a young man who's just had a diagnosis and just had his first episode of a psychotic illness. I think his carers, his parents as it happens, actually, despite the fact that we've given them a lot of information, are actually still in denial. It's very much, I think, a bit like a grieving process in some ways. I think the denial is there for quite a long time and that can be just as much with service users as with carers. And it sort of gradually changes, I think, over time.*
> *CFC9.5 Mental Health Nurse*

Notions of life and death

At a more extreme and worrying level, some staff mentioned that the caring role may affect family carers' attitudes towards life and death. The burden of caring was reported to be so emotionally draining that it led to family carers resenting their role and the person that they supported. Carers saw little improvement in the care-recipient, so felt that their efforts were wasted. One social worker recalled such a troubling case:

> *He was saying that a number of times he thought he would like to kill his wife. He said: 'I knew I wouldn't, but I was thinking it because my life was over'. He was a man in his late fifties and I think we've got to try and avoid this – We've got to try and take the strain off before people get to this point. And then they have this awful guilt about feeling that about someone they love.*
> *CFC6.5 Social Worker*

Ostman and Kjellin (2002) found that the burdens of family caring seriously affected thoughts about life and death. Isolation, hopelessness and feeling that life was over led to despair. This is a startling and worrying finding.

Worries and fears about the end of the caring role

Staff reported that whilst the majority of family carers want to continue in their role for as long as they can, there comes a point when for many it is not in either their best interests, or those of the care-recipient. Maintaining the care-recipient in the community and keeping them out of institutional settings is of pivotal importance to family carers and often underpins their motivation to provide support and care. In circumstances where this is no longer possible, the potential guilt is enormous. Reaching the decision to place someone in an institutional setting is therefore extremely difficult and engenders considerable emotional turmoil. This is exacerbated by the fact that most admissions to care are made at a time of crisis, usually following an acute episode of ill-health. As summarised by the two respondents in the extracts cited below, the end of the caring role is perceived to involve particularly challenging feelings:

> *It promotes more guilt, but a whole range of feelings and also, of course, at the end, when their caring role may end for whatever reason.*
> *CFC7.5 Director of Mental Health Services*

> *Carers are constantly worried as to the person they're looking after and how they're going to be able to carry on looking after them. Because carers, I would stress, have made it quite clear to me that they're very worried that they won't actually, obviously, be around forever and who is going to look after their loved one when they're no longer around to do so?*
> *CFC35.5 Social Worker*

According to Nolan *et al*. (1996), the end of the caring role involves a process of letting go of caring, moving on and reclaiming a new life. In the present study and confirmed in Nolan *et al*.'s research, with scant few exceptions carers received minimal assistance at this difficult period and generally thought they were left to 'sink or swim':

> *They don't seem to have anything else in place, this is what they're telling us, 'there's nothing there out, there for us, you know, to cope'.*
> *CFC32.6 Field Officer Voluntary Organisation*

Many family carers are left with a legacy of guilt and continued stress.

Lack of emotional support

Emotional support in the statutory and voluntary sectors was said by professionals to be very basic. There were limited resources and long waiting lists for more specialised interventions such as counselling and cognitive behavioural therapy:

> *You sort of hide and get on with it because we have a waiting list.*
> *CFC6.6 Area Manager Voluntary Organisation*

This lack of any concerted emotional support led to feelings of being trapped in the caring role, as well as anger at not getting answers and appropriate emotional reassurance:

> *So there's a very grave problem and terrible isolation because it's difficult to talk to anybody else. I'm afraid carers get little information and support. There's a strong sense of being trapped. There's anger that nobody's providing any support.*
> *CFC49.5 Social Worker*

> *I would think there is – there is a stigma, definitely, and the – the lack of – of service provision for them, you know, if you haven't got a support group that sort of consists of mental health carers together then who do they share? When they*

come to our groups and drop-ins we have, you know, they can't share that, their concerns with other carers because it's totally a different time of caring role they're dealing with isn't it?
CFC32.6 Field Officer Voluntary Organisation

Yes, I mean I think we've got a huge range of experiences, you know people with mental health problems come in all sorts of shapes and sizes and you know it's not a specific diagnosis in its own right. Whereas if the person you were caring for had MS, then you'd join the MS Society and met up with carers with people, it's a very specific condition [….] But this is so generic, that I think you're not necessarily going to find peer support as easily.
CFC36.6 Occupational Therapist

This lack of emotional support with accompanying feelings of marginalisation was perceived by professionals to be compounded by family carers' feeling that they were often not consulted about or involved by services, particularly statutory health and social care services:

Family carers do get very down, they get very frustrated by the lack of being involved. It's frustration and anger sometimes at not getting answers.
CFC3.5 Mental Health Nurse Manager

A troubling consequence of not getting answers or being involved by health and social care services was carer depression and feelings of desolation:

From my personal experience, family carers get very tired and can become quite low, really. And you sometimes think whether there is anybody out there who is able to help you through some of the difficult times.
CFC60.5 Director of Voluntary Service

Twigg and Atkin (1994) also found that services were often lacking and were frequently ad hoc and ill-equipped. Although social work staff are willing and want to help, according to Repper *et al*. (2006), professionals in many settings say they lack the time, resources and expertise to work in depth with carers and relatives about their emotional issues. Some of the practitioners that we spoke to confirmed this, mentioning limited training on mental health issues, aside from basic awareness raising, and limited knowledge of how

to support this particular group of carers and help them work through the emotional issues that they face:

> *I think our training is quite limited [….] I'll go out and do the assessment and because I've had no training in mental health um, I'm not always sure about my role. [….] I don't think our training gives us the confidence to offer that support. [….] I think really they should be as equal to somebody who'd been looking after you know, if it's a physical problem. But I think that in the organisation that I work in because we haven't got the training, I don't feel confident enough to give them that support. So I think it's a lack of training.*
> *CFC3.6 Area Manager Voluntary Organisation*

> *I think it's an area that we don't get that much training on […] I think it would be quite useful in a sense to make us more aware of [….] if we have it for, you know, carers themselves providing the kind of training, you know, like having their own sorts of feelings or the struggles that they get, you know, involved in and maybe, 'cause you know, we maybe don't always realise the difficulties that they are experiencing.*
> *CFC31.6 Social Worker*

A further difficulty is that even when services are available, attempts to recruit families to appropriate psychological and emotional interventions during remission or periods of stable community tenure are linked with difficulties in engagement. The indications are that in these circumstances, only about half of carers are likely to take up offers of emotional and psychological support. Once the situation of the care-recipient has stabilized, many families may be unwilling to rock or upset the status quo, preferring to keep their distance from services so as to maintain a sense of normality (Sellwood *et al*. 2001).

In summary, managers and practitioners suggested that health and social care service responses to family carers' emotions were neither comprehensive, holistic nor specialized. The voluntary sector was reported to be more successful in tackling carers' emotional needs than the statutory sector but was still limited in scope and specialization. Emotional support was very basic and only included such things as carer support groups, face-to-face work with voluntary workers and befriending with peers. By way of contrast, the majority of staff believed that carer support groups were an economical, holistic and effective way of meeting the emotional needs of carers. They suggested that group work can take several forms: family-led self-help groups, carers' circles, family groups run

by professionals and mutual support groups. Each of these programme types has been shown in the research literature to decrease isolation and stigma and has been suggested to assist carers acquire knowledge, information, new skills and a sense of mastery over their personal situation (Nolan *et al*., 1996; Ostman & Kjellin, 2002; Pinfold *et al*., 2004; Sellwood *et al*., 2001). Through sharing life experiences and befriending other carers and professionals, individual family members are noted by professionals in this study to be able to express their feelings, gain new ideas about managing mental illness and report on their coping strategies. Family carers experience the validation and support of other carers in similar situations. Other research has highlighted that moving-on groups and groups dealing with grieving carers are especially important as they address gaps in carers' emotional needs (Nolan *et al*., 1996; Ostman & Kjellin, 2002; Pinfold *et al*., 2004; Sellwood *et al*., 2001).

Patterns of exclusion of carers for people with mental health problems — the perspectives of managers and practitioners

Managers and practitioners observed patterns of social exclusion amongst carers. Patterns relating to the social exclusion of carers for people with mental health problems can be grouped into four main themes, each with its own sub-set themes involving the personal, social, service and financial disadvantage faced by carers:
- Personal exclusions: stigma; keeping mental health problems 'a secret'; mental health caring 'a taboo'.
- Social exclusions: isolation; narrowing of social networks; time commitments — caring a 24/7 role; restrictions in education, training, employment and leisure; young carers.
- Service exclusions: carers 'taken for granted' by services; difficulties with access.
- Financial exclusions: 'paying' for care.

Personal exclusions

Stigma

As noted in the presentation of findings relating to confidentiality and smokescreens, stigma not only affects people with mental health problems but also their carers:

> *An awful lot of them still say that they feel embarrassment and a sense of stigma in having family and friends that, you know, their husband or child has developed a mental illness. CFC31.5 Social Worker*

There is more of a stigma perhaps to be suffering from mental health issues than a – than a physical issue really [….] if somebody says 'Oh so and so's not well' if they've got a physical illness they'll talk about it, but if it's a mental illness, people are less likely to you know, and the media, it's because really a lot of things that are written in the media about people with mental .… they only really write about it when there's a problem [….] so you know, if somebody wants to start say about their partner might – might be schizophrenic, people say 'Oh well, I was reading in the paper …' and that's it, you know, you just don't … people I think are reluctant to come forward really and ask for help.
CFC1.6 Area Manager Voluntary Organisation

It's also the stigma attached, you know, the stigma itself around mental health, the carers often suffer the same stigma. So if you have a son or a daughter who has schizophrenia, you're not going to tell anybody that your son or daughter has schizophrenia.
CFC20.5 Mental Health Nurse

Managers and practitioners reported that stigma impeded the ability of carers to lead a *normal* life and isolated them from the wider community:

Obviously with mental health problems there are issues of stigma — it's distressing, it's anxiety provoking, which increases the stigma and possibly difficulty then with resuming normal life.
CFC6.5 General Practitioner

In relation to their caring, carers might not have opportunities to fit into normal community life. They may well be stigmatized.
CFC48.5 Social Worker

Mental illness remains highly stigmatized; Chang and Horrocks (2006) suggest that the impact of stigma on family caregivers is pervasive and strong. Managers and practitioners who we interviewed confirmed this; mental illness was perceived as a shameful secret that many carers kept silence over:

You don't know who to talk to, who to turn to — it was that secret that you just kept secret.
CFC56.5 Mental Health Nurse

> *There's stigma, that's the word I'm looking for, yes, so it's something you sort of keep to yourself — a secret.*
> *CFC60.5 Voluntary Sector Worker*

Silence leaves little room for the dialogue so important between carers and professionals to target appropriate and effective support. Even assessing the prevalence of mental health problems is made problematic because of the considerable discrimination towards mental illness in society, leading to high levels of secrecy and shame (Cree, 2003a, 2003b; Tanner, 2000). There is the keeping of secrets and maintenance of silence — again due to the fear of punitive professional responses and/or public hostility.

Transgressions and taboos

According to participants, caring for someone with mental health problems is a taboo given to silence, secrecy and fear:

> *People are frightened by mental health. Carers must be very frightened, probably try to hide what goes on. How many people want to admit that their husband or wife or son or daughter or whatever has a mental health problem? I'm sure some of us have seen it in our families where people don't want to admit to it. It's just taboo, isn't it?*
> *CFC12.5 Social Worker*

Mental illness is largely a taboo because it transgresses accepted social norms (Turner, 2001) and can be negatively associated with feelings of shame and as a sign of weakness (Slowik *et al*., 2004). Managers and practitioners recognize that in order to break down the barriers and taboos of caring in mental health it is necessary to replace fear, secrecy and silence with openness, hope and dialogue between carers, people with mental health problems and professionals across services and sectors.

Social exclusions

Isolation

As previously noted, isolation was reported to be a major problem and suggested to result in even more problematic issues of marginalization and stigma as well as resulting in patterns of social exclusion:

> *I imagine that it can be a very lonely job and a job where you feel entirely unsupported and very much on your own. I would think the sense of isolation that you must feel because, depending on how debilitated the person is that you're caring for, will also impinge on how much you can get out yourself and actually get away from that situation of being a carer and become a, if you like, a different human being, a human being that's not a carer. So I always think that loneliness and isolation will be quite major emotions in a carer's life.*
> *CFC37.5 Mental Health Nurse*

Being a carer limits the possibilities and opportunities that are available in society. Loneliness, isolation and marginalization were identified as typical and problematic experiences in the caring role. Professionals reported that compared with other types of carers, carers for people with mental health problems were particularly vulnerable, and marginalized:

> *The other thing I think is because of the stigma around mental health problems, is that carers for people with mental health problems are perhaps even more isolated in some instances than other sorts of carers.*
> *CFC7.5 Social Worker*

Most of the research on carers involves older people and those with dementia, including Alzheimer's Disease. In their comprehensive review, Jeon *et al*. (2005) note that the growing literature on carers remains largely silent in relation to those suffering from serious mental illness (SMI) and their family carers. Jeon *et al*. (2005) note that provision for people with SMI and their carers has been both scarce and poorly investigated.

There is a copious amount of literature on the alienation and estrangement from society of people with mental health problems, particularly ethnic minorities (Erdner *et al*., 2005; Fernando, 2002; Littlewood & Lipsedge, 1997), but little research on such an important subject with carers. Feelings of loss, hopelessness, and even hatred toward the person with mental health problems intensify feelings of stigma and alienation:

> *Sometimes it's not easy to care for somebody who is perhaps not the person who you married or the person that you've known for a long time because the illness, or whatever's happened to them, changes them. So they often feel guilty, they often feel, 'I wish I wasn't doing this'.*
> *CFC11.5 Social Worker*

Narrowing of social networks

Professionals report that the care-giving role had a profound effect on carers' social networks, which narrowed due to excluding feelings of embarrassment, guilt and fear:

> *Carers are unable to maintain the social networks they had previously, because of their caring responsibilities, or often they find themselves not invited to places or they exclude themselves because of maybe their feelings that they can't do it or feelings of guilt if they do go out.*
> *CFC60.5 Voluntary Worker*

> *Carers are especially excluded because family and friends tend to fall away when there is a problem in the family, that's something that just happens. Their friendships break down and that's all through embarrassment and leads to a sense of being on their own.*
> *CFC24.5 Social Worker*

Ostman and Kjellin (2002) found that a high proportion of relatives in their study considered that their care-recipient's mental health problem had affected the possibilities of having company of their own or had influenced relations with others, and had also led to mental health problems in the relatives themselves. Withdrawal from social contacts because people 'do not understand' testifies to negative attitudes as a source of family stigma (Phelan *et al.*, 1998; Pejlert, 2001). Carers experience less problems when their networks are dense, perceived as supportive and the carer spends a significant amount of time with the person with mental health problems. We also found that contact with others leads to a more positive sense of morale (Carpentier *et al.*, 1992; Cook *et al.*, 1999).

Time commitments: caring a 24/7 role

Staff reported that carers are severely excluded because the care-giving role takes up much of their time. Getting out of the house, socializing with neighbours, other family members or friends, participation in the community and carer breaks were all curtailed.

Carers were reported to feel guilty asking others for help and taking time for themselves. Feelings of guilt entrench feelings of failing the person with mental health problems and lower self-esteem. Practitioners note that caring in mental health can be a full-time, all encompassing role:

I think very often carers are excluded just as a result of their caring role; just the fact that very often it takes up 24 hours a day, seven days a week. Carers may well be socially excluded because of lack of time to be getting involved in other things apart from looking after the service user.
CFC15.5 Social Worker

Carers are excluded because of time commitment mostly. Their time commitment for caring and probably the burden of responsibility in terms of things like going out for a night out; there's always the possibility that things may go wrong and they need to be available even when socializing.
CFC33.5 Voluntary Worker

Restrictions in education, training, employment and leisure

Managers and practitioners report that the impact of mental illness is felt across a broad spectrum of family life: employment; income; education and training; leisure; children; family health; and, relationships with extended family, friends and neighbours:

I think caring responsibilities mean that people can't always be available to be involved in education, leisure or involvement, but I think with mental health carers in particular it's because they've got to be silent because they're afraid not only for the people they care for, they're afraid for themselves if they let anybody else know that there's mental illness in the family.
CFC51.5 Social Worker

I know many carers that have had to give up work just to care for their loved one, which is such a shame. That shouldn't be happening. It's difficult for them to participate in education, training — a whole pile of different things.
CFC16.5 Mental Health Nurse

Carers UK (2006a), Carers Wales (2006a) and Crossroads Care (Crossroads Care, 2008) suggest that the difficulties faced by carers who wish to combine paid employment with their caring role is one of the pivotal factors in creating and maintaining social exclusion. These organizations call for the development and promotion of more flexible policies that enable carers to combine employment and care and thereby reduce carer poverty and promote social justice and inclusion.

Service exclusions

Carers 'taken for granted'

Managers reported that the needs of carers, as individuals requiring support in their own right, may often not be addressed. Carers may not be regarded as part of the social care or health care team and a low value may be accorded to their role. The willingness of carers to 'just get on with it' means that many are often taken for granted. In staff narratives, service users were the priority, while carers were a secondary concern:

> *I think carers are a group that are often taken for granted in the sense that they're there offering daily support or whatever and I think their needs, as much as you try and accommodate for the carers and the user of the service, I think perhaps sometimes they are disadvantaged because it's taken for granted that they will be the ones that are offering the 24 hour care.*
> *CFC41.5 Voluntary Worker*

> *Carers are a hugely disadvantaged group and it's generally because the professionals will play games with them — they will expect them to carry out the responsibilities of caring, they'll expect them to reduce the work load that the system should be taking up, but they won't equip them to do the job—they won't provide them with the appropriate finance, the sort of hoops that you have to jump through. It's not very easy for carers to carry out the caring responsibilities. It is just assumed in a lot of instances that carers will pick up the pieces when things go wrong.*
> *CFC2.5 Social Worker*

Several action points to deal with carers being taken for granted are highlighted by Warner and Wexler (1998):

- Statutory services should not make the assumption that a relative will automatically be able to put their life on hold in order to act as a carer.
- Carers should be involved in decision-making about the future care of the person they are looking after and their expertise should be acknowledged.
- When a care-recipient is discharged from hospital and needs intensive home care, carers should not be taken for granted and 'just left to get on with it'.
- It is essential that the whole team — health, social services, voluntary organizations and the carer — should be consulted and work together holistically.

- A higher value must be placed on the role of carers by statutory authorities. Their role as equal partners in providing community care must be acknowledged.

However, although most staff we interviewed were committed to the idea of involving carers as well as users, and were positive about its effects, they perceived processes of involvement as very time-consuming and not viable to implement within existing resources.

Difficulties with access

According to interviewees, carers experienced problems with accessing timely, flexible and effective services. Access to statutory and even primary care services was sometimes complicated and services lacked a joined-up approach with which to effectively address and coordinate appropriate responses to carers' complex needs. Problems with access were partly due to difficulties of getting a carer assessment as well as service users being given priority. Practitioners reported that carers were often unaware of the services that were available locally:

> *It's just difficult for carers to access things. I think exclusion happens unconsciously. I think that people actually, at an unconscious level, organizations just want carers to get on with it and to not complain about it. That's the worst stuff — I think really the unconscious institutional exclusion that happens where services just make themselves really difficult to be contacted. They're actually creating hoops for people to jump through, I think, systems that exclude carers. There aren't support systems even for those who know about the service and want to get engaged.*
> *CFC6.5 General Practitioner*

> *Carers just need that support and to be allowed not to be guilty about wanting support. Some people feel a failure when they ask for help.*
> *CFC29.6 Social Worker*

According to Arksey (2002, 2003), there are four main principles for how services should be delivered in order to promote access, flexibility and effectiveness. First, services need to be positive and inclusive. Professionals should have a positive approach to carers, involve them in decision making and recognize carers as 'experts' or 'partners'. Second, packages of care need to be flexible and individualized. Services should be person-centred. Third, services should be accessible and responsive, particularly to those in remote rural areas as well as to hidden carer groups such as young carers,

refugees and ethnic minorities. Services should also be available at all times, including outside of office hours, and able to offer rapid access to mental health support, especially in times of crisis. Fourth, services should be integrated and coordinated and access to different teams joined-up.

Financial exclusions

'Paying' for care

Practitioners report that carers not only pay a social and psychological cost for caring but also pay a financial and economic cost associated with the caring role. Carers often face severe difficulties in combining care with paid employment. Carers often do not know which benefits they are entitled to receive and are often in the dark about direct payments that may help support them in their efforts to care. Many carers experience poverty and are unable to pay for basic things such as local travel, domestic appliances, household bills and holidays:

> They're not able to go to work, so there's a lack of money, there's poverty, people aren't able to go and get involved in things because there's barely enough money to live on, plus just feeling safe to leave somebody who they know needs a lot of support. I think there's huge restrictions on carers. They may have to pay for care.
> CFC59.5 Social Worker

> They don't get paid, they don't get holidays and they don't get support — they don't get any of those things and they don't get a choice.
> CFC13.5 Voluntary Worker

> A lot of the challenges of the, of carers that I come across are financial [….] a lot of parent carers support their children, you know, with mental health issues[….] so they sort of, they're living at home with them and yet are not being supported financially, they basically are keeping, you know, are both cared for now, and you know, two or three of our carers have voiced their concerns that they've no benefit to help them 'cause they're retired, they don't get any carer's allowance obviously.
> CFC32.6 Field Officer Voluntary Organisation

One of the main reasons for social exclusion is the previously noted difficulty of combining caring with paid employment.

Invisible Children: Young Carers of Parents with Mental Health Problems - The Perspectives of Professionals

Managers and practitioners were encouraged to reflect on the challenges facing young carers involved in supporting parents with mental health problems. Three overarching themes emerged from the data: first, the isolation, restricted opportunities and associative stigma of young carers; second, fears about child protection and family separation; and third, examples of good practice and effective working with young carers and their families. Table 4.1 shows the list of themes referred to and the number of participants that mentioned each theme.

Table 4.1 Themes mentioned by participants (n = 65)

Theme	Number of participants	%
Feeling of associative stigma	57	88
Social and peer group isolation	56	86
Young carers invisible and hidden	54	83
Restrictions in education, leisure time, prospects and employment	50	77
The importance and beneficial affects of young carer groups and forums	50	77
Poverty and social exclusion	47	72
Lack of understanding from peers and professionals about young carers circumstances and lives	46	71
Bullying at school	44	68
The importance of key workers and outreach staff in helping, supporting and involving young carers	44	68
The importance of raising awareness of young carers and young carer issues	42	65
Fears about child protection and family separation	41	63
The importance and beneficial affects of young carer days	33	51
Raising awareness of young carers and their issues via technology such as the internet and DVDs in schools	15	23

Isolation, restricted opportunities and stigma

Professionals perceived the greatest challenge that young carers face as being social and peer-group isolation as captured in the comments below:

> *Social isolation is always a big issue for young carers. They feel that they are unable to integrate with their own peers or groups because of their care requirements. So I think there's an issue about trying to give them some respite or some other support where they can actually maintain their own social integration.*
> *CFC31.6 Social Worker*

> *Young people who are caring for a parent with mental illness are probably one of the most invisible cases of being a carer trying to go to school and maintain friendships with peers and coming home to a parent who's desperately unwell. I don't think there's any support for them at all. To some extent they're lost, aren't they? They don't get much attention and they're allowed to struggle on.*
> *CFC3.5 Mental Health Nurse Manager*

> *Young carers were viewed by professionals as being invisible and marginalised by their peers and within the education system and as disadvantaged in terms of their prospects or opportunities for employment. There's not enough thought given to young carers and their education, to their emotional and social development. It must be terrible to look after an older person or parent in terms of relationships with their peer group. I think the pressure's probably on young carers from the point of view of missed opportunities, education and progression through to the work environment. Perhaps pressures or conflicts of interest in terms of them having some enjoyment and getting away from the responsibility of looking after their parent with mental illness.*
> *CFC60.5 Director of a Voluntary Organisation*

> *I recently came across a young carer who can't go to university because he has to stay home to care for his mentally ill mother.*
> *CFC23.5 Manager of a Voluntary Organisation.*

Feelings of stigma were also frequently mentioned:

> *There's stigma in school. Young carers know that they can't go out and join their friends playing - they're often tired.*

Homework is an issue. There's all sorts of pressures on them. They're a stigmatised group.
CFC64.5 Senior Social Worker

Fears of child protection procedures and family separation

Although it is important to ensure children's safety and well-being, child protection is an issue that could potentially discourage professionals and young carers from working together:

We don't provide services to young carers on the basis of there are so many child protection issues to consider. We're not experts in the child protection issues so we need to team up with someone who is.
CFC27.5 General Practitioner

There are huge child protection issues. There could be no parenting going on, and how do you support the child who wants to continue care and feels that great sense of responsibility, but also that responsibility needs to be taken by the parent.
CFC64.5 Senior Social Worker

Examples of good practice and effective working with young carers

Positive examples of good practice included:
• Young carer groups and young carer forums
• Young carers days
• Raising awareness of young carers, with information packs, DVDs, on young carers and young minds websites, especially in schools
• Having specialist key workers or outreach workers

Young carer groups and forums were said to be a particularly successful method that encouraged young carers to befriend one another as well as helping to establish consistent and trusting relationships with peers and staff. These groups established a safe context for young carers to interact with each other and staff, building up much needed feelings of safety, which combated negative emotions of stigma and isolation, and which also facilitated informal information sharing between young carers and with staff. This meant that young carers did not feel alone:

Young carers are being covered in terms of a carers forum. We have had young carers groups running for some time. We fund a young carers project that supports between 35 and 40 young carers at any one time - those young carers being carers who have identified needs about their development,

their education and not missing out on growing up, really. With carer groups, young people realize that they're not on their own. Some of them feel until they go and see a group that they're the only ones experiencing all the trauma that they experience.
CFC16.5 Manager of Mental Health Services

Information packages and information sharing were identified as particularly important in raising awareness of young carers in the context of the school; a new finding was that young carers were particularly interested and involved in information sharing via the internet and DVDs. Much has been written on technological interventions to support people and children with learning disabilities and SENs but little research has been conducted on the importance of technology in the lives of carers and young carers (Aldridge & Wates, 2005). According to one manager:

Young carers have recently produced something like 250 copies of a DVD that can go out into the schools to raise awareness of young carer issues. We've looked at the young minds website. What we're trying to do at the moment is make sure the information packs are in school so that young people who might be living in that situation know that they can ring a number to get some advice. We're trying to raise awareness.
CFC48.5 Director of Mental Health Advocacy Group

Finally, key workers and outreach staff were said to befriend young carers and facilitate the skills required in supporting a parent with mental illness. As a participant suggested, young carers had particularly complex needs:

There are huge advantages if we use key workers and outreach staff. I think it's about making sure that young carers know where to go to, who to ask for help, giving them practical skills but also taking away the isolation, giving them more of a support network, giving them a break as well. It works to meet their needs in terms of maintaining education, maintaining work. It's important because the key worker can say: Look, I think this young carer needs a lot more support, they need a life of their own as well. It's important to give young carers permission to want a life of their own, to have a break from caring and feel that this isn't the end and this isn't forever.
CFC36.5 Director of Social Services

Chapter 4: Findings from carer interviews

Introduction

This Chapter presents key findings from the carer interviews, focusing on the relationship between carers and professionals, service provision, the caring role and factors contributing to social exclusion as identified by carers. We also consider phases in the carer journey and changing support needs.

As with the chapter presenting the findings from staff, this chapter reflects on a number of important areas but does not represent the full scope of the data. We have used quotes from carers to illustrate the findings. The notation below each quote indicates the unique identification number given to the interviewee; this is followed by the relationship of the carer with the care-recipient and the diagnosis of the care-recipient.

The caring role

Ayres (2000) described the meaning of caring as a process of integrating expectations, explanations, and strategies into the carer role. Becoming a carer can change a life course and dramatically change expectations; it has a ripple effect on all aspects of a carer's life such as family relationships, the ability to form and maintain friendships, being able to undertake paid employment and financial expectations:

> *When I became a carer when my son unfortunately had a breakdown. This was so traumatic and difficult to deal with, hmm, that I just had to sort of put everything on hold, my life, my ambitions and so on to try and help him recover, which has taken eleven years. And it's been a very, very hard journey indeed.*
> *CFC 634.6, mother, diagnosis bi-polar*

Most of the carers we interviewed mentioned having to keep track of everything ranging from running a household to finances and constantly having to follow-up issues in relation to the care-recipient:

> *But the most difficult things I find are sometimes it's overwhelming how much I've got to do, because with the usual set up, I know there's a lot of women separated from their husbands and they're living by themselves, but sometimes I just find I've got so much to do and the jobs that*

[husband] would normally have done, I've got to find someone to do because there's certain things I can't do.
CFC889.6, wife, diagnosis depression

There is relentlessness to caring including dealing with day-to-day tasks, completing forms, making phone calls, and so forth which can be wearing:

I am still struggling. But you do feel internally... you have an internal struggle to get these things sorted. And we have moments of everything is going good and moments of calm and you know, it's all right. But I always feel as if I am on – they say an uphill struggle and I know what they mean now. Because I sometimes feel…I always feel that I am running standing still. That's the way I often describe it. And I am trying to do all this and I am not getting anywhere you know. […] Things aren't changing. It's the same old repetitive thing. […] I've had enough.
CFC 949.6, wife, diagnosis depression

I've always felt I could never be ill as a carer. There was never ever, I wanted to be ill, I wanted to have cancer, that sounds terrible. I wanted somebody to feel sorry for me and that's a horrible way to feel. […]It must have been I was so screwed up in my head, that I just wanted to be ill and I thought that would really really sort of… all responsibilities and everything, you know the whole carer thing is about looking after all the money, it's dealing with everything you know.
CFC 350.6, wife, diagnosis schizophrenia

Carer identity and role

Several carers mentioned not being aware of 'being a carer' until they had been on their carer journey for some time. Whilst some rejected the notion of being a carer, others emphasised the importance of developing other identities and some felt that their live had been taken over by the carer role:

And it was [Name], the nurse, who said to me…I think [Name, husband] had gone earlier that day…and she said "you should be registered as the carer" …and she put me on to the receptionist, who registered me and I then started. So that was about this time last year. But essentially, I had probably been a carer a long time before…but I said I did it just as a wife!
CFC 877.6, wife, does not know diagnosis

Others did not want to be defined as a carer as they felt that this gave more emphasis to the mental illness. One of the carers reported that this was her way of rejecting the illness:

> *I think also it may be an emotional reaction to her [daughter] illness, I want to reject her illness, I don't want her to be ill, I want her to be well, I don't want to be a carer. Mother, fine, employee, fine, member of local church and various groups, fine. Carer, no, I, I know I do it. […] I think I'm particularly anti because my daughter started to define herself by her illness and to define me as her carer.*
> *CFC 544.6, mother, diagnosis schizophrenia*

Carers' emotions

We found, in keeping with previous research and our interviews with professionals, that carers needed to learn to cope with the symptoms of the mental health illness but even more so with their own intense emotional responses (Cormac & Tihanyi, 2006; Karp & Tanarugsachock, 2000). Carers' narratives about emotions suggest a complex picture and findings from professionals in the previous chapter suggest that some but not all professionals are aware of the complexities. Carers talked about the harrowing experience of witnessing the emotional and mental state of the care-recipient and feeling helpless, the stress and worry caused by the unpredictability of the condition and concerns about the future. Symptoms such as hearing voices or paranoia can be frightening and withdrawal and apathy frustrating and saddening. We found that carers tend to empathise with the emotional or physical pain of the care-recipient, a concept sometimes called compathy (Morse & Mitcham, 1997) or pain by proxy (Moran-Ellis, 1996):

> *What I feel is, it's so hard to see somebody you love so much in so much pain. The physical side of it, the running him [son] around, the messy side of it is nothing, truly it's nothing. The worst thing for a carer is watching the pain but that is the worst thing […] that is the worst thing is watching somebody you love in so much pain and they don't know what to do about it.*
> *CFC 785.6, mother, diagnosis schizophrenia*

All carers expressed a sense of loss and grief. Carers can grieve over the loss of the person they knew or for themselves and their loss of future hopes and ambitions. There is also an element of grief in relation to changes in relationships and sometimes even role reversals:

It was the worst time of my life. I'd lost the son I knew and loved, he was a different person, he sort of used to be this very caring, very loving boy and now he was this very slow, dopey, messy, no thought for anyone else person, who slept a lot, ate a lot and drank a lot and I didn't recognise him. He's so different to how he was, he's so different to the person he should have been.
CFC 854.6, mother, diagnosis paranoid psychosis

But I am…it is sad… the whole situation is so sad. I mean, [name, husband] and I… we should be out doing things, we should be… able to go out for walks, doing things together. And it is very sad but yes I do feel cross and… I wish I could do something to help him. And also the helplessness, that is another strong…is the helplessness. […] You know I just keep giving him the tablets, I keep giving his food, and I keep doing what I can for him. But there is nothing else I can do. And I suppose it's just frustration as well.
CFC 889.6, wife, diagnosis depression

So I guess I was kind of… I've always worried about my mum. You know I have always worried about her, it's like having a child, only I think people don't worry that much about their children.
CFC 563.6, daughter, diagnosis schizophrenia

In order to cope, social or professional support can be helpful (Reinhard, 1994). Low perceived control over service provision and treatment can increase feelings of stress and helplessness (Oybode, 2003). Nearly all carers we interviewed mentioned periods of depression or physical symptoms which they thought were brought on by stress. Several of the carers we interviewed were on anti-depressants or had been previously. Forty-one percent of carers taking part in our survey rated their health as 'fair' or 'poor'.

Our findings suggest that in particular carers whose narrative centred on empathising with the pain of the care-recipient (compathy) together with a lack of trust in services and/or a lack of social support, struggled. These carers voiced thoughts about suicide or had actually tried to commit suicide. This seems to be related to the grieving process and gaining a measure of acceptance of expectations having to change for both, the carer and the care-recipient. Research in the area of expressed emotions (EE) by families and carers suggests that individuals are more likely to relapse in an environment with high levels of EE (Hooley, 2007). Patterson *et al.* (2005) suggested that levels of EE experienced by carers may be linked to the carers' appraisal of loss. Carers in the

current study who have gained a measure of acceptance seemed to cope better:

> *I think initially I desperately wanted [name, husband] to get better, now I've accepted he possibly won't. He'll get better than he was, but he won't get well and I think initially, I kind of thought that he would. I now don't think he will, don't think so you know. But he's better in himself, [name] is not suffering as much now, do you understand what I mean? […] But yeah I think it's an acceptance now of chronic illness isn't it? You know knowing that it is chronic and it's not going to go away.*
> *CFC 877.6, wife, does not know diagnosis*

It is important to remember that managing or a level of acceptance is not an end state, but can change at any point in time due to circumstances such as a crisis in the health of the care-recipient. Ninety percent of carers indicated in the survey that the condition of the care-recipient can change rapidly and nearly fifty percent of the carers stated that in the last month the care-recipient had been well 'none of the time' or 'a little of the time':

> *So I had a hell of a fortnight with [name, wife], I had a hell of a fortnight with the kids and then this, I thought I've had enough, I've really had enough. It was the first time I felt really suicidal, so I went home and decided I'm going to get in, I'm going to get the hover […] and I thought I'm going to put it on the banisters and I was going to hang myself on the banisters, just garrotte myself and that was the plan and I got in and [name, wife] was hovering. Now she never lifted a finger in the house, she didn't do any housework and that day that I went, she had decided to hover.*
> *CFC225.6, husband, diagnosis bi-polar*

> *I have had one bad period myself of hmm feeling that I wanted to end it all myself and I've never felt that before ever but I did you know, some months ago […] and you know, hmm, because I'm over that now, I'm fine, I'm absolutely fine but hmm […] I felt like hmm, I felt like hmm, the quality of life that we had got is awful. I feel that hmm I'd like to be in the position we were in before, you know when he [son] was a lot younger and he was happy and I'd rather have that then and I'd rather just take the two of us, you know, that was my lowest time.*
> *CFC 553.6, mother, diagnosis schizophrenia*

Deep in my heart, I still read about these odd cases where they've found social workers who were... psychiatrists, psychologists, and they turn their life around and I still believe somebody is out there somewhere and it would be wonderful to find somebody. Well I hope so, because either me or [name, son] are going to end up dead or in hospital very soon and okay, and a couple of weeks ago I really felt like putting the two of us in the car and driving over a cliff edge.
CFC 785.6, mother, diagnosis schizophrenia

Many of the carers who we interviewed sought to find an explanation or a 'theory' for the cause of the illness; this seemed to be a coping mechanism, if the explanation or cause lies outside the control of the carer. Carers were looking for and constructing explanations such as genetic influences, one-off events (traumatic birth), drug taking or alcohol consumption and accumulation of stress. This helped to relieve feelings of guilt or questions around blame and may be part of the process of acceptance:

It was and I didn't know much about mental health at all then, it is really frightening. I felt annoyed with his [husband] parents and I blamed, I was looking for blame, why is he ill, why is he like this? […] 10 years later, I came across some research about if you have a traumatic caesarean birth, quite often it can cause this and he was a traumatic caesarean birth and I, to me now in my head I've always said that's the reason why he is.
CFC 350.6, wife, diagnosis schizophrenia

Consistent with the findings from our work with professionals, all older carers talked about concerns and worries in relation to their deaths as they did not know who would take on the caring role after them. Additionally, carers mentioned particular concerns around adequate service provision as previous experiences often left them in doubt about the quality of services that might be provided:

Um, we were still saying to these people, "Look, he needs independence, we cannot cope with him [son] forever, we're getting, we're both over sixty, many reasons why we need something set up for him for the future, for his future".
CFC 595.6, mother, diagnosis Aspergers syndrome, depression and psychosis

This has also been found in previous research (Rose *et al.*, 2002).

Carer and care-recipient relationships

Carer and care-recipient relationships can be fraught with tension and change quickly depending on the well-being of the care-recipient. This is influenced by the level of functioning of the care-recipient such as decision-making abilities and level of independence. People with serious mental health illnesses often find it difficult to accept a diagnosis and can have periods of distrustfulness or paranoia which means that they might resist treatment and may be less likely to want the carer involved in their lives, let alone in treatment decisions or relationships with professionals. During these times relationships can be very strained and particularly difficult:

> *Hmm and I'm feeling fairly upbeat at the moment because she's okay, but my mood goes up and down with her health so it's - and when things go pear shaped with her they do seem to go a bit pear shaped a bit quickly, you know, and it's only like from having been "oh yeah fine" you know, to hmm feeling, feeling dreadful and really not, not knowing how to cope, where to turn, what to do, is life worth living sort of mentality hmm. Urrh and it can happen frighteningly quickly actually. Although she has been pretty stable I don't - yeah I - there's that semi-con… semi-constant anxiety of "is she going to stay well, is she going to relapse back, is something going to trigger things off?"*
> *CFC 544.6, mother, diagnosis schizophrenia*

Some carers described the care-recipient as a different person when they were ill and this allowed them to disassociate the behaviour (challenging and often hurtful) from the person they loved; this was an important coping mechanism. Some carers even went as far as giving this 'other person' a name:

> *Now, it's not been diagnosed as schizophrenia, and I don't feel it is schizophrenia, but it's like two people because I actually call her [name 1] and [name 2], because when she goes off on one, you can directly go hiya [name 1].*
> *CFC 576.6, husband, no diagnosis*

> *He [son] will change in a second and say the most terrible things to me, sort of cold, we call him Shark Eyes… And he's – he's a lovely chap, you know.*
> *CFC 929.6, mother, diagnosis schizophrenia*

Even though carers talked about care-recipients' difficulties with taking responsibility for their lives and managing day-to-day issues, all carers we interviewed felt that they would like the care-recipient

to take more responsibility and become more independent. In addition, some carers felt overwhelmed by taking responsibility for some of the critical decisions, including decisions about changes in medication:

> *It's hard, because you're – you're dealing with adults and it's as if sometimes – you know you're sort of, what's the word I want, sort of, oh I can't think, intruding on them. You know, intruding on their sort of, their lives, their – it's just for their own sake really.*
> *CFC 806.6, mother, multiple carer, three children diagnosed with schizophrenia and one with autism*

> *His ideas are very very childish. Just like a 10 year old boy – that's the nearest I can get. You've got to treat him like that in some ways, which is awful. But when you try and treat him like an adult to do something which you know, your husband would normally… you just get these blank looks you know.*
> *CFC 949.6, wife, diagnosis depression*

Very few carers mentioned anger directed towards the care-recipient. Where anger was mentioned it was generally in relation to drugs and alcohol, which carers felt could have contributed to the condition manifesting itself or making it worse:

> *He's [husband] had a …well part of me…Yes. Yes. Er… because part of me feels he has brought a lot of it on himself. I am not saying that it has all been brought on himself because he has been diagnosed with ME and with this… er… repetitive stress syndrome and er…. and that. So I realise that it isn't all his drinking but I think a lot of it is.*
> *CFC 889.6, wife, diagnosis depression*

Coping strategies

Some carers, in particular those who had cared for a considerable period of time, mentioned a range of coping strategies, including walking, meeting friends, availing of respite care, and emotionally distancing themselves from certain aspects of care:

> *But it's recognising I can't do everything, yeah and pulling back and I do look after myself a lot more than I used to.*
> *CFC 350.6, wife, diagnosis schizophrenia*

Carers living with a partner who had mental health problems found it liberating to realise that they could potentially separate from their partner, and one of the interviewees had done so, but decided to

return to her husband. Some of the parental carers and one of the children caring for a parent decided that they could not live with the care-recipient:

> *When I moved here, it was the first time that I chose not to share my address with my Mother and because it is like having a stalker and it's the first time that I feel that I've had a normal life and I can choose what I tell people and how much they know about me.*
> *CFC 563.6, daughter, diagnosis schizophrenia*

Several parents who had decided that they could not live with the care-recipient mentioned encountering strong resistance from professionals:

> *He went to a hostel for a while, then he went into hospital and then he had a sheltered accommodation away from home, but I was accused by the social worker actually of the psychiatric ward of abandoning my son and it was horrendous and it ruined the relationship I had with my son. The – I had social workers trying to get us to take him back. They were trying to blame it on to [name] my eldest daughter [autistic] who was just a little girl then.*
> *CFC 806.6, mother, multiple carer, three children diagnosed with schizophrenia and one with autism*

Carers talked about respite in terms of either the care-recipient going away from home for a few days or going away themselves. Although carers would like some respite, most talked about difficulties; there were problems of finding appropriate respite places or staff to support the care-recipient at home:

> *Like I said, with working, working, caring for someone who is in mental health you need to get away, you can't move to another room because they can come and follow you. So it is time that you need on your own, whether it be an hour, a day, a weekend, a week every month, something, you need time to get that break, because like I said it's just, it's hard.*
> *CFC 576.6, husband, no diagnosis*

Several carers mentioned that going away meant that the care-recipient was worse on their return:

> *I mean I go, I mean I've been to, I went to the [area] this year, went for seven days and friends, we went, but if I do something like that, if I do something like me time to get away, to do things for me, for me to enjoy myself and to*

recharge my batteries, I pay for it when I get back. I mean I go back and she'll [wife] just hit you know rock bottom, become really depressed, really low.
CFC 255.6, husband, diagnosis bi-polar

Third sector organisations

Other coping strategies included looking for counselling and emotional support. In this respect, third sector organisations played a very important role for carers, as already highlighted by professionals in the previous chapter. Several carers mentioned using telephone support lines and private counselling.

Generally speaking, responses from carers indicated that voluntary organisations played a major role in their lives or had at some point. Voluntary organisations provided support for carers in times of crisis, information and the possibility to talk to others who had had similar experiences. Most carers had to find out about organisations themselves and often stumbled across them in their search for help:

She [friend] knew of [name, voluntary organisation] and so she gave me their number. So I rang her up and hmm, you know, I was at my lowest ebb obviously at the time and hmm yes, she was brilliant, absolutely brilliant. So hmm, you know, I obviously probably saw more of her at the time because my situation was different hmm but hmm, yes she's been marvellous.
CFC 553.6, mother, diagnosis schizophrenia

Some of the carers we talked to got involved in the organisations themselves, setting up support groups and attending conferences:

One of the reasons that, err, my friend and I started the [name] Group because we didn't want other people to, you know, if there was anybody else around who had a child or a carer with severe mental illness, we didn't want anybody else to sort of go through the – like fog that we had gone through. And, you know, whether – I don't know, whether it needs – when your child is first given the diagnosis, whether you're given an information pack or, I don't know, I don't know.
CFC 888.6, mother, diagnosis schizophrenia and bi-polar

Carer contact with organisations changed as their circumstances and support needs changed. It appears that there is a point when individuals have gained enough inside into the 'mental health system' and gathered a range of information (or have identified information sources). Some maintained contact with the

organisations which provided them with access to someone to talk to whereas others stopped going to carer meetings as they did not want to talk and think about their difficulties or listen to other people's problems. A few carers said that they had developed friendships with individuals from these groups who they met independently. Several of the carers mentioned that there came a stage when they needed more practical help and advocacy and that this was not always provided by the voluntary agencies:

> *They'll have carers meetings and half the time the professionals will – you know, in fact, they don't turn up so we end up talking about, you know, just general conversation and, er, to me, I've always looked upon those meetings as information gathering. […] I don't really want to be anywhere Friday afternoon 'cause I know I've got a mad weekend coming ahead, you know, but if I was getting something out of them, which I never was, so I just stopped going.*
> *CFC 806.6 mother, multiple carer, three children diagnosed with schizophrenia and one with autism*

> *Somebody to come and fill all the forms out.[…] when you have to do it yourself, …well at the moment, because you've got so many other things on your mind – which is what used to happen with people who came to us [Welfare Office] – they only came to you because they were desperate. And you've got all these things going …and you can't …you just cannot.*
> *CFC 949.6, wife, diagnosis depression*

Carers highlighted a key role of voluntary organisations, describing the support they provide to the care-recipient in terms of social networking, building up skills for independence, and involving in meaningful activities:

> *A friend of a friend got us into a sort of, a charity that actually deal with people that have learning difficulties, but they have this special project going and [name, son] just about fell under the umbrella and he actually had a placement there, somebody funded it, for about 18 months, which was a sort of you know learning to – one was working in a café, the other was in a pottery and that was – that came at quite a critical time for – it was a godsend.*
> *CFC 811.6, mother, diagnosis schizophrenia*

This was highly valued by carers although several emphasised that there was a need for a wider variety of opportunities, such as practical and educational courses tailored to individuals with mental

health problems, supported work opportunities, and meaningful leisure activities.

Relationships between carers and professionals

The relationship between professionals and carers has been described as pivotal by all participants and presented a major backdrop to all aspects of caring. All carers mentioned that having confidence in professionals, knowing that the cared-recipient was looked after well and received appropriate support would make their lives less stressful. However, in keeping with previous literature, carers we talked to generally felt that this was not the case (Askey *et al*., 2009; Bee *et al*., 2005; Finkelman, 2000; Schulze & Rössler, 2005).

Ideally, carers would like a relationship between themselves and professionals that is underpinned by respect, trust and good communication. However, consistent with the findings from previous research (Arksey *et al*., 2002, Askey *et al*., 2009), carers we interviewed generally perceived their relationship with professionals as fractious, ambiguous, antagonistic and very challenging. They saw the root of these problems in the way the relationship between services and carers is enacted. Although they recognised that professionals are circumscribed by professional codes of conduct and guidelines, particularly those relating to confidentiality and information sharing, they felt that there was a lack of respect towards and acknowledgement of carers:

> *These psychiatrists know – they – they do a little bit of a job, which is out there a few hours a day, but the carer's there twenty four hours a day and when – and severe mental health, when this person becomes MI5 or dangerous or whatever, the carer is the first one on the frontline, not the social worker, not the, er, not the professionals out there … and they should really, really just give a bit of time to these carers, a bit of time that they will not give 'cause they just – they know – they're only interested in the service user's perspective, right, and it should be – they should be hearing the carer's perspective.*
> *CFC 293.6, husband, diagnosis bi-polar*

Although fifty percent of carers indicated in the survey that professionals involved them in decision-making, about half of those felt that the involvement was 'tokenistic', 'looks good on paper', or that decisions are already made before the consultation. Twigg (1989) outlined three types of relationships between social care professionals and carers: carers as resource, carers as co-workers and carers as co-clients. In the conceptualisation of the *carer as a*

resource, carers are taken for granted and not seen as part of formal service provision. The focus is on the care-recipient and the welfare or inclusion of the carer is not seen as relevant. In the conceptualisation of carers as co-workers or -clients, there is a shift to interweaving formal and informal care in order to enable the best possible care for the care-recipient. However, although the carer is recognised as an essential part of care provision, and support and co-operation play a part, the focus is still on the care-recipient. Mental health, and in particular medical service provision, still centres very much on the doctor and patient relationship and there is a reluctance to include the carer as a legitimate recipient of professionals' time and expertise (Oybode, 2003), which resonates with Twigg's (1989) model of the carer as resource. Others have suggested that carers are still viewed as a problem or possible contributor to the ill-health of the care-recipient (Kaas *et al*., 2003; Krupnik *et al*., 2005; Shooter, 2004). During the interviews, several carers mentioned that they felt professionals blamed them as a contributing cause for the illness or a relapse, which further strained relationships between carers and professionals:

> *I said "I am an intruder and nobody notices me, I'm not there at all…only when its twenty-four hour care wanted!" So that was the first sort of…I was against the whole thing! Or, they were against me is how I felt…that it was my fault. I felt it was my fault that she [daughter] was ill because I was over-protective and over-this and over-that!*
> *CFC599.6, mother, diagnosis schizophrenia*

Carers felt that they were seen as a resource in the background, someone who would, and is indeed expected, to provide care and act in the best interest of the care-recipient but who does not need to be consulted, involved or supported. Carers felt that this led to a power imbalance between themselves and professionals:

> *Um, he'd [son] go and see a psychologist or a psychiatrist but there was no report, you know, "I've seen this person and this is my opinion" there was nothing. So – so we asked, we wrote to this person and we said, you know, "Please could we, could we have a copy of the report to help him with his assessment?" and they just took – took exception to that, back to the mental health team, start again. You know, it's like snakes and ladders you know, you – you start to climb the ladder, you ask a question and they don't like it, back to the bottom, start again.*
> *CFC 595.6, mother, diagnosis Aspergers syndrome, depression and psychosis*

Carers as experts

Carers wanted their own role and expertise to be recognised and valued. Even though not all carers lived with the care-recipient they spent a large amount of time caring for a loved one and had built up expertise and skills, as well as a wealth of biographical knowledge. In this respect, they can be described as 'experts' (Brown, Nolan & Davies, 2001). Carers reported that great frustration arises from not being listened to or taken seriously or having their expertise acknowledged. This can clash with professionals' attitudes of holding special knowledge:

> *I would say that is a complaint from a lot of carers…people who visit once a month think they know more about the person than someone who is living with them twenty-four/seven! But, she would always ask him [husband] was he was having intrusive thoughts…there was another question she asked him...and she always asked him if he was suicidal […] and nine times out of ten, he would take a Valium before she came because he didn't want to see her. So they never actually saw him as I saw him most of the time.*
> *CFC 877.6, wife, does not know diagnosis*

Carers felt that not being listened to can have very serious consequences. A major point of frustration is that carers are not believed or their concerns taken seriously:

> *… but they'll – they'll never – in fact, my wife when she's been ill at times, she hasn't told quite the truth, in fact most of them don't – or hundred percent of the truth, so they'll never get the – mind you, I – in fact I feel at the moment if I rang up the psychiatrist at [Place] and said, "She's telling me the Martians have landed" they'd say, "Yes they have" because they don't seem to want to listen to the carers. […] We – we had this before, by the way, about four years ago, they dropped the medication, the anti-psychotic drug, and she started going really ill and I had – at the finish, I had to write a letter to the, um, social worker and ask him to fight for me … and eventually we got her some help.*
> *CFC 293.6, husband, diagnosis bi-polar*

This can be particularly frustrating for carers when they feel that professionals do not seem to understand that some things the person with mental health problems may say are not real, but only exist in the care-recipient's mind as this quote illustrates:

> *"Excuse me, Dr [Name, psychiatrist], I have been through this with you before …" I said, "… these things that you say could*

happen, aren't happening, can't you get it, can't you understand that?" I says to him, "Because if you – if you can't you're not supposed to be with [Name, daughter]" because it's so dangerous for [Name, daughter] and it has been over the years.
CFC 547.6, mother, diagnosis schizophrenia and bi-polar

From the carer's perspective professionals do not seem not to value carers' judgement of how well the care-recipient is doing or if any help is needed. Consequently, professionals often take too long to respond to calls for help, which is very stressful for the carer:

> *She [social worker] said "we've got you an appointment for July". Well, it turned out to be for the end of July. I just burst into tears! I said "I cannot wait that long! Since February, [Name, husband] has been ill, he's gotten increasingly worse…I really feel he needs to be seen!" and her first words were "well, you have got a right to complain!" … and I'm sobbing now! And I said "do I look like someone who wants to complain!? I just want help for [Name, husband]! I've got no complaint about anybody! I just need him to see a doctor!"*
> *CFC877.6, wife, does not know diagnosis*

One of the carers talked about the stress of having to cope with her mother being very ill and waiting for an appointment with the psychiatric team. Her mother tried to commit suicide but was found by her family before she could hang herself. The family had tried to get help before the event and also immediate support afterwards:

> *Um we had to ring doctor, the doctor in um [Area] and he gave her antidepressants then straightaway and he said "You have to – you have to be with her [mother] for twenty-four hours" and then he phoned, this was the psychiatry – psychiatry team and then she got an appointment, but she didn't get an appointment for about two weeks and I thought how the hell are we going to cope with her for two weeks? And I had to watch her like a … well it was like when she was going to the bath […] and she used to go and then I used to leave the door open, I was – I was paranoid that she was going to try and drown herself or something.*
> *CFC 593.6, daughter, diagnosis depression*

Initial contact

The first contact with services is a very important event and how this is managed and professionals' conduct is perceived by carers has a major influence on subsequent relationships both between

carers and professionals, and also between the care-recipient and services.

In keeping with the literature (Askey *et al.*, 2009, Judge *et al.*, 2005), most carers we talked to described the first contact with services as traumatic and very difficult. In particular, carers struggled to get help when they realised that a child, partner or parent was unwell. In the context of mental health, professionals cannot intervene until the person themselves asks for help or it becomes clear that the person is not able to take responsibility for themselves or may harm others (Rethink, 2005). Carers perceive this as unnecessary and reported having had to wait for help until there is a major crisis situation:

> *He [son] became ill when he was seventeen. He was very aggressive and I tried to get help from everywhere, social services, GP and no-one wanted to know. As a family we were living in fear. You knew there was something wrong, but you didn't know what it was. In the end he was threatening to kill and he was acting strangely, I went down to the police station and talked to the police and in the end the only way he got help was the police picking him up, having him seen by a doctor.*
> *CFC 806.6, mother, multiple carer, three children diagnosed with schizophrenia and one with autism*

Several carers mentioned that they felt that the long-term outcome might have improved if services had intervened quicker. In addition, as found previously, carers perceived that services tend to focus on crisis intervention rather than on on-going support (Jones *et al.*, 2009):

> *I write to the consultant expressing my concerns, we get a letter from him to say he's going to be away for a month and he would contact us on his return and at that point I felt absolutely shattered because everything I'd read in the meantime about mental health illness seemed to suggest that early intervention was really important and we were now months down the line.*
> *CFC 811.6, mother, diagnosis schizophrenia*

Tensions carers and professionals

Carers felt that professionals did not understand their motivation in trying to get the best services and support for the care-recipient. Carers talked about a range of motivations such as 'maternal instincts' and 'love'. Indeed, some carers mentioned that the need

to fight for or ask for help turned them into a person they did not want to be, and they resented professionals for that:

> *And on the train on the way up I rang and shouted at everybody in the Local Authority office. I didn't care who heard me on the train, I just was past it. […] I lost all inhibition over this completely. It brings out very powerful maternal instincts. […] Yeah. And that turns you into a monster really and you are not in a state to be a monster. […] I say you are going to have to turn yourself into some kind of nagging machine, because that is how you get stuff. But…when you are dealing with severe mental health you are not in a fit state to do that.*
> *CFC 874.6, mother, diagnosis depression, psychosis and addictive behaviour*

This eventually can lead to anger and frustration directed towards professionals:

> *They want to fob you off all the time. And then if …. They wonder why er… you know, we get so annoyed with them. But they don't live our life so theirs is all easy going. And they can go home. You know. Whatever you phone, whatever you do, there's always tears isn't there. Because you can't … and I hate having to ask for things. And that's… I think that's an embarrassment that you've got to ask.,… or plead with people for thing what you should be…or my children are entitled to. I think to give them an easy and comfortable life. Basic, basic things. Basic needs.*
> *CFC 973.6, mother, multiple carer, two children diagnosed with dyspraxia*

This perception that professionals do not care 'enough' contributes to carers wanting or needing to be involved even more. However, professionals perceive this as carers being over-protective, pushy or interfering, which adds to the fractious relationship between professionals and carers:

> *I didn't go all the time to his appointments, because you mustn't be seen to interfere because otherwise they'll have interfering mum or carer down in their notes, you know, which I've seen.[…] you don't want to be seen as interfering, though I don't see why not, you know, and now I don't care, if they write, they can write what they like about me now as long as he's well, so I don't care. I've seen what they've written so I don't care.*
> *CFC 948.6, mother, diagnosis paranoia*

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Negative experiences with services for both care-recipient and carer can lead eventually to a break-down of trust. Some of the carers we talked to felt that poor care was worse than no care at all as it could lead to a worsening of the condition of the care-recipient:

> *Um, for people with mental health problems to be offered poor care is far more damaging, they are better off without it and I feel you're better off because the damage… […] You've got to respect the person that's offering care, the healthcare professional. If you don't respect the person it's a waste of time.*
> *CFC 785.6, mother, diagnosis schizophrenia*

Carers described some professionals as being patronising, not listening and sometimes providing contradictory information in order to shield themselves:

> *They [staff in hospital] put him [son] back on some medication that had given him this bad, very bad reaction, physical reaction and it made him come out in big blotches. […] and when I went to see the man in the office he was saying like, with his feet up on the chair, watching the television and he was eating his lunch and I said, "Could I have a word with you?" and he said "Yes", but he didn't take his eyes off the telly even and he was eating his lunch and he said… I said about these pills, he said "Oh that's nonsense that is, that doesn't happen". I said "Oh right". So I came home and I got [husband] to print it off, off the computer and the next day I took it in and I told… I said to him, in front of somebody else, I said "So here we are, it's in black and white, I'm not making it up!" and he said, "What do you mean you're not making it up?" and I said "I'm not making up what I told you yesterday" and he said "You didn't tell me anything yesterday." They mess with your head in that place. They mess with your head.*
> *CFC 643.6, mother, diagnosis schizophrenia*

A few of the carers talked about taking forward official complaints. Other carers mentioned not complaining as the care-recipient did not want them to do so out of fear that this would adversely affect their care. Nearly all of the carers who had complained felt that was a pointless exercise. For some this eventually resulted in them trying to minimise contact with the health and social care services as much as possible:

> *I wouldn't do it [complain] again 'cause I don't see the point of sitting there. The only thing I gained was when we went to*

the solicitor and we got compensation out of court, that was a tangible – I could see why people can blame and sue because they certainly don't put in place the recommendations, so at least you have the satisfaction of knowing that unless you hit their pocket they're not going to do anything. Then it stirs them up a little bit for a while, but that seems to be the only thing that matters, you know.
Cfc 948.6, mother, diagnosis paranoia

I said a complaint can't make people care, I said and [name, social worker] and her boss don't care. I said and they never will care, I said all they want to do is cover their backs and by now they will already be lying in [name, husband] notes, 'cause they were.
CFC 877.6, wife, diagnosis not shared

Service provision

Carers identified a range of issues around service provision and support, including care co-ordination, the care plan approach, carer assessment and multi-agency working.

Several carers mentioned that they did not have a care co-ordinator or did not seem to be aware that they should have one. Others talked about the Care Plan Approach (CPA) not being in place, or if it was in place not being followed up and reviewed:

I think they just need more staff in social services so they can spread themselves around everybody that needs them, […] I keep fighting, but you know you can visit the doctor and get referred to somebody else, and somebody else. You need somebody who is co-ordinating and I think that should be somebody from social services because that's what they are – social services. So they should be aware of everything that's happening and just be there.
CFC 949.6, wife, diagnosis depression

All we really ask is – is for [Name, son]'s CPN to implement the CPA, and he's supposed to be [Name]'s care coordinator, he's supposed to write a decent plan, it's supposed to be reviewed, we're all … anybody that has care or supporting [Name] are supposed to get together on a regular basis and discuss it …and it doesn't happen, the only time it's vaguely happened was when [Name] was in the nuthouse.
CFC 929.6, mother, diagnosis schizophrenia

Issues around multi-agency working centred on difficulties in communication between health and social care teams, primary and

secondary care and hand-over from one team to another. This could seriously inhibit or delay the provision of care:

> *They need to have that information fed into them. Not wait until there is a crisis. And you say oh well I went so and so, so and so. And they say it should be coming back to them. Or the doctor should be passing on. But apparently doctors don't always know what's happened because the hospitals don't send them the information. So you are going in there telling them what's happened and I think, oh it's crazy it really is.*
> *CFC 949.6, wife, diagnosis depression*

> *I've – I've referred you to the mental health intake team" and that's – that's the end of that, that's all she [GP] can do, refer you onto somebody else, you know, and we keep going back and saying "That doesn't work, can you do it again, please?" and – and – and she'll perhaps try somebody different. […] It's a bit like a pass the parcel game …the music stops, the wrapping comes off …but instead of taking the wrapping off and passing to the next person, they just give it you back, they just give it you back and you start all over again. So whatever direction, you know, wherever you're going, you're just hitting a brick wall, you're just hitting a brick wall every time.*
> *CFC 595.6, mother, diagnosis Aspergers syndrome, depression and psychosis*

Several carers stated the need for a crisis team in their area and some mentioned having had access to a crisis team previously. Support is needed 24/7 and not only during working hours:

> *I think one of the best things that happened with mental health was […] the crisis team. I think that is brilliant, you know because if there was a problem […], you could get hold of somebody and also at weekends if you were lucky, so not always there'd be – because I think it would be… You want help, you want someone to intervene or someone to check up that someone's alright.*
> *CFC 806.6, mother, multiple carer, three children diagnosed with schizophrenia and one with autism*

Carer assessments

Just over two-thirds of carers indicated in the survey that they had received a carer assessment. Of those, thirty-three percent were offered support from a voluntary organization, fourteen percent were offered respite and one respondent received a one-off

payment to help with house maintenance following their assessment. Thirty-three percent of carers indicated that nothing happened as a result of the assessment.

Carer assessments should be there to support the carer and identify their needs and how these might best be met. Consistent with our findings from our work with practitioners, carers suggested that in practice carer assessments are not particularly effective. Carer experiences were varied; some talked about the experiences in a very negative way, far removed from the in-depth assessment of need envisaged in policy and practice guidance. Assessments were conducted by social workers, CPNs or individuals from a voluntary organisation. Some carers had had an assessment a long time ago but no review since then; others had requested a carer assessment and were still waiting. The following is a quote from a carer who had requested an assessment two years ago:

> *I don't know what to say really. I phoned up and asked for a carer's assessment for myself, for [husband] […] And they took all the details, never heard anything. So I am still waiting.*
> *CFC 973.6, mother, two children diagnosed with dyspraxia*

Several carers felt that the assessment at best was a waste of time and at worst potentially damaging:

> *It was a terrible experience, absolutely awful and we went through the form, she had no understanding of the mental health problems […] I came out of there feeling totally unsupported, I was nearly crying and she made me feel I shouldn't be in this relationship at all.*
> *CFC 350.6, wife, diagnosis schizophrenia*

> *I thought it was an utter failing, it was a waste of time because they – they actually, it depends who's doing it, but what's the point of carers' assessments if you feel at the end of it the carer's made to feel it's a waste of time? What's the point? They have enough to do with their time without feeling it's a waste of time. They want to feel – feel that it's um, well they've gained something from it or achieved something from it. Why bother?*
> *CFC 948.6, mother, diagnosis paranoia*

One carer, when requesting a carer assessment, was told that social workers in her local authority now make notes whenever a carer calls and transfer these onto a carer's assessment form; this is then filed as a completed carer assessment:

> *When I asked could I have a carer assessment they told me I'd already had one. News to me!*
> *CFC 881.6, wife, diagnosis MS, memory problems, damage frontal lobe*

Expectations around service provision and recovery

For some carers there was disparity between their expectations and what services might be able to deliver; however, they also recognised that there were issues around resources, finances and training:

> *The overall impression that I have of the service is that the people try their best and they're sort of fighting against the odds all the time. They're all very caring people and they all want to do the best they can, but there's limited funds, limited time and a great number of clients. […] And very often they talk about the psychiatric side of the NHS being the poor relation and it certainly is.*
> *CFC 889.6, wife, diagnosis depression*

> *Doctor [name, psychiatrist] openly said to me, saying she said the general care is not good, she said, there's too many changes in staff, they don't know their patients, we don't feel, we don't feel supported by the team and you know we're hoping that when they go back out to the community, people with mental illness are being supported and they're not.*
> *CFC 877.6, wife, does not know diagnosis*

Carers mentioned that some professionals had admitted to not being able to provide any more help:

> *He [psychiatrist] did spend a lot of time with her [daughter]. But he held his hands up and said "We can't… she needs in-patient… tailored for her". She needed something that fitted… The psychiatrist said as much. He said that we are chemists. "We sort them out, we send them home, then they can start a psychotherapy of some sorts, the talking therapies". But there was a fifteen month waiting list for talking therapy and they had failed to put her on the list when she first came. […]And they had nothing more they could… they couldn't detain her anymore. I mean that's not just his failure, it's the failure in the system, the sectioning system.*
> *CFC 874.6, mother, diagnosis depression, psychosis and addictive behaviour*

Some carers stated that professionals had very low expectations of recovery for the care-recipient, which carers felt was not helpful and could potentially impede recovery:

> *I did my own research on the internet mostly … particularly the medication side effects and … well, all sorts of things! I mean I'd get told that "oh, its like a revolving door, they go out, they come back in…they go out, they come back in". If they haven't experienced the support when patients do go out, I can understand why they keep going back in!*
> *CFC 182.6, mother, diagnosis schizophrenia*

One carer talked about her daughter who had been severely ill. She and her husband managed to get her into private care after disillusionment with the public sector. This was made possible through financial assistance from the local authority and through an inheritance. She compared the public and private systems in her account and saw the main difference between the two in the level of expectations:

> *Nobody in the mental health team steps towards a patient it felt like. They… the mental health team would say – "you are discharged from hospital, go home and I will see you in three weeks". The CPN might phone up and say "How are you?" And she [daughter] would say "I am fine". And she [CPN] would say "Okay I will ring next week". […] I mean the difference and I…. it goes against my old socialist heart to say but… the difference once she was in the private sector. They had trained everybody – the cleaners, the women who sat one to one at night with them who were probably paid … basic wages, just the same as the ones on the ward here. They engaged with her, they talked with her, they had her talking. The ones at [place] never managed to get her to talk to them at all. She just clammed up. They hadn't been given basics training in… there was no expectation, there was low expectations …no expectations of recovery I think.*
> *CFC 874.6, diagnosis depression, psychosis and addictive behaviour*

Some carers talked about professionals having difficulties to change the system from within because of fears for their job security:

> *I think carers should effect change because I think we're the only group who can in any safety effect change because they can't - what can they do to us? They can't suddenly cut our pay down can they? Someone once said I'm a nurse, she said yes I agree with you there are lot's of problems but I can't*

speak up, I'm a nurse, you know I'm afraid for my career. They find it very hard to think freely when their careers at stake, don't you think so?
CFC 634.6, mother, diagnosis bi-polar

Communication and confidentiality

A common theme throughout the whole of the carer's journey relates to difficult encounters with professionals. Poor communication aggravates the situation and can often lead to a deterioration of the relationship between the carer and professionals and eventually give rise to mistrust and cynicism.

Specific information about the condition of the care-recipient and more general information on a range of issues such as treatment options, benefits, and available services are essential to carers:

I, I, I think there ought to be something, maybe a website or something that points you in the right direction for whatever your problem is. You know, whether it's finances or, you know, because it's all so spread out and you've got to really dig for the information. […] But it's – I don't know, all the services - it's a waste of time for carers, it's a waste – the services are a waste of time in general because nobody tells you anything. You ask and nobody seems to know until you find out yourself "oh yeah well", you know, "we knew that".
CFC 542.6, mother, awaiting diagnosis

We found that all this time we received no information, so we were given no – or I was given no information about his illness or about the services that we could expect, like benefits, we had no idea he was entitled to benefits. So it was like going through treacle and fog, it was almost impossible to find out any information about anything and I found it almost by default or talking to other people, there was no – I wasn't put in touch with anybody.
CFC 888.6, mother, diagnosis schizophrenia and bi-polar

In particular, carers felt that they needed information at times of discharge from hospital. However, all carers mentioned that information at discharge was very sparse and often unhelpful:

There was a difficulty of seeing a psychiatrist when my daughter left the hospital and I wanted to see the psychiatrist for 10 minutes to tell me what should I do and shouldn't, he said he wouldn't give me an appointment, I caught him in the passage of the hospital and I said we are going home, what can you tell me what – he said "As far as I am concerned, she

can sky dive" and so that wasn't a reply to a worried mother and I remember that, I would remember that for the whole of my life.
CFC 599.6, mother, diagnosis Schizophrenia

Conflict between the agendas of service users and carers can be a major barrier to information sharing (Goodwin & Happell, 2006). As noted in the previous chapter, in some situations, such as at times of crisis, the care-recipient may withhold consent to sharing information. In other situations, professionals' maintain confidentiality without consideration of or discussion with the parties involved, using it as a smokescreen. However, the literature suggests that guidance fails to address the practicalities of information sharing as well as sometimes being inconsistent. This can leave practitioners and carers uncertain (Pinfold *et al.*, 2004). The following example illustrates this point. A mother is talking about concerns for her son whose condition is deteriorating and her difficulties of conveying these concerns to professionals. There is an added barrier to talking to professionals in front of the care-recipient:

So I tried to tell … without upsetting my son, because he was in a bad state by this time, it's very difficult to relate to – to explain to others when somebody's not well when they're present especially with that illness, you know, it's – it's very difficult to relate, and they don't actually make it easy for you, because they don't say, "Well look, I'll ring you later and we'll talk about it" because of confidentiality, which is the worst thing we've ever come up against. […] He [son] had a meeting, like a ward round, a meeting with his doctor, consultant that day and it turned out he never wanted to speak to us again and he didn't want anything to do with us. And the doctor turned round and said, "I can't do anything about it because of confidentiality". […] We couldn't find out how he was, we couldn't give any input into his care, what his background was, how he'd been, which affected his treatment badly.
CFC 948.6, mother, diagnosis paranoia

Confidentiality was described by several carers as a shield professionals used to hide behind or even to cover up mistakes or service failings. Very few carers mentioned that some staff managed to work with the concept of confidentiality in a positive way. Carers felt that this needed to be addressed urgently but that issues around confidentiality are only a representation of the power imbalance existing between carers and professionals:

I was told it was confidential and there's nothing we can do and that makes me very suspect about the word confidential because to me it just translates to secrecy. […] So I think sometimes confidentiality is a veil behind which an awful lot is hidden.
CFC 636.6, husband, diagnosis bi-polar

Er… some professionals hide behind it […]. Some of them use it imaginatively. They maintain the confidentiality but they make absolutely sure that they are hearing everything from you. Some of them just say can't talk – she's an adult. Er…. I know it's at tricky one and I know it's important. But you can work with it rather than hiding behind it. And it varied from person to person.
CFC 874.6, mother, diagnosis depression, psychosis and addictive behaviour

The findings reported here mirror the comments made by practitioners in the previous chapter, highlighting the need to address this issue.

Different professional groups

Relationships with professionals varied greatly for carers and generally did not seem to be connected to a particular professional group, but rather depended on the competence, experience and training of the individual. There were great differences between the services received by the care-recipient: for example, some carers mentioned that the care-recipient had not had a social worker assigned for a long-time, whereas others had one at the time of the interview. Issues mentioned included: not keeping appointments, poor understanding of mental health issues, and a lack of empathy and respect for carer and care-recipient. Several carers commented on:

- the youth and inexperience of social workers
- the lack of training in and understanding of mental health issues by GPs
- the lack of empathy and respect for care-recipients by hospital staff on mental health wards
- the exclusion of carers by mental health teams

For example, professionals might miss appointments without informing the care-recipient or cancel at the last minute:

Although I don't really want to criticize because they do help a lot but the unreliability of it often knocks my son back quite a lot and impacts on everybody else around him then. I particularly find the Mental Health Team unreliable…in as

much as people arranging to come and see him, pick him up and take him out and not turning up or cancelling at the last minute. He finds it really stressful coping with that…and how that affects family members, too.
CFC 182.6, mother, diagnosis schizophrenia

Carers felt that GP support depended strongly on their understanding of mental health issues. As GPs are often the first port of call for carers, all carers felt that GPs needed to have more training and be better prepared to understand and deal with mental health issues:

The GP was – when I went – when I went to see the GP about [name, son] and then when [name, son] went to the see the GP, um, and he didn't think there was anything wrong with him […] – and then I went back to see my GP and he apologised for missing it. He [son] can present, yeah, I mean less so now because he's got iller but, yeah, I mean you could – he could walk in here and sit down and, you know, you wouldn't know. So, I don't – it's not entirely the Doctor's fault and once he'd had the diagnosis he apologised and he was fantastic.
CFC 888.6, mother, diagnosis schizophrenia and bi-polar

Comments about hospital staff tended to be negative and carers felt that staff were poorly trained and, in some, cases even negligent:

We spent the best part of three quarters of an hour actually looking for him because I went on the ward that he was booked in on, oh they said, we don't know where he is, we don't know where he is. […] You know, you put your trust in them and you've got no choice because they've sectioned him, you've got no choice and then when I said this, when I pointed this out, I said well that was fairly inconsiderate, then the next thing we're going out and they said, he said… "Well Mrs [name] I think your visits are being disruptive, you'd better not come again", you know, well no, I'm sorry we will come again because it's the only way we can keep our eye on him, because another time, it's a really rubbish place, oh listen, I'm moaning like anything aren't I.
CFC 643.6, mother, diagnosis schizophrenia

Relationships with psychiatrists tend to be key for carers but, as mentioned previously, were often experienced as very challenging and fraught with tension:

So they took her [wife] into [place] in [area], it's like a halfway house for people with mental problems and they wouldn't allow me to see her for the first week and I went in there and the Psychiatrist said "Have you tried giving her a clip round the ear, saying this isn't acceptable, you've got to get up" and I said "It's nothing to do with that".
CFC 938.6, husband, ME (Myalgic Encephalopathy) and depression

Some carers felt that it was not necessarily a lack of training or knowledge that prevented professionals from performing well, but rather management and organisational issues that needed to be addressed:

If there's sloppy workmanship at the top, it's going to follow through. I don't know. I don't know. I think what I do find of concern is that they think that sloppy workmanship is okay. What more do you expect you know. I think that's what's really worrying, is how they think that their best which is well below par, is okay, and it isn't okay. I think that's scary. I think that's scary because I know with [name, son] last CPN, she genuinely thought she was doing an A1 job, he was the problem, she was not the problem, he was the problem. […] So I'm not sure if it's a generation thing or a training thing, I don't know what the hell it is…
CFC 785.6, mother, diagnosis schizophrenia

Carer perspectives on the relationships between care-recipient and professionals

The lack of respect for carers but also for the care-recipient was mentioned frequently during the interviews. Carers felt that professionals could be patronising and disrespectful towards the person with mental health problems:

Well she did talk to him [husband], she always asked him how was he feeling, was he having any unwanted thoughts and did he feel suicidal, so she's ticked the boxes hasn't she, so she could go away and say well he wasn't feeling suicidal on Monday morning, I can't understand why he hung himself on Friday. That, you know that was the feeling you got, that it was ticking boxes.
CFC 877.6, wife, does not know diagnosis

You know the occupational therapist, meaning well, 'well come on we're going to be motivated today' well you don't talk to adults like that do you? You don't talk down to people.

And also you feel so patronised by their attitudes. It's as though you've got learning difficulties. […] You get an awful lot of 'they', 'they do this'. […] I've heard people in mental health teams talk about, "I met a truck load of SMI's this morning". Do you know what SMI's means? Serious mental illness. Can you imagine being called an SMI how well does that do for you self- esteem?
CFC 634.6, mother, diagnosis bi-polar

Carers felt that good communication between professionals and the care-recipient is the cornerstone of successful support and service provision; however, carers mentioned numerous times that professionals did not communicate well with the care-recipient. There were incidences, were carers felt that professionals used the 'mental health excuse' - that is implying that it is the fault of the care-recipient who is ill and cannot remember:

If the social worker was late, he wouldn't apologise, he would turn up and pretend that he'd … he'd say that he'd [son] forgotten the time because he's mentally ill you see. And um there's that subtleness, "Oh no, I'm perfect, I'm well, so I'm the one that's right, it was 3 o'clock, you've made the mistake 'cause you're – you're ill'.
CFC 948.6, mother, diagnosis paranoia

A major stumbling block identified by carers was that people with mental health problems often lack insight into their condition which makes it difficult for them to access or accept help. This problem threads through the whole carer and care-recipient journey:

And I don't see him [son] ever getting better […] But, part of the problem is that because he doesn't think, um, the Mental Health Services can help, he doesn't engage. […] But I think the problem – there is the help out there I think but the nature of his illness means that he can't or won't take advantage of it.
CFC 888.6, mother, diagnosis schizophrenia and bi-polar

From the carers' perspective a particular difficulty arose out of the treatment approach that individuals with mental health problems needed to take responsibility for themselves – for example, making appointments, renewing prescriptions and asking for help:

My son, he just said very politely you know, if you'd just like to leave me alone for a couple of months I would appreciate it. But then of course they withdraw their services then. He has denied our services. Which is so – what's the word -

bureaucratic – and it's really quite silly but also ultimately damaging because of the way they work.
CFC 634.6, mother, diagnosis bi-polar

People with mental health problems were expected to take responsibility for their behaviour and their recovery. However, from the carer's perspective, individuals were not supported enough to do so and this approach was seen as an opt-out and at worst as putting the care-recipient at risk. This is illustrated by a mother who has looked after her daughter for about twenty years. Her daughter went into a manic phase due to an unsupervised medication change and attacked a nurse whilst in hospital. The police were involved and the psychiatrist confirmed to the authorities that the carer's daughter was fully aware at the time of her behaviour:

In her opinion, this Dr [Name] had said that in her opinion [Name, daughter] knew exactly what she was doing when she – when she did that, so I was shocked, absolutely shocked 'cause I couldn't understand how she could've said that when she'd seen [Name, daughter] all this time and how she had … […]. 'Well I want to teach [Name, daughter] that when she um gets manic that there are consequences to being manic'. And I said, 'Yes, there's consequences of being manic, yes …' I said, "… but that's not fair …" I said, "… because it wasn't – it wasn't [Name, daughter] not taking her medication that put her in this situation, Doctor …"
CFC 547.6, mother, diagnosis schizophrenia and bi-polar

Other issues centred on service provision which is available but deemed not adequate or appropriate for the care-recipient. In this example, the husband's CPN was withdrawn as the husband did not take-up the offer of group therapy; according to the mental health team this indicated that he did not need any support:

It's all about recovery, unless he [husband] would agree to go to groups, or cognitive behavioural therapy, which again is in groups, not one to one, there's nothing they could do. […] He [husband] never has done, one to one is fine, but he could never go to a group with other people with similar problems, the worst possible thing for him.
CFC 350.6, wife, diagnosis schizophrenia

Examples of good practice

Very few of the carers we interviewed told us that they were happy with service provision at the point of the interview and felt informed and involved in treatment decisions. When this was the case,

support from all the relevant agencies came together, including support for the carer through third sector organisations.

For example, one of the carers talked about her daughter who had only recently been diagnosed with schizophrenia and both she and the carer had had good experiences with the mental health team, her GP and a social worker. The carer is supported by a voluntary organisation and acknowledged that she needs a lot of emotional support to come to terms with what has happened. The carer mentioned access to a family support group:

> *I think hmm another support we are getting is some sort of - it's - I don't think it's called family therapy, it's a family support group with [Name, psycho-social interventions] hmm. Where we all - well it's an opportunity for us I suppose to discuss but with somebody else there, so it's controlled hmm. And that has helped me being more forthright with both [Name, daughter] and very much with [Name, ex-husband]. […] I think hmm but I - yeah I've, I've - I sometimes think I, I've just sort of pussy footed around [Name, daughter] for too long and sometimes setting a few firm frontier… boundaries has actually been quite helpful.*
> *CFC 544.6, mother, diagnosis schizophrenia*

Whilst the narratives of other carers tended to centre on more negative than positive experiences, some did mention one individual or a particular team which they perceived as outstanding or very supportive:

> *He [member of staff] turned round and said you know for all we know you could have been off for a walk he said and gone up the road and jumped off that bridge there and I just – when [name, son] told me, I couldn't believe you know, they've just put that idea in his head. [Name, son] might not have realised that bridge was there, he could have just gone off wondering round the hospital grounds and I just, where was the support there? […] and I just, after that day, I had no time and no respect whatsoever for any of them on that ward. I just didn't want to know, I didn't talk to them, I just talked to [name] key workers and Doctor [name], who was absolutely wonderful.*
> *CFC 854.6, mother, diagnosis paranoid psychosis*

> *The CPN has been brilliant, we had that for about 10 years, 10, 12 years and that made a massive difference to our life and it was somebody coming perhaps once a month, just emotional support really but he [husband] could talk to*

somebody away from the family about everything. It was brilliant for him. The CPN went off on long term sick, so there was nobody available.
CFC 350.6, wife, diagnosis schizophrenia

Issues around social inclusion

Factors that influence the experience of carers through the stages of caring in addition to access to services are: experiences around stigma; opportunities for education and employment; financial impact of caring; and social participation and networks. These factors can promote or inhibit social inclusion.

Stigma

It is a paradox that although most adults in society know someone or know of someone who has been affected by mental health problems, there is still strong stigma attached due to a lack of knowledge and negative attitudes:

> *I can't see any way that, you know people have always treated mental illness as a stigma. It's far easier to say that somebody is psychologically ill than they're physically ill from what I see with the Doctor.*
> *CFC 938.6, husband, diagnosis ME*

> *And the friend and I who set up the [name] group decided that we would er… we spoke to a local journalist and they put us in the paper – Mothers speak out against …! […] But after that, my goodness! The number of people who spoke to us, it was quite extraordinary. So there is a great sort of seething mass of people who have kept this in over the years.*
> *CFC 874.6, mother, diagnosis depression, psychosis and addictive behaviour*

The previous chapter considered stigma from the perspectives of those involved in supporting people with mental health problems and their families. Our interview work with carers suggests that experiences of carers in relation to stigma varied strongly and were influenced by expectations of, and actual reactions of others, as well as carer personality and previous experiences.

> *I've only ever had one negative one […] we were sitting having a bit of lunch, at this ruby wedding lunch, and then this lady next to me said, "Oh, what are you talking about?" "We're talking about mental illness", "I blame the families myself" and I burst out laughing, I just couldn't help it, you know, so there's probably a lot out there like her, you know.*

[…] [Place] is lovely like that, actually, it's really – he's [husband] very popular and he's liked and um everybody – he hasn't – I don't think he's experienced stigma, they haven't …they know him when … before that, from when he was well.
CFC 949.6, wife, diagnosis depression

And – and as far as I'm concerned, I'm so open about everything, that I think it's everybody else's problems anyway. So I think because I'm – I'll just say, "Oh [Name] was sectioned" and I hide nothing, and I, I think that is really good to be so open. […] I think the more we talk about it and just not hide it under the carpet, I think the better everybody else is.
CFC 891.6, mother, diagnosis schizophrenia

There was a continuum from not wanting to share the mental health illness with family, friends and the wider community to being completely open. Although, carers indicated that mental health illness was still stigmatised, several felt that family, friends, and sometimes communities, were supportive. The behaviour and reactions of others were strongly influenced by the behaviour of the care-recipient:

There is a stigma, there's no doubt about it. And people are frightened of people with mental illness. Some mental illnesses manifest themselves in very frightening ways, don't they? Unpredictable I suppose is the … she [daughter] was very frightening when she was at her worst. Er… but she wasn't a danger to anybody else. But you can't explain that to …mental illness is one big…
CFC 874.6, mother, diagnosis depression, psychosis and addictive behaviour

The decisions around openness were often influenced by the wishes of the care-recipient or negative expectations of the carer. Carers who tried to preserve secrecy and distanced themselves from others were highly likely to feel isolated and lack a support network:

I lived at the time four doors from my parents, but I was too embarrassed to tell them that my husband had gone to a psychiatric hospital, so for the whole time he was in, which was about three weeks, I said he was on a course, I lied because of the stigma. […] Later it was when I told everybody […] when I got, when everything was out in the open and I'm not married to a murderer and he's just got mental health problems and he's not well and people were understanding.
CFC 350.6, wife, diagnosis schizophrenia

We talked to some carers who did not have an existing social network for a number of reasons, but felt that they benefited from sharing their experiences with someone:

> *The psychiatric nurse had asked me did I want to, did I need some support and I said yes, it would be great to have someone to talk to, because there's still a big problem with stigma attached to mental health issues, so I can't really talk to people in work about it. […] it's not something you can discuss, to me it's not a shameful thing, but there's nobody you can really talk to about it.*
> *CFC 636.6, husband, diagnosis bi-polar*

As found previously (Lyons, Hopley & Horrocks, 2009; Schulze, 2007), some carers felt that mental health professionals perpetuated stigma by the way they communicated and interacted with people with mental health illness:

> *I think she [daughter] will get a certain amount of stigma with her illness. […] I mean from the unit they say "if anybody from school's here [unit] don't discuss that you're here" or … "you know them from here [unit]". That sort of puts it in the brain though, that there is a stigma to it!*
> *CFC 542.6, mother, awaiting diagnosis*

Employment and education

About a third of the carers we interviewed were in some form of employment – either part-time or full-time. This reflects findings from the survey where just under a third of carers were in employment. The possibility of employment depended not only on the attitude of employers, but also on the health of the care-recipient and support from family and friends.

Some of the carers we talked to had left employment at an earlier point in their carer journey but returned at a later stage, often on a part-time basis. Others stopped at an earlier stage and could not manage to return to employment:

> *In the meantime, I'd taken time off this job, I couldn't go to work, which, [name, partner] wasn't working at the time, the day I told him, I said look I can't keep going, I need to take sick leave or whatever. I said I need to take time off and he was adamant I shouldn't do it and no you know, we need the money blah, blah, blah and I said I don't care, [name, son] needs me most.*
> *CFC 854.6, mother, diagnosis paranoid psychosis*

At the time I was working in a school as like a one to one person who sits with a child who's got problems and so I had to give that up because he [son] got so out of control really. He couldn't control himself and he couldn't control… I couldn't control him, 'cause at one time he came bursting into the kitchen and he was going to kill [name] my other daughter. You know he was going to kill her.
CFC 643.6, mother, diagnosis schizophrenia

Well, I was working as a, you know, only part time, but I did find that, um, when I went to work I was worried about what he'd be doing. He had tried to commit suicide a few times and, err, as I say, he just doesn't want to be left on his own […] I can remember several times trying to go to work and he'd just come out of the window and say, you know, "You can't go, you can't leave me", you know, "I'll kill myself", so in the end I decided that it just wasn't worth the effort and, um, gave up.
CFC 872.6, wife, diagnosis bi-polar

The ability to engage in employment (paid or voluntary) not only meant that carers and their families were better off financially, but also that they had forged another identity and had the opportunity to take a break from the caring role. It allowed them to be in a different environment, socialise and feel a sense of achievement, particularly if employers were supportive:

I work in the mental health field, which is good and has been a massive help to me in my personal life. I have got a very supportive team who I work with and they're very, very good about my role as a carer, encourage me to go on things that will benefit me as a carer, so that has helped and I've been able to work because he's [husband] up all night and sleeps in the day. […] I mean work was almost as in my respite, that's the way probably I would describe it. Work has been my respite.
CFC350.6, wife, diagnosis schizophrenia

Being reliant on benefits and unable to be in employment was perceived as demoralising and shaming by some carers. Carers generally felt that there was a lack of acknowledgement and valuing of the carer role:

And I suppose had my life been different I would have had you know a job that – so, you know had things been different we possibly would have been working, we wouldn't have had to sort of, well it's not begging exactly you know, but sort of

depend on benefits, but there again, how much money am I saving the taxpayer you know […] so it's a full time – and they don't recognise that do they, yeah.
CFC 806.6, mother, multiple carer, three children diagnosed with schizophrenia and one with autism

And the other thing, about giving your job up is… it's the embarrassment. Yeah. People say what do you do? And I get really, really embarrassed, because it's hard to admit, to say well …Because people don't understand that…. although I am not actually going out to work, I am still doing stuff here do you know what I mean? People look down on you. They think you are a drain on the system. And they don't understand because your children are walking … they don't understand that there is other […] So you know if we go away, with the kids, I make a job up.
CFC 973.6, father, multiple carer, two children diagnosed with dyspraxia

Some carers indicated that they did not feel that professionals took on board that finances mattered:

In 2001 she [wife] tried to commit suicide here one day. She'd been in bed for seven months and she rang up the Doctor and the Doctor said he wrong thing and that sort of pushed her over the edge and Doctor said that if I didn't give up work to look after her, she would commit suicide so I said where are we supposed to live and he said "Oh you'll get all the benefits going", which I gave up a job that was paying £500 a week, to have £45 a week as a carer and it took 39 weeks to get any money.
CFC 938.6, husband, diagnosis ME

As mentioned in the previous chapter, mental health problems can have a huge financial impact throughout all the phases of the carer journey. There are additional costs such as travelling and supporting the care-recipient. Also, some care-recipients tended to spend a lot of money when in a manic phase:

She's [wife] got herself in debt quite a lot, which I've had to cover. I mean during the late 90's, early 2000's, we were up to our eyeballs in debt, because [name] had spent, spent, spent, spent, spent and that was, we're still in debt for that. We've not been able to afford to buy a house, because you know black marks against our name, again she blames herself for that, that's by the by.
CFC 225.6, husband, diagnosis bi-polar

Carers talked a lot about a lack of understanding by public services. Care-recipients generally struggled to manage their finances and their affairs, particularly during times of crisis; rules and regulations as well as a lack of understanding can create great difficulties for carers when trying to sort out bills or speak on behalf of the care-recipient:

> *… they [electricity board] will not accept – they won't accept it from me because I'm not the account holder, [Name, son] has to do it, but I said, "But he doesn't do telephones" "Oh, well tell him to write us a letter", he doesn't do letters … you know what can you …*
> *CFC 595.6, mother, diagnosis Aspergers syndrome, depression and psychosis*

> *And he's [son] got debts, you know – um, and we've got one there from an Agency and he owes gas, electric, water from his last flat 'cause he hasn't been able to pay because he hasn't had any benefits. And if he does get money he'll often go and blow it on ridiculous things [laughs] which I think is part of the illness as well.*
> *CFC 888.6, mother, diagnosis schizophrenia and bi-polar*

Wider family aspects and social support

It has been suggested that support from family members and friends can play an important role in how well carers cope with the situation (Doornbos, 1996). Results from the survey showed that twenty-five percent of carers received help from family, friends or neighbours on a weekly basis, about forty-two percent received help occasionally or in emergencies, and about thirty-three percent indicated that they never received any help.

The care function tends to fall on one person in the family (a parent, partner or child) but if there is a lack of support, that person will struggle and feel angry or abandoned:

> *The rows we've had [name, husband] and I over the years. We've had good screaming rows, screaming rows. He can't understand me and I can't understand him basically. […] Poor [name, son] was extremely ill at this rate, extremely ill, um, and we did it up but while I was in the process of doing that house up, I think that was probably one of the most difficult times because I had to leave because I couldn't do anything with [name, son] over there, there was no heating and all the rest of it. He had to stay over here with [name, husband]. So I think, maybe that was one of the worst times, I don't know.*
> *CFC 785.6, mother, diagnosis schizophrenia*

Contact with the wider family only reduces caregiver's stress if there are no other stressful events present:

> *Like it's been hard lately because my mother in law has been, got Dementia and again that's mental health again.*
> *CFC 350.6, wife, diagnosis schizophrenia*

Several of the carers we talked to were single parents and others did not have any close family left or were not in contact with them:

> *We have no family near. All my family live in [place]. He has two children but they want nothing to do with him and haven't done for, well since we've been married really. They knew he was ill and I think that's what they can't understand because he just still denies he's got problems.*
> *CFC, 881.6, wife, diagnosis MS, memory problems, damage frontal lobe*

The support a wider family can offer is illustrated by this quote:

> *Um, no, I feel myself personally and my sisters have said, myself, I feel um we needed more help really, but they – they've got no staff apparently, they're – they're totally short-staffed there …so I – I … you know, well we're lucky we – we had, we're quite a close family anyway, and there's three of us and my auntie, so we could also help each other. Because I was just thinking if I was on my own …no, never, I could never do it on my own, ever, ever, not …*
> *CFC 593.6, daughter, diagnosis depression*

Carers may feel stress and guilt because they are so strongly involved with the care-recipient that they may neglect other family members, including young children and spouses:

> *I went through everything, absolutely everything, but then my life became focused on [name, son] and I know I shut out my husband and my other two sons, who were struggling with it too. […] I kind of, I couldn't do, I couldn't be there for everybody, it was just, I was so afraid I was going to lose him, because he was – he'd talked about suicide.*
> *CFC 854.6, mother, diagnosis paranoid psychosis*

Some carers looking after a child mentioned that focusing on the child could mean the break-up of a relationship:

> *And, you know, he [partner] did actually give me an ultimatum before that and I doubt at the time that he thought*

> *that I was going to choose [Name, son], he must have been naive at the time but hmm, he did tell me, you know, it's either me or [Name, son], you know, and it was just absolutely no contest, you know you're a mother for life, and that's it.*
> *CFC 553.6, mother, diagnosis schizophrenia*

Consistent with the findings reported in the previous chapter, carers perceived that caring for an individual with mental health problems can impede the development or maintenance of social networks. For carers who managed to build and maintain friendships, these friends played an important role. In order to be able to maintain friendships, friends have to have an understanding of what mental health problems are like. Other difficulties included finding time to meet friends and not wanting to burden friends with personal problems:

> *Well I knew at the beginning that my friends, because we were not going anywhere, they didn't know how to deal with it, they didn't ask us, you know we didn't go anywhere, because that was awkward. It was awkward for them, but it wasn't hostile or anything, they were just not knowing how to – they didn't want to hurt us.*
> *CFC 599.6, mother, diagnosis schizophrenia*

> *I didn't discuss it with anybody. Only [name], my lovely friend and that was only when it was so bad because it isn't something you can discuss with anybody, not even your closest friend. It really isn't until you reach crisis point.*
> *CFC 785.6, diagnosis schizophrenia*

Caring stages or the caring journey

Previous research has established that there are temporal elements to the caring experience (Karp & Tanarugsachok, 2000; Repper *et al.*, 2008); whilst this is not necessarily the same for all carers, as each individual experience is unique, there are some broad stages that can be identified and matched to the nature of support required. Based on our analysis we identified the following stages and support needs:

Before diagnosis and early involvement with professionals:
▪ Realisation that something is wrong and help is needed. This time is full of uncertainty, distress and worry and can be a short or a protracted period;
▪ Carers start looking for help and support to stop things from getting progressively worse and to avoid a crisis; however, often

carers must wait until a crisis occurs before professionals intervene; this can cause the first rift in the professional - carer relationship;

- As GPs are often first port of call they need adequate training and understanding of the nature of mental health illnesses.

Confirmation of mental illness and diagnosis (these do not necessarily coincide)

- This is often linked to a period of hospitalisation for the care-recipient;
- Seen as pivotal by the carer where an explanation will be forthcoming and treatment or even a cure becomes possible; there is hope and cautious optimism;
- However this is the stage when carers tend to be faced with confidentiality issues; how these are managed has a significant impact on later relationships;
- There is a need for good communication which can create trust between carers and professionals;
- Information about the illness, what to expect and where to look for help and support is needed;
- Carers need emotional support to come to terms with what is happening.

Realisation of permanency and unpredictability of the illness

- This is generally accompanied by coping with good and bad periods; the potential of disillusionment with and disengagement from the system is high;
- Carers have to come to terms with relinquishing certain hopes and ambitions for themselves and the care-recipient; there may still be anger, resentment and feelings of loss;
- This tends to be the time when carers begin to realise that they are 'carers' and think about the implications this role has for them;
- Some carers adjust and recognise that they have to adjust their expectations and that the illness will continue in some form;
- Ambivalence around good periods might lead to tiredness, depression and ill-health;
- Continuous support from services is needed; professionals need to acknowledge the importance of carers as the main source support for the care-recipient.

Management of the illness

- Some carers mange the illness by accepting the caring role as part of their life;
- This is about living with the illness on a day to day basis; it depends partly on the level of independent functioning of the care-recipient and the level of acceptance by carer;

- Management of the illness can be a very fine balance and carers can be very vulnerable and stressed;
- Some carers seem to move on to a position of strength and develop a range of coping strategies;
- The situation is unlikely to remain static; carers might move back and forth between distress and hope;
- Continuous support from services may be needed

Carer experiences may vary according to the number of years of care-giving experience, stage of the mental illness, level and quality of support from professionals and social networks and the nature of their relationship with the care-recipient. Initially, carers expect help and support and are cautiously optimistic that with the help of professionals the problem may be cured and the situation brought under control. However, experiences tend to show that this is not the case and carers need to come to terms with an illness that tends to be very changeable and might not be curable.

Several authors have suggested that there is a focus on the negative side of caring and that not enough attention is focused on the rewards or potential satisfaction that might be gained from caring (e.g., Finkelman, 2000; Nolan *et al.*, 1996). Although we found evidence that some carers adjusted to their situation to the best of their ability and devised coping strategies, it seemed that very few moved to complete acceptance or developed satisfaction with their caring role.

Although most carers we talked to, were coping at the point of the interview, acceptance can be very difficult, especially against a backdrop of poor service provision and a lack of social networks and family support. A good example to illustrate the importance of supportive services and the complex interaction of other factors within a carer's life is a mother who looks after her son who started behaving 'strangely' when he was seventeen. She described all the emotions from shock at realising something was wrong, to the feeling of loss and bereavement on to a complete break-down when she tried to commit suicide. Up to this time she did not feel that she had any support from her family or partner, who could be abusive at times. She left paid employment to care for her son. Her experiences with services tend to be positive and inclusive and there was a very quick response in the initial phase of illness for her son. However, she had not accessed or had any professional support for herself up to that time. From the time of her break-down, she was offered and accessed services for herself such as bereavement counselling which helped her to move towards acceptance of her son's illness and to recognise that:

> '*I couldn't fix the world and I couldn't fix my sons, I could be there and do what I could for them, but they were going to make their own choices*'

also, she realised that:

> '*Of course I've got my worries about [name, son], but now I've got to that point where I know [name, son] will do what [name, son] wants to do and all I can do is you know be there, if and when he needs me to a point and things are pretty settled and I'm peaceful and nice.*'
> CFC 854.6, *mother*, *diagnosis paranoid psychosis*

The carer became aware that she needed some distance and asked her son to move out. He moved into a supported housing unit run by a voluntary organisation and his life and way of living with the illness has since then improved dramatically. The carer has returned to employment. This example shows how service provision for the care-recipient and the carer can have a positive effect on the whole of the carer's life but also show the important role of other factors such as family support.

Follow-up interviews

We returned after about seven and a half months, to twelve of the carers we spoke to initially, to discuss any changes and policy and practice recommendations that we had drafted based on the preliminary analysis of the other data. Our ongoing analysis will consider changes over time in detail and inform future publications in academic and practitioner journals.

Of the twelve interviewees only three described their situation more positively. Nine described their situation as more uncertain or worse compared to the first time we spoke to them. Length of time spent caring or the relationship to the care-recipient (e.g., husband or child) did not seem to have any influence on perceptions of carers.

Of the three carers who described their situation more positively one had come to terms with and accepted the illness; as a consequence she realised that she needed to have her own life and not perceive herself as a carer only. One carer had had good responses and support from services in a time of crisis and felt more positive about the future. The last carer, who was one of the oldest we interviewed (88 years old) had made provisions for and planned ahead for her death. In addition, the health of the care-recipients had been stable during the last seven and a half months.

The four carers who described their perception of the situation as uncertain had had negative experiences with the services in the past and were in particular concerned about the future arrangements of care for the care-recipient. This was despite all four care-recipients improving somewhat during the intervening months.

Out of the five carers who described their situation or feelings as worse, three of the carers felt worse in themselves and were questioning their situation although the care-recipients' health had improved or stayed stable. The other two carers talked about the health of the care-recipient progressively deteriorating and a feeling of not getting any help or being listened to.

All carers agreed that the recommendations we drew up reflected their needs. These are described in the final chapter.

Chapter 5: Summary and discussion

Relationship between services and carers – the overall picture

There have been a number of changes in recent years such as an increased recognition of carers through legislative initiatives (such as the *Carers and Disabled Children Act*, 2000; the *Carers Equal Opportunities Act*, 2004), policies (such as the National Service Frameworks, Department of Health, 1999, 2004; Welsh Assembly Government, 2005, 2008) and the introduction of a number of guidance and good practice documents (such as the Guidelines on Schizophrenia, NICE, 2003; Good Psychiatric Practice Guidance, Royal College of Psychiatrists, 2010; Triangle of care, The Princess Royal Trust for Carers and the National Mental Health Development Unit, 2010). These initiatives recognise the importance of carers and emphasise the need for their inclusion in service provision. At the same time, changes in the organisation of mental health care delivery mean that services have moved into the community in the form of community mental health teams (CMHTs). Some have argued that as a consequence of this shift from hospitalisation towards community care much of the responsibility for care has moved to informal carers such as families and relatives (Nicholls & Pernice, 2009; Repper, 2009). Research suggests that the quality of care provided in the community is closely related to the amount invested in the service (Thornicroft & Tansella, 2004).

Our findings suggest that carers feel very much responsible for providing care, which includes practical and emotional support for the person with mental health problems and co-ordinating input from formal services; however, there is only limited support for people with mental health problems and their families and this seems to be focused mainly on crisis management. From the carers' point of view, their role and contribution is undervalued and often unrecognised by statutory services. Findings from the carer interviews emphasised the importance of understanding the temporal nature of caring and a need for professionals at all levels to be able to recognise changes in caring and thus variations in support needs. This would include, for example, adequate training and support of GPs as they are often the first port of call and information about the illness and where to look for help and support at the first contact with mental health professionals.

Findings from the carers' interviews pointed to fundamental tensions with professionals, characterised by difficulties in communication and differences in expectations. Most carers described disillusionment with services added to by a feeling of not

being taken seriously, misunderstood or seen as a nuisance, and treated in a disrespectful manner. Carers also described incidences where they felt that professionals lacked empathy and understanding towards the individual with mental health problems. In some situations relationships between services and carers seemed to have deteriorated and eventually broken down and were characterised by a feeling of mistrust. This has been found in other studies (Kaas *et al*., 2003; Nicholls & Pernice, 2009).

Practitioners and managers acknowledged this in the interviews and referred to ambiguities about the carer role, and a lack of training and guidance. Thus, carers are not seen as legitimate recipients of professionals' time and expertise as the main focus is on the person with mental health problems. Findings suggest that carers are at worst seen as a resource and at best as a co-worker but never as co-clients (Twigg, 1989). This seems to be partly linked to the treatment approach which focuses on the individual with mental health problems and often relies on treating symptoms rather than a holistic approach and partly to an inherent attribution of the cause of mental health problems and incidences of relapse to family and carers (Kaas *et al*., 2003; Mubarak & Barber, 2003; Jeon, 2003; Shooter *et al*, 2004; Krupnick *et al*, 2005; McCann & Clarke, 2003, Pilgrim, 2008). There are strong tensions in the practice and policy field around underlying assumptions of the nature of mental health and illness, which surface in values and attitudes towards recovery and the role of mental health services (Pilgrim, 2008; Warriner, 2010). These need to be brought out in the open and debated in order to develop an underpinning philosophy that informs policies and guidelines for practice and directions for future directions (Warriner, 2010).

There are now a large number of recently published guidance and review documents, outlining good practice and holistic care in relation to carers and individuals with mental health problems, but their translation into practice is slow. Several authors have suggested that only a change in education and training of mental health staff, in practice culture, and in policy can achieve successful partnerships (Repper *et al*., 2008; Simpson & Benn, 2007). However, Repper *et al*. (2008) emphasise the challenge of translating existing policy and guidance into practice. They argue, based on a review of the *Modernising Adult Social Care programme* by Newman and Hughes (2007), that this can only be achieved through an integration of two types of processes: transactional and transformational. Transactional processes generate compliance and deliver results and transformational approaches seek to change values and beliefs with the aim to produce commitment for change.

More of a transformational approach is needed to tackle complex situations and systems as can be found in the field of mental health.

Simpson and Benn (2007) argue that a comprehensive organisational structure and strategy is needed that includes explicit support throughout all levels of health and social care organisations. Their recommendations include the following:

- Establishment of user and carer forums,
- Have a credible and suitably skilled person to lead developments,
- Provide staff training and supervision,
- Identify champions for family work and the recognition of carer needs,
- Establish a steering group and strategy
- Prepare managers and organisations,
- Obtain backing and commitment and senior levels,
- Target middle managers and work prioritisation,
- Establish links between teams and organisations.

There are suggestions for models of interaction between professionals, carers and individuals with mental health problems which could help to build better relationships and consequently improved long-term outcomes for both the carer and care-recipient. These include the therapeutic quadrangle which comprises of four elements: professionals, carer/family, person with mental health problems and the illness (*Nolan et al.*, 2008), and the triangle of care, which includes professionals, service users and carers (Princess Royal Trust for Carers with the National Mental Health Development Unit, 2010). Both these approaches necessitate a culture change.

Confidentiality and smokescreens

Our findings suggest that professionals may sometimes withhold information from carers and hide behind 'confidentiality smokescreens'; they sometimes find it easier and safer to say nothing. Carers for people with mental health problems are left out of the loop, and thus, are a largely invisible group. This accentuates carers' feelings of isolation, guilt, and stigma but also creates distress. To add to this dilemma, service users are a vulnerable group, and professionals need to be alert to possibly abusive or antagonistic relationships with the carer.

It is now well established that carers have the capacity to be 'experts' in care, and their experiences and knowledge should be valued as part of the package of support (Nolan *et al*. 1996). However, carers' expertise still also needs to be facilitated by professionals, in terms of better information sharing and carer

training. Carers want service organizations and their staff to listen to them, value their knowledge and expertise and treat them as partners, especially in the assessment and care planning processes. Carers also need respect for their personal values and cultural beliefs, together with professionals that acknowledge carers' established routines and ways of caring and *do not* make assumptions about their willingness to continue caring. The provision of information that helps to facilitate positive ways of coping on a day-to-day basis and at times of crisis is also important. Examples given by managers and practitioners of good practice, which broke down the barriers of confidentiality and shared information with carers, were various and included:

- The provision of information about medication and side effects.
- The setting-up of advance agreements when the service user was well, so that they could specify their preferred treatment and to whom information could be shared during periods of illness.
- Facilitation by professionals of carers to support groups, which promoted peer support, coping strategies and the sharing of non-confidential information.
- Raising the consciousness about carers in general (for example, with leaflets) and specifically in doctors' surgeries, a context in which previous studies have said that carers felt invisible.
- Professionals acting as intermediaries between carers and users to promote better understanding and information sharing.

However, from the perspective of the carers, too little was still being done to address issues around confidentiality and information sharing. In their experience, good practice could not be expected as standard and was most likely to be offered by dedicated individuals.

Our findings suggest that professionals require training particularly in carer rights (relating to carer legislation and to recent equality legislation) and the conduct of carer assessment. Previous studies have highlighted the fact that carer assessments are crucial to meeting carers' needs, especially in relation to information provision (Pinfold *et al*. 2004, Rapaport *et al*. 2006, Repper *et al.* 2006, Seddon *et al.,* 2007). A major finding of this study was that professionals felt uncertain about offering carer assessments because they sometimes felt that this might breach confidentiality and the maintenance of trust with the user. There are little resources or training for professionals on how to deal with confidentiality barriers and little exploration of the complex moral,

ethical, legal and practical dilemmas facing professionals, carers and service users concerning confidentiality and information sharing. Policy is ambiguous and confusing for practitioners; even in scenarios of risk management and possible harm, some professionals in this study still felt reticent and unable to share information with carers. Pinfold *et al*. (2004) provide a starting point for professionals to be positive and inclusive. With appropriate and regularly reviewed consent, professionals can better support carers by giving three types of information: general information (for example, information in the public domain on mental health problems, available treatments or resource directories for local services); personal information (for example, specific information such as diagnosis, medication types or content of the care plan); and sensitive personal information (for example, information such as HIV status, history of sexual and emotional abuse or views on relationships with family members). In this way, professionals can be positive and inclusive, facilitating information sharing with carers as well as discussing the best modes of support available (for example, carer or self-help groups, carer breaks, carer assessments). Slade *et al*. (2007) have extended the work by Pinfold *et al*. (2004) in relation to situations where service users do not give their consent to sharing information. Slade and colleagues (2007) reviewed existing policy, and conducted a national survey of current practice and individual interviews with professionals, carers and service users. One of the findings was that there is not yet a consensus on best practice. However, results from their study allowed them to formulate a framework for best clinical practice, integrating a distinction between personal and general information, which allows supporting the carer without confidentiality being broken. The authors emphasise that planning and implementation needs to take place at an organisational level and provide several recommendations including: a positive organisational approach to working with carers; the availability of guidance and policy documents and training to staff; and maintaining continuity of care. The framework is set at the clinical level and emphasises the need of professionals to take responsibility for action, based on their clinical judgement.

Information sharing may decrease family stigma, isolation, fear, and distress, as well as offering families more choice and control over their lives and the range, nature and timing of services which they need in line with government policy. It would be useful for further research to study conflicts in confidentiality and how barriers to information sharing are resolved ethically and in practice.

Carer emotions

To date, the emotions that family carers of people with mental health problems go through remain relatively unexplored. This study has gone some way to redress this by exploring the challenging feelings associated with caring for a family member with mental health problems from key stakeholder and carer perspectives. The majority of managers and practitioners perceived caring for a family member with mental health problems as deeply challenging and emphasised highly negative emotions associated with the caring role. Rewards and satisfaction, both for carers and the professionals involved, were downplayed and given less emphasis when compared to negative emotions. Family carers for people with mental health problems go through complex, and ambivalent emotions including feelings of guilt, psychosocial isolation, as well as satisfaction and relief when things are going well.

Findings from the carers' interviews are in line with these perceptions but in addition, carers mentioned anger and frustration with professionals and services which can increase feelings of helplessness and stress. The key challenge for professionals therefore is to minimise negative emotions and maximise positive emotions through emotionally supportive and therapeutic interventions such as carer groups and psychosocial and family interventions. There is an extensive body of literature documenting the benefits of family interventions in the treatment of individuals with mental health illness. The focus is often on reducing expressed emotions in the relationship between families/carer and the individual with mental health problems. The concept of expressed emotions was developed in the 60s and is based on the notion that some families/carers exhibit higher levels of criticism, emotional over-involvement or hostility. It has been suggested that this can slow down recovery or lead to a relapse, although more recent research suggests that the overall picture is more complex and that there is a danger of shifting blame onto families/carers (Bhugra & McKenzie, 2003; Hatfield et al., 1987; Hooley, 2007; Leff & Vaughn, 1985).

A range of psychosocial family interventions have been developed that include education, support and management to reduce expressed emotion within families but also support and education on how to improve problem solving abilities, deal with stressors and improve communication between all family members (Smith & Velleman, 2002). Two of the core components of these approaches should be a non-blaming attitude by staff members and the establishment of a collaborative working relationship with the carer, members of the family and the individual with mental health

problems (Fadden, 1998). In addition, interventions work towards providing an understanding of the illness and the development of coping mechanisms (Fadden, 1998; Smith & Velleman, 2002). The NICE guidelines for the treatment of schizophrenia (2003) concluded that family interventions should be available to families of people with schizophrenia. Recent research suggests that the use of family interventions could be beneficial for other mental disorders including early onset psychosis (Addington *et al*., 2005; Baguley & Dulson, 2004; Drake & Mueser, 2000; Jones *et al*., 2005; Hooley, 2007; Pinfold *et al*., 2007; Sartorius *et al*., 2005; Sheils & Rolfe 2000; Sin *et al*., 2007; Walker, 2004).

Caring in the family is often a thankless task and can even affect notions of life and death. Professionals said that many carers report that they see little improvement in their loved ones, meaning that feelings of hopelessness, loss, desolation and despair are often part and parcel of the caring role. Results from carers confirmed these perceptions and brought into sharp focus the potential of carers to develop mental health problems such as depression and anxiety. This is a worrying but not surprising finding and emphasises the need of a holistic treatment approach. Carers mentioned several coping strategies in the interviews such as physical activity, seeking social support and keeping busy. However, the success of the coping strategies used seemed to depend on a range of other factors such as stage of illness, level of support experienced, relationship with care recipient, demands and support of other family members, and financial circumstances. Coping strategies can have a major impact on carers' distress and some coping strategies have been shown to alleviate carers' distress whereas others may aggravate distress (Huang *et al*., 2008; Kartalova-O'Doherty & Tedstone Doherty, 2008).

More research is needed on carers' emotions and coping strategies and successful practices and interventions, such as carer support groups. Reviews by Arksey (2003) and Victor (2009) focusing on interventions for carers emphasise the difficulty of drawing conclusions from the literature. Both reviews concluded that more research was needed, and in particular on the effectiveness of voluntary sector care organisations, interventions designed to support carer employment and carer physical and emotional health, and carer support groups. More attention needs to be paid to the individual characteristics of carers, such as age, gender or the relationship to the care-recipient, and at different phases of mental illness, and how these factors influence the outcomes of interventions. For example, results from the current study indicate that carer breaks might not always be beneficial and that for some

carers, carer support groups might be more effective at the earlier stages in the carer journey.

Further research is necessary to evaluate the impact of carers' emotions for particular groups. The emotions of young carers and ethnic minorities, who are hidden and socially excluded groups, need to be brought more fully into focus and researched in a multidisciplinary way. Certainly, there is growing interest in marginalized groups such as young carers and ethnic minorities (Repper *et al*. 2006, Gray *et al*. 2008). The implications of carers' emotions need to be addressed by policy and practice. For example, there needs to be more weight and focus on family carers' emotional needs by social workers, for instance, as part of carer assessments (Repper *et al*. 2006) which currently focus on the practical, task-based aspects of caring (Seddon *et al.,* 2007). Emotions and the emotional needs of groups such as carers for people with mental health problems are often implicit and tacit in policy; therefore, this needs further elaboration by policy-makers, carers, service users and professionals working together in order to be codified, taken account of and their place acknowledged in professional training and education.

Finally, although negative emotions are given more emphasis by participants in this study, an interesting avenue of further research would be to explore the positive emotions of family carers, and interventions that sustain and build upon these positive carer experiences, to contribute to best social and healthcare practice and in order to be positive and inclusive.

Exclusion

Carers suffer from multiple sources of exclusion and there is pervasive stigma, alienation and isolation. Social exclusion has been linked to aspects of mental health (Barnes, 2004). However, the literature on social exclusion tends to focus more on individuals with mental health problems than carers. Of particular importance is the government's 10-year strategy for carers (Department of Health, 2008), which outlines the government's commitment to support carers to enable them to be included within service provision, access integrated and personalised services and to have a 'life of their own'. However, results from the current study suggest that barriers still exist in the form of restricted information, stigma and access to personal, social, and service support and financial exclusion. There are several recent documents that outline approaches to good practice: for example, in the area of education and training of mental health staff; how to tackle discrimination and stigma; and a mental health and social inclusion statement from the

Royal College of Psychiatry (Royal College of Psychiatry, 2009; Simpson & Benn, 2007; Thornicroft, 2006).

As documented in the previous chapter, and discussed previously, experiences of social exclusion and stigma can make carers feel very isolated and unsupported. This is compounded by services taking the carer for granted and a lack of comprehensive and joined-up services. Carers, who were able to participate in paid employment were better off financially and tended to feel better as work provided them with opportunities. However, several of the carers we spoke to were unlikely to participate in paid employment or worked fewer hours. Other studies have shown similar results (Arksey & Glendinning, 2008; Evandrou & Glaser, 2003; Seddon *et al*., 2004). Arksey and Glendinning (2008) reported that decisions around participation in paid employment are influenced by a number of interacting factors such as flexibility of working arrangements, carer characteristics, constraints due to means-tested income benefits, and level of service provision. Others have argued that broad changes to health, tax and benefit systems are needed to support the effectiveness of carer policies (Rankin, 2005). Based on their findings, Arksey and Glendinning (2008) recommended a review of carers' benefits to see how carers may be better supported financially in, and into, work; and that national and local government need to develop strategies to encourage employers to create more and better opportunities for full- and part-time work in meaningful jobs that offer flexibility.

There are some indications that sensitively and appropriately conducted carer assessments and carer inventions such as respite, family therapy, and carer support groups that are aimed to facilitate social inclusion, may empower carers and reduce worry about the family member with mental illness. Improvements in social inclusion and family members' empowerment might also enhance their ability to advocate for better care, which in turn could result in more appropriate treatment for people with mental health problems (Dixon *et al*., 2001). Social inclusion can be enhanced by: involving families in defining their own needs, for example, as part of carer assessments; encouraging staff to adopt a carer-centred and holistic approach; sharing information with families; and using vigorous outreach to recruit families, for example, to carer or self-help groups; addressing the social and cultural context through conducting sensitive anti-stigma campaigns such as 'time to change', which is organised by Mind and Rethink (http://www.time-to-change.org.uk) and ensuring that carers have access to paid employment. Importantly, carers of people with mental health problems are still a hidden and socially excluded group whose needs should be brought more fully into focus.

Although we did not speak to young carers themselves, feedback from professionals suggested that young carers of parents with mental health problems experience isolation, restricted opportunities (especially in education and free time for leisure activities); and associative stigma. This is consistent with research which has found that young carers face severely restricted opportunities for developing stable and consistent peer friendships (Dearden & Becker, 1998, 2004; Thomas *et al*., 2003). Such challenges also promote poverty and social exclusion (Dearden & Becker, 2000, 2005; Roche & Tucker, 2003). Examples of good practice that provide holistic, sensitive and effective support highlighted in this study include:

- Young carer groups and young carer forums
- Young carers' days
- Raising awareness of young carers, with information packs, DVDs, on young carers and young minds websites, especially in schools

There are a range of tools available for practitioners to respond to the needs of families where there are young carers, including refugee families where there can be particular cultural perceptions of mental health and how this can impact upon carers in these families:

- Whole Family Pathway, available at: www.youngcarer.com.
- Refugee Toolkit for supporting refugee families with ill health and disability and carers in these families: www.refugeetoolkit.org.uk
- Crossroads Care: www.crossroads.org.uk (Crossroads, 2008).

Overall, the implications of carers' exclusion need to be comprehensively addressed by policy and practice. There needs to be more weight and focus on carers' social exclusion, for example, as part of carer assessments (Repper *et al*., 2006). Although the carers' strategy (Department of Health, 2008) is in place, findings highlighted that this strategy has not yet resulted in immediate changes for families. Our findings highlight the challenge social care, health and voluntary professionals as well as planners and policy makers need to address in a holistic manner. Of importance is the recognition that carers all undertake individual journeys and have differing needs at different times.

Implications for policy and practice

Here we summarise the key implications for policy and practice arising from our work:

- There needs to be a debate about the meaning of mental health and illness, notions of recovery and underlying values and approaches in the practice and political arenas.

- Government needs to ensure that professionals work towards the vision for carers set-out in the Carers Strategies (Department of Health, 2008; Welsh Assembly Government, 2008), such as recognition of carers as experts with access to integrated and personalised services.

- Government needs to ensure that legislation and policies unambiguously set out carer's right to information and promote a clear-cut framework for sharing information such as those developed by Pinfold *et al*. (2004) and Slade *et al*. (2007).

- Comprehensive education and training about carers' rights and issues around confidentiality and inclusion of carers should be provided at all levels of mental health service provision, including at primary care level; Benn and Simpson's (2007) three stage model is a good example.

- Professionals should aim to develop a relationship with carers and care-recipients based on mutual respect and dignity; use of models such as the *therapeutic quadrangle* (*Nolan et al.*, 2008) and *the triangle of care* would be helpful in this respect (Princess Royal Trust for Carers with the National Mental Health Development Unit, 2010)

- Responsibilities for conducting carer assessments needs to be clearly defined and appropriate training needs to be offered to staff to conduct these in an empathic and sensitive manner.

- The type and range of services offered need to be sensitive to individual' needs; given the significant distress associated with caring, resources and programmes need to be developed and implemented to assist carers in acquiring skills and information necessary to manage caring demands.

- Issues around social exclusion of carers need to be addressed at policy and practice level; for example:

  o Tax and benefit systems should facilitate carers' participation in employment.

  o More widespread implementation and evaluation of anti-stigma campaigns (such as '*time to change*'; http://www.time-to-change.org.uk) with particular groups including school children, police, and health and social care staff.

- For carers to have access to interventions or services that are relevant to them such as family therapy, counselling, respite, access to carer support groups or independent advocacy.

- Timely support for carers with a recognition that needs might change over the caring journey.

Carer recommendations

- Recognition of carers – tackle issues of confidentiality and inclusion of carers in the CPA

- Access for carers to financial support and free legal advice/ independent advocacy

- Appropriate respite

- Training for carers – understanding the illness and what to do

- Information about:

  o available services and support for carers and care-recipient

  o rights of carers and care recipients

  o procedures

  o treatment options and medication

  o financial support for carers and care-recipient

- After a hospital stay:

- available services

  o more preparation and support for when the care-recipient comes home from hospital

  o support from professionals to develop a good relationship with the person in hospital

- Improved communication between services **and** between services and carers

- Raising awareness of mental health issues in the wider community

- A more coherent approach to dealing with a family where several members have mental health difficulties

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Appendix A – Example of participant information sheet

Carer Information Sheet (Interviews)

Introduction
You are being invited to take part in a research study. Before you decide whether or not to participate, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information and discuss it with your relatives and friends if you wish.

What is the purpose of the study?
This study will look at the support needs of carers for people with mental health problems and will highlight areas of good practice in relation to the delivery of support to carers and those they care for. The findings from this study will be used to make recommendations about policy and practice to help carers.

Why have I been chosen?
(   ) have kindly lent their support to the research and have forwarded this information to you on our behalf.

Do I have to take part?
It is up to you to decide whether or not to take part. If you decide to take part you should keep this information sheet and sign the enclosed consent form. You are free to withdraw at any time without giving a reason. Your involvement **will not** affect the standard of care and services you or the person you care for receive.

What will happen if I decide to take part?
A member of the research team will arrange to meet with you to complete a short interview, which will take about 30 minutes. This interview can take place in your own home or at a mutually agreeable venue, during the day-time or in the evening. The interview can be completed in English, Welsh or another language if you prefer. During the interview you will be asked to share your experiences and to describe the types of help you receive. *Some* carers will be contacted again during the course of the project to see if anything has changed. Your contact details will be stored on a **confidential database**.

Will my taking part in this study be kept confidential?
All the information you provide about yourself and the person you care for will be treated in the **strictest of confidence.** Neither you nor the person you care for will be identified in any reports.

What will happen to the results of the research study?
The research findings will provide useful insights into the local needs and circumstances of carers and those they care for. The findings will be presented in a Final Report to the Big Lottery Fund. If you decide to take

part in the study, you will receive feedback sheets that describe some of the key findings. These will also be published on a study web site.

Who is organising and funding the research?
The research is being co-ordinated by researchers at the Centre for Applied Research and Evaluation Science at Bangor University in collaboration with Crossroads Wales. The research is funded by the Big Lottery Fund.

Contact for further information
If you have any questions about this study or would like more information, please feel free to contact [….]. Her telephone number is 01248 388203. She can also be contacted by email using the following address [….] @bangor.ac.uk

Next steps
If you decide that you would like to take part, please complete the consent form that is enclosed and return it using the free-post envelope provided.

Thank you for taking the time to read this information and for considering taking part in this study.

Appendix B – Carer questionnaire

This questionnaire is designed to find out about the needs and experiences of people supporting someone with mental health problems. The questions cover general information about you and the person you care for, your health, services available to you and areas of your life affected by your caring role. We appreciate you taking the time to complete this questionnaire. The information that you provide is **strictly confidential.**

We appreciate that you may be caring for more than one person and we'd like to gather information relating to everyone you care for. Rather than asking you to complete 2 or 3 questionnaires we've enclosed a multi-coloured pen. Please choose a different colour for each person you care for. If you would like any help to complete this questionnaire, please contact […] at Bangor University, either by telephone [01248 388203] or by email [cfc@bangor.ac.uk]

PART 1 – ABOUT YOU AND THE PERSON YOU CARE FOR

1. How old are you?   _____

2. Are you   ❐ Male   ❐ Female

3. How would you describe the place where you live?

❐Rural   ❐ Urban   Postcode _____

4. What is your present employment status?

Employed/self-employed full-time   ❐
Employed/self-employed part-time   ❐
In full-time/part-time education   ❐
Voluntary work   ❐
Retired   ❐
Unemployed   ❐
Unavailable for work due to caring responsibilities ❐
Unavailable for work due to own health problems   ❐

5. Is the person you are caring for your:

Husband/Wife or Partner   ❐
Parent or Parent-in-law   ❐
Child   ❐
Brother/Sister   ❐
Friend/Neighbour   ❐

Other, please specify: _____

6. Do you live with the person you care for?

☐Yes   ☐No

7. How long have you been caring?

_____years

8. Approximately how many hours per week do you spend caring?

1-19 hours   ☐
20-49 hours   ☐
50 hours or more   ☐

9. When does this person need your help?

During the day and the night   ☐
During the day only   ☐
During the night only   ☐

10. Does the person you care for have a diagnosis? If so please tell us what it is?

_____

11.a Are there times when the person you care for does not need your help because they can manage their everyday activities?

☐ Yes   ☐ No

b) If so, how long do these times usually last?

No more than a few days   ☐   A few months   ☐
Two or three weeks   ☐   A year or more   ☐

12. Is the severity of their condition changeable?

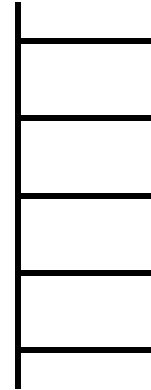If yes can you: (please only tick one box)

Usually predict the severity   ☐
Sometimes predict the severity   ☐
Rarely predict the severity   ☐
Each day is an unknown   ☐

13. How severe do you think the condition of the person you care for is on a 'bad day'?

Please place a cross on the appropriate rung of the ladder:

Really good, no
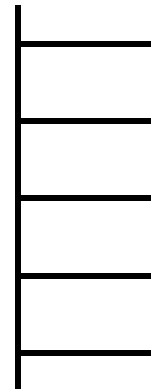problem at all

Really bad, endless
problems

14. How severe do you think the condition of the person you care for is on a 'good day'?

Please place a cross on the appropriate rung of the ladder:

Really good, no
problem at all

Really bad, endless
problems

15. Thinking about the last month, how much of the time has been 'good'?

All the time	☐	A little of the time	☐
Most of the time	☐	None of the time	☐
About half the time	☐		

16. Is there anything else you'd like to add about the changeable nature of the condition of the person you care for?

_____

_____

PART TWO: JUST ABOUT YOU

17. Do you receive and help from family, friends or neighbours?

A few times a week ☐   Only in emergencies ☐
Weekly ☐   Never ☐
Occasionally ☐

18. Do YOU receive any help from Health, Social Care or Voluntary Organisations? If so please tell us about it.

_____

19. Have you had a carer assessment, to talk about YOUR needs as a carer?

☐ Yes   ☐ No

If so, did anything happen as a result?

_____

20. Do YOU have any needs for help that are not being met at the present time?

☐ Yes   ☐ No

If yes, please tell us about these needs and how they may be met:

_____

21. Do professionals involve you in making decisions about the person you care for?

☐ Yes   ☐ No

If yes, please tell us more:

_____

22. Have you been offered any training? If so please tell us about it.

_____

23. Do you have any other training needs? Please tell us about them and how they may be met.

_____

Your Health and Well-Being

This section asks for your views about your health. This information will indicate how you feel and how well you are able to do your usual activities. For each of the following questions, please tick the box that best describes your answer:

24. In general, would you say your health is:

Excellent	Very good	Good	Fair	Poor
▼	▼	▼	▼	▼
❐ 1	❐ 2	❐ 3	❐ 4	❐ 5

25. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, limited a lot ▼	Yes, limited a little ▼	No, not limited at all ▼
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	❐ 1	❐ 2	❐ 3
Climbing several flights of stairs	❐ 1	❐ 2	❐ 3

26. During the past four weeks, how much of the time have you had any of the following problems with your work or other daily activities as a result of your physical health?

	All of the time ▼	Most of the time ▼	Some of the time ▼	A little of the time ▼	None of the time ▼
Accomplished less than you would like	❐ 1	❐ 2	❐ 3	❐ 4	❐ 5
Were limited in the kind of work or other activities	❐ 1	❐ 2	❐ 3	❐ 4	❐ 5

27. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	All of the time ▼	Most of the time ▼	Some of the time ▼	A little of the time ▼	None of the time ▼
Accomplished less than you would like	❒ 1	❒ 2	❒ 3	❒ 4	❒ 5
Did work or other activities less carefully than usual	❒ 1	❒ 2	❒ 3	❒ 4	❒ 5

28. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all ▼	A little bit ▼	Moderately ▼	Quite a bit ▼	Extremely ▼
❒ 1	❒ 2	❒ 3	❒ 4	❒ 5

29. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

	All of the time ▼	Most of the time ▼	Some of the time ▼	A little of the time ▼	None of the time ▼
Have you felt calm and peaceful?	❒ 1	❒ 2	❒ 3	❒ 4	❒ 5
Did you have a lot of energy?	❒ 1	❒ 2	❒ 3	❒ 4	❒ 5
Have you felt downhearted and low?	❒ 1	❒ 2	❒ 3	❒ 4	❒ 5

30. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

All of the time ▼ ☐ 1	Most of the time ▼ ☐ 2	Some of the time ▼ ☐ 3	A little of the time ▼ ☐ 4	None of the timey ▼ ☐ 5

More about you…
Please **circle** the appropriate number to indicate how much you agree or disagree with the following statements

	Disagree						**Agree**
When I make plans I persevere with them	1	2	3	4	5	6	7
I usually manage one way or another	1	2	3	4	5	6	7
I am able to depend on myself more than anyone else	1	2	3	4	5	6	7
I can be on my own if I have to	1	2	3	4	5	6	7
I feel that I can handle many things at the time	1	2	3	4	5	6	7
I seldom wonder what the point of it all is	1	2	3	4	5	6	7
I can get through difficult times because I have experienced difficulties before	1	2	3	4	5	6	7
I keep interested in things	1	2	3	4	5	6	7
In an emergency, I'm someone people generally can rely on	1	2	3	4	5	6	7
I can usually look at a situation in a number of ways	1	2	3	4	5	6	7
Sometimes I make myself do things whether I want to or not	1	2	3	4	5	6	7
I do not dwell on things that I can't do anything about	1	2	3	4	5	6	7
I have enough energy to do what I have to do	1	2	3	4	5	6	7
It's okay if there are people who don't like me	1	2	3	4	5	6	7

32. And finally, more about yourself and your role as a carer. To what extent do you feel each of the statements below applies to how you feel about yourself and your situation?

Show how you feel by circling a number from *-3 ('strongly disagree') to +3 ('strongly agree')*. The more you feel the statement applies to you, the higher the number you should circle. The less you feel the statement applies to you, the lower the number you should circle.

SECTION A	Strongly disagree						Strongly agree
My relationship with the person I care for is strained	-3	-2	-1	0	1	2	3
The person I care for lets me know how much s/he appreciates what I do	-3	-2	-1	0	1	2	3
The person I care for doesn't appreciate what I do as much as I would like	-3	-2	-1	0	1	2	3
I feel irritable/grouchy when I am around the person I care for	-3	-2	-1	0	1	2	3
I wish I had a better relationship with the person I care for	-3	-2	-1	0	1	2	3
Caring has made me closer to the person I care for	-3	-2	-1	0	1	2	3
I feel that the person I care for asks for more help than s/he needs	-3	-2	-1	0	1	2	3
SECTION B							
Caring for this person makes me feel good about myself	-3	-2	-1	0	1	2	3
The responsibility of caring gives me an important sense of satisfaction	-3	-2	-1	0	1	2	3
Caring makes me feel valued	-3	-2	-1	0	1	2	3
Caring for this person is a real source of pleasure to me	-3	-2	-1	0	1	2	3
I find my caring activities fulfilling/rewarding	-3	-2	-1	0	1	2	3
Caring for this person makes me happy	-3	-2	-1	0	1	2	3

Thank you for taking the time to complete this questionnaire.

Appendix C – Strategic staff interview schedule

Introduction

We are interested in the way your organization works with and supports carers for people with mental health problems. We want to know more about the services you provide or would like to be able to provide. We want to better understand the needs of carers for people with mental health problems and the challenges they face. We are talking to carers and people with mental health problems as well as public and independent sector organizations across Wales.

There will be time during the discussion for you to identify any further issues you feel are important.

Each of the topics will be introduced with one of the following:

- *Please tell me about…..*
- *Please describe….*
- *What do you think about…..*

Your Organisation
- in general
- in relation to people with mental health problems.
- in relation to carers for people with mental health problems.

Your Role
- in general.
- in relation to people with mental health problems.
- in relation to carers for people with mental health problems.

Carers for people with mental health problems
- challenges of caring for someone with mental health problems
- rewards of caring for someone with mental health problems

National Policies

National Strategy for Carers
- supporting carers for people with mental health problems.
- empowering carers for people with mental health problems (greater control over the range, nature and timing of services)
- responding to the diversity of care-giving contexts in mental health (e.g., the needs of carers from minority ethnic groups.

Carers' Equal Opportunities Act
- anticipated difference for carers

- effects on assessment of carer need (number and methods)
- difficulties in implementing

National Service Framework
- recognition of carers

Mental Health Act (forthcoming)
- implications for carers

Local implementation of policies to support carers
- strategic arrangements and local approach to supporting and working with carers for people with mental health problems
- priority areas for carers for people with mental health problems;
- priority areas for future development in relation to carers for people with mental health problems

Providing Care and Support to carers for people with mental health problems
- practical support
- psychological and emotional support
- support to facilitate employment
- support in times of crisis and respite care for carers
- accessibility, flexibility, sensitivity and reliability of services
- comprehensiveness of services for carers for people with mental health problems
- examples of: good practice and practice that is not working well or could be improved

Information
- information strategy
- type of information available
- accessibility, clarity and relevance of information
- specialist information or training needs for carers for people with mental health problems

Joint working
- local joint working arrangements
- unified assessment and joint assessment of carer need
- strengths and weaknesses of joint working
- barriers and facilitators to joint working

Carer-focused services
- consulting with carers for people with mental health problems when developing services.
- raising awareness of the needs of carers
- responding to the needs of carers

Particularly disadvantaged or marginalized groups
- reaching *hidden* carers for people with mental health problems and particularly disadvantaged groups of carers
- reaching out and providing support to young carers and carers in remote and rural areas
- supporting socially isolated and socially excluded carers for people with mental health problems

Unmet needs
- identification
- mobilising community support to carers for people with mental health problems
- priority areas for future development

Appendix D - Practitioner interview schedule

Introduction:
This research will provide an evidence base to inform the development of services for carers who are looking after someone with mental health problems. Using a multi-method approach, it draws on the perspectives of carers, people with mental health problems and practitioners via:

1. An all-Wales sample of carers for people with mental health problems invited to complete two postal surveys.
2. Carers and those for whom they care in receipt of services from Crossroads in North Wales interviewed at service take-up and again six months later.
3. Telephone interviews to elicit the perceptions of health and social care practitioners in North Wales.

Consent:
- Obtain consent to record the interview and **press record**.

Supporting carers for people with mental health problems - practitioner perspectives on the caring experience:
Tell me about.......
- Challenges/rewards experienced by carers for people with mental health problems:
  - *Nature of.*
  - *Key aspects of lives affected - everyday and longer term.*
  - *Distinctiveness from other carer groups.*
- Identifying carers who are supporting someone with mental health problems:
  - *Strategies used.*
  - *Challenges faced in practice and ways these might be addressed.*

Supporting carers for people with mental health problems – general issues:
Tell me about......
- Defining professional roles and responsibilities towards this carer group.
- Making information available to carers:
  - *Types of information.*
  - *Challenges.*
  - *Successes.*
  - *Examples of good practice.*
  - *Information deficits.*

Supporting carers for people with mental health problems – assessment and care planning:
Tell me about.....
- Establishing relationships with carers and discussing the caring role:
  - *Approach[es] used in practice.*
  - *Challenges.*
  - *Successes.*

- Process of assessment:
  - *Separate/specialist or joint within UA framework.*
- Focus of assessment:
  - *Key aspects covered.*
- Ways of involving carers and ensuring a person-centred approach.
- Care planning:
  - *Outcome-focused approaches.*
- Examples of good and innovative practice.
- Effects of carer legislation [Carers Equal Opportunities Act].

Supporting carers for people with mental health problems – service provision:
- Providing and co-ordinating support:
  - *Local arrangements in place.*
  - *Challenges.*
  - *Successes.*
  - *Examples of good and innovative practice.*
  - *Service deficits.*
  - *Priority areas for development and ways forward.*
  - *Providing support during times of crisis.*
- Enabling carers to shape the future direction of services:
  - *Strategies used in practice.*
- Unmet need amongst carers and how this might be met.
- Working at a multidisciplinary level to provide support:
  - *Challenges.*
  - *Successes.*
  - *Examples of good practice.*
  - *Ways forward.*

Supporting carers for people with mental health problems – wider policy context:
Tell me about.....
- Implementation of current guidelines and protocols, including:
  - *National Service Framework for Mental Health [DoH 1999]. and Revised Action Plan for Wales [WAG 2005].*
  - *Mental Health Act 2007.*
  - *Stronger in Partnership 2.*
  - *Carers Strategy in Wales – Action Plan [2007].*
  - *UK Revised Carers Strategy [2008].*

Supporting carers for people with mental health problems - staff training needs:
Tell me about.....
- Staff training and support needs in relation to above.

In conclusion:
- Key message to inform service development.

Appendix E - Carer interview schedule

Carer interview schedule

Consent: Please remember that what you tell me today will remain confidential. Your name will not appear on the interview notes that I am making today or in any reports.

It would be helpful if we could record this interview so that the information we collect is as accurate and complete as possible. If you are agreeable to this, please sign the form giving us your permission. Thank you. **Turn on MP3**

Framing: *As you know, we are looking at the experiences of carers who look after someone with mental health problems. The research will inform the development of services for carers who look after someone with mental health problems. In a minute, I am going to ask you to please tell me about your experiences as a carer up to now. Please take the time you need. I will listen and I won't interrupt. I will just take some notes in case I have any further questions for after you have finished telling me your story.*

Phase 1:
  Please tell me the story of your life from when you started to move towards becoming a carer up to now, including all the events and experiences that have been important to you personally.

Please begin wherever you like. I won't interrupt you but I will take some notes for after you have finished telling me your story.

Additional prompts
- Is there anything more you would like to add?
- Does anything else come to mind?
- Thinking back about what you've said so far, is there anything else you'd like to say to make sure I understand fully what you've told me?

Short break
Suggest a short break as you will need a few minutes to have a look at the notes you made.

Phase 2: Cue phrases
Select a number of cue phrases from the list. The decision of how many cue phrases to use depends partly on the length of phase 1. It is useful to rank the cue phrases. Cue selection should be based on the following: strong emotion words, particular incidence, research aim relevance, or apparently irrelevant remark.

I noted down some key points as you were telling me your story and I would like us to go back and talk about these some more:

You said [cue-phrase 2-6 words]. Can you remember a particular [magic word]… how it all happened

Magic words: Situation, happening, event, incident, occasion, time, day, memory of a moment, example

If the carer cannot remember/give no specific example keep asking; if nothing is forthcoming, ask the negative – *"Can you remember a particular [magic word] when X did not happen?*

Break
Before starting phase 3, have a short break where you turn off the recorder. This gives the carer time to ask anything they want off the record.

Phase 3: Semi-structured questions
You have kindly told me your story, about your life as a carer and your experiences. I now have some specific questions that I would like to ask you. There are not right or wrong answers. Please take as long as you like to think about and answer them.

- *Can you tell me about your experiences with the health and social care professionals who are involved in the care of X?*
- *Based on your experience, how do you feel about service provision and support? Please tell me about any barriers that you have encountered.*
- *Based on your experience, how have services supported you and X?*
- *Based on your experience, what are there barriers to accessing services and support?*
- *Based on your experience, can you suggest anything that you think would improve service provision for you and X in the future?*

Closing questions after phase 3:
- *What, if anything, in the future might change the way you see things now?*
- *Is there anything else that you would like to tell me, perhaps something that you were expecting us to talk about that we have not covered?*

Close
Close and thanks.
Leave the study pack for the person with mental health problems. Make it clear that the decision to pass it on rests with the carer.

Appendix F – Carer follow-up interview schedule

Please note:
The following are examples of questions we might want to ask. The interviewer needs to be familiar with the previous interview and tailor the questions accordingly.

Consent: *Please remember that what you tell me today will remain confidential. Your name will not appear on the interview notes that I am making today or in any reports.*

It would be helpful if we could record this interview so that the information we collect is as accurate and complete as possible. If you are agreeable to this, please sign the form giving us your permission. Thank you. **Turn on MP3**

Questions

About the last interview
Clarify anything that was unclear in the transcript/ask any follow-up questions

- Thinking back to last time we met in [….], is there anything else you thought of afterwards?
- There are a few points you mentioned the last time we met I would like to come back to. Could you please tell me a bit more about…. OR You said that…. am I right in thinking that you meant that…..

Developments since the last interview
- Have there been any changes/developments since we last met?
- You mentioned last time that you were waiting for X, could you please tell me what happened?

Specific questions
Use these where appropriate – some of the issues will already have been covered previously

Services and support
- You talked about your experiences with services and professionals last time. These tended to be negative or difficult - are there any positive examples or things that work well?
- How do you feel about the role voluntary services such as Hafal or Rethink play?
- Thinking about health and social care professionals and their approach to care, from you experience, do you feel that there are any differences between the two?
- Looking back at the first crisis and comparing this to now, have your perceptions of the services changed?
  - in terms of service provision
  - in terms of confidentiality issues
  - in terms of changes in support needs

Individual reflections on changes in coping/expectations over time
- Thinking about yourself and the way you cope/deal with difficult situations, has anything changed since X first became ill?
- Thinking back, do you feel that your expectations have changed?
    - In terms of services and support
    - In terms of home situation

'Social inclusion'
- I wondered if you could tell me a bit more about your experience of working/ trying to find time to work/ how you made the decision not to work…
- You talked a bit about financial considerations last time we met, could you tell me a bit more about any constraints or difficulties you might have experienced?
- How do you feel that your friends and neighbours/ colleagues/ acquaintances react to X being unwell?
- Could you tell me a bit more about how you feel about society's attitude towards mental health illness/problems?

List of recommendations
The interviewee could be asked to rate all or some of the recommendations. The recommendations are based on other interviews. Individual's ratings of recommendations could then be discussed in relation to each interviewee's personal experience.

List of recommendations

- Recognition of carers – tackle issues of confidentiality and inclusion of carers in the CPA
- Access for carers to financial support and free legal advice/ independent advocacy
- Respite
- Training for carers – understanding the illness and what to do
- Information about:
    - available services and support for carers and care-recipient
    - rights of carers and care recipients
    - procedures
    - treatment options and medication
    - financial support for carers and care – recipients
- After a hospital stay:
    - more preparation and support for when the cared-recipient comes home from hospital
    - support from professionals to develop a good relationship with the person in hospital
- Improved communication between services **and** between services and carers
- Raising awareness of mental health issues in the wider community
- A more coherent approach to dealing with a family where several members have mental health difficulties